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A PSYCHOSOCIAL SUPPORT PROGRAMME FOR CAREGIVERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES IN GHANA

DOREEN ASANTEWA ABEASI

A THESIS SUBMITTED TO THE FACULTY OF HEALTH SCIENCE, UNIVERSITY OF THE WITWATERSRAND, IN FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN NURSING

JOHANNESBURG, 2024

DECLARATION

I, Doreen Asantewa Abeasi, hereby declare that this thesis is the result of my own original research. It is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. No part of it has been presented for another degree in this University or elsewhere.



Signature: ----------

Doreen Asantewa Abeasi

21st March, 2024

Date: ----------

DEDICATION

I dedicate this work to the Almighty God.

It is also dedicated to my husband, Mr. Obese-Djomoah and my children, Emmanuel and Reginald Obese-Djomoah.

PUBLICATIONS ARISING FROM THE STUDY

Abeasi DA, Nkosi NG, Suglo JN. Well-being focused interventions for caregivers of children with developmental disabilities: a scoping review protocol BMJ Open 2023;13: e066179. doi: 10.1136/bmjopen-2022-066179

ABSTRACT

Background: Informal caregivers, mainly family members of children diagnosed with developmental disabilities [DD], are often left with the responsibility of caregiving. Usually, they receive little or no training, have no time to prepare for the caregiving role, or do not have adequate resources to carry out their responsibilities as caregivers. The complex nature of care and its continuous nature make caregiving stressful, leading to adverse health effects on caregiver's and child with DD.

Aim: The current study's main goal was to develop a psychosocial support programme for caregivers of children with DD in the Ghanaian context to improve their wellbeing.

Methodology: A multi-method research design was employed in this study. This study was organized into three phases. In phase one, a qualitative study and scoping review were done. The phenomenological design was used to explore experiences and needs of caregivers, which influenced the components of the psychosocial support programme. A scoping review was conducted to inform the psychosocial support programme's design and structure. Phase two consisted of developing the components of the psychosocial support programme by triangulating the results of phase one, guided by the Medical Research Council [MRC] framework for development of complex interventions. Phase three involved the pilot testing and evaluation of the support programme.

Results: Phase one a of the study revealed that caregivers mainly saw caregiving as stressful and time-consuming. Five themes were generated, namely: perception of caregiving, stressors, caregiver needs, negative health outcomes and coping resources.

Different caregiver support programmes were reviewed from included studies in the scoping review, which were varied in the scope of interest. All the studies were conducted in lower- and middle-income countries.

A psychosocial support programme referred to as Caregiver Well-being Improvement [CaWELLIS] programme was developed, confirmed by a group of experts, and implemented for caregivers of children with developmental disabilities in Ghana. There was improvement in caregiver outcomes, namely; stress, burden, anxiety, depression, support, blood pressure, and cortisol levels.

Conclusion: The study provided evidence that the CaWELLIS programme had a positive influence on stress, the primary outcome of the study, as well as on secondary outcomes like

anxiety, depression, burden, and blood pressure levels. The CaWELLIS programme is a comprehensive, context-specific programme that has the potential to respond to the needs of caregivers of children with DD. The use of a one group pre-test post-test design to evaluate the effectiveness of the CaWELLIS programme has some limitations, therefore the gold standard of randomised control trial is suggested for future research.

Keywords: Developmental disability, Caregiver, Well-being, Children, Support Programme

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TABLE OF CONTENTS

DECLARATION i
DEDICATION ii
PUBLICATIONS ARISING FROM THE STUDY iii
ABSTRACT iv
ACKNOWLEDGEMENT vi
TABLE OF CONTENTS vii
LIST OF TABLES xx
ACRONYMS AND ABBREVIATIONS xxii
CHAPTER ONE 1
OVERVIEW OF THE STUDY 1
1.1 INTRODUCTION AND BACKGROUND 1
1.1.1 Developmental disabilities: Prevalence, trends and global perspectives 1
1.1.2 Risk factors of developmental disabilities 3
1.1.3 Addressing health inequalities in children with developmental disabilities: Challenges and global initiatives 3
1.1.4 The untold challenges of children with developmental disabilities 4
1.1.4 Caregivers by default: the multidimensional impact of caregiving 5
1.2 PROBLEM STATEMENT 7
1.3 RESEARCH QUESTION 9
1.4 PURPOSE (AIM) OF THE STUDY 9
1.4 RESEARCH OBJECTIVES 9
1.5 SIGNIFICANCE OF THE STUDY 10
1.5.1 Nursing research 10
1.5.2 Nursing practice 10
1.5.3 Policy makers 10
1.5.4 Caregivers 10
1.6 OPERATIONAL DEFINITIONS 11
1.6.1 Caregiver 11
1.6.2 Developmental disability 11
1.6.3 Caregiver burden 11
1.6.4 Child 11
1.6.5 Well-being 12

1.6.6 Psychosocial support programme....12
1.7 THEORETICAL MODEL....12
1.8 SUMMARY OF THE RESEARCH METHODS AND DESIGN....12
1.8.1 Research setting....13
1.9 OVERVIEW OF THESIS....17
1.10 SUMMARY OF CHAPTER ONE....19
CHAPTER 2....20
LITERATURE REVIEW....20
2.0 INTRODUCTION....20
2.1 THEORETICAL FRAMEWORK: STRESS PROCESS MODEL....20
2.1.1 Rationale for choice of theoretical framework....20
2.1.2 Assumptions of Stress Process Model....21
2.2 BACKGROUND AND CONTEXT OF STRESS....23
2.2.1 Age of caregiver....23
2.2.2 Gender of caregiver....24
2.2.3 Educational level of the caregiver....26
2.2.4 Income level of caregiver....27
2.2.5 Marital status of caregiver....27
2.2.6 Caregiving history....28
2.2.7 Age of child with DD....29
2.2.8 Gender of the child with DD....29
2.3 PRIMARY AND SECONDARY STRESSORS....30
2.3.1 Burden of care among caregivers of children with DD....31
2.3.2 Behaviour problems of the child....32
2.4 MEDIATING CONDITIONS FOR BURDEN OF CARE....32
2.4.1 Role of social support in caregiving outcomes....33
2.5 CAREGIVING OUTCOMES....34
2.5.1 Physical well-being of caregivers of children with DD....34
2.5.1.1 Sleep problems of caregivers of children with DD....34
2.5.1.2 Pain-related symptoms in caregiver....35
2.5.1.3 Fatigue in caregiver....36
2.5.1.4 Cardiovascular functioning in caregivers....36
2.5.1.5 Altered levels of cortisol....37

2.7.2 Psychological well-being of caregivers of children with DD 38
2.8 SUMMARY OF EMPIRICAL STUDIES 38
2.9 SUMMARY OF CHAPTER 39
CHAPTER 3 40
RESEARCH METHODOLOGY 40
3.0 INTRODUCTION 40
3.1 PHILOSOPHICAL WORLDVIEWS GUIDING THE CURRENT RESEARCH 40
3.2 RESEARCH CONTEXT 41
3.3 RESEARCH SETTING 42
3.3.1 Overview of the research setting 42
3.3.2 Geographic location of KBTH 43
3.3.3 Organisational culture 44
3.4 STUDY DESIGN 44
3.5 SAMPLE AND SAMPLING TECHNIQUE 45
3.6 DATA COLLECTION METHODS 45
3.7 DATA ANALYSIS 46
3.8 RIGOUR OF THE STUDY 46
3.9 PHASE 1 RESEARCH METHODS: EXPLORATORY PHASE 48
3.9.1 Objective 1 48
3.9.1.1 Research Design: Descriptive phenomelogical design 48
3.9.1.2 Sampling technique 48
3.9.1.3 Sample Size 50
3.9.1.4 Data collection instrument: Semi-structured interview guide 50
3.9.1.5 Data collection procedure 51
3.9.1.6 Data analysis 52
3.9.1.7 Trustworthiness of qualitative research 54
3.9.2 Objective 2 57
3.9.2.1 Scoping review 57
3.9.2.2 Data analysis 62
3.10 PHASE 2 RESEARCH METHODS: DEVELOPMENT PHASE 62
3.10.1 Objective 3 62
3.10.1.1 Identifying the evidence base 63
3.10.1.2 Identifying or developing theory 64

3.10.1.3 Modelling process and outcomes 64
3.10.1.4 Core components 65
3.10.2 Objective 4 66
3.10.2.1 Sampling technique 66
3.10.2.2 Sample size 66
3.10.2.3 Data collection 66
3.10.2.4 Data collection procedure 67
3.10.2.5 Data analysis 67
3.11 PHASE 3 RESEARCH METHODS: IMPLEMENTATION PHASE 68
3.11.1 Research Design: Pre-test post-test design 68
3.11.2 Sampling technique 69
3.11.3 Sample size 69
3.11.4 Data collection instruments 70
3.11.4.1 Zarit Burden Interview (ZBI) 70
General overview of the ZBI 70
Rationale for choosing ZBI-22 71
Scoring of the ZBI 71
Validity and reliability of the ZBI 72
3.11.4.2 Depression Anxiety and Stress Scale (DASS) 72
General overview of the DASS 72
Rationale for choosing DASS-42 73
Scoring of the DASS-42 74
Validity and reliability of the DASS-42 74
3.11.4.3 Physical Health Questionnaire (PHQ)-15 75
General Overview (PHQ)-15 75
Structure of the PHQ-15 76
Scoring of the PHQ-15 76
Validity and Reliability of the PHQ-15 77
3.11.4.4 Multidimensional Scale of Perceived Social Support (MSPSS) 77
General overview of MSPSS 77
Sub-scales of the MPSS 78
Scoring of the MSPSS 78
Validity and Reliability of the MSPSS 79

3.11.4.5 Cortisol analyser....80
3.11.4.6 Blood pressure equipment....80
3.11.5 Data collection procedure....81
3.11.5.1 Administration of questionnaires....81
3.11.5.2 Measurement of cortisol levels....81
3.11.5.3 Measurement of blood pressure....82
3.11.6 Validity and reliability....82
3.11.6.1 Applicability to the current study....83
3.11.7 Data analysis....83
3.12 ETHICAL CONSIDERATION....83
3.12.1 Informed consent....84
3.12.2 Privacy....84
3.12.3 Confidentiality....84
3.12.4 Respect and responsibility....84
3.13 SUMMARY OF CHAPTER THREE....85
CHAPTER 4....86
DESCRIPTIVE PHENOMENOLOGICAL STUDY (PHASE 1a)....86
4.0 INTRODUCTION....86
4.1 CAREGIVER AND CHILD SOCIO-DEMOGRAPHIC CHARACTERISTICS....86
4.2 THEMES AND SUB-THEMES GENERATED FROM THE INTERVIEWS....87
4.2.1 Familiarisation with the data....88
4.2.2 Generating initial codes....88
4.2.3 Generating themes....89
4.2.4 Reviewing the themes....89
4.2.5 Defining and naming the theme....90
4.2.6 Write-up....90
4.3 THEME 1: PERCEPTION OF CAREGIVING ROLE....93
4.3.1 Sub-theme: Stressful nature of caregiving....93
4.3.2 Sub-theme: Time-consuming....94
4.4 THEME 2: STRESSORS....94
4.4.1 Sub-theme: Child's ADL needs....94
4.4.2 Sub-theme: Communication barrier....96
4.4.3 Sub-theme: Managing challenging behaviours....97

4.4.4 Sub-theme: Child's health needs 98
4.4.5 Sub-theme: Unmet educational needs 99
4.4.6 Sub-theme: Economic burden 100
4.5 THEME 3: NEGATIVE HEALTH OUTCOMES 102
4.5.1 Sub-theme: Decline in physical well-being 102
Pain-related effects 102
Fatigue 103
Compromised sleep 103
4.5.2 Sub-theme: Decline in mental well-being 104
Lack of concentration 104
Anger 105
Sadness 105
Anxiety 106
4.5.3 Sub-theme: Decline in social well-being 106
4.6 THEME 4: CAREGIVER NEEDS 107
4.6.1 Sub-theme: Informational support needs 107
4.6.2 Sub-theme: Financial support needs 109
4.6.3 Sub-theme: Psychospiritual support needs 110
4.6.4 Sub-theme: Social support needs 110
4.7 THEME 5: COPING STRATEGIES 111
4.7.1 Sub-theme: Adaptive coping 111
4.7.2 Sub-theme: Maladaptive coping 112
4.8 FINDINGS FROM PHENOMENOLOGIAL STUDY EXAMINED IN CONTEXT OF THE STRESS PROCESS MODEL(SPM) 113
4.9 DISCUSSION OF FINDINGS FROM QUALITATIVE STUDY 114
4.9.1 SOCIODEMOGRAPHIC CHARACTERISTICS 114
4.9.1.1 Caregiver's age 114
4.9.1.2 Caregiver's gender 115
4.9.1.3 Caregiver's marital status 115
4.9.1.4 Caregiver's educational background 116
4.9.1.5 Caregiver's income 116
4.9.1.6 Caregiving history 116
4.9.1.7 Age of the child with DD 117
4.9.1.8 Gender of child with DD 117

4.9.2 PERCEPTION OF CAREGIVING ROLE 117
4.9.2.1 Stressful nature of caregiving 117
4.9.2.3 Time consuming 118
4.9.3 STRESSORS 119
4.9.3.1 Child's ADL needs 119
4.9.3.2 Communication barrier 119
4.9.3.3 Managing challenging behaviour 120
4.9.3.4 Child's health needs 121
4.9.3.5 Unmet educational needs of the child with DD 122
4.9.3.6 Economic burden 122
4.9.4 NEGATIVE HEALTH OUTCOMES 123
4.9.4.1 Decline in physical well-being of caregivers 123
4.9.4.2 Decline in mental well-being of caregivers 125
4.9.4.3 Decline in social wellbeing of caregivers 125
4.9.5 SUPPORT NEEDS OF CAREGIVERS 127
4.9.5.1 Informational support needs 127
4.9.5.2 Financial support needs 128
4.9.5.3 Psychospiritual support needs 129
4.9.5.4 Social support needs 129
4.9.6 COPING STRATEGIES OF CAREGIVERS 129
4.9.6.1 Adaptive coping strategies 129
4.9.6.2 Maladaptive coping strategies 130
4.10 SUMMARY OF CHAPTER FOUR 130
CHAPTER 5 132
SCOPING REVIEW (PHASE 1b) 132
5.0 INTRODUCTION 132
5.1 THE SCOPING REVIEW PROCESS 132
5.2 STAGE 1: IDENTIFYING THE RESEARCH QUESTION 132
5.3 STAGE 2: IDENTIFYING RELEVANT STUDY 133
5.3.1 Step 1: Initial search 133
5.3.2 Step 2: Search across five databases 133
5.4.3 Step 3: Searching the reference list of identified studies/other sources 135
5.4 STAGE 3: STUDY SELECTION 135

5.5 STAGE 4: CHARTING THE RESULTS 137
5.6 STAGE 5: COLLATING, SUMMARIZING AND REPORTING THE RESULTS 146
5.6.1 Distribution of the studies 146
5.6.2 Geographic distribution of the articles 146
5.6.3 Distribution of articles by journal 146
5.6.4 Distribution of articles by year of publication 147
5.6.5 Participants 148
5.6.6 Inclusion and exclusion criteria 149
5.6.7 Assessment instruments 153
5.6.8 Number of assessments done in the studies 154
5.6.9 Interventions for caregivers 156
5.6.10 Outcomes in the studies used in the scoping review 163
5.6.11 Quality assessment 164
5.6.11.1 Quality assessment of the quasi-experimental design of studies included in the scoping review 164
5.6.11.2 Quality assessment of RCTs of studies included in the scoping review 166
5.7 ANALYSIS OF THEMES 169
5.7.1 TYPE OF INTERVENTION 170
5.7.1.1 Sub-theme 1: Mindfulness-based interventions 170
5.7.1.2 Sub theme 2: Parent training programmes 170
5.7.1.3 Sub theme 3: Cognitive-behavioural interventions 171
5.7.1.4 Sub-theme 4: Resilience based interventions 172
5.7.1.5 Sub-theme 5: Spirituality-integrated Programmes 172
5.7.1.5 Sub-theme 5: Mind-body programmes 173
5.7.2 DURATION OF THE INTERVENTION 173
5.7.3 DELIVERY OF INTERVENTION 173
5.7.4 EFFECT OF THE INTERVENTION ON THE CAREGIVERS' OUTCOMES 174
5.7.4.1 Changes in psychological well-being: Stress 175
5.7.4.2 Changes in psychological well-being: anxiety 176
5.7.4.3 Changes in psychological wellbeing: depression 177
5.7.4.4 Changes in physical wellbeing/ somatic symptoms 178
5.7.4.5 Changes in social well-being 178
5.7.4.6 Changes in burden or strain 179
5.8 LIMITATIONS 179

5.8.1 Small sample size 179
5.8.2 Self-report measures 180
5.8.3 No control group 180
5.8.4 No follow-up 181
5.9 DISCUSSION 181
5.9.1 Distribution of studies 182
5.9.1.1 Geographic distribution of studies 182
5.9.1.2 Distribution by journals 182
5.9.1.3 Distribution by year of publication 182
5.9.1.4 Participants distribution 182
5.9.2 Assessments 183
5.10.2.1 Assessment instruments 183
5.9.2.2 Number of assessments 183
5.9.3 Nature / types of intervention 183
5.9.3.1 Mindfulness-based interventions 183
5.9.3.2 Parent training programmes/interventions 185
5.9.3.3 Cognitive and behavioural related programmes 185
5.9.3.4 Resilience-based Interventions 186
5.9.3.5 Spirituality-integrated interventions or programmes 187
5.9.3.6 Mind-body interventions or programmes 187
5.9.4 Delivery of the intervention 188
5.9.5 Level of evidence of the studies reviewed 188
5.10 SUMMARY OF CHAPTER FIVE 189
CHAPTER 6 190
PHASE TWO: DEVELOPMENT PROCESS OF A PSYCHOSCOIAL SUPPORT PROGRAMME 190
6.0 INTRODUCTION 190
6.1 DEVELOPMENT OF THE PSYCHOSOCIAL SUPPORT PROGRAMME: APPLICATION OF THE MRC FRAMEWORK 190
6.2 IDENTIFYING THE EVIDENCE 192
6.2.1 Phenomenological study 192
6.2.2 Scoping review of interventions 192
6.3 IDENTIFYING OR DEVELOPING THE THEORY 192

6.4 MODELLING PROCESS AND OUTCOME OF THE CaWELLIS PROGRAMME: Identifying items for the support programme 193
6.5 MODELLING PROCESS AND OUTCOME OF THE CaWELLIS PROGRAMME: The Delphi Technique 195
6.5.1 Recruitment of experts 195
6.5.2 Procedure for the confirmation of the psychosocial support programme 196
6.5.2.1 Round 1 of delphi technique 196
6.5.2.2 Round 1 comments from the experts 198
6.5.2.3 Round 2 of the delphi technique 199
6.5.3 Final items of the CaWELLIS programme 201
6.5.4 THEMES/SUB-THEMES GENERATED FROM CHAPTER FIVE AND THEIR CORRESPONDING MODULES OF THE CaWELLIS 203
6.6 OVERVIEW OF THE CaWELLIS PROGRAMME 204
6.7 SUMMARY OF CHAPTER SIX 208
CHAPTER 7 209
PHASE 3: IMPLEMENTATION PHASE 209
7.0 INTRODUCTION 209
7.1 PRE-TESTING [BASELINE ASSESSMENT] 209
7.2 PILOT TESTING 210
7.3 POST TESTING 211
7.4 RESULTS: PRE AND POST INTERVENTION 211
7.4.1 Socio-demographic characteristics of the caregivers 211
7.4.2 Sociodemographic characteristics of children with DD 212
7.4.3 Caregiver stress 213
7.4.4 Caregiver depression 215
7.4.5 Caregiver anxiety 217
7.4.6 Caregiver burden 219
7.4.7 Caregiver somatic symptoms 223
7.4.8 Social support 225
7.4.9 Cortisol test 228
7.4.10 Blood pressure measurement 229
7.4.11 Caregiver/child demographics and caregiving outcomes 230
7.5 DISCUSSION 232
7.5.1 Subjective caregiver stress using DASS [Stress] 232

7.5.2 Objective caregiver stress [Cortisol levels] 233
7.5.3 Caregiver anxiety level 234
7.5.4 Caregiver depression 235
7.5.5 Caregiver burden 237
7.5.6 Caregiver somatic symptoms 237
7.5.7 Social support 238
7.5.8 Caregiver blood pressure 239
7.6 SUMMARY 240
CHAPTER EIGHT 241
SUMMARY OF THE STUDY, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION 241
8.0 INTRODUCTION 241
8.1 SUMMARY OF FINDINGS 241
Phase 1a: Phenomenological study 241
Phase 1b: Scoping review 242
Phase 2a: Development of the CaWELLIS Programme 242
Phase 2b: Expert review (confirmation of the CaWELLIS programme) 243
Phase 3: Implementation phase [Pre-test, piloting and post-test] 243
8.2 CONCEPTUAL FRAMEWORK OF THE STUDY 243
8.3 JUSTIFICATION OF THE STUDY 246
8.4 LIMITATIONS OF THE STUDY 246
8.5 IMPLICATIONS OF THE STUDY 247
8.6 RECOMMENDATIONS 248
8.6.1 Policy makers: 249
8.6.2 Nursing practice: 251
8.6.3 Nursing education 252
8.6.4 Nursing research 252
8.7 CONCLUSION 252
REFERENCES 254
APPENDICES 295
Annexure A: Caregiver Well-being Improvement Support [CaWELLIS] Programme 295
Annexure B: Semi-structured interview guide 344
Annexure C: Socio-demographic questionnaire 346
Annexure D: Zarit Burden Interview 348

Annexure E: DASS scale 350
Annexure F: PHQ-15 somatic symptoms questionnaire 353
Annexure G: Multidimensional Scale of Perceived Social Support 354
Annexure H: Permission to conduct study at the Korle-Bu Teaching Hospital 356
Annexure I: Study information sheet-caregivers of children with disability in the qualitative phase 357
Annexure J: Study information sheet-Experts 359
Annexure K: Study information sheet-Caregivers of children with developmental disability in the quantitative phase 361
Annexure L: Consent form-caregivers of children with developmental disability in the qualitative phase 364
Annexure M: Consent form-caregivers of children with developmental disability in the quantitative phase 365
Annexure N: Consent Form-Experts 366
Annexure O: Consent form-caregivers of children with developmental disability for recording of interviews in the qualitative phase 367
Annexure P: Institutional approval to conduct study at KBTH, Ghana 368
Annexure Q: Ethics approval from the Institutional Review Board, KBTH 369
Annexure R: Approval from Scientific and Technical Committee, KBTH 370
Annexure S: Approval of title 371
Annexure T: Ethics Approval from Human Research Ethics Committee 372
Annexure U: Proofreading certificate 373

LIST OF FIGURES

Figure 2.1 Stress Process Model (Adapted from Pearlin et al., 1990).....22
Figure 3.1 Geographic location of KBTH 43
Figure 3.2: Design and research methods for the three phases of the study.....47
Figure 3.3 MRC framework for development of complex interventions 62
Figure 3.4 MRC framework as applied in current study 63
Figure 4.1 Initial thematic mapping.....89
Figure 4.2 Finalised thematic mapping demonstrating five themes 90
Figure 4.3 Findings of descriptive phenomenological study examined in context of SPM ..114
Figure 5.1: PRISMA flow diagram for the scoping review article selection process.....136
Figure 5.2 Article distribution by year of publication 148
Figure 5.3 Distribution of participants by gender.....149
Figure 5.4 Distribution of articles with most assessments.....155
Figure 6.1 Iterative development process of the CaWELLIS Programme 191
Figure 6.2 Iterative process of Delphi technique 201

LIST OF TABLES

Table 1.1 Overview of research methods 14
Table 1.2: Summary structure of thesis 18
Table 3.1 Elements influencing researcher's choice of worldview 41
Table 3:2 Inclusion and exclusion criteria for study selection 60
Table 3:3 Sample data extraction sheet 61
Table 3.4 Pre-determined criterion questions used by the expert panel as recommended by CHNRI 67
Table 3.5 Cohen's kappa 68
Table 3.6 Example of the ZBI 71
Table 3.7 Scoring of the DASS-42 74
Table 3.8 Cortisol reference range 80
Table 3.9 Blood pressure categories in adults 80
Table 3.10 Average time for administration of instruments 81
Table 3.11 Cronbach alpha for the instruments 83
Table 4.1 Detailed socio-demographic characteristics of caregivers and child with DD 86
Table 4.2 Descriptive statistics of caregiver/child socio-demographic characteristics 87
Table 5.1 Key words and alternative words for database search 133
Table 5.2 Details of search across five databases 134
Figure 5.1: PRISMA flow diagram for the scoping review article selection process 136
Table 5.3 Extraction of results from studies used in the scoping review 138
Table 5.5 Distribution of articles by location 146
Table 5.6 Article distribution by journals 147
Table 5.7 Inclusion and exclusion criteria of studies included in the scoping review 150
Table 5.8 Assessment instruments used across studies 154
Table 5.9 TIDieR Checklist for interventions of the studies used in the scoping review 157
Table 5.10 Well-being related outcomes 163
Table 5.11 JBI Critical Appraisal Checklist for Quasi-Experimental Studies 165
Table 5.12 JBI Critical Appraisal Checklist for Randomized Control Trials 167
Table 5.13 Themes and sub-themes from analysed data 169
Table 6. 1 Items generated from scoping review and qualitative interviews 193
Table 6.2 Demographic details of experts 195
Table 6.3 Round 1 level of agreement among experts 197
Table 6.4 Comments generated from Round 1 of Delphi technique 199
Table 6.5 Round 2 level of agreement among experts 200
Table 6.6 Description of final items of CaWELLIS programme 202
Table 6.7 Themes from qualitative study and their corresponding modules 203
Table 6.8 Summary of models in CaWELLIS Programme 204
Table 7.1 Sociodemographic characteristics of caregivers (n=53) 211
Table 7.2 Sociodemographic characteristics of children with DD 212
Table 7.3 Overall stress pre-intervention and post-intervention (n=53) 213
Table 7.4 The mean DASS (Stress) items pre- (n=53) and post- (n=53) intervention 213
Table 7.5 Stress scores pre-intervention and post-intervention (n=53) 215
Table 7.6 Overall depression pre-intervention and post-intervention (n=53) 215
Table 7.7 The mean DASS(Depression) items pre- (n=53) and post- (n=53) intervention 216
Table 7.8 Depression scores pre-intervention and post-intervention 217

Table 7.9 Overall anxiety pre-intervention and post-intervention.....217
Table 7.10 The mean DASS(Anxiety) items pre- (n=53) and post- (n=53) intervention.....218
Table 7.11 Anxiety scores pre-intervention and post-intervention (n=53).....219
Table 7:12 Overall care burden pre-intervention and post-intervention.....220
Table 7:13 The mean care burden items pre- (n=53) and post- (n=53) intervention.....220
Table 7:14 Care burden pre-intervention and post-intervention.....222
Table 7:15 Overall PHQ-15 pre-intervention and post-intervention.....223
Table 7:16 The mean PHQ-15 items pre- (n=53) and post- (n=53) intervention.....223
Table 7.17 Caregiver somatic symptoms pre-intervention and post-intervention.....224
Table 7:18 The mean MSPSS subscales and total pre- (n=53) and post- (n=53) intervention 225
Table 7:19 The mean MSPSS items pre- (n=53) and post- (n=53) intervention.....226
Table 7.20 Relationship between social support and stress, anxiety and depression 227
Table 7:21 Descriptive Information on Cortisol levels.....228
Table 7:22 Paired Samples Differences Test Between Pre-Test and Post-Test.....228
Table 7:23 Descriptive statistics of caregivers' blood pressure.....229
Table 7:24 Paired Sample test of caregivers' blood pressure.....229
Table 7.25 Caregiver/child demographics and caregiving outcomes.....231

ACRONYMS AND ABBREVIATIONS

ACTH	Adrenocorticotropin Hormone
ADH	Antidiuretic Hormone
ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activities of Daily Living
ANS	Autonomic Nervous System
ASD	Autism Spectrum Disorders
BDNF	Brain-derived Neurotrophic Factor
BMR	Basal Metabolic Rate
CaWELLIS	Caregiver Well-being Improvement Support
CBR	Community-based Rehabilitation
CEO	Chief Executive Officer
CHNRI	Child Health and Nutrition Research Initiative
CRH	Corticotrophin Releasing Hormone
DASS	Depression Anxiety and Stress Scale
DD	Developmental Disability
DHEA	Dehydroepiandrosterone
DS	Down Syndrome
DSM	Diagnostic and Statistical Manual of Mental Disorders
GHS	Ghana Health Service
HCC	Hair Cortisol Concentration
HIC	High Income Countries
HPA	Hypothalamic Pituitary Adrenal
ID	Intellectual disability
IRB	Institutional Review Board
JBI	Joana Briggs Institute
KBTH	Korle-Bu Teaching Hospital
LBP	Low Back Pain
LMIC	Low- and Middle-Income Countries
MOH	Ministry of Health
MRC	Medical Council Framework for developing complex interventions
MSPSS	Multidimensional Scale of Perceived Social Support

NHIS	National Health Interview Survey
OPD	Outpatient Department
PHQ-15	Patient Health Questionnaire-15
SPM	Stress Process Model
STC	Scientific and Technical Committee
Sub-BMC	Sub-Budget Management Centre
WHO	World Health Organization
ZBI	Zarit Burden Index

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

1.1.1 Developmental disabilities: Prevalence, trends and global perspectives

Developmental disabilities (DD) are a group of heterogeneous conditions with an onset in childhood caused by certain impairments that affects a child's functioning in domains such as physical, cognitive and self-care (Zablotsky *et al.*, 2015). DDs are life long and impact negatively on an individual's cognition, behaviour and body systems (Zablotsky *et al.*, 2015; Zablotsky, Black & Blumberg, 2017). According to Blaskowitz, Hernandez and Scott (2019), DD may persist throughout the life of the individual, but the onset occurs before age 22. Developmental disability is an umbrella term for disorders such as attention-deficit/hyperactivity disorder [ADHD], cerebral palsy [CP], intellectual disability [ID], and autism spectrum disorders[ASD](Global Research on Developmental Disabilities Collaborators, 2018). The concepts of DD and ID are often used interchangeably; however, both terms are not the same. The former is broader, comprising a wider range of disabilities as compared to the latter. Individuals with ID may need little or no assistance in adulthood if the associated cognitive impairment is mild (Boat & Wu, 2015).

Obtaining the actual estimates for the prevalence of DD has been a problem largely due to the definitions of DD, which keep changing over time (Zablotsky *et al.*, 2015). Another factor is the number of co-occurring conditions that are placed under the umbrella term DD. The common ways, surveys and administrative classification that are available for use in estimating the prevalence have also been cited as a problem since they have their own limitations. First, surveys often used are based on participants' reporting. These designs are largely dependent on the effectiveness of the reports. This could be affected by how the participants understand the questions in the survey, their ability to remember the diagnosis, and their ability to report an accurate diagnosis (Zablotsky *et al.*, 2015). Second, administrative classification may reduce access for some portions of the population to the administrative count systems (Durkin *et al.*, 2010).

Globally, it is estimated that 100 million children under the age of 15 are reported to have DD (World Health Organisation [WHO], 2011). In a more current analysis of findings from two

databases on the global prevalence of disabilities, high estimates of DD were reported. Using a parent-reported functional difficulty, United Nations Children's Fund [UNICEF] reported 240 million children having developmental disabilities. On the other hand, the Global Burden of Diseases based on statistical modelling techniques reported prevalence of 290 million (Olusanya *et al.*, 2022). Though differences exist in the estimates, for children 5-19 years, the difference was not statistically significant. These two databases provide the most comprehensive estimates on the prevalence of DD among children and adolescents. In both databases, Sub-Saharan Africa and South Asia accounted for more than half of the children with disabilities (Olusanya *et al.*, 2022).

A previous study, confirms that the burden of developmental disabilities in low- and middle-income countries (LMICs) is high as compared to high-income countries (HICs) (Global Research on Developmental Disabilities Collaborators, 2018). Ghana, like many LMICs, has a paucity of data on the actual prevalence of childhood disability. It is estimated that there were 737,743 persons with disabilities, and they represent 3 percent of the total population. Out of this number, females contributed to a majority (52.5%) of persons with disabilities, with the remaining 47.5% being males (Ghana Statistical Service [GSS], 2013). In a more recent study by Global Research on Developmental Disabilities Collaborators (2018), the authors reported that between 1990 and 2016, there was 54.8% increase in children living with disabilities in Ghana, from 241, 529 in 1990 to 373, 912 in 2016.

Several contributory factors have been associated with increasing trends in DD, including the increase in number of children who survive conditions such as preterm birth, brain trauma and congenital conditions (Durkin, 2019) both in HICs and LMICs. In HICs, there have been significant improvement in obstetric and neonatal care leading to decreased brain injuries arising from birth complications. Comparing to LMICs, child survival has also improved as a result of scaling-up of intensive new born care leading to more children surviving and less mortality rates (Lawn *et al.*, 2012). However, for these surviving children, there is increased rates of disability (Blencowe *et al.*, 2013). Additionally, while children with disabilities in HICs may have access to high quality care and educational services, such opportunities may be rare in LMICs (Lawn *et al.*, 2013). Other determinants of the increasing prevalence are the improvement in knowledge and awareness of neurodevelopment by health care providers, the broadening of diagnostic criteria to include a spectrum of behavioural and functional

limitations, developmental screening improvements, and increased access to diagnostic and treatment services (Gottlieb *et al.*, 2009).

1.1.2 Risk factors of developmental disabilities

The onset of DD can be due to prenatal, perinatal and postnatal causes as well as biological and environmental risk factors (Gordon-Lipkin, Hoon & Pardo, 2021). For example, pregnant women who do not take adequate supplementation of prenatal vitamins like folic acid (Schmidt *et al.*, 2011) may have children with defects of neural tube leading to DD. Maternal factors like smoking, alcohol intake, inadequate nutrition, and very young or old age are associated with preterm delivery or brain injury of the foetus or low birth weight (Torchin & Ancel, 2016; Pusdekar *et al.*, 2020; Chang, Tseng & Chen, 2020). Comparing babies born with normal weight with their counterparts with preterm, the odds are high for the onset of DD. For example, a study reported that children born very preterm and very low birth weight have ten times higher odds of meeting criteria for ASD and five times higher odds of meeting criteria for ADHD than controls (Anderson *et al.*, 2021). Environmental factors such as exposure to lead poisoning, poor infant nutrition, infection, neglect, traumatic brain injury, and abuse (Carlier & Roubertoux, 2014) have been linked to the onset of DD.

1.1.3 Addressing health inequalities in children with developmental disabilities: Challenges and global initiatives

A significant amount of research from high-income countries (HICs) shows that children with DD face a shorter life expectancy compared to those without such disabilities (Wallander *et al.*, 2014; Divan *et al.*, 2015; Schlebusch *et al.*, 2022). These children also suffer from poorer health outcomes than their peers without developmental issues (Rimestad *et al.*, 2019; Rinaldi *et al.*, 2021). While some health differences, like congenital heart issues and early dementia in Down syndrome cases, are due to the nature of the disability, others are unjust and could be mitigated. These disparities often stem from social determinants such as poverty, exclusion, violence, and discrimination, including ingrained prejudices in education and healthcare systems (Downs *et al.*, 2018; Brignell *et al.*, 2021).

Children with developmental disabilities often face significant barriers in accessing health promotion, healthcare, and education services compared to their peers without such disabilities (Reichow *et al.*, 2019). This disparity is influenced by a range of social, economic, cultural, and institutional factors that exacerbate inequalities in health and overall well-being.

Additionally, certain children with developmental disabilities are at a greater disadvantage due to a combination of various elements that can amplify or mitigate exclusion, such as the economic status of their country, their family's socioeconomic position, and their racial or ethnic background. The lack of comprehensive healthcare services, especially in low- and middle-income countries (LMICs), leads to unmet healthcare needs among individuals with developmental disabilities (Global report on children with developmental disabilities, 2023). Consequently, the disability-adjusted life years (DALYs) or years of healthy life lost due to disability among children with developmental disabilities rose slightly from 3.8 million in 1990 to 3.9 million in 2016 (Global Research on Developmental Disabilities Collaborators, 2018).

The push to reduce health disparities between high-income countries (HICs) and low- and middle-income countries (LMICs) aligns with the Sustainable Development Goals' (SDGs) aim for universal health coverage (United Nations, 2015). This commitment seeks to ensure that children with developmental disabilities can access a comprehensive range of high-quality health services, including health promotion, prevention, treatment, rehabilitation, and palliative care throughout their lives (Missing Billion Initiative and Clinton Health Access Initiative, 2022). The SDGs' enhanced emphasis on early childhood development and inclusive education marks a significant step towards prioritizing the health needs of children with developmental disabilities as a critical issue worldwide. This focus is highlighted by the inclusion of specific disability-friendly measures in five of the 17 SDGs, a notable advancement from the Millennium Development Goals, which lacked such considerations (United Nations, 2015).

1.1.4 The untold challenges of children with developmental disabilities

Children with DD have several problems, including challenges with feeding, sleeping and behaviour. Feeding is a sensorimotor activity, therefore, a problem with the structure and/or function of the gastrointestinal, cardiorespiratory or neurological systems (Goday *et al.*, 2019), results in difficulties performing feeding-related activities such as chewing, swallowing and drinking (Anil, Shabnam & Narayanan, 2019). Additionally, **c**hildren with DD tend to experience a higher prevalence of sleep problems than typically developing children and the general population (Richdale & Baker, 2014; Esbensen & Schwichtenberg, 2016). These problems are typically severe and long-lasting (Sutton, Huws & Burton, 2019).

It is common for individuals with DD to exhibit challenging behaviour (Farmer *et al.*, 2015). Aggression, hyperactivity, impulsivity, self-injurious and destructive behaviours are among the most prevalent challenging behaviours (Lundqvist, 2013; McQuire *et al.*, 2015). According to

Kearney and Healy (2011) findings, those exhibiting extreme challenging behaviours were more likely to score significantly high or low on measures of social skills and psychiatric symptoms. Asthma, gastrointestinal symptoms, eczema, skin allergies, migraine headaches are some health conditions that have been found to be common among children with developmental disabilities (CDC, 2022).

Beyond activity limitation and complex health needs of children with DD, they are blamed for the misfortunes and are called spirit children in Ghana and some parts of Africa (Sossou and Yogtiba, 2009; Denham *et al.*, 2010; Bayat, 2015) because they are considered to have some relationship with the spirit world, as a result, they are killed (Abdullah *et al.*, 2022), abused and abandoned (Bayat, 2015). They are not treated with noticeable degree of human dignity and respect (Bayat, 2015).

1.1.4 Caregivers by default: the multidimensional impact of caregiving

The impact of caring for a child with DD is pervasive and could influence family functioning in both positive and negative ways. Positively, outcomes such as increased inner strength, cohesion and resilience have been documented (Ellingsen *et al.*, 2014). For example, Potter, (2016) explored 198 fathers' perspectives on perceived benefits of parenting children with autism and reported positive experiences like appreciating children's individual qualities, valuing the strong emotional bond, nurturing role and its associated personal bond. Conversely, negative outcomes such as strained marital relationships (Freedman *et al.*, 2012), financial pressure (Parish *et al.*, 2012), sibling adjustment (Manor-Binyamini, 2012) and decreased parenting efficiency.

In Ghana, family members usually take up the responsibility of caring for a sick person, be it acute or chronic (Opoku *et al.*, 2017). Dealing with the needs of children with DD on long term basis are usually stressful as a number of studies have reported that caregivers of such children experience higher levels of stress (Rani, Ehsan & Arshad, 2016; Cramm & Nieboer, 2011) and increased burden of care (Ahanotu, Ibikunle & Hammed, 2018; Freitag, Milbrath & Corso Da Motta, 2018). Subsequently, high stress levels negatively affects caregivers physical (Byrne *et al.*, 2010), psychological and social wellbeing (Yilmaz, Erkin & İZKİ, 2013; Okewole *et al.*, 2011).

For example, chronic stress has been documented to negatively affect caregivers body systems including cardiovascular, immune and gastrointestinal (Yaribeygi *et al.*, 2017; Mariotti, 2015) which are linked to disturbances in cortisol patterns (Lovell, Moss & Wetherell, 2012). There have been reports of somatic complaints such as headaches, backaches, gastrointestinal issues, and respiratory infections (Gallagher & Whiteley, 2013; Ha, Greenberg & Seltzer, 2011) in caregivers of children with disabilities. Gallagher and Whiteley (2012) compared the blood pressure of caregivers of children with DD to that of parents of children without DD. They sampled 35 parents of children with DD and 30 controls who wore ambulatory blood pressure (BP) monitors throughout the day for a day. The study showed that caregivers of children with DD had a higher mean systolic BP than parents of children without developmental problems. Measuring blood pressure levels of caregivers is significant because there has been an established link with onset of cardiovascular diseases (Vara-García *et al.*, 2018).

Moreover, the caregivers of children with DD experience higher psychological morbidities like anxiety and depression than the general population. These challenges may be due to caregiving demands and uncertainties of the future (Cramm & Nieboer, 2011). Research has linked depression to inflammatory or autoimmune conditions, which may consequently alter the caregivers immune system (Brian, 2010), making them more prone to ill health (Calmasini *et al.*, 2019). Caregivers with depression may struggle with insomnia (Byun *et al.*, 2016) which can make them feel exhausted leading to difficulty coping with both physical and mental health. When caregivers struggle to achieve daily activities, including the care of their children with DD, they become anxious. Anxiety is also related to unhealthy lifestyle choices like smoking, drinking and poor diet (Mental Health Foundation, 2014). The findings above are of a great significance because a caregiver's functioning can be impaired by depression and anxiety in physical, social and emotional domains (Byun *et al.*, 2016; Mitter, Ali & Scior, 2019). Consequently, the impact of anxiety and depression can affect the care to be rendered to children with DD and may threaten the sustainability of home care. This is because anxiety and depression, may drain the caregivers' energy and express irritability towards care recipients.

Caring for and having children with DD has consequences beyond anxiety and depression, such as stigmatization, discrimination and isolation that can affect the entire family, most especially the caregivers which may impact negatively on their social well-being (Mitter, Ali & Scior, 2019). Ngo *et al.* (2012) examined the effects of stigma on social lives of 70 caregivers of children with intellectual disabilities in Vietnam, caregivers reported high levels of restrictions

on their social lives. A study by Liu, Buckwalter and Burgener (2014) found that perceived stigma by caregivers led to depression. In Ghana, one of the barriers affecting persons with disabilities is stigma (Baffoe, 2013) which extends to their caregivers. Many reasons have been cited as contributing to stigma, including superstition, lack of empathy, and the belief that children with disabilities are children of rivers (Opoku *et al.*, 2017). Decreased levels of social support have been identified as influencing stress and psychological distress (van Aswegen *et al.*, 2019; Yamaoka *et al.*, 2015). This means that increased social support can be a coping strategy to buffer the effects of stress.

Caregivers whose health is compromised by the demands of caregiving cannot offer the best care for the child with DD, and this has several implications. First, it is not in congruence with the Sustainable Development Goal [SDG] 3, which emphasizes good health and well-being (United Nations, 2015). Second, it is likely to put pressure on the already stretched healthcare system in Ghana, which is attributable to the central government's poor financial commitment (Adua *et al.*, 2017). Third, it may compromise the concept of Community-Based Rehabilitation (CBR) which emphasizes community integration of people with disabilities.

1.2 PROBLEM STATEMENT

Parents of children with DD have reported greater levels of stress during various stages of their children's development including infancy, early childhood and adolescence (Woodman, Mawdsley & Hauser-Cram, 2015). High stress levels tend to remain stable or may increase over time (Woodman, Mawdsley and Hauser-Cram, 2015) and have been linked to caregivers' parenting style where they may be less responsive, more authoritarian and neglectful in their caregiving duties (Ponnet *et al.*, 2013; Rousseau *et al.*, 2013). It may also lead to inconsistent discipline, lack of appropriate structure and guidance and unrealistic expectation for the children (Crawford & Manassis, 2011). Less attachment to children with DD have been reported among caregivers with high stress and could impact negatively on the child with DD. For example, Spruit *et al.* (2020) reported that insecure attachment is associated with emotional problems in children.

Poor health status of the caregiver is linked to frequent hospitalizations of the child with DD (Murphy *et al.*, 2007), emotional and behavioural problems (Goodman *et al.*, 2011), lower health-related quality of life of the child (Ferro & Speechley, 2009), and lower quality of supervision (Phelan *et al.*, 2014). Although a number of studies have explored the experiences

of caregivers of children with DD in Ghana (Oti-boadi, 2017; Kyerematen*g et al.*, 2019; Amo-Adjei *et al.*, 2023), with most reporting poor health outcomes, there is general lack of literature on interventional studies that are designed to ameliorate the effects of increased stress and burden of caregiving in caregivers. There are limited caregiver-focused interventions done in Africa (Masulani-Mwale *et al.*, 2019), often with small sample sizes (van Aswegen *et al.*, 2019; Abedin & Molaie, 2010) and focusing on only one aspect of well-being of the caregivers while neglecting other areas (Masulani-Mwale *et al.*, 2019).

In Ghana, the rising incidence of DD has led to an increased need for informal caregivers who take on the role of caregiving. However, support services for these caregivers remain scarce (Acheampong et al., 2017), underscoring the importance of enhancing caregivers' capacities. According to Amo-Adjei et al. (2023), caregivers of children with special needs receive training from various non-governmental organisations (NGOs) at the community level, typically lasting few days. This training covers areas such as counselling, financial assistance, and educational opportunities for the caregivers, with churches and NGOs often being the organisers (Amo-Adjei et al., 2023). At the district level, the Department of Social Welfare provides counselling support to address the emotional needs of caregivers (Amo-Adjei et al., 2023).

Zuurmond *et al.* (2019) adopted and implemented the "Getting to Know Cerebral Palsy" programme among caregivers of children with cerebral palsy, focusing on empowering caregivers as the main goal. Nevertheless, the authors noted that focusing solely on empowerment could be problematic, as it does not address other significant issues such as poverty, stigma, and discrimination (Zuurmond *et al.*, 2019). The Government of Ghana, have made strides towards providing support to caregivers. The Department of Social Welfare of the Ministry of Gender, Children and Social Protection and UNICEF Ghana have developed a training manual for caregivers with disabilities. The focus of the manual is to equip caregivers with knowledge and skills for them to provide the needed quality of care (UNICEF, 2020). Though the training manual aims to enhance the capacity of staff at both the national and sub-national levels, the execution process remains ambiguous. The training manual fails to highlight how the holistic well-being of the caregivers will be enhanced. The study, therefore, seeks to develop a culturally appropriate and sustainable psychosocial support programme to improve the well-being of caregivers of children with DD in Ghana. Thus, the current study will not focus on only empowering the caregivers in terms of skills, but also apply practical ways of promoting physical, psychological and social well-being.

1.3 RESEARCH QUESTION

How can a psychosocial support programme tailored for Ghanaian context improve the well-being of caregivers of children with DD?

1.4 PURPOSE (AIM) OF THE STUDY

The overall purpose of the current study was to develop a psychosocial support programme for caregivers of children with DD in Ghana.

1. The primary outcome of the study was to decrease stress among caregivers of children with DD.
2. The secondary outcome was to evaluate the impact of the support programme in reducing anxiety, depression, burden, blood pressure, somatic symptoms, and cortisol levels.

1.4 RESEARCH OBJECTIVES

Phase 1: Exploratory phase

1. To explore experiences and health needs of caregivers of children with DD.
2. To describe support programmes implemented for caregivers of children with DD and their outcomes.

Phase 2: Development phase

3. To develop a psychosocial support programme for caregivers of children with DD using the Medical Research Council [MRC] framework.
4. To verify the psychosocial support programme through an expert panel review.

Phase 3: Implementation phase/Pilot testing

5. To conduct a baseline assessment of caregivers' burden of care, stress levels, cortisol levels, blood pressure, anxiety, depression, somatic symptoms and perceived social support.
6. To pilot-test the psychosocial support programme among a sample of CGs of children with DD.
7. To evaluate the caregivers' outcomes (burden of care, stress levels, cortisol levels, blood pressure, anxiety, somatic symptoms and perceived social support) immediately after the psychosocial support programme.

1.5 SIGNIFICANCE OF THE STUDY

1.5.1 Nursing research

This study will possibly add to the body of knowledge especially in the context of interventions for caregivers of children with DD. Thus, it can serve as a baseline study for other studies that will be done in the same field as well as related context.

1.5.2 Nursing practice

In addition to the above, an evidenced-based psychosocial support programme which is sustainable and culturally specific will be developed and administered by nurses with the potential of promoting the health and well-being of caregivers of children with DD. There is a global initiative to improve the quality of care provided for clients and their informal caregivers, one of the core components is nurse-led intervention research (Sidani and Braden, 2011), which should be evidence-based.

1.5.3 Policy makers

Findings from the current study may help policy makers like Ministry of Health and Ghana Health Service to develop programmes and policies aimed at improving the well-being of caregivers of children with DD. For example, a policy where caregivers of children with DD will be enrolled unto the National Health Insurance Scheme for free can be initiated. Again, a free health screening policy during each visit to the hospital with children with DD can be implemented. Policy that allows integrated health care services and support systems at the community level or home environment for children with DD just as midwives and nurses provide home-based health services in maternal and newborn care can be developed. In such policies, public health/community health nurses can offer support to care giving in the home environment; for instance, in medical review, medical appointments, feeding support, self-care, oral/skin hygiene, diaper hygiene, among others.

1.5.4 Caregivers

Caregivers will have adequate information on factors that usually contribute to their burden and increase their stress levels during the support programme. They will be empowered to take care of their mental health as well as their general well-being.

1.6 OPERATIONAL DEFINITIONS

1.6.1 Caregiver

A caregiver is any individual significantly related to another person who has a chronic or disabling condition and provides a range of assistance without charging any amount of money (Sanuade & Boatemaa, 2015). In this study, a caregiver refers to a person who is mainly responsible for the day-to-day care and spending an average of 8 hours with the child with DD yet has not received any formal training in terms of managing such conditions.

1.6.2 Developmental disability

These are disabilities associated with limitations as well as impairment in cognitive functions. The limitations could be that of learning, skills and adaptive behaviour (Salvador-Carulla *et al.*, 2011). In this study, DD refers to any condition that affects the child's ability to manage physical, learning and behaviour. It will include Cerebral Palsy (CP), Autism Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Intellectual Disability (ID) and Down Syndrome (DS).

1.6.3 Caregiver burden

Burden is described as the response that occurs when someone takes up the responsibility of caring for another individual who is ill. This response is as a result of perceived stress and it has been described as multidimensional in nature (Kim *et al.*, 2012). In this study, burden refers to imbalance created by caregiving demands on the person caring for the child with DD which directly and negatively affects them in multiple aspects including physical, emotional and social lives.

1.6.4 Child

A child is an individual who by his/her chronological age is placed between the developmental period of infancy and puberty (Rathus, 2013). In this study, a child is described as person between the ages of 5 and 14 who have received a diagnosis of DD specifically ID, CP, ASD, ADHD and DS.

1.6.5 Well-being

Well-being describes a condition of the individual that is usually characterized by good mental health, life satisfaction, sense of meaning and ability to manage stress (Galderisi *et al.*, 2015; Trudel-Fitzgerald *et al.*, 2019). In this study, well-being refers to psychological (being able to manage stress), physical (ability to improve functioning of the body) and social (ability to develop and maintain a support network).

1.6.6 Psychosocial support programme

Psychosocial support programme is a programme aimed at facilitating resilience within an individual or a group of individuals such as a family or community with the overall goal of helping them cope with the impact of crises now and also in future. The focus is both preventive and curative. It is preventive when it decreases the risk of developmental health problems and curative when it helps deal with psychosocial problems that may have risen as a result of effects of the crises. In the current study, psychosocial support programme is described as a curative and preventive programme aimed at improving the well-being of caregivers and to meet their needs which could be informational, emotional, physical, spiritual or social (Teeffelen, Nieuwenhuijze & Korstjens, 2011). The psychosocial support programme in this study is multicomponent which addresses skills training, education of the caregivers, caregiver support, caregiver self-care, and stress management (Brodaty & Arasaratnam, 2012).

1.7 THEORETICAL MODEL

The theoretical model for this study was the Stress Process Model. The model acknowledges that there is an interplay of factors leading to negative outcomes in the stress process. The factors include caregiving context, primary and secondary stressors and moderators (Pearlin *et al.*, 1990; Pearlin & Bierman, 2013). It is further described in Chapter 2.

1.8 SUMMARY OF THE RESEARCH METHODS AND DESIGN

Detailed research methods and design is described in Chapter three.

1.8.1 Research setting

The study was conducted at the Korle-Bu Teaching Hospital (KBTH), in Accra, which is the oldest and largest tertiary facility located in the Southern part of Ghana.

1.8.2 Research design

Research design refers to the overall approach used by the researcher to conduct a study. It is a concise and coherent plan to handle stated research question(s) through the collection, interpretation, analysis, and discussion of data. The methodologies and methods consolidated in the design of this research study are influenced by several factors. One of such is the researchers' point of view over their beliefs in the nature of knowledge (epistemology) and reality (ontology), often shaped by the disciplinary areas the researcher belongs to. A research design is a framework that has been created to find answers to the research questions. The study employed a multi-method approach for the purpose of developing a psychosocial support programme for caregivers of children with DD. Different designs were employed at different phases of the study. Both qualitative and quantitative designs were used. Table 1.1 presents the overview of the research methods that are explained in detail in Chapter 3.

Table 1.1 Overview of research methods

Phase	Studies	Objective	Design	Sample/Sampling	Data Collection Process	Instrument	Analysis
Phase 1	1.	To describe the experiences and health needs of caregivers of children with DD.	Qualitative design	Purposive sampling based on saturation	Semi-structured interview	Interview guide Voice Recorder Diary	Thematic analysis
	2.	To describe support programmes implemented for caregivers of children with DD and their outcomes.	Scoping Literature review (Levac et al., 2010; Arksey & O'Malley, 2005)	Intervention studies for caregivers of children with DD.	Electronic databases: PubMed, PSYCHINFO, Cochrane Library, ERIC and CINAHL complete and also from grey literature.	-	Thematic analysis
Phase 2	3.	To develop a psychosocial support programme for caregivers of children with DD using the Medical Research Council [MRC] framework for development of complex interventions.					
	4	To verify the psychosocial support programme through an expert panel review.	-	Purposive Sampling= 12 (general nurses, mental health nurses, psychologists, and psychiatrist, doctors, physiotherapist)	Delphi Technique	-	Cohen's kappa

Phase	Studies	Objective	Design	Sample/sampling	Data collection process	Instrument	Analysis
Phase 3	5	To conduct an assessment of the caregivers' burden of care, stress, cortisol level, level of anxiety, somatic symptoms, blood pressure and perceived social support.	Pre-test and post-test design	Simple random sampling Sampling n=53	Survey	**Subjective measures** Zarit Burden Interview Depression Anxiety and Stress (DASS) scale Patient health Questionnaire-15 (PHQ-15) Multidimensional Scale of Perceived Social Support **Objective measures** Cortisol analysis BP measurement	Descriptive and inferential statistics Pearson correlation (Relationship between caregivers' demographic variables and scores on stress, burden, depression and anxiety)
	6	To pilot test the psychosocial support programme on the caregivers of children with DD.					

Phase	Studies	Objective	Design	Sample/sampling	Data Collection process	Instrument	Analysis
	7	To evaluate the caregivers' outcomes (burden of care, stress levels, cortisol levels, blood pressure, anxiety, somatic symptoms and perceived social support) immediately after the psychosocial support programme and at 3 months post-intervention.	Pre-test and Post-test design	Simple random Sampling n=53	Survey	Same as 5	Paired sample t test and the Wilcoxon ranked test were used to compare scores of caregivers who participated completed the pre- and post-programme assessments.
	8	Justification and recommendation					

1.9 OVERVIEW OF THESIS

Chapter 1: Orientation

The chapter focuses on the overview of the study by providing insight into the overall structure of the study. It begins by contextualizing the background and rationale of the study and then stating the problem. The primary and secondary outcomes of the study are highlighted. The significance of the study which seeks to emphasize the study's role and contribution in societal and scientific context is discussed. Finally, the research context and summary of the research methods are presented.

Chapter 2: Literature review

The chapter discusses the theoretical foundations of the study, and carefully reviews related studies that identify existing gaps in relation to the subject matter.

Chapter 3: Research methodology

Chapter three presents the methods used in conducting the study. The chapter begins by throwing light on the research design used for the study. Other areas discussed include the research setting, sampling technique and sample size, data collection methods and instruments, and data analysis. The ethical consideration for the study is also emphasised.

Chapters 4: Phase 1a

The chapter examines the phenomenological approach employed to explore the experiences and health needs of the caregivers of children with DD. The findings from the study are discussed.

Chapter 5: Phase 1b

The scoping review done to identify interventions and programmes that exist for caregivers of children with DD is represented in this chapter as well as discussion of the findings.

Chapter 6: Phase 2

Chapter 6 examines mixing of the data obtained from the phenomenological study and the scoping review in phase 1. It also includes the expert review of the psychosocial support programme for the caregivers of children with DD. The approach and methods employed as well as details of the intervention are also presented.

Chapter 7: Phase 3

This chapter emphasised the evaluation of the caregiver psychosocial support programme and outcomes. The primary and secondary outcomes are assessed prior to roll out of the support programme. The duration and nature of the programme is described. The post-assessment of the outcome variables after the programme is described.

Chapter 8: Justification and recommendation

The final chapter of the thesis presents the summary and concluding remarks, the study limitations as well as recommendations for improving the well-being of caregivers of children with DD.

Table 1.2: Summary structure of thesis

CHAPTER		DESCRIPTION
1	**Overview of the Study**	The introduction and background of the study
2	**Theoretical framework and Literature Review**	Theoretical framework and Literature review on stress and burden, physical, psychological and social well-being of caregivers of children with DD
3	**Research Methodology**	The methods and tools used to reach the results of this study are described, thus, answering the research question and meeting the objectives to fulfil the purpose of the study.
4	**Experiences and health needs of caregivers**	The experiences of caregivers of children with DD as well as identify their health needs which have arisen out of their caregiving role are explored.
5	**The Scoping Review**	The current state of interventions available for caregivers of children with DD are established through a scoping review in order to develop a psychosocial support programme
6	**The Development of Psychosocial Support Programme**	A psychosocial support programme to assist improve the physical, psychological and social well-being of caregivers of children with DD is developed
	Confirmation of the Psychosocial Support Programme	The psychosocial support programme developed for caregivers of children with DD is evaluated and revised through the expert panel review
7	**Pre-intervention**	The primary and secondary outcome variables of the caregivers before the commencement of the psychosocial support programme is assessed
	Intervention	Describes the nature and characteristics of the psychosocial support programme for caregivers of children with DD
	Post-intervention	Evaluates the outcome variables after the completion of the psychosocial support programme among caregivers of children with DD
8	**Justification and recommendation**	To discuss the results of the study, conclude and made recommendations.

1.10 SUMMARY OF CHAPTER ONE

Chapter one provided an introduction and background to the study. The aim, objectives, and operational definition of terms were described. An overview of the research and the research methods were also described. The next chapter outlines review of scholarly work on stress and burden of caregivers of children with DD guided by the Stress Process Model.

CHAPTER 2

LITERATURE REVIEW

2.0 INTRODUCTION

The chapter describes, summarises, evaluates and clarifies relevant information about the research topic, especially emphasising the specific research objectives. Specifically, the chapter reviews studies on caregiver health, with emphasis on those caring for children with DD from 1990 to 2021, though the evidence was also drawn from other caregiving studies, especially caregivers caring for persons chronic conditions and the elderly. A number of databases were used. Examples of databases used for the search included CINAHL, PubMed, Biomed Central, and Science Direct. To obtain the literature, a combination of the broad key terms joined by the Boolean operators "AND" and "OR" were used to conduct the search. The keywords for the search were as follows: *child*, *developmental disability*, *caregivers*, *stress*, *burden*, *depression*, *anxiety*, and *well-being*. The evidence gathered from the reviewed studies was crucial in shaping the discussions in this study.

2.1 THEORETICAL FRAMEWORK: STRESS PROCESS MODEL

2.1.1 Rationale for choice of theoretical framework

The Stress Process Model (Pearlin *et al.,* 1990) is described as one of the influential models used to describe the complex construct of stress. The Stress Process Model serves as a framework for understanding mechanisms by which stressors lead to health outcomes (Pearlin *et al.*, 1990; Pearlin, 1999; Aneshensel & Mitchell, 2014). The SPM has been used for the purpose of tailoring interventions and programmes targeted at the caregiver (Guay *et al.*, 2017). The stress process model has garnered substantial empirical support and has been applied across a wide range of samples including caregivers of dementia (Judge, Yarry & Orsulic-Jeras, 2010; Geiger *et al.*, 2015; Wang *et al.*, 2023), persons with schizophrenia (Yu *et al.*, 2020); persons with traumatic brain injury (Chronister and Chan, 2006), and working-age husbands with mild to moderate stroke (Kniepmann, 2014). The SPM has also been applied to caregivers of children with inherited metabolic diseases (Manalel *et al.*, 2024), ASD (Mumtaz, Fatima & Saqulain, 2022), and cerebral palsy (Majnemer *et al.*, 2012).

The SPM is adopted in the study because 1) the model is flexible and supports inclusion of a broad range of variables, an important feature given the complexity of this topic and 2) the

model includes multiple caregiver outcomes which is important as the psychosocial programmes aims at addressing multiple caregiver outcomes. 3) the inclusion of protective factors and resources in this model is particularly important given that not all caregivers who encounter stressors provide low-quality. Identifying the right resources and including them in the psychosocial programme could be key in mitigating the negative effect of stress.

2.1.2 Assumptions of Stress Process Model

The overarching theoretical foundation for this study is the Stress Process Model. The theory is guided by three key assumptions. The first is the interrelationship existing between different factors that come together to influence an individual's well-being (Aneshensel & Mitchell, 2014; Aneshensel, 2015). This interconnectedness and interrelationship imply that a change in one factor can lead to variation in other factors, which sets in motion a series of ripple effects. The effects can be observed in two ways: they can occur immediately or later. The interrelationship that exists between factors and the series of effects that may arise from them explains why stress is considered a process. The second assumption is that stress does not concern individuals who do unusual things or have extraordinary experiences. On the contrary, it covers people who are socialised to participate in normal life activities (Aneshensel, 2015). Thus, how stress is conceptualised in this context is distinguishable from how it is conceptualized in psychiatry as an unusual response to unusual circumstances. The assumption that mental disorders are abnormal leads to the perception that the causes are abnormal. The third assumption of the model is the naturalistic origins of stress (Aneshensel, 2015). The emphasis, though, is not on the historical circumstances leading to stress as that could be difficult to establish. Other researchers may be able to rely on laboratory investigations to examine stress, using animals, but it is not same with the stress process, as humans are indispensable.

2.1.3 Components of Stress Process Model

The framework of the SPM comprises four main components, namely: background and context of stress; stressors; mediators of stress and outcomes or manifestations of stress (Pearlin et al., 1990; Pearlin & Bierman, 2013; Wilborn-Lee, 2015). The background and context begin the stress process, while the outcomes end it. In between these two are the stressors, which could be primary or secondary. Mediators of stress influence the relationship between stressors and outcome variables directly or indirectly.

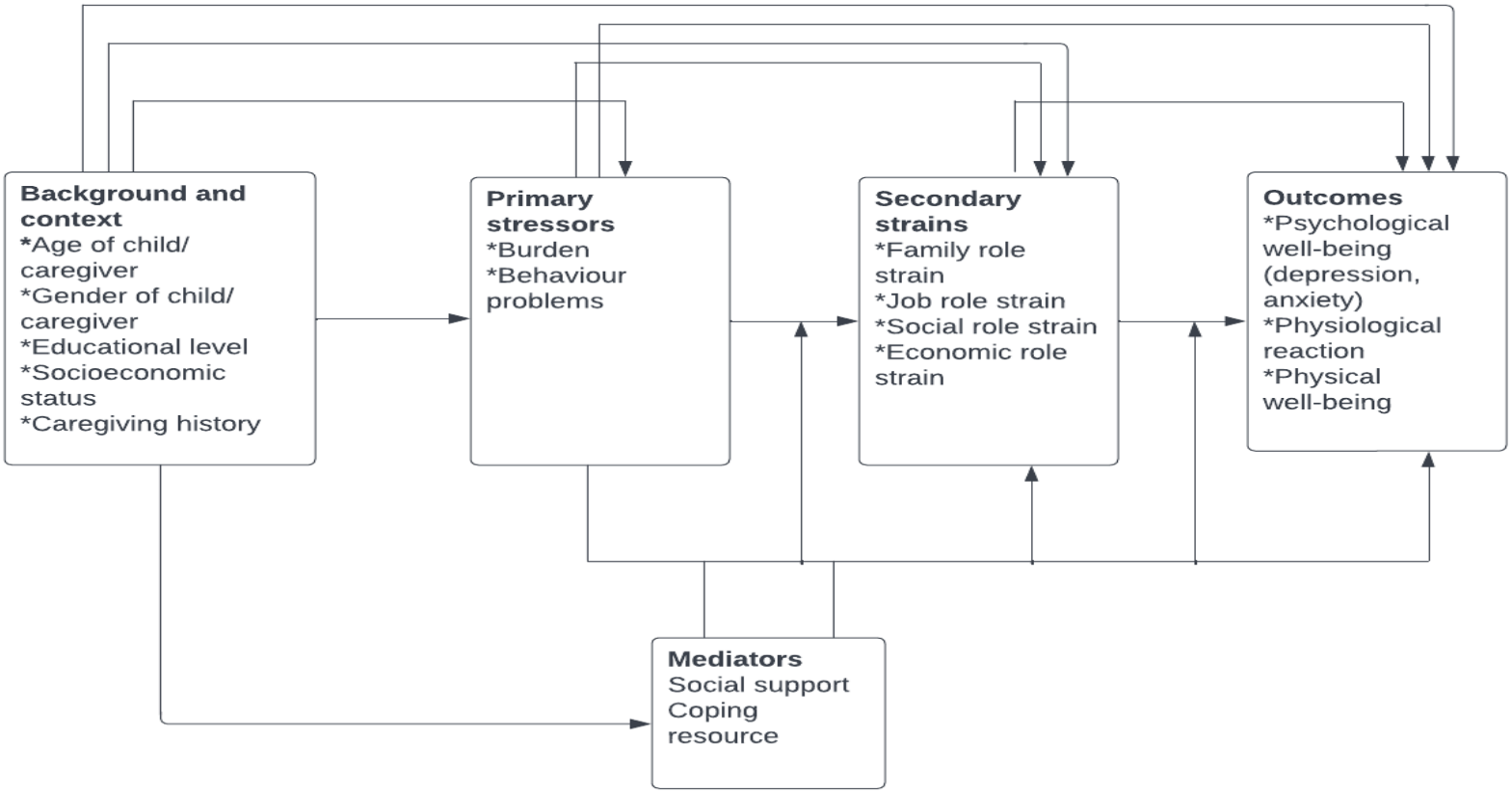

Figure 2.1 Stress Process Model (Adapted from Pearlin et al., 1990)

2.2 BACKGROUND AND CONTEXT OF STRESS

In the stress process, background and context are considered antecedents and are fundamental as they influence the outcome of stress for caregivers (van Ryn *et al.*, 2011; Wilborn-Lee, 2015). They are linked to every other component of the stress process and influence outcomes of well-being directly or indirectly. The caregiver's characteristics, such as ascribed and achieved statuses, influence the caregiving process as well as its consequences. Ascribed status includes variables like caregiver age, gender, and race, while achieved status includes variables like educational level (Pearlin & Bierman, 2013; Aneshensel & Mitchell, 2014). These statuses are more likely to influence the kind and intensity of stressors encountered by caregivers, their resources, and how stress is even expressed. This is possible as statuses define the persona and identity of the individual.

Statuses are often stratified and consist of certain intrinsic inequalities that are embedded in power, prestige, and privilege (Herbo, 2017). These inequalities are likely to intrude on one's daily existence, affect the experiences that arise out of it, and are seen as the tool that causes diseases (Pearlin & Bierman, 2013). Apart from the caregivers' status, caregiving history is equally considered. An example is how long the caregiver has been in the caregiving role, the average hours of care provided per day, and the relationship of the caregiver to the care-recipient, which could be a mother, father, daughter, son, or mother-in-law. For the purpose of this study, the following background and contextual factors will be considered: (a) caregiver's age; (b) caregiver's gender; (c) marital status; (d) caregiving history; (e) care recipient's age; and (f) gender. These have been described below.

2.2.1 Age of caregiver

Researchers have highlighted the role of age in the perception of stress (Thoits, 2010; Wilborn-Lee, 2015) and how it influences the well-being of the caregiver. Studies have established some form of relationship between caregiver's age and psychological outcomes like depression, anxiety (Chou *et al.*, 2010; Dave *et al.*, 2014; Martins & Couto, 2014; Pocinho & Fernandes, 2018). Though some studies have found a positive relationship between age and psychological well-being [depression or anxiety] (Martins & Couto, 2014; Pocinho & Fernandes, 2018), others have also found a negative relationship between caregiver age and psychological well-being (Mbugua, Kuria & Ndetei, 2011; Dave *et al.*, 2014). No relationship has been reported between age and caregivers psychological well-being (Chou *et al.*, 2010; Sit *et al.*, 2020).

Additionally, age has been reported to be linked to the physical well-being of caregivers (Martins & Couto, 2014).

Increased caregiver's age was found to be significantly associated with anxiety but not with depression (Pocinho & Fernandes, 2018). In a qualitative study conducted in Portugal, the researchers explored the everyday experiences of parents aged 65 years and older with disabled children (Martins & Couto, 2014). They found that caregivers may experience changes in their health both psychologically and physically. However, since the study was limited to older caregivers aged 65 years or older, it would be erroneous to conclude from this study that younger caregivers experience fewer or no psychological changes. Additionally, while the study provides some insight, it has some limitations. Only five caregivers were recruited for the study, making it difficult to generalise the findings.

Conversely, Dave *et al.* (2014) found that although there was no statistically significant relationship between the age of caregiver and anxiety, younger caregivers scored higher on anxiety. Depression and caregiver's age had a statistically significant negative relationship. It was determined that younger caregivers had a higher chance of developing depression. However, caregivers may be susceptible to anxiety regardless of their age. They went on to say that the elderly caregivers may have acquired coping mechanisms to manage the anxiety that comes with their roles as carers. In line with the previous findings, Bhatia *et al.* (2015) found a significant inverse relationship between the age of carers and depression, but not anxiety. However, Sit *et al.* (2020) and Wijesinghe *et al.* (2015) did not find any relationship between caregivers' age and burden, though burden had a significant positive relationship with depression, anxiety and stress.

2.2.2 Gender of caregiver

Studies done on the role of gender in the outcomes of caregiving have mainly provided evidence to support the idea that females are more likely to have poor caregiving outcomes (Foody, James & Leader, 2014; Pocinho & Fernandes, 2018). That notwithstanding, some studies have posited that gender does not play a role (Charnsil & Bathia, 2010; Dave *et al.*, 2014). Foody, James and Leader (2014) sought to find out the differences between mothers and fathers caring for children with ASD in terms of parental distress, anxiety, and depression. Mothers mean scores on anxiety, depression and parental distress was high as compared to fathers. Parental responsibility scores were high among mothers, which could partly explain why they scored higher than fathers who were also providing care. Consistent with the above,

Pocinho and Fernandes (2018) compared mothers and fathers who are caregivers of children with and without disabilities. Mothers scored high on stress, anxiety and depression. After subjecting it to further statistical testing, gender was found to have a significant relationship with depression. Zamora and Labao (2020) investigated the variables affecting low back pain (LBP) among twenty-two Filipino caregivers of children with disabilities. Compared to fathers, mothers who provided care were more likely to report LBP. Despite the modernization of family roles and structures in the Philippines, women are more actively involved in raising their children and also bear the additional responsibility of caring for their husbands and other extended family members, according to the researchers. Consequently, mothers who provide care for their disabled children may experience physical health issues as a result of taking on these extra duties when raising a child with a disability.

Sit *et al.* (2020) found a relationship between being a female caregiver of a family member with an ID or mental disability and increased caregiver burden in China. In their study, increased burden was linked with increased levels of anxiety and depression. Yiengprugsawan *et al.* (2012) established that being a caregiver for a person with a disability, mental illness, or the aged was linked with lower back pain and psychological distress. However, poor or very poor health was reported by females. On the other hand, Dave *et al.* (2014) did not find any relation between the gender of caregivers and caregiving outcomes like anxiety and depression. Likewise, no relationship was found between gender and depression in those who care for children with ASD (Charnsil & Bathia, 2010).

Several theories have been used to explain the gender difference in caregiving. First, according to the sociological explanation, how men have been socialised in society affects their approach, perception, and response to caregiving. Men are not typical caregivers and may approach caregiving in ways that are not similar to those of females (Sharma, Chakrabarti & Grover, 2016). The second explanation is according to the stress-coping theory. Females prefer emotion-focused coping mechanisms (distancing from the source of stress) while males prefer problem-focused coping mechanism (engaging with the source of stress) (Williams *et al.*, 2019). These could explain why there is a link between females and high burden and psychological or physical morbidity.

2.2.3 Educational level of the caregiver

Studies reviewed have mostly reported the influence of education on outcomes of caregiving (Yildirim Sari & Başbakkal, 2010; Charnsil & Bathia, 2010; Pocinho & Fernandes, 2018; Farajzadeh *et al.,* 2021). Pocinho and Fernandes (2018) examined the relationship between caregivers' educational level and anxiety, depression, as well as stress. The mean scores for anxiety, depression, and stress decreased with increasing levels of education, which was statistically significant (p= 0.00). They came to the conclusion that lower poorer psychological outcomes were linked to lower educational attainment. Similarly, among caregivers of children with neurodevelopmental disorders, Maridal *et al.* (2021) reported a significant relationship psychological distress and caregiver illiteracy.

In a study done in Thailand, Charnsil and Bathia (2010) established that the level of education was the only factor that predicted poor caregiving psychological outcomes (major depressive disorder and dysthymic disorder) (p = 0.03). While Yildirim Sari and Başbakkal (2010) discovered that mothers of children with intellectual disabilities whose educational attainment was low also had high levels of depression, Farajzadeh *et al.* (2021), on the other hand, reported a relationship between low education and high levels of anxiety but not depression or stress. Sit *et al.,* (2020) did not find any relation between level of education and burden or perceived caregiving difficulty. Similarly, Dave *et al.* (2014) did not find any significant relationship between educational level of caregivers assisting children with intellectual disabilities and their anxiety and depression. Consistent with the findings above, Ribeiro *et al.* (2014) did not find a relationship between education and psychological outcomes like depression and anxiety.

Some studies have explained the link between level of education and outcomes of caregiving. Factors like burden, self-esteem, and access to resources have been cited. Yildirim Sari and Başbakkal (2010) posit that the level of education of the caregiver is significant as it can influence their perception of burden. Increased educational attainment is associated with a decreased perception of burden. Finally, caregivers who are educated are likely to have information about formal support systems and resources and how to access them (Duvdevany & Abboud, 2003; Yildirim Sari & Başbakkal, 2010). Concerning resources, Charnsil and Bathia (2010) mentioned that caregivers with low education may not explore resources available to assist them in their caregiving duties. The factors elaborated above are likely to positively influence the well-being of caregivers who are more educated than those with little or no education (Yildirim Sari & Başbakkal, 2010).

2.2.4 Income level of caregiver

The income level of caregivers has been linked to negative psychological outcomes. A study conducted in Kenya by Mbugua, Kuria and Ndetei (2011) found a significant relationship between being unemployed as a caregiver for a child with an intellectual disability and increased risk of developing negative psychological outcomes like depression. The researchers explained that caregivers who are unemployed have limited income. In Brazil, Ribeiro *et al.* (2014) reported that mothers of children with CP who were being paid had reduced parental stress. Farajzadeh *et al.* (2021) conducted a study to examine the predictors of mental health among 160 parents of children with CP in Iran, low-income level was found to predict caregiver anxiety but not depression or stress. In a study involving 355 mothers of children with intellectual disability in Turkey by Yildirim Sari and Başbakkal (2010), poor financial status of the family with a child with disability was related to depression among caregivers. This was confirmed as monthly family income among caregivers of adolescents had a statistically significant relationship with depression and anxiety but not stress (Power *et al.*, 2019).

Income has been linked to quality of life of caregivers of children with DS (Amaral *et al.*, 2020). Though Zamora and Labao (2020) reported a negative correlation between caregivers' income and physical health (−0.384), the relationship was not statistically significant (0.078). Contrary, to the above studies, conflicting results have also been reported. Bourke-Taylor *et al.* (2013) in a study conducted in Australia established that there was no association between maternal depression and family income in mothers who are caregivers of school-aged children with intellectual and developmental disabilities.

2.2.5 Marital status of caregiver

A common agreement in numerous studies is that marriage provide considerable benefits to mental health. In these studies, individuals who are married as compared to their counterparts who are unmarried showed lower levels of depression, psychological distress, and psychiatric disorder. At the same time, they exhibited higher levels of life satisfaction and subjective well-being (Williams, Frech & Carlson, 2010). Farajzadeh *et al.* (2021) reported a significant relationship between being married and high anxiety scores of the caregiver, however, no such relationship was found between being married and depression and stress. Mbugua, Kuria and Ndetei (2011) established a significant relationship between marital status and depression. In their study caregivers who were married were at a higher risk reporting high levels of

depression, than those caregivers who were single, divorced or separated. They concluded that it was possible that the married caregivers were not getting the needed emotional support from their spouses. Zamora and Labao (2020) reported no statistically significant relationship between marital status of the caregiver and physical health (LBP).

Three models have been used to explain the role of marriage; marital resource, selection bias and marital distress (Williams, Frech & Carlson, 2010). The marital resource model projects that the mental health of unmarried individuals (single, divorced, widowed) will be poorer as compared to those who are married due to the fact that they lack resources provided by marriage that would enhance health (Williams, Frech & Carlson, 2010). On the other hand, the selection bias model insists marriage may not necessarily lead to a better well-being, rather an individual having a good mental health has the likely odds of entering and remaining in marriage. (Williams, Frech & Carlson, 2010). Finally, the marital crisis model posits that the strains of marital dissolution undermine mental health, though it might be transitory (Umberson & Powers, 2009). There is an emerging evidence that being in a strained, unhappy, or inequitable marriage is worse for mental health than being single (Williams, Frech & Carlson, 2010).

2.2.6 Caregiving history

Caregiving history is either conceptualized as the duration of caregiving or the number of hours of providing care in an hour. Minichil *et al.* (2019) observed that caregivers of children with mental illness who had provided care for more than five years were four times more likely to experience depression than those who had cared for less than one year. They explained that the stressors experienced by the caregiver could increase over time, contributing to the caregiver's poor mental health outcome. On the contrary, Fernanda *et al.* (2016) reported that there was no significant relationship between duration of caregiving and burden among caregivers (0.09).

Charnsil and Bathia (2010) found that the number of hours spent during the day on the child with ASD was not significantly related to depression among Thai caregivers. They attributed it to cultural and contextual factors. According to the researchers, the collective nature of the Thai people leads to living together as extended family. In instances where the individual nuclear family lives together, there exist other close relations including sisters or brothers who live close to them. The other caregivers may serve as a source of support buffering the burden. Consistent with the above, Nam and Park (2017) reported that caregivers of children with ID who spent more time perceived more subjective burden and were more depressed than those with most severe disabilities.

2.2.7 Age of child with DD

While some studies have reported a negative correlation between the age of the child with disability and stress (Lee, 2013a), others too have found no changes between age of the child with disability and levels of stress (Lecavalier, Leone and Wiltz, 2006) or depression (Yildirim Sari and Başbakkal; 2010; Bourke-Taylor *et al.*, 2013) or psychological distress (Maridal *et al.*, 2021) or family functioning (Povee *et al.*, 2012) or physical health (Zamora and Labao, 2020) among caregivers. Other studies have found a positive relationship between age of a child with disability and stress (Ribeiro *et al.*, 2014) and worsening of self-reported maternal health (Eisenhowera, Bakera & Blacher, 2009).

Bhatia *et al.* (2015) examined the psychiatric morbidity and their correlates in caregivers of individuals with ID. The findings of their study showed that there was a significant relationship between caregiver's anxiety and patient's age. Children with a disability who are old predicted higher scores of depression and anxiety in their parent caregivers than those who were young. However, both groups did not differ significantly on the scores of stress (Pocinho & Fernandes, 2018). Inconsistent with the above, Ribeiro *et al.* (2014) reported that mothers of old children with CP were more stressed than mothers of younger children and adolescents. A study by Lee, (2013) observed that the level of stress experienced by the caregiver decreased as age of child with the disability increased (Lee, 2013a).

However, other studies have found no relationship between age of the child with disability and mental health outcomes. For example, Zamora and Labao (2020) reported a negative correlation between LBP of caregivers and age (X^2 = -0.078), however, this relationship was not statistically significant (0.731). Similarly, Yildirim Sari and Başbakkal (2010) did not find any significant relationship between age of child with intellectual disability and the level of depression in caregivers. In consistent with the above, Maridal *et al.* (2021) reported no significant relationship between the age of the child with neurodevelopmental disorder and psychological distress (0.762). Power *et al.*, (2019) did not find the age of adolescents with CP as a predictor of poor mental health outcomes (stress, anxiety and depression).

2.2.8 Gender of the child with DD

According to Houtrow *et al.* (2014), childhood disabilities are more common in boys than in girls. Only a small number of researches, have examined the relationship between caregiver stress and the gender of the child with disability. The majority of research has found no

relationship between the gender of the disabled child and family functioning (Churchill *et al.*, 2010), psychological distress (Maridal *et al.*, 2021), depression (Power *et al.*, 2019), or anxiety (Power et al., 2019).

Chandravanshi *et al.* (2017) examined the relationship between the gender of children with intellectual disability and prevalence of depression in mothers. The findings of the study show that females with disabilities were more likely to pose a risk in negative caregiving outcomes of their caregivers. They observed that the contextual setting of the study might offer some explanation. In India, females with disabilities are regarded as a burden in society. Additional to caregivers assisting them with ADL, ensuring menstrual hygiene may lead to increased stress and burden.

Being a female with a neurodevelopmental disorder was not significantly related to high psychological distress (Maridal *et al.*, 2021). Power *et al.* (2019) observed that being a male or female adolescent with CP did not affect caregivers' high levels of stress depression and anxiety. The gender of the disabled child did not have any significant-relationship with the psychological well-being of the caregivers (Pocinho & Fernandes, 2018). Dave *et al.* (2014) concluded that the gender of the child with a disability was not associated with high levels of anxiety among caregivers of children with intellectual disability. Churchill *et al.* (2010), in a study among caregivers of children with special needs, reported that there was no relationship between the gender of the care recipient and psychological outcomes like depression. Furthermore, Povee *et al.* (2012) found no evidence of a gender effect on marital adjustment or family functioning in households caring for a child with Down syndrome.

2.3 PRIMARY AND SECONDARY STRESSORS

Stressors are those things that create a problem for the caregivers, be it their experiences, conditions, or activities they are involved in. These are considered not only to frustrate their efforts but also act as a threat and create fatigue. Aneshensel & Mitchell (2014) defined stressors in the context of caregiving defined stressors in the context of caregiving as the challenging conditions and tough circumstances encountered by caregivers. Emphasised in this conceptualization is that stress originates at an intersection between one's external environment and internal state; it arises when a patient's needs conflict with a caregiver's ability to meet those needs, or when such demands interfere with achieving other objectives (Pearlin & Bierman, 2013).

Primary stressors arise from patient's or care recipients' needs as well as care that will have to be rendered as a result of those needs (Wilborn-Lee, 2015). The nature and magnitude of care are dependent on the kind of needs demanded by care recipient. The behaviour problems exhibited by the care recipient and the ADL dependencies are examples of the primary stressors. The burden or overload experienced by the caregiver which is considered as subjective is equally placed under primary stressors. Others include the functional and cognitive status of the care recipient and relational deprivation.

The primary stressors may lead to other stressors referred to as secondary stressors (Aneshensel & Mitchell, 2014; Wilborn-Lee, 2015). Secondary stressors are thus the product of other stressors (Wilborn-Lee, 2015). For example; caregiving demands may at one point in time or permanently put a strain on the job of the caregiver. Other times, the demands can affect the caregivers' social relations and recreation activities. It may also lead to economic strain as caregiving for someone with a chronic condition may require substantial financial investments. The positioning of primary and secondary stressors in the stress process model does not suggest the superiority of primary stressors over secondary stressors, but rather how those two concepts are related. The burden of care and behaviour problems will be considered in this study. They are described in the subsequent paragraphs.

2.3.1 Burden of care among caregivers of children with DD

Numerous studies indicate that carers of children with disabilities experience burden more frequently (Koehler *et al.*, 2014; Barros *et al.*, 2017). Poor health outcomes and psychiatric morbidity are linked to high carer burden (Okewole *et al.*, 2011). Specifically, it has been associated with increased depression (Valenca *et al.*, 2012; Marrón *et al.*, 2013; Bhatia *et al.*, 2015; Lerthattasilp and Charernboon, 2015; Sit *et al.*, 2020), anxiety (Valenca *et al.*, 2012; Bhatia *et al.*, 2015; Sit *et al.*, 2020), psychological distress (Al-dujaili and Al-mossawy, 2017), low quality of life (Koehler *et al.*, 2014) and stress (Bhatia *et al.*, 2015).

The findings on the exact prevalence of burden of care have been varied across studies. Some studies have reported high burden (Vogan *et al.*, 2014; Suresh, Benjamin and Crasta, 2014), moderate burden (Barros *et al.*, 2017; Al-dujaili and Al-mossawy, 2017), moderately high (Oh and Lee, 2009) and no burden (Pineda-Frutos *et al.*, 2016). Pineda-Frutos *et al.* (2016) attributed the no burden reported in their study to how mothers perceive the caregiving role. According to the researchers, mothers (primary caregivers) may be attached strongly to the

problems of the child with a disability. When this happens, the mothers develop tolerance and temperance to the burden that is associated with caring for a child with a disability. They further explained that in the Mexican culture, the social role is assumed by the mother regardless of the state of the child (Pineda-Frutos *et al.*, 2016).

2.3.2 Behaviour problems of the child

Behaviour issues have been noted more frequently in children with DD than in typically developing children (Lach *et al.*, 2009; Freedman *et al.*, 2012). Numerous studies involving caregivers have revealed a correlation between behavioural issues in children with disabilities and stress (Firth and Dryer, 2013; Lee, 2013; Falk, Norris and Quinn, 2014; Woodman, 2014; Lovell, Moss and Wetherell, 2015; Zaidman-Zait *et al.*, 2018), depression in caregivers (Churchill *et al.*, 2010; Firth and Dryer, 2013; Lee, 2013; Falk, Norris and Quinn, 2014; Gallagher and Hannigan, 2014; Gallagher, Pilcha and Hannigan, 2018) , distress (Long *et al.*, 2015), poorer family functioning (Povee *et al.*, 2012), caregiver self-reported physical health problems (Lach *et al.*, 2009; Eisenhower, Blacher and Baker, 2013; Gallagher and Whiteley, 2013), fatigue (Seymour *et al.*, 2013), caregiver self-reported stigma (Gray, 2002), caregiving burden (Vogan *et al.*, 2014; Lerthattasilp and Charernboon, 2015), and poor immune responses in caregivers (Gallagher *et al.*, 2009). In contrast, Zaidman-Zait *et al.* (2018) reported that child problem behaviours did not predict parent distress.

2.4 MEDIATING CONDITIONS FOR BURDEN OF CARE

Some caregivers with overwhelming caregiving demands may not exhibit poor outcomes whilst others in the same category may have very poor physical, psychological or physiological outcomes. On the other hand, some caregivers with less caregiving demands may display vary poor outcomes and others who find themselves in the same situation may not show any poor outcomes. In trying to find answers to the above, Pearlin and Bierman (2013) summed it as caregivers react and respond to stressors differently. Researchers have tried to provide explanations for these occurrences or differences in the outcomes of the stress and have attributed it to the role of resources (Pearlin & Bierman, 2013). Resources can be described as those things upon which individuals rely in their response to stress and has the capacity of decreasing the impact of stressors (Au, 2017). These resources may act as mediators.

A mediator is a variable that explains the relationship between two variables, usually a predictor and outcome variable (Fairchild & McQuillin, 2010). The key assumption of a mediating variable is that the predictor variable leads to changes in the mediator variable which in turn causes a change in the outcome variable (Breitborde *et al.*, 2010). In intervention studies, Breitborde *et al.* (2010) and Fraser and Galinsky (2010) note that being able to identify mediating variables is very important. It is possible to refine intervention programs because mediators explain how these interventions yield positive clinical benefits (Breitborde *et al.*, 2010). Social support and coping have been identified as the two cardinal mediators in the SPM (Wilborn-lee, 2015). That is not to say other mediators do not exist. The role of social support has been extensively described in studies (Benson, 2012; Pearlin and Bierman, 2013; Werner and Shulman, 2013) and have been mentioned to reduce the impact of stress on well-being and health (Thoits, 2010). Three types of social support have been described; emotional, informational and instrumental (Pearlin & Bierman, 2013).

2.4.1 Role of social support in caregiving outcomes

According to Singh, Ghosh and Nandi (2017), the concept of social support can be divided into four main domains: quantity, role, quality, and source. Each one of these categories is assessed differently. The ability to offer instrumental, emotional, or informational support is how social support role is evaluated (Benson, 2012). There are two categories for social support quality: positive and negative (Lee *et al.*, 2019). The source is categorised in two ways, formal or informal (Shiba, Kondo and Kondo, 2016) and perceived or received (Benson, 2012). Singh, Ghosh and Nandi (2017) highlight that perceived support can be obtained from informal social networks such as family, friends and significant others.

Previous studies posit that perceived social support rather than quantity of support (Benson 2012; Werner and Shulman 2013) affects the mental health of caregivers of children with disabilities (Benson, 2012). The pathway it takes can be directly or indirectly to mitigate the detrimental effects of negative stress appraisal on mental health of caregivers (Falk, Norris and Quinn, 2014; Singh, Ghosh & Nandi, 2017). More specifically, high social support has been linked with decreased stress (Lima, Cardoso and Silva, 2016; Wang, Huang and Kong, 2017), burden (Wijesinghe *et al.*, 2015), general health (Diaz et al., 2019), anxiety (Toledano-Toledano and Moral de la Rubia, 2018) and depression (Feldman *et al.*, 2007; Minichil *et al.*, 2019).

Contrary to the studies above, Lima, Cardoso and Silva (2016) found no significant association between stress and social support ($p>0.05$). The participants' perception of social support was high but did not appear to influence the level of parental stress as it was found to be high. The researchers conclude the constructs of the MOS-SS centre not on the specific demands of parenthood such as sharing care-related tasks. Thus, the constructs available were perceived to be high but that did not translate into reducing the stress of caregivers.

2.5 CAREGIVING OUTCOMES

Outcomes end the stress process and are considered as the injurious impact of stressors (Pearlin and Bierman, 2013) which could be the overall well-being of the caregiver, their physical and psychological wellness (Aneshensel & Mitchell, 2014). Wheaton (2010) agrees that multiple outcomes could be observed in caregivers when they go through stress.

2.5.1 Physical well-being of caregivers of children with DD

The available studies on physical well-being of caregivers compared to psychological well-being is quite limited especially on those caring for children with DD (Eisenhower, Blacher & Baker, 2013; Miodrag *et al.*, 2015). Out of the limited number of studies that compared the physical health of caregivers and non-caregivers of children with some form of disabilities, mixed findings have been documented. Some studies have revealed that caregivers experience poorer physical health than non-caregivers (Eisenhower, Bakera & Blacher, 2009; Eisenhower, Blacher & Baker, 2013; Fairthorne, De Klerk & Leonard, 2015). Conversely, others have found no differences in physical health between caregivers and non-caregivers (Seltzer *et al.*, 2001). The impact of poorer physical health is enormous both for the caregiver and the care-recipient. It leads to increased health cost, difficulties in managing the caregiving responsibilities. For the care-recipients, it could possibly lead to their institutionalisation since the caregiver may not have the required physical health to provide care. The current study focused on physical problems like pain-like symptoms, fatigue and sleep problems of the caregivers.

2.5.1.1 Sleep problems of caregivers of children with DD

A variety of sleep problems have been documented among caregivers of children with a disability. These sleep problems include but are not limited to lack of sleep, perceived poor sleep quality, changed sleep patterns, reduced sleep duration, impaired sleep efficiency, and

increased wakefulness after sleep onset (Gallagher, Phillips & Carroll, 2010; Bourke-Taylor *et al.*, 2013; Lee, 2013; Mörelius & Hemmingsson, 2013; Vincent *et al.*, 2021). Studies have found a relationship between poor sleep quality and poor mental health (Bourke-Taylor *et al.*, 2013; Lee, 2013a), and poor physical health (Bourke-Taylor *et al.*, 2013).

In a comparative study, Gallagher, Phillips and Carroll (2010) examined the association between parental stress and sleep quality in 67 parents of children with DD and 42 parents of typically developing children. Poorer sleep quality was found among parents of children with DD. The authors further reported that the majority (70%) of parents of children with DD were more likely to be classified as "poor sleepers" as compared to only 22% of parents of typically developing children. The effect of poor sleep is detrimental; thus, it is not surprising that day time fatigue was found to be higher in parents who were caring for children with DD. Stress was found to be the most robust/vigorous predictor of poor sleep in parents caring for children with DD.

2.5.1.2 Pain-related symptoms in caregiver

Low back pain (LBP) is considered a common musculoskeletal symptom in caregivers (Suzuki, Tamakoshi and Sakakibara, 2016; Sharan & Rajkumar, 2018) and may be a result of the huge physical demands of caring for a child with a disability (Zamora & Labao, 2020). It is not surprising that it has been reported in several studies (Yiengprugsawan *et al.*, 2012; Habib *et al.*, 2014; Neves, Pietrovski & Claudino, 2015; Suzuki, Tamakoshi & Sakakibara, 2016; Zamora & Labao, 2020). Apart from LBP, Nimbalkar *et al.* (2014) reported shoulder pains, back pains, and generalised body aches among parents caring for children with CP. Sharan and Rajkumar (2018) also reported knee pain, neck pain, and shoulder pain.

Low back pain other musculoskeletal problems have been associated with providing more assistance with transfer, caregiver's mood (increased depression), caregivers' history of LBP (Brehaut *et al.*, 2009); dealing with problem behaviours and the level of difficulty in daily activities (Zamora & Labao, 2020); extent of motor commitments (Neves, Pietrovski & Claudino, 2015); assisting the child with CP in performing ADL, seeing to other responsibilities in the home like taking care of other children (Vadivelan *et al.*, 2020).

2.5.1.3 Fatigue in caregiver

Fatigue is also commonly reported among caregivers of children with DD. Giallo *et al.* (2013) assessed the prevalence of fatigue among 50 mothers who are caregivers of children with ASD ranging in age from 2 to 5 years. They were compared to the mothers of typically developing children. They reported that the mothers of the children with DD reported a moderate level of fatigue, and the difference between the two groups was statistically significant. High fatigue levels have been associated with poor maternal sleep, poor physical activity, a high need for social support and lower parenting efficacy (Giallo *et al.*, 2013; Chau, Giallo & Giallo, 2014). Increased fatigue has been linked to parental stress, lower parental competence, difficulty in parent-child interactions, decreased social support, poor diet, and poor sleep (Cooklin, Giallo & Rose, 2011). Parents who were fatigued were more likely to exhibit high levels of parenting hostility towards their children (Giallo, Rose and Vittorino, 2011; Chau, Giallo and Giallo, 2014), and low parental self-efficacy as well as low parental warmth (Chau, Giallo and Giallo, 2014), maladaptive coping (Cooklin, Giallo & Rose, 2011). Fatigue has been found to mediate the relationship between stress experienced by the mothers and the behaviour problems of the children (Seymour *et al.*, 2013).

2.5.1.4 Cardiovascular functioning in caregivers

Earlier evidence indicates that the risk of the onset of cardiovascular disease can be increased by caregiving. The onset of hypertension and cardiovascular diseases (CVD) are linked to chronic stress and have been identified as the major causes of mortality and morbidity. Uncontrolled blood pressure is linked with poor cardiovascular (coronary heart disease), cardiovascular (stroke), and renal (chronic kidney disease) outcomes (Mazzaglia *et al.*, 2009; Bautista *et al.*, 2012). Long-term caregiving was found to be associated with double the risk of cardiovascular disease onset in a longitudinal study among spousal caregivers who were aged 50 and above (Capistrant *et al.*, 2012). Fairthorne *et al.* (2014) in a retrospective cohort study, examined the mortality of mothers of children with ID or ASD and reported that they were more exposed to cardiovascular disease, a major cause of mortality among such mothers than those without children with disabilities.

Gallagher and Whiteley (2013) compared the objective blood pressure of two groups of parents; those with children with DD and those without DD. The systolic and diastolic BP measurements were taken multiple times during the 24-hour period, and this was made possible

as participants wore ambulatory blood pressure apparatus. Caregivers of children with DD reported higher levels of BP. There was a difference between the caregivers and controls systolic blood pressure for the 24-hour period, daytime and at night. The 24-hour period presented the highest mean, followed by daytime and night. This was expected as the 24-hour period consisted of more readings. The differences in the means between the two groups were subjected to further statistical testing and were significant. However, no significant differences were found for the diastolic blood pressure or the pulse rate for the two groups of parents.

Yamaki, Hsieh and Heller (2009) examined the health profile of 206 female caregivers of adults with intellectual and developmental disabilities (IDD) at home. Caregivers were asked to complete a survey in which they were to indicate if they had ever been told by a health professional if they had chronic conditions like high blood pressure, arthritis, asthma, diabetes, angina or coronary heart disease, heart attack, stroke, high blood cholesterol, and/or osteoporosis. The authors classified this as an objective measure because it is a self-report of what had been diagnosed by a health professional. The finding showed that there was increased blood pressure among caregivers of children with IDD. On the contrary to the above studies, Ice *et al.* (2012) found no association between caregiving and increased blood pressure levels among grandparents caring for their orphaned grandchildren.

2.5.1.5 Altered levels of cortisol

In human stress adaptation, the hypothalamic pituitary adrenal (HPA) forms part of the stress adaptation system (Tsigos *et al.*, 2020). Caregivers of children with DD are reported to have elevated stress levels (Ribeiro *et al.*, 2014; Lima, Cardoso & Silva, 2016; Wang, Huang & Kong, 2017). Chronic stress increases the production of inflammatory markers such as cortisol and C-reactive protein (Gouin *et al.*, 2016). The release of cortisol in healthy individuals as a result of long-term stress can have negative consequences for the individual, such as high blood pressure, atherosclerosis, diabetes, immune suppression, osteolysis, and myolysis (Çay *et al.*, 2018).

The studies on the altered level of cortisol among caregivers has been inconclusive (Seltzer *et al.*, 2010; Dykens & Lambert, 2013; Çay *et al.*, 2018). Some studies report low values of cortisol (Seltzer *et al.*, 2010) while others report high values of cortisol (Çay *et al.*, 2018). Another study has reported both low and high cortisol levels in their participants (Dykens & Lambert, 2013). The studies that report declines in cortisol levels during the day explain that

such patterns are usually associated with chronic stress. Thus, considering the fact that the caregiving role continues for a long period of time, such findings are expected (Seltzer *et al.*, 2009, 2010).

2.7.2 Psychological well-being of caregivers of children with DD

Anxiety and depression among caregivers have been commonly reported (Estes *et al.*, 2013; Bhatia *et al.*, 2015; Power *et al.*, 2019). Studies have reported low (Bhatia *et al.*, 2015), average (Minichil *et al.*, 2019), and high (Power *et al.*, 2019) prevalence of anxiety and depression. A study by Bhatia *et al.* (2015) reported 38% and 39% of mild to extremely severe anxiety and depression, respectively. The percentage of caregivers reporting anxiety and depression was relatively low as compared to other studies (Dave *et al.*, 2014; Power *et al.*, 2019). Dave *et al.* (2014) reported that the prevalence of depression and anxiety were high, at 63% and 57%, respectively. The prevalence of depression was 57.6% among primary caregivers of children and adolescents with mental illness (Minichil *et al.*, 2019). The findings by Power *et al.* (2019) revealed that the majority of the caregivers reported anxiety (73.5%) and depression (76.6%). Mbugua, Kuria and Ndetei (2011) found that about 79% of caregivers were at risk of clinical depression.

While comparisons of studies provide significant insight, there a need to do so with caution. The difficulty here is that while some studies considered children with ID (Mbugua, Kuria and Ndetei, 2011; Dave *et al.*, 2014; Bhatia *et al.*, 2015), others focused on adolescents with CP (Power *et al.*, 2019) or children with mental illness (Minichil *et al.*, 2019). Different categories of care-recipients may have different needs which could influence caregivers' perception of stress or burden and subsequently caregiver outcomes. Different instruments were used to measure same psychological outcomes. For example, depression was measured with DASS-42 (Bhatia *et al.*, 2015), PHQ (Minichil *et al.*, 2019), BDI (Mbugua, Kuria and Ndetei, 2011) DASS-12 (Power *et al.*, 2019) and Zung's self-rating scale (Dave *et al.*, 2014).

2.8 SUMMARY OF EMPIRICAL STUDIES

Several studies have highlighted the negative consequences of caregiving on various aspects of caregiver wellbeing (Pinquart & Sorensen, 2007; Eisenhower, Blacher & Baker, 2013; Mörelius & Hemmingsson, 2013; Lima, Cardoso & Silva, 2016; Pineda-Frutos *et al.*, 2016) which arise as a result of the stressors faced by these caregivers in rendering their caregiving

role (Okewole *et al.*, 2011; Bhatia *et al.*, 2015). While some studies have reported on the negative impact of caregiving on the physical health of the caregiver (Eisenhower, Blacher and Baker, 2013; Fairthorne, De Klerk and Leonard, 2015; Miodrag *et al.*, 2015; Zamora and Labao, 2020), others have documented findings on the psychological outcomes, mainly depression and anxiety (Gallagher *et al.*, 2008; Estes *et al.*, 2013; Dave *et al.*, 2014; Al-Farsi *et al.*, 2016; Pocinho & Fernandes, 2018; Minichil *et al.*, 2019; Scherer, Verhey & Kuper, 2019). The studies also suggested caregivers are at risk of poor cardiovascular functioning (Foody, James and Leader, 2014; Gallagher & Whiteley, 2016) and altered cortisol levels (Seltzer *et al.*, 2010; Dykens & Lambert, 2013; Çay *et al.*, 2018) which is mainly a response to the stress they go through. Social support appears to have a buffering effect on the negative outcomes of caregiving (Dave *et al.*, 2014; Lima, Cardoso & 2016; Minichil *et al.*, 2019). Overall, these studies provide valuable insights into the complexity of caring for a child with DD, but there is a need examine the evidence in light of a LMIC like Ghana as contextual factors could influence caregiving and its outcomes.

2.9 SUMMARY OF CHAPTER

This chapter provided a detailed description of the theoretical model used in this study, the Stress Process Model. Empirical studies were reviewed focusing on background characteristics such as age, gender, marital status; primary and secondary stressors; and the outcomes of stress. The next chapter describes the research methodology used in the study.

CHAPTER 3

RESEARCH METHODOLOGY

3.0 INTRODUCTION

Research methodology describes the reasons behind the processes, methods, and techniques utilised in research methods (Opoku, Ahmed & Akotia, 2016). The vivid explanation of the logic involved in the stages of the research makes it easy for the researcher or others to evaluate the results. The research design, settings, sample, and sampling techniques are first presented. The collection and analysis of data for all three phases of the study, as well as the ethical considerations are described subsequently.

3.1 PHILOSOPHICAL WORLDVIEWS GUIDING THE CURRENT RESEARCH

In order for researchers to decide on the nature and design of the research to be used, they have to take a stance vis-à-vis the philosophical worldview that underlines their inquiry. Paradigms are described as methods by which individuals respond to the core philosophical questions. Kivunja and Kuyini (2017) referred to a paradigm as a worldview, which describes a set of conjectures or patterns of belief about the rudimentary categories of entities in the world. More specifically, the focus is on the interactions existing between these entities and the appropriate methods to be utilised for building and testing theories associated with these entities. Thus, paradigms are made of specific assumptions ontologically, epistemologically, and methodologically (Kivunja & Kuyini, 2017). A paradigm directs the researcher's viewpoint to an inquiry in any given field of study (Kivunja and Kuyini, 2017) aimed at supporting the creation of knowledge that is scientifically based. A paradigm serves as a 'lens', a frame or an organized set of principles through which a researcher approaches and interprets reality. A plethora of paradigms exist and have been applied in nursing research, including positivism, critical theory, post-positivism, pragmatism, and interpretivism (Welford, Murphy & Casey, 2012).

Pragmatism asks questions about how people can cope, deal with, or describe their situations. The ontology of this paradigm is about practical world or situational responsiveness. The epistemology is subjective or practical. The methodology emphasises the use of different methods in different situations. According to Hall (2013), an alternative epistemological paradigm is offered by pragmatism. This is because the argument about the nature of reality and the possibility of truth is different from the philosophical argument (Kivunja & Kuyini,

2017). The need for action and change are core principles of pragmatism. Thus, in pragmatism, there is an interaction between knowledge and action (Goldkhul, 2012). The pragmatic paradigm is ideal for studies that focus on intervening in the world and not just observing it (Goldkhul, 2012). Based on the premise above, the researcher asserts that the pragmatic approach was appropriate for use in this study. Table 3.1 below presents different worldview elements concerning the pragmatism paradigm used in this study.

Table 3.1 Elements influencing researcher's choice of worldview

Worldview element	**Pragmatism perspective in this study**
Ontology (Nature of reality)	The researcher believes that reality lies in caregivers of children with DD; the Ghanaian people and people who share the same characteristics as those from LICs and LMICs.
Epistemology (nature of knowledge)	The theoretical framework of *stress process*. It was also necessary to resort to more than one method to answer the initial research question, hence, the use of both qualitative and quantitative methods.
Axiology (Role of values)	Ghanaian caregivers of children with DD needed a psychosocial support programme which is context-specific to help improve their well-being and not a support programme based on that of other countries.
Methodology (Nature of the approach to research)	Qualitative data were collected via interviews by researcher and with research assistants who understood the field of caregiver burden. Quantitative data were collected via questionnaires. Researcher also used the scoping review as a method to identify interventions in countries with similar settings.
Rhetoric (The language of research)	Formal and informal language was used in the study.

3.2 RESEARCH CONTEXT

The research context is the Korle-Bu Teaching Hospital, a tertiary facility in Ghana. The tertiary institutions serve as the apex of the referral system, and they include; Korle-Bu Teaching Hospital, Cape Coast Teaching Hospital, Tamale Teaching Hospital, and 37 Military Teaching Hospital. These institutions are semi-autonomous with independent boards and are not under the GHS. At the regional level, the regional hospitals provide specialised clinic and diagnostic care. The provision of health services at the district, subdistrict and community levels is done by a mix of health care providers. These providers are public, faith-based and

private facilities (GHS, 2021). The study took place at a tertiary level, specifically at the Korle-Bu Teaching Hospital.

3.3 RESEARCH SETTING

A research setting is described as an environment or a context within which a study takes place. Such an environment could be physical, social or cultural site where the study is conducted (SAGE Encyclopaedia of Qualitative Research Methods, 2022). This is usually considered significant due to the implications it can have on the study. An accurate description of the setting could have an influence on the results and their interpretation. The research setting could be a more controlled one like the laboratory or less controlled one like the outpatient department of a hospital.

3.3.1 Overview of the research setting

The research setting was the Korle-Bu Teaching Hospital (KBTH), Ghana which was established on October 9, 1923. It is a tertiary facility and is considered the third largest referral centre in Africa. It has a bed capacity of 2000 and consists of 21 clinical and diagnostic departments including Child Health, Surgery, Obstetrics and Gynaecology, Anaesthesia, Pharmacy, Laboratory and Radiology. The hospital operates as a semi-autonomous organisation based on the Ghana Health Service and the Teaching Hospitals Act, Act 525 of 1996. To facilitate the administrative management of the hospital, it operates the Sub-Budget Management Centre (Sub-BMC) concept (Korle-Bu Teaching Hospital, 2022).

The Child Health Department is one of the 14 Sub-BMCs of the hospital, established in 1964 as a referral for children under 13 years. It manages the medical and surgical problems of children. The department has seven main units which are the Outpatient Department (OPD), the Emergency Room, General Paediatric ward, Children's Surgical Ward, Neonatal Intensive Care Unit, Paediatric Oncology Unit and Child Protection Unit. The OPD consists of specialty clinics and acute care OPD. The specialty clinics include the Neurodevelopmental Clinic, Asthma Clinic, Diabetes/Endocrine Clinic, Cardiac Clinic, HIV Clinic, Sickle Cell Clinic and Neonatal Follow-up Clinic. The neurodevelopmental clinic runs on Mondays and sees wide array of cases. The setting is seen as having a high patient-load and being accessible for most caregivers, which is the reason why it was chosen for the current study (Korle-Bu Teaching Hospital, 2022).

3.3.2 Geographic location of KBTH

The Korle-Bu Teaching Hospital is situated in the Ablekuma South Sub Metropolitan district of the Accra Metropolitan District. The Ablekuma South Sub Metropolitan District is one of the three (3) Sub Metropolitan District of Accra Metropolitan Assembly (AMA) with the other two being; Okaikoi South and Ashiedu Keteke. The Sub Metro is the largest in the Metropolis and shares its boundaries with Ablekuma Central to the north, Ablekuma West to the west and Ashiedu Keteke to the east. It covers an area of 15.1 square kilometres (sqkm). Korle-Bu Teaching Hospital covers a total land space of approximately 441 acres and shares boundary with Korle Lagoon to the east, Korle-Gonnor to the south, Laterbiokorshie to the north and Mamprobi to the west (Accra Metropolitan Assembly[AMA], 2022). The geographic location is described in Figure 3.1 below:

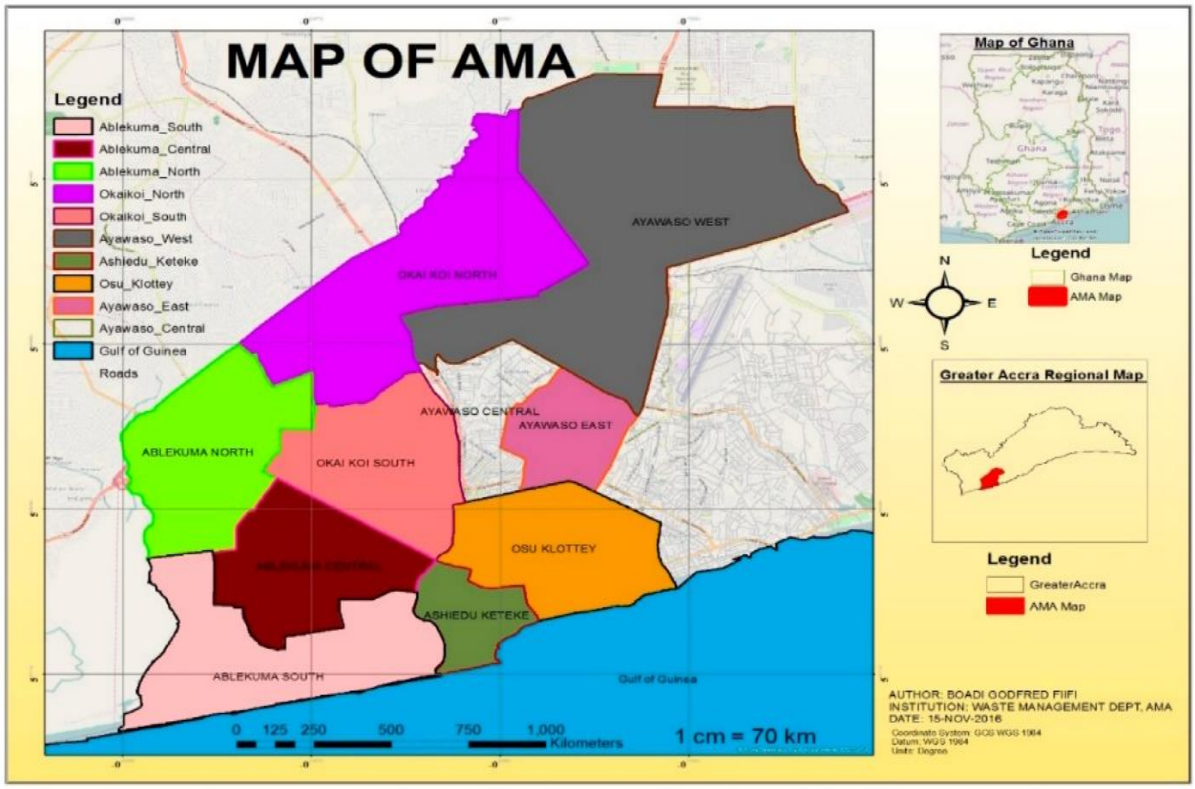

Figure 3.1 Geographic location of KBTH

Source: (Oduro-Appiah *et al.*, 2019)

3.3.3 Organisational culture

The success of an organisation depends on many factors, one of which is the organisational culture. Organisational culture consists of a system of shared behavioural norms and underlying beliefs and values that shape the way of doing things in the organization (Zohar & Hofmann, 2012). Korle-Bu Teaching Hospital has an organizational culture that prioritises the needs of patients aim to treat them with respect. It also sets out to provide the best possible work environment for its employees, which will enable them to live a fulfilled social and professional life. The philosophy of the organisation is premised on; "the patient comes first, all the time". The mission of the Hospital is "to provide quaternary health care facilities and services, training, research, and advocacy for clients' within and outside Ghana." The vision is "to become the preferred centre of excellence and innovation for specialist health care provision, training, research and advocacy in Ghana and West Africa." The hospital has six core values, namely: customer satisfaction, respect for one another and the rights of our clients, commitment to excellence and innovation, commitment to a healthy environment, excellent stewardship of all resources and transparency and accountability. The motto of the hospital is "excellence in healthcare." (Korle-Bu Teaching Hospital, 2022).

3.4 STUDY DESIGN

Creswell (2014) asserts that one of the core duties of researchers is to ask questions concerning the knowledge claims and theoretical perspectives that they are bringing to any research. This basically involves reflecting on the various strategies they intend to use within their study. Consequently, a decision on the strategies will influence the methods to be used in the research, how they will collect and analyse information. A thorough evaluation of the above informs the researcher on the likely bias they may contribute to the study, especially its effects on the kind of approach to be utilised and the data collection tools (Vogt, Gardner & Haeffele, 2012). This calls for a thorough description of the approach to be used in the study.

The design used in this study was a multi-method design. This method was developed in recognition of the fact that different methods, when combined, produce more credible results because the weakness in one method may be compensated for by the robustness in another method (Hunter & Brewer, 2015). This design is usually confused with the mixed method design. However, mixed methods' focal point is the combination of qualitative and quantitative methods. While multimethod does not limit itself to combining both qualitative and

quantitative methods in a single study, it does combine them regardless of whether they are qualitative or quantitative methods (Hunter & Brewer, 2015). Though mixed methods are more frequently used in studies, they are considered to be a type of multimethod. Tashakkori and Teddlie (2010) explained mixed methods as using parallel or sequential qualitative and quantitative methods.

Therefore, the key distinguishing feature between a multi-method and a mixed-method research design has to do with the point where they are integrated, known as the point of integration or point of interface (Guest, 2013; Schoonenboom & Johnson, 2017). In a mixed-methods study, the point of integration occurs where the qualitative and quantitative components are brought together. The points of integration can be one or more; integration is usually carefully done and not just mixed; thus, determining the point where integration should occur is very crucial in mixed-methods research design. Schoonenboom and Johnson (2017) have identified several points of integration of a mixed-methods approach including but not limited to the purpose, research questions, data analysis, and results. Anguera *et al.* (2018) further clarify that in a multimethod design, integration may not be necessary until inferences are being made.

3.5 SAMPLE AND SAMPLING TECHNIQUE

A sample is a representative segment derived from a population through the process of sampling (Cash *et al.*, 2022). Taherdoost (2016) confirms that a sample is essential in research because it is usually impossible to use the entire population in research due to limited resources or availability of time. Sampling is a process to draw a representative sample from the population in such a way that the sample elements selected represent the population (Cash *et al.*, 2022). Once the elements selected represent the population, they can be used to make inferences about the population in the study (Taherdoost, 2016). Taherdoost (2016) highlights that researchers need to go through a clear process to arrive at a sample, namely: clearly defining the target population, selecting the sampling frame, choosing sampling technique, determining sample size, collecting data, and assessing response rate.

3.6 DATA COLLECTION METHODS

Polit and Beck (2010) observed that data collected in a study differ in four main dimensions, namely: structure, quantifiability, researcher obtrusiveness and objectivity. In terms of structure, for a highly structured data collection, the same information may be collected by the

researcher from all participants. With regard to obtrusiveness, it implies the degree to which the researcher is obtrusive. Objectivity is usually utilised by quantitative researchers. Even for those who conduct qualitative studies, the subjective judgement of the researcher plays a critical role. Polit and Beck (2010) further emphasise that these dimensions of data collection are usually influenced by the type of research question. Additionally, for phenomenological studies, data collection methods that are low on structure, quantifiability, and objectivity are more appropriate. The opposite is true for a quantitative study where the research utilises a survey or questionnaire. Data collection instruments are the tools including tests, questionnaires, inventories, interview schedules or guides, rating scales, and survey plans or any other forms utilised by researchers to actually collect data in the research process. Data collection procedure describes the processes used in collecting data.

3.7 DATA ANALYSIS

Data analysis is described as a process used to reduce data to a story and interpret it to derive insights. The process helps reduce a large chunk of data into smaller fragments, which makes sense. Polit and Beck (2014) refer to data analysis as the systematic organization and synthesis of research data, and the testing of a research hypothesis using those data.

3.8 RIGOUR OF THE STUDY

Rigour is described as the degree to which the researchers worked to strengthen the quality of the studies (Heale & Twycross, 2015). The researcher took the necessary steps to ensure rigour throughout the conceptual, empirical, and interpretive phases of the study. Trustworthiness was put in place for qualitative designs, while validity and reliability were ensured for the quantitative methods. The ensure internal consistency, the Cronbach alpha of all the instruments was tested.

The research designs and methods that were applied in the phases of this study are described in Figure 3.2 below:

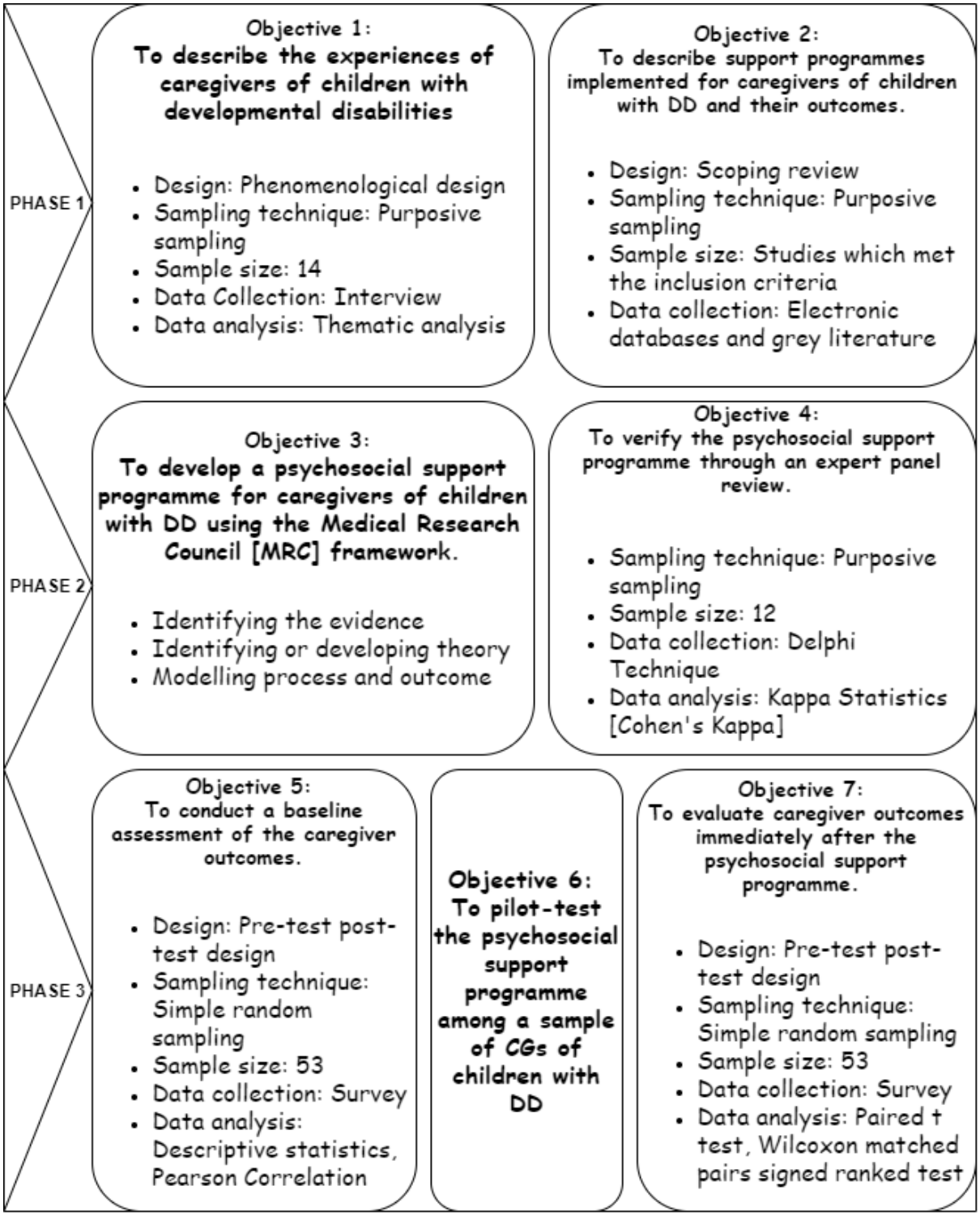

Figure 3.2: Design and research methods for the three phases of the study

3.9 PHASE 1 RESEARCH METHODS: EXPLORATORY PHASE

3.9.1 Objective 1

The objective 1 aimed to explore experiences and the health needs of caregivers of children with DD. The methods and design are described.

3.9.1.1 Research Design: Descriptive phenomelogical design

To achieve the objective of exploring the experiences and health needs of caregivers of children with DD, a phenomenological descriptive design was used. In phenomenological research, the researcher is interested in describing, understanding and explaining the lived experiences of the participants with regard to a particular phenomenon (Creswell, 2014). Phenomenological inquiry is an orderly endeavour to come into direct contact with this world, reveal and depict the significant constructions of lived experience, and arrive at a more profound comprehension of the nature or meaning of phenomena (Cilesiz, 2010). In doing so, it is concerned with the *a priori*, or intuitive premise of knowledge, looking at the world with an 'unadulterated mind' (Cilesiz, 2010). The choice of this design was considered because the researcher was interested in exploring the experiences of caregivers of children with DD in a natural setting, with the researcher being the key instrument of data collection using in-depth interviews.

3.9.1.2 Sampling technique

Purposive sampling was used for objective 1. It is a type of non-probability sampling, also referred to as judgemental, expert or purposeful sampling (Gentles *et al.*, 2015), in which selection of participants is done based on subjective methods (Etikan, Musa & Alkassim, 2016). Subjectivity here means that the selection of the participants is dependent on the experience and judgement of the researcher. It is one of the most widely used approaches for sampling in qualitative research (Palinkas *et al.*, 2015). According to Patton (2015), the main premise of purposeful sampling is being able to select information-rich cases, which would allow the researcher to gain in-depth insights into the study.

The researcher, prior to the study, decides what needs to be known and tries to identify and select people or a group of people who are deemed knowledgeable in or experienced with a phenomenon of interest to the researcher (Etikan, Musa & Alkassim, 2016). Apart from the above, the availability and willingness to participate, as well as the individuals or group of

individuals' abilities to communicate very well, influence the choice of a sample size. In communicating their experiences and opinions, it should be done in an articulate, expressive, and reflective manner (Etikan, Musa & Alkassim, 2016). The general principle of purposive sampling is to consider which person, place, or situation possesses the greatest potential for advancing one's understanding of a subject of inquiry (Etikan, Musa & Alkassim, 2016).

A number of purposeful techniques have been identified in the literature, including stakeholder sampling, extreme or deviant case sampling, expert sampling, typical case sampling, paradigmatic case sampling, maximum variation case sampling, criterion sampling, theory-guided sampling, critical case sampling, and disconfirming or negative case sampling (Palinkas *et al.*, 2015; Etikan, Musa & Alkassim, 2016). Gentles *et al.* (2015) stated that in qualitative research, some ambiguity is associated with the term purposeful sampling in the literature, and thus suggested that researchers should describe what the term means in their specific context of the study. Criterion sampling was used for objective 1 of phase 1. Criterion sampling is a sampling procedure in which the researcher focuses on individuals or group of individuals who meet a certain criterion.

The inclusion criteria were:

- Being a primary caregiver of the child with DD and is 18 years and above.
- Having provided care for 6 months or more for the child with DD.
- Having a child with DD who is between 5 and 14 years old and has received a formal diagnosis of DD.
- Primary caregiver who is capable and willing to give consent.

The exclusion criteria were a caregiver:

- Receiving a form of psychological or behavioural treatment.
- Having more than one child with DD.
- Facing other major life stressors at the time of the study, example, the loss of a spouse or significant other, loss of job, asset loss.

Application to the study

Caregivers who brought their children with DD to the Neurodevelopmental Clinic of the Korle-Bu Teaching Hospital were briefed on the study emphasizing on voluntary participation. The purpose was to minimize coercion. They were assessed using the inclusion and exclusion criteria. Those who met the criteria were included, while those who did not the criteria were excluded.

3.9.1.3 Sample Size

Sample size in qualitative studies cannot be determined *a priori* (Gentles *et al.*, 2015; Braun & Clarke, 2021). Saturation is the most commonly known criteria for arriving at the sample size in qualitative studies (Vasileiou *et al.*, 2018) and is defined as getting to a point where nothing new is encountered or information redundancy occurs (Malterud, Siersma & Guassora, 2015; Braun and Clarke, 2021). Similarly, Braun and Clarke (2021) described saturation is identified as the criterion for determining when a sufficient sample size has been reached. In such instances, information collected becomes redundant and data collected additionally does not significantly impact the study. A sample size of <10 if participants are followed intensely and ≥30 if the participants are followed less intensely for hermeneutic phenomenological studies. On the other hand, around 12 participants have been suggested for descriptive phenomenology (Gentles *et al.*, 2015). Generally, in qualitative research, to be able to get rich data, the sample size should not be too large or too small (Omona, 2013). A larger sample size makes it difficult to extract rich data, while smaller sample size may negatively affect data saturation and theoretical saturation (Vasileiou *et al.*, 2018).

Application to the study

Caregivers who met the criteria were interviewed, using a semi-structured interview guide. Since the sample size could not be determined before the interviews were conducted, the interview process continued until no new themes were generated. Thus, the sample size for this phase of the study was 14.

3.9.1.4 Data collection instrument: Semi-structured interview guide

A semi-structured interview guide was developed by the researcher. Baumbusch (2010) emphasises that in using a semi-structured interview guide as a data collection strategy, a number of phases needs to be considered. The first is the development of the interview guide. The author highlights that it is crucial in getting data that will address the purpose and objectives of the research. In this study, the semi-structured interview guide included a five broad, guiding questions. Some of the questions began with “Tell me about…” or “Can you describe…”. These allowed participants to fully narrate descriptive response and stories which are their lived experiences. The guiding questions were supported by prompts or probes which were sub-questions that encouraged the research participants to expand on their answers where necessary or redirect them back to the main topic if they deviated from the main issue of

discussion. Example of probes used include: “Can you tell me more?” and “What was that like for you?”

The questions were structured such that factual questions which were less emotionally intense were asked first. These were followed by questions which were more emotionally intense. The essence of this was to enable participants prepare for closure. After formulating the semi-structured interview guide, it was pretested in an independent setting which allowed for few modifications. The questions elicited the appropriate responses and there was no ambiguity in their wording. The semi-structured interview guide can be found in Annexure B.

3.9.1.5 Data collection procedure

Data were collected using a semi-structured interview guide (see Annexure B for the interview guide). Information about the study, such as the purpose, risks, benefits, confidentiality and anonymity, were given to participants who met the inclusion criteria. They were informed that the interview would be recorded and given the opportunity to ask questions. Those who agreed to participate in the study were supported to sign consent forms.

Baumbusch (2010) highlights an interview as a social interaction and for interaction to yield positive outcomes, there is a need to create an environment where the participant will not be passive during the process but will rather play an active role. Furthermore, it is important to exhibit certain skills like careful listening, non-verbal communication, and the ability to observe and interpret what the participant is saying on several levels simultaneously in order to make an appropriate response. The interview was conducted in a serene environment where privacy was ensured.

During the interview, the stages outlined by Baumbusch (2010) were used a guide. These include (a) introductions and introducing the research topic; (b) beginning interview questions with a factual focus; (c) shifting into more in-depth questions that may solicit an emotional response; (d) moving back into more factual, less emotional questions; and (e) ending the formal interview, possibly chatting casually for a bit, and expressing gratitude to the participant for his or her time.

In the first stage of the interview process, introduction was done. The interviewer introduced herself as a nurse researcher and also allowed the participants to introduce themselves, getting to know how they would like to be addressed during the interview process. An opportunity was given to the participants to ask questions pertaining to the study and its purpose before

beginning the interview. Self-disclosure can contribute to developing rapport and building trust with the participant, which will ultimately affect the degree of disclosure on the part of the participant.

Next, in the second stage, there was a shift to more in-depth questions, which was still part of building rapport and making the participant comfortable. These questions had more factual focus than asking the participant to share emotional experiences or reflections. In this study, the interview began with demographic questionnaire, which allowed the participants to share factual information about themselves, their families, and their children with DD without delving into great detail. This gave an overview of the families and their health before delving more into in-depth questions and potentially emotional issues.

Then, in the third stage, the focus was on asking more difficult questions that may elicit emotional responses. The question about becoming the parent of a child with DD was very emotional for participants. Many of the participants cried during the interviews. When participants' emotions overwhelmed them, the interviewer would wait quietly until they composed themselves and continued speaking; there was no need to rush their stories.

In the fourth stage of the interview, less emotional and stressful questions were the focus in order to be able to close the interview. In the study, there was a shift from talking about areas of emotional impact on the caregiver to asking questions about formal and informal supports for the caregiver. This led participants to share experiences about programmes and services that their children were involved with and to talk about how family and friends were involved in supporting them.

In the fifth and last stage of the interview, gratitude was expressed to the participants for their time and contributions to the research. After the formal interview had ended, the interviewer and participant continued to chat in a more casual way, similar to their conversation before the interview began. The interviews lasted between 30 to 60 minutes.

3.9.1.6 Data analysis

Thematic analysis was followed systematically to analyse qualitative data. Thematic analysis is a method used to identify, analyse, organise, describe and report themes within dataset (Braun & Clarke, 2012). Though a lot of patterns could be identified across any dataset, the focus is on those patterns that are relevant especially in answering a particular research question(s). The analysis was guided by Braun and Clarke’s six-phase process of thematic

analysis which are familiarisation with the data, generating initial codes, generating themes, reviewing the theme, defining and naming the theme and write-up (Braun & Clarke, 2012; Byrne, 2022).

Phase one: Familiarisation with the data

The essence of familiarisation was to become intimately familiar with the data and also to identify information that may be relevant to the research question (Braun & Clarke, 2012; Byrne, 2022). The audio-recordings of the interviews were actively listened to before the transcription began. Before the transcription, the researcher, who is proficient in the native language (Twi) and English, translated the responses of the participants into English. A professional translator translated the Twi transcripts into English, and another independent translator read the English transcripts, translated them back into Twi and compared them to the original Twi transcripts to ensure accuracy. Manual transcription of the data was done which helped to facilitate deep immersion into the data. While transcribing, the following were noted; breaks, pauses and tones (Braun & Clarke, 2012). The transcribed data or transcripts were read severally. While doing this, initial trends, patterns, interesting points and meanings were taken note of.

Phase two: Generating initial codes

Codes are considered as the building blocks of themes. Coding was done to produce succinct, short hand descriptive or interpretive labels for information that may be important to the research question. Codes generated were brief but offered sufficient details to stand alone (Braun & Clarke, 2012).

Phase three: Generating themes

This phase involved reviewing and analysing different codes, and possible combination of the codes to form an aggregated meaning and subsequently a sub-theme or theme. A thematic map was generated.

Phase four: Reviewing the theme

A review of the initial themes generated was done in relation to the coded data items and the entire data set (Byrne, 2022). While reviewing the potential themes, the following questions were considered as stipulated by Braun and Clarke (2012):

a) Is this a theme or it could just be a code?

b) If it is a theme, what is the quality of the theme?
c) What are the boundaries of the theme?
d) Are there enough meaningful data to support the theme?
e) Are there themes within themes?
f) Are the data too diverse and wide ranging?

During the review of the themes, themes found to be overlapping were collapsed.

Phase five: Defining and naming the theme

Analysis continued with the purpose of refining the specifics of each theme. Definitions and names were generated for each theme. The names were concise, informative and memorable.

Phase six: Write up

Themes were built in a coherent manner. They were organised such that they built on previous reported themes.

3.9.1.7 Trustworthiness of qualitative research

Trustworthiness is a way of assessing the quality of the measurement procedure for collecting data in a qualitative study (Connelly, 2016). It is also known as the rigour of the study. Polit and Beck (2014) referred to trustworthiness as the measure of a study's quality arising out of the confidence in the data, interpretation and methods used in the study. The concept of trustworthiness has been described by Cope (2014) as a way of ensuring transparency in the conduct of qualitative studies so that the findings can be considered useful and of high integrity. According to Amankwaa (2016), for a study to be considered worthy, the researchers need to establish clear procedures during the conduct of their study. Though the concept of trustworthiness is considered important by most experts and researchers, there have been debates on what trustworthiness in qualitative research is made up of (Leung, 2015). The criteria widely used are credibility, dependability, confirmability, transferability, authenticity and reflexibility (Cope, 2014). These criteria were applied as follows:

Credibility

Credibility, the most important criterion, is described as the truth of the data collected and its interpretation (Polit & Beck, 2014). Credibility in qualitative research is comparable to internal validity in quantitative research (Connelly, 2016) and it seeks to answer the question; "How

congruent are the findings with reality?" (Merriam, 1998;Shenton, 2004). To enhance credibility, researchers need to describe their experiences and verify the research findings with the participants (Ghosh, Greenberg & Seltzer, 2012; Cope, 2014). For credible qualitative research, the experience described should be acknowledged by others who have similar experiences (Hammarberg, Kirkman & De Lacey, 2016). For the conduct of qualitative research, researchers are to follow the standard procedures typically used; thus, in assessing credibility, a researcher needs to justify any variations from the standard (Connelly, 2016). Establishing credibility can be done in a number of ways, including prolonged engagement of the researcher with research participants, persistent observation if appropriate to the study, peer debriefing, negative case analysis or alternative explanations, referential adequacy, member-checking, and reflective journaling (Solomon & Amankwaa, 2016; Connelly, 2016).

Credibility was ensured in the study in several ways. Methods that have been well established in qualitative research and scientific inquiry in general were used. In doing so, the procedures used in this study were not derived in isolation. There was a careful comparison of the procedures of this study with those of similar projects. In addition, there was prolonged engagement with the participants to gain insight from them, familiarise with the setting, and build trust. Furthermore, to ensure data was collected from people who genuinely wanted to take part in the study, participants were allowed to consent before participation and were informed of their right to withdraw without facing any negative consequences. This allowed participants to be honest with the information provided.

Again, iterative questioning was included to uncover deliberate lies. Matters that were previously raised by the participant were brought up by rephrasing the questions. Contradictions and falsehoods that emerged after the iterative questioning were tagged as suspect data and subsequently discarded. Frequent debriefing sessions occurred with the supervisor. Lastly, member checks, considered the single important criterion for improving a study's credibility were conducted. Accuracy of the data was checked at every stage of data collection process. Transcripts of dialogues that occurred with the participants were given to them to read. This was to help verify if their intentions had been accurately captured.

Dependability

Dependability refers to research data's stability over time and over the conditions of the study (Polit & Beck, 2014). Dependability and reliability as applied in qualitative and quantitative research respectively are similar (Connelly, 2016). To establish dependability, Amankwaa

(2016) suggested a technique known as an inquiry audit. In this technique, the process and outcome of the research are examined by another researcher who is external to the study. The overall purpose of an inquiry audit by an external researcher is to assess the accuracy of the research findings, interpretations, and conclusions considering the data presented by the researcher (Amankwaa, 2016). It was ensured that the analysis process was in line with the accepted standards for the research design that was used in this study.

Confirmability

Confirmability is the degree to which findings are consistent and could be repeated. This is analogous to objectivity in quantitative research (Polit & Beck, 2014). To ensure confirmability, an audit trail was kept so that others could follow it to confirm the findings. An audit trail is described as the detailed recording of the research interview transcripts; raw data field notes including the date and time of the interview, how consent was obtained, and the process of the interviews. Similarly, Connelly (2016) explains that an audit trail involves describing the research steps at every stage of the research process in a transparent manner. Thus, in the study, confirmability was ensured by clearly describing the research from the development to the reporting of the findings.

Transferability

Transferability, which reflects the extent to which findings obtained in a particular research can be applicable to persons in other settings, is different from other aspects of research in that readers determine how applicable the findings are to their situations, settings and people (Polit & Beck, 2014; Connelly, 2016). The concept is regarded as similar to generalisation as applied in quantitative research. However, it is different from statistical generalisation. Usually, the emphasis is on the participants and their stories without saying that this is everyone's story. Researchers need to provide a vivid picture that will inform and resonate with readers (Amankwaa, 2016). The story of the research should be detailed enough so the consumers of the research or readers would have a clear picture of the events of the research This can be accomplished through journaling and maintaining records, whether digital or handwritten, for review by the consumer/reader. Transferability was ensured by giving a detailed description of the research design and methods, as well as the processes applied.

Reflexivity

Reflexivity, though an important concept in qualitative research, is poorly understood by many researchers (Olmos-Vega *et al.*, 2022).

Berger (2015) defined reflexivity as:

> A researcher's conscious and deliberate effort to be attuned to one's own reactions to respondents and to the way in which the research account is constructed; it helps identify and explicate the potential or actual effect of personal, contextual, and circumstantial aspects on the process and findings of the study and maintain their awareness of themselves as part of the world they study. (Berger, 2015; p. 221)

One way of ensuring reflexivity is by involving multiple researchers. The use of multiple researchers promotes discourse and opens the door to the occurrence of complementary and different understandings of research. It also allows a situation in which researchers' belief systems and assumptions can be divulged and challenged. Second, a reflexive journal where a researcher makes regular entries during the research process should be developed.

Decisions made on the research methods and rationale for such decisions are taken note of. Third, the researcher should report research perspectives, positions, values and beliefs in manuscripts and other publications. It is crucial for the one carrying out the study to reflect on their background and role in the study, and how they are likely to affect the meaning that is given to the data they have collected. This is important because, as the researcher is deeply involved with the participants, there may be ethical and personal issues that may be introduced into the research process (Locke, Spirduso & Silverman, 2013). Reflexibility was ensured by the researcher keeping a diary and examining how her assumptions, beliefs, and values would affect the research decisions.

3.9.2 Objective 2

The objective 2 sought to describe support programmes implemented for caregivers of children with DD and their outcomes using scoping review.

3.9.2.1 Scoping review

A scoping review was conducted to identify interventions available for caregivers of children with DD. Scoping review, a relatively new and emerging approach, was first described in detail

by Arksey and O'Malley (2005). Scoping reviews, also called mapping reviews (Joanna Briggs Institute, 2015), have been described as useful tools in determining the body of literature on a given topic or area, especially with emphasis on the available volume of literature (Munn *et al.*, 2018). Currently, there are many indications for choosing a scoping review over other forms of review which includes as a precursor to a systematic review, mapping out evidence in a given field, clarifying key concepts in the literature, identifying and analysing gaps in knowledge.

Essentially, scoping reviews are interested in getting the available evidence that exists on a topic with less emphasis on the quality of the studies as compared to other forms of review like systematic reviews (Levac, Colquhoun and O'Brien, 2010; Tricco *et al.*, 2018). In the context of interventions that have been used to improve the well-being of CCs of children with DD, the evidence is still emerging, especially in low-resource settings, hence the choice of a scoping review over a systematic or integrative review.

The methodological framework for conducting scoping reviews as published by Arskey and O'Malley as well as the Joanna Briggs Institute's guidelines was used in this study (Arksey & O'Malley, 2005; Levac, Colquhoun and O'Brien, 2010; Joanna Briggs Institute, 2015). It comprises six stages, and they are as follows: 1) identifying the research question; 2) identifying relevant studies; 3) study selection; 4) charting the data; 5) collecting, summarising and reporting the results; and 6) a consultation exercise. The last stage is usually considered optional.

3.10.2.1.1 Identifying the research question

The research question in a scoping review is usually broad. In spite of its broad nature, there is a need for clarity, which plays a key role in enhancing the effectiveness of the literature search. The development of the scoping report is associated with the clarity of the review question. Though a scoping review question can have sub-questions that examine certain issues, this study focuses on just one primary review question. The scoping review question was framed around the PCC [Population, Concept, and Context] elements (Joanna Briggs Institute, 2015).

3.10.2.1.2 Identifying relevant studies

Regardless of whether the research approach is qualitative or quantitative, the search is typically broad because it is not restricted to data from particular forms of evidence (Joanna

Briggs Institute, 2015). The goal of the search is to be thorough enough to find additional primary study sources, or grey literature. The Joanna Briggs Institute (2015) provides a three-step strategy. The first step involves a limited search of at least two relevant databases related to the topic. The objective of this section is to analyse text words that are found in the retrieved papers, focusing on the title and the abstract. The key words, or index terms, are also analysed. The second step entails conducting another search using all the identified index terms from the first step, but this time, the search is done across all databases that are to be used in the scoping review. The third step involves looking for additional studies in the reference list of all identified studies.

3.10.2.2.3 Study selection

Predetermined inclusion and exclusion criteria were used in the study selection process. Studies that satisfied the requirements for inclusion were accepted, while those that didn't were rejected. In order to prevent obtaining studies that were not the main focus of the study, the inclusion and exclusion criteria were strictly applied. Details of the criteria are provided in Table 3.2.

Table 3:2 Inclusion and exclusion criteria for study selection

CRITERIA	INCLUSION	EXCLUSION
Population	▪ Primary caregivers of children with DD who are at least 18 years and above ▪ Children with DD aged 5 to 14 years	▪ Caregivers of children with DD under age of 18 years ▪ Caregivers who are not the primary caregivers ▪ Adults suffering from DD
Rationale: 1. Compared to the primary caregivers, caregivers who are merely playing a supportive role and are not heavily involved in the care of the child with DD may have different health needs and experiences. 2. Adults with DD may differ from children with DD in terms of needs.		
Concept	▪ Interventions to improve wellbeing of caregiver	▪ Interventions not focused on the health of the caregiver ▪ Interventions focused on the child with DD
Rationale: Interventions directed towards the child with DD might not always affect the primary caregiver. Again, not every intervention is designed with the caregiver's well-being in mind.		
Context	▪ All geographical areas	▪ Not applicable
Rationale: Although it would have been appropriate to take into account studies from low resource settings, where the current study is being conducted, there are not many studies that have been conducted, so it is important to take into account studies from all geographical areas.		
Type of source	▪ Randomized Control Trial ▪ Quasi-experimental (Cohort) Trial ▪ Single Group Trial ▪ Single Subject Experimental Design	▪ Opinions ▪ Conference presentations ▪ Dissertations ▪ Discussion papers ▪ Case study ▪ Book ▪ Editorials or commentaries ▪ Systematic review
Rationale: Interventions are aimed at assessing its impact on certain outcome variables. It may be impossible to achieve this with opinion papers and others. Though SR and MA are evidence-based, they are also a pool of interventions put together and such evidence may not be relevant for the scoping review.		
Language	▪ English	▪ Not in English language
Rationale: Languages other than English were excluded as the researcher may need to translate those studies before they could be used.		
Time frame	▪ Published between 2010-2020	▪ Published before 2010
Rationale: A few studies were conducted prior to 2010. For example, a search in PubMed without any restriction on the date of publication retrieved 778 results whilst a restriction yielded 482 results.		

3.10.2.2.4 Charting data

According to the Joanna Briggs Institute (2015) charting the data is also referred to as extraction of results. A logical and descriptive summary of the results is provided by the results chart. Because the charting table is updated continuously, the process is iterative. Charting of data could be done in several ways; map format, diagrammatic or tabular format and descriptive format (Nye, Brunton & Wendt, 2016). The information was charted using the tabular format with the following details: author(s), year of publication, country of origin, purpose of study, study population, sample size, methodology, intervention type, and key findings. A sample of the sheet used for data extraction is provided in Table 3.3 below:

Table 3:3 Sample data extraction sheet

Author / year	Country of origin	Purpose of study	Study population	Sample size	Methodology	Intervention type	Key findings

3.10.2.2.5 Collecting, summarizing and reporting the results

Tint and Weiss (2016) posit that several methods could be utilised in summarising studies; numeric, narrative and thematic approaches. The current study utilised all the approaches summarizing and reporting the results.

3.10.2.2.6 Consultation exercise

The consultation exercise is an optional stage. It involves meeting with stakeholders to interpret findings. These could be the actual or potential recipients of the services, such as patients or caregivers. They could also be practitioners, such as teachers or health professionals. The stakeholders could also be policymakers or researchers. Stakeholders are involved to reduce or uncover biases, usually through an approach that is transparent and critical; in doing so, it improves the quality as well as the process (Nye, Brunton & Wendt, 2016). The consultation stage was not included.

3.9.2.2 Data analysis

There is no direct method of analysing the results in a scoping review. However, the results were summarised using thematic, numeric and descriptive approaches.

3.10 PHASE 2 RESEARCH METHODS: DEVELOPMENT PHASE

3.10.1 Objective 3

The MRC framework for developing complex interventions (Skivington *et al.*, 2021) was used as a guide. Corry *et al.* (2013) in a review of key guidelines for developing complex interventions, highlight that the MRC framework is the most commonly used. The MRC framework comprises four phases, namely: development, feasibility/piloting, evaluation, and implementation (Bleijenberg *et al*., 2018; O'Cathain *et al*., 2019). The MRC framework is described in Figure 3.3 and its application in the current study is described in Figure 3.4 below:

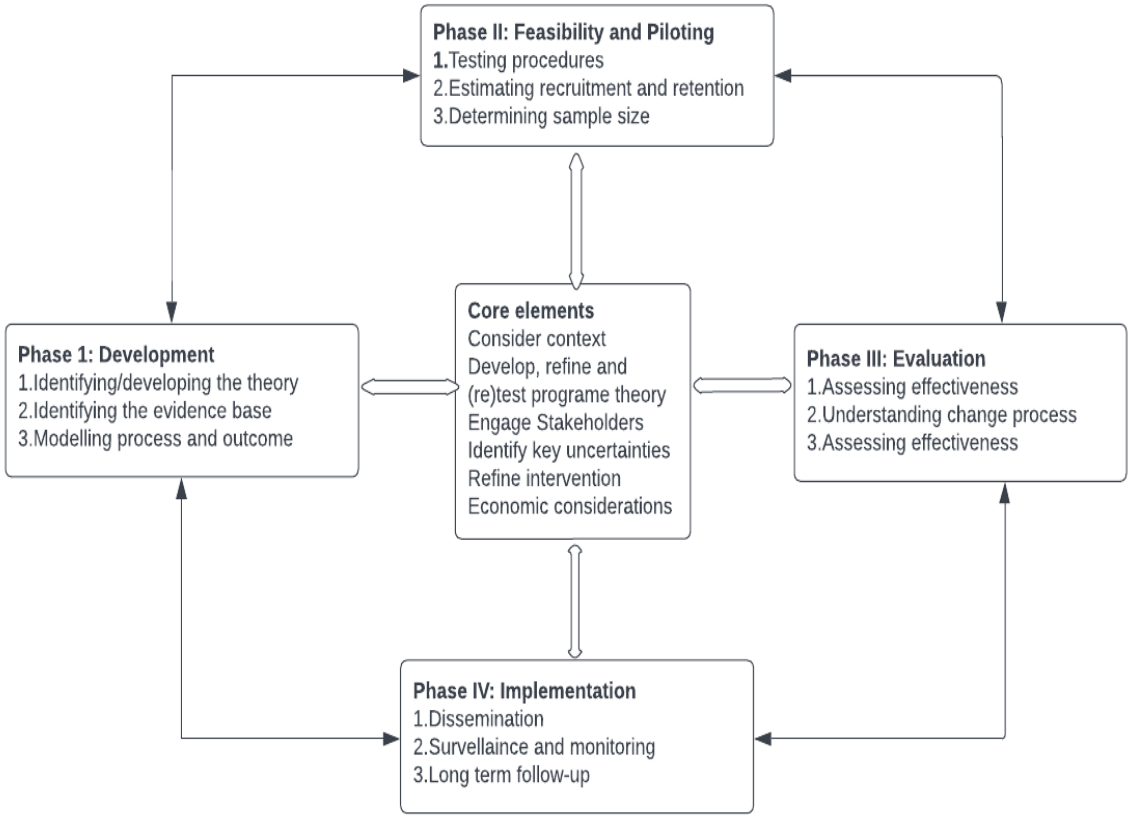

Figure 3.3 MRC framework for development of complex interventions

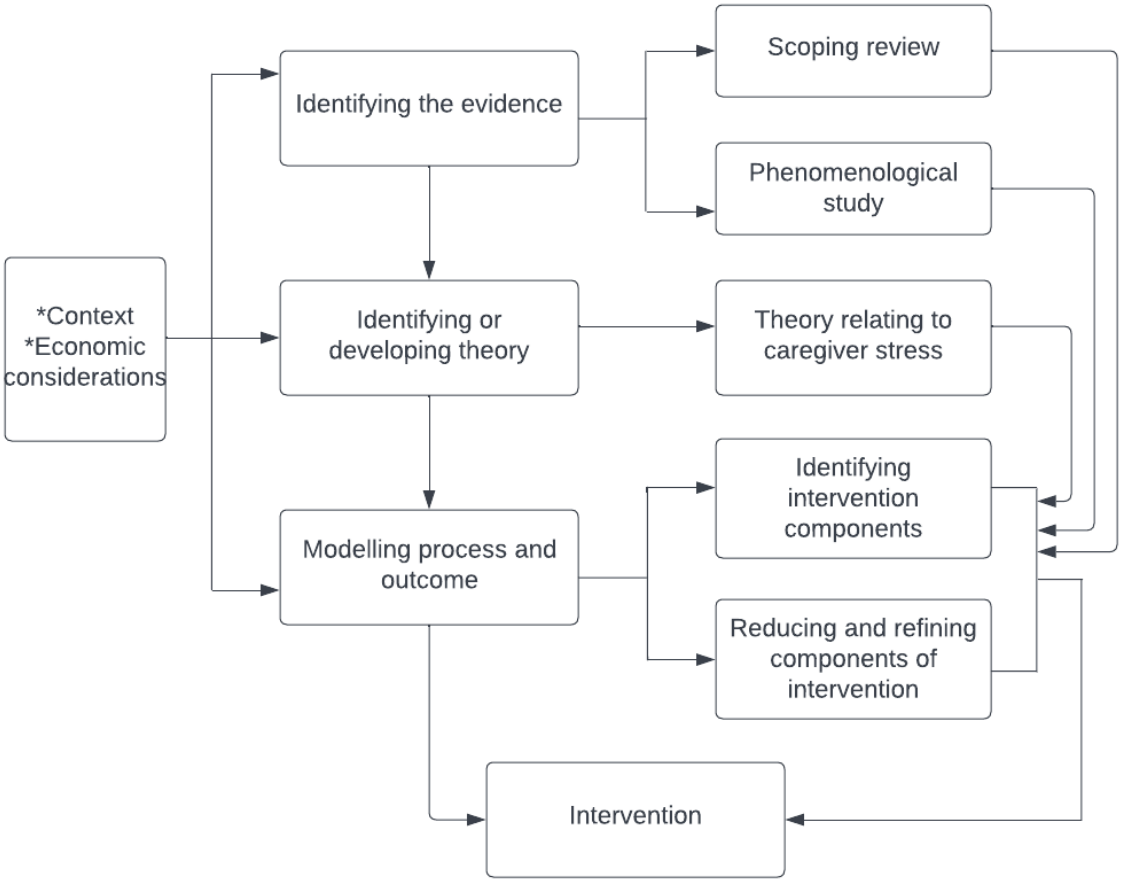

Figure 3.4 MRC framework as applied in current study

The developmental phase of an intervention is the first phase in the MRC framework, which is underpinned by theoretical rationale depicting input, process, and mechanisms through which positive outcomes are expected after the delivery of the intervention (Fletcher et al., 2016). Thus, this phase of the MRC framework outlines the components or "active ingredients" of the intervention and how those are supposed to interact to generate outcomes (Fletcher & Murphy, 2016). The stages outlined in this phase are identifying the evidence base, identifying or developing theory and modelling the process and outcomes. There are also core elements that run through all four phases of the MRC framework (Skivington *et al.*, 2021).

3.10.1.1 Identifying the evidence base

The first step of the MRC framework development phase is identifying the evidence. The framework proposes some form of review, meta-analysis or individual patient data analysis should be done at this stage (Bleijenberg *et al.*, 2018). Additionally, this stage may incorporate

qualitative testing, using interviews, surveys, or observational studies to enable investigators to fully describe component parts in terms of the aspects that are considered essential (constant) and those that can be adapted (variable) to fit with the local context (Blackwood & Halloran, 2010). The essence of this stage is to identify if existing interventions have been effective, acceptable, and feasible (Bleijenberg *et al.*, 2018). To ensure that studies included in the review have methodological rigour, a critical appraisal of the methodological quality should be done (Bleijenberg *et al.*, 2018). The current study identified the evidence using a scoping review and phenomenological study. The methodological quality of studies included in the scoping review was assessed, using the Joanna Briggs Institute Critical Appraisal Tools (Tufanaru *et al.*, 2020).

3.10.1.2 Identifying or developing theory

The second stage in the development phase of the MRC framework is identifying or developing theory. This is considered crucial (Petticrew *et al.*, 2013). In some instances, multiple theories can be used to demonstrate linkages and how the various concepts can be intertwined. In identifying or developing an appropriate theory, insight is gained into how the components leading to the outcomes are related (Bleijenberg *et al.*, 2018). This subsequently influences how the key elements generated for the intervention can be well defined with a good understanding of how they are linked and influence each other. The basis for the intervention components and their expected outcomes are based on the determinants, which are modifiable (Bleijenberg *et al.*, 2018). Understanding these modifiable determinants is based on the causal mechanisms, or how these components are related or intertwined. Translating the theory into a practical basis where it fits into the context and characteristics of the target population is important (Bleijenberg *et al.*, 2018). When this is not done properly, it can undermine the effectiveness of a method. The Stress Process Model was utilised in this study [details are described in Chapter 2].

3.10.1.3 Modelling process and outcomes

This is aimed at modelling the key components that will form the intervention. This is achieved by synthesising the knowledge gathered from the identification of the evidence and the theory. These elements speak about the determinants, how the determinants are susceptible to change, and the nature or strength of the relationship between the determinants and the outcome. This stage also involves prioritising, reducing, selecting, and refining the components of the intervention. In doing so, the aim is to achieve balance between the components and costs

involved. The key purpose is not only to achieve successful treatment but also to identify what components fit current practise and the context in which the intervention will be delivered. Bleijenberg *et al.* (2018) propose that after modelling the process, there is a need to make choices with regards to the content, intensity, and dose, these cannot be overemphasised.

3.10.1.4 Core components

The core elements are considering context, developing and refining programme theory, engaging stakeholders, identifying key uncertainties, refining the intervention, and considering economic reflections. They are core elements because they are not limited to a particular phase of the MRC framework but can be utilised in all phases (Bleijenberg *et al.*, 2018). To get the most out of these core elements, they are to be continually revisited throughout the research process, especially before moving between phases [for example, between development and feasibility] (Bleijenberg *et al.*, 2018). The context is the environment in which the intervention is to be implemented, and this could be physical, cultural, political, or economic (Skivington *et al.*, 2021).

Stakeholders should be engaged meaningfully during the development of the intervention and even in the other phases. The aim of engaging stakeholders is to be able to identify or develop an appropriate intervention considering the context and the economic factors, leading to an appropriate intervention that could improve outcomes for the target population (Skivington *et al.*, 2021). Stakeholders are those individuals who are the target of intervention, those involved in its development or delivery, or those whose personal or professional interests are affected (Skivington *et al.*, 2021). Patients and the public are key stakeholders (Skivington *et al.*, 2021).

The data from phase one were triangulated during the development of the intervention. Though the starting and ending points of this iterative process are not always clear, some indicators were used to identify the end points. The production of a document or manual describing the intervention and how it should be delivered is identified as a useful indicator in guiding researchers in identifying the end of the development phase (O'Cathain *et al.*, 2019).

3.10.2 Objective 4

3.10.2.1 Sampling technique

Expert sampling, a type of purposive sampling technique, was used to achieve objective 4 of phase 2. In this type of technique, the researcher recruits experts (Etikan, Musa & Alkassim, 2016). The technique was used because the researcher needed the opinions of people with knowledge of caregiver experiences and burdens. Some criteria have been set to help in determining who an expert is. These include having knowledge and some level of experience in the area that is to be discussed; having the willingness to participate; having ample time to participate; and being able to communicate effectively (Latif *et al.*, 2016). Patients or users of an intervention are considered experts (Niederberger & Spranger, 2020).

The inclusion criteria were:

- An expert (psychologist, doctor, psychiatrist, physiotherapist, mental health nurse, nurse, lecturer) who has been working with children with developmental disabilities and their caregivers for at least 3 years.
- A caregiver who has been involved in a caregiving role for at least 2 years.
- An expert/caregiver who was willing to participate.
- An expert with valid professional license from professional regulatory body.

The exclusion criteria were:

- Receiving a form of psychological or behavioural treatment
- Facing other major life stressors at the time of the study, for example loss of a spouse or significant other.

3.10.2.2 Sample size

The sample size for phase 2 used in the development of the support programme included 12 experts. They were: one researcher (1), one general nurse (1), one mental health nurse (1), two psychologists (2), one psychiatrist (1), one physiotherapist (1), two lecturers (2), one caregiver (1) and two doctors/paediatricians (2).

3.10.2.3 Data collection

The Delphi technique was used (Habibi, Sarafrazi and Izadyar, 2014), with a minimum of two rounds. There are several types of Delphi techniques, in this study, the decision-making type was used. In using this technique, the panel of experts were asked to give inputs on the designed

programme in round one, which was adapted according to their recommendation, and in the second round, the experts gave a final review.

3.10.2.4 Data collection procedure

In rounds 1 and 2, participants were asked to rate potential components of the psychosocial support programme from not a priority to an essential priority. The guidelines for identifying which components were likely to be acceptable, feasible and effective was based on the Child Health and Nutrition Research Initiative (CHNRI) criteria described in Table 3.4 below. The experts, apart from rating the items on the scale, also had the opportunity to write down their comments on the rationale guiding their choice.

Table 3.4 Pre-determined criterion questions used by the expert panel as recommended by CHNRI

CRITERIA	EXPLANATION OF CRITERIA
Criterion1: assessment of the cultural and ethical acceptability of the intervention	1. Taking into account the socio-cultural context (including care belief systems) wherein the intervention is to be used, would you say that the intervention is culturally acceptable? 2. Taking into account that mental health intervention might harm beneficiaries, would you say that this intervention safeguard and protect its recipients?
Criterion 2: assessment of feasibility (deliverability and affordability) of the intervention	1. Taking into account the resources available to implement the intervention, would you say that the intervention is affordable in a low-income setting? 2. Taking into account the level of difficulty with intervention delivery (i.e. standardizability, required human resources, community infrastructure), would you say that the intervention would be deliverable within the context of interest?
Criterion 3: assessment of likelihood that the intervention would be effective	1. Based on the best existing evidence and knowledge, would the intervention that would be utilized be effective?

3.10.2.5 Data analysis

The analysis was done using kappa statistics. In terms of achieving consensus, there are no agreeable guidelines for determining what consensus is in a Delphi technique. Only items that achieved a consensus of fair agreement and above were utilised in the study. Cohen's Kappa and its interpretation are described in Table 3.5:

Table 3.5 Cohen's kappa

Value of Kappa	Level of Agreement
<0	No agreement
0.0-0.20	Slight agreement
0.21-0.40	Fair agreement
0.41-0.60	Moderate agreement
0.61-0.80	Substantial agreement
0.81-1.00	Almost perfect agreement

3.11 PHASE 3 RESEARCH METHODS: IMPLEMENTATION PHASE

The methods and design for objective 5, 6 and 7 are described in this section.

3.11.1 Research Design: Pre-test post-test design

A one group pre-test and post-test design, a type of quasi experimental design, was used in the study. In this type of design, a group of participants is measured on a dependent variable(s) of interest and then measured again to determine if there are any changes after being exposed to a particular treatment or intervention (Knapp, 2016). Thus, measurement is done prior to the treatment or intervention and post-treatment or intervention. Changes in the post-test score can be attributed to other factors other than the treatment or intervention. For example, maturation and testing effects can affect treatment outcomes. Therefore, mapping out a complicated design can help delineate between the former and the latter in a one group pre-test and post-test design (Knapp, 2016). Another approach, was to assign participants randomly to the various measurement occasions surrounding the treatment and compare the findings for those subgroups within the one-group context (Knapp, 2016). In addition to the above, before implementing the treatment, two pre-tests should be done. The magnitude of the changes between the first and second pre-test should be lesser than that of any of the pre-test and post-test. When this happens, an argument can be made for the impact of the treatment or intervention.

3.11.2 Sampling technique

A simple random sampling technique, which is a type of probability sampling was used. Probability sampling strategies are any methods of sampling that utilise some form of random selection, which entails setting up a process or procedure that assures that different members of the target population have equal probabilities of being chosen (Jager, Putnick & Bornstein, 2017). The key advantage of probability sampling strategies is that, when carried out properly, they should yield an unbiased sample that is representative of the target population (Jager, Putnick & Bornstein, 2017). As a result, the researcher can safely assume that the estimates that were obtained from the probability samples were both unbiased and generalizable because:

The sample was selected based on an inclusion criterion:

- Being the primary caregiver for the child with DD.
- Being 18 years of age and above.
- Provided care for 6 months or more for the child with DD.
- Could read in English language.

The exclusion criteria were a caregiver:

- Receiving a form of psychological or behavioural treatment.
- On antihypertensive medication.
- Having more than one child with DD.
- Facing other life stressors at the time of the study, for example, the loss of a spouse or significant other.

3.11.3 Sample size

In (2017) posits that sample size is often not calculated in pilot studies. This view is supported by Thabane *et al.* (2010). Studies have recommended a sample size of 12 to 30 for pilot studies (Browne, 1995; Julious, 2005; Whitehead *et al.*, 2016; In, 2017). Considering a standardized effect size of 0.5 and 95% upper confidence limit, a pilot sample size of 52 is recommended (Whitehead *et al.*, 2016). Consistent with the recommendations above, Sim and Lewis (2012) recommends that a sample size of 50 is advisable considering a desired level of confidence and power. In the current study, a sample size of 53 was used.

Necessary measures were put in place to decrease the number of participants who will be lost to follow-up. The researcher ensured loss to follow-up is decreased in the following ways:

a. Collecting baseline information that facilitate tracking subjects, e.g., addresses, phone numbers and email addresses not only for the subject, but also for contacts such as next of kin or close friends.
b. Maintaining regular contact via personal contact, mail, phone, or email.
c. Periodically updating participants on the progress of the study.
d. Collecting only what was necessary to answer the research question.

3.11.4 Data collection instruments

A questionnaire was designed to take the sociodemographic characteristics of the participants (Annexure C). The Zarit Burden Interview, Depression Anxiety and Stress Scale, Physical Health Qustionnaire-15 and Multidimensional Scale of Perceived Social Support (Annexures D to G) were used to collect data of caregiver burden, depression, anxiety, stress, somatic symptoms and social support respectively. Cortisol analysis and blood pressure measurements were taken.

3.11.4.1 Zarit Burden Interview (ZBI)

General overview of the ZBI

The Zarit Burden Interview (ZBI) (see Annexure D), a self-report tool for caregivers, is recognised as one of the most established and widely used instruments (Yu, Yap & Liew, 2019). Its purpose is to assess the perceived impact of caregiving on the caregiver's life, including their physical, social, psychological, and emotional well-being. The ZBI was created by its authors to assess burden among community-dwelling caregivers for people with dementia (Yu, Yap and Liew, 2019); however, its application has been expanded to include caregivers for people with brain injury, cancer, and heart failure.

The ZBI has been translated to Chinese, French, Japanese, German, Hebrew, Spanish and Portuguese. The original version consists of 29 items and four-point Likert scale responses (Ballesteros *et al.*, 2012; Gratão *et al.*, 2019). However, the original version was revised to a 22-item instrument with 5-point Likert scale responses. The items on the ZBI are worded subjectively and it focuses on the affective response of the caregiver. The responses ranges from 0(never) to 4(nearly always) for all the first 21 items. The final item is rated from 0(not at all) to 4(extremely). An example of an item on the ZBI is demonstrated in Table 3.6:

Table 3.6 Example of the ZBI

Statement	Ratings				
Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?	0	1	2	3	4

Though initially developed as a unidimensional measure of burden, more than two dimensions have been reported in the literature, including personal strain, role strain, psychological burden and emotions, embarrassment, anger or frustration, guilt or self-criticism, exhaustion and uncertainty, patient's dependence and the consequences of caregiving (Siegert *et al.*, 2010; Flynn Longmire & Knight, 2011; Springate & Tremont, 2014; Al-Rawashdeh, 2016).

Rationale for choosing ZBI-22

Apart from the ZBI-22, other short versions of the instrument have been proposed including the 14-item ZBI (Knight et al., 2000), 12-item ZBI (Ballesteros *et al.*, 2012), 8-item ZBI (Arai, Tamiya and Yano, 2003), 7-item ZBIs (Zhou, 2011), 6-item ZBI (Higginson *et al.*, 2010), 4-item ZBIs (Gort *et al.*, 2010), 1-item ZBI (Higginson *et al.*, 2010). The abridged versions are said to minimise participants burden since it takes less time to respond (Hagell *et al.*, 2017) and is also easy to administer, especially in busy settings (Yu *et al.*, 2018). They are also more appropriate for clinical screening purposes or in instances where burden is the main outcome (Hagell *et al.*, 2017). Though they have been reported to have good internal consistency, these short forms have a restricted outcome range because of their few items. They also reported that there was a reduced precision of score with a decreasing number of items. They found that the correlation between ZBI-22 and ZBI-12 was higher, than for ZBI-8, ZBI-4 and ZBI-1 (Hagell *et al.*, 2017). Additionally, the ZBI -22 is considered the most common for assessing the burden of caregivers both in the clinical and research setting (Al-Rawashdeh, 2016). Based on the above premise, the ZBI-22 was chosen for the study.

Scoring of the ZBI

The highest score for the ZBI is 88, while the lowest score is 0. A higher score indicates a greater burden and vice versa. Score of 0-21, 21-40, 41-60, 61-88 are interpreted as little or no burden, mild to moderate burden, moderate to severe burden and severe burden respectively (Seng et al., 2010). The burden cut-off point is 21 (Higginson *et al.*, 2010).

Validity and reliability of the ZBI

The psychometric properties of ZBI have been tested across continents such as Europe (Chattat *et al.*, 2011; Braun et al., 2010), Africa (Imarhiagbe *et al.*, 2017; Ojifinni and Uchendu, 2018) and Asia (Seng *et al.*, 2010; Yu *et al.*, 2018; Pinyopornpanish *et al.*, 2020). Commonly reported psychometric properties of the ZBI are found in caregivers of dementia, cancer, brain trauma, and cardiovascular diseases. Similarly, a study by Seng *et al.* (2010) among 238 dementia caregivers reported a reliability of .93 and a test-retest reliability of .89. Most recently, Springate and Tremont (2014) also reported a Cronbach alpha of .90 among 206 caregivers. Flynn Longmire used 175 and 225 black and white samples respectively and reported .92 and .93 Cronbach alpha respectively (Flynn Longmire & Knight, 2011). Among 64 cancer caregivers, a Cronbach alpha of .85 was reported (Higginson & Gao, 2008). The above is an indication of an acceptable internal consistency reliability since they were all greater than .70 (Taber, 2018).

Literature has reported on the item total as well as item-item correlations of the ZBI (Al-Rawashdeh, 2016). When the item total correlation is greater than 0.20, it is acceptable. For an item-item correlation, an acceptable range is between 0.30 and 0.70 (Al-Rawashdeh, 2016). This is because if the correlation is greater than 0.70, it is an indication of redundancy. On the other hand, if the correlation is less than 0.30, then the item is not related to other items on the scale. There is evidence for criterion validity. Seng *et al.* (2010) found that the ZBI had a strong positive correlation ($r = 0.73$, $p < 0.0001$) with the Burden Assessment Scale. Conversely, there is evidence of ZBI's construct validity with the General Health Questionnaire (GHQ)-28. Al-Rawashdeh (2016) found that ZBI's convergent validity was supported by a positive correlation between the ZBI scores with time as well as the difficulty tasks on the Oberst Caregiving Burden Scale [OCBS] ($r = 0.466$ and $r = 0.583$, $p < 0.001$ respectively).

3.11.4.2 Depression Anxiety and Stress Scale (DASS)

General overview of the DASS

DASS (see Annexure E) was developed as a subjective and self-report instrument for assessing the three negative emotional states of depression, anxiety, and stress (Lovibond & Lovibond, 1995; Beaufort *et al.*, 2017). The DASS has no forthright ramification in terms of putting patients into clear diagnostic categories as stated in classification systems such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International

Classification of Diseases and Related Problems (Beaufort *et al.*, 2017). The instrument is used for assessing the severity of symptoms in relation to depression, anxiety, and stress in both clinical and non-clinical samples (Beaufort *et al.*, 2017). Thus, the purpose of the DASS is not to replace the diagnostic psychometric instrument used in evaluating the dimensional components of anxiety, depression and stress characterised by distinct syndromes/symptoms (Osman *et al.*, 2012). It was developed to address the inability of earlier emotional measures to discriminate between depression and anxiety, which are considered to be intertwined (Lovibond & Lovibond, 1995; Oei *et al.*, 2013).

The original version comprises 42 items with subscales of the DASS-Depression, DASS-Anxiety and DASS-Stress each having 14 items. A short version of 21-items was developed with 7 items on each subscale of the instrument (Lovibond & Lovibond, 1995). The DASS-Depression scale assesses components like self-esteem, hopelessness, anhedonia and dysphoria. The DASS-Anxiety focuses on autonomic arousal and situational anxiety. The DASS-Stress assesses the difficulty in relaxing, nervous arousal, over reactivity and impatience (Lovibond & Lovibond, 1995).

The respondent must indicate how much the statement applies to over the past week when using the DASS – 42. A four-point Likert scale, with 0 representing "did not apply to me at all" and 3 representing "applied to me very much or most of the time," is used to rate the responses. An example of items on the different sub scales are:

- DASS(Depression)-I couldn’t seem to experience any positive feeling.
- DASS(Anxiety)-I experienced breathing difficulty.
- DASS(Stress)-I was intolerant of anything that kept me from getting on with what I was doing.

Rationale for choosing DASS-42

The DASS-42 is the preferred choice of instrument for the current study. Though the short form allows for easy administration and interpretation by a non-mental health person (Yıldırım, Boysan and Kefeli, 2018), some items have been removed making the DASS-42 ideal. For example, the original version of the DASS which is the DASS-42 contains items on somatic complaints such as sleep disturbances, changes in appetite, and changes in energy level (Yıldırım, Boysan & Kefeli, 2018) which have been excluded in other short versions.

Scoring of the DASS-42

Depending on the overall score for each of the subscale, it is categorised as normal, mild, moderate, severe, or extremely severe. To calculate scores on the DASS-21, they have to be multiplied by 2 (Lovibond & Lovibond, 1995). The breakdown of scoring for each subscale is described in Table 3.7:

Table 3.7 Scoring of the DASS-42

Meaning	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28+	20+	34+

Validity and reliability of the DASS-42

The factor analysis of the instrument supports the factor structure. A three-factor structure has been mainly reported both in samples dwelling in the community and in the normal population (Asghari, Saed and Dibajnia, 2008; Sinclair *et al.*, 2012; Mellor *et al.*, 2015). Henry and Crawford (2005), however, reported general psychological distress as a second order factor. Two-factor model (Willemsen *et al.*, 2011) and quadripartite model (Szabó, 2010) have also been reported. Duffy, Cunningham and Moore (2005) who reported on a two-factor model considered generalised negativity factor and physiological hyperarousal factor. Tulley et al's three factor model mentioned the general factor of negative emotions, the specific depression factor and the specific anxiety factor (Tully, Zajac & Venning, 2009). Willemsen *et al.* (2011) reported a tripartite factor model of general negative affectivity, physiological hyperarousal and anhedonia. Lovibond and Lovibond's three original factor model of depression, anxiety and stress was used in the study (Lovibond & Lovibond, 1995).

Validation of the DASS-42 has been done across many adult populations and cultures including British, American, Hispanic, Turkey, Iran, Malaysia and Asian (Crawford *et al.*, 2009; Oei *et al.*, 2013; Jiang *et al.*, 2020). Good psychometric properties are suggested by the results of studies published in the literature for DASS-42 (Bilgel & Bayram, 2010; Ramli, Rosnani & Fasrul, 2012; Habibi *et al.*, 2017). Internal consistency reliability was reported to be 0.94, 0.90 and 0.87 for the Depression, Anxiety, and Stress scales, respectively (Ramli, Rosnani and Fasrul, 2012). Comparably, the Cronbach alpha of the DASS-Depression, Anxiety and Stress subscales was determined Bilgel and Bayram (2010) to be 0.92, 0.86 and 0.88, respectively.

According to Habibi *et al.*, (2017), the Cronbach alpha for stress was 0.92, for anxiety it was 0.89, and for depression it was 0.94. In a more recent study, Shayan *et al.*, (2021) discovered that the internal consistency of the stress, anxiety and depression subscales was 0.833, 0.888 and 0.866 for respectively. The DASS-42 has been found to be correlated with the Hospital Anxiety and Depression Scale (Ramli, Rosnani & Fasrul, 2012). There have been reports of good construct validity (Habibi *et al.*, 2017).

3.11.4.3 Physical Health Questionnaire (PHQ)-15

General Overview (PHQ)-15

The Physical Health Questionnaire-15 (see Annexure F) is a self-report instrument for screening for somatic symptoms or the evaluation of the potential for the presence of somatization and somatoform disorder as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV (van Ravesteijn *et al.*, 2009; Körber *et al.*, 2011; Steinbrecher *et al.*, 2011). It is a self-administered version of the Primary Care Evaluation of Mental Disorders (PRIMEMD) (Kroenke, Spitzer & Williams, 2002). The PHQ-15 is derived from the complete version of the Patient Health Questionnaire (Hinz *et al.*, 2017).

The concept of somatic symptoms has changed in the last two versions of the DSM, namely DSM-IV and DSM-V. In the DSM-V, somatic symptoms and related disorders have replaced somatoform disorders in the DSM-IV. The difference is a result of the emphasis placed on the concept. The DSM-IV emphasises "medically unexplained," while the DSM-5 places emphasis on the "distress" of somatic discomforts (Rief *et al.*, 2010). The use of "medically unexplained" as postulated in the DSM-IV reflects the absence of a clear diagnosis; thus, the DSM-V's emphasis on distress may increase the consistency of the diagnosis as well as the size of this group of disorders. The 15 items of the PHQ-15 do not specifically ask about "medically unexplained" symptoms though it was developed during the era of DSM IV (Kroenke, Spitzer & Williams, 2002). As a result, the PHQ-15 is applicable in evaluating somatic symptoms and related disorders in the DSM-5. Evidence shows the applicability of the PHQ-15 to the evaluation of somatic symptom disorders as defined by the DSM-V (Häuser *et al.*, 2014).

The questionnaire consists of fifteen common somatic symptoms, and the respondents are to indicate on a three-point Likert scale how much they have been bothered or burdened with those symptoms for the past seven days (Gierk *et al.*, 2014). The symptoms in the order in which they appear on the instrument are chest pain, dizziness, fainting, palpitations, shortness

of breath, bowel complaints (constipation or diarrhoea), dyspeptic complaints (nausea, gas, or indigestion), stomach pain, back pain, headache, fatigue, trouble sleeping, pain in joints or limbs, menstrual pain or problems and pain or problems during sexual intercourse. According to Kocalevent, Hinz and Brähler (2013), these symptoms are the most prevalent in the outpatient setting.

Structure of the PHQ-15

Several studies have explored the structure of the PHQ-15 and reported the existence of 1 to 5 factors (Lee, Ma and Tsang, 2011; Witthöft *et al.*, 2013; Liao *et al.*, 2016). Lee, Ma and Tsang (2011) in their study reported four factors: cardiopulmonary, gastrointestinal, pain, and neurological. Witthöft *et al.* (2013) reported on one bifactor which includes one general factor and four specific symptom factors. In Laio and colleagues study, exploratory factor analysis led to the identification of three factors: cardiopulmonary-related symptoms (shortness of breath, palpitation, chest pain and fainting spells); pain-related factors (pain in the extremities, back pain, headache, dizziness, sleep disturbance, and fatigue); and gastrointestinal factors (nausea due to indigestion, stomach ache, constipation or diarrhoea, sexual problems). Item 4 (menstrual cramps) was identified as an independent factor. Similar to Kroenke et al.'s original 3-factor model, the discriminant validity of item 15 increased after the removal of item 4 (Liao *et al.*, 2016).

Scoring of the PHQ-15

The Likert scale responses are not bothered (0), bothered a little (1), and bothered a lot. The minimum and high total score for the instrument are 0 and 30 respectively. The scores of the scale are 0-4, 5-9, 10-14, and 15-30 and are interpreted as no, low, medium and high respectively. Though the items on the scale are 15, only 14 items are used for males since the item "menstrual cramps or other problems with your periods" refers to only females (Kroenke, Spitzer & Williams, 2002). Participants are usually encouraged to complete all the items on the questionnaire.

Out of the 15 items on the questionnaire, if 4 or more items are not answered by the participants, the total score is not calculated, hence, the participants are encouraged to respond to as many items as possible. If 1 to 3 items are left unanswered, the raw score should be prorated. This can be done by summing the scores of the answered items to get a partial raw score. The partial raw score is multiplied by the number of items on the PHQ-15. The value obtained is divided

by the number of items that were answered. If the final prorated score is a fraction, it is rounded up to the nearest whole number. The total prorated score is interpreted, using the same interpretation of the scale (Kroenke, Spitzer & Williams, 2002; Gardner *et al.*, 2016).

Validity and Reliability of the PHQ-15

The original English version of the PHQ-15 by Kroenke, Spitzer and Williams (2002) has been translated to several languages and validated across culture, including Dutch (van Ravesteijn *et al.*, 2009), Korean (Han *et al.*, 2009), Spanish (Montalbán, Vives and Garcia-Garcia, 2010), Chinese (Liao *et al.*, 2016; Zhang *et al.*, 2016) and Swedish (Nordin, Palmquist & Nordin, 2013). Strong validity (construct and criterion) and reliability (internal consistency and test retest) have been demonstrated (Kroenke, Spitzer & Williams, 2002; van Ravesteijn *et al.*, 2009). The PHQ-15 was determined to be the most valid and useful somatic symptoms questionnaire in a systematic review (Zijlema *et al.*, 2013). A high internal consistency of 0.80 was reported by Gierk *et al.* (2014). According to Liao *et al.* (2016) the PHQ-15 total, factor 1, factor 2 , and factor 3 had test-retest reliability of 0.930, 0.928, 0.803, and 0.911, respectively, and internal consistency of 0.861, 0.811, 0.781, and 0.637. The PHQ-15 is highly correlated with the Somatic Symptom Scale [SSS-8] [r = 0.83] (Gierk *et al.*, 2014), physical component of the SF-8 [r = 0.58] (Hinz *et al.*, 2017).

3.11.4.4 Multidimensional Scale of Perceived Social Support (MSPSS)

General overview of MSPSS

The Multidimensional Scale of Perceived Social Support (MSPSS) [see Annexure G] is a self-report measure developed by Zimet *et al.* (1988) and is aimed at assessing varying types of perceived sources of social support. The instrument was developed based on two factors; (i) the conceptual framework and (ii) findings from the social support literature. The conceptual framework guides the definition of different and specific sources of social support. The social support literature, on the other hand, highlights the distinct functions of the sources of social support. As a result, the MSPSS was developed with three distinct dimensions of perceived sources of social support: those from friends, family, and significant others. Each dimension of the construct comprises items intended to evaluate two aspects of the support: its perceived availability (item number 10) and its function (item number 2), respectively. For instance, item 10 of the Significant Other Support scale, “There is a special person in my life who cares about

my feelings" assesses the perceived availability of social support while item 2, "There is a special person with whom I can share joys and sorrows" measures the function of the support.

Participants in the initial MSPSS version answered questions on a 5-point Likert scale across 24 items. Some of the items were removed because they had no bearing on the validity and reliability of the family, friend, and significant other categories on the scale. As a result of this, the number of items was lowered from 24 to 12 (Hardan-Khalil & Mayo, 2015). The procedure for rating the items on the MSPSS was modified by the authors to increase the variability of the responses (Osman *et al.*, 2014) and to avoid a ceiling effect of the responses (Hardan-Khalil & Mayo, 2015). Thus, the response options of the revised MSPSS have increased from 5 to 7. The response options range from 1 (very strongly disagree) to 7 (very strongly agree). The MSPSS has been translated into Thai, Polish, Swedish (Akhtar *et al.*, 2010; Wongpakaran, Wongpakaran & Ruktrakul, 2011; Adamczyk, 2013; Ekbäck *et al.*, 2013). The instrument has been used in clinical and non-clinical settings (Schneider & Chesky, 2011;Uchino *et al.*, 2012) in various age groups (Veselska *et al.*, 2010; Schneider & Chesky, 2011) and in samples with various cultural backgrounds (Sawant & Jethwani, 2010; Karukivi *et al.*, 2011; Séjourné *et al.*, 2012).

Sub-scales of the MPSS

A three-scale structure was proposed by Zimet *et al.* (1988). Similarly, Vaingankar *et al.* (2011) confirmed the scale's structure of three sub-scales through confirmatory factor analysis among outpatients with schizophrenia in Singapore. This was confirmed in a more recent study (Ramos *et al.*, 2017). The three social support sub-scales of the MSPSS comprise four items each: the family subscale (items 3, 4, 8, and 11), the friends' subscale (items 6, 7, 9, and 12), and the significant Others subscale (items 1, 2, 5, and 10). Examples of items on each of the sub-scales are as follows; (1) family (FA) (i.e. ''My family is willing to help me make decisions''), (2) friends (FR) (i.e. ''I can talk about my problems with friends''), and (3) significant other (SO) (i.e. ''There is a special person who is around when I am in need'') (Zimet *et al.*, 1990a).

Scoring of the MSPSS

A total subscale score is obtained by summing the total number of responses to the items on the subscales. Scores on all 12 items are summed up to obtain a composite MSPSS scale score otherwise known as the global perceived social support score (Osman *et al.*, 2014). The

possible score range is between 12 and 84, the higher the score, the higher the perceived social support, and vice versa. Scores for each of the subscales can be put together equally. The possible score range for the subscales/dimensions is between 4 and 28 (Zimet *et al.*, 1988, 1990b). A high observed total mean score on any specific subscale indicates high levels of perceived social support from that source. The instrument is easy to administer and score in research settings (Osman *et al.*, 2014) since it is comprised of brief and complete sentences (Zimet *et al.*, 1990a).

Validity and Reliability of the MSPSS

Multidimensional Scale of Perceived Social Support has been found to be reliable and valid both in its original language (Zimet *et al.*, 1990a) and in other language versions (Wongpakaran, Wongpakaran & Ruktrakul, 2011; Adamczyk, 2013; Ekbäck *et al.*, 2013; Osman *et al.*, 2014). The internal reliability for the MSPSS total score and for the sub-scales has been reported as (0.93-0.98) and (0.91-0.81) respectively (Zimet *et al.*, 1990; Dahlem, Zimet & Walker, 1991; Stanley, Beck & Zebb, 1998). Test-retest which requires two administrations, has been used to explore the stability of MSPSS over time between a period of 1 month to 3 months after the initial administration (Zimet *et al.*, 1990; Wongpakaran, Wongpakaran & Ruktrakul, 2011) and reliability was high. According to Waltz et al. (2010), the recommended time frame for test-retest is 2 weeks after the initial administration of the instrument. Since the studies that did test retest exceeded this recommended time span, the MSPSS can be said to be a stable instrument for a longer period.

Wongpakaran and colleagues, using data from 462 Thai participants, sought to establish the divergent and convergent validity of the MSPSSS. The researchers reported a significant negative correlation of the total score of the MSPSS with the State Trait Anxiety Inventory ($r = -0.20$, $P = .004$) and the Thai Depression Inventory ($r = -0.19$, $P = .007$) (Wongpakaran, Wongpakaran and Ruktrakul, 2011). There was a positive correlation between the total score of the MSPSS and the Rosenberg Self-esteem Scale ($r = 0.33$, $P < .0001$), establishing convergent validity. Hardan-Khalil and Mayo (2015) also examined the validity of the MSPSS among 276 Arab American women and divergence was established as there was a significant negative correlation of the MSPSS with the Psychological Stress Measure 9 ($r = -0.27$, $P < .01$).

3.11.4.5 Cortisol analyser

Cortisol test was run using VITROS 5600, an automatic biochemistry analyser designed to run clinical chemistry and immunoassay testing. It reduces errors and the potential for retesting. It has been documented to deliver results of high quality (Ortho Clinical Diagnostics, 2022). The reference range for cortisol is shown in Table 3.8:

Table 3.8 Cortisol reference range

Parameter	Unit	Time	Reference range
Cortisol	nmol/L	Morning[am]	123-626
		Evening[pm]	46.2-389

3.11.4.6 Blood pressure equipment

The blood pressure was measured with the Omron HEM 7124 fully automatic digital blood pressure monitor. The device is able to obtain measurements that are precise and accurate by using the oscillometric principle. Comfortable, controlled inflation is possible because of the advanced IntelliSense technology. As a result, there is no need for pressure pre-setting or re-inflation, as the smallest changes in pressure can be detected, leading to an accurate measurement. The blood pressure ranges are described in Table 3.9:

Table 3.9 Blood pressure categories in adults

Blood pressure category	Systolic [mmHg]		Diastolic [mmHg]
Normal	Less than 120	and	Less than 80
Elevated	120-129	and	Less than 80
High blood pressure [Stage 1]	130-139	or	80-89
High blood pressure [Stage 2]	140 or higher	or	90 or higher
High blood pressure [Stage 3]	Higher than 180	and/or	Higher than 120

Source: (American Heart Association, 2017)

3.11.5 Data collection procedure

3.11.5.1 Administration of questionnaires

Structured questionnaires including the Zarit Burden Interview, Depression Anxiety and Stress Scale, Physical Health Questionnaire and Multidimensional Scale of Perceived Social Support were administered and details are described in Table 3.10 below:

Table 3.10 Average time for administration of instruments

Questionnaire	Average time for administration
DASS-42	7 minutes
PHQ-15	5 minutes
MSPSS	5 minutes
ZBI	10 minutes

The participants were made comfortable and the process was thoroughly explained before they started answering the questionnaire. Prior to this, a consent form had been signed. A conducive environment was provided for the participants to sit comfortably and answer the questionnaire. They were provided with a bottle of water, and were allowed to take breaks in between if they wanted to.

3.11.5.2 Measurement of cortisol levels

Cortisol levels were measured, using blood samples. A day was scheduled for all the participants for their samples to be taken. The decline of cortisol levels throughout the day necessitated that at least two samples were taken. The first samples of participants were taken between 7-9 a.m. and the second, 3-5 p.m. About 0.6 millilitre (ml) of blood samples were taken by licenced Medical Laboratory Scientists of the Reference Laboratory at the Korle-Bu Teaching Hospital. The following steps were followed in the sample collection:

i. The caregivers were offered comfortable seats.
ii. The site was cleaned using aseptic techniques.
iii. Participants were positioned with hyperextended arms.
iv. A tourniquet was applied approximately 3-4 inches above the selected site.
v. Participants were asked to make a fist.
vi. The venepuncture site was prepared by cleansing the area with an alcohol pad for 30 seconds and allowing it to air dry for 30 seconds.

vii. The participant's lower hand was grabbed firmly (below site of puncture) to draw the skin taut and prevent the vein from rolling.
viii. A needle was inserted at a 15 to 30-degree angle into the vessel.
ix. The required tube was attached to remove about 0.6 ml of blood.
x. The tourniquet was removed as the last amount of blood was drawn.
xi. The needle was removed from the patient's arm and pressed down on the vessel with gauze.
xii. The tubes were labelled appropriately and sent to the laboratory for further analysis.

3.11.5.3 Measurement of blood pressure

Blood pressure measurements were done on the day that blood samples were collected at 9 a.m. 12 noon and 3 p.m. The researcher ensured standardised techniques were used to reduce three types of errors (Muntner *et al.*, 2019).

- Patient-related: Caregivers were advised to minimise movement and not cross legs during measurement. Taking of caffeine, exercise and smoking were discouraged at least 30 minutes before the procedure.
- Device-related: The researcher ensured a validated device was used. In this study, Omron M6 was used.
- Procedure-related: An appropriate cuff size was used to avoid artificial high or low readings. The cuff was applied at the level of the right atrium and on the bare skin. Caregivers were in a seated position with feet flat on the floor for the procedure. Registered nurses together with the researcher performed the procedure.

3.11.6 Validity and reliability

In quantitative research, to achieve rigour, validity and reliability must be ensured (LoBiondo-Wood & Haber, 2013). Validity refers to the degree to which there is the precise measurement of a concept (Heale & Twycross, 2015). Reliability is the consistency of a research instrument in providing the same results if it is used in the same situation on repeated occasions (Heale & Twycross, 2015).

3.11.6.1 Applicability to the current study

The Cronbach alpha for the instruments was calculated and details are provided in Table 3.11 below:

Table 3.11 Cronbach alpha for the instruments

Instruments	**Cronbach alpha**
DASS [total]	0.89
Depression	0.82
Anxiety	0.79
Stress	0.86
PHQ-15	0.72
MSPSS	0.75
ZBI	0.92

3.11.7 Data analysis

Phase 3 data analysis involved the application of both descriptive and inferential statistical methods. The study employed Pearson correlation analysis to investigate the association between the demographic variables of caregivers and their scores on stress, burden, depression, and anxiety. The results of participants who finished the pre- and post-program assessments were compared using the Wilcoxon ranked test and the paired sample t test.

3.12 ETHICAL CONSIDERATION

A research proposal was developed and submitted to the Department of Nursing Education, University of the Witwatersrand for review by the faculty. The initial departmental review process was quite crucial, as the faculty members provided very insightful contributions. Based on the inputs, the proposal was amended and further submitted to the Faculty of Health Sciences for postgraduate assessment. The Postgraduate Assessors Committee of the Faculty of Health Science also made certain inputs and the changes were carried out. The topic was approved (see Annexure S). An online application was made to the Human Research Ethics Committee (HREC) of the University of the Witwatersrand and the study protocol was approved with Human Research Ethics Committee number, M201160 (Annexure T). The study was approved by the Institutional Review Board (IRB) as well as the Scientific and Technical Committee (STC) of the Korle Bu Teaching Hospital, Ghana with approval numbers KBTH-

IRB/00021/2021 and KBTH-STC/00021/202 respectively (see Annexures Q and R). The principles of informed consent, privacy, confidentiality, respect, and responsibility were applied in the study and are described in details below.

3.12.1 Informed consent

Informed consent refers to a legal and ethical document that describes the participants willingness to partake in a study after the purpose, nature, consequences, and risks of the intervention of the study are explained to them (Guraya, London & Guraya, 2014). A research participant's decision to take part in research is entirely voluntary (Vanclay, Baines and Taylor, 2013) and as such, there should be no form of coercion. The process involved in informed consent has been classified into two parts. The first stage is where the participant is provided with relevant information about the research (Annexures I-J). Here, no amount of information should be considered too little not to be disclosed. This stage involves the participant signing a consent form. The nature of the study, the potential risks involved, and the benefits were thoroughly explained to participants involved in all phases of the study, after which they signed a consent form (Annexures L to O).

3.12.2 Privacy

Privacy is an ethical principle that refers to the research participants deciding on the extent of information about aspects of their lives they would like to make available (Guraya, London & Guraya, 2014). Personal identifiers of the participants, such as name and place of residence were not collected.

3.12.3 Confidentiality

Confidentiality implies that there is a limitation on how much information can be disclosed to a third party (Guraya, London & Guraya, 2014). The participants were informed that confidentiality will be maintained such that information made available to will not be shared with just anybody but rather with those who have the authority to have such information.

3.12.4 Respect and responsibility

Respect in research is in two dimensions: respect of people and respect for truth (Guraya, London & Guraya, 2014). Guraya, London and Guraya (2014) describes respect for truth as integrity and honesty for other researchers' intellectual rights. The researcher in this study

made all the necessary attempts to avert plagiarism, making false deductions and interpretations. The rights of the participants who have given their consent to take part in the study were respected, including maintaining confidentiality and anonymity. During the process, the researcher was not judgemental of the responses of the participants; thus, their views were recorded as they were and given due recognition in the assessment (Vanclay, Baines & Taylor, 2013).

3.13 SUMMARY OF CHAPTER THREE

This chapter discussed the research methods, settings, design, sampling and sample size, data collection and instruments, data analysis, rigour of the study and ethical considerations. The next chapter presents findings from the phenomenological study.

CHAPTER 4

DESCRIPTIVE PHENOMENOLOGICAL STUDY (PHASE 1a)

4.0 INTRODUCTION

The research methods for the study were presented in the previous chapter. The study's initial phase had two primary goals. The first goal of Phase one is outlined in this chapter. The aim was to delineate the experiences and needs of parents raising children with DD. The themes and subthemes that arose from the qualitative data will be discussed, along with the characteristics of caregivers and children with DD. Section 3.9 of Chapter 3 provides a detailed description of the data collection techniques used for this chapter. The section also covers the findings of the qualitative investigation.

4.1 CAREGIVER AND CHILD SOCIO-DEMOGRAPHIC CHARACTERISTICS

The socio-demographic characteristics of the caregivers and children with DD is described in terms of caregiver's age, gender, marital status, occupation, duration of caregiving and relationship to the patient. Details are presented in Tables 4.1 and 4.2:

Table 4.1 Detailed socio-demographic characteristics of caregivers and child with DD

Participant	Gender	Age	Marital status	Employment status	Duration of caregiving	Gender of child	Specific diagnosis
1	Female	31	Married	Employed	8 months	Male	CP
2	Female	35	Single	Employed	2 years	Male	ASD
3	Male	42	Married	Unemployed	2.5 years	Female	DS
4	Female	27	Cohabiting	Unemployed	5 years	Female	ADHD
5	Female	24	Single	Employed	3 years	Female	CP
6	Female	28	Married	Unemployed	2 years	Male	ASD
7	Male	36	Divorced	Employed	3 years	Male	DS
8	Female	34	Single	Employed	4 years	Male	ID
9	Female	35	Married	Unemployed	2.5 years	Female	CP
10	Female	29	Married	Unemployed	7 years	Male	ADHD
11	Female	30	Cohabiting	Unemployed	3 years	Male	ASD
12	Male	39	Single	Unemployed	2 years	Male	ID
13	Female	44	Divorced	Unemployed	8 years	Male	ASD
14	Female	26	Married	Employed	1.8 years	Female	CP

Table 4.2 Descriptive statistics of caregiver/child socio-demographic characteristics

Variable	**Mean**	**SD**
Caregiver's age	32.86	3.48
Child's age	6.86	2.03
Variable		**N**
Caregiver's gender	Male	3
	Female	11
Marital status	Married	5
	Cohabiting	2
	Divorced	3
	Not married	4
Occupation	Employed	6
	Unemployed	8
Duration of caregiving	6 months-2yrs	3
	>2-4yrs	6
	>4-6yrs	3
	>6-8yrs	2
Relationship to the patient	Son	9
	Daughter	5
Child's gender	Male	9
	Female	5
Variable		**N**
Child's diagnosis	CP	4
	ASD	4
	DS	2
	ID	2
	ADHD	2

The findings from Table 4.1 indicates that caregivers and children with DD in the study were relatively young. Majority of the caregivers were females (n=11), cohabiting or divorced or unmarried (n=9), unemployed (n=8). Additionally, majority of caregivers had provided care more than 2 years (11). Most children with DD were males (n=9) with a diagnosis of CP (n=4) or ASD (n=4) being very common.

4.2 THEMES AND SUB-THEMES GENERATED FROM THE INTERVIEWS

The phases described in section 3.9.1.6 of the study was followed to generate 5 themes and 17 sub-themes. A summary of activities for each of the stages is described in this section.

4.2.1 Familiarisation with the data

The transcripts were actively read and the initial trends and interesting points were taken note of. An example of preliminary notes taken during familiarisation is presented below:

Participants often constructed caregiving as stressful emanating from performing ADLS for their children with DD.

Participants face stress in trying to secure a special school for their school-aged child with developmental disabilities. Those who consider mainstream public schools face similar stress.

Children with DD exhibit different forms of challenging behaviour and managing such behaviours was considered as a source of stress for caregivers.

Participants communicating their expectations to their children with DD was meet with some barriers. Thus, effective communication between the participants and their special children was difficult.

4.2.2 Generating initial codes

Initial codes were generated at this phase. The same code was produced for both C5 and C6. This code highlights on the demands of caregiving versus demands of caregivers' job. It was prevalent throughout the entire dataset and would subsequently be informative in the development of a theme or sub-theme. Again, C1, C2, C3, C4 and C8, emphasised the increased cost involved in caring for children with developmental disability, and would also form a theme or sub-theme. An example of data extracts and initial codes generated is described in Table 4.1:

Table 4.1: Initial codes with accompanying data extracts

Data Extracts	**Code number**	**Codes**
The medications for my child are expensive and is really draining me	C1	Cost of medications
We go for physiotherapy……and it is really expensive	C2	Cost of adjunct treatment
The medications I buy for my child are costly…every day we go for doctor's appointment, I buy medications.	C3	Cost of medications
Sometimes there is no money to cater for other siblings since all the money goes into caring for my child who needs extra support and care	C4	Cost of catering for other siblings
I used to be a seamstress but now I have stopped because of him	C5	Loss of job as a result of caregiving role
Currently, I am not working, I use to sell but now I have stopped because of him	C6	Loss of job as a result caregiving role
Though I still work, I can say my income has reduced because I am unable to spend more time with my work like I previously use to	C7	Reduced income due to caregiving role
I have not been able to purchase a wheel chair for easy movement of my child	C8	Cost of assistive devices

4.2.3 Generating themes

During phase 3, the codes were assembled into initial candidate themes. A thematic map of the initial candidate theme can be seen in Figure 4.1.

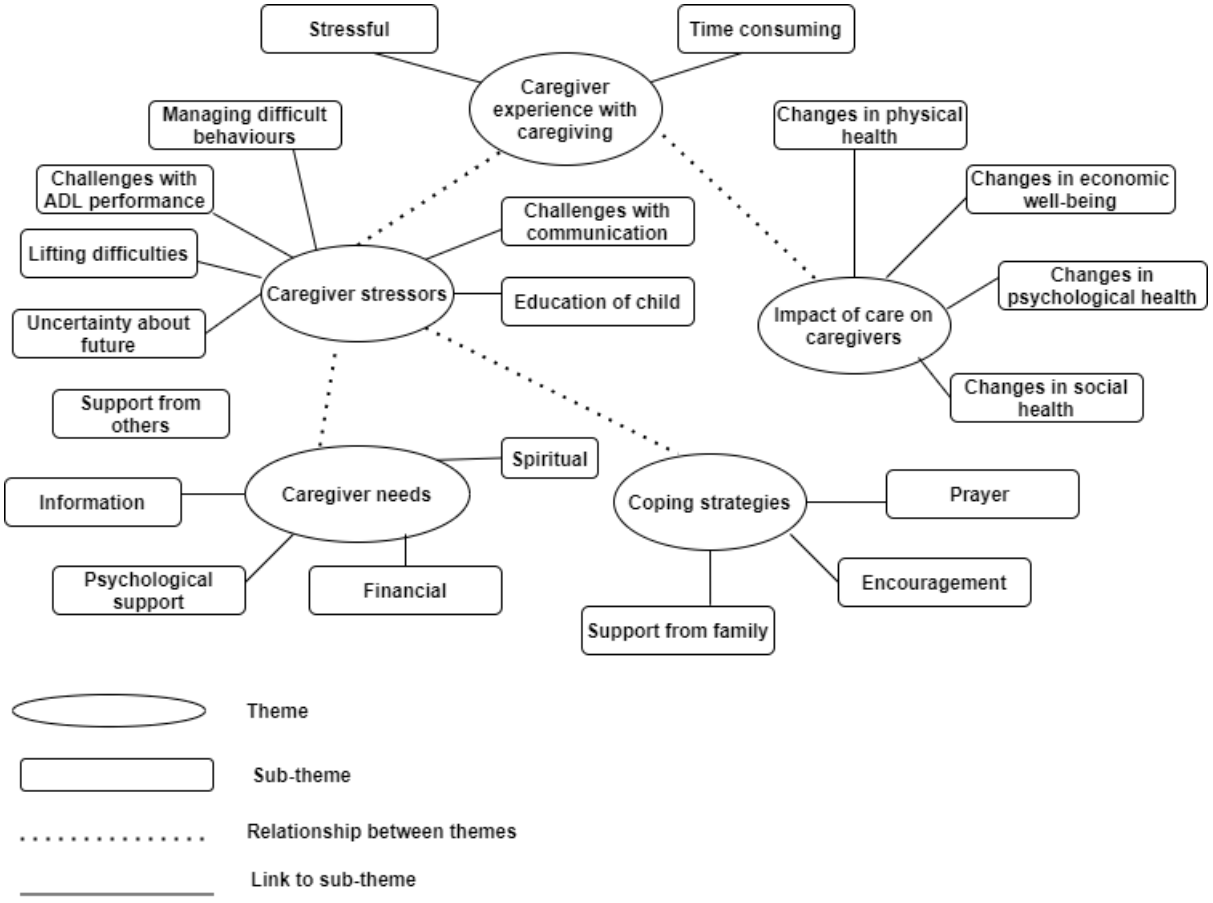

Figure 4.1 Initial thematic mapping

4.2.4 Reviewing the themes

The analysis conducted at this phase involved two levels of review. Level one was a review of the relationships among the data items and codes that informed each theme and sub-theme. The items/codes which formed a coherent pattern, were assumed that the candidate theme/sub-theme made a logical argument and may contribute to the overall narrative of the data. At level two, the candidate themes were reviewed in relation to the data set. Themes were assessed as to how well they provide the most apt interpretation of the data in relation to the research question. Overlapping sub-themes were revised. The reviewed themes and sub-themes is presented in Figure 4.2.

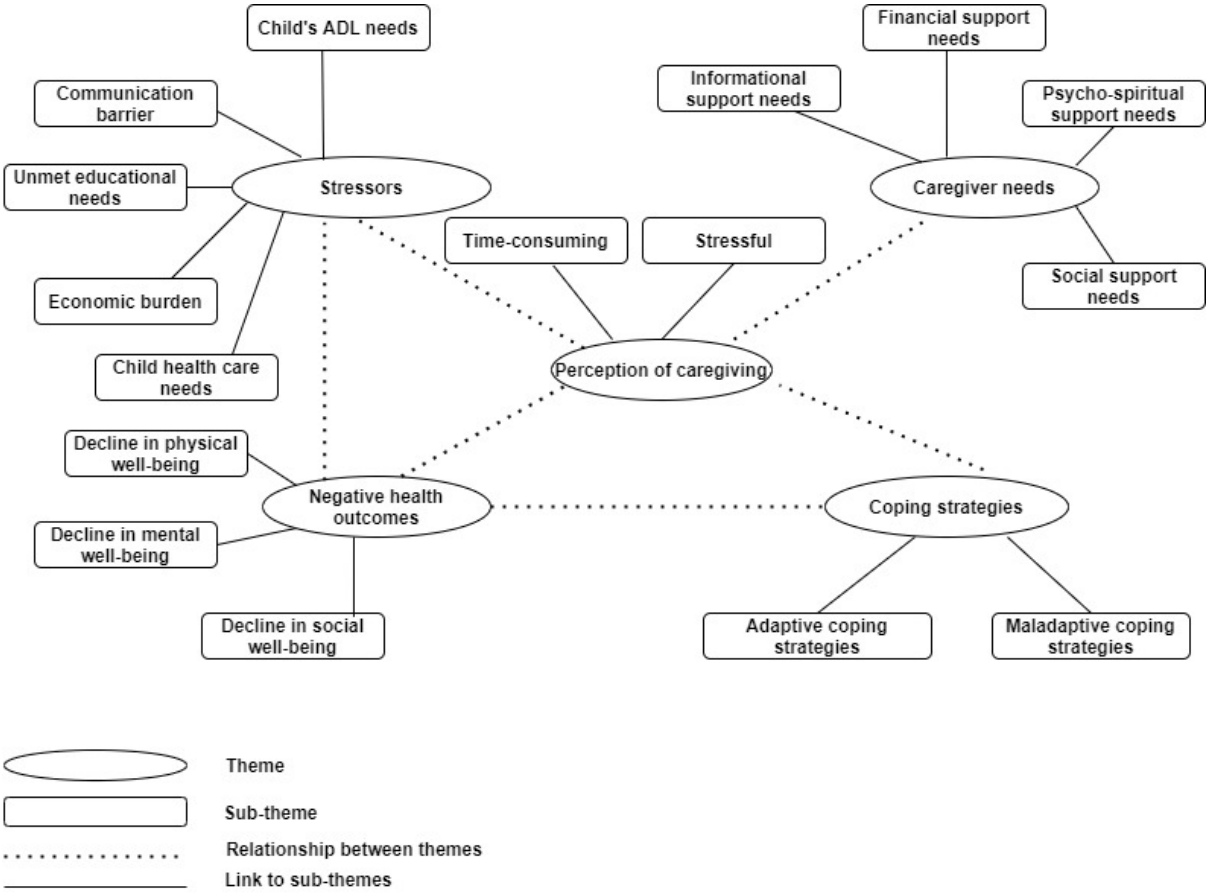

Figure 4.2 Finalised thematic mapping demonstrating five themes

4.2.5 Defining and naming the theme

During this phase, a detailed analysis of the thematic framework. The theme and sub-them were expressed in relation to the data set and research question. Data extracts were presented illustratively, providing a description of the participants said.

4.2.6 Write-up

The order in which themes would be reported was established. Themes were reported such that they build on previously reported themes. The order in which the themes and the sub-themes are reported are presented in Table 4.3.

Table 4.3 Themes, sub-themes and codes

Themes	Subthemes	Codes
Perception of caregiving role	Stressful nature of caregiving	Overwhelmed with caregiving Tiredness from caregiving role Difficulty combining caregiving role and other social roles
	Time consuming	Caregiving takes a lot of time Caregiving is extended Caregiving takes away one's leisure Caring for a child with DD is a task that needs time
Stressors	Child's ADL needs	Assisting with feeding Assisting with bathing Assisting with elimination
	Communication barrier	Caregiver communicating expectations Child with DD communicating his or her needs
	Managing challenging behaviour	Forms of difficult behaviours Triggers of difficult behaviours Dealing with usual behaviours
	Child's health needs	Proximity of the hospital to caregiver's home Visiting the hospital many times Preparing for hospital appointments Difficulty obtaining prescribed medication from hospital pharmacy Time spent at the hospital during visits or appointments
	Unmet educational needs	Difficulty getting a special school for the child with DD Proximity of special schools High cost of enrolling in special school Gaining admission into mainstream school Attitude of teachers from mainstream school
	Economic burden	Cost of medications Cost of assistive devices Cost of other therapies Loss of job Conflicting demands of job and caregiving

		Under employment Decreased output at work
Negative health outcomes	Decline in physical well-being	Low back pains General body pains Headaches Fatigue Difficulty in sleeping at night Interrupted sleep at night
	Decline in mental well-being	Decreased concentration Feeling angry Feeling sad Feeling anxious
	Decline in social well-being	Unable to take part in social functions Limited social contact Loss of interest in social activities Negative attitudes from other people Strained relationship with partners Strained relationship with friends Strained relationship with community members
Support needs	Informational support needs	Inadequate information on diagnosis from professionals Complex online information Inadequate information on managing the child
	Financial support needs	Lack of financial support towards child's management Lack of financial support towards caregiver
	Psychospiritual support needs	Counselling Spiritual support
	Social support needs	Family support Support from friends Support groups
Coping strategies	Adaptive coping strategies	Religious coping through prayer Self-encouragement Support from immediate family/nuclear family
	Maladaptive coping strategies	Blaming self Blaming others Blaming supreme being

The themes and sub-themes are described below supported by direct quotes from the participants and afterwards a discussion follows. Participant numbers, for example, P-50 were used to protect the person's identity.

4.3 THEME 1: PERCEPTION OF CAREGIVING ROLE

Generally, caregivers perceived that caring for a child with DD as negative. Two sub-themes were generated: caregivers perceived caregiving as stressful and time consuming.

4.3.1 Sub-theme: Stressful nature of caregiving

Caregivers were overwhelmed with the caregiving activities for children with DD, which led to high levels of stress, fatigue and exhaustion. The level of dependence of the child with DD on the caregiver comparable to that of a typically developing child did not appear to be the same. Children with DD were more dependent on their caregivers, had extra needs and required adequate support to thrive. A caregiver had this to say:

> *"Caring is stressful. I have other children, so I usually compare them, and you notice that as the "normal" is growing they begin to acquire some level of independence and are able to do some little things for themselves. In the case of the child with the disability, it's not like that. You do everything for them." (P5, mother, 24 years)*

The task of having to perform activities of daily living (ADL) for the child with DD appeared to be stressful for caregivers especially in the absence of mechanic devices. These activities are performed daily and it would be impossible for the caregiver to skip or ignore. Any attempt by the caregiver not to perform such activities imply, the child with DD will suffer. The inability to accomplish essential activities of daily living may lead to unsafe conditions and poor quality of life. A female caregiver with a child with CP recalled:

> *"The experience in taking care of the child is difficult. As you know, as a caregiver, I do everything for the child. If I don't, meaning the child won't feed, bath, dress and so forth." (P11, mother, 30 years)*

Some other caregivers shared that performing multiple roles in addition to being a caregiver was stressful. The caregiver had to work either full time or part time in order get some money to take care of their child with special needs. Social roles like taking care of other children and their partners made caregiving quite stressful. One caregiver narrated:

> *"This task is not easy at all. Taking care of such a child is full time job. But you cannot also say you won't work. Where will the money be coming from to take care of the child?*

You have to work; you have to take care of his siblings and you have to perform your role as a wife. In one instance I am a caregiver, in another a mother and in another a wife. All these come with responsibilities." (P14, mother, 26 years)

4.3.2 Sub-theme: Time-consuming

Other caregivers were concerned with the time-consuming nature of caregiving. The activities performed during caregiving took caregivers time. In the opinion of some caregivers, the activities start in the morning and continues till the evening. One caregiver remarked:

"I spend a lot of time in taking care of this child. Once you start the day's activities, by the time you realise it's evening." (P3, father, 42 years)

Caregivers barely had time to take care of themselves. Many of them channelled their energy and time in taking care of their children with DD. Possibly as result of children with DD not being able care for themselves and caregivers had to do that for them. One caregiver narrated her experience in the following:

"Caring for my child takes all my time. Everything is almost about him now. To be frank, I hardly get time for myself these days." (P10, mother, 29 years)

4.4 THEME 2: STRESSORS

Caregivers had stressors that increased their burden of care and subsequently affected their well-being. The sub-themes generated were child's ADL needs, communication barrier, managing challenging behaviours, child's health needs, unmet educational needs, and economic burden.

4.4.1 Sub-theme: Child's ADL needs

For this sub-theme, caregivers believed they were responsible for making sure that their children were comfortable by ensuring they provided them with all their needs, however, this was a major stressor to caregivers. Caregivers had to feed, bath and assist their children with elimination because they could not do these activities without assistance. This is explained in detail below:

Feeding

Caregivers expressed that they had challenges feeding the child with DD. For some caregivers, children with DD preferred certain types and textures of food. Feeding also took longer than

usual and any attempt to feed hurriedly resulted in negative consequences such as choking for the child with DD. Though other types of food have been tried, those foods were not well tolerated by the children with DD. Thus, caregivers were reluctant in trying new foods. A caregiver had this to say:

> *"My daughter can only take liquid diets. If you're not careful and you overfeed or don't feed well, she will vomit everything. Because of this, I am always very careful when feeding, so it takes a while to finish with one feeding. If you do not feed her well too, she will be crying throughout the day because she is hungry. Anytime I try solid food, it is as if she is choking, so I have stopped." (P5, mother, 28 years)*

Children with DD had preference for certain foods and would reject any food out of their preference. Thus, in some instances they could not be fed with what the entire family would eat. This meant extra work and cost to the caregivers. Caregivers had to spend extra money to prepare different types of foods for the chid with DD. Separate times were needed to prepare different foods. One caregiver narrated her experience in the following:

> *My child prefers only smooth foods. If the texture of the food is not what she wants, she will reject it. No matter what you do, he will not eat it. So most often, I have to prepare his food differently from what the whole family is coming to eat."(P13, mother, 44 years)*

Some caregivers had successfully trained their children to perform some activities of daily living, however, those activities could not be performed without supervision. In terms of feeding, some children could feed themselves but spent more time in doing so. Apart from the time spent, the children with DD spread food particles all over creating additional work for the caregivers after every feeding episode. A caregiver remarked:

> *"In terms of his feeding, it is not easy. He will soil himself with the food, a large quantity of food particles will be spread on the floor after eating. He will not also allow me to feed, but we end up taking a lot of time because I have to supervise. After feeding, what spreads on the floor is greater than what goes inside." (P11, mother, 30 years)*

Elimination

Caregivers mentioned they had difficulty regulating elimination as the children could not communicate their needs and would soil themselves. Sometimes, immediately, after bathing them, they needed to be cleaned again because they have soiled themselves. One caregiver illustrated:

> *"My son is not 100% strong compared with the elder sibling, who is not facing any challenge. Due to his condition, taking care of him is very difficult. One problem is his*

inability to inform me when he wants to urinate or defecate. He totally depends on me. Sometimes after bathing, he soils himself." (P1, mother, 31 years)

The use diapers had become part of caregivers' strategies to deal with issues of elimination among children with DD. The use of diapers was more preferable as non-use was associated with more work and stress for the caregiver. One caregiver narrated:

"He is always in diapers because you cannot be sure when he will want to urinate or defecate. If you allow him to soil himself, usually that is more difficult work, compared with him having diapers on." (P12, father, 39 years)

Bathing

Another activity of daily living which was mentioned by caregivers was bathing. For those children with DD who have challenges with movement and coordination, the caregivers had to carry them to the bathroom. The issue of gaining the cooperation of children whilst performing activities of daily living is a concern for caregivers. For them, without cooperation, more time is spent on performing certain activities including bathing. A caregiver's experience is excerpted in the following:

"He cannot walk. So, you have to carry him to the bathroom. A lot of time is spent because sometimes there is no cooperation and for a shared bathroom, I worry a lot." (P2, mother, 35 years)

For some caregivers, they preferred to improvise by bathing their children with DD in basins so as not to cause undue stress for the child with DD. A caregiver recalls her experience as:

"I most often bathe her in a basin and afterward go and pour the water away. When I take him to the bathroom, she cannot stand, and I cannot let him sit on the bare floor, so that is the strategy I use. As she is maturing, I am becoming more concerned about this."- (P9, mother, 35 years)

4.4.2 Sub-theme: Communication barrier

Caregivers experienced challenges communicating their expectations to the children with DD. There are things they expected the children to do but they did not seem to understand the expectations of the caregivers. Caregivers had resorted to inappropriate ways of communicating to the children with DD such as screaming. A caregiver shared her experience as follows:

"Caring for him is difficult because, currently, he is not communicating, so you have to be very smart and be able to read his patterns. When I want him to do something, it's difficult to tell him. Sometimes, regardless of how hard I try, he just seems not to get what

I am saying. I end up screaming. Screaming has now become part of the way I talk to him. I know it is wrong, but I don't know how to get him to either do something or stop doing something bad or negative." (P8, mother, 34 years)

Other caregivers observed that the children with DD also had difficulty communicating their needs to them as caregivers. Caregivers often misunderstood the needs of the children and this made them feel helpless. Two caregivers gave the following account:

"I am trying hard to learn how he communicates his needs, but it looks like I have not gotten there yet. I sometimes feel so helpless when I am unable to figure out what exactly he needs or wants. Sometimes it's like he's demanding something and I also do something else." (P12, father, 39 years)

"This child does not talk, nor is he able to express his mood or feelings to you for you to be able to identify the problem he is facing and the necessary help you need to offer." (P1, mother, 31 years)

4.4.3 Sub-theme: Managing challenging behaviours

Inappropriate behaviours were seen as posing a lot of stress for caregivers. Children with DD when idle, seem to be a precursor for exhibiting challenging behaviours like hyper-activeness. Identifying ways to meaningfully engage the child with DD, serves as a step for decreasing challenging behaviours. A female caregiver's experience is excerpted in the following:

"I have experienced a lot of challenges. The child easily messes his immediate environment; he fights with people around him; and he becomes hyperactive. He makes you complain and correct him over and over again because of his hyperactivity. He usually thinks his actions are right, but they end up damaging things around him. He is distracted when he watches cartoons on the television set, before I can also concentrate on my house chores." (P10, mother, 29 years)

Caregivers reported some level aggressiveness in their children with DD. Challenging behaviours were triggered by some factors. Identifying the triggering factors and dealing with them was a good way of manging children with DD. Thus, it is the responsibility of caregivers to identify and manage triggering factors which will help decrease the incidence of challenging behaviours. One caregiver, for instance, indicated that hunger in her child with DD triggered aggressiveness. She gave the following account:

"She sometimes becomes aggressive. I observed that this happens when she is very hungry. So, I ensure there is always food available, and I don't let her get hungry. I have timed her feeding pattern so I know the right time to feed him. However, there are times

she will stop eating and may not really be satisfied; that is when she will display aggression, though it may not be time to feed her." (P9, mother, 35 years)

Caregivers observed that children who exhibit challenging behaviours need constant monitoring and supervision in order to prevent them from causing injury to themselves or other people around. A caregiver recounted:

"My child is very hyperactive and it is almost impossible to let him sit for a few seconds. He is always up, doing something. He is here, and the next moment he is there. You have to be monitoring him continuously; otherwise, he may injure himself before you can even tell. I keep chasing him around and screaming. That alone takes a lot of energy. It really drains me and makes me exhausted". (P11, mother, 30 years)

4.4.4 Sub-theme: Child's health needs

Caregivers knew the importance of seeking medical attention for their children with DD and considered as one of the priority areas for them. However, preparing for hospital appointments required a lot of planning and efforts. Hospital visit implied caregiver could not engage in any other activity. This is because they spent most of the time at the hospital and returned home late. A caregiver had this to say:

"When you have hospital appointments, you cannot say you will miss them because you think about your child first. You have to wake up very early and prepare. When you get to the hospital, you may end up spending almost the whole day there." (P4, mother, 27 years)

Proximity of the hospital was a problem mentioned by caregivers. For some caregivers, they had to travel from other regions to the capital city in order to access health care for their children with DD. Getting prescribed medications created a challenge for them as the medications were sometimes unavailable at hospital pharmacy. A caregiver recounted:

"Anytime we have an appointment, I begin to think, and it makes me anxious. Travelling to the hospital, going through the OPD, meeting the doctor, going to the laboratory, going for the medications, and travelling back home is stressful. Sometimes getting the medications is really a struggle, you may not get some at the hospital pharmacy, so you have to roam from pharmacy to pharmacy just to get what has been prescribed." (P11, mother, 30 years)

4.4.5 Sub-theme: Unmet educational needs

Caregivers also mentioned difficulty in accessing quality education and maintaining children with DD in school. Caregivers would have preferred if their children could easily have some form of special education, which they believed would have assisted the child in developing certain key skills. Unfortunately, it does not appear so, and hence, caregivers identified the unmet educational needs of their children with DD as a stressor. They were concerned about enrolling the children in school and the challenges associated with keeping them there.

Caregivers expressed worries about finding the appropriate schools for their children, for them inclusive education would have been ideal. However, the concept appears not to be practical and most mainstream schools rejected children with special needs. Therefore, caregivers were usually forced to consider special schools for their children with DD. Unfortunately, special schools were few, expensive and inaccessible to a lot of caregivers. Some caregivers expressed their concerns as follows:

> *"I really had a tough time enrolling her in the mainstream school. In Ghana, we always talk about inclusive education, but I doubt if it is really working. No school wants to accept him. It makes me consider special schools, but these schools are not common, especially the government-based ones, and the private-based ones are also quite expensive." (P3, father, 42 years)*

> *"Special schools are expensive. The one I know of is not so close. You have to pick up about three vehicles before you get there. In government schools, once they know the child has a problem, they won't even admit him or her. But I believe when he is enrolled, at least he will be taught some basic things that will be useful at home." (P8, mother, 34 years)*

Due to the unique nature in addressing the needs of children with DD, some teachers in mainstream schools often complained about the behaviour of children with DD. Caregivers were not comfortable receiving constant negative reports about their children. One caregiver illustrated:

> *"There are too many complaints that sometimes I can't bear. Today your child did this; tomorrow your child has done that. Every day and its story. This can be really stressful. So, once he goes to school, I keep wondering what complaints I will receive when I pick him up from school." (P6, mother, 28 years)*

Caregivers attributed the constant complaints by teachers in the mainstream schools to the inadequate knowledge they had on managing children with special needs. There are teachers

who have been specifically trained to understand and manage children with special needs. Inadequate knowledge may translate into poor skills leading to frustration on the part of the teacher and finally constant complaints. One caregiver had this to say:

> *"Teachers complain a lot about my child's behaviour in school, but I also think it's because the teachers do not have much knowledge in taking care of such children. You can't blame them. Taking care of one is difficult, so in a class where you have 30 to 40 children, it's going to be extremely difficult. And you cannot also spend time on only one child." (P11, mother, 30 years)*

4.4.6 Sub-theme: Economic burden

Caregivers explained that caregiving had a negative impact on their finances as they invested money in the pre-diagnosis, diagnostic, and post-diagnostic stages. All caregivers were at the post-diagnostic stage, where their children had received a definite diagnosis from the specialist. The caregivers were overwhelmed with the cost of medications, other therapies and assistive devices.

Caregivers did not receive any form of financial support and they recounted the medications were expensive. The National Health Insurance Scheme did not cover all the medications, usually brands of medications covered were not preferred by the caregivers. They shared their experiences as follows:

> *"The medication for the child is expensive and is really draining me financially, especially considering the fact that I have no form of support and my income is also nothing to write home about. When they get finished and you do not have money, it is a big problem. The medications I buy are very expensive. Sometimes the National Health Insurance covers some of the medications, but those are not the original medication brands prescribed by the doctors. I usually do not go for those ones. I usually buy the original medication brands. Monthly, I spent not less than five hundred Ghana Cedis (GH¢ 500.00) on medication. The greatest challenge is money to buy those medications to last for a month." (P13, mother, 44 years)*

Apart from medications, other services like physiotherapy was expensive. A caregiver had this to say:

> *"There is physiotherapy, there are other devices that we buy as well as medications. These are very expensive. Sometimes, there is no money to cater for her and her other siblings." (P9, mother, 35 years)*

Some concerns were raised about lifting the children, especially in the absence of assistive devices, which could have made it quite easy for the caregivers. For caregivers with little or no financial support, purchasing assistive device may be difficult. The challenge involved with lifting increases as the child with DD ages which is associated with weight gain. Increased weight requires caregivers to exert a lot of energy to lift their children with DD. A caregiver had this to say:

> *"I have not been able to purchase a wheel chair for easy movement around, so I end up carrying him. Initially, it wasn't so stressful. But now, day in and day out, he is gaining weight, so it is becoming increasingly difficult to carry him and be lifting him around like I used to do." (P1, mother, 31 years)*

The job of caregivers was directly linked with their income levels. Being under employed or finding difficulty balancing work and caregiving could negatively impact the finances of caregivers. Fully employed caregivers had to be asking permissions from the work place especially when they had hospital appointments. This affected their efficiency at the work place, however, they had no options. It was also likely to lead to their dismissal especially if the institution is private. One caregiver asserted:

> *"I am a nurse, and I am supposed to be on duty. I frequently ask permission to absent myself from work. My employer knows my child's condition, so I am able to seek permission so I can attend to her or bring her to the hospital. My employer does not complain whenever I ask permission, but I know others will complain." (P3, father, 42 years)*

Self-employed caregivers had difficulty balancing their caregiving role with their job. They believed their role has caregivers interfered with their jobs. Caregivers had to desert their jobs which was the only option. This could afford the caregivers ample time to perform their caregiving roles. The narratives below throw more light on these reports:

> *"I used to be a seamstress, but now I have stopped because of him. He takes all my time. I don't want to be in a situation where I take people's clothing and I won't be able to sew for them. Besides, taking care of him is quite stressful." (P6, mother, 28 years)*

> *"Caring for him has affected my job. I was a local contractor who was hustling to take care of the family. Now I don't get the chance to move around like I used to do before." (P12, father, 39 years)*

> *"She is unable to stand or sit, so even if you get a work, you can't leave her and go. Currently, I am not working. I use to sell but no more." (P5, mother, 24 years)*

4.5 THEME 3: NEGATIVE HEALTH OUTCOMES

Caregivers mentioned that their caregiving role affected them negatively. Three sub-themes were generated: decline in physical, mental and social well-being. In terms of the decline in physical well-being, caregivers mentioned pain-related effects, fatigue, and compromised sleep. The decline in mental well-being was marked by lack of concentration, feelings of anger, sadness and anxiety. Sense of social isolation and changes in social relationships were highlighted in the sub-themes of decline in social well-being.

4.5.1 Sub-theme: Decline in physical well-being

The participants highlighted that caregiving had multifaceted impact on their physical well-being. Caregivers' ability to perform physical activities and carry out social roles were hindered by physical limitations and experiences of low back pains, body pains, fatigue, poor and compromised sleep. Caregivers observed deterioration in physical well-being, which hampered their ability to achieve optimal functioning. Thus, carrying out normal daily tasks was marked with exhaustion and discomfort.

Pain-related effects

Pain-related effects were mentioned by caregivers. They mentioned they experienced low back pains and body pains which they attributed mainly to carrying the children with DD around whilst performing other activities. Two caregivers shared their experiences as:

> *"You know…. you have to carry her wherever you go. When I am going to church, she's at my back. When I am going to the market, she is at my back. When I am going to the hospital, she's at my back. She cannot walk so you have to carry her. I have low back pains and feel very tired. The only instances I do not carry her is when there is someone at home especially the father. Even in those instances, I am in a hurry to come home." (P5, mother, 24 years)*

> *"It is something I did not expect but it has come. Sometimes I really find it difficult. Caring for him has been stressful. I experience body pains, backpains." (P9, mother, 35 years)*

Caregivers experienced body pains and resorted to taking over-the-medications. Though the caregivers knew taking unprescribed medications had negative consequences, they had to take the medications. Other caregivers found some time to rest. The essence of taking the medications and resting was to ensure the caregivers had renewed strength for the next day's caregiving activities. Two caregivers shared their experiences as:

"Sometimes, I feel very tired with a lot of body pains. You have to be lifting, feeding, bathing and do almost everything for him. You know I have two other children, so combining all those tasks makes it difficult. I end up relying on pain killers just to make sure I have enough strength to carry on for the next day. I know too much of pain killers is not good especially when they are not prescribed by the doctor but I'm unable to stop." (P3, father, 42 years)

"She is very heavy, carrying her leave me with a lot of body pains. Sometimes it is like you have been beaten. I carry her throughout the day unless of course she's sleeping. If not, she's at my back. She doesn't like going to other people. If I attempt, she will cry uncontrollably. I sometimes take pain killers, other times I try to sleep when she's also asleep." (P9, mother, 35 years)

Fatigue

Beyond the low back pain and the body pains, the caregiving demands affected the caregivers with some reporting palpitations and exhaustion. They attributed the above to their inability to get adequate rest and sleep for themselves. One caregiver stated below as:

"Sometimes, I get palpitations, my heart beats very fast. This I am sure is as a result of the stress in taking care of him. You know you don't actually get adequate time for yourself. The attention shifts from yourself to ensuring that your child has the best. Then you end up getting drained." (P8, mother, 34 years)

Some caregivers had to visit the hospital for medical attention because their experiences were beyond what they could manage at home. For some caregivers they were given medications while others were advised to reduce the stress. To reduce caregiving stress and burden, caregivers have had to rely on spousal support. Two caregivers shared their experiences as:

"After feeding, bathing, and doing all the other tasks I feel very exhausted. My heart beats so loud. At a point I had to even visit the hospital, to go for medications." (P11, mother, 30 years)

"I sometimes experience palpitations from my inability to sleep at night and also the stress in caregiving. I have even visited the hospital to check my blood pressure. They advised me to reduce my work load. Sometimes my husband supports but you cannot leave everything for him to do. I end up performing most of the tasks." (P6, mother, 28 years)

Compromised sleep

Caregivers observed that there had been changes in their sleep patterns, they did not have adequate sleep and most at times stayed awake during the night. The caregivers did not sleep because of poor sleep patterns in their children with DD. It was extremely difficult to sleep

during the day as well as they were engaged with caregiving activities. Two caregivers commented:

> *"Sometimes, I become very restless. Sometimes in the night when I am sleeping, I have to get up just watching him, looking at him. Thus, most at times whilst he is sleeping, I am awake. You know that in the day I can't sleep because of the caregiving roles, so once I am unable to sleep at night, then during the day the work continues. So, the cycle of not having adequate sleep at night is really draining me. Most at times, I feel restless. I need adequate sleep." (P8, mother, 34 years)*

> *"My son prefers to be active during the night, so you can imagine. How can you comfortably sleep whilst he is awake? It is practically impossible. When he's awake, you also have to be awake. When he sleeps, you also sleep. Most nights I don't have a good sleep and during the day I'll be at work so no time to have some nap during the day." (P7, father, 36 years)*

The challenge of some children with DD not being able to sleep well at night and being overly active at night had been reported to the hospital. However, the side effects of the prescribed medications deterred the caregivers from adhering to the right time of medication administration. A caregiver narrated:

> *"As for having adequate sleep, it is out of the picture. He does not sleep. He could go a week without sleeping well at night. In instances when he sleeps at night, it is very short. I am thinking, he thinks when he sleeps, I will run away. So, I am unable to sleep and I get tired. I even reported at the clinic about his inability to sleep and they gave him some medications. However, the medications make him very weak so I don't often give them to him." (P6, mother, 28 years)*

4.5.2 Sub-theme: Decline in mental well-being

Caregivers mentioned that there were some changes in their psychological well-being. They mentioned they could not concentrate, they experienced sadness, anger and anxiety. Additionally, they blamed themselves and others.

Lack of concentration

Caregivers expressed that they could not concentrate and were easily forgetting things because their thoughts were always flooded with that of their children. It caused them to make some unavoidable mistakes on their job. They shared their experiences as:

> *"It's too tough, it has really affected me to be frank psychologically it has affected me. It is something I did not expect but it has come. it's so frustrating and I can't concentrate. At work I easily lose focus of what I am doing. Sometimes some mistakes are so avoidable*

but I still go ahead and make them because of lack of concentration." (P2, mother, 35 years)

"It's interesting how I easily forget these days. Sometimes, I'll keep something in the room. Only the next day I try to recollect where I have kept them, I don't even remember where exactly I placed them. I have to search and search till I find them or sometimes even forget about the searching because I am unable to find the thing." (P4, mother, 27 years)

"For me, I am unable to think clearly. My thoughts are always flooded with a lot of questions bothering on my child's condition. I ask myself if ever my child will walk, will be able to have a fulfilling life. This even becomes worse when I see other "normal" children who are of my child's age." (P8, mother, 34 years)

Anger

Caregivers admitted that expressing anger was a natural response to situations, however, the frequency with which they expressed anger was beyond normal. The issues were not things they needed to be angry with. Some had this to say:

"I am a well composed person. I used to hardly react to issues. It was difficult to make me angry but off late I noticed I am losing myself. I am no longer me. I can't find myself any longer. Why do I say so? It's because I get angry when I truly I am not supposed to be. I guess it is as a result of the stress I am going through." (P 11, mother, 30 years)

"It's normal to be angry once a while. But when it becomes continuous, then you can say that something is really wrong. I get angry more often and I know this is not good for my health. I don't know if I am right but I have heard that getting angry often may give you high BP." (P7, father, 36 years)

Caregivers were mainly angry towards themselves or others. The frequent expressions of anger had affected their relationship with their immediate family. One caregiver illustrated:

"I easily become angry these days. It used not to be like that. I noticed that with the least provocation then I get angry. I think it's even affecting those around me in a way. They feel I would scream or shout at them so they as much as they can to avoid having contacts with. Sometimes I would regret my actions but most often you can turn back the hands of time." (P2, mother, 35 years)

Sadness

Caregivers felt sad and at times cried. This feeling is usually triggered when caregivers are alone or isolated. Two caregivers illustrated:

"I don't know how to describe how I sometimes feel to you. I sometimes feel very sad. I can be in the room crying and asking myself a lot of questions. The crying does not make me feel better but I become sadder." (P5, mother, 24 years)

"The thoughts of having to deal with this difficult situation really makes me sad. You see when you started asking me questions, I began to have tears in my eyes. When I am outside, I try to show that I am strong but the story is different when I am alone. When I am alone, I feel sad and cry a lot." (P4, mother, 27 years)

The feeling of sadness was attributed to stress they were going through and the stigma they face from society. A caregiver shared her experiences as:

"I feel down most of the times. Not knowing what the future holds and if really, I will be able to go through all these stresses. The society even makes it worse. The comments they will make are so painful. Some of them when you hear them you just can't control yourself, the only response that comes is tears flowing down your eyes." (P13, mother, 44 years)

Anxiety

Another theme that evolved was caregivers being anxious about how the caregiving process was going to evolve. P2 and P10 expressed their views as:

"Personally, I don't know what the future holds for my son. I keep thinking about how our lives, I mean myself and my child, will evolve." (P2, mother, 35 years)

"When you cannot predict what will happen to your child it's really disturbing. Sometimes you feel like your hopes and aspirations have been brought to a halt." (P10, mother, 29 years)

4.5.3 Sub-theme: Decline in social well-being

Caregivers expressed that caregiving affected their social interactions and relationship. Caregivers mentioned that they felt isolated and were unable to take part in social functions because it was difficult to manage their children in public and also because of the negative attitudes from the public. Hence, to avoid these, they stay at home. Some caregivers had this to say:

"I hardly go for social functions like funerals, weddings and others. If the ceremony is not really close, I mean if it is not family-related ceremonies you won't find me there. I stay at home most often. When you take her, you may have to feed her, she will soil herself and yourself as well. She will also cry especially when she sees crowd and all attention will be drawn towards you. Some people will say take her for walk and all that. To avoid all of these, I stay at home." (P2, mother, 35 years)

"I have lost interest in the activities I use to enjoy, so most often you would find me indoors. I tell myself it's better not to hear anything form people which will irritate me and create problems for me." (P9, mother, 35 years)

For some caregivers, they defied all odds and attended public gatherings, however, they kept to themselves during these gatherings. So, though they were in public, they were still socially isolated. A caregiver narrated:

"I can't mingle as I used to. I have a feeling when I approach people they talk about my situation and my ridicule me when I am not even around. Because of that I do go out very often. When I do, I try as much as I can to keep to myself so that people do not insult or laugh at me." (P5, mother, 24 years)

Caregivers mentioned that there had been changes in their social relationships. The changes had affected the relationship between their partners/spouse, their families, friends and society at large. Some caregivers narrated their experiences as:

"As for the rejection and the stigma it is not easy. Initially, there was a battle between myself and my husband's family. They said they don't have such children in their family and that it was coming from my family. As it stands now, I don't have a cordial relationship with them like I use to have. Even now my husband is also behaving in some way, anytime I ask for money to buy something for the child, he tells me he is not having money which I know he has." (P9, mother, 35 years)

"Once your child is a special child, you lose your friends. Currently speaking, I don't have friends. All my friends are gone. They just don't want to have anything to do with you any longer through no fault of yours." (P6, mother, 28 years)

"There is so much discrimination. Society makes you feel there is something really wrong and as a result of that you and the child should not come close to people. The public stares are enough to bring you down any day." (P14, mother, 26 years)

4.6 THEME 4: CAREGIVER NEEDS

Caregivers expressed that they had some needs that, when addressed, they thought could help them in the caregiving process. Four sub-themes were generated from caregiver needs: informational, financial, psychospiritual, and social supports.

4.6.1 Sub-theme: Informational support needs

One of the sub-themes that was generated was the need to receive information. Caregivers admitted that health professionals had not provided them with adequate information on their children's diagnosis. However, they had also not attempted to gain information from elsewhere

particularly reading on their own. The caregivers believed health professionals were in the better position to provide them with adequate information. Caregivers expressed their views as follows:

> *"I have not had enough education on the cause of the condition or what triggers the condition. I have also not asked about it, nor have I read about the condition. I think because I am an old client and I usually come here for regular review; they only attend to the issues that made me seek medical attention. I would wish more education was given to me, either by the nurses or doctors. It shouldn't just be a routine hospital. At least, in coming to the hospital, I lose my time, my money, and I think gaining information wouldn't be bad." (P4, mother, 31 years)*

> *"When we started coming here, they told us the child has cerebral palsy. But the details of that have not really been given. For example, the causes and what to expect." (P1, mother, 27 years)*

Other caregivers mentioned that they did not have adequate information on how to manage their children with DD. They perceived that having adequate information on managing their children with DD, would make their caregiving easier because they would attain the basic skills needed in performing some activities of daily living. Some caregivers had this to say:

> *"I think we need information on how to manage the child. I'm sure when we are given information on how to handle the children, it will become much easier. We should be equipped with some skills in feeding them, communicating with them." (P11, mother, 30 years)*

> *"Managing them is quite difficult, but when we are taught the techniques and styles, it may not entirely take the burden off, but it will definitely go a long way to decreasing the level of stress experienced in taking care of them. For example; if I get to know how to manage my child when he becomes aggressive, it will help a lot." (P13, mother, 44 years)*

Some caregivers, though had not received adequate information on the management of their children with DD from health professionals, however, how the information is presented makes it difficult for them to understand. The caregivers believed health professional would be in better position to provide simple yet detailed information. A caregiver narrated:

> *"I was told my child has an ID, but how to handle my child I was not told. These children have a lot of issues, unlike normal children, so it would be good if we were given detailed information. Sometimes I try to read, but some of this information online is quite complex so even if you read you cannot understand. We need more information on how to handle them from the health workers and the information should be simple but at the same time detailed." (P5, mother, 24 years)*

4.6.2 Sub-theme: Financial support needs

Strain on financial resources was commonly reported, thus, one area where caregivers wanted support was finances. Generally, caregivers wanted support towards managing the child and caregiver.

Caregivers perceive caring for a child with DD as very expensive as it is associated with regular hospital visits, a series of diagnostic investigations, adjunct therapy like physiotherapy, and the purchase of medications, among others. According to caregivers, supporting them in these areas could decrease the financial strain. Some expressed their views as:

> *"Caring for a normal child is expensive, so you can imagine caring for a child who is not "normal". Their needs are enormous. You have to visit the hospital every now and then. Then buying medications as well. It will be good to have some funds to support the care of these children." (P2, mother, 35 years)*

> *"Physiotherapy is expensive. Medications are expensive. Considering the fact that most of us are not working as hard as we used to because of these children, there should be some form of financial support. It should be a sustainable project." (P13, mother, 44 years)*

Caregivers believed the best form of support was to migrate children with DD unto the National Health Insurance Scheme at a free cost and also provide some monthly stipends to cover for other needs of the children. A caregiver illustrated:

> *"I think the health insurance scheme, together with the government and other stakeholders, should consider making the care of such children entirely free. Again, they should give them a monthly allowance." (P5, mother, 24 years)*

Caregivers sources of income were affected by caregiving as some could no longer work because of their caregiving responsibilities. For those who worked, their income level had dropped because they could not effectively balance their work and caregiving responsibilities. They mentioned that financial support could go a long way towards helping them. One caregiver expressed her views as:

> *"As caregivers, we really need financial support. Most people have stopped working because of their children. Others are working alright but the level of finance has totally decreased." (P12, father, 39 years)*

Caregivers are in need of sustained financial support, thus, recommend some start-up capital so they could re-establish their collapsed businesses. A caregiver narrated:

"To be able to provide quality care for our children with disabilities, one of the fundamentals is money. Without money, caregiving becomes more stressful. They have a lot of needs, and many caregivers' businesses have collapsed because they have invested all the money in caregiving. We could be given start-up funds to help us re-establish ourselves." (P14, mother, 26 years)

4.6.3 Sub-theme: Psychospiritual support needs

Caregivers mentioned that they needed to be supported psychologically and spiritually. The need for proper counselling sessions to be provided was stated by caregivers. In the current situation, they expressed that they were left on their own by the health professionals. Some caregivers expressed their views as:

"They need to encourage us very often. It is like fighting a battle, when you encourage the person, they get the strength to fight on and end up winning. Without any encouragement, you sometimes lose the strength to carry on." (P11, mother, 30 years)

"We need counselling. I see it as very important. It will really help us to build ourselves in our caregiving role and even be a support for other new caregivers." (P12, father, 39 years)

Beyond counselling, a spiritual exercise like prayer also helped caregivers in their attempt to navigate their caregiving trajectory. Caregivers often felt neglected as the focus was mainly on the children with DD. One caregiver shared his experience as:

"I think when we bring the children to the hospital, there should be some counselling for us. The focus should not only be on the children. It looks like, as caregivers, we have been neglected in the caregiving cycle. But we play a major role." (P1, mother, 31 years)

4.6.4 Sub-theme: Social support needs

Getting support from family, friends, significant others and groups was seen as very instrumental by caregivers. Families and friends were identified as instrumental support systems that could help in the provision of care for children with DD. They mentioned various aspects of support, encouragement and assisting with the care of the child with DD. Some caregivers expressed their views as:

"Our families should be able to support us in these difficult times. At least words of encouragement would go a long way towards helping us. If we are being ridiculed by others, our family should be there for us. When you know you have the support of others, it really helps." (P5, mother, 24 years)

"Support is really good. We need support from our families. They can help take care of the children. When we want to go out, we know there are people we can leave the children with without being worried." (P9, mother, 35 years)

In terms of support from groups, they mentioned that it would help them share their experiences. With this, caregivers believed they could learn and take some cues from each other's experiences. Some caregivers expressed their views as:

"There is no support group, nothing like that. We usually meet at the hospital and have our individual conversations. We also take consolation from each other and go home after you have been attended to. We usually come on different dates for appointments. When you come, you are likely to meet another group of parents with their ward. This makes you meet different batches of people as you visit the hospital. The medications prescribed for the child will determine when you will come for review. Some may take a week, three weeks, or a month. I think there should be some form of support group." (P3, father, 42 years)

"Getting a shoulder to cry on could be helpful in difficult times. If not for anything, you get someone to share their experiences with you." (P4, mother, 27 years)

4.7 THEME 5: COPING STRATEGIES

Caregivers expressed how they have been dealing with the stress they go through. Some coping strategies were adaptive, others were maladaptive. One adaptive coping mechanism frequently mentioned was prayer. They expressed that anytime they felt overwhelmed, they resorted to prayer, and the prayer really made them feel good afterwards. Others expressed that they encouraged themselves. Some caregivers also had some support from their families. Other caregivers blamed themselves, others, or God as a way to deal with stress.

4.7.1 Sub-theme: Adaptive coping

Caregivers included in the study relied so much on prayer to a higher being. They mentioned it was an avenue to pour their hearts out. They felt better after prayer because they got the opportunity to talk about their problems not with man but God. Some caregivers had this to say:

"…. What has really helped me all these periods is prayer. I pray a lot by myself. Anytime I pray, I feel relieved as if a burden has been lifted from me." (P8, mother, 34 years)

"One thing that has really helped me cope is prayer. In instances where the feeling is uncontrollable but, at the same time, you have no one to talk to, the option becomes God. And for God, the only way we can talk to him is through prayer." (P9, mother, 35 years)

Encouraging themselves as caregivers was also used as a coping strategy. The caregivers used the opportunity to talk to themselves about the situation. The encouragement was mainly based on positive things. Some caregivers expressed their views as:

"I encourage myself a lot. I tell myself; it shall be well with me and my child." (P10, mother, 29 years)

"If you don't encourage yourself, nobody will do that for you. I talk to myself a lot and encourage myself. After all, I can't change the situation." (P12, father, 39 years)

Caregivers were able to cope due to the support of their partners and children. Some partners fully understand that the caregivers are not to be blamed for the happenings and a such offer them the needed support. Support is mainly emotional. Some of the caregivers shared their experiences as:

"My family has been very supportive as well as my other children. My husband is educated, so he is fully aware it is no fault of mine, and hence I cannot be blamed for having a child with a disability." (P2, mother, 35 years)

"My husband has been helpful. He is a pastor, so he encourages me a lot. When I'm sad, down and feel very worried, he advises and encourages me not to worry. He tells me that worrying will not change the situation and that we should leave everything to God." (P10, mother, 29 years)

4.7.2 Sub-theme: Maladaptive coping

Shifting blame was identified as a way of dealing with stress and making some caregivers feel better. They either blamed a supreme being for failing her after many years of trust. A caregiver mentioned:

"As hard as I try, there are moments when I question God about what is happening in my life and to my child. Why did he have to let it happen to me? Especially when over the years I trusted him so much." (P8, mother, 34 years)

Caregivers believed negligence and lack of prompt response from health workers caused the negative outcome on their children. Issues surrounding delivery and post-delivery care were cited as the cause of the DD. A caregiver shared her experience as:

"My brother is outside the country and has explained to me what really causes such conditions. He told me that when there is a delay in delivery or if the child is pulled wrongly during delivery, such conditions can develop. When I went to deliver, it took so long for the baby to be delivered, and when the baby came, she was blue and needed special care. And so, when I reflect on such issues, I blame the midwives and doctors for my child's condition." (P10, mother, 29 years)

Caregivers blamed themselves for getting pregnant at an old age. They believed there was a connection between old age and giving birth to a child with DD. A caregiver illustrated:

"Sometimes, I blame myself. I was told some of these conditions occur when you give birth in your old age. At the time I became pregnant, I was 44 years old. Maybe if I had not been pregnant in the first instance, the child would not go through this." (P13, mother, 44 years)

4.8 FINDINGS FROM PHENOMENOLOGIAL STUDY EXAMINED IN CONTEXT OF THE STRESS PROCESS MODEL(SPM)

The findings in the phase 1a of the study was examined in the context of the Stress Process Model, the underpinning theory for the study. The study revealed that caregivers experienced both primary and secondary stressors as described in the SPM. Additionally, poor health outcomes were also reported, like the SPM. Caregivers used certain resources: spirituality/prayer, support from family and self-encouragement to cope with the stressors of caregiving. Though not part of the SPM, caregivers had certain needs when met, may be crucial to decreasing stress among caregivers. How the current study fits into the SPM is outlined in Figure 4.3:

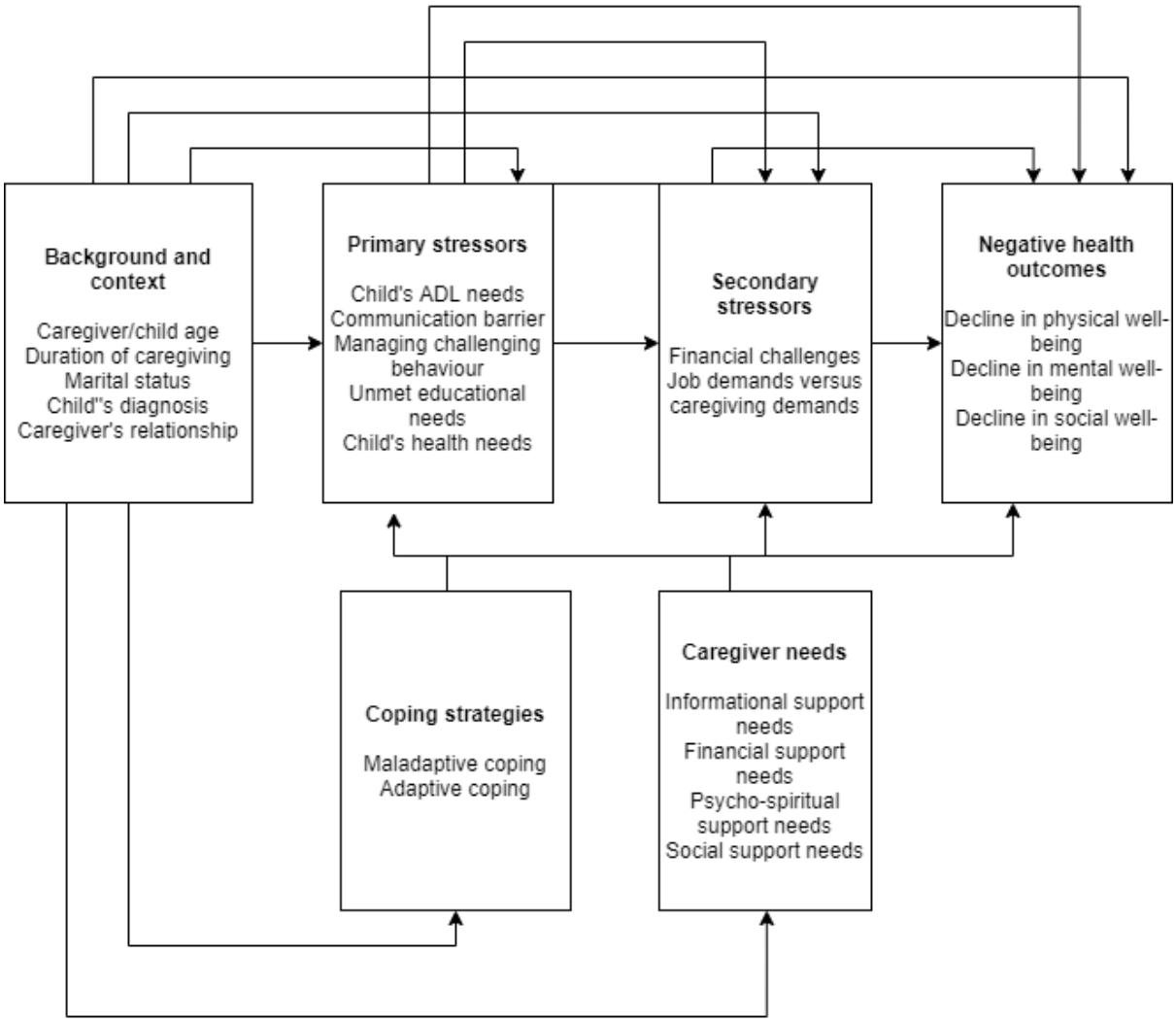

Figure 4.3 Findings of descriptive phenomenological study examined in context of SPM

4.9 DISCUSSION OF FINDINGS FROM QUALITATIVE STUDY

4.9.1 SOCIODEMOGRAPHIC CHARACTERISTICS

4.9.1.1 Caregiver's age

Researchers have highlighted the role of age in the perception of stress (Thoits, 2010; Wilborn-Lee, 2015) and how it influences the well-being of the caregiver. In the current study, caregivers' mean age was 32.86 years, suggesting they were young. Though the qualitative approach of the study did not allow for relationships to be established between variables, caregivers expressed that they were stressed out as well as experiencing the negative impact of caregiving on their mental, physical, and social well-being. Thus, it could be said that younger

caregivers in this study experienced negative mental and physical health outcomes. Consistent with the current study, younger caregivers were at risk of being depressed (Dave *et al.*, 2014). Contrary to the findings, several studies have either found a positive relationship or no relationship between age and stress (Pandey & Dubey, 2019; Maridal *et al.*, 2021). Several reasons could be given for the findings of the current study. Nine out of fourteen caregivers had provided care for less than four years and may be still adjusting to their caregiving roles. Additionally, younger caregivers might be worried about the future of their children. They may also have some social commitments that might compete for their caregiving time, making caregiving more stressful.

4.9.1.2 Caregiver's gender

In the current study, most of the caregivers were females. This confirms the assertion that females usually assume the caregiving role and that they experience more stress. It may explain why caregivers largely described their caregiving experience as stressful. Additionally, the socialisation of men as not being typical caregivers influences their approach, perception and response to caregiving (Sharma, Chakrabarti & Grover, 2016). Furthermore, females prefer emotion-focused coping mechanisms while males prefer problem-focused coping mechanisms (Williams *et al.*, 2019). Males caregivers are also more likely to receive some form of support as compared to female caregivers. These could possibly explain why there is a link between women and high levels of perceived stress and burden.

4.9.1.3 Caregiver's marital status

Only a few caregivers (5 out of 14) were married, the rest were unmarried, divorced, or cohabiting (9 out of 14). The finding of the current study is consistent with other studies that have found a high divorce rate among parents of children with DD as compared to typically developing children (Cauda-Laufer, 2017). The increasing needs of the child with a disability may interfere with satisfying the needs of the spouse, which may create tension, separation, and consequently divorce (Cauda-Laufer, 2017). In the Ghanaian context, male spouses play a significant role in decision-making and financial contributions to the home. Without them, caregivers who are single or divorced may be faced with the challenge of having to make major decisions concerning the child's health and health services as well as providing all the financial needs of the child with DD, leading to stress and negative psychological outcomes. Williams, Frech and Carlson (2010) project that the mental health of unmarried individuals (single,

divorced, widowed) will be poorer as compared to that of those who are married due to the fact that they lack the resources provided by marriage that would enhance their health.

4.9.1.4 Caregiver's educational background

The findings of the current study suggest that most caregivers' educational attainment was below tertiary level, and caregivers reported stressful caregiving experiences that had a negative impact on their physical, psychological, and social well-being. Low levels of education have been associated with poorer psychological outcomes (Charnsil & Bathia, 2010; Pocinho and Fernandes, 2018), anxiety (Farajzadeh *et al.*, 2021), depression (Yildirim Sari and Başbakkal, 2010), and psychological distress (Maridal *et al.*, 2021). Factors like perception of burden (Yildirim Sari and Başbakkal, 2010), self-esteem, and access to resources (Charnsil and Bathia, 2010) have been cited in relation to the educational attainment of caregivers and their impact on caregiving outcomes.

4.9.1.5 Caregiver's income

The findings of the current research revealed that caregivers were unemployed. This means that they may have an irregular or inadequate source of income. A study conducted in Kenya by Mbugua, Kuria and Ndetei (2011) found a significant relationship between being unemployed as a caregiver for a child with an intellectual disability and the increased risk of developing negative psychological outcomes like depression. Ribeiro *et al.* (2014) reported that mothers of children with CP who were being paid had reduced parental stress. Low income levels were found to predict caregiver anxiety (Power *et al.*, 2019; Farajzadeh *et al.*, 2021) and depression (Yildirim Sari and Başbakkal, 2010; Power *et al.*, 2019). The cost involved in managing a child with DD has been described as high. In a country where there is little or no support for caregivers of children with DD, caregivers' income may continuously be strained, which may affect their health.

4.9.1.6 Caregiving history

Caregiving history is either conceptualised as the duration of caregiving or the number of hours of providing care in an hour. It was difficult for caregivers to describe the number of hours involved in caregiving. Generally, most describe the caregiving experience as time consuming. In terms of duration of caregiving, most caregivers had provided care for over 2 years.

Providing care continuously for a long period of time may lead to stress, especially in instances where there is not adequate social support. Minichil *et al.* (2019) observed that stressors experienced by the caregiver could increase over time, contributing to the caregiver's poor mental health outcome. On the contrary, Fernanda *et al.* (2016) reported that there was no significant relationship between duration of caregiving and burden among caregivers.

4.9.1.7 Age of the child with DD

The findings of the current study suggest that the mean age of the children with DD was 6.03 years old. Studies report different findings on the relationship between caregiver stress and the age of the child with a disability; negative correlation (Lee, 2013a), no correlation/relationship (Lecavalier, Leone and Wiltz, 2006) and a positive relationship (Ribeiro *et al.*, 2014; Eisenhower et al., 2009). Consistent with the above, a study by Lee (2013) observed that the level of stress experienced by the caregiver decreased as the age of the child with the disability increased (Lee, 2013). Thus, caregivers of younger children with DD were more likely to experience stress. On the contrary, Ribeiro *et al.* (2014) found that caregivers of older children were more stressed than those with younger children and adolescents. Similarly, both young and old children did not differ significantly on the scores of stress (Pocinho & Fernandes, 2018).

4.9.1.8 Gender of child with DD

Most of the children (n=9) with DD were males. The prevalence of disabilities in high in males than females (Houtrow *et al.*, 2014). The majority of the studies have reported no relationship between the gender of the child with a disability and psychological distress (Maridal *et al.*, 2021), depression (Power *et al.*, 2019), anxiety (Power *et al.*, 2019), family functioning (Churchill *et al.*, 2010).

4.9.2 PERCEPTION OF CAREGIVING ROLE

4.9.2.1 Stressful nature of caregiving

Caregivers in the current study mentioned that caregiving was a stressful experience. One of the primary stressors in the SPM is the burdensome nature of caregiving. The diagnosis of DD alone has been identified as a significant predictor of stress among caregivers (Smith *et al.*, 2014). Studies have confirmed that parents of children with DD who are the primary caregivers

are highly prone to experiencing stress (Lee, 2013; Woodman and Hauser-Cram, 2013). Stress may affect the caregiver as well as how they handle their children with DD. Parents whose level of stress is high may respond in several negative ways, including by being less responsive towards the child, excluding an authoritarian style of parenting, exhibiting neglectful behaviour (Ponnet *et al.*, 2013). Other outcomes of stress include being inconsistent with the disciplining of a child with a disability, having unrealistic expectations for the child with DD, and poor guidance (Crawford & Manassis, 2011). The SPM affirms that, regarding the caregiver, stressful caregiving experiences may lead to negative mental health outcomes.

The finding of the current study is not surprising because being stressed is linked to being a female caregiver and in the current study, most caregivers were females. Also, stressful caregiving experiences are linked with low income levels (Mbugua, Kuria and Ndetei, 2011) and most caregivers were unemployed or under-employed. Additionally, being married has been reported to buffer the stressful caregiving experience by providing certain resources (Williams, Frech and Carlson, 2010) but most caregivers were not married or had strained marital relationship (Williams, Frech & Carlson, 2010).

4.9.2.3 Time consuming

In the current study, caregivers expressed that caregiving was time consuming. This finding has been reported by several studies. The National Alliance for Caregiving in collaboration with American Association of Retired Persons (AARP) reported that caregiving among children with special needs and adults with special needs was quite intense, and this was attributed to the increased number of caring hours (AARP & National Alliance for Caregiving, 2020). They further reported that the estimated average number of caring hours for children with special needs was 29.7 hours per week, while the average caring hours for adults was 18.9 hours per week. The difference between the caring hours for children with special needs and adults is approximately 11 hours per week (AARP & National Alliance for Caregiving, 2020). In a systematic review assessing the time used by parents in providing care for children with complex needs, parents whose children had complex needs spent considerable time performing healthcare related tasks that were outside the normal parenting role (McCann, Bull & Winzenberg, 2012). This increased time commitment affects the time needed to perform other tasks, including work, leisure activities, and personal care (McCann, Bull & Winzenberg, 2012). As a result, most caregivers end up giving up on employment opportunities because they find it difficult to combine that with caregiving (McCann, Bull & Winzenberg, 2012).

4.9.3 STRESSORS

4.9.3.1 Child's ADL needs

Caregivers mentioned that assisting the child with the performance of ADL was a source of stress. This is consistent with the SPM, which identifies the ADL ability of the child with DD as a primary stressor. Primary stressors arise from the patient's or care recipient's needs as well as the care that will have to be rendered as a result of those needs (Wilborn-Lee, 2015). The performance of ADL has been linked with stress. For example, Maridal *et al.* (2021) reported that in caregivers of children with neurodevelopmental disorders, there was a correlation between caregivers' psychological distress and the performance of feeding ADL. To be able to effectively perform ADLs, certain cognitive and perceptual abilities are needed. Unfortunately for children with DD, one or more of these areas may be impaired, making it difficult for them to perform certain ADLs (Mlinac & Feng, 2016). Bieńkiewicz *et al.* (2014) explain that to perform ADLs, distinct types of skills are needed, including sequencing of action, conceptual knowledge, and the ability to manipulate to reach the intended goal.

As a child matures, it is expected that they will begin to perform certain ADLs with little or no assistance. However, with children with DD, it is not so with the primary caregiver responsible for doing those activities. According to the National Alliance for Caregiving (2020), it is estimated that almost half of primary caregivers of children with special needs assist their children in the performance of at least one ADL. Parents were asked to compare the ADL for their children with special needs with that of typically developing children. They were only to report the ADL in instances where the child with special needs was not able to perform in relation to other children of the same age. They found that getting the child dressed (35%), and bathing the child (28%), were the most commonly performed ADLs for children with special needs. Others included feeding the child (20%), dealing with incontinence (16%) and getting in and out of bed (23%), these were much more common problems for caregivers of adults with special needs.

4.9.3.2 Communication barrier

Under child care related stressors, caregivers identified challenges with communication as a stressor. In a literature review, Dervishaliaj (2013) identified that the communication skills of a child with DD were strongly linked to caregiver stress. Poorer communication skills of the child with DD led to high levels of caregiver stress and vice versa. Akmese and Kayhan (2016)

sought to find out the effect of the communication skills of children with DD and their relationship to the mental health outcomes of caregivers. The findings of their study revealed that there was a statistically significant relationship between communication skills and caregiver wellbeing. Comparing children with DD to typically developing children, children with DD exhibit some delay in their language development, articulation, and fluency (Akmese & Kayhan, 2016). This makes their level of communication very limited because of their inability to comprehend language. Communication skills, together with other special skills, are adaptive skills that help every individual. For children with DD, these skills are impaired.

4.9.3.3 Managing challenging behaviour

The problem behaviour exhibited by the children was identified as a main source of stress by caregivers of children with DD. The SPM as well as other studies identify challenging behaviour as a primary stressor (Bourke-Taylor *et al.*, 2012; Lovell, Moss and Wetherell, 2015; Zaidman-Zait *et al.*, 2018) and is linked to depression in caregivers (Falk, Norris and Quinn, 2014; Gallagher and Hannigan, 2014), distress (Long *et al.*, 2015), poorer family functioning (Povee *et al.*, 2012), caregiver self-reported physical health problems (Eisenhower, Blacher and Baker, 2013; Gallagher and Whiteley, 2013), fatigue (Seymour *et al.*, 2013), caregiver self-reported stigma (Gray, 2002), caregiving burden (Vogan *et al.*, 2014; Lerthattasilp and Charernboon, 2015), and poor immune responses in caregivers (Gallagher *et al.*, 2009). Studies have highlighted that there seems to be a transactional relationship between the challenging problem of child with DD and caregiver stress (Woodman, Mawdsley & Hauser-Cram, 2015).

Behaviour problems in children have been classified as internalising and externalising behaviours (Woodman, Mawdsley & Hauser-Cram, 2015). Behaviours such as anxiety, sadness, social withdrawal and fearfulness have been identified as internalising behaviours. Externalising behaviours included being hyperactive, having poor impulse control, being aggressive towards others (Woodman, Mawdsley & Hauser-Cram, 2015). In the current study, participants mentioned more externalising behaviours as the source of stress. Some studies have argued that the exhibition of a dominant dimension of behaviour problem, is influenced by the developmental stage of the child (Woodman, Mawdsley & Hauser-Cram, 2015), in which externalising behaviour is more common in children while internalising behaviour is dominant among adolescent (de Ruiter *et al.*, 2007). In the current study, the children with DD who were included were between 5 and 14 years old with a mean age of 8.21 years. It is not surprising why externalising behaviour were mainly mentioned by the caregivers.

Some studies have reported that gender had influence on challenging behaviour rates among children with DD (Kozlowski, Matson & Rieske, 2012; Kristoffersen & Smith, 2013). In an earlier study, however, challenging behaviour was more common in males than females (Emerson *et al.*, 2001; National Collaborating Centre for Mental Health, 2015; Bowring, Painter & Hastings, 2019). The children of the caregivers in the current study were mostly males, which may account for why caregivers saw challenging behaviour as a problem because it was more prevalent in males. Furthermore, Bowring *et al.* (2017) posited that children who had communication problems had a higher risk of exhibiting challenging behaviours. In the current study, caregivers mentioned the problem of communication, which may explain the increased levels of challenging behaviour, subsequently becoming a source of stress. Increased challenging behaviour may suggest that the children be supervised and monitored so that they are safe and others around them especially their siblings, are also safe (Dervishaliaj, 2013).

4.9.3.4 Child's health needs

Caregivers understood the health needs of their children with DD; therefore, they did not underestimate the need for frequent medical assessment and care. Frequent visits to the hospital was identified as a source of stress. A systematic review indicated that children with developmental disabilities were more likely to visit the emergency department as compared to children without DD (Nicholson *et al.*, 2022). Similarly, Lindgren *et al.* (2021) posited that children with intellectual and developmental disabilities used inpatient and emergency department services care at 1.8 times the rate of the general population. Frequent visits may imply caregivers will have to neglect their own schedule of activities.

The study findings show that apart from the frequent visits, proximity of the hospital or clinic created a lot of stress for the caregivers since they were not staying close to the facility. Thus, transporting their children was a major concern. Similarly, Adib *et al.* (2019) reported a positive relationship between caregiver stress and distance of 25 km or more from the caregiver's residence to the health facility. The distance created transportation difficulties for the caregivers in transporting their children to a health facility for care. Caregivers living in under-resourced or more distant areas from the health facility could attribute these issues to delaying or missing the child's appointment (Ballantyne *et al.*, 2019). During the extended journey to a healthcare facility, behavioural issues could intensify, leading to the child becoming increasingly uncooperative, thereby limiting the value of the visits (Langkamp,

McManus & Blakemore, 2015). Consequently, the child's condition, cognitive functioning, and social interaction may not able to be improve and/or could even worsen.

4.9.3.5 Unmet educational needs of the child with DD

Caregivers were worried about the education of their children. This set of unmet needs in education for the child with DD appears to be similar in both low, middle- and high-income countries (Ambikile & Outwater, 2012; Gomes *et al.*, 2015; Tilahun *et al.*, 2016). Tilahun *et al.* (2016) found that the majority of Ethiopian caregivers (74.5%) mentioned that their children did not have an appropriate educational provision. Ambikile and Outwater (2012), reported that caregivers in Tanzania had social challenges pertaining to the child getting an education as a result of the inadequate number of schools. In their study, caregivers, had to spend a lot of time trying to secure a school that could take their children. Similarly, Gomes *et al.* (2015) reported scarcity of educational activities as one of the main stressors of caregivers. This is known to impair the quality of life of the caregiver. Every parent would like their children to have access to education so they can become independent. Thus, not having access may be quite stressful for the caregivers.

4.9.3.6 Economic burden

Caregivers mentioned that caregiving had affected their finances. They argued that the cost of medication, diagnostic procedures, and other related treatments were huge, therefore, having a negative impact on the finances. In congruent with the findings above, Van Puymbroeck, Payne and Hsieh, (2007) and Asa *et al.* (2020) reported that female caregivers experienced economic impact which was as a result of increased expenses involved in health and transport, the loss of their jobs as caregivers and a lack of savings. They further posit that the increased expenses needed for the daily needs as well as the medical needs of the children were mechanisms through which further negative psychological consequences could be induced. Thus, a caregiver who is already experiencing negative psychological changes as a result of caregiving, may have their psychological health further worsened. Increased availability-related cost has been linked to greater subjective burden and is also the strongest predictor of burden (Oh & Lee, 2009). Caregiving had a negative effect on caregivers' economies (Maridal *et al.*, 2021) because caregivers were mostly housebound and had limited opportunities for working outside the home (Stabile & Allin, 2012). In most LMICs, like Ghana, there is usually little or no governmental support which could lead to increased poverty. Consequently, it could affect not

only the caregiver but also the entire family. Studies have found a strong correlation between disability and poverty. The presence of disability heightens poverty risk and vice versa (WHO, 2011).

Caregivers reported that the caregiving demands led to inability to work, job loss, decreased work output and frequent excuses from work. The SPM identifies job strain as a secondary stressor that could affect the health of the caregiver negatively. Stabile and Allin (2012) reported that caregiving could have three pathways in relation to economic cost; direct and indirect, and long-term cost. Accordingly, direct costs are those associated with those involving child's disability. Indirect cost involves those cost involving directions in how to effectively cope with the disability by the family. Long-term cost, however, is linked to the economic performance of the child in future.

Caregivers often have to make decisions about their employment. Caregivers with children with disability decrease the number of working hours or stop working (Cidav, Marcus and Mandell, 2012; Stabile and Allin, 2012; Gomes *et al.*, 2015). The finding is consistent with those of the current study. This could be explained to mean that the caregiving demands often are overwhelming coupled with inadequate social support may lead caregivers to make such decisions about work. In the current study, few participants were in the formal sector whilst most were involved in the informal sector. Regardless, caregiving has made caregivers decide to quit their jobs because their time was diverted into caregiving such that they could no longer support their business. To others, the hours involved in caregiving did not allow them to effectively combine or continue with their jobs and had to quit. Brehaut and colleagues reported that caregivers of children with disability were more likely to be unemployed (Brehaut *et al.*, 2004). In the current study, most caregivers were unemployed (8/14).

4.9.4 NEGATIVE HEALTH OUTCOMES

4.9.4.1 Decline in physical well-being of caregivers

Caregivers mentioned low back pain, headache and general body pains. Consistent with the above, other studies have also mentioned low back pain (Habibi, Sarafrazi and Izadyar, 2014; Zamora and Labao, 2020), generalised body ache (Nimbalkar *et al.*, 2014). The frequent use of pain relievers was used by caregivers in this study. Findings from one study indicated that caregivers buy over-the-counter medications, mostly painkillers, in order to deal with the

negative effect of caregiving on their health (Moosa-Tayob & Risenga, 2022). These problems have been linked to increasing fatigue (Sharan & Rajkumar, 2018).

Factors that have been associated to pain-related effect in caregivers include assisting with transfer of children, caregivers mood and history of pain effects (Brehaut *et al.*, 2009), dealing with problem behaviours and level of difficulty in performance of daily activities (Zamora and Labao, 2020), regular carrying of the children (Nimbalkar *et al.*, 2014), assisting with performance of ADL (Vadivelan *et al.*, 2020). In the current study, caregivers had challenges assisting with ADLs of their children with DD. Caregivers may be overwhelmed with activities like grooming, feeding, bathing and dressing. Again, they reported challenges with lifting the child with DD in the absence of assistive devices. These may put musculoskeletal strain on the caregiver, and in a situation where the social support was seen available or inadequate, caregivers may have to deal with this daily, leading to pain-related effects. Again, they may not have adequate time to rest and recuperate. Pain-related effects is something to be worried about because the caregivers may resort to poor coping mechanisms. For example, some caregivers in the current study resorted to regular abuse of analgesics which may have negative health consequences on the caregivers. Again, increased pain related symptoms could interfere with the amount of available time needed to provide care for the child with DD.

Caregivers reported that they had interrupted sleep, were restless especially during the night and woke up frequently during the night. Consistent with the above, other studies documented similar sleep problems among caregivers including lack of sleep, changed sleep patterns, increased wake after sleep, reduced sleep duration (Gallagher, Phillips & Carroll, 2010; Bourke-Taylor *et al.*, 2013; Vincent *et al.*, 2021). The caregivers in the current study attributed the sleep changed to worrying and poor sleep pattern from their children with DD. Similarly, Richdale and Baker (2014) reported that changes in sleep patterns of children with DD may negatively influence the sleep patterns and daytime functioning of other family members. Poor sleep quality has been linked to increased levels of stress, anxiety and depression (Gallagher *et al.*, 2008).

In the current study, caregivers experienced palpitations, fatigue and exhaustion. Several studies have reported fatigue among caregivers (Giallo *et al.*, 2013; Seymour *et al.*, 2013). High levels of fatigue have been linked to poor maternal sleep, stress, anxiety, poor physical activity (Giallo, Rose and Vittorino, 2011; Giallo *et al.*, 2013) poor diet, difficulty in parent-

child interactions (Seymour et al, 2013), high levels of parenting hostility (Giallo, Rose & Vittorino, 2011; Chau, Giallo & Giallo, 2014).

4.9.4.2 Decline in mental well-being of caregivers

Caregivers reported lack of concentration, feeling angry, shifting of blame and sad feeling. The SPM identifies changes in psychological well-being of the caregiver as outcomes of caregiving. In the line with the study above, a qualitative study examining burden of caregivers of children with CP, reported that mothers experienced guilt, blame, worry in relation to the future of the child with DD disability (Vadivelan *et al.*, 2020). In a qualitative study; Asa *et al.* (2020) reported caregivers feeling frustrated, sad, angry, worried, inferior attributed to rejection of their children by other children without disability.

Caregivers were anxious about the future. Gomez et al (2014) reported in a literature review that caregivers had concerns about the children's future, attributed to the caregivers identifying that they had limitations in providing support for them. In a systematic review, Mkabile *et al.* (2021) posits that one of the themes identified was caregivers worries about the future. Other studies have reported the same (Gona *et al.*, 2011; Ajuwon & Brown, 2012). It is possible caregivers of the current study had little or no emotional support as many mentioned they felt socially isolated and had strained social relationship.

4.9.4.3 Decline in social wellbeing of caregivers

In the current study, caregivers reported social isolation mainly due to the difficulty of managing the child with DD in public and negative attitudes from the public. Consistent with the above, Vadivelan *et al.* (2020) reported that caregivers felt a sense of isolation in society. Mkabile *et al.* (2021) further explain that caregivers felt ashamed about their child's condition, which influenced their inability to take them out, thus hiding them from the community to avoid discriminating and stigmatising them. The views expressed by Mkabile *et al.* (2021) are similar to the findings of the current study, as caregivers mentioned that they kept away from the public because of the negative attitude from members of the community, leading to feelings of isolation.

Additionally, for caregivers in the current study, difficulty managing behaviour problems in public prevented them from attending social functions, subsequently leading to social isolation. In line with the above, Lamptey (2019) reported that parents had difficulty managing behaviour

challenges in children with IDD in public. One other factor that has been linked to social isolation where caregivers are generally housebound is the lack of access to mobility and transport services (Maridal *et al.*, 2021). On the contrary to the findings of the current study and other previous studies (Vadivelan *et al.*, 2020; Mkabile *et al.*, 2021), Hajek, Kretzler and König (2021) in a systematic review reported that informal caregiving did not affect social isolation. Though related but not the same concept, other studies have found a relationship between informal caregiving and loneliness (Gallagher & Wetherell, 2020; Zwar, König & Hajek, 2020). Loneliness refers to the feeling of the poor quality or size of caregiver's social network, while social isolation is the perception of the caregiver that he or she does not belong to society.

In terms of relationships, caregivers reported strained relationships with partners, family, friends, and society at large. The above means that their social network size has reduced, leading to the feeling that they are no longer part of society. The SPM identifies family strains as a secondary stressor, meaning they could lead to negative physical and mental health outcomes. In line with the current study, the findings by Asa *et al.* (2020) showed that caregivers experienced reduced social interaction. Caregivers explained it was a result of fathers not accepting their children with disabilities, increased time spent providing care for the child, and stigmatisation and discrimination towards their children with disabilities.

Other studies have reported that caregivers receive abuse from their partners (Vadivelan *et al.*, 2020). In a qualitative study, Asa *et al.* (2020) found that female caregivers faced separation or divorce. Zahaika *et al.* (2021) found that the majority of participants (78%) mentioned that their relationships with others, i.e., family members, friends and acquaintances, had suffered because of caregiving. There are changes in social relationships because many studies have highlighted that caregivers of children with disabilities are often stigmatised and discriminated against (Broady, Stoyles and Morse, 2017; Tekola *et al.*, 2020; Mkabile *et al.*, 2021). In a narrative synthesis of qualitative studies, Mkabile *et al.* (2021) reported elevated levels of stigma and discrimination, especially within the African context, where such children are perceived to have been cursed or possessed by spirits or because of the sins of the caregivers, this is not any different from the solemn con. Thus, the outcome of such a situation is that children with such disabilities are receiving a punishment from a supreme being.

4.9.5 SUPPORT NEEDS OF CAREGIVERS

Caregivers mainly reported informational, financial, psychological, spiritual, and social support needs. In a systematic review by Gomes *et al.* (2015), similar needs were identified. Consistent with the above, Ambikile and Outwater (2012) reported social support, health education and information, professional assistance, and support with schooling. Tilahun *et al.*, (2016) posited that the lack of variability in the needs of caregivers across studies may be attributed to the fact that, regardless of the setting, children with DD present with similar needs, behaviours, and challenges.

4.9.5.1 Informational support needs

The results of the qualitative study provided evidence that caregivers wanted information on the diagnosis and management of children with DD. It is not surprising, as one of the unmet needs mentioned by caregivers in most studies is the need the for information (Tilahun *et al.*, 2016; Sukeri *et al.*, 2017; Eloreidi *et al.*, 2021; McKibben *et al.*, 2021). Tilahun *et al.* (2016) reported that caregivers wanted information to be provided by experts on their child's condition. McKibben *et al.* (2021) reported that the information needs were centred around the disease, its course and its management. Huus *et al.* (2017) also reported that parents of children with disabilities had informational needs related to available social support, future support, managing their children's behaviour, and teaching their children new skills. The findings are similar to those of the current study, as the caregivers identified the need for information on diagnosis and management.

Information needs, as a term, have been used to mean when the provision or receiving of information is considered poor (McKibben *et al.*, 2021). Having appropriate knowledge and adequate information on the development of the child, the impairments, and the resources available could have positive outcomes for the caregiver. The level of information caregivers have could influence the strategies they use in dealing with the stress and burden associated with their caregiving role (McKibben *et al.*, 2021). Additionally, it is not just about information; but how the information is delivered and who gives the information have been identified as crucial (McKibben *et al.*, 2021). Furthermore, the availability of information to the caregiver could enhance caregiver competency (McCabe, You & Tatangelo, 2016; McKibben *et al.*, 2021). A positive relationship has been found between adequate information and strong self-efficacy (Huus *et al.*, 2017). It could influence the caregiver's perception of the control they have over the services they need. In addition to the above, adequate information

could decrease the risk of social isolation and its negative physical and emotional impact (Palisano *et al.*, 2010). It may affect the care given to a child with a disability. Inadequate or lack of information could affect the communication between the caregiver and health care team, which may lead to miscommunication (Alaee *et al.*, 2015; Eloreidi *et al.*, 2021).

4.9.5.2 Financial support needs

Caregivers mentioned that caregiving had negatively impacted their finances. Tilahun *et al.* (2016) reported that one of the unmet needs of caregivers was financial support. It was the third most reported unmet need (30.4%) after educational provision for their child with DD (74.5%) and treatment by a health professional (47.1%). Similarly, Eloreidi *et al.* (2021) reported that one of the needs expressed by caregivers was financial needs. These were associated with the cost of equipment used in the child's care with DD, treatments, and other therapies. Caregivers may have low levels of income due to the number of hours associated with caregiving (Cidav, Marcus & Mandell, 2012). This may lead to a change in caregivers work schedule. The impact of allocating more hours to caregiving may include a reduction in the number of work hours, changing from a full time job to a part-time job, or totally leaving the workforce (Cidav, Marcus & Mandell, 2012). Thus, trying to provide for the needs of their children may be stressful and affect their quality of life (Palisano *et al.*, 2010; Eloreidi *et al.*, 2021). Studies report that some countries provide some form of financial assistance to persons with disabilities and their caregivers (Palisano *et al.*, 2010), usually done by governmental agencies through social support services.

Mohd Nordin, Shan and Zanudin (2019) expressed that financial support was in relation to getting or purchasing special equipment for the children with disabilities, most of these equipments are expensive. In consistent with the above, Ueda *et al.*(2013) reported caregivers unmet financial needs were in relation to getting special equipment for the child, for therapy and for child care. Sukeri *et al.* (2017) on the other hand, reported that caregivers' assistance was in relation to paying for the daily expenses. For Kertoy *et al.* (2012) the focus of financial assistance was the payment of bills. Regardless of the reason leading to the financial need, getting financial assistance to take care of the children with DD is a problem. Available evidence suggests that caregivers who are reported to have a high financial need or burden are more likely to report high levels of other unmet needs.

4.9.5.3 Psychospiritual support needs

Mohd Nordin, Shan and Zanudin (2019) examined the unmet needs of parents of highly dependent children and identified getting psychological support as one of the unmet needs. In the current study, caregivers mentioned that due to the stressful nature of caregiving, which is usually compounded by the relatively slow progress of their child, their emotional needs are usually unmet. Thus, the need for emotional and spiritual support through counselling. Such a need is not usually fulfilled because such services are usually not provided for caregivers, if provided, may not be easily available (Mohd Nordin, Shan & Zanudin, 2019). Sukeri *et al.* (2017) reported that over 50% of caregivers expressed their willingness to meet with a counsellor. Consistent with the above, a study in Japan revealed that 45% of caregivers wanted to meet a counsellor. In most developed countries, psychological support services are well established to meet the emotional needs of caregiver. However, in developing countries, the same cannot be said.

4.9.5.4 Social support needs

Ibrahim *et al.* (2019) reported that the need for social support received the second highest rating after the need for information. The researchers mentioned caregivers felt it was important to talk about it with other caregivers with children with similar DD. They believed that sharing information among caregivers could relieve stress. Parent support groups have been described as the best, as caregivers get to share their experiences and also receive some form of emotional support. Several studies frequently expressed caregivers wanting to talk to other people either friends or family, about their problems (Ueda *et al.*, 2013; Sukeri *et al.*, 2017).

4.9.6 COPING STRATEGIES OF CAREGIVERS

4.9.6.1 Adaptive coping strategies

The caregivers identified that they used prayers to cope. A review of the literature indicates that one of the main mechanisms used in coping with stress associated with caring for a child with DD is the use of spirituality (Masulani-Mwale *et al.*, 2016; Tilahun *et al.*, 2016; Chukwu *et al.*, 2019). Asa *et al.* (2021), in a qualitative study, reported that all participants in their study mentioned that they prayed to God. In their study, spiritual resources included not only praying but also attending church, taking part in spiritual activities in the communities. Resorting to

religious coping has been identified as an effective way of coping with stress (Ezeonu *et al.*, 2021).

The exact mechanism by which it works cannot be determined; however, it may be because it helps in accepting the current situation and accepting to deal with it according to God's will (Mkabile *et al.*, 2021). Additionally, religious belief may produce endurance and resistance in individuals dealing with stress (Ezeonu *et al.*, 2021). Engaging in religious coping is likely to lead to being calm, feeling peaceful, and being less stressful. While some studies support the idea that religious coping may reduce stress and other mental health outcomes, other studies did not find such a relationship both in the short term (Hastings *et al.*, 2005) and the long term (Gerber, Boals & Schuettler, 2011).

Caregivers in the current study mentioned that they depended on themselves to cope with the stress associated with caregiving. They did this by encouraging themselves during difficult situations. Asa *et al.* (2021) reported that caregivers used self-reliance to cope with challenges in caring for children with disabilities. The researchers report that caregivers relied on their own capabilities. In the current study, caregivers sought support from family. It was emotional support, and they believed it helped them deal with the stress involved in caregiving. Consistent with the above, Ezeonu *et al.* (2021) identified seeking support (37.8%) as the second most useful coping resource.

4.9.6.2 Maladaptive coping strategies

The findings of the current study indicate that some caregivers use maladaptive coping strategies to deal with stress. Rahmani *et al.* (2019) reported that caregivers especially females used maladaptive coping strategies. Specifically, the use of blame was quite significant. Studies have indicated that blame is used as a defense mechanism to avoid feelings of guilt, sadness, powerlessness, and shame (Stuewig *et al.*, 2010).

4.10 SUMMARY OF CHAPTER FOUR

The chapter described the findings from the phenomenological study as well as the discussion. Fourteen caregivers were interviewed, and after thematic analysis was done, five themes and seventeen sub-themes were generated. The demographic characteristics of the caregivers indicated that the majority were females, not married, unemployed, and had provided care between 6 months to 4 years. The five themes were perceptions of caregiving, stressors,

negative health outcomes, support needs, and coping strategies. The findings indicated that caregiving was perceived as time consuming and stressful with stressors including child-care stressors, unmet educational needs, and financial burden. The stress was observed to have negative outcomes for caregivers' health including their physical, psychological, and social well-being. The next chapter describes a scoping review of interventions and programmes that have been conducted for caregivers of children with DD.

CHAPTER 5

SCOPING REVIEW (PHASE 1b)

5.0 INTRODUCTION

Chapter five focuses on the scoping review, which is phase one of the study. This chapter describes in detail the scoping review process guided by the methodological framework of Arksey and O'Malley as well as the Joanna Briggs Institute's (JBI) guidelines. The scoping review process comprises six stages: 1) identifying the research question; 2) identifying relevant studies; 3) study selection; 4) charting the data; 5) collecting, summarising and reporting the results; and 6) a consultation exercise (Arksey & O'Malley, 2005; Levac, Colquhoun and O'Brien, 2010; Joanna Briggs Institute, 2015). The scoping review protocol has been published in BMJ Open.

5.1 THE SCOPING REVIEW PROCESS

For the several types of literature reviews that exist, identifying the research problem and subsequently developing the research question(s) begins the process. The question usually gives the review a focus and direction (Joanna Briggs Institute, 2015). A search of literature is usually conducted based on the question with the aim of answering the question. The data gathered from the search is analysed in order to make sense of it, and then the findings are reported. Likewise, scoping reviews follow such a process. The methodological framework for conducting scoping reviews [Described in Chapter 3] as published by Arskey and O'Malley as well as the JBI guidelines was used in this study (Arksey & O'Malley, 2005; Levac, Colquhoun and O'Brien, 2010; Joanna Briggs Institute, 2015)

5.2 STAGE 1: IDENTIFYING THE RESEARCH QUESTION

The scoping review question was framed based on the PCC [Population, Concept and Context] elements (Joanna Briggs Institute, 2015). The scoping question was: ***"What type of interventions for improving the wellbeing of caregivers of children with DD have been reported?"***. The population consisted of caregivers of children with DD. The concept involved interventions for improving well-being. The context was not restricted to a particular geographical location because the initial search revealed there were scanty studies done in low- and middle-income countries; hence, the need to include all locations.

5.3 STAGE 2: IDENTIFYING RELEVANT STUDY

JBI's three-step strategy was used to identify relevant studies (The Joanna Briggs Institute, 2015). The first step began with a limited search of at least two databases that were relevant to the topic. The aim of this section was to analyse text words that were found in the retrieved articles, with the focus being on the title and the abstract. The key words, or index terms, were also analysed. The second step involved conducting another search using all the index terms that were identified in the first step. In this case, the search was not limited to only two databases but rather was done across five databases and also grey literature from Google Scholar. The final step involved searching the reference list of all identified studies for additional and related studies.

5.3.1 Step 1: Initial search

Two databases (CINAHL Complete and Psych Info) were used for the initial search. The search terms were caregiver, carer, child, children, developmental disability, intellectual disability, developmental delay, intervention, programme, training, well-being, wellbeing, well being. Boolean operators like 'OR', 'AND' were used to link the words for the search. The search was limited to January 2010 to June 2021, journal articles in English. Twenty-five and forty-three articles were retrieved from CINAHL Complete and PsychINFO, respectively.

5.3.2 Step 2: Search across five databases

Five databases were searched, namely PubMed, PsychINFO, Cochrane Library, ERIC and CINAHL Complete. Grey literature was also searched for on Google Scholar. The following key words were used: caregiver, well-being, interventions, child, and developmental disabilities. The keywords with their respective alternative words are described in Table 5.1:

Table 5.1 Key words and alternative words for database search

Key word	Alternative words
Caregiver	father, mother, parent, family, carer
Children	juvenile, young adult, teenager, adolescent
Developmental disability	developmental delay, cognitive disabilities, developmental disorders, intellectual disability, learning disabilities, neurodevelopmental disabilities, intellectual and developmental disabilities, cognitive impairment, mental retardation
Intervention	education, training, programme, therapy
Well-being	wellness, health

Table 5.1 describes the five key words that were used in the search across the databases, along with their corresponding alternative words.

Building an extensive search strategy is crucial for a scoping review in order to ensure that no study or article is overlooked. The indexing terms or medical subject headings (MeSH) unique to that database were used for the database search. Other keywords were used in addition to the MeSH, or indexing term, for a given keyword. For instance, alternative key words like developmental delay, cognitive disability, neurodevelopmental disability, or mental retardation were used in place of the phrase "developmental disabilities." In order to increase the search's scope, the truncation symbol was added at the end of the root word. Family*, for instance, produced outcomes for families and families.

To make sure the search engine's results were accurate, quotation marks were used when searching for specific phrases. Search terms containing developmental, disabilities, or both terms were returned when the phrase developmental disabilities was entered without the quotation marks. For instance, searching for "developmental disabilities" in PubMed yielded 28,735 results, but searching for developmental disabilities without quotation marks produced 32,208 results. The search terms were linked using Boolean operators such as 'OR' and 'AND'. The supervisor and a librarian from the University of Witwatersrand's Faculty of Health and Medical Sciences library created the final search strategy. Table 5.2 provides information on how the search was conducted across the five databases:

Table 5.2 Details of search across five databases

Database	Date of search	Search criteria
PubMed	12/10/2021	((((("Caregivers"[Mesh] OR father* OR mother* OR parent* OR famil* OR care-giver*) AND ("Mental Health"[Mesh] OR "Health"[Mesh] OR "well-being")) AND ("Psychosocial Intervention"[Mesh] OR educat* OR train* OR program* OR therap* OR intervention* OR treatment* OR skill*)) AND ("Child"[Mesh] OR child* OR juvenile OR "young adult*" OR teenage* OR adolescen*)) AND ("Developmental Disabilities"[Mesh] OR "developmental delay*" OR "cognitive disabilit*" OR "developmental disorder*" OR "intellectual disabilit*" OR "learning disabilit*" OR "neurodevelopmental disabilit*" OR "intellectual and developmental disabilit*" OR "cognitive impairment*" OR "mental* retard*") Filters: Journal Article, Humans, English, from 2010/1/1 - 2021/9/30
Psych INFO	12/10/2021	(MH "Caregivers" OR father* OR mother* OR parent* OR famil* OR care-giver* OR caregiver* OR carer*) AND (MH "Wellness" OR “well-being” OR health) AND (MH "Psychosocial Intervention" OR educat* OR train* OR program* OR therap* OR intervention* OR treatment* OR skill*) AND (MH "Child" OR child* OR juvenile OR “young adult*” OR teenage* OR adolescen*) AND (MH "Developmental Disabilities" OR “developmental delay*” OR “cognitive disabilit*” OR “developmental disorder*” OR “intellectual disabilit*” OR “learning disabilit*” OR “neurodevelopmental disabilit*” OR “intellectual and developmental disabilit*” OR “cognitive impairment*” OR “mental* retard*”)

Database	Date of search	Search Criteria
Cochrane Library	12/10/2021	caregiver* OR father* OR mother* OR parent* OR famil* OR care-giver* OR carer* in Title Abstract Keyword AND "mental health" OR health OR well-being in Title Abstract Keyword AND child* OR juvenile OR young adult* OR teenage* OR adolescen* in Title Abstract Keyword AND "developmental disabilit*" OR "developmental delay*" OR "cognitive disabilit*" OR "developmental disorder*" OR "intellectual disabilit*" OR "learning disabilit*" OR "neurodevelopmental disabilit*" OR "intellectual and developmental disabilit*" OR "cognitive impairment*" OR "mental* retard*" in Title Abstract Keyword AND "psychosocial intervention" OR educat* OR train* OR program* OR therap* OR intervention* OR treatment* OR skill* in Title Abstract Keyword - (Word variations have been searched)
ERIC	12/10/2021	(DE "Caregivers" OR father* OR mother* OR parent* OR famil* OR care-giver* OR caregiver* OR carer*) AND (DE "Mental Health" OR DE "Physical Health" OR DE "Well Being" OR well-being) AND (DE "Treatment" OR educat* OR train* OR program* OR therap* OR intervention* OR treatment* OR skill*) AND (child* OR juvenile OR "young adult*" OR teenage* OR adolescen*) AND (DE "Developmental Disabilities" OR "developmental delay*" OR "cognitive disabilit*" OR "developmental disorder*" OR "intellectual disabilit*" OR "learning disabilit*" OR "neurodevelopmental disabilit*" OR "intellectual and developmental disabilit*" OR "cognitive impairment*" OR "mental* retard*")
CINAHL complete	12/10/2021	(MH "Caregivers" OR father* OR mother* OR parent* OR famil* OR care-giver* OR caregiver* OR carer*) AND (MH "Wellness" OR "well-being" OR health) AND (MH "Psychosocial Intervention" OR educat* OR train* OR program* OR therap* OR intervention* OR treatment* OR skill*) AND (MH "Child" OR child* OR juvenile OR "young adult*" OR teenage* OR adolescen*) AND (MH "Developmental Disabilities" OR "developmental delay*" OR "cognitive disabilit*" OR "developmental disorder*" OR "intellectual disabilit*" OR "learning disabilit*" OR "neurodevelopmental disabilit*" OR "intellectual and developmental disabilit*" OR "cognitive impairment*" OR "mental* retard*")

The table above provides details of how the search was done on PubMed, PsychINFO, Cochrane Library, ERIC, and CINAHL Complete.

5.4.3 Step 3: Searching the reference list of identified studies/other sources

The reference lists of the identified studies were searched to identify additional studies. The process did not generate any new articles to be included in the scoping review.

5.4 STAGE 3: STUDY SELECTION

Based on inclusion and exclusion criteria (explained in Table 3.2 in Chapter 3), the studies were chosen. To get rid of duplicates, the results from each database were imported into Mendeley, a reference manager. The articles were exported to the review management system, Covidence for screening following the removal of duplicates. Two reviewers (DAA and JN) independently screened the abstracts and titles to determine eligibility. The study's inclusion and exclusion criteria served as a guide for the reviewers during this process. NN settled

disagreements that surfaced among the reviewers. Two reviewers (DAA and JN) independently completed a full text review after titles and abstracts were screened. Nineteen studies in all were included in the scoping review. The process followed in retrieving the studies is presented in the PRISMA flow diagram in Figure 5.1:

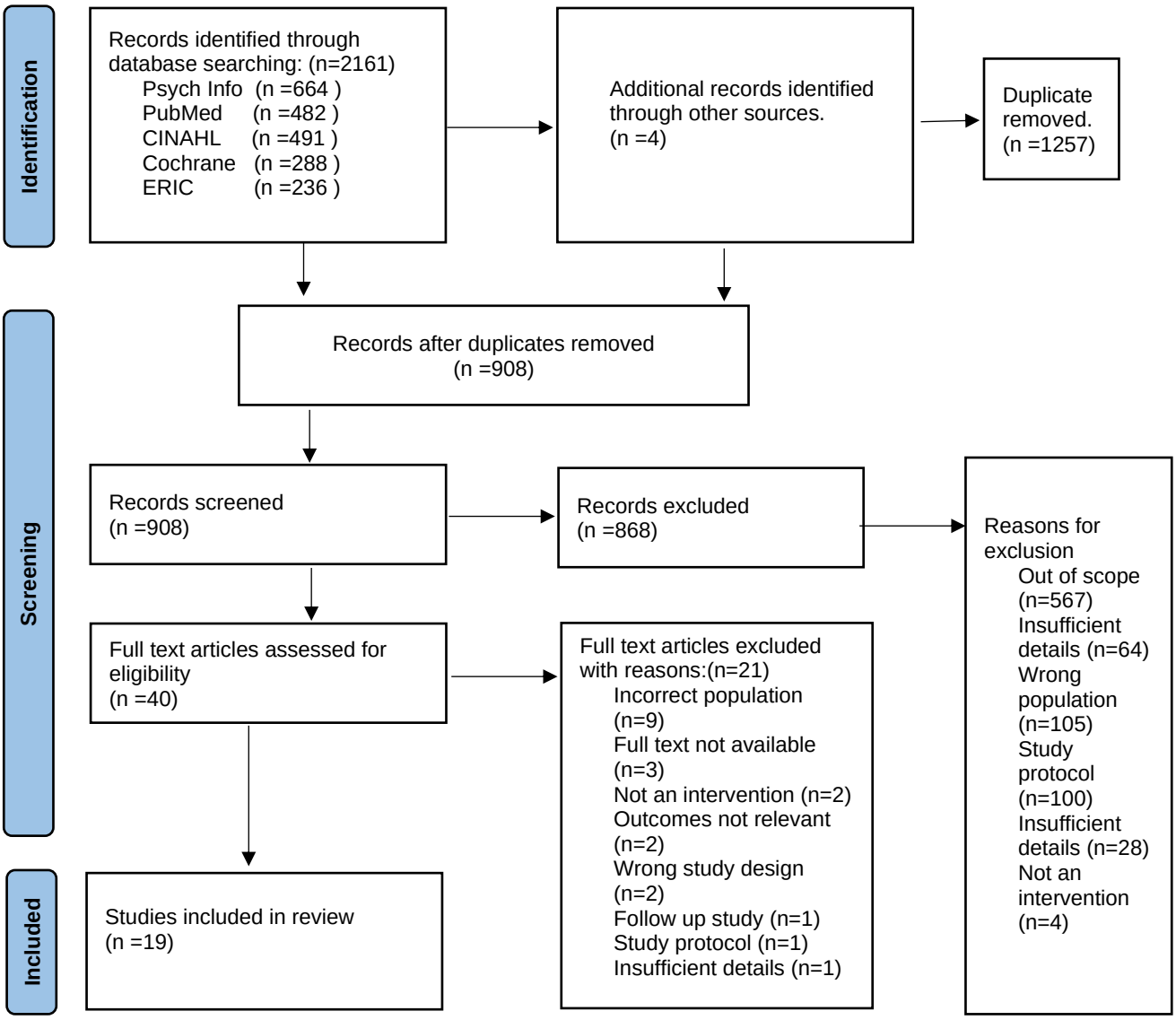

Figure 5.1: PRISMA flow diagram for the scoping review article selection process

The PRISMA flow diagram, as indicated in Figure 5.1 provides details on the number of studies identified through the search across five databases and grey literature, the number of duplicates removed, the number of studies screened, and those that were excluded with reasons. The last part of the flow diagram described the number of studies included in the scoping review process.

5.5 STAGE 4: CHARTING THE RESULTS

The information retrieved from the selected studies was charted using the following headings: author(s), year of publication, origin/country of origin, purpose of study, study population and sample size, research design, intervention type, outcome measures, and key findings. Table 5.3 provides details of the data extracted from the 19 studies included in the scoping review:

Table 5.3 Extraction of results from studies used in the scoping review

AUTHOR/ YEAR OF PUBLICATION	COUNTRY	PURPOSE	STUDY POPULATION	SAMPLE SIZE	RESEARCH DESIGN	INTERVENTION	COMPARISON	OUTCOME MEASURES	KEY FINDINGS
Ashori et al., 2019	Iran	To examine the effectiveness of positive parenting program (Triple-P) on the mental health of mothers of children with intellectual disability (ID)	Mothers of male students with ID whose children were in elementary schools	**Experimental group** (n=18) Age of caregivers (33.97± 2.24) Age of children (8.47± 0.32); **Control group** (n=18) Age of caregivers [33.65± 2.49] Age of children [8.51± 0.37]	Quasi-semi-experimental research with pre-test, post-test design, and a control group	Triple P; 12 sessions; duration of 80 minutes once a week; delivered to them in groups	None	General Health Questionnaire (somatic symptoms, anxiety, depression and social function)	Significant effect of the intervention on the somatic symptoms, anxiety, depression, social dysfunction, and mental health of mothers of children with ID. Mothers in the intervention group experienced reduced somatic symptoms, anxiety, depressive, social dysfunction and improvement in mental health as compared to the control group.
Bazzano et al., 2013	USA	**(1)** To develop an MBSR program adapted for parents and caregivers of individuals with DD using a community-based participatory research (CBPR) framework **(2)** To conduct a feasibility study measuring the effects of the MBSR program on stress, mindful awareness, self-compassion and psychological well-being	Parents or primary caregivers of an individual (or individuals) with a DD	n=66 **Age of caregivers** [45.7±11.1]; **Age of children with DD** (not provided)	Quasi experimental design; one group pre-test post -test without a control group	Mindfulness-based stress reduction (MBSR) program; 2-hour session and 4 hour silent retreat for 8 weeks. Delivered by experienced MBSR teacher	None	Mindful Awareness (Mindful Attention Awareness Scale [MAAS]); Stress (PSS10 and Parent SS); Psychological Well-being (Ryff's Psychological Well-Being scales); Self compassion (Self-Compassion Scale); (Self-Rated Physical Health) Short-Form 12	Parents and primary caregivers experienced a significant reduction in the level of perceived stress and the difference between the pre-test and post-test scores. Decrease in stress levels continued to reduce 2 months after the intervention. There was significant increase in scores of mindfulness, self-compassion, and well-being ($p<0.05$).
Brookman-Fraaze et al., 2021	Canada	To examine the impact of training therapists to deliver AIM HI for children with ASD on caregiver outcomes	Caregivers of children with ASD	**Experimental group**(n=156), mean age of caregivers [40.55±8.56]age of children[9.06±	Randomized Control Trial	An Individualized Mental Health Intervention for Autism Spectrum Disorder (AIM HI). An introductory	Usual care	Caregiver Strain Questionnaire; Parenting Sense of Competence; Eyberg Child	No significant change in caregiver strain level between the experimental group [AIM HI] and the control group[usual

		and the mediating role of changes in caregiver outcomes on child outcomes		2.46]; **Control group** (n=46) mean age of caregivers[38.76± 6.97]Age of children [9.35± 2.38] **Age of children** [5-13 years]		training workshop and 11 consultative meetings with AIM HI expert trainer (9 group sessions and 2 individual sessions); 1 hour in length over 6 months period		Behaviour Inventory	care] after the 6 months period; There was significant changes in the caregiver sense of competence between the two groups. Caregiver characteristics [such as race, preferred language, maternal level of education] and child's challenging behaviour did not moderate the differences between the two groups on the sense of competence
Callanan et al., 2021	Australia	To extend the investigation of PCRI-EI to explore its impact on parental stress levels, sense of competence and psychological well-being in a larger sample of 22 parents of children diagnosed with developmental disabilities.	Parents of children with a variety of disabilities presenting to a community early childhood development service	n=22	Quasi experimental design	Parent Child Relationally Informed - Early Intervention (PCRI-EI); 12-week block	None	Parenting Stress Index-Short Form 4th edition; Parenting Sense of Competence Scale; The Kessler Psychological Distress Scale	There was statistically and clinically significant changes in overall stress levels (Parenting Stress Index), psychological wellbeing (K6) and sense of competence (PSOC) were observed across time ()
Dindar et al., 2016	Iran	To evaluate the effects of spiritual self-care training on care giving strain in mothers of mentally retarded children	Mothers of mentally retarded children hospitalized in Elahi Rehabilitation Centre	**Experimental group** (n=30), mean age of mothers [30.06±9.76], mean of children [7.10±3.43]; **control group** (n=30), mean age of mothers [24±10.6], mean age of children [10.43±3.08]	Quasi experimental design	Spiritual Self-Care Training; six 45-minute sessions, for a 2-week period every other day (3 sessions on the even days of the week on morning work shift)	None	Multidimensional Caregiver Burden Inventory	There was no significant difference between the mean score of caregiving strain in intervention and control groups before and immediately after the intervention. However, among the members of the intervention group the score of mother caregiving strain decreased within two weeks after the intervention, which

									was statistically significant over time (p=0.001). The observed differences between the two groups were also statistically significant even after controlling the effects of such intervening factors as marital status, children age and the years of caring for children (p=0.001).
Dykens et al., 2014	USA	To find out if MBSR would confer some advantages over PAD.	Primary caregivers of offspring with developmental disabilities	**Experimental group** (n=116); **control group** (n=127) Mean caregiver age[40.87± 8.92]; mean child age [10.85±7.53]	Randomized Control Trial	Mindfulness-Based Stress Reduction; 6 weeks of group treatments in 1.5-hour weekly sessions	Positive Adult Development	**Primary Outcome**: Parenting Stress Index-Short Form (PSI); Secondary **outcomes:** Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), Insomnia Severity Index, Ryff Scales of Psychological Well-Being (short form total score), Life Satisfaction Scale.	Mothers enrolled in MBSR showed significantly greater improvements in depression, anxiety, sleep, and life satisfaction as compared to those in the PAD group
Lida et al., 2018	Japan	To assess the effectiveness of PT in improving the stress-coping style of mothers raising children with ASD	Mothers of children with ASD aged 4–11 years	n=16; Mean age of mothers [40.3±4.6]; Mean age of children [6.8±2.0]	Quasi experimental design	Parent Skills Training Program; Sessions 1–7 were held every 2 weeks for a total duration of 3 months. Follow-up was held 2 months after Session 7; conducted by psychologists and doctors.	None	Stress Coping Inventory (SCI), the Beck Depression Inventory Second Edition (BDI-II), the State–Trait Anxiety Inventory (STAI), and Child Behavior Checklist (CBCL)	The stress-coping strategy "positive appraisal" significantly increased and "escape/avoidance" significantly decreased. The BDI-II and STAI (trait anxiety) score decreased significantly after PT. Though STAI (state anxiety) also decreased, the

									difference was not significant.
Jones et al., 2018	UK	To carry out a pilot evaluation of an eight-week Mindfulness-Based Well-Being Course for Parents (MBW-P) with parents of children with ASD and/or ID	Parents of children with autism and related disabilities(CP, DS, ID)	n=21 Mean age of parents [45, 6.48]; Mean of age of children [10.53±3.16, range 4–16)	Quasi experimental design	Mindfulness Based Well-Being for Parents (MBW-P); 8 weeks	None	Hospital Anxiety and Depression Scale (HADS); Depression Anxiety Stress Scale; Parent and Family Problems Subscale of The Questionnaire on Resources and StressShort Form (QRS-F); Positive Gain Scale (PGS)	There was increase in mindfulness and self-compassion, and reduced general stress. Parents also reported reductions in anxiety and depression, although these changes were not statistically significant. No significant reductions in their child's behaviour problems or increases in the child's prosocial behaviour were found.
Lodder et al., 2020	UK	**(1)**To evaluate the feasibility and acceptability of SOLACE. **(2)** To explore the preliminary impact of the intervention on the mental health of the parents and carers as well as other outcome measures including courtesy and affiliate stigma; self-esteem; self-compassion, positive meaning of caregiving; self-blame; social support; and social isolation	Parents and carers of autistic children	**Experimental group** (n=9), Mean age of parents [35.00±6.42]; Mean of children [4.83±1.73] **Control group** (n=8), Mean age of parents [39.25±8.83]; Mean of children [7.13±2.95]	Parallel Randomized Control Trial	SOLACE; Eight weeks; weekly sessions were delivered either face to face (session 1, 4 and 8) or via videoconference (session 2, 3, 5, 6 and 7)	None	**Primary outcomes**-Mental Health Inventory; **Secondary Outcomes**-Perceived Courtesy Stigma Scale; Affiliate Stigma Scale; Self-Esteem Scale; Self-Compassion Scale–Short Form; Social Support Survey; Short-form UCLA Loneliness Scale	There was a significant improvement of the mental health scores for those who took part in SOLACE compared to no significant changes for control group participants. In addition, changes in secondary outcome measures were in favour of SOLACE.

Lo et al., 2017	China	To examine the effectiveness of the Brief Mindfulness-Based Program	Parents of children with developmental disabilities	**Experimental group**(n=91); Mean age of caregivers [39.31]; Mean age of children [5.24] **Control group**(n=89); Mean age of caregivers [38.40]; Mean age of children [5.12]	Randomized Control Trial	Brief Mindfulness-Based Program; 6 weeks, 1.5 hours per session	None	Parenting Stress Index–Short Form; Center for Epidemiologic Studies Depression Scale; Eyberg Child Behavior Inventory; Interpersonal Mindfulness in Parenting; Kansas Marital Satisfaction Scale	Parents in the intervention group had significant improvements in parental stress, depression, and stress from parent–child dysfunctional interaction.
Mills et al., 2020	Canada	To examine the clinical utility of a community-based, manualized, peer-delivered group counselling program to address the need for culturally responsive counselling for parents of children with autism in the South Asian community	Parents of Children with Autism	n=63; Mean age of parents [43.7]	Quasi experimental design	CARES program; group-based intervention; six-weeks; 1-hour sessions once per week	None	Depression Anxiety Stress Scales–21; Quality of Life Enjoyment Satisfaction Questionnaire–Short Form (QLESQ-SF); Parental Stress Scale (PSS); Brief Family Distress Scale (BFDS); Outcome Rating Scale	Parents in the intervention group reported significant decreases in levels of depression, anxiety, and stress following completion of the program, including lower percentages of clinically significant mental health concerns.
Millstein et al., 2020	UK	To describe health behaviours among this understudied population and assess the changes after a resilience intervention	Parents of children with learning and attentional disabilities (LADs) and ASD	Parents of children with Learning and Attentional Disabilities (n = 53) and Autism Spectrum Disorders (n = 51)	Secondary analysis of Randomized Control Trial	Virtual mind-body resilience intervention; 8 weeks; 1.5 hours per week	None	Sleep Quality Index; Fatigue Analogue Scale; Cigna Healthy Eating Survey; physical activity questionnaire	Both groups reported increase in the sleep hours, though the LAD group attained more than the ASD group. the combined effect size was small. The effect size in fatigue size improvement was moderate for both groups combined. Light physical activity and moderate-to-vigorous also increased in both groups. Overall, the LAD group had better improvement in healthy behaviour than the ASD group.

Moghimi et al 2018	Iran	To determine the effectiveness of resilience teaching via short message service (SMS) on stress of mothers of educable mentally retarded children	Mothers of Educable Mentally Retarded Children	**Experimental group**(n=35), Mean age of mothers [33.72 ± 3.8]; **Control group**(n=35), Mean age of mothers [34.1 ± 4]	Randomized Control Trial	Resilience Teaching; four text messages each day(totally 180 messages); 1.5 months	None	Abidin Short Form Parenting Stress Index; Connor-Davidson Resilience Scale	There was a statistically significant difference in stress and resilience scores for the SMS group than that of the control groups (P < 0.05) after the intervention.
Neece 2014	USA	To examine the efficacy of mindfulness-based stress reduction (MBSR) for parents of children with DD by investigating whether this intervention is effective in reducing parenting stress and whether decreases in parenting stress lead to reductions in behaviour problems among children with DD	Parents of Young Children with Developmental Delays	**Experimental group**(n=21), Mean age of parents [34.14±8.71]; Mean of children [3.59±0.88] ; **Control group**(n=25), Mean age of parents [36.40±8.41]; Mean of children [4.12±0.90]	Randomized Design	Mindfulness-Based Stress Reduction; eight weekly 2-h sessions, a daylong 6-h meditation retreat after class 6 and daily home practice based on audio CDs with instruction	None	Parenting Stress Index–Short Form; Family Impact Questionnaire; Center for Epidemiologic Studies Depression Scale; Satisfaction with Life Scale; Child behaviour checklist for ages 1.5–5	Parents who received the intervention reported significant reductions in parental stress using two different questionnaires (i.e. the PSI and FIQ) as well as decreases in depression and increases in their general life satisfaction at the second assessment compared with parents who had not participated in MBSR. Additionally, parents who received MBSR reported reductions in their children's ADHD symptoms and attention problems
Soffronof et al., 2011	Australia	To examine the effects of the SSTP seminars as a time efficient, cost-effective parenting intervention for parents of a child with a disability	Parents of a child with disability	**Experimental group**(n=26); **Control group**(n=27); Overall mean age of parents [38.64±5.57]; Overall mean age of children [6.15±2.48]	Randomized Control Trial	Stepping Stones Triple P seminars; 2-h seminars	None	Family Background Questionnaire (FBQ); Eyberg Child Behaviour Inventory (ECBI); Parenting Scale (PS); Parenting Sense of Competence Scale (PSOC); Parent	Parents reported significant reductions in the number of child behaviour problems, less frequent use of dysfunctional parenting styles and fewer conflicts over child-rearing.

								Problem Checklist (PPC); Relationship Quality Index (RQI); Depression Anxiety Stress Scale (DASS-42); Family Assessment Device-General Functioning Scale (FAD-GF)	
Suzuki et al., 2014	Japan	To examine the effectiveness of group psychoeducation to relieve the psychological distress of mothers of children with high-functioning pervasive developmental disorders (HFPDD) and to improve the behaviours of the children	Mothers of preschool outpatients with High Functioning Pervasive Developmental Disorders	**Experimental group**(n=36); Mean age of mothers [35.14±4.55]; mean of children [4.4±0.88]; **Control group**(n=36); Mean age of mothers [34.94±4.90]; mean of children [4.6±1.01]	Randomized, parallel group study	Brief group psychoeducational program (GP)+treatment as usual [TAU]; four sessions; each session lasting for 120 minutes and held every second week	treatment as usual [TAU]	General Health Questionnaire (GHQ-28); Aberrant Behaviour Checklist (ABC); Zarit Burden Interview (ZBI); Medical Outcomes Study 36-item Short Form Health Survey (SF-36);	The psychoeducational program did not alleviate maternal distress, aberrant behaviours of the children, or caregiver burden
Ullas et al 2021	India	To assess the impact of a 1-month yoga intervention on anxiety, depression, stress and sleep quality in mothers of children with intellectual disabilities.	Mothers of Children With Intellectual Disability	**Experimental group**(n=28); **Control group**(n=25); Mean age of mothers [40.2±7.1]	Quasi experimental design	Yoga; 1.5 hours every other day for 1 month;	Group discussion session; twice weekly for 1 month	Hospital Anxiety and Depression Scale (HADS), stress with the Perceived Stress Scale (PSS), and sleep quality with the Pittsburgh Sleep Quality Index (PSQI)	The between-group comparison of post-intervention scores revealed a significantly better improvement in anxiety ($P < .001$), depression ($P < .001$), perceived stress ($P < .001$) and sleep quality ($P = .012$) in the yoga group compared with the control group.
Vijayasamundeeswari et al., 2020	India	To assess the effectiveness of stress management training on stress among mothers of mentally disabled children.	Mothers of Mentally Disabled Children	n=50; Age of mothers (20 to 37 years); Age of children (1-5years)	Quasi experimental design pre-test and post-test with control group	Stress Management Training; 10 session of 60 minutes	None	Parental Stress Scale	The findings showed significant difference in the pre-test mean score of stress and post-test mean score

Wong et al., 2010	Australia	To test the efficacy of culturally attuned Cognitive Behavioural therapy for Chinese parents with children with developmental disabilities at risk of developing mental health problems	Chinese parents with children with developmental disabilities	**Experimental group**(n=29); **Control group**(n=29)	Randomized Control Trial	Cognitive Behavioural Group Treatment (CBT); 10 weeks	None	General Health Questionnaire-12; Parenting Stress Index-Parent Domain; Quality of life enjoyment and satisfaction questionnaire; Dysfunctional Attitude Scale	The CBT group showed greater reduction in the levels of stress and improvement in their general mental health and overall quality of life as compared to the control group and the difference was significant(p=0.00). However, no statistically significant difference existed between the groups on dysfunctional beliefs

5.6 STAGE 5: COLLATING, SUMMARIZING AND REPORTING THE RESULTS

The results were summarised using multiple methods: numeric, narrative, and thematic approaches. The studies were summarised under the headings; distribution by geographical location, journals, year of publication, number of participants. Others included; number of assessments, inclusion and exclusion criteria, interventions, quality assessment, and analysis of themes.

5.6.1 Distribution of the studies

The number of studies included in the scoping review was 19. The studies evaluated the outcomes of interventions provided for caregivers of children with developmental disabilities.

5.6.2 Geographic distribution of the articles

Majority of studies (n=8, 42.1%) were conducted from Asia, followed by North America (n=5, 26.3%), Europe (n=3, 15.7%) and Australia (n=3, 15.7%). No study was found in Africa, South America and Antarctica. Details are provided in Table 5.5 below:

Table 5.5 Distribution of articles by location

Continent	Country	Number of studies
North America	USA	3
	Canada	2
Australia	Australia	3
Europe	UK	3
Asia	Japan	2
	India	2
	China	1
	Iran	3

5.6.3 Distribution of articles by journal

Two studies were published in the Neuropsychiatric Disease and Treatment and two also in Journal of Autism and Developmental Disorders. The remaining studies (n=15) were published in separate journals. The details of the article publication in the journals are described in Table 5.6:

Table 5.6 Article distribution by journals

Journal name	Number of articles	Article
Journal of intellectual disabilities	1	Ashori et al., 2019
Journal Child Fam Stud	1	Bazzano et al., 2013
Journal of the American Academy of child and Adolescent Psychiatry	1	Brooke-man Fraaze et al., 2021
Research in Developmental Studies	1	Callanan et al., 2021
Journal of Clinical and Diagnostic Research	1	Dindar et al., 2016
Paediatrics	1	Dykens et al., 2014
Neuropsychiatric Disease and Treatment	2	Lida et al., 2018 Suzuki et al., 2014
European Journal of Special Needs Education	1	Jones et al., 2018
Journal of Autism and Developmental disorders	2	Lodder et al., 2020 Mills et al., 2020
Mindfulness	1	Lo et al., 2017
Journal of Dev Beh Pediatr	1	Millstein et al., 2020
Iran Psychiatry Behav Sci	1	Moghimi et al., 2018
Journal of Applied Research in Intellectual Disability	1	Neece, 2014
Research in Developmental Disabilities	1	Soffronof et al., 2011
Alternative Therapies	1	Ullas et al., 2021
Indian Journal of Public Health Research and Development	1	Vijayasamundeeswari et al., 2020
Australian and New Zealand Journal of Psychiatry	1	Wong et al., 2010

5.6.4 Distribution of articles by year of publication

The studies included in the scoping review were published across ten different years. Between 2010 and 2021, studies included in the scoping review were found in each of the years with the exception of 2013. Distribution of article per year of publication is described in figure 5.2:

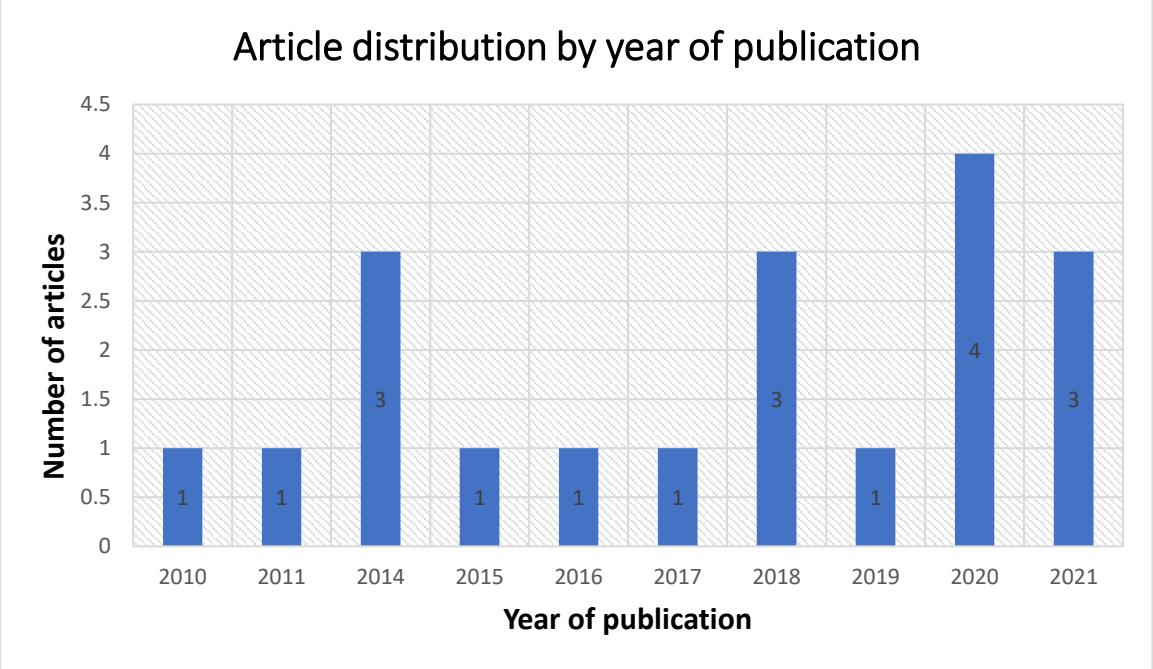

Figure 5.2 Article distribution by year of publication

Figure 5.2 indicates that four studies were published in 2020 (n=4, 21.1%). For the three studies each were published in 2014, 2018 and 2021 totalling nine studies (n=9, 47.4%) across those three years. In 2010, 2011, 2015, 2016, 2017 and 2019, one study was published each (n=6, 31.6%).

5.6.5 Participants

The total number of participants across the 19 studies involved in the scoping review were n=1,432. Some of the studies (n=8) were conducted across both sexes, however, more than half (n=11) were limited to only females. No study reported only male participants. Majority of the participants were parents either mothers or fathers of the child with DD (n=1425, 99.5%). Only few (n=7, 0.5%) were caregivers with no relationship with the child with DD. Figure 5.3 provides the male to female ratio of the participants involved in the study:

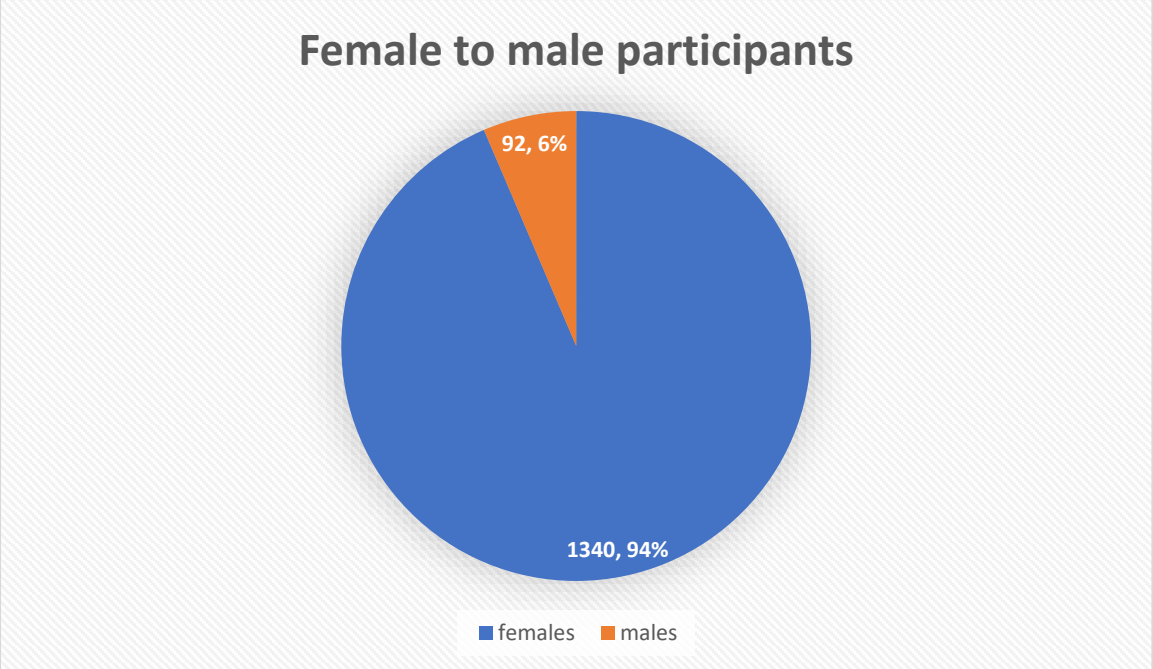

Figure 5.3 Distribution of participants by gender

The participants in the study as shown in figure 5.3 were mainly females (n=1,340) representing 93.6% whilst the remaining were males (n=92) representing 6.4%.

5.6.6 Inclusion and exclusion criteria

All 19 studies reported on inclusion criteria but in in terms of exclusion criteria, only 9 studies reported whilst n=10 did not report. Details are provided in the table 5.7 below:

Table 5.7 Inclusion and exclusion criteria of studies included in the scoping review

AUTHOR/ YEAR OF PUBLICATION	INCLUSION CRITERIA	EXCLUSION CRITERIA
Ashori et al., 2019	Mothers were having a child with mild ID; age range of 27–40 years; living with husband, mothers of children with IQ of 60–70 and their children	Mothers were currently participating in similar training program; consumption of stimulant drugs; presence of each type of sensory, and physical and motor impairment except for ID in their children.
Bazzano et al., 2013	Parents or primary caregivers of an individual (or individuals) with a developmental disability receiving services from the local non-profit agency. Parents and caregivers who communicated in English and/or Spanish and cohabitated with the individual (or individuals) were included in the programme	Not provided
Brookman-Fraaze et al., 2021	Parents or primary caregivers of children between 5 to 13 years with ASD	Not provided
Callanan et al., 2021	Parent of child aged between 0 and 72 months, falling below the first percentile (compared to same aged peers) in three of five developmental categories (cognitive, gross motor, fine motor, speech and language, and activities of daily living/social emotional functioning) as measured by standardized assessments of developmental capacity (either the Griffiths Mental Development Scales (GMDS) or the Bayley Scales of Infant and Toddler Development(Bayley III)	Not provided
Dindar et al., 2016	Having a mentally retarded child, being Muslim, primary school education (minimum), having filial and parental relationship, lack of definite depression diagnosis, and non-use of antidepressants and narcotics.	Mothers who are illiterates, having half mother-child relationship, definite depression diagnosis, using antidepressants and narcotics, and rejecting to participate in the study.
Dykens et al., 2014	Primary caregivers of offspring with developmental disabilities, willingness to be randomized into groups, and no previous training in mindfulness or positive psychology practices. Current or past psychiatric problems were not used as eligibility criteria.	Not provided
Lida et al., 2018	Mothers should consent to attending all the programs	Not provided

Jones et al., 2018	Parents of children with autism and related disabilities (CP, DS, ID)	Not provided
Lodder et al., 2020	Parents and carers of children up to the age of 10 years who had been diagnosed as autistic within the past 12 months or were still undergoing diagnostic assessment at the time of recruitment	Not provided
Lo et al., 2017	Parents of children with DD (developmental delays, ASD, ADHD, other)	Parents or caregivers whose children did not have developmental disabilities, and individuals with severe mental disorders, who were engaging in substance abuse, or who had experienced individual or family crisis in the previous 6 months were excluded
Mills et al., 2020	Parents of children with autism from Toronto, Canada who were already receiving services from the South Asian Autism Awareness Centre (SAAAC Autism Centre) or who had recently been referred to the centre for service	Not provided
Millstein et al., 2020	All parents were at least 18 years old, proficient in English, and able to engage in an online intervention	Not provided
Moghimi et al 2018	Mothers who are full conscious, with reading and writing skills, ability to communicate and answer questions, no multiple disabilities of children, no family member with hard curable physical or mental disease, knowing and full access to cellphone, having a cellphone, consent to participate in the study and signing the informed consent form, using SMS and the ability to read SMS, no use of neurological and psychiatric medications since 4 months ago, parenting stress score greater than 90, Children with an IQ of 55 - 70 whose mental retardation was diagnosed by a paediatrician and an expert on diagnostic tests of the Exceptional Education Office, and resilience score less than 50.	Dissatisfaction of mother with the continuation of the study, encountering of mother or family with a new crisis during the research, and persons' death or immigration
Neece 2014	(i) having a child aged 2.5–5 years, (ii) parent(s) reported child to have a developmental delay as determined by Regional Center (or by an independent assessment), (iii) parent(s) reported more than 10 child behaviour problems (the recommended cut-off score for determining risk of conduct problems) on the Eyberg Child Behaviour Inventory (ECBI; Robinson et al. 1980), (iv) the parent	Parents of children with debilitating physical disabilities or severe intellectual impairments that prevented the child from participating in a parent–child interaction task that was a part of the larger laboratory assessment protocol (e.g. child is not ambulatory).

	was not receiving any form of psychological or behavioural treatment at the time of referral (e.g. counselling, parent training, parent support group), (v) parent agreed to participate in the intervention and (vi) parent spoke and understood English	
Soffronof et al., 2011	Having a child aged 2 to 10 with a disability	Not provided
Suzuki et al., 2014	1) A diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified made by a child psychiatrist or developmental paediatrician according to the Diagnostic and Statistical Manual (DSM-IV-TR); 2) No intellectual disabilities with an intelligence quotient (IQ) or developmental quotient (DQ) of .70; 3) Aged 2–6.5 years; 4) diagnosis made more than 3 months previously; 4) entry to an elementary school scheduled more than 6 months later; and 5) A native Japanese speaker. Furthermore, only birth mothers who were actively involved in raising their child were enrolled.	1) Inability to understand the study contents or anticipation of an excessive burden on the potential participant for any reason; or 2) assessed as being an unsuitable candidate for participation in this study for any reason by the doctors of the affected child, who are independent of study intervention.
Ullas et al 2021	Mothers caring for children with mental disabilities, were between age 30 to 50 years and were willing to participate in the study	Mothers who had any psychiatric diagnoses or were taking antipsychotic medication, had exposure to any form of yoga in the past year, had a chronic health problem, had recent abdominal surgery or hospitalization for any serious health issue or were pregnant
Vijayasamundeeswari et al., 2020	Mothers with mentally disabled children, between the age group of 20 to 45 years, who come regularly to school, who are willing to participate in the study	Mothers who cannot understand and follow Tamil or English, who have severe mentally disabled children, who have undergone any complementary therapies
Wong et al., 2010	Parents who (i) age 18-60 years; (ii) suffering from poor mental health and at risk of developing mental health problems as indicated by a score of at least four symptoms on the GHQ-12	Parents who had psychosis or severely acute depressive symptoms at the time of interview, or had attempted suicide or had suicidal ideation in three months before the interview

Table 5.7 indicates that similar characteristics were found across studies in terms of inclusion criteria. First and foremost, one of the criteria reported was that the participant had to be the mother, father, parent or primary caregiver of a child with DD actively involved in caring (Sofronoff, Jahnel & Sanders, 2011; Dykens *et al.*, 2014; Bazzano *et al.*, 2013; Ashori, Norouzi & Jalil-Abkenar, 2019). Again, another criterion was the willingness of the caregiver to participate (Sofronoff, Jahnel & Sanders, 2011; Dykens *et al.*, 2014; Neece, 2014; Iida *et al.*, 2018; Vijayasamundeeswari, Sathiya & Poongodi, 2020). Furthermore, the child's diagnosis had to be based on DSM IV TR or expert diagnosis (Neece, 2014; Suzuki *et al.*, 2014; Callanan, Signal & Mcadie, 2021). Additionally, the caregiver should not be receiving any other form of treatment that appeared similar to the intervention that was going to be provided. For example, non-use of depressants (Dindar *et al.*, 2016); not receiving any behaviour or psychological treatment (Neece, 2014); no use of neurological and psychiatric medications (Moghimi *et al.*, 2018).

Interestingly, Dykens *et al.* (2014) did not consider the current or past psychiatric problems of the primary caregivers as a criterion for inclusion and exclusion. Most of the studies (n=15) did not include the age of the caregiver as a criterion. The studies that specified age indicated ages between 27-40 years (Ashori, Norouzi and Jalil-Abkenar, 2019); 30-50years (Ullas, Gupta and Maharana, 2021); at least 18 years and above (Millstein, Lindly, Luberto, Giselle, *et al.*, 2020); 20 to 45 years (Vijayasamundeeswari, Sathiya and Poongodi, 2020); 18-60 years (Wong & Poon, 2010). However, for some studies a detailed description of the child with DD was given and caregivers were rather chosen if their children met the inclusion (Sofronoff, Jahnel & Sanders, 2011; Neece, 2014; Suzuki *et al.*, 2014; Lodder, Papadopoulos & Randhawa, 2020; Brookman-Frazee *et al.*, 2021; Callanan, Signal & Mcadie, 2021). For exclusion criteria; unwillingness to participate (Dindar *et al.*, 2016; Ashori, Norouzi and Jalil-Abkenar, 2019; Vijayasamundeeswari, Sathiya and Poongodi, 2020); consumption of stimulants, antidepressants, or narcotics (Dindar *et al.*, 2016; Lo *et al.*, 2017; Ashori, Norouzi and Jalil-Abkenar, 2019); a potential participant who experienced an individual or family crisis (Lo *et al.*, 2017; Moghimi *et al.*, 2018).

5.6.7 Assessment instruments

Several assessment instruments were used in the 19 studies included in the scoping review, however, instruments described here are those that are related to the primary outcomes and

secondary outcomes of the current study. A brief description is given for those instruments in Table 5.8:

Table 5.8 Assessment instruments used across studies

Outcome	Instrument
Stress	Perceived Stress Scale
	Parental Stress Scale
	Parenting Stress Index
	Depression, anxiety, stress scale
Anxiety	General Health Questionnaire
	Beck Anxiety Inventory
	State-trait Anxiety Index
	Hospital Anxiety and Depression Scale
	Depression, anxiety, stress scale
Depression	General Health Questionnaire
	Beck Depression Inventory
	Hospital Anxiety and Depression Scale
	Depression, anxiety, stress scale
	Centre for Epidemiologic Study Depression Scale
Physical health/Somatic Symptoms	Physical Health Short Form
	Sleep Quality Index
	General Health Questionnaire
	Insomnia Severity Index
	Fatigue Analogue Scale
Caregiver burden/strain	Zarit Burden Interview
	Caregiver Strain Questionnaire
	Multidimensional Caregiver Burden Inventory
Social function/support	General Health Questionnaire
	Social Support Survey

Table 5.8 indicates that 24 different assessment instruments were used to measure outcomes. Four different instruments were used to measure stress. Five each were used to measure depression, anxiety and somatic symptoms respectively. Three instruments were used to measure caregiver burden/strain whilst two instruments for social function/support.

5.6.8 Number of assessments done in the studies

Assessments were done at baseline across all studies. Follow-up assessment differed across the studies. Figure 5.4 presents articles with most assessments done:

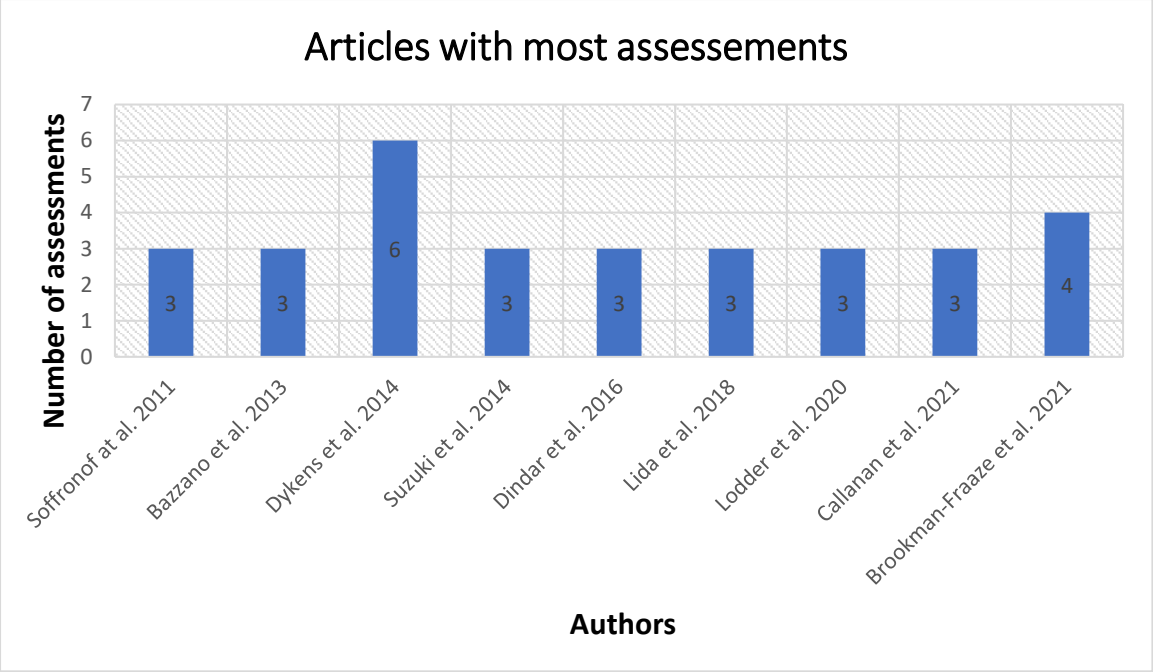

Figure 5.4 Distribution of articles with most assessments

Only one study as shown in figure 5.4 reported on mid treatment assessment; thus, assessment was conducted whilst treatment was not completed (Dykens *et al.*, 2014). Almost all the studies conducted assessment immediately after treatment (Wong and Poon, 2010a; Lo *et al.*, 2017; Jones *et al.*, 2018; Millstein, Lindly, Luberto, Perez, *et al.*, 2020; Vijayasamundeeswari, Sathiya and Poongodi, 2020; Mills *et al.*, 2021; Ullas *et al.*, 2021). However, for one study, post intervention assessment was not done immediately but rather one month after the intervention (Moghimi *et al.*, 2018). Some studies[n=9] conducted follow-up studies (Dykens *et al.*, 2014; Bazzano *et al.*, 2013; Iida, Wada, Yamashita1, *et al.*, 2018; Lodder, Papadopoulos and Randhawa, 2020; Brookman-frazee *et al.*, 2021; Callanan, Signal & McAdie, 2021). Some studies[n=9] did not conduct any follow-up assessments (Wong and Poon, 2010a; Neece, 2014; Lo *et al.*, 2017; Jones *et al.*, 2018; Ashori, Norouzi and Jalil-Abkenar, 2019; Millstein, Lindly, Luberto, Giselle, *et al.*, 2020; Vijayasamundeeswari, Sathiya and Poongodi, 2020; Mills *et al.*, 2021; Ullas *et al.*, 2021). Studies that conducted most assessments ranged from 3 to 6 assessments.

5.6.9 Interventions for caregivers

The template for intervention description and replication (TIDieR) checklist was used to review the various interventions included in the scoping review. The details of the 19 scoping reviews are described in Table 5.9:

Table 5.9 TIDieR Checklist for interventions of the studies used in the scoping review

Author (s)	Intervention Name	Why	What (materials/ Procedure	Who	How	Where	When/ how much	Tailoring	Modification	How well planned
Ashori et al., 2019	Parent Training Programme (Triple P)	The behaviour training therapy based on social learning theory of Bandura, gives an insight that the programme can be used for reducing behavioural problems in children, promoting mother-child relationship, offering information about the needs of mothers and children, There is no evidence that the programme helps to improve the mental health of mothers of children with intellectual disability	Group discussion, modelling, role-play, video demonstration and behavioural rehearsal Positive parenting. Promoting child development, ineffective behaviour management	Psychologist (1)	Face to face, group and individual	School	12 sessions 80 minutes once a week	Not described	Not described	Not described
Bazzano et al., 2013	Mindfulness Based Stress Reduction (MBSR) programme	Few studies have assessed the effect of MBSR programmes for parents and caregivers of those with DD. For example, Singh et al. (2007) used 4 parents of children with DD which may limit the ability to draw conclusions	Teaching mindful meditation practices, gentle yoga, mindfulness and stress theory discussion. Practices comprises awareness of breathing, body scan, loving kindness intention practice	MBSR teacher	Face to face, group and individual	Community	8 weeks 2-hour session 4-hour silent retreat	Not described	Not described	A committee (parents of children with DD, researchers and staff from mindfulness institute/ community-based organization) planned and the following; *free CDs *duration of class/ in-home practice decreased *incentive of child care *taxi voucher *simultaneous Spanish translation 76 participants were recruited 66 participants (87%) completed

Brookman-Fraaze et al., 2021	An Individualized Mental Health Intervention for Autism Spectrum Disorder (AIM HI)	Evidenced based strategies aimed to reduced challenging behaviours in children with ASD aged 5 to 13	Introductory training workshop involved didactic lecture, video examples, planning Consultation meetings with expert trainer involved modelling, behavioural reinforcement and in-home practice Therapist manual printed and electronic forms	AIM HI therapists	Face to face	Community	6 months 11 sessions (9 group sessions, 2 individual sessions) 1 hour per session	Not described	Not described	Families were given gift cards worth $40 at the initial assessment and $25 during subsequent interviews.
Callanan et al., 2021	Parent-Child Relationally Informed Early Intervention (PCRI-EI)	To simplify the application of constructs such as insightfulness, reflective functioning, parent embodied mentalizing, active imitation, intensive interaction and circle of security with the aim of expanding the list of parents as well as clinicians to address the challenges involved in parenting a child with DD		Psychologist, speech pathologist, occupational therapist or physiotherapist	Face to face	Clinic	12-week treatment block	High complexity involving multiple therapist programme done weekly Low complexity involving single therapist, programme done fortnightly	Not described	Not described
Dindar et al., 2016	Spiritual Self Care Training	Guided by Richard and Berginil religious spiritual strategies and Islam's in areas such as self-awareness, invocation, reliance, patience, forgiveness and praise aimed at managing the psychological needs and helping the adaptation of mothers of children with mental retardation	All participants received training on communicating with God and listening to inner voice, the word of God or any higher power that the mother believes in, trust in God, the history of religious figures, communicating with sanctities, prayer, sacrifice, penance and charity, gratitude and thanksgiving	One Educator (religious authority)	Face to face	Clinic	Six 45-minute sessions, for a 2-week period every other day (3 sessions on the even days of the week on morning work shift)	Not described	Not described	Not described
Dykens et al., 2014	Mindfulness Based Stress Reduction (MBSR) programme	Use of peer mentors to lead group interventions in a community setting which may reduce cost and reach out to at risk mother who ordinarily may not have access, with the peer mentors	Includes breathing, meditation and movement techniques, self-observation without self-evaluating, the sitting body scan and loving kindness mediation.	Four peer mentors (well-trained mothers of children with disabilities)	Face to face; group; individual	Community	6 weeks of group treatment in 1.5-hour weekly sessions	Not described	Not described	High treatment fidelity was ensured by clinical supervisors based on the following accepted criteria:

		taking advantage of the parent-to-parent rapport that exist among them	Curriculum available at: www.vanderbilt.edu/cttc/							*preparing the rooms and materials for the meetings *adhering to the lesson and its content on weekly basis *ensuring participants understood materials *reviewing homework *properly collecting data. High recruitment was ensured by providing: *intervention during the day or evening in community setting easily accessible *onsite child care for child with disability and sibling
Iida et al., 2018	Parents Skills Training Programme	The programme was based on Hizen Parenting Skills Training which dwells on social learning theory, principles of operant theory and behaviour modification focusing on equipping mothers to learn parenting and coping skills against the problem behaviours of their children with ASD	Lecture on behaviour therapy, individual consultation, group workshop Homework sheet for mothers to record child's behaviour and mothers' responses to those behaviours	Psychologists/doctors	Individual consultation Group workshop	Community and clinical settings	Sessions 1-7 were held every 2 weeks for 3 months	Not described	Not described	Not described
Jones et al., 2018	Mindfulness Based Wellbeing for parents (MBW-P) programme	Pilot evaluate a mindfulness programme specifically tailored/designed to examine its impact on parents' positive and negative outcomes	Mindfulness practice exercise, reflection period on practices, orientation to home practices CDs of short practices	Mindfulness teacher	Face to face	School (one specialist autism school and two ID special schools)	8 weeks 2-hour session weekly	Not described	Not described	Decrease of practice time from 30-45 minutes to 5-20 minutes

										Telephone support by the mindfulness teacher to participants if the need be Contact of participants who become distressed during sessions
Lodder et al., 2020	SOLACE	The use of multiple components like psychoeducation, cognitive restructuring strategies and compassion focused techniques to reduce the effects of stigma and improve the health needs of parents and carers of autistic children	Lecture Group discussion Guided activities Sharing of experiences Video material of parents of autistic children talking about way of coping (http://autism.sesamestreet.org/) Instructions on how to join Facebook page Instructions on how to use the video conferencing programme (Zoom)	Facilitators (2) Main-A PhD student with experiences in working with families of autistic children Assistant-Masters student of Health Psychology	Face to face, video conference	Not described	8 weeks	Not described	Not described	Face to face session (only sessions 1, 4 and 8) More video conference sessions (2, 3, 5, 6, and 7) Secret Facebook group only accessible to the experimental group was used to support the intervention group where participants could ask questions and share experiences Done to increase recruitment and adherence
Lo et al., 2017	Brief Mindfulness Based programme	A low intensity parenting programme that will reduce parental stress and be attractive to parent caregivers who are busy with their caregiving roles as well as their house duties	Body scan, mindfulness stretching, mindful sitting, loving kindness exercise, informal practice and psychoeducation	Two instructors with training in MBSR and MBCT	Face to face	Not described	6 weeks Each session 1.5 hours	Not described	Not described	Audio recording of all sessions Instructors were assessed using MB Intervention Teaching Assessment Criteria Scale

										Attrition was only 7.7% and attendance 83.0%
Mills et al., 2021	CARES programme	A programme focusing on the social, emotional or psychological challenges among caregivers of children with autism	Progress check, mindfulness exercise, relaxation exercise, psychoeducation, discussion, interactive activities	Peer facilitators (volunteers form the community supervised by a physician)	Face to face, group	Not described	Six weeks, 1 hour per week	Not described	Not described	Not described
Millstein et al., 2020	Virtual Mindbody Resilience intervention	Multimodal mind body intervention that targets resiliency and relaxation to decrease distress and increase growth enhancement	Breath awareness, body scan, mindful awareness, guided imagery, yoga, brief mindfulness activities	Clinical psychologist	Virtual synchronous groups	Not described	8 weeks, 1.5 hours weekly sessions	Not described	Not described	Not described
Moghimi et al., 2018	Resilience Teaching	A resilience teaching via short message service (SMS) that will reduce the stress of mothers of educable mentally retarded children	the concept of resilience, the characteristics of resilient people, internal and external support factors, and familiarity with methods of resilience creation	Nurses	SMS	Not described	1.5 months 4 text message a day	Not described	Not described	Not described
Neece, 2014	Mindfulness-Based Stress Reduction	Though several studies have been conducted on MBSR, its efficacy for reducing stress in parents of young children with developmental delays is	Didactical material on mindfulness, stress and anxiety Audio CDs with instruction Mindfulness exercise Discussion	MBSR instructor	Face to face	Not described	8 weeks 2-hour session per week	Not described	Not described	Not described
Soffronof et al., 2011	Stepping Stones Triple Seminars	a time efficient, cost-effective parenting intervention for parents of a child with a disability to reduce child behaviour problems, decrease dysfunctional parenting styles, improve parenting satisfaction and parental efficacy, and lower levels of conflict over child-rearing	printed version of the presentation, SSTP Tip Sheet The Power of Positive Parenting, Raising Confident, Competent Children	Not described	Face to face	Not described	6 weeks 2 seminars 90 minutes each	Not described	Not described	Not described
Suzuki et al., 2014	Brief group psychoeducational programme	Few studies have shown the effectiveness of family interventions for PDD in Japan in improving parental mental health and behaviour of children. Brief	Lecture Handout	Psychiatrist Nurses Psychologist Speech pathologists Social worker	Face to face	Not described	4 sessions 120 minutes every second week	Not described	Not described	Ensuring attendance of trained therapists at all the interventional sessions

		Psychoeducation programme based on McFarlance Model, the evidence-based practices toolkit for family Psychoeducation and the standard model of the Japanese Network of Psychoeducation and Family Support Programme								
Ullas et al., 2021	Yoga	No studies on the use of yoga as a complementary therapy, on mothers of children with mental illness as it has been shown to alleviate anxiety, depression, stress and improve quality of life and sleep	Physical postures, breathing techniques, yoga-based relaxation techniques and meditation	Certified yoga expert	Face to face	Community	1.5 hours every other day for 1 month	Not described	Not described	Not described
Vijayasamundeeswari et al., 2020	Stress Management Training	Use of cognitive behaviour method to reduce stress among parents	Stress management techniques Relaxation techniques	Not described	Face to face	Not described	10 sessions 60 minutes	Not described	Not described	Not described
Wong et al., 2010	Cognitive behavioural group therapy	Providing a CBT designed and tailored (focusing on less ambiguity, structured counselling sessions and directive therapist approach) to meet the needs of Chines parents with poor mental health who were at risk of developing mental health problems	Alarm signals, thought stopping, disputing question, distraction, positive self-statement/cue cards, the auction game-game of life.	Mental health social worker (2) Clinical psychologist (1)	Face to face	Not described	10 sessions 3 hours per session	Not described	Not described	Independent reviewers reviewed the video tapes using a check list of tasks to be completed developed by the researchers. There was no disagreement between the reviewers on the task to be completed by the group leaders

The TIDieR checklist in Table 5.9 reported on variables such as type of intervention, materials and procedure, the person who delivered the intervention, how the intervention was delivered, where the intervention was done, tailoring, modification, and how well planned the intervention was.

5.6.10 Outcomes in the studies used in the scoping review

The studies included in the scoping review reported on a wide range of outcomes; however, the study limited its report to those relating to well-being. Table 5.10 provides the outcome measures reported by the various studies included in the scoping review:

Table 5.10 Well-being related outcomes

Authors	Stress	Anxiety	Depression	Physical health/ somatic symptoms	Social function/ support	Burden/strain
Ashori et al., 2019		✓	✓	✓	✓	
Bazzano et al., 2013	✓			✓		
Brookman-Fraaze et al., 2021						✓
Callanan et al., 2021	✓					
Dindar et al., 2016						✓
Dykens et al., 2014	✓	✓	✓	✓		
Lida et al., 2018		✓	✓			
Jones et al., 2018	✓	✓	✓			
Lodder et al., 2020					✓	
Lo et al., 2017	✓		✓			
Mills et al., 2020	✓	✓	✓			
Millstein et al., 2020				✓		
Moghimi et al., 2018	✓					
Neece, 2014	✓		✓			
Soffronof et al., 2011	✓	✓	✓			
Suzuki et al., 2014		✓				
Ullas et al., 2021	✓	✓	✓	✓		
Vijayasamundeeswari et al., 2020	✓					
Wong et al., 2010	✓					

Details on the outcomes as shown in table 5.10 are as follows: stress (n=12), anxiety (n=7), depression (n=9), physical health/somatic symptoms (n=5), burden/strain (n=2) and social support (n=2).

5.6.11 Quality assessment

Quality assessment of the data is not part of the processes involved in a scoping review as compared to a systematic review (Armstrong *et al.,* 2011), which is seen as a limitation according to Arksey and O'Malley (2005). The Joanna Briggs Institute (2015) emphasises that the non-inclusion of quality assessment in a scoping review could limit its practical usefulness. Although some authors have argued whether or not a quality assessment is needed in this type of study, no further recommendations have been made to date (Pham *et al.*, 2015). Daudt, Van Mossel and Scott (2013) posited that quality assessment should be performed. The studies included in the scoping review were either quasi experimental designs or randomised control trials, thus, the JBI Critical Appraisal Checklists for quasi-experimental studies and RCTs were used for assessing methodological quality.

5.6.11.1 Quality assessment of the quasi-experimental design of studies included in the scoping review

Table 5.11 indicates that nine studies included in the scoping review used quasi-experimental designs, and the JBI Critical Appraisal Checklist for quasi-experimental studies was used to evaluate the studies. Details are provided in Table 5.11

Table 5.11 JBI Critical Appraisal Checklist for Quasi-Experimental Studies

Critical Appraisal Checklist	Ashori et al., 2019	Bazzano et al., 2013	Callanan et al., 2021	Dindar et al., 2016	Lida et al. 2018	Jones et al., 2018	Mills et al. 2020	Vijayasamundeeswari et al., 2020	Ullas et al., 2021
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Were the participants included in any comparisons similar?	Yes	Yes	Yes	Not clear	Yes	Yes	Yes	Yes	Yes
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Was there a control group?	Yes	No	No	Yes	No	No	No	No	Yes
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	No	No	Yes	Not clear	No	Yes	Yes	No	No
7. Were the outcomes of participants included in any comparisons measured in the same way?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
8. Were outcomes measured in a reliable way?	No	No	Yes	No	No	No	Yes	No	No
9. Was appropriate statistical analysis used?	Yes	Not clear	No	No	Yes	Yes	Yes	No	No

Table 5.11 indicates that the cause (intervention) is described by all the studies (n = 9) and the effects on the dependent variables are observed. The description of the participants in the comparison group was similar for all studies, with the exception of Dindar *et al.* (2016), who reported that the participants were similar on most variables, including caregiver strain, occupation, and income, yet they differed on marital status. All the studies reported that the participants received similar treatment other than the exposure or intervention of interest. Only three studies had a control group (Dindar *et al.*, 2016; Ashori, Norouzi & Jalil-Abkenar, 2019; Ullas *et al.*, 2021).

All the studies reported multiple assessments; at least each of them reported pre-test and post-test assessments. Four studies reported three assessment measurements (Bazzano *et al.*, 2013; Dindar *et al.*, 2016; Iida, Wada, Yamashita, *et al.*, 2018; Callanan, Signal & Mcadie, 2021). Only two studies reported the reliability of the instrument used for assessment (Callanan, Signal and Mcadie, 2021; Mills *et al.*, 2021). Two studies described incomplete follow-up and the number of participants as well as the reason for loss (Jones *et al.*, 2018; Mills *et al.*, 2021) while one (Callanan, Signal and Mcadie, 2021) reported that all participants completed the study. For example, Jones mentioned that four people did not complete the study, citing time constraints and family bereavement. Bazzano *et al.* (2013) reported that 87% completed the pre-test and post-test but further details were not provided. Outcomes of participants included in the comparison were measured in the same way for all the studies (n=9). Four studies did not provide details on the assumptions of statistical tests, statistical power analysis, and objective of statistical analysis(Bazzano *et al.*, 2013;Dindar *et al.*, 2016; Vijayasamundeeswari, Sathiya & Poongodi, 2020; Callanan, Signal & Mcadie, 2021; Ullas *et al.*, 2021).

5.6.11.2 Quality assessment of RCTs of studies included in the scoping review

Table 5.12 indicates that ten studies reported using Randomized Control Trials (RCT), however, one was a secondary analysis of an RCT. Details are provided in Table 5.12.

Table 5.12 JBI Critical Appraisal Checklist for Randomized Control Trials

Critical Appraisal Checklist	Brookman et. al.,	Dykens et al., 2014	Lodder et al., 2020	Lo et al., 2017	Moghimi et al., 2018	Neece, 2014	Soffronof et al., 2011	Suzuki et al., 2014	Wong et al., 2010
1. Was true randomization used for assignment of participants to treatment	Yes	Yes	Yes	Not	Yes	Yes	Not	Yes	Not
2. Was allocation to treatment groups concealed?	No	No	Not	No	No	No	No	Yes	Not
3. Were treatment groups similar at the baseline?	Yes	Yes	Not	Yes	Yes	Yes	Yes	Yes	Yes
4. Were participants blind to treatment assignment?	No	No	No	No	No	No	No	No	No
5. Were those delivering treatment blind to treatment assignment?	No	No	No	No	No	No	No	No	No
6. Were outcomes assessors blind to treatment assignment?	No	No	No	No	No	No	No	No	No
7. Were treatment groups treated identically other than the intervention of	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
8. Was follow up complete and if not, were differences between groups in	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
9. Were participants analyzed in the groups to which they were randomized?	Yes	No	Yes	No	No	No	No	Yes	No
10. Were outcomes measured in the same way for treatment groups?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
11. Were outcomes measured in a reliable way?	Yes	No	Yes	Yes	No	Yes	Yes	No	Yes
12. Was appropriate statistical analysis used?	Yes	Yes	Yes	Yes	Yes	Not	No	Yes	Yes
13. Was the trial design appropriate, and any deviations from the standard	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 5.12 indicates that all the studies used the appropriate trial design. Randomization and other details were not provided in the study (Millstein *et al.*, 2020); thus, nine studies were assessed using the JBI Critical Appraisal Checklist for RCTs. However, four did not specify how the randomization was done (Wong & Poon, 2010; Sofronoff, Jahnel and Sanders, 2011; Lo *et al.*, 2017; Moghimi *et al.*, 2018). The other studies specified how randomization was done, for example, n (4) reported that randomization was done using a computer-generated allocation (Dykens *et al.*, 2014; Suzuki *et al.*, 2014; Lodder, Papadopoulos & Randhawa, 2020; Brookman-Frazee *et al.*, 2021). One study reported that randomisation was done as participants were asked to draw a piece of paper from a box, which would indicate whether they belonged to the treatment or control group (Neece, 2014).

Concealment of allocation was not reported in six studies. Two studies were not clear on whether concealment was done or not. Lodder, Papadopoulos and Randhawa (2020) and Wong and Poon (2010) mentioned that an independent researcher and statistician were involved. Suzuki *et al.* (2014) were the only study to report on the concealment of allocation. Eight studies reported that the groups were similar at baseline, though in one of the studies it was not clear. At baseline, the intervention group had a significantly higher score on self-blame and perceived social support than the control group (Lodder, Papadopoulos & Randhawa, 2020).

All studies (n = 9) reported that participants were not blind to the assignment, those delivering the treatment were not blind to the treatment assignment, outcome assessors were not blind to treatment, treatment groups were treated identically other than the intervention group and outcomes measures were measured the same way as for the treatment groups

In terms of complete follow-up, Lodder, Papadopoulos and Randhawa (2020) reported that all participants recruited in the intervention were able to complete. The description of loss to follow-up and the description of the reasons for loss to follow up were done by seven studies. Three studies did not provide details on the loss to follow-up. For example, Lo *et al.* (2017) reported that 7 participants dropped out of the intervention group (attrition of 7.7%) but no further details were provided. Only three studies (n = 3) reported on the intention-to-treat (Suzuki *et al.*, 2014; Lodder, Papadopoulos and Randhawa, 2020; Brookman-Frazee *et al.*, 2021) with most not reporting (n = 6).

Reliability of the instruments used for measuring the outcome variable was reported in most of the studies (n = 6) with only three not reporting (Dykens *et al.*, 2014; Suzuki *et al.*, 2014; Moghimi *et al.*, 2018). Assumptions of statistical tests, statistical procedures, and the objective of statistical analysis were reported in seven studies; two studies did not provide such details (Sofronoff, Jahnel & Sanders, 2011; Neece, 2014).

5.7 ANALYSIS OF THEMES

In this study, coding and categorization were done in analysing the interventions or programmes used by other researchers to improve the health outcomes of caregivers of children with DD (described in Chapter 3, section 3.9.2.2). A summary of the various themes and sub-themes is presented in Table 5.13.

Table 5.13 Themes and sub-themes from analysed data

Theme	Sub-theme	Number of articles
Type of intervention	Mindfulness-based interventions	5
	Parent training interventions	5
	Cognitive behavioural interventions	5
	Resilience-based interventions	2
	Spirituality-integrated interventions	2
	Exercise-based intervention	1
Duration of intervention	Less than a month	1
	1-2 months	11
	2.5-3 months	6
	More than 3 months	1
Expert in delivery of intervention	Health professionals	6
	Peer mentors/facilitators	2
	Intervention experts	5
	Others	2
Mode of delivery of intervention	Face-to-face	16
	Virtual	2
	Mixed method (face-to-face/online)	1

Theme	Sub-theme	Number of articles
Effect of the intervention	Changes in psychological well-being	
	Stress	12
	Anxiety	7
	Depression	9
	Changes in physical well-being	5
	Changes in social-well-being	2
	Changes in caregiver burden	2

Table 5.13 indicates, five main themes and ten sub-themes were generated from the analysis of the studies.

5.7.1 TYPE OF INTERVENTION

5.7.1.1 Sub-theme 1: Mindfulness-based interventions

Five studies used mindfulness approaches as interventions to improve the wellbeing of caregivers of children with DD. Three of the studies used Mindfulness Based Stress Reduction [MBSR] programmes (Dykens *et al.*, 2014; Neece, 2014; Bazzano *et al.*, 2013). One of the studies, used Brief Mindfulness (Lo *et al.*, 2017) and the other used Mindfulness Based Well-being Parenting [MBPW] (Jones *et al.*, 2018). Regardless of the intensity and focus of the mindfulness programme, certain constructs were found among them. The concept of mindfulness was explained to the participants of the various studies (Neece, 2014; Bazzano *et al.*, 2013; Lo *et al.*, 2017; Jones *et al.*, 2018). Additionally, the mindfulness intervention emphasised the psychology and physiology of stress, thus, how the body and mind are involved in the reaction and responding to stress (Neece, 2014; Lo *et al.*, 2017). Furthermore, four out of the five interventions highlighted the development of loving-kindness and compassion in their participants (Dykens *et al.*, 2014; Bazzano *et al.*, 2013; Lo *et al.*, 2017; Jones *et al.*, 2018). Breathing exercises and body scans were mentioned in all the studies (Bazzano *et al.*, 2013; Dykens *et al.*, 2014; Neece, 2014; Lo *et al.*, 2017; Jones *et al.*, 2018).

5.7.1.2 Sub theme 2: Parent training programmes

Five studies focused on interventions or programmes that were related to providing training for the parents of children with DD (Sofronoff, Jahnel & Sanders, 2011; Iida, Wada, Yamashita, *et*

al., 2018; Ashori, Norouzi & Jalil-Abkenar, 2019; Brookman-frazee *et al.*, 2021; Callanan, Signal and Mcadie, 2021). The studies had a similar focus, which was to empower caregivers or parents to have the requisite skills, knowledge, and attitude to care for their children with DD. Three of the studies highlighted problem behaviours exhibited by children with DD. For example, Iida, Wada, Yamashita, *et al.* (2018) emphasised how parents could reduce problem behaviours. Ashori, Norouzi and Jalil-Abkenar (2019) on the other hand, looked at the causes of problem behaviours and strategies that could be employed by caregivers to manage ineffective behaviours. Brookman-Frazee *et al.* (2021) focused on identifying the functions of problem behaviour. One other focus, of the parent-training programmes was teaching the child important skills. Sofronoff, Jahnel and Sanders (2011) focused on strategies that could be used to teach the child communication and problem-solving skills.

Ashori, Norouzi and Jalil-Abkenar (2019) emphasised strategies for teaching the child new behaviours, while Brookman-Frazee *et al.* (2021) were concerned about skill-building in the child with DD. In terms of helping the child develop skills, Ashori, Norouzi and Jalil-Abkenar (2019) highlight that it needs to start with having a positive relationship with the child, which could be done by using strategies including talking to the child, having fun, allocating useful time to the child. Similarly, Callanan, Signal and Mcadie (2021) emphasised the use of play to develop skills in children with DD. Closely related to problem behaviour and teaching the child important skills is observing the child's behaviour, which was reported by Ashori, Norouzi and Jalil-Abkenar (2019) and Iida, Wada, Yamashita, *et al.* (2018). Finally, two studies highlight the use of reinforcement to help the child improve on positive and desirable behaviours (Iida, Wada, Yamashita, *et al.*, 2018; Ashori, Norouzi & Jalil-Abkenar, 2019).

5.7.1.3 Sub theme 3: Cognitive-behavioural interventions

Five studies focused on cognitive-based programmes for caregivers of children with DD (Wong and Poon, 2010; Suzuki *et al.*, 2014; Lodder, Papadopoulos and Randhawa, 2020; Vijayasamundeeswari, Sathiya and Poongodi, 2020; Mills *et al.*, 2021), and some constructs were common through these interventions. Three studies highlighted stress. Wong and Poon (2010) were concerned about responding to stressful events. Vijayasamundeeswari, Sathiya and Poongodi (2020) emphasised on causes of stress and the response to factors causing stress. Mills *et al.* (2021)

on the other hand, emphasised stress education. In addition to the above, the interventions focused on being aware of dysfunctional, automatic, and negative thoughts and behaviours (Wong and Poon, 2010; Lodder, Papadopoulos and Randhawa, 2020; Vijayasamundeeswari, Sathiya and Poongodi, 2020; Mills *et al.*, 2021) and how to deal with them using cognitive behaviour strategies (Wong and Poon, 2010), cognitive restricting skills with psychoeducation (Mills *et al.*, 2021), replacement of illogical thoughts (Vijayasamundeeswari, Sathiya and Poongodi, 2020), psychoeducation (Lodder, Papadopoulos and Randhawa, 2020). Mills *et al.* (2021) and Suzuki *et al.* (2014) both emphasised problem solving skills. Two studies, Mills *et al.* (2021) and Lodder, Papadopoulos and Randhawa (2020) included self-compassion in their interventions. Social support related issues were highlighted in three studies. For example, Lodder, Papadopoulos and Randhawa (2020) emphasised importance of social support for participants receiving the SOLACE intervention and how it could be utilised or improved. Suzuki *et al.* (2014) on the other hand, emphasised information on social support resources. Vijayasamundeeswari, Sathiya and Poongodi (2020) also included social support in the intervention.

5.7.1.4 Sub-theme 4: Resilience based interventions

Millstein, Lindly, Luberto, Perez, *et al.* (2020) and Moghimi *et al.* (2018) focused on resilience, while the former do not provide adequate details of the components of the resilience, the later emphasised method of resilience creation, awareness of internal and external factors of resilience.

5.7.1.5 Sub-theme 5: Spirituality-integrated Programmes

Only one study fell under this category (Dindar *et al.*, 2016). The components of the intervention included self-awareness, patience, forgiveness, trust, invocation and praise. Self-awareness involved communicating with God and listening to inner voice. Invocation focused on the word God or a higher power that the caregiver had faith in. Trust dealt with trusting in God and resorting to him. Patience involved the history of religious figures. Forgiveness highlighted on communicating with sanctities, prayer, sacrifice, penance, and charity. Praise involved gratitude and thanksgiving.

5.7.1.5 Sub-theme 5: Mind-body programmes

Ullas *et al.* (2021) used a mind-body programme for caregivers of children with mental disabilities. The components included physical postures (asanas), breathing techniques (pranayama), yoga-based relaxation techniques and meditation.

5.7.2 DURATION OF THE INTERVENTION

Data from the various studies included in this scoping revealed that the duration of intervention ranged from two weeks to six months. Only one study was conducted over two weeks (Dindar *et al.*, 2016) and the other four weeks (Ullas *et al.*, 2021). Four interventions or programmes lasted for six weeks (Dykens *et al.*, 2014; Lo *et al.*, 2017; Moghimi *et al.*, 2018; Mills *et al.*, 2021). Six interventions lasted for 8 weeks (Bazzano *et al.*, 2013; Neece, 2014; Suzuki *et al.*, 2014; Jones *et al.*, 2018; Lodder, Papadopoulos & Randhawa, 2020; Millstein, Lindly, Luberto, Perez, *et al.*, 2020). Two programmes lasted for ten weeks (Wong & Poon, 2010; Vijayasamundeeswari, Sathiya and Poongodi, 2020). Two programmes were ran for 12 weeks (Iida, Wada, Yamashita, *et al.*, 2018; Callanan, Signal & Mcadie, 2021). It was only one intervention that was provided for a period of six months (Brookman-Frazee *et al.*, 2021). Regardless of the duration of the intervention, all studies reported that the programmes, interventions or trainings led to improvements in the well-being of the caregivers.

5.7.3 DELIVERY OF INTERVENTION

Almost all the interventions were delivered face to face (n = 16) and two were delivered virtually (Moghimi *et al.*, 2018; Millstein, Lindly, Luberto, Giselle, *et al.*, 2020). Only one used a blended approach, where some of the sessions were held face-to-face and others virtually (Lodder, Papadopoulos & Randhawa, 2020). According to Lodder, Papadopoulos and Randhawa (2020), the participants mentioned after the programme that, they preferred the virtual sessions over the face to face sessions. Most of the interventions were carried out by health professionals: psychologists (Wong and Poon, 2010a; Suzuki *et al.*, 2014; Iida, Wada, Yamashita, *et al.*, 2018; Ashori, Norouzi and Jalil-Abkenar, 2019; Millstein, Lindly, Luberto, Perez, *et al.*, 2020; Callanan, Signal and Mcadie, 2021); nurses (Suzuki *et al.*, 2014; Moghimi *et al.*, 2018); psychiatrists, speech therapists and pathologists (Suzuki *et al.*, 2014). Other professionals included social

workers (Wong and Poon, 2010; Suzuki *et al.*, 2014). Some studies used professionals who had received training in the delivery of that particular intervention (Bazzano *et al.*, 2013; Lo *et al.*, 2017; Jones *et al.*, 2018). Two studies used peer mentors in the delivery of the intervention (Dykens *et al.*, 2014; Mills *et al.*, 2021).

5.7.4 EFFECT OF THE INTERVENTION ON THE CAREGIVERS' OUTCOMES

All the interventions reported changes in the caregiver wellbeing in one way or another. Though, Suzuki *et al.* (2014) failed to confirm the effectiveness of a brief group psychoeducational programme for mothers of children with high functioning pervasive developmental disorder in an RCT, the authors attributed it a small number of sessions, the selection of assessment measures, sample size calculation, the contents and quality of programmes and controlling bias. In that particular study, the participants in the control group reported better outcomes. For example, at baseline, the mean scores of the control group were higher than those of the treatment/intervention group on the GHQ (9.08 > 8.56). After the intervention, however, the treatment group reported poorer/ declining health [6.92 ± 5.34] than the control group [9.19 ± 6.95].

Suzuki *et al.* (2014) and Wong and Poon (2010) measured mental health in general, while Callanan et al. (2021) measured psychological well-being. Hence, it was difficult to determine the specific aspects of mental health. For example, in a quasi-experiment by Callanan, Signal and Mcadie (2021) among 22 parents of children with disabilities, the psychological wellbeing scores as measured by the Kessler Psychological Well-being scales indicated differences existed between the baseline, post-intervention and follow-up scores. The difference was statistically significant. Lodder, Papadopoulos and Randhawa (2020) also measured the mental health of parents using a 5-item Mental Health Inventory of the SF-36. The findings of the study revealed that the mean pre-test score, post-test and follow-up scores (45.78, 53.78 and 60.00 respectively) for the intervention group had improved following the SOLACE programme. The control group mean scores were 49.00, 56.57, 58.50 for the pre-test, post-test and follow-up. The differences between the groups was statistically significant ($p < 0.05$). Wong et al. (2020) measured the mental health of Chinese parents of children with DD using the GHQ. Significant differences existed between the intervention and control group after CBT ($p = 0.00$). Other studies were specific in which areas of well-being they were concerned about. Some looked at stress (Bazzano *et al.*, 2013; Dykens *et*

al., 2014; Jones *et al.*, 2018; Callanan, Signal and Mcadie, 2021), others were concerned with anxiety (Dykens *et al.*, 2014; Iida *et al.*, 2018; Jones *et al.*, 2018; Ashori, Norouzi and Jalil-Abkenar, 2019), and others focused on depression (Sofronoff, Jahnel & Sanders, 2011; Dykens *et al.*, 2014; Ashori, Norouzi and Jalil-Abkenar, 2019; Mills *et al.*, 2021; Ullas *et al.*, 2021).

5.7.4.1 Changes in psychological well-being: Stress

Twelve studies reported on stress levels improving among caregivers after going through the various intervention programmes. Bazzano *et al.* (2013) conducted a feasibility study to measure the effects of the MBSR programme on stress, mindful awareness, self-compassion and psychological wellbeing. Stress levels were measured using the parental stress scale and the perceived stress scale. The findings of the study revealed that there was a significant improvement in the level of perceived stress immediately after the intervention and during the 2- month follow-up. The researchers found, a 22% reduction in parental stress ($p < 0.001$) and a 33% reduction in perceived stress ($p < 0.001$). The researchers concluded that community-based MBSR is feasible and a potentially effective intervention for reducing stress and improving other stress related outcomes.

In accordance with the above, Callanan, Signal and Mcadie (2021) in a quasi-experimental study, after administering a PCRI-EI programme for a period of 12 weeks, the overall stress levels as indicated by the scores on the Parenting Stress Index reduced, and the differences were not only statistically but also clinically significant [T1 and T2 (0.000), T2 and T3 (0.001), T1 and T3 (0.000)]. Similarly, Dykens *et al.* (2014) in a study involving 243 mothers, randomly assigned them either to the MBSR programme or the Positive Adult Development programme. The programme ran for six weeks after the initial assessments were taken. They concluded that though both treatments led to significant reductions in stress, MBSR offered a greater advantage.

In a brief mindfulness-based programme for parents of preschool children with DD, the results after completion of the six-week programme indicated a significant improvement in parental stress score on the Parenting Stress Index Short Form. The mean score for the intervention group at the pre-test was 118.88 ± 19.11 and at the post-test was 112.40 ± 19.45. The control pre-test and post-test mean scores were 119.55 ± 22.43 and 117.74 ± 21.02. The differences were significant ($F [1,176] = 4.76$, $p = 0.03$) (Lo et al., 2017). Jones et al. (2018) using the stress subscale of the DASS

to measure the stress levels of 21 caregivers before and after the MBSR intervention indicated changes. The mean baseline [T1] and post-intervention scores [T2] were 12.74 ± 4.27 and 10.53 ± 4.75 respectively. The difference was statistically significant (0.031).

Mills *et al.* (2021) reported that for scores on the stress scale subscale of the DASS, 54% of participants indicated clinically significant stress levels before the intervention, thus, decreased to 35% after the intervention ($X^2 = 9.00$, $p = 0.004$). In another study, the stress score on the Parenting Stress Index (PSI) was 126 ± 23.9 and 129.39 ± 21.8 in the intervention and control groups before being taught resilience through SMS for six weeks. After the intervention, the stress scores were 86.08 ± 18.5 and 135.2 ± 23.1 for the intervention and control groups. The difference was statistically significant ($p < 0.05$) (Moghimi *et al.*, 2018).

5.7.4.2 Changes in psychological well-being: anxiety

Seven studies reported changes in the anxiety levels of participants. Some studies reported statistically significant changes after the intervention (Moghimi *et al.*, 2018; Ashori, Norouzi and Jalil-Abkenar, 2019; Mills *et al.*, 2021) while others did not reach such a conclusion (Iida, Wada, Yamashita1, *et al.*, 2018; Jones *et al.*, 2018). Ashori, Norouzi and Jalil-Abkenar (2019) in a quasi-experimental design sought to examine the effectiveness of the Positive Parenting Programme on the mental health of mothers of children with ID. The programme was conducted over 12 sessions, and the anxiety subscale of the GHQ was used to assess the anxiety level. The mean pre-test and post-test scores for the intervention group were 10.15 ± 1.12 and 7.05 ± 1.01 respectively. The pre-test scores for the control group was 10.15 ± 1.20 while the post-test score was 10.00 ± 0.99. The differences between the groups were statistically significant [$p = 0.001$].

Another study reported that, based on the scores on the anxiety subscale of the DASS, 73% of the participants had clinically significant levels of anxiety at the pre-test stage. After going through the CARES programme for 6 weeks, only 35% indicated clinically significant anxiety levels [$X^2 = 22.15$, $p < 0.001$] (Mills *et al.*, 2021). In another study, the stress score on the Parenting Stress Index (PSI) was 126 ± 23.9 and 129.39 ± 21.8 in the intervention and control group before being taught resilience through SMS for six weeks. After the intervention, the stress scores were 86.08 ± 18.5 and 135.2 ± 23.1 for the intervention and control groups. The difference was statistically significant ($p < 0.05$) (Moghimi *et al.*, 2018).

A study by Iida *et al.* (2018) indicated that the pre-test scores of trait anxiety and state anxiety were 53.3 ± 8.4 and 50.6 ± 10.7 respectively. After going through the Parent training programme which lasted for 12 weeks, the mean score reduced to 47.7 ± 9.5 for trait and 46.9±12.7 for state anxiety. The difference between the pre-test and post-test score for state anxiety was not significant (P = 0.2). However, the difference for trait anxiety was statistically significant (p = 0.009). Jones *et al.* (2018) assessed anxiety using the anxiety subscale of the HADS before and after parents of children with autism and related disabilities had gone through a MPWB course for 8 weeks. The mean pre-test and post-test scores were 11.55 ± 3.62 and 10.55 ± 4.02 respectively, however, the difference was not statistically significant (p = 0.204).

5.7.4.3 Changes in psychological wellbeing: depression

Nine studies reported on depression, with some concluding the interventions had a statistically significant improvement on depression (Lo *et al.*, 2017; Ullas *et al.*, 2021) while others did not (Sofronoff, Jahnel & Sanders, 2011). Ullas *et al.* (2021) using a quasi-experimental design, provided Yoga intervention to mothers of children with mental disabilities. The level of depression was measured using the depression subscale of the HADS prior to the yoga intervention; the mean baseline scores for the intervention and control group were 10.11 ± 1.47 and 10.16 ± 1.46 respectively. After one-month intervention, the scores decreased in the treatment group [8.5 ± 1.37] as compared to the control group [9.28 ± 1.62], which was significant (p< 0.001).

Consistent with the above, Lo *et al.* (2017) confirmed in a RCT that significant differences (p = 0.004) existed between the intervention and control groups. For example, the mean pre-test scores for both intervention and control groups were 23.24 ± 9.40 and 21.47 ± 9.96. After going through a 6-week brief mindfulness-based programme, the mean post-test scores for the intervention group decreased to 19.67 ± 8.70, while that of the control group decreased to 21.47 ± 9.96. Similarly, in a study using a quasi-experimental design, mothers of children with autism were measured on the BDI-II to assess their level of depression. The pre-test and post-test scores were 16.1 ± 8.4 and 11.9 ± 8.1, respectively, the difference was statistically significant (p = 0.01) (Iida, Wada, Yamashita, *et al.*, 2018).

On the contrary, in a study conducted by Sofronoff, Jahnel and Sanders (2011), the researchers did not find a statistically significant difference in the Depression scores on the DASS during a RCT

in which a Stepping Stones Triple P seminar was provided for parents of children with disabilities (ASD, ID, developmental delay, CP, specific learning difficulty, acquired brain injury and Maroteaux-Lamy syndrome).

5.7.4.4 Changes in physical wellbeing/ somatic symptoms

Five studies reported on the physical well-being of caregivers. Ashori, Norouzi and Jalil-Abkenar (2019) measured somatic symptoms using the GHQ and found a statistically significant difference between the intervention and control groups ($p = 0.004$). In Bazzano et al.'s study, parents and caregivers of individuals were asked to self- assess their overall physical health. The findings indicated that physical health improved after the MBSR programme, and the difference was statistically significant (Bazzano *et al.*, 2013). Dykens was more specific by measuring insomnia among caregivers using the Insomnia Severity Index. The findings indicated that there was a statistically significant improvement in sleep (Dykens *et al.*, 2014). In agreement with Dykens et al study, Millstein, Lindly, Luberto, Perez, *et al.,* (2020) observed there was improvement in sleep duration among parents of children with special needs. In the same study, the level of fatigue was also lower. Ullas *et al.* (2021) measured sleep quality using the PSQI. After the yoga intervention, the scores improved significantly. The mean baseline scores on the PSQI for the intervention and control groups were 7.11 ± 2.22 and 7.04 ± 1.14 respectively. However, after the intervention, the mean baseline scores of the intervention group decreased to 5.32 ± 1.22 whilst that of the control group decreased to 6.64 ± 1.04. While the intervention group had a 25.17% decrease, the control group had only 5.68%.

5.7.4.5 Changes in social well-being

Two studies reported specifically on the social wellbeing of the caregivers (Ashori, Norouzi and Jalil-Abkenar, 2019; Lodder, Papadopoulos and Randhawa, 2019). Ashori reported that the Parenting Programme (Triple P) had a significant effect on social dysfunction ($p=0.001$), thus, the social dysfunction of parents decreased. Lodder, Papadopoulos and Randhawa (2020) reported that the parents who took part in the SOLACE programme reported an increase in their social support scores after the programme. However, the researchers mention that the intervention group reported higher baseline scores for perceived social support than the control group. Mental health

scores were low at baseline for the intervention group; therefore, the increase in social support at baseline was not related to mental health scores.

5.7.4.6 Changes in burden or strain

Two studies reported on the burden (Dindar *et al.*, 2016; Brookman-Frazee *et al.*, 2021). Dindar *et al.* (2016) assessed the effectiveness of spiritual training on caregiver strain using a 24-item multi-dimensional caregiver burden Inventory. The pre-test, post-test and follow-up scores were 78.11 ± 21.36, 65.30 ± 13.74 and 57.23 ± 13.74 respectively for the intervention group. For the control group, the mean scores of 75.70, 75.70 and 74.23 were obtained before, immediately after and during follow-ups. The difference was statistically significant. Brookman-Frazee *et al.* (2021) provided an Individualised Mental Health Intervention for Autism Spectrum Disorder (AIM HI) to observe changes in caregiver outcomes. Caregiver strain was measured using the Caregiver Strain Questionnaire. The findings of the study revealed that, between the intervention group and the control group, no significant differences existed in their GSQ scores.

5.8 LIMITATIONS

Studies that had been selected for the scoping review, most of which cited significant limitations, including small sample size (n = 11)**,** use of self-report measures (n=19)**;** no control group (n = 6), no follow up (n = 9).

5.8.1 Small sample size

Eleven of the 19 studies reported a small sample size as a limitation. Suzuki *et al.* (2014) failed to confirm the effectiveness of a brief group psychoeducational programme for mothers of children with high functioning pervasive DD using a RCT. In their study, 72 mothers were randomly assigned to the two groups. Each group intervention had 36 participants. The researchers concluded that a larger sample size and a more rigorous approach might have led to better results. Neece (2014) used 46 mothers in an MBSR programme. They stated that there was an inability to detect a smaller effect size due to the small sample size. Lodder, Papadopoulos and Randhawa (2020) randomly assigned 9 participants to the intervention group and 8 participants to the control

group. Though the SOLACE programme showed potential effectiveness, the researchers cautioned against statistical inference because the small sample size made it statistically underpowered. In Jones et al.'s study, 21 parents were used, of which 18 were mothers and only 3 were fathers; thus, inferring positive outcomes for fathers may be inappropriate (Jones *et al.*, 2018). Generally, from the studies small sample sizes may affect generalizability (Jones *et al.*, 2018; Ashori, Norouzi and Jalil-Abkenar, 2019), determination of small effect sizes (Sofronoff, Jahnel and Sanders, 2011; Neece, 2014), and statistical power (Lodder, Papadopoulos & Randhawa, 2020).

5.8.2 Self-report measures

All the studies used self-report measures; however, only eight reported as a limitation (Sofronoff, Jahnel and Sanders, 2011b; Dykens *et al.*, 2014; Neece, 2014; Lo *et al.*, 2017; Iida, Wada, Yamashita1, *et al.*, 2018; Lodder, Papadopoulos and Randhawa, 2020). Some studies recommend the use of multiple methods for assessments or measuring outcomes. The use of self-report is not a gold standard (Sofronoff, Jahnel and Sanders, 2011), as multi-modal or multi-informant assessments are more preferable (Neece, 2014; Lo *et al.*, 2017; Mills *et al.*, 2021). The researchers propose the use of observational methods (Neece, 2014) and biomarkers (Dykens *et al.*, 2014; Neece, 2014; Lo *et al.*, 2017) such as heart rate variability and salivary cortisol (Lo *et al.*, 2017). Lodder, Papadopoulos and Randhawa (2020) reported that the ratings on self-report measures could improve just because participants are taking part in an intervention. Self-report measures could lead to reporting biases (Neece, 2014; Iida, Wada, Yamashita1, *et al.*, 2018), potential type II errors (Iida, Wada, Yamashita, *et al.*, 2018), and skewing of the results (Iida, Wada, Yamashita, *et al.*, 2018).

5.8.3 No control group

Six studies mentioned there was no control group (Bazzano *et al.*, 2013; Iida, Wada, Yamashita, *et al.*, 2018; Jones *et al.*, 2018; Vijayasamundeeswari, Sathiya and Poongodi, 2020; Callanan, Signal and McAdie, 2021; Mills *et al.*, 2021). Bazzano *et al.* (2013) did not include a control group, which, according to the researchers, could affect drawing a cause and effect relationship. Thus, it could not be strictly inferred that the difference between the intervention and the observed improvement in the outcomes was causal. Similarly, Iida, Wada, Yamashita, *et al.* (2018) observed

that the lack of a control group in their study, made it difficult to conclude if the differences between the pre-test and post-test scores were solely due to the effectiveness of the Parental training programme. In congruent with the above studies, Jones *et al.* (2018) also maintain that the observed improvements in the wellbeing of the parents of children with autism and related disabilities are difficult to attribute solely to the mindfulness intervention. This is because improvement could also occur due to group attendance, which may lead to an increased social support network.

5.8.4 No follow-up

Nine studies did not conduct follow-up assessments (Wong and Poon, 2010b; Neece, 2014; Lo *et al.*, 2017; Jones *et al.*, 2018; Ashori, Norouzi and Jalil-Abkenar, 2019; Millstein, Lindly, Luberto, Giselle, *et al.*, 2020; Vijayasamundeeswari, Sathiya and Poongodi, 2020; Mills *et al.*, 2021; Ullas, Gupta and Maharana, 2021). However, Wong et al. conducted a separate study with a six months follow-up (Wong & Poon, 2010). Mills and colleagues reported they did not follow up in their study, however, they acknowledge that to be able to determine the maintenance of the changes that were observed in the mental health of parents after going through the CARES programme, it would be appropriate to do a follow-up (Mills *et al.*, 2021).

5.9 DISCUSSION

This scoping review examined the existing studies on interventions designed to support caregivers of children with developmental disabilities. Despite the magnitude of caregivers involved in informal caregiving role, this is the first review published on the subject matter. Nineteen studies met the inclusion criteria and were all published in peer-reviewed journals from 2010 to 2021. Scoping reviews done in this area have been limited to interventions for children with disabilities (Kiling *et al.*, 2018; Lee & Meadan, 2021). Those scoping review that have looked at caregiver related issues did not specifically consider interventions to improve their well-being but rather the burden of case, impact and needs of caregiver (Ademosu *et al.*, 2021). Though one study examined interventions for primary caregivers (Fewster, Govender and Uys, 2019), but the focus was on only one aspect of well-being and was limited to caregivers of children with ASD. The distribution of studies, type of interventions, nature of assessments and delivery of interventions is discussed.

5.9.1 Distribution of studies

5.9.1.1 Geographic distribution of studies

The findings of the current study revealed that the majority of the studies were carried out in Asia and North America (a total of 11 studies). In congruent with the above, a study by Fewster, Govender and Uys (2019) found that 11 and 5 studies were conducted in the USA or Asia respectively (a total of 16 studies). Just like the current study, no study was found in Africa and Antarctica. Intervention studies are usually resource intensive, and the low socio-economic standards in Africa may have contributed to the inability of researchers to undertake such intervention studies in this part of the world (Masulani-Mwale *et al.*, 2019).

5.9.1.2 Distribution by journals

All the articles used in the scoping review were published in peer-reviewed journal. Articles published in such journals give the researcher and other readers the impression that the articles have been scrutinised; limiting the probability of having articles of poor quality and increasing the faith researchers place in such articles (Koshy *et al.*, 2018).

5.9.1.3 Distribution by year of publication

The findings indicate that seven out of nineteen studies were published between 2020 and 2021. The above shows that, researchers are becoming increasingly interested in developing interventions or training programmes to ameliorate the effect of caregiving on the caregivers of children with DD as several studies have established that caregiving is associated with negative outcomes, especially for the caregiver (Eisenhower, Blacher & Baker, 2013; Estes *et al.*, 2013; Fairthorne, De Klerk & Leonard, 2015; Gallagher & Whiteley, 2016; Minichil *et al.*, 2019).

5.9.1.4 Participants distribution

The findings of the current studies revealed that the majority of the participants were females. Women or females comparable to males, have been identified as the predominant group of persons involved in informal care (Sharma, Chakrabarti & Grover, 2016). Swinkels *et al.* (2019) posited

that women are more often than not pushed into caregiving responsibilities, possibly because of ethno-religious, economic or socio-cultural factors (Asuquo & Akpan-Idiok, 2021).

5.9.2 Assessments

5.10.2.1 Assessment instruments

Assessment instruments used to measure outcomes were all assessed for reliability and validity and were reported to be valid and reliable. Sullivan (2011) asserts that the credibility of the results of a study is dependent on how reliable and valid the instruments are. Considering the fact that they were valid and reliable, the results of their studies can be said to be credible.

5.9.2.2 Number of assessments

All studies included in the current scoping review conducted pre-test and post-test assessments. Alessandri, Zuffianò and Perinelli (2017) assert that data collection from different points in time is important in instances where the researcher is interested in evaluating the long-term effects of the programme. In terms of follow-up assessments, only nine out of the 19 studies conducted at least one or more follow-up assessments. Though follow-up assessments are important to evaluate the sustained effectiveness of the programme or intervention, several factors could affect them. Factors such as the unavailability of financial resources and participants discontinuation in research due to issues like relocation, ill health or life crises (Alessandri, Zuffianò & Perinelli, 2017).

5.9.3 Nature / types of intervention

5.9.3.1 Mindfulness-based interventions

Five studies were mindfulness-based interventions (Bazzano *et al.*, 2013; Dykens *et al.*, 2014; Neece, 2014; Lo *et al.*, 2017; Jones *et al.*, 2018). As the years go by, the use of mindfulness-based interventions is increasingly becoming popular and many researchers continue to utilise such approaches both clinically and non-clinically (Spijkerman, Pots & Bohlmeijer, 2016). Mindfulness Based Stress Reduction (MBSR) and Mindfulness Based Cognitive Therapy (MBCT) have been identified as the two most common mindfulness-based interventions (Canby *et al.*, 2021). This

was confirmed as three of the studies that used a mindfulness-based intervention employed MBSR (Bazzano *et al.*, 2013; Dykens *et al.*, 2014; Neece, 2014).

Kropp and Sedlmeier (2019) indicate that mindfulness comprises several techniques. The common techniques include body scanning, loving kindness meditation and meditative breathing (Cau et al., 2015). Body scan (Dykens *et al.*, 2014; Neece, 2014; Lo *et al.*, 2017; Jones *et al.*, 2018; Bazzano *et al.*, 2013), loving kindness (Bazzano *et al.*, 2013; Dykens *et al.*, 2014; Lo *et al.*, 2017; Jones *et al.*, 2018) and breathing exercises (Bazzano *et al.*, 2013; Dykens and Lambert, 2013; Neece, 2014; Lo *et al.*, 2017; Jones *et al.*, 2018) were employed in the studies that used mindfulness-based intervention.

The effectiveness of mindfulness-based interventions cannot be overemphasised, as evidenced by a number of meta-analyses. Studies have shown that mindfulness-based interventions are effective in reducing psychological distress, especially anxiety and depression (Khoury *et al.*, 2017), somatic illness (Piot et al., 2012) and wellbeing (Eberth & Sedlmeier, 2012). This is similar with the findings reported by studies that used mindfulness-based interventions. In the current study, decreased stress levels (Bazzano *et al.*, 2013; Neece, 2014; Lo *et al.*, 2017; Jones *et al.*, 2018), decreased anxiety (Dykens *et al.*, 2014; Neece, 2014; Jones *et al.*, 2018), decreased depression (Dykens *et al.*, 2014; Neece, 2014; Jones *et al.*, 2018) improved wellbeing (Bazzano *et al.*, 2013) and life satisfaction (Neece, 2014) were reported.

Though the standard duration for mindfulness-based interventions is eight weeks, in the current study, some studies used six weeks (Dykens *et al.*, 2014; Lo *et al.*, 2017). A systematic review by Howarth et al. (2019) examined the effects of brief mindfulness-based interventions on health-related outcomes. Though the researchers agree that there is no standard definition of what constitutes brief, brief interventions do not match the standard MBSR in terms of the duration of the individual sessions as well as the overall programme. They indicated that the number of minutes per week need not exceed 100 minutes and the duration of the programme should be around 4 weeks. These brief interventions were also found to have a positive impact on outcomes, including anxiety and depression.

5.9.3.2 Parent training programmes/interventions

As many as five of the studies utilised parent training programmes (Sofronoff, Jahnel & Sanders, 2011a; Iida, Wada, Yamashita, *et al.*, 2018; Ashori, Norouzi and Jalil-Abkenar, 2019; Brookman-Frazee *et al.*, 2021; Callanan, Signal & Mcadie, 2021). The benefits of such programmes cannot be over emphasised. According to the World Health Organisation such programmes could be helpful in increasing the confidence of caregivers and empowering them to obtain parenting skills (World Health Organisation, 2022). Parent training programmes have also been identified as being able to lead to improved well-being for caregivers as well as children. In addition to the above, when parents are able to acquire useful skills, it can reduce the stressful nature of the interactions between the parents and their children. Machalicek, Lang and Raulston (2015) agreed this could decrease the child's level of dependence.

Parent training programmes have often been targeted at conduct disorders and their management (Hastings, Robertson and Yasamy, 2012), improving the functional life skills of the child with DD (Keen, Brannigan and Cuskelly, 2007), toileting (Kroeger & Sorensen, 2010). The reviewed studies are consistent with the findings of the current study as the focus of the parent training programmes was on managing ineffective behaviours (Sofronoff, Jahnel and Sanders, 2011; Ashori, Norouzi and Jalil-Abkenar, 2019; Brookman-Frazee *et al.*, 2021) and teaching communication and problem-solving skills (Sofronoff, Jahnel & Sanders, 2011). The gold standard of parenting training programmes for caregivers of children with DD includes didactic sessions, role play and rehearsal, and performance feedback (Machalicek, Lang and Raulston, 2015), as mentioned in the studies that utilised parenting programmes (Ashori, Norouzi & Jalil-Abkenar, 2019; Brookman-Frazee *et al.*, 2021). Parent training programmes were reported to decrease somatic symptoms (Ashori, Norouzi and Jalil-Abkenar, 2019), anxiety (Iida, Wada, Yamashita, *et al.*, 2018; Ashori, Norouzi and Jalil-Abkenar, 2019), depression and stress (Callanan, Signal & McAdie, 2021).

5.9.3.3 Cognitive and behavioural related programmes

The findings of the current scoping review indicate that five studies focused on cognitive and behavioural programmes (Wong & Poon, 2010; Masako Suzuki *et al.*, 2014; Lodder, Papadopoulos and Randhawa, 2020; Vijayasamundeeswari, Sathiya & Poongodi, 2020; Mills *et*

al., 2021). The basic premise of such interventions is that psychological distress experienced by individuals is sustained by cognitive factors. When an individual's cognition becomes maladaptive, sustaining psychological and behavioural problems becomes easier. The cognitions that have become maladaptive involve certain beliefs or schemas that are developed about the world, the self and the future, leading to specific and automatic thoughts in particular situations (Hofmann *et al.*, 2012). Thus, the aim of such programmes is to change or alter maladaptive cognitions. Usually, patients are active in the therapeutic and problem-solving processes and are considered collaborators (Hofmann *et al.*, 2012).

Current day CBT comprises various techniques, including cognitive, behavioural and emotional. CBT has been found to be effective against stress (Coull and Morris, 2011), anxiety (Beltman, Oude Voshaar and Speckens, 2010) and depression, chronic pain, fatigue, and insomnia (Okajima, Komada and Inoue, 2011). In consistent with the above, studies that used CBT also reported positive outcomes against stress (Wong and Poon, 2010b; Vijayasamundeeswari, Sathiya and Poongodi, 2020; Mills *et al.*, 2021), general mental health (Wong and Poon, 2010), anxiety (Mills *et al.*, 2021) and depression (Mills *et al.*, 2021).

5.9.3.4 Resilience-based Interventions

The findings of the current study showed that two studies focused on resilience interventions (Moghimi *et al.*, 2018; Millstein, Lindly, Luberto, Perez, *et al.*, 2020). The American Psychological Society defines resilience as a process of "bouncing back" from experiences that have been categorised as different and adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress" (Joyce *et al.*, 2018). Luthar and Cicchetti (2000) defined resilience as a "dynamic and amendable process". It has been observed that "no single accepted theoretical framework or consensus statement exists to guide the development or application of these programmes" (Leppin *et al.*, 2014).

In terms of individuals ability to adapt to stress and overturn the negative impact of stressors, resilience-based interventions have been identified as one of the most important approaches (Gheshlagh *et al.*, 2016). In resilience interventions, individuals adapt to adversity by utilising resources (Wang *et al.*, 2021). Positive outcomes have been reported for resilience interventions, including improving quality of life, stress and emotional distress (Palacio *et al.*, 2020), and

reducing anxiety (Loprinzi *et al.*, 2011). The findings are consistent with those in the current study. Improved sleep and reduced fatigue were reported by Millstein, while Moghimi reported reduced stress levels (Moghimi *et al.*, 2018; Millstein, Lindly, Luberto, Giselle, *et al.*, 2020).

In spite of the promising outcomes of resilience-based interventions, the heterogeneity in the design, content and outcome measure of such interventions has made it difficult to evaluate them (Wild *et al.*, 2020). Most studies have not compared resilience to other interventions, making it difficult to attribute the observed changes only to the intervention or other factors like group contact (Wild *et al.*, 2020).

5.9.3.5 Spirituality-integrated interventions or programmes

Only one study focused on the use of spiritual care to improve caregiver outcomes (Dindar *et al.*, 2016). In terms of coping with stressful life situations and events, religiosity and spirituality have been considered significant resources (Villani *et al.*, 2019). Though evidence is being gathered as to the exact mechanism(s) by which it works, it influences the belief system of an individual, consequently assisting them to appropriately assess or make judgements about negative events. Thus, equipping the individual to be able to develop a greater sense of how to effectively manage problems (Salamizadeh, Mirzaei & Ravari, 2017). Kiyani, Mohammadi and Pourahmad (2011) have reported that prayer and religious belief improved mental health. Similarly, correlation have been reported between spirituality and anxiety and distress (Kashani *et al.*, 2014) and caregiving burden (Tan *et al.*, 2012). Similarly, Zhang *et al.* (2020) in a systematic review, reported that spirituality integrated interventions reduced caregiver burden or distress, depression, anxiety, physical or emotional fatigue and increased quality of life. Dindar *et al.* (2016) included in the current scoping review, also found that spiritual self-care training decreased caregiver strain among mothers of mentally retarded children.

5.9.3.6 Mind-body interventions or programmes

Only one study focused on mind-body interventions using yoga (Ullas *et al.*, 2021)**.** McCall (2013) posits that the use of yoga in the treatment of varying forms of health conditions is increasing day in and day out. It is defined as the restriction of the fluctuations of mind-stuff (Danucalov *et al.*, 2013). In the practice of yoga, the focus is for the individual to develop an increased ability to pay

focused attention to the present moment. Subsequently, the individual does not get imprisoned by thoughts and ruminations. This observed effect of mental stability achieved through yoga has some correlation with sympathetic reduction and conversely, improvement in the parasympathetic activity contributing to stress and anxiety reductions (Danucalov *et al.*, 2013). Though yoga has been applied to different categories of caregivers, few studies have examined the effectiveness of yoga on caregivers of children with special needs. Irrespective of that, a literature review of 18 studies showed that yoga has been effective in the reduction of stress, anxiety, depressive symptomology as well as improving quality of life, well-being, immunity (McCall, 2013). In line with the literature, Ullas *et al.* (2021) reported improvements in stress, anxiety, depression and sleep quality for the yoga intervention group as compared to the control group that received group discussion.

5.9.4 Delivery of the intervention

In the current scoping review, most of the interventions were conducted or led by health professionals and two studies used peer mentors. In congruent with the above, Fewster, Govender and Uys (2019) reported that eleven out of 21 interventions were led by individuals with some experience in the area of ASD. They went further to state that six of those individuals were professionals. Peer mentors were used in two of the studies, these were caregivers who had received some training in the intervention and were supervised to administer it. The question of who is qualified or not to deliver an intervention remains unanswered. Both studies which have used professionals and peer mentors (non-professionals), have all reported improvements at the end of the intervention. Using either of them has its own merits and demerits. For sustainability of the intervention, it favours the use of peer mentors, especially in low-resource settings like Ghana. However, offering peer mentors special training prior to the start of the intervention and supervision during the delivery of the intervention may come at an additional cost.

5.9.5 Level of evidence of the studies reviewed

Studies included in the scoping review had strong levels of evidence. Most of the studies were randomised control trials and were at level 1a. The remaining quasi experimental designs at level 2d. Randomised control trials (RCTs) have a high level of evidence; however, it is important to

emphasise that some RCTs lack methodological rigour and quality. Thus, results from such RCTs undergo some form of scrutiny (Burns, Rohrich & Chung, 2011). Furthermore, in interpreting RCT based results, the types of errors and the power of the studies should be considered. Additionally, other things could be considered, such as the description of power analysis randomisation, blinding, and concealment of allocation to treatment groups (Burns, Rohrich & Chung, 2011). In using the JBI critical appraisal checklist for RCTs in the current study, the studies had moderate to high quality. The quasi experimental studies also had high to moderate quality on the JBI tool. Though RCTs are considered as the gold standard (Panko *et al.*, 2015) it is not always possible to conduct them. In such instances, a quasi-experimental is considered.

5.10 SUMMARY OF CHAPTER FIVE

The chapter described the results and discussion of phase 1b of the study after a scoping review was conducted. The results after synthesis of the evidence regarding the programmes and interventions that have been applied to ameliorate stress, burden or caregiver strain and improve other caregiver outcomes. Six main types of intervention evolved: mindfulness-based, parent training, cognitive behavioural, resilience based, spirituality-integrated and exercise-based interventions. The duration of the programmes ranged from less than a month to more than 3 months, with the majority conducted over one to two months. Health professionals were the main experts used for the delivery of the intervention. The main mode of delivery for the intervention/programme was face-to-face. Several studies reported improvement in psychological outcomes mainly stress, anxiety and depression. Other outcomes included improvements in caregiver burden, social well-being and physical well-being. The next chapter, chapter six describes the development process of a psychosocial programme aimed at improving the well-being of caregivers of children with DD.

CHAPTER 6

PHASE TWO: DEVELOPMENT PROCESS OF A PSYCHOSCOIAL SUPPORT PROGRAMME

6.0 INTRODUCTION

The first phase of the study comprised two parts. Part one involved a descriptive phenomenological study in which caregivers of children with DD were interviewed to find out their experiences and health needs in their caregiving role. The second part was a scoping review to map out existing interventions and programmes that have been used for caregivers of these children. The main aim was to generate the data needed for the development of a well-being psychosocial support programme for caregivers of children with DD in Ghana.

The second phase of the research also consists of two parts. The first part was the development of a well-being programme, while the second part was the expert review process for the confirmation of the programme. The method and process involved in the development of the programme and the expert review are described in this chapter.

6.1 DEVELOPMENT OF THE PSYCHOSOCIAL SUPPORT PROGRAMME: APPLICATION OF THE MRC FRAMEWORK

The development of the psychosocial support programme was guided by the MRC framework for the design and evaluation of complex interventions, which splits complex interventions into phases. The MRC framework comprises four phases: development of the intervention, feasibility, evaluation, and implementation [described in chapter 3, Figure 3.4] (Skivington *et al.*, 2021a). In this study, the first phase, which is the development phase was utilised. The development phase consists of three stages, namely: identifying the evidence, identifying or developing the theory and modelling the process and outcomes. The core elements that run through all four phases of the framework and applied to this study were the context of the intervention, programme theory development and refinement, and engaging key stakeholders. Others include identifying uncertainties, refining the programme and considering economic factors. The psychosocial support programme developed in this study is named the Caregiver Well-being Improvement Support [CaWELLIS] Programme. The iterative process for developing the programme guided by the MRC framework is described in Figure 6.1.

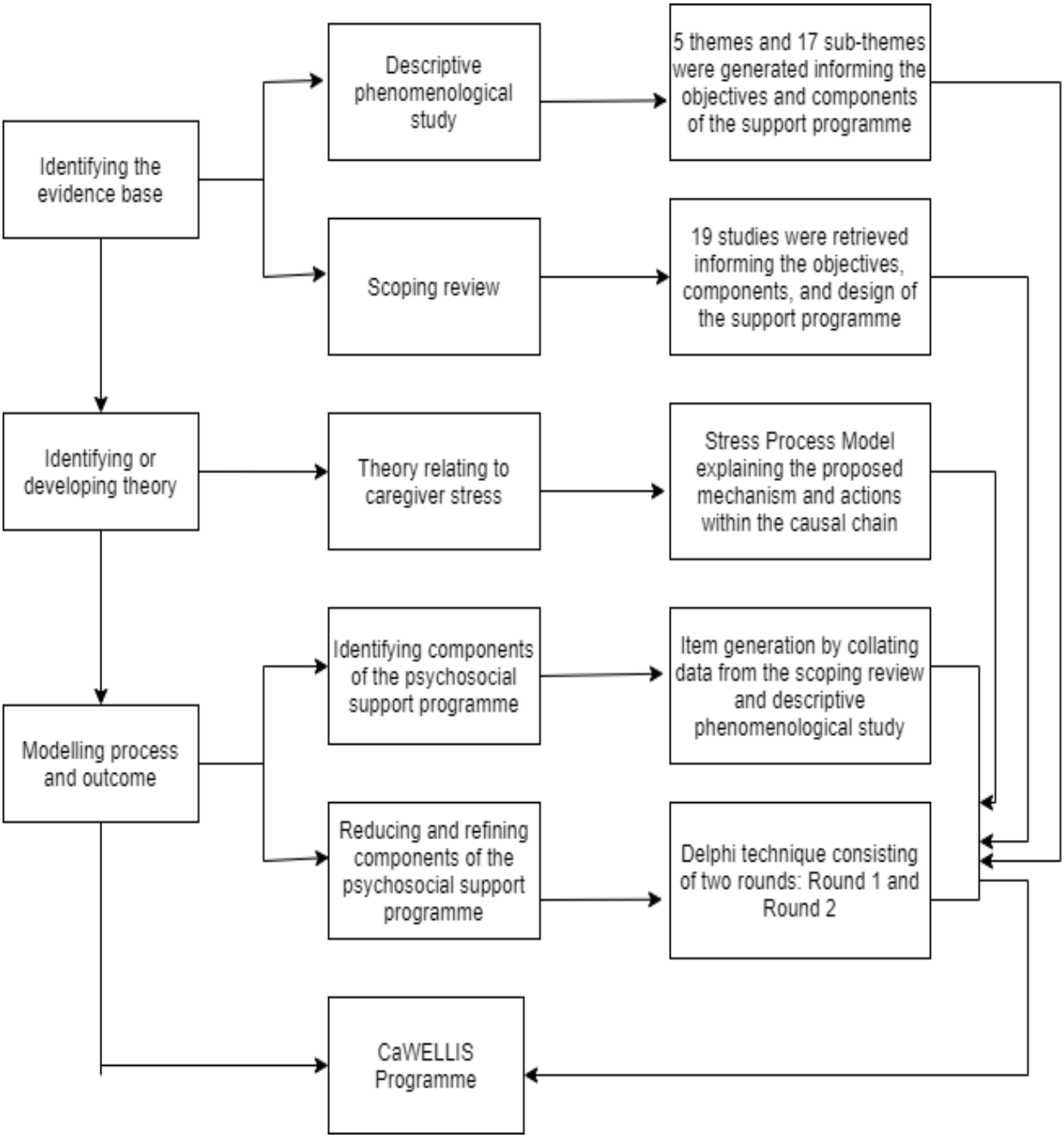

Figure 6.1 Iterative development process of the CaWELLIS Programme

6.2 IDENTIFYING THE EVIDENCE

6.2.1 Phenomenological study

A phenomenological study was conducted with the aim of identifying the experiences and needs of caregivers of children with DD. A total of five themes and seventeen sub-themes were generated [details are described in Chapter 4]. Generally, caregivers described their experiences as stressful and time-consuming mainly due to the demands of the child with DD. The needs expressed by the caregivers were informational, psychological, spiritual, social and financial.

6.2.2 Scoping review of interventions

The scoping review was done to identify literature for evidence-based programmes, trainings or interventions for caregivers of children with DD. The aim was to identify various programmes that have been used for caregivers of children with DD as well as their modalities. The scoping review influenced the objectives of the support programme. Furthermore, the structure of the psychosocial support programme was influenced, including the duration of the programme (sessions per day, number of weeks for the entire programme), how the programme should be delivered (face-to-face, online or blended), what materials should be used, where the programme should be done and who should deliver the programme. A total of 19 full text studies were included after title, abstract and full text screening. Interventions that could influence practice, research, and policy were included [details are provided in Chapter 5].

6.3 IDENTIFYING OR DEVELOPING THE THEORY

According to the MRC framework, this stage involves either identifying or developing a theory. A thorough review of the literature showed that an appropriate theory that could explain and guide the psychosocial support programme was the Stress Process Model [SPM]. The SPM provides a detailed flow of the onset and context of stress, stressors, the moderating factors influencing stress and the outcomes of stress. The psychosocial support programme developed is aimed at reducing stress, the SPM was utilised to identify the main stressors and how they could be reduced to improve caregiving outcomes. Thus, the SPM guides through all the stages of the development of

the support programme. The SPM provides an easy conceptualization of the caregiver, stress and caregiving outcomes [details of the SPM are described in Chapter 2, Figure 2.2].

6.4 MODELLING PROCESS AND OUTCOME OF THE CaWELLIS PROGRAMME: Identifying items for the support programme

Based on the scoping review and the phenomenological descriptive study, the items for the psychosocial support programme (CaWELLIS) were identified. The data from the scoping review and the phenomenological descriptive study was triangulated. Some of the items were identified by both the scoping review and interviews. Other items were identified by either the scoping review or interviews only. Overall, 31 items identified were placed under six main modules, which have been described in Table 6.1:

Table 6. 1 Items generated from scoping review and qualitative interviews

		Scoping review	Interviews
Module 1: Information about developmental disabilities			
1	Increasing understanding on DD	✓	✓
2	Addressing the myth and stereotypes associated with DD	✓	✓
3	Understanding developmental milestones	✓	
4	Increasing the skills needed in performing ADLs for child with DD		✓
5	Understanding the caregiving role		✓
Module 2: The caregiver and stress			
6	Understanding the physiology of stress	✓	
7	Understanding the physiological, cognitive, behavioural response to stress	✓	
8.	Emotional response to stress		
9	Identifying caregiver common stressors	✓	✓
10	Adaptive and maladaptive ways of dealing with stress	✓	
Module 3: Managing stress and other psychosocial issues			

11	Deep breathing exercises among caregivers	✓	
12	Cognitive restructuring: breaking negative thought cycle	✓	
13	Mindfulness meditation	✓	
14	Physical activity	✓	
15	Prayers or relating to higher powers	✓	✓
Module 4: Improving caregiver role			
16	Effective communication skills	✓	✓
17	Financial management skills		✓
18	Time management skills		✓
19	Principles of positive parenting	✓	
Module 5: Managing behavioural problems			
20	Knowing your child: identifying the likes/dislikes and idiosyncratic behaviour	✓	
21	ABCs of behaviour management at home	✓	
22	Inaccurate methods of managing behaviour problems	✓	
23	Developing positive relationship with child	✓	
24	Recording and analyzing behaviour of child with DD	✓	
25	Setting reasonable expectations for the child with DD	✓	
Module 6: Caregiver self-care			
26	Maintaining interest and hobbies	✓	✓
27	Overcoming self-blame and guilt	✓	
28	Cultivating loving kindness and self-compassion	✓	
29	Resources available for caregivers: accessing and utilization of social support	✓	✓
30	Dealing with stigma associated with having a child with DD	✓	
31	Self-awareness	✓	

Table 6.1 describes the items generated for the proposed CaWELLIS programme which was to be confirmed by the experts using a Delphi technique for their input.

6.5 MODELLING PROCESS AND OUTCOME OF THE CaWELLIS PROGRAMME: The Delphi Technique

Expert review of the proposed CaWELLIS programme began with recruitment of experts. This process was followed by Rounds 1 and 2 of the Delphi technique.

6.5.1 Recruitment of experts

Participants (experts) who had the potential to be part of the study were identified by the researcher through existing contacts (See Chapter 3, Section 3.5.2). The experts who met the inclusion criteria were sent an online invitation via email. The potential participants were to indicate their acceptance by responding to the email. Thus, experts who did not respond to the initial email were sent a reminder via email and short message service (SMS). For experts who did not provide feedback, no further follow-up was made with the assumption that they were not interested in participating. Out of the 13 experts, 12 gave feedback. To improve rigour, the professional affiliation of the experts was confirmed before they were recruited into the study. Table 6.2 describes the demographic details of the experts.

Table 6.2 Demographic details of experts

Serial no	Gender	Age	Years of experience	Academic qualification	Profession
1	Female	36	2	PhD Psychology; MPhil Clinical Psychology; B.A. Psychology and Music	Clinical Psychologist
2	Male	40	18	Master of Mental Health	Mental health nurse
3	Male	42	16	Diploma in Mental health nursing; B. ED Health Science; MPH	Lecturer
4	Male	32	8	BSc in Nursing	General nurse
5	Male	37	7	PhD	Clinical Psychologist
6	Female	43	12	PhD	Lecturer
7	Male	62	30	PhD	Psychiatrist
8	Female	34	3	PhD, MPhil, BA	Researcher
9	Male	35	5**	BSc	Caregiver
10	Female	60	23	MBBS; MGPS	Paediatrician
11	Male	62	25	FRCPCH; MRCP(UK)	Paediatrician
12	Male	38	10	MPhil; BSc	Physiotherapist

** Number of years of being a caregiver

6.5.2 Procedure for the confirmation of the psychosocial support programme

After recruitment of experts into the study, the experts were sent a link via email specifically providing instructions on how they were to complete the survey and timelines for providing feedback to the survey. They were provided with a study information sheet [Annexure J] and asked to sign a consent form [Annexure N] before assessing the link to the survey.

The survey was to be accessed at [https://redcap.link/expert_review_caregiver_intervention]. The approach was user-friendly and ensured anonymity, one of the principles of the Delphi technique. As such, to further deepen this, no identifying information was obtained from the experts apart from age, gender, profession and educational attainment. The survey was done in two rounds.

6.5.2.1 Round 1 of delphi technique

A reminder was sent via email and SMS after their acceptance to be part of the expert review. Experts were required to rate each of the proposed items of the intervention on a 7-point ordinal Likert scale for acceptability, feasibility and effectiveness. The guideline for identifying which items were likely to be acceptable, feasible and effective was based on the Child Health and Nutrition Research Initiative (CHNRI) criteria [described in Chapter 3, Table 3.4]. The experts, apart from rating the items on the scale, also had the opportunity to write down their comments on the rationale guiding their choice. Thus, the experts were provided space for free text responses after each question/statement. A total of 31 items were sent to the experts. All experts provided feedback. The level of agreement was calculated using the Kappa Statistics and details provided in Table 6.3.

Table 6.3 Round 1 level of agreement among experts

	Items	Acceptability	Feasibility	Effectiveness
Module 1: Information about developmental disabilities				
1.	Increasing understanding on developmental disabilities	0.46	0.4	0.4
2.	Addressing the myth and stereotypes associated with developmental disabilities	0.49	0.41	0.45
3.	Understanding developmental milestones	0.5	0.45	0.46
4.	Basic skills needed in performing Activities of Daily Living [ADLs] for child with developmental disabilities	0.35	0.45	0.43
5.	Understanding the caregiving role	0.2	0.18	0.14
Module 2: The caregiver and stress				
6.	Understanding the physiology of stress	0.4	0.42	0.34
7.	Physical, cognitive and behavioural response to stress	0.46	0.51	0.41
8.	Emotional response to stress	0.37	0.44	0.37
9.	Identifying caregiver common stressors	0.43	0.43	0.46
10.	Adaptive and maladaptive ways of dealing with stress	0.16	0.2	0.18
Module 3: Managing stress and other psychosocial issues				
11.	Deep breathing exercises among caregivers	0.26	0.31	0.31
12.	Cognitive restructuring: breaking negative thought cycle	0.28	0.4	0.34
13.	Mindfulness meditation	0.2	0.18	0.2
14.	Physical activity	0.07	0.16	0.19
15.	Prayers or relating to higher powers	0.38	0.31	0.40
Module 4: Improving caregiver role				
16.	Effective communication skills	0.39	0.40	0.29
17.	Financial management skills	0.32	0.28	0.37
18.	Time management skills	0.14	0.15	0.04
19.	Principles of positive parenting	0.48	0.45	0.44
20.	Knowing your child: identifying the likes/dislikes and idiosyncratic behaviour	0.41	0.44	0.47
Module 5: Managing behavioural problems				
21.	Antecedents Behaviour and Consequences [ABCs] of behaviour management at home	0.44	0.47	0.44
22.	Inaccurate methods of managing behaviour problems	0.08	0.05	0.02
23.	Positive caregiver-child relationship	0.46	0.49	0.41
24.	Recording and analyzing behaviour of child with developmental disabilities	0.40	0.43	0.39

Module 6: Caregiver self-care				
25.	Maintaining interest and hobbies of caregiver	0.23	0.20	0.20
26.	Setting reasonable expectations for the child with developmental disabilities	0.46	0.45	0.52
27.	Overcoming self-blame and guilt	0.46	0.46	0.45
28.	Cultivating loving kindness and self-compassion	0.35	0.40	0.45
29.	Resources available for caregivers: accessing and utilization of social support	0.48	0.46	0.46
30.	Dealing with stigma associated with having a child with developmental disabilities	0.50	0.42	0.48
31.	Self-awareness	0.14	0.17	0.06

Table 6.3 is the outcome of expert review from round 1 of the Delphi technique. The Kappa statistics was used to determine which items achieved consensus. Out of the 31 items, 23 achieved consensuses. Thus, items with Kappa of 0.2 or below were considered not to have achieved consensus.

6.5.2.2 Round 1 comments from the experts

Experts made comments on some of the items of the proposed CaWELLIS programme. The comments included rewording, change of modules, merging of concepts and addition of new concepts. The comments were important to improve the overall development of the CaWELLIS programme. In summary, Table 6.4 indicates the comments from the experts which led to the refinement of the programme.

Table 6.4 Comments generated from Round 1 of Delphi technique

Expert evaluation	Initial statement	Revised statement/remarks
Rewording	Increasing the skills needed in performing ADLs for child with DD	Methods and techniques of teaching ADL for a child with DD
	Increasing understanding on DD	Basic information on DD and its management
	Deep breathing exercises among caregivers	Deep breathing exercise for caregivers
	Effective communication skills	Improving communication with children with developmental disabilities
	Overcoming self-blame and guilt	Dealing with self-blame and guilt
	Understanding physiology of stress	Understanding the stress pathway
Change of modules	Increasing the skills needed in performing ADLs for child with DD	Change from module 1 to module 4
Merging of concepts	Knowing your child: identifying the likes/dislikes and idiosyncratic behaviour	In ABCs of home management, identifying behaviour will be made
	Emotional response to stress	To be merged with other response to stress
	Recording and analyzing behaviour of child with DD	In ABCs of home management, behaviour is recorded and analyzed.
	Developing a positive relationship with child with DD	In principles of positive parenting, this can be achieved
New concepts to be considered for support programme	Progressive Muscle Relaxation	Included for review in round 2
	Guided imagery	Included for review in round 2

The experts received feedback on the first round. Out of the 31 possible items of the support programme, 23 achieved consensus while 8 did not. In addition to the 8 items that did not achieve consensus, two new items generated from the experts' comments from the round one was included, making a total of 10 items for review by experts. In summary, the above table indicates the comments from the experts that led to the refinement of the programme.

6.5.2.3 Round 2 of the delphi technique

The same procedure as indicated in 6.3.2.1 was repeated for round 2. The outcome of the expert review for round 2 is provided in Table 6.5 below.

Table 6.5 Round 2 level of agreement among experts

	Items	Acceptability	Feasibility	Effectiveness
1.	Understanding the caregiving role	0.21	0.16	0.14
2.	Adaptive and maladaptive ways of dealing with stress	0.15	0.18	0.17
3.	Mindfulness meditation	0.21	0.19	0.16
4.	Physical activity	0.14	0.15	0.16
5.	Time management skills	0.15	0.16	0.09
6.	Inaccurate methods of managing behaviour problems	0.09	0.08	0.04
7.	Maintaining interest and hobbies of caregiver	0.19	0.18	0.18
8.	Self-awareness	0.08	0.05	0.06
9.	Progressive Muscle Relaxation	0.51	0.52	0.49
10.	Guided imagery	0.21	0.18	0.19

Table 6.5 shows that out of the ten responses, only one achieved consensus. The remaining nine did not achieve consensus and thus were not included in the final items considered for the development of the CaWELLIS psychosocial support programme. No comments were made in round 2. The iterative process of the Delphi technique, including round 1 and round 2 is described in Figure 6.2.

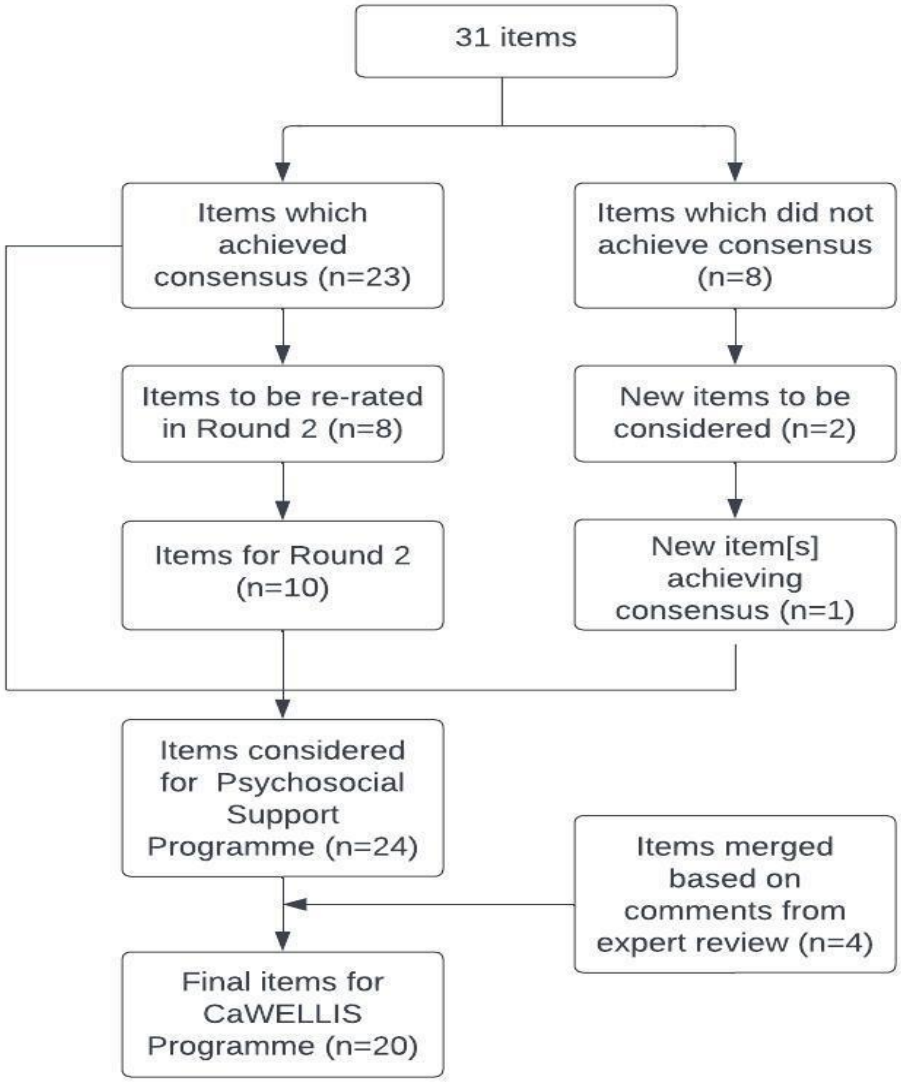

Figure 6.2 Iterative process of Delphi technique

6.5.3 Final items of the CaWELLIS programme

A total of 24 items achieved consensus after round two of the Delphi technique. Based on expert recommendation, a total of four items were deleted because their items were like other items of the programme, thus, a total of 20 items made the items of the psychosocial support programme, classified under 6 main modules and is described in Table 6.6.

Table 6.6 Description of final items of CaWELLIS programme

Module 1: Information about developmental disabilities	
1	Understanding developmental milestones
2	Basic information on developmental disabilities
3	Addressing the myth and stereotypes associated with developmental disabilities
Module 2: The caregiver and stress	
4	Identifying caregiver common stressors
5	Understanding the stress pathway
6	Understanding the physiological, cognitive, emotional and behavioural response to stress
Module 3: Managing stress	
7	Cognitive restructuring: breaking negative thought cycle
8	Deep breathing exercises for caregivers
9	Progressive Muscle Relaxation
10	Prayers or relating to higher powers
Module 4: Improving caregiver role	
11	Improving communication with children with developmental disabilities
12	Financial management skills
13	Principles of positive parenting
14	Methods and techniques of teaching ADL for a child with DD
Module 5: Managing behavioural problems of the child with DD	
15	ABCs of behaviour management at home
16	Setting reasonable expectations for the child with DD
Module 6: Caregiver self-care	
17	Dealing with self-blame and guilt
18	Cultivating loving kindness and self-compassion
19	Resources available for caregivers: accessing and utilization of social support
20	Dealing with stigma associated with having a child with DD

6.5.4 THEMES/SUB-THEMES GENERATED FROM CHAPTER FIVE AND THEIR CORRESPONDING MODULES OF THE CaWELLIS

To give meaning to the modules in the CaWELLIS programme, there is the need to reflect on and link the themes and sub-themes generated in Chapter 5 with the modules developed. The details are described in Table 6.7:

Table 6.7 Themes from qualitative study and their corresponding modules

Main themes	Sub themes	Categories	Modules
Stressors	Communication barrier		Modules 5, 2, 1
	Managing challenging behaviour	Forms of difficult behaviours Triggers of difficult behaviours Dealing with usual behaviours	Modules 2, 5, 6
	Child's ADL needs	Assisting with feeding Assisting with bathing Assisting with elimination	Modules 2, 3, 4
	Child health needs	Proximity to the hospital Frequent hospital visits	Modules 2,3
	Unmet educational needs	Enrolling child with DD in school	Module 2, 4
		Maintaining child with DD in school	Module 2, 4
	Economic burden	Financial challenges	Modules 2, 4
		Job demands versus caregiving role	Modules 1, 2, 4
Negative health outcomes	Decline in physical well-being	Pain related effect	Modules 2, 3, 4
		Fatigue	Modules 2, 3, 4
		Compromised sleep	Modules 2, 3, 4
	Decline in psychological well-being	Lack of concentration	Modules 2, 3, 4
		Anger	Modules 2, 3, 4
		Anxiety	Modules 2, 6
		Feeling sad	Modules 2, 3, 4
	Decline in social well-being	Social isolation	Modules 2, 4
		Change in social relationships	Modules 2, 4
Support Needs	Informational support	Information on diagnosis	Module 1
		Information on management	Module 1
	Financial support	Support towards child's management	Module 4
		Support towards caregivers	Module 4

	Psychospiritual support	Counselling	Module 3, 6
		Prayers	Module 3
	Social support	Support from family	Module 6
		Support from groups	Module 6

6.6 OVERVIEW OF THE CaWELLIS PROGRAMME

The CaWELLIS programme [Annexure A] is summarised in Table 6.8. The objectives for each session are described, as is the duration of the sessions. The materials needed for each session are provided here. The duration for the entire programme was 720 minutes with 120 minutes per week over a period of 6 weeks. The programme was run by the researcher, who is a professional nurse and is currently lecturing at Presbyterian University, Ghana.

Table 6.8 Summary of models in CaWELLIS Programme

MODULE 1: INTRODUCTION AND INFORMATION ABOUT DEVELOPMENTAL DISABILITIES				
SESSIONS	**TIME**	**ACTIVITY**	**AIM OF ACTIVITY**	**EQUIPMENT NEEDED**
Session 1	30 mins	Welcome and introduction of participants	▪ To ensure familiarization among facilitator and participants ▪ To create a relaxed atmosphere for the roll-out of the study. ▪ To discuss on ground rules that will establish a safe space for shared learning reflection and growth.	Laptop, Projector, Marker Chairs Others (Refreshment) Snack and Lunch
	10 mins	Objectives of the psychosocial support programme	▪ To communicate the importance of the training to participants ▪ To provide a road map for successful implementation of the programme. ▪ To provide insight to participant what they will be learning during the programme.	

	5 mins	Discussion of expectations	▪ To provide participants to express their expectations ▪ To provide facilitators with the opportunity to express their expectations.	
	15 mins	BREAK/REFRESHMENT		
Session 2	30 minutes	Understanding developmental milestones and red flags	▪ To educate caregivers on developmental milestones	
Session 3	30 mins	Basic information on DD and its management	▪ To gain knowledge about DD (types, risk factors, problem of the children)	
Session 4	20 mins	Addressing the myths and stereotype associated with DD	▪ To assist caregivers to demystify the myths and stereotypes associated with DD	
MODULE 2: THE CAREGIVER AND STRESSORS				
Session 1	30 mins	Identify caregiving stressors	▪ To identify stressors in caregiving and assist caregivers to understand the nature of stressors	Laptop, Projector, Marker, White board, Chairs Others (Refreshment) – Snack and Lunch
Session 2	30 mins	Understanding stress pathway	▪ To gain knowledge on the mechanism of stress	
	15 mins	BREAK/REFRESHMENT		
Session 3	45 mins	Understanding the impact of stress	▪ To gain knowledge on the impact of stress on (digestive system, immune system, circulatory system, social relationship, psychological wellbeing)	
MODULE 3: STRESS MANAGEMENT				
Session 1	30 mins	Cognitive restructuring:	▪ To establish the relationship between	Laptop, Projectors,

		Breaking negative thought cycle	thoughts, mood and behaviour ▪ To identify negative automatic thoughts ▪ To gain knowledge on how to break negative thought cycle ▪	Markers, White board and Chairs Others (Refreshment)
Session 2	30 mins	Deep breathing exercise	▪ To help participants/ caregivers relax their muscles and release immediate stress	
	15 mins	BREAK/REFRESHMENT		
Session 3	30 mins	Progressive muscle relaxation	▪ To help participants/ caregivers relax their muscles and release immediate stress	
Session 4	15 mins	Prayers or relating to higher power	▪ To identify and utilize spiritual resources in coping with stress	
MODULE 4: IMPROVING CAREGIVER ROLE				
Session 1	25 mins	Methods and techniques of teaching ADL	▪ To identify effective ways of assisting children with DD to learn the performance of ADL	Laptop, Projector, Marker Chairs Others (Refreshment) Snack and Lunch
Session 2	25 mins	Improving caregiver communication with child with DD	▪ To improve communication of the caregivers with children with DD. ▪ To identify barriers to effective communication with their children with DD	
	15 mins	BREAK/REFRESHMENT		
Session 3	25 mins	Financial management skills	▪ To provide the caregiver with the needed/ accurate information on managing their	

			finances effectively to decrease or minimize financial burden associated with caregiving.	
Session 4	30 mins	Principles of positive parenting	▪ To assist the caregiver to identify principles that could be helpful and ultimately decrease stress ▪ To identify parenting tips that will enhance parenting and help develop a positive relationship between the caregiver and the child with DD	
MODULE 5: MANAGING BEHAVIOUR PROBLEM				
Session 1	75 mins	ABCs of behaviour management at home	▪ To gain knowledge on the antecedents and patterns of problem behaviour. ▪ To identify the types of problem behaviours. ▪ To identify the appropriate ways of dealing with behaviour problems. ▪ To identify the steps involved in managing behaviour	Laptop, Projector, Marker, White board, Chairs Others (Refreshment) – Snack and Lunch
	15 mins	BREAK/REFRESHMENT		
Session	30 mins	Setting reasonable expectations	▪ To identify the impact of low and high expectations on caregiving ▪ To set reasonable expectations	
MODULE 6: CAREGIVER SELF-FOCUS				
Session 1	25 mins	Dealing with self-blame and guilt	▪ To assist the caregiver to identify the impact of self-blame and	Laptop, Project, Whiteboard, markers,

			learning ways of dealing with it	comfortable chairs, flip chart, paper and stands. Others (Refreshment) – Snack and Lunch
Session 2	25 mins	Cultivating loving kindness and self-compassion	▪ To identify ways of cultivating a non-judgmental attitude and evaluation towards self	
	15 mins	BREAK/REFRESHMENT		
Session 3	25 mins	Resources available for caregivers: accessing and utilization of social support	▪ To identify the relevance of social support and especially its role in reducing social isolation and stress. ▪ To learn to recognize who is helpful and who can support.	
Session 4	20 mins	Dealing with stigma associated with having a child with DD	▪ To identify ways of dealing with stigma	
	20 mins	EVALUATION		

6.7 SUMMARY OF CHAPTER SIX

The chapter describes in detail the development of the support programme, guided by the MRC framework for developing complex interventions. The first step was to identify the evidence. The evidence was identified by conducting a phenomenological study and a scoping review. The findings of the phenomenological study revealed that caregivers had unmet needs, which informed the items of the support programme. The scoping review included 19 studies; the findings indicated the effectiveness of different programmes used for caregivers of children with DD. The second step was to identify or develop a theory and Stress Process Model was used. The third step involved modelling the process and outcome. In this step, the items for the psychosocial support programme were identified, and expert review was done using the Delphi technique. Overall, 20 items were included in the support programme, which was named CaWELLIS programme.

CHAPTER 7

PHASE 3: IMPLEMENTATION PHASE

7.0 INTRODUCTION

Chapter six described the process of development and expert review to confirm the CaWELLIS Programme. In this chapter, the pilot testing, implementation of the CaWELLIS programme and post-testing are presented. The purpose of this phase was to address the following:

- To conduct a baseline assessment of the caregivers' burden of care, stress levels, cortisol levels, blood pressure, anxiety, depression, somatic symptoms and perceived social support.
- To pilot-test the psychosocial support programme among a sample of caregivers of children with DD.
- To evaluate the caregivers' outcomes (burden of care, stress levels, cortisol levels, blood pressure, anxiety, somatic symptoms and perceived social support) immediately after the support programme.

7.1 PRE-TESTING [BASELINE ASSESSMENT]

The register of the Neurodevelopmental Clinic was used to identify caregivers of children with DD who met the inclusion criteria. However, the caregivers were given prior information by the clinic in-charge, and they agreed that their details should be released. Therefore, those who met the inclusion criteria were contacted via telephone. They were provided with a consent form, which those who agreed to take part in the study signed. The participants were given a day for the pretesting to be done. Because the morning cortisol levels were to be taken between 7 and 9 p.m., therefore, caregivers were required to be present at the Anaesthesia Conference room of the Korle Bu Teaching Hospital by 6:30 a.m. Caregivers who did not have any support to assist in taking care of their children were permitted to bring their children along. Two research assistants who are nurses were assigned to take care of the children while data collection was in session. Apart from the cortisol test, the blood pressure of the caregivers was measured. The DASS, PHQ-15, MSPSS and ZBI were also filled out by the caregivers in order to get baseline data on caregiver stress,

burden, anxiety, depression, somatic symptoms and perceived social support. They were refreshed with snacks and food, after which the evening cortisol was taken between 3 p.m. and 5 p.m.

7.2 PILOT TESTING

A day was scheduled for the pilot testing of the programme. Caregivers were given daily reminders of the programme via SMS and with their permission, a WhatsApp group was created to facilitate the easy dissemination of information. A few caregivers who did not use android phones that had WhatsApp installed were reminded through phone calls and SMS. The day prior to the commencement of the programme, the caregivers were contacted through phone calls. On the morning of the programme, they were called again to be reminded of the programme.

On the first module of the programme, the researcher officially welcomed the participants to the CaWELLIS programme and expressed her gratitude to the participants for making time to be part of the programme. Conscious effort was made to establish rapport with the participants. Participants introduced themselves. The researcher informed them of the purpose and benefits of the programme, the expectations of the participants were discussed. Small groups consisting of 8 participants each were created to enhance discussions.

Each module lasted for an average of 120 minutes; the sessions for the module lasted between 20 and 75 minutes, with a break of 15 minutes for each module. Each module had its own specific objectives, which were clearly displayed on a screen via an overhead projector. The modules of the psychosocial support programme were:

1. Introduction and information on DD
2. The caregiver and stress
3. Stress management
4. Equipping the caregiver
5. Managing behaviour problem
6. Caregiver self-focus

Each module began with caregivers sharing their experiences and discussing homework, where applicable, before proceeding to the day's sessions. The programme began on the 29th December, 2022 and ended on the 9th February, 2023. A detailed description of how the programme was delivered and presented is available in appendices (Annexure A).

7.3 POST TESTING

The post-test was conducted a day after the intervention. The caregivers were aware a post-test would be done. They reported around 6:30 a.m. to allow the morning cortisol testing to be done between 7:00 a.m. and 9:00 a.m. and the blood pressure was measured afterwards. The caregivers then responded to the questionnaires [ZBI, DASS, PHQ-15, and MSPSS]. They were refreshed and then the samples for the evening cortisol were taken between 3:00 to 5:00 p.m.

7.4 RESULTS: PRE AND POST INTERVENTION

The section described the following outcomes in the current study: burden, depression, anxiety, stress, social support, somatic symptoms, cortisol levels and blood pressure. The total number of participants who completed the pre-test and post-test was n (53).

7.4.1 Socio-demographic characteristics of the caregivers

The majority of the participants were between 26 and 45 years old (71.7%). The ages of the caregivers ranged between 26 and 64 years. Males and females were not equally represented, as 45 females and 8 males participated. The greatest percentage of caregivers (77.4%; n = 41) were mothers of the children with DD, full-time employers (47.2%; n = 25), married (60.4%; n = 32), had provided care between 3 to 5 years (45.3%; n = 24) and the caring hours ranged between 8 and 10 hours per day (41.5%; n = 22). Most of the caregivers (83%, n = 44) did not have an underlying health condition, specifically DM or hypertension. Table 7.1 presents the details.

Table 7.1 Sociodemographic characteristics of caregivers (n=53)

Variable		Frequency	Percent
Age	26-35	14	26.4
	36-45	24	45.3
	46-55	8	15.1
	56 and above	7	13.2
Gender	Male	8	15.1
	Female	45	84.9
Employment	Fully employed	25	47.2
	Partially employed	11	20.8
	Unemployed	17	32.1
Marital Status	Married	32	60.4

	Divorced	2	3.8
	Single	15	28.3
	Cohabiting	2	3.8
	Widowed	2	3.8
Relationship to child	Mother	41	77.4
	Father	6	11.3
	Other (grandparent, aunt, uncle, guardians)	6	11.3
Caring years	½(6 months)-2	4	7.5
	3-5 years	24	45.3
	6-9 years	16	30.2
	>10 years	9	17
Caring hours	2-4 hours	8	15.1
	5-7 hours	14	26.4
	8-10 hours	22	41.5
	11-15 hours	9	17
Health condition	Diabetes Mellitus	2	3.8
	Hypertension	7	13.2
	None	44	83

7.4.2 Sociodemographic characteristics of children with DD

The demographic data of the children was taken from the caregivers. The details are presented in Table 7.2.

Table 7.2 Sociodemographic characteristics of children with DD

Variable		Frequency	Percent
Childs age	5-8 years	32	60.4
	9-11 years	16	30.2
	12-14 years	5	9.4
Childs's gender	Male	34	64.2
	Female	19	35.8
Childs diagnosis	Attention deficit hyperactivity disorder	7	13.2
	Intellectual disability	13	24.5
	Down Syndrome	2	3.8
	Cerebral Palsy	15	28.3
	Autism Spectrum Disorder	16	30.2

Table 7.2 indicates the ages of the children ranged between 5 and 14 years with a mean and standard deviation of 8 years and 2.51 respectively. Most of the children with disabilities (64.2%, n = 34) were males. The majority of children with DD presented with ASD (30.2%; n = 16), followed by CP (28.3%; n = 15) and ID (24.5%; n = 13).

7.4.3 Caregiver stress

This session describes the findings from the pre- and post-tests for caregiver stress. The overall caregiver stress, individual item analysis of the DASS [Stress] and level of stress are described in Tables 7.3, 7.4 and 7.5.

Table 7.3 Overall stress pre-intervention and post-intervention (n=53)

DASS(Stress)	**Pre-intervention**		**Post intervention**		**P value**
	m± SD	**Range**	**m± SD**	**Range**	
	15.25±9.95	0-30	9.28±2.99	0-15	0.000

* Significant change occurred p<0.05

Table 7.3 illustrates that there was an improvement in the stress level after the intervention according to the Wilcoxon matched pairs single rank test (p = 0.000). The pre-intervention mean score was (m=15.23; SD ±9.95), compared to the post-intervention mean score (m=9.28; SD ±2.99).

Table 7.4 The mean DASS (Stress) items pre- (n=53) and post- (n=53) intervention

DASS [Stress items]	**Pre-intervention**		**Post-intervention**		**P value**
	m± SD	**Range**	**m± SD**	**Range**	
I find myself getting upset by quite trivial things	1.55±0.97	0-3	0.4±0.49	0-2	0.000
I tended to overact to situations	1.15±1.17	0-3	0.57±0.57	0-2	0.001
I found myself in situations that made me so anxious	1.15 ±1.15	0-3	0.38±0.67	0-2	0.000

I found myself rather getting upset too easily	1.02±1.15	0-3	0.5±0.64	0-2	0.002
I felt I was using a lot of nervous energy	0.94±0.99	0-2	0.23±0.43	0-1	0.000
I find myself getting impatient when I am delayed in anyway	1.15±1.03	0-3	0.38±0.63	0-2	0.000
I felt I was touchy	0.21±0.49	0-1	0.11±0.32	0-2	0.218
I felt hard to wind down	0.81±0.86	0-2	0.25±0.43	0-1	0.000
I felt I was very irritable	0.92±1.05	0-3	0.34±0.52	0-2	0.000
I found it hard to calm down after something upset me	0.87±1.02	0-3	0.23±0.47	0-2	0.000
I found it difficult to tolerate interruptions to what I was doing	0.85±1.05	0-3	0.25±0.43	0-2	0.000
I was in a state of nervous tension	0.81±0.86	0-3	0.17±0.38	0-2	0.000
I was intolerant of anything that kept me from getting on with what I was doing	0.85±0.99	0-3	0.25±0.43	0-2	0.000
I found myself getting agitated	0.94±1.17	0-3	0.26±0.45	0-2	0.000

* Significant change occurred p<0.05

Table 7.4 describes the mean score of the individual items pre- and post-intervention. The analysis of the 14 individual Stress items before the intervention showed that, “I find myself getting upset by quite trivial things” had the highest mean score (*m*=1.55; ±SD 0.97) and the least score was “I felt I was touchy” (*m*=0.21; ±SD 0.49). After the intervention, “I tended to overreact to situations had the highest mean score” (*m*=0.57; ±SD 0.57) and the lowest was “I felt I was touchy” (*m*=0.11; ±SD 0.32).

Table 7.5 Stress scores pre-intervention and post-intervention (n=53)

DASS-Stress	Score	Pre-intervention		Post-intervention	
		Frequency	Percentage	Frequency	Percentage
Normal	0-14	24	45.3	45	84.9
Mild	15-18	9	17.0	8	15.1
Moderate	19-25	13	24.5	0	0
Severe	26-33	7	13.2	0	0
Extremely severe	34+	0	0	0	0

Table 7.5 details the results of the pre-test and post-test. Pre-intervention, a near average proportion of caregivers (45.3%, n=24) reported having normal stress levels, while the remaining proportion reported having mild (17%, n=9), moderate (24.5%, n=13), severe (7%, n=13.2) stress. No caregiver reported extremely severe stress. Post-intervention, most participants (84.9%, n=45) reported having normal stress, while 15.1%(n=8) reported mild stress.

7.4.4 Caregiver depression

The caregiver depression was measured with the DASS-depression. The results are presented as the overall caregiver depression, individual items, and the scoring on the scale. Table 7.6 presents the overall depression before and after the intervention. Table 7.7 describes the mean score of the individual items pre- and post-intervention. Table 7.8 presents the level of depression among caregivers before and after the CaWELLIS programme.

Table 7.6 Overall depression pre-intervention and post-intervention (n=53)

DASS(Depression)	Pre-intervention		Post intervention		P value
	m± SD	Range	m± SD	Range	
	10.91± 7.77	1-30	2.79±2.15	0-9	0.000

* Significant change occurred p<0.05

As illustrated in Table 7.6, there was an improvement in the depression level after the intervention according to the Wilcoxon matched pairs single rank test (p=0.000). The pre-intervention mean score was (m=10.9; SD ±1.77), compared to the post-intervention mean score (m=2.79; SD ±2.15).

Table 7.7 The mean DASS(Depression) items pre- (n=53) and post- (n=53) intervention

DASS items (Depression)	Pre-intervention			Post-intervention			P value
	m± SD		Range	m± SD		Range	
I couldn't seem to experience any positive feelings at all	.91	.925	0-3	.503	.401	0-2	0.000
I just couldn't seem to get going	.60	.768	0-2	.547	.648	0-2	0.029
I felt that I had nothing to look forward to	.75	.853	0-3	.412	.532	0-1	0.000
I felt sad and depressed	1.75	1.017	0-3	.480	.527	0-1	0.000
I felt that I had lost interest in just about everything	.66	.831	0-3	.323	.356	0-1	0.000
I felt I wasn't worth much as a person	.40	.660	0-3	.295	.342	0-1	0.001
I felt that life was not worthwhile	.36	.710	0-2	.423	.513	0-1	0.169
I couldn't seem to get any enjoyment out of the things I had	.79	.948	0-2	.409	.422	0-1	0.000
I felt down hearted and blue	1.40	.947	0-3	.395	.428	0-1	0.000
I was unable to become enthusiastic about anything	.79	1.063	0-3	.395	.401	0-1	0.000
I felt I was pretty worthless	.58	.949	0-3	.354	.394	0-2	0.001
I could see nothing in the future to be hopeful about	.85	.928	0-3	.320	.376	0-1	0.000
I felt life was meaningless	.30	.668	0-2	.342	.585	0-1	0.074
I felt it difficult to work up the initiative to do things	.75	.897	0-3	.445	.525	0-1	0.001

* Significant change occurred p<0.05

Table 7.7 indicates that when analysing the 14 individual depression items, before the intervention, "I felt sad and depressed" had the highest mean score (m=1.75; ±SD 1.02) and the lowest score was "I felt life was meaningless" (m=0.30; ±SD 0.66). After the intervention, "I just couldn't seem to get going" had the highest mean score (m=0.55; ±SD 0.65) and the lowest was "I felt I wasn't worth much as a person" (m=0.29; ±SD 0.29). The difference between the pre- and post-intervention scores for the individual items was all significant ($p<0.05$) with the exception of "I felt that life was not worthwhile" ($p=0.169$) and "I felt life was meaningless" ($p=0.074$).

Table 7.8 Depression scores pre-intervention and post-intervention

DASS-Depression	**Score**	**Pre-intervention**		**Post-intervention**	
		Frequency	Percentage	Frequency	Percentage
Normal	0-9	28	52.8	38	71.7
Mild	10-13	5	9.4	10	18.9
Moderate	14-20	12	22.6	5	9.4
Severe	21-27	7	13.2	0	0
Extremely severe	28+	1	1.9	0	0

Table 7.8 illustrates that pre-intervention, a larger proportion of caregivers (52.8%) reported having normal depression levels, while the remaining proportion (47.2%) reported having mild to extremely severe depression. Post-intervention, most participants (71.7%) reported having normal levels of depression, while 28.3% reported mild to moderate depression. No caregiver reported severe and extremely severe depression.

7.4.5 Caregiver anxiety

The results of the caregiver anxiety are presented in Tables 7.9, 7.10 and 7.11 as overall caregiver anxiety, individual items on the DASS Anxiety scale and caregiver anxiety score respectively.

Table 7.9 Overall anxiety pre-intervention and post-intervention

DASS(Anxiety)	**Pre-intervention**		**Post intervention**		**P value**
	m± SD	**Range**	**m± SD**	**Range**	
	8.85±7.94	0-27	2.62±1.93	0-8	0.000

As illustrated in Table 7.9, there was an improvement in the anxiety level after the intervention according to the Wilcoxon matched pairs single rank test (p=0.000). The pre-intervention mean score was (m=8.85; SD ±7.94), compared to the post-intervention mean score (m=2.64; SD ±1.93).

Table 7.10 The mean DASS(Anxiety) items pre- (n=53) and post- (n=53) intervention

DASS items (Anxiety)	Pre-intervention		Post-intervention		p-value
	m± SD	Range	m± SD	Range	
I was aware of dryness of the mouth	0.51±0.8	0-2	0.23±0.423	0-1	0.015
I experienced breathing difficulty	0.4±0.631	0-2	0.15±0.361	0-1	0.012
I had a feeling of shakiness	0.45±0.845	0-2	0.13±0.394	0-1	0.008
I found it difficult to relax	1.47±1.137	0-2	0.56±0.698	0-1	0.000
I had a feeling of faintness	0.38±0.657	0-2	0.13±0.345	0-1	0.011
I perspired noticeably in the absence of high temperature or physical exertion	0.77±1.086	0-2	0.25±0.477	0-1	0.000
I felt scared without any good reason	0.79±0.793	0-2	0.21±0.409	0-1	0.000
I had difficulty in swallowing	0.15±0.411	0-2	0.11±0.32	0-1	0.564
I was aware of the action of my heart	0.53±0.775	0-2	0.13±0.342	0-1	0.001
I felt that I was close to panic	0.68±0.956	0-2	0.09±0.295	0-1	0.000
I felt that I would be thrown by some trivial but rather unfamiliar task	0.62±0.82	0-2	0.21±0.409	0-1	0.002
I felt terrified	0.73±0.91	0-2	0.11±0.32	0-1	0.000
I was worried about situations in which I might panic and make a fool of myself	0.83±1.014	0-2	0.19±0.395	0-1	0.000
I experience trembling	0.57±0.821	0-2	0.13±0.342	0-1	0.001

Table 7.10 describes the mean score of the individual items pre- and post-intervention. When analysing the 14 individual Anxiety items, before the intervention, "I found it difficult to relax" had the highest mean score" (m=1.47; ±SD 1.13) and the least score was "I had difficulty swallowing" (m=0.15; ±SD 0.41). After the intervention, "I found it difficult to relax" had the highest mean score (m=0.55; ±SD 0.99) and the lowest was "I felt I was close to panic" (m=0.09; ±SD 0.29). The difference between the pre- and post-intervention scores for the individual items, were all significant ($p<0.05$) with the exception of "I had difficulty in swallowing", which had a p value of 0.564.

Table 7.11 Anxiety scores pre-intervention and post-intervention (n=53)

DASS-Anxiety	**Score**	**Pre-intervention**		**Pre-intervention**	
		Frequency	Percentage	Frequency	Percentage
Normal	0-7	30	56.6	50	94.3
Mild	8-9	4	7.5	2	3.7
Moderate	10-14	4	7.5	1	2.0
Severe	15-19	6	11.3	0	0
Extremely severe	20+	9	17.0	0	0

Table 7.11 presents the pre-intervention, a larger proportion of caregivers (56.6%) reported having normal anxiety levels, while the remaining proportion (43.4%) reported having mild to extremely severe anxiety. Post-intervention, most participants (94.3%) reported having normal levels of anxiety, whilst the 5.7% reported mild to moderate depression.

7.4.6 Caregiver burden

Caregiver burden findings is illustrated in three tables. Table 7.12 highlights overall care burden. Table 7.13 describes the individual items on the ZBI scale before and after the intervention. Table 7.14 describes the level of burden among caregivers before and after the CaWELLIS programme.

Table 7:12 Overall care burden pre-intervention and post-intervention

Caregiver ZBI	**Pre-intervention**		**Post intervention**		**P value**
	m± SD	**Range**	**m± SD**	**Range**	
	48.23±14.95	8-84	16.81±9.09	0-41	0.000

* Significant change occurred p<0.05

Based on Table 7.12 there was an improvement in the caregiver perceived burden after the intervention according to the Wilcoxon matched pairs single rank test (p=0.000) as illustrated in table 7.12. The pre-intervention mean score was (m=48.23; SD ±14.95), compared to the post-intervention mean score (m=16.81; SD ±9.09).

Table 7:13 The mean care burden items pre- (n=53) and post- (n=53) intervention

Caregiver ZBI Items	Pre-intervention		Post intervention		P value
	m± SD	Range	m± SD	Range	
Do you feel that your child asks for more help than he/she needs?	2.25±1.29	0-4	0.69± 0.64	0-2	0.000
Do you feel that because of the time you spend with your child that you don't have enough time for yourself?	2.53±4.48	0-4	0.85±0.69	0-2	0.000
Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?	2.89±1.23	0-4	1.00±0.73	0-2	0.000
Do you feel embarrassed over your child's behaviour?	1.42±1.28	0-4	0.74±0.65	0-2	0.001
Do you feel angry when you are around your child?	1.87±1.11	0-4	0.79±0.72	0-2	0.000
Do you feel that your child currently affects our relationships with other family members or friends in a negative way?	1.74±1.29	0-4	0.87±0.78	0-2	0.000
Are you afraid what the future holds for your child?	2.87±1.34	0-4	1.08±0.83	0-3	0.000

Do you feel your child is dependent on you?	2.85±1.34	0-4	0.91±0.79	0-3	0.000
Do you feel strained when you are around your child?	2.74±1.30	0-4	1.15±0.77	0-3	0.000
Do you feel your health has suffered because of your involvement with your child?	2.28±1.47	0-4	0.83±0.69	0-2	0.000
Do you feel that you don't have as much privacy as you would like because of your child?	1.74±1.29	1-3	0.74±0.79	0-2	0.001
Do you feel that your social life has suffered because you are caring for your child?	1.52±1.39	1-3	0.75±0.70	0-3	0.000
Do you feel uncomfortable about having friends over because of your child?	1.54±1.38	0-4	0.87±0.92	0-2	0.000
Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on?	2.17±1.34	0-4	0.66±0.73	0-2	0.000
Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?	3.30±0.93	0-4	0.58±0.66	0-4	0.000
Do you feel that you will be unable to take care of your child much longer?	2.42±1.23	0-4	0.69±0.77	0-3	0.000
Do you feel you have lost control of your life since your child's illness?	2.06±1.45	0-4	0.72±0.66	0-2	0.000
Do you wish you could leave the care of your child to someone else?	1.66±1.45	0-4	0.75±0.78	0-2	0.000
Do you feel uncertain about what to do about your child?	2.30±1.39	0-4	0.64±0.52	0-3	0.000
Do you feel you should be doing more for your child?	3.056±1.17	0-4	1.49±0.87	0-2	0.000

Do you feel you could do a better job in caring for your child?	3.13±1.07	0-4	0.69±0.64	0-2	0.000
Overall, how burdened do you feel in caring for your child?	3.23±1.25	0-4	0.85±0.69	0-3	0.000

Table 7.13 describes the mean score of the individual items pre- and post-intervention. The 22 individual caregiver burden item analysis indicated that before the intervention, "Overall, how burdened do you feel in caring for your child?" had the highest mean score" (m=3.23; ±SD 1.13) and the least score was "Do you feel embarrassed over your child's behaviour?" (m=1.42; ±SD 1.28). After the intervention, "Do you feel you should be doing more for your child?" had the highest mean score (m=1.42; ±SD 0.99) and the lowest was "Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?" (m=0.59; ±SD 0.66). The difference between the pre- and post-intervention scores for the individual items, were all significant($p<0.05$).

Table 7:14 Care burden pre-intervention and post-intervention

ZBI-burden	**Score**	**Pre-intervention**		**Pre-intervention**	
		Frequency	Percentage	Frequency	Percentage
Little or no burden	0-20	3	5.7	36	67.9
Mild to moderate	21-40	8	15.1	16	30.2
Moderate to severe	41-60	34	64.2	1	1.9
Severe	61-88	8	15.1	0	0.0

As presented in Table 7.14, during the pre-intervention, a larger proportion of caregivers (64.2%, n=34) reported having moderate to severe burden, while the remaining proportion reported having little or no burden (5.7%, n=3), mild to moderate (15.1%, n=8), severe (15.1%, n=8) anxiety. Post-intervention, most participants (94.3%) reported having normal levels of anxiety, whilst the 5.7% reported mild to moderate depression.

7.4.7 Caregiver somatic symptoms

The findings of the somatic symptoms are presented as overall, individual items and scoring range of the PHQ-15 scale in Tables 7.15, 7.16 and 7.17 respectively.

Table 7:15 Overall PHQ-15 pre-intervention and post-intervention

PHQ-15	Pre-intervention		Post intervention		P value
	m± SD	Range	m± SD	Range	
	10.57±6.30	0-23	3.40±2.06	0-9	0.000

As illustrated in table 7.15, there was an improvement in the caregiver somatic symptoms after the intervention according to the Wilcoxon matched pairs single rank test (p=0.000). The pre-intervention mean score was (m=10.57; SD ±6.30), compared to the post-intervention mean score (m=3.40; SD ±2.06).

Table 7:16 The mean PHQ-15 items pre- (n=53) and post- (n=53) intervention

PHQ-15 items	Pre-intervention		Post-intervention		P value
	m± SD	Range	m± SD	Range	
Stomach pain	0.64±0.653	0-2	0.09±0.295	0-1	0.000
Back pain	1.47±0.75	0-2	0.58±0.535	0-2	0.000
Pain in your arms, legs, or joints	1.6±0.768	0-2	0.57±0.572	0-2	0.000
Menstrual cramps	0.3±0.607	0-2	0.13±0.342	0-1	0.074
Headaches	1.4±0.631	0-2	0.43±0.572	0-1	0.000
Chest pain	0.51±0.75	0-2	0.02±0.137	0-2	0.000
Dizziness	0.66±0.732	0-2	0.15±0.361	0-1	0.000
Fainting spells	0.3±0.575	0-2	0±0	0-1	0.001

Feeling your heart pound or race	0.91±0.904	0-2	0.23±0.505	0-0	0.000
Shortness of breath	0.4±0.748	0-2	0.04±0.192	0-2	0.002
Pain or problems during sexual intercourse	0.15±0.456	0-2	0.04±0.192	0-1	0.107
Constipation, loose bowels or diarrhoea	0.55±0.722	0-2	0.21±0.409	0-1	0.004
Nausea, gas and indigestion	0.66±0.831	0-2	0.17±0.379	0-1	0.001
Feeling tired or having low energy	1.02±0.951	0-2	0.26±0.445	0-1	0.000
Trouble sleeping	1.55±0.722	0-2	0.47±0.541	0-2	0.000

Table 7.16 describes the mean score of the individual items pre- and post-intervention. The results obtained from the analysis of the 15 individual somatic symptoms items before the intervention indicated that "Pain in your arms, legs, or joints" had the highest mean score (m=1.60; ±SD 0.76), followed by "trouble sleeping" and "back pain" with mean scores of (m=1.55; ±SD 0.72) and (m=1.47; ±SD 0.75) respectively. The least score was "fainting spells" and "menstrual cramps" (m=0.3). After the intervention, "backpain" had the highest mean score (m=0.58; ±SD 0.54) and the lowest was "fainting spells" (m=0). The difference between the pre- and post-intervention scores for the individual items, were all significant($p<0.05$), with the exception of menstrual cramps($p=0.074$) and painful sexual intercourse($p=0.107$).

Table 7.17 Caregiver somatic symptoms pre-intervention and post-intervention

PHQ-15	**Score**	**Pre-intervention**		**Pre-intervention**	
		Frequency	Percentage	Frequency	Percentage
No	0-4	9	17.0	38	71.7
Low	5-9	17	32.1	15	28.3
Medium	10-14	9	17.0	0	0.0
High	15-30	18	34.0	0	0.0

Table 7.17 shows that pre-intervention, a larger proportion of caregivers (64.2%, n=44) reported having low to moderate caregiver somatic symptoms, while the remaining proportion reported having no somatic symptoms (5.7%, n=9). Post-intervention, most participants (n=38, 71.1%)

reported experiencing no somatic symptoms, whilst the 28.3% reported experiencing low somatic symptoms.

7.4.8 Social support

Caregiver perceived social support varied before and after the intervention on the three subscales as indicated in Table 7.18. Pre-intervention mean scores for family, friends and significant others subscales were (*m*=15.75; ±SD 7.86), (*m*=13.26; ±SD 6.67), and (*m*=15.11; ±SD 8.33) respectively. Post-intervention, the mean scores improved as for family, friends and significant others improved as (*m*=21.00; ±SD 3.56) (*m*=17.25; ±SD 5.06) (*m*=17.83; ±SD 5.35) respectively. The difference between the pre- and post-intervention scores for family and friends' subscales were significant. However, difference between the pre- and post-intervention scores for significant others subscale was not statistically significant (0.23).

Table 7:18 The mean MSPSS subscales and total pre- (n=53) and post- (n=53) intervention

MSPSS subscales and total	**Pre-intervention**			**Post-intervention**			**P value**
	m± SD		**Range**	**m± SD**		**Range**	
Family	15.75	7.86	4-28	21.00	3.56	11-28	0.000
Friends	13.26	6.67	4-28	17.25	5.06	8-28	0.000
Significant others	15.11	8.33	4-28	17.83	5.35	8-28	0.230
Total	44.13	19.41	12-84	56.08	10.03	37-84	0.000

Table 7:19 The mean MSPSS items pre- (n=53) and post- (n=53) intervention

MSPSS items	Pre-intervention			Post-intervention			P value
	m± SD		Range	m± SD		Range	
Family							
My family really tries to help me.	3.85	2.107	1-7	5.26	1.059	2-7	0.000
I get the emotional help and support I need from my family.	3.92	2.217	1-7	5.32	.956	2-7	0.001
I can talk about my problems with my family.	3.91	2.078	1-7	5.19	1.194	2-7	0.001
My family is willing to help me make decisions.	4.08	2.037	1-7	5.23	1.086	2-7	0.001
Friends							
My friends really try to help me.	3.13	1.765	1-7	4.19	1.494	2-7	0.002
I can count on my friends when things go wrong.	3.17	1.707	1-7	4.32	1.465	2-7	0.001
I have friends with whom I can share my joys and sorrows	3.60	2.124	1-7	4.36	1.374	2-7	0.018
I can talk about my problems with my friends.	3.36	2.030	1-7	4.38	1.259	2-7	0.000
Significant others							
There is a special person who is around when I am in need.	3.74	2.220	1-7	4.57	1.538	2-7	0.005
There is a special person with whom I can share my joys and sorrows.	3.74	2.271	1-7	4.47	1.395	2-7	0.011
I have a special person who is a real source of comfort to me.	3.91	2.247	1-7	4.30	1.488	2-7	0.247

There is a special person in my life who cares about my feelings.	3.74	2.132	1-7	4.49	1.353	2-7	0.016

Table 7.19 describes the mean score of the individual items pre- and post-intervention. The findings from analyzing the 12 social support items of the MSPSS before the intervention indicated that "My family is willing to help me make decisions." had the highest mean score (*m*=4.08; ±SD 2.03), followed by "I get the emotional help and support I need from my family" with mean score of (*m*=3.92; ±SD 2.22). The least score was "My friends really try to help me" (*m*=3.13; ±SD 1.76). After the intervention, "I get the emotional help and support I need from my family" had the highest mean score (*m*=5.32; ±SD 0.96) and the lowest was "I can talk about my problems with my friends" (*m*=4.19; ±SD 1.49). The difference between the pre- and post-intervention scores for the individual items, were all significant($p<0.05$), with the exception of "I have a special person who is a real source of comfort to me" ($p=0.25$).

Table 7.20 Relationship between social support and stress, anxiety and depression

	Family	Friends	Significant others	Social support [total]
Depression	-.282*	-.452**	-.618**	-.531**
	0.041	0.001	0.000	0.000
Anxiety	-0.167	-.418**	-.493**	-.406
	0.232	0.002	0.000	0.002
Stress	-0.255	-.483**	-.596**	-.421
	0.065	0.000	0.000	0.000

* Significant at 0.05 (2 tailed)

** Significant at 0.01 (2 tailed)

Table 7.20 indicates that there was a negative relationship between social support and anxiety, stress and depression. The caregivers' level of stress, anxiety and depression were found to decrease as the amount of social support increased and the relationship was statistically significant.

7.4.9 Cortisol test

The findings of the cortisol test conducted on the caregivers of children with DD are described in tables 7.21 and 7.22.

Table 7:21 Descriptive Information on Cortisol levels

	Pre-intervention		**Post intervention**	
	Morning	**Evening**	**Morning**	**Evening**
Minimum	119	42	100	40
Maximum	468	216	456	205
Mean	268.40	103.08	276.87	98.7
Std. Deviation	95.12	41.65	88.14	34.37

Table 7:22 Paired Samples Differences Test Between Pre-Test and Post-Test

Variable	**Mean**	**Std. Deviation**	**T**	**Df**	**p-value**
Cortisol level [Morning]	8.4717	60.31093	1.023	52	0.311
Cortisol level [Evening]	-4.37736	28.08382	1.135	52	0.262

The results as indicated in Table 7.21 shows that mean morning cortisol levels was high after the intervention whilst the mean evening cortisol was low after the intervention. The result also indicates that there was difference in the mean but the difference was not significant ($p > 0.05$) for the morning and evening cortisol level before and after the CaWELLIS Programme. This is described in table 7.22.

7.4.10 Blood pressure measurement

The pre and post-test results for caregivers' blood pressure is described in tables 7.22 and 7.23.

Table 7:23 Descriptive statistics of caregivers' blood pressure

	N	Minimum	Maximum	Sum	Mean	Std. Deviation
Pre-test systolic Bp	53	100	183	6922	130.60	17.924
Pre-test diastolic Bp	53	50	115	4399	83.00	12.591
Post-test systolic Bp	53	100	165	6663	125.72	13.196
Post-test diastolic Bp	53	55	96	4176	78.79	7.734

Table 7:24 Paired Sample test of caregivers' blood pressure

	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
				Lower	Upper	t	df	P-value
Pre-test and Post-test Systolic Bp	4.887	7.612	1.046	2.789	6.985	4.673	52	0.000
Pre-test and Post-test Diastolic Bp	4.208	8.342	1.146	1.908	6.507	3.672	52	0.001

The results as indicated in Table 7.23 shows that pre-intervention mean Systolic Bp and Diastolic Bp was 130.60mmHg and 83.00mmHg respectively. The post-intervention mean Systolic Bp and Diastolic Bp was 125.72mmHg and 78.79mmHg respectively. The result indicates that there was difference in the mean Systolic Bp before and after the CaWELLIS which was statistically significant (p =0.000). Likewise, table 7.24 indicates the difference between the mean Diastolic Bp before and after the CaWELLIS programme was statistically significant (p=0.001).

7.4.11 Caregiver/child demographics and caregiving outcomes

Caregivers gender and employment was positively correlated to depression, anxiety, stress and burden but was not statistically significant ($p > 0.05$). Educational status of caregivers was positively correlated to depression anxiety, stress and somatic symptoms but negatively correlated to burden. Thus, caregivers who are educated are likely to experience less burden and vice versa. Caregivers age was negatively correlated to depression, anxiety, stress, burden and somatic symptoms. However, the relationship among caregiver's age and depression [$p = 0.029$] and somatic symptoms were statistically significant [$p = 0.041$].

Marital status was negatively correlated to depression, anxiety, stress, burden and somatic symptoms. Child's age was negatively correlated to depression, anxiety, stress and somatic symptoms but positively correlated to burden. All relationships were statistically significant except for child's age and depression. Child's diagnosis was negatively correlated to depression, anxiety and stress but positively correlated to burden and somatic symptoms.

The correlation between caring years and the outcomes (depression, anxiety, stress, burden and somatic symptoms) was negative. Caregivers who had provided care for a long time were less likely to report stress, anxiety and depression. The relationship is significant [$p > 0.05$]. Caring hours positively correlated to depression, anxiety, stress, somatic symptoms and burden. The more caring hours spent, the more likely the burden, stress, anxiety, depression and somatic symptoms. The relationship between caring hours and stress [0.05], burden [0.033] and depression [0.034] was statistically significant.

Table 7.25 Caregiver/child demographics and caregiving outcomes

	Depression	Anxiety	Stress	Burden	Somatic symptoms
Age	-0.299*	-0.224	-0.245	-0.157	-0.282*
	0.029	0.106	0.077	0.261	0.041
Gender	0.126	0.059	0.071	0.143	0.209
	0.368	0.673	0.612	0.306	0.134
Educational background	0.146	0.077	0.165	-0.125	0.048
	0.298	0.586	0.238	0.374	0.734
Employment	0.011	0.145	0.08	0.203	0.234
	0.936	0.301	0.571	0.145	0.091
Marital status	-0.001	-0.026	-0.009	-0.123	-0.06
	0.993	0.855	0.948	0.381	0.669
Relationship to child	-0.091	0.039	-0.005	-0.019	-0.137
	0.516	0.782	0.97	0.894	0.326
Child’s age	-0.296*	-0.199	-0.207	0.005	-0.118
	0.032	0.154	0.136	0.971	0.4
Child’s gender	0.152	0.231	0.158	-0.057	0.251
	0.278	0.096	0.259	0.684	0.07
Child’s diagnosis	-0.069	-0.082	-0.116	0.108	0.008
	0.624	0.558	0.407	0.44	0.952
Caring years	-0.699**	-0.658**	-0.666**	-0.291*	-0.546**
	0.000	0.000	0.000	0.035	0.000
Caring hours	0.292*	0.244	0.271*	0.294*	0.251
	0.034	0.078	0.05	0.033	0.07

7.5 DISCUSSION

The findings of the study highlight that caregivers are affected by their caregiving role. Caregivers mainly reported stress, burden, which lead led to poorer caregiver outcomes like anxiety, and depression (Pearlin & Bierman, 2013). The SPM emphasizes that the caregiving is associated with negative health outcomes. However, resources like social support and coping could ameliorate the negative effects of caregiving (Pearlin & Bierman, 2013). Such resources, were the considered in the CaWELLIS programme.

7.5.1 Subjective caregiver stress using DASS [Stress]

The results indicated that the majority of caregivers reported mild to severe stress, this is consistent with the theoretical model of demands and support, where individuals who are found to be providing care are seen as stressed out. Other studies are consistent with the findings of the current study(Cantwell, Muldoon & Gallagher, 2014; Weitlauf *et al.*, 2014; Valicenti-Mcdermott *et al.*, 2015; Adib *et al.*, 2019). For example, Ramachandran, Vyas and Pothiyil (2020) reported that 64.3% of caregivers of children with mental disabilities [ASD, ID and ADHD] had severe levels of stress.

Stress levels were high prior to the support programme; levels were found to decrease after the pilot testing of the CaWELLIS programme, and the difference was statistically significant. The difference can be attributed to the fact that the CaWELLIS programme was aimed mostly at meeting the needs of the participants. In a randomised control trial involving family caregiver of patients with mental disorders, the findings showed that the total mean score of the perceived stress by the caregivers in the intervention group was significantly less than those in the control group, immediately and one month after the intervention (Hajisadeghian, Ghezelbash & Mehrabi, 2021).

The finding is in line with the study by Bazzano *et al.* (2013). They showed that MBSR adapted for parents and caregivers of individuals with DD can decrease the level of stress experienced. Callanan, Signal and McAdie (2021) also reported statistically and clinically significant changes in overall stress levels. Moreover, Vijayasamundeeswari, Sathiya and Poongodi (2020) reported a significant decrease in distress among caregivers after partaking in a brief group

psychoeducational programme. Fuller-Tyszkiewicz *et al.* (2020) reported a reduction in the level of stress after the intervention, which was statistically significant (b=-2.07; p=0.04).

7.5.2 Objective caregiver stress [Cortisol levels]

The CaWELLIS programme did not lead to any significant differences in the cortisol levels of caregivers. This is consistent with previous studies. In a systematic review and meta-analysis, Martins *et al.* (2020) reported that parenting training intervention did not have any effect on cortisol outcomes. Other studies have found that cortisol levels were affected in children after a training programme but not in caregivers (Slopen, McLaughlin & Shonkoff, 2014). Few studies have reported changes in the cortisol level for children but not adults (O'Brien et al., 2019). Though the finding was not significant, the effectiveness of the support programme on other variables or outcomes is well established.

Bernardi *et al.* (2018) in a cross-sectional study, did not find any relationship between salivary cortisol and stress among caregivers of patients with ASD. They conclude that the endocrine marker or biomarker cortisol may not be a good marker. They further state that the stress mechanism may be more complex and may be affected by a lot more factors than just the hormone. A study has also reported that caregivers may be more stressed than non-caregivers though there may not be an increase in the daily level of cortisol.

The way cortisol is measured could affect the findings of the study (Noushad *et al.*, 2021). For example, saliva samples for measuring cortisol do not measure "toxic stress" (Noushad *et al.*, 2021). In instances where saliva samples are used, to measure "toxic stress", they have to be repeated on several occasions over a number of weeks or months. Hair samples are considered a technique to get a more accurate measure of chronic stress (Noushad *et al.*, 2021). This is known not to be influenced by immediate concurred variables like the use of medicines. Cortisol estimation from urine, saliva and blood has some limitations. Thus, hair cortisol concentration is a useful tool for evaluating long-term cortisol levels. This is because, hair cortisol concentration (HCC) provides reliable measurements of hypothalamic pituitary adrenal (HPA) axis activity (Noushad *et al.*, 2021).

Emerging evidence has reported that apart from cortisol, other steroids undergo significant changes in response to stress (Bernardi *et al.*, 2018). Other hormones like Brain-derived neurotrophic factor [BDNF] (Issa *et al.*, 2010), Dehydroepiandrosterone [DHEA] (Dong and Zheng, 2012) and progesterone (Gaffey and Wirth, 2014) have been mentioned. For example, other studies have suggested that the cortisol-DHEA ratio is considered a better biomarker than cortisol or DHEA alone (Jeckel *et al.*, 2010).

7.5.3 Caregiver anxiety level

The findings of the current study showed that 43.4% caregivers reported mild to moderate anxiety. The majority (56.6%) did not report any level of anxiety. However, this should not create the impression that the current sample is free from anxiety. While Dave *et al.* (2014) found a high prevalence of anxiety among caregivers, Power *et al.* (2019) reported that caregivers and non-caregivers differed in their levels of anxiety. In the current study, the majority of caregivers of children may not have been observed to be anxious for several reasons. First, many caregivers experience anxiety at the early stages of diagnosis, when they are uncertain how the caregiving and diagnosis will unfold. All caregivers had passed the pre-diagnosis and diagnosis stages and were at the post-diagnosis stage. Additionally, at the initial stages, caregivers may lack adequate and appropriate information on the resources available and how to access those resources for maximum benefit. As time unfolds, caregivers will have identified one or two coping resources to use in their caregiving journey. In the current sample, most caregivers cared for children with DD with a mean age of 8.17years and caregivers had provided care for a duration of 3 years. Thus, during this period, caregivers might have adopted coping mechanisms to deal with the stressors associated with caregiving.

The findings indicated that caregiver anxiety significantly decreased after having access to the CaWELLIS programme for six weeks. In a study by Ashori, Norouzi and Jalil-Abkenar (2019), the effectiveness of a positive parenting programme was observed on the mental health of mothers who cared for children with intellectual disabilities. In their study, two groups comprising intervention and control groups were used. The findings of the study indicated that the pre-test mean and SD for the intervention group were 10.15±1.12 and 10.15± 1.20 respectively. The post-test was 7.20±1.84 and 10.00±0.99 for the intervention and control groups respectively. The difference was found to be significant (p=0.001).

In congruent with the above, Dykens *et al.* (2014) found that the MBSR programme led to less anxiety in mothers of children with ASD. Similarly, caregivers of children with ASD reported that parents had significant improvement in their levels of anxiety after the CARES programme which targeted the social, emotional and psychological challenges. Approximately, participants reported anxiety before the intervention and 35% after the intervention. The differences were significant (X^2=22.15, p<0.001).

On the contrary, Jones *et al.* (2018) found that differences existed between the pre-intervention mean scores [11.55±3.62] and post intervention mean scores [10.55±4.02] after parents of children with ASD and other related disabilities had gone through a Mindfulness-based Well-being course. However, the differences were not statistically significant (p=0.204). In line with the above study, Fuller-Tyszkiewicz *et al.* (2020), in a randomised control trial involving 183 caregivers of individuals with mental and physical disabilities were allocated to intervention (n=73) and control group (n=110). In their study, StressLess, a 5-week, self-directed intervention was rolled out. The findings of their study indicated that there were differences between the control group [pre-intervention, 8.14± 6.76; post intervention, 8.61± 6.90] and the intervention group [pre-intervention, 7.56±7.60, post-intervention, 6.11±5.86]. However, the differences in anxiety scores after the intervention was not significant. Additionally, they observed that the changes in the symptoms were in the opposite direction. While the intervention group saw improvement, for the control group, the symptoms worsened.

Picard, Morin and De Mondehare (2014) after a psychosocial programme, reported that the experimental and control groups differed on the mean score of anxiety, but the differences were not statistically significant. The researchers concluded that the small sample size used may have limited the statistical power of the analysis. Additionally, the instruments used for measuring anxiety may not be sensitive enough to detect little changes (Dave *et al.*, 2014; Minichil *et al.*, 2019; Power *et al.*, 2019).

7.5.4 Caregiver depression

Though the majority of caregivers in the current study reported a normal level of depressive symptomatology (52.8%) and the remaining reported mild to extremely severe depression (48.2%), the proportion with depression was higher than studies that have been done in some

countries. The following low prevalence have been reported in Mexico 22.7% (Pineda-Frutos *et al.*, 2016) and Texas 19% (Resch, Elliott & Benz, 2012). On the contrary, other studies have reported high prevalence ranging from 56.2% to 79% (Dave *et al.*, 2014; Minichil *et al.*, 2019; Power *et al.*, 2019). Variation in the inclusion criteria may contribute to the differences observed among studies. For example, in the current study, caregivers were included if their child with DD was aged between 5 and 14 years. However, with the study done in Texas, caregivers of children aged between 5 and 21 years were included. Furthermore, the difference could be attributed to a number of sociocultural factors. The perception of caregiver's role is likely to influence caregivers' mood positively and their interpretation of the situation. Again, the differences in the tools used to measure depression could explain the variability. The current study used DASS; others studies have used DASS, BDI, PHQ-15 and Zung's self-rating anxiety and depression scale (Resch, Elliott and Benz, 2012; Dave *et al.*, 2014; Pineda-Frutos *et al.*, 2016).

The findings on the measure of depression pre-intervention and post-intervention indicated that caregiver depression significantly decreased after having access to the CaWELLIS programme for six weeks. Several studies have reported similar results (Neece, 2014; Ashori, Norouzi and Jalil-Abkenar, 2019; Mills *et al.*, 2021). Parents of children with DD were recruited in a randomised control trial to assess the feasibility of a brief mindfulness-based programme, the findings indicated that parents had significant improvements in depression [F (1,176) =8.017, P=0.01] (Ashori, Norouzi & Jalil-Abkenar, 2019). Similarly, Mills et al. administered a group-based intervention, CARES programme, to parents of children with Autism over a period of six weeks. The findings indicated a significant decrease in depression post intervention. In their study, 60% of participants indicated depression pre-intervention and 41%, post-intervention. The difference between pre-intervention and post-intervention were significant (X^2=7.20, p=0.01) (Mills *et al.*, 2021). Similarly, Neece recruited 46 parents of children with DD and randomly assigned them to the treatment and waist list control groups. Participants in the treatment group received MBSR. They reported that the intervention group had decreased levels of depression (Neece, 2014).

Contrary to the findings above, a study conducted by Jones *et al.*, (2018) did not find any statistically significant changes after parents of children with ASD and other developmental disabilities underwent a six-week training programme [p=0.459]. They concluded that, though no statistically significant changes were observed, improvements were observed in the effect sizes.

They opine that the sample size in their study was small, so using statistical significance alone as a measure of outcome to judge and conclude that there was lack of treatment effect may be inaccurate. Furthermore, they reported that the relatively moderate levels of depression observed in their sample, may be contributing to the small changes in depression scores.

7.5.5 Caregiver burden

Majority of caregivers (64.2%) reported having a moderate to severe burden. There is a wide range of evidence that suggests that burden is prevalent among caregivers of children with disabilities than non-caregivers (Koehler *et al.*, 2014; Barros *et al.*, 2017). Vogan *et al.* (2014) reported that 54.9% of caregivers of people with ASD experienced high levels of burden. Contrary to the studies above, some studies did not report a significant burden in caregivers of children with disabilities. One study found that only 30% reported intense burden, the majority 56.4% were without burden whilst only 13.6% had a mild burden (Pineda-Frutos *et al.*, 2016).

The findings on the measure of caregiver perceived pre-intervention and post-intervention indicated that caregiver burden significantly decreased after having access to the CaWELLIS programme after six weeks. González-Fraile *et al.* (2019) examined the efficacy of psychoeducational intervention among caregivers of people with intellectual disabilities using randomized control trial. The findings showed that the difference between the intervention and control group at four month and eight months follow-up was not statistically significant. In consistent with the above, Hassiotis *et al.* (2011), after an applied behaviour analysis on caregivers, reported that though caregiver burden improved, the effect was not statistically significant. On the contrary, Magaña *et al.* (2015), after By Caring for myself, I can care programme on Latina mothers of youth and adults with intellectual developmental disabilities reported that though the intervention and control group were similar on the mean burden score, the two groups differed significantly.

7.5.6 Caregiver somatic symptoms

Caregivers in the current study reported medium level of somatic symptoms. Some studies have revealed that caregivers experience poorer physical health than non-caregivers (Eisenhower, Bakera & Blacher, 2009; Eisenhower, Blacher & Baker, 2013; Fairthorne, De Klerk & Leonard,

2015). Item analysis indicated that the common caregiver symptoms were pain in arms, legs or joints, trouble sleeping, backpain, headaches and feeling tired or having low energy. Backpain is reported by several studies (Yiengprugsawan *et al.*, 2012; Habib *et al.*, 2014; Neves, Pietrovski & Claudino, 2015; Suzuki, Tamakoshi & Sakakibara, 2016; Zamora & Labao, 2020). Low back pain is considered as a common musculoskeletal symptom in caregivers (Suzuki, Tamakoshi & Sakakibara, 2016). Vincent *et al.* (2021) and Gallagher, Phillips and Carroll (2010) have also reported poor sleep among caregivers. In addition, other studies have reported high level of fatigue among caregivers (Giallo *et al.*, 2013; Giallo, Rose and Vittorino, 2011; Seymour *et al.*, 2013).

The findings in the current study could be due to several reasons. First, caring for a child with a disability may lead to physical strain that produces musculoskeletal injury and may also lead to an exacerbation of chronic illnesses such as arthritis. Second, there may be undesired alterations in health-related behaviours, including the caregiver's eating habits and exercise. Third, psychological distress could affect the caregiver physiologically, contributing to their vulnerability to infectious agents. Fourth, there may be modifications in sympathetic arousal and cardiovascular reactivity that increase the risk of cardiovascular disease, like high blood pressure.

The current study also found that caregivers somatic symptoms decreased after the CaWELLIS programme. This is consistent with other studies. Ashori, Norouzi and Jalil-Abkenar (2019) reported that the triple P training had a significant effect on the somatic symptoms of caregivers. More specifically, Millstein, Lindly, Luberto, Giselle, *et al.* (2020) reported that parents of children with DD showed an increase in the average hours of sleep. In the same study, there was a greater reduction in perceived fatigue after the intervention. Dykens *et al.* (2014) in line with the studies, reported improved sleep among caregivers. Ullas *et al.* (2021) found sleep quality had improved after the intervention.

7.5.7 Social support

Perceived social support improved after the intervention. The difference the between pre- and post-test scores was statistically significant. Previous studies posit that perceived social support and not the quantity of support (Benson, 2012; Werner and Shulman, 2013) affects the mental health of caregivers of children with disabilities (Benson, 2012). More specifically, high social support has been linked with decreased stress (Lima, Cardoso and Silva, 2016; Wang, Huang and Kong, 2017),

burden (Wijesinghe *et al.*, 2015), general health (Diaz et al., 2019), anxiety (Toledano-Toledano and Moral de la Rubia, 2018) and depression (Feldman *et al.*, 2007; Minichil *et al.*, 2019). The findings of the current study showed that high levels of social support was linked to decreased stress, anxiety and depression.

7.5.8 Caregiver blood pressure

The findings of the current study showed that caregivers had elevated blood pressure. Other studies have reported elevated levels of blood pressure among caregivers (Yamaki, Hsieh & Heller, 2009; Ice *et al.*, 2012). Gallagher and Whiteley (2013), using an ambulatory blood pressure apparatus reported that objective blood pressure was higher in caregivers than non-caregivers. The prevalence of hypertension in Ghana was reported at 35% (Atibila *et al.*, 2021). A report by the Ministry of Health indicates that 50% of all adults in Ghana have hypertension (Ministry of Health, 2012).

Caregivers may not be aware of their elevated blood pressure because, when asked to indicate the presence of an underlying health condition, the majority of them indicated none. A survey by the Ghana Demographic and Health Survey indicated only 45.6% of people in Ghana are aware of their blood pressure status (Ghana Statistical Service (GSS), 2013). Similarly, Beaney *et al.* (2019) reported that 59.5% of people were unaware of their hypertensive status. In congruent with the above, Tannor *et al.*, (2022) reported that 66.8% of participants did not know they were hypertensives. Caregivers not being aware of their blood pressure status is a cause for concern because elevated blood pressure is considered a major risk factor for stroke, heart failure, and chronic kidney disease (Shlomai *et al.*, 2013).

The CaWELLIS Programme was observed to have influenced the blood pressure of caregivers. Differences were observed in the mean pre- and post-intervention systolic and diastolic blood pressure levels of the caregivers. The CaWELLIS programme targeted several areas of the caregivers' life. For example, caregivers were made to understand stress and taken through stress management practises. A study has found that adequate stress management could control elevated blood pressure levels (Lui et al., 2017).

7.6 SUMMARY

Chapter seven presented the results of the pretesting, piloting and post-testing. Descriptive and inferential statistics were used to analyse the data and the findings presented in tables. The findings of the pre-test showed that caregivers had elevated levels of stress, burden, anxiety, depression, and somatic symptoms. The post-test after the CaWELLIS Programme indicated that stress, burden, depression, anxiety and somatic symptoms decreased. In the final chapter, the study will be justified, the limitations presented, recommendations will be made and conclusions drawn.

CHAPTER EIGHT

SUMMARY OF THE STUDY, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

8.0 INTRODUCTION

Chapter seven, the previous chapter, highlighted on the pre-test, pilot testing of the CaWELLIS programme. The final chapter of this thesis highlights the summary of the findings in the study, the recommendation, limitations and conclusion.

8.1 SUMMARY OF FINDINGS

The theoretical underpinning of this study was the Stress Process Model, and was organised in three phases. Phase one examined the needs of caregivers and the interventions that have been done to support caregivers in meeting their needs. Phase two involved developing a CaWELLIS programme through triangulation of data from phase one and confirming the programme through expert review. In phase three, the CaWELLIS programme for caregivers of children with developmental disabilities was pilot tested.

Phase 1a: Phenomenological study

Phase 1a of the study was done using a phenomenological descriptive design to explore the experiences and health needs of the caregivers of children with DD. Data saturation was achieved with 14 participants. Five themes and 17 sub-themes were generated. The findings indicated caregivers had a negative perception of caregiving as many observed that it was stressful and time-consuming. They attributed these negative perceptions to the stressors associated with their caregiving role. It is therefore not surprising that stressors were the second theme that was generated. Five sub-themes were generated from the stressors including child's ADL needs, communication barriers, managing behaviour problems, unmet educational needs, and child's health needs.

The above stressors had negative consequences for caregivers; thus, the third theme which was generated. Three sub-themes were generated, namely: decline in physical, mental and social well-being. Physically, pain-related changes, fatigue, and compromised sleep were reported. Decline in

emotional/mental well-being included decreased concentration, anger, sadness and anxiety about the future. Being overwhelmed by caregiving may require that caregivers adapt methods and strategies to deal with the stressors they face each day in their journey of caregiving. Coping strategies was the fourth theme that was generated. Caregivers used adaptive coping strategies like prayer, self-encouragement as well as support from immediate family and maladaptive strategies like blaming themselves and others. The last theme generated was caregiver needs, including informational, financial, psychospiritual, and social support needs.

Phase 1b: Scoping review

A scoping review guided by the Arskey and O'Malley methodological framework as well as the Joanna Briggs Institutes' guidelines was conducted in Phase 1b. Based on the inclusion criteria, n=2,165 studies were retrieved. After duplicates were removed, records were screened and full text articles were assessed for eligibility. Nineteen full text studies were included in the scoping review. The quality assessment of these studies was done using the JBI Critical Appraisal Checklist and revealed that the studies were either quasi experimental studies or randomised control trials. Analysis of the review showed that the duration of most interventions was between four and eight weeks. Additionally, interventions were mindfulness-based, parent training, cognitive behaviour, resilience-based, spirituality-integrated and exercise-based interventions. Experts used for the delivery of the intervention were mostly health professionals, followed by trained intervention experts and peer facilitators or mentors. Most of the interventions were delivered face to face while two were done virtually and one was a blended approach. The studies reported interventions led to positive changes in stress, anxiety, depression, somatic symptoms and burden.

Phase 2a: Development of the CaWELLIS Programme

Phase 2a involved the development of a psychosocial programme guided by the MRC framework. Three stages of the development phase of the framework were utilised including identifying the evidence base, identifying or developing theory and modelling the process and outcome. In identifying the evidence base, the phenomenological study and scoping review from phase one were used. The theme and subthemes from the phenomenological study informed the objectives

and components of the support programme. The scoping review informed the objectives, components and design of the support programme.

In identifying or developing the theory, the Stress Process Model (SPM) was utilised. The SPM explained the mechanism of action within the causal chain of factors associated with caregiving stress. The last stage is modelling the process and outcome. The first step in modelling the process and outcome involved identifying the components of the support programmes. Data triangulated from the phenomenological study and scoping review was used to generate the components of the support programme. A total of 31 items were generated.

Phase 2b: Expert review (confirmation of the CaWELLIS programme)

The second step in modelling the process and outcome was reducing and refining components of the support programme. A Delphi technique consisting of two rounds was done using experts like nurses, doctors, psychologists, caregivers, researchers, and psychiatrists. The review saw a reduction of the components from 31 to 20, which constituted the final Caregiver Well-being Improvement Support (CaWELLIS) Programme.

Phase 3: Implementation phase [Pre-test, piloting and post-test]

The final phase of the study involved pre-testing, pilot testing and post-testing. A total of 53 participants were recruited via simple random sampling and pre-tested on the caregiver outcomes. The primary outcome of the study was stress. The secondary outcomes include burden, anxiety, depression, cortisol level and blood pressure. The pre-test showed that caregivers reported elevated levels of stress, anxiety, depression and blood pressure.

The pilot test was done with 53 caregivers over a period of six weeks with a total of six modules. Each module lasted approximately 120 minutes.

8.2 CONCEPTUAL FRAMEWORK OF THE STUDY

The framework described in Figure 8.1 highlights the key variables in the study and how they are related. The framework comprises of how caregivers appraised their caregiving role, background and context of caregivers and children with DD. It also illustrates caregiver stressors and how they

impact on caregiver well-being. Caregiver needs and their coping mechanism is outlined in the framework. Furthermore, the framework illustrates how the CaWELLIS programme is linked to the other components described above. Figure 8.1 described the conceptual framework of the study.

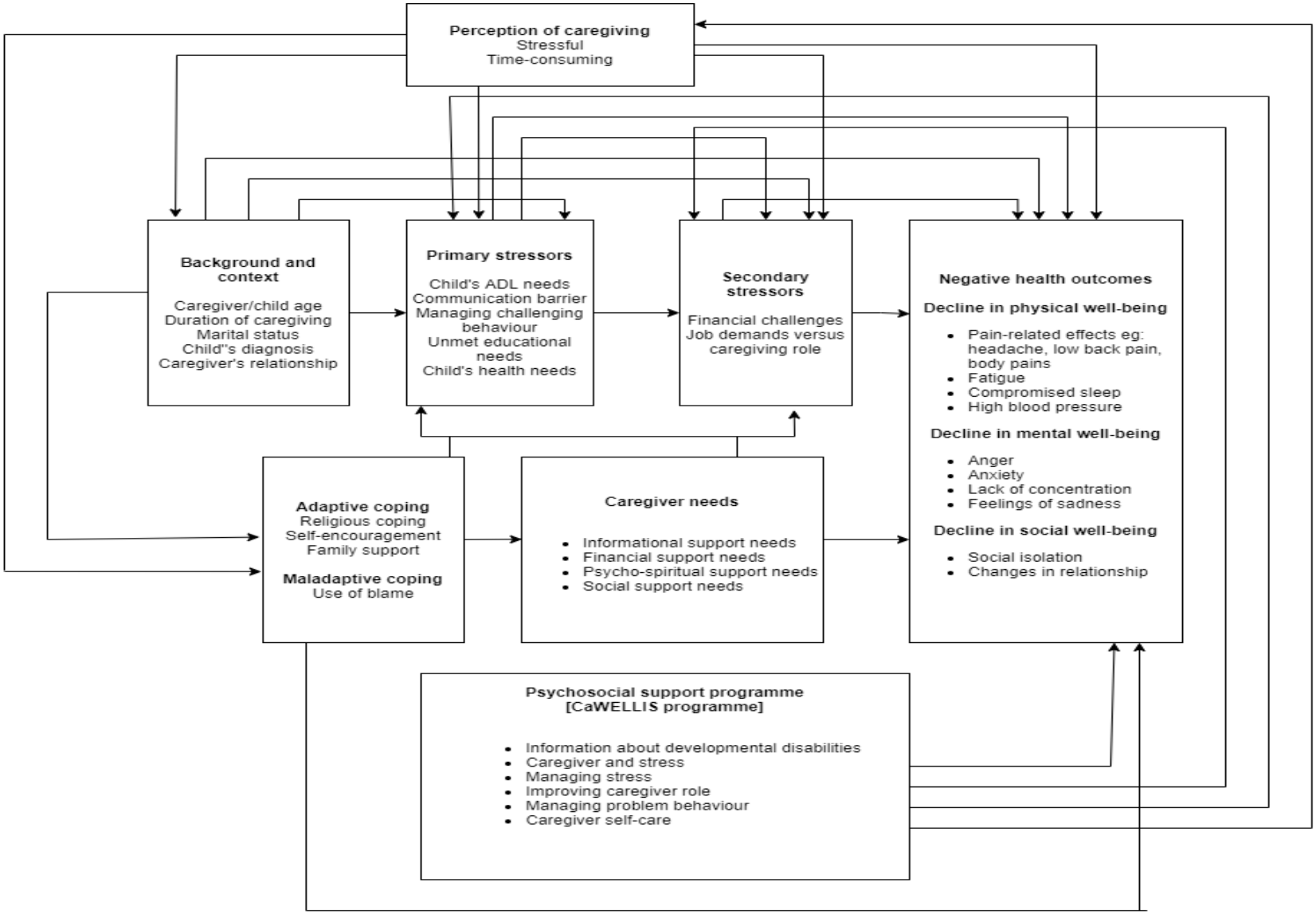

Figure 8.1: Conceptual Framework

8.3 JUSTIFICATION OF THE STUDY

The purpose of the study was to improve the well-being of caregivers of children with DD in the Ghanaian context through the development of a psychosocial support programme. This study successfully achieved the development of the support programme as presented in Chapter six. Achieved were the objectives described below:

i. Exploration of the experiences and health needs of caregivers of children with DD (Phase 1-Chapter 4).
ii. Description of the support programmes implemented for caregivers of children with DD and their outcomes using a scoping review (Phase 1- Chapter 5).
iii. Development of a psychosocial support programme for caregivers of children with DD using the MRC framework for the development of complex interventions (Phase 2- Chapter 6).
iv. Verification and confirmation of the psychosocial support programme through expert review (Phase 2-Chapter 6).
v. Conducting a baseline assessment of caregiver well-being using outcomes such as stress, burden of care, anxiety, depression, somatic symptoms and perceived social support (Phase 3-Chapter 7).
vi. Pilot testing of the CaWELLIS Programme in caregivers of children with DD (Phase 3-Chapter 7).
vii. Evaluating caregiver well-being using outcomes such as stress, burden of care, anxiety, depression, somatic symptoms and perceived social support after the CaWELLIS programme (Phase 3-Chapter 7)

8.4 LIMITATIONS OF THE STUDY

The study has some limitations:

i. The use of self-report measures is not the gold standard, and multi-modal or multi-informant assessments are more preferable. Though a biomarker [cortisol test] was used, most of the measures were self-reported. The ratings on self-report measures could improve

just because participants are taking part in an intervention. Self-report measures could lead to reporting biases, potential type II errors and skewing of the results.

ii. Some caregivers declined to participate in the study. Those who declined to participate may have poorer outcomes than the current sample included in the study. Thus, the findings may not have been the same if they were included.

iii. The translation of the interview transcripts was done from Twi to English, this carries inherent limitations that need to be acknowledged. Some words in Twi do not have direct translation in English; in some cases, words near in English meaning are used or adopted to (re)present participants' experiences.

iv. Though the study aimed at conducting a follow-up after three months, the financial constraints and limited time availability of caregivers made it impossible. Therefore, a follow-up was not conducted.

8.5 IMPLICATIONS OF THE STUDY

The implications of the research findings are multifaceted, reflecting the complexity of caregiving roles, the impact of these roles on caregivers' health and well-being, and the potential benefits of support programmes. Key implications of the study are as follows:

Health and well-being of caregivers: High stress and burden can significantly impact the physical and mental health of caregivers, potentially leading to issues like depression, anxiety, burnout, and even physical health problems. This necessitates enhanced support systems and interventions targeted at caregivers' well-being.

Quality of care: The well-being of caregivers directly affects the quality of care provided to children with developmental disabilities. Stressed and burdened caregivers may find it challenging to engage effectively in the care and support their children need, potentially impacting the children's developmental outcomes.

Economic impact: The stress and burden on caregivers can have economic implications, including lost productivity, increased healthcare costs for caregivers, and potential long-term costs associated with inadequate support for both the caregivers and the children with developmental disabilities.

Policy and service provision: These findings underscore the need for policies and services that support caregivers, such as respite care, counselling, support groups, and financial assistance. Recognizing the role of caregivers is crucial in the development of inclusive policies that support the whole family.

Awareness and social support: The findings highlight the need for increased societal awareness and understanding of the challenges faced by families of children with developmental disabilities. Enhancing community support mechanisms and reducing stigma can play a critical role in improving the lives of both caregivers and their children.

Research and intervention development: The findings should encourage further research into effective interventions that can alleviate the stress and burden on caregivers. This includes developing and testing support programs tailored to the unique needs of these families.

Professional training: There is an implication for the training of professionals (e.g., educators, healthcare providers, social workers) to ensure they are equipped to recognize and address the needs of families of children with developmental disabilities, including the provision of resources and support for caregivers.

In summary, recognizing and addressing the stress and burden reported by caregivers of children with developmental disabilities is crucial for the well-being of both the caregivers and the children they support. It calls for a comprehensive approach that includes policy changes, support services, community awareness, and ongoing research.

8.6 RECOMMENDATIONS

Based on the findings that caregivers of children with developmental disabilities experience significant stress and a decline in well-being, and that support programs can alleviate these issues, recommendations are structured under the specified headings:

8.6.1 Policy makers:

Adoption and modification of CaWELLIS programme:

Policy makers like the Ministry of Health and the Ghana Health Service should adopt and replicate the psychosocial support programme in other settings with similar characteristics. For those with different characteristics, the CaWELLIS programme should be adopted and modified.

Enhancing funding and resources:

Government should allocate more resources and funding to develop and sustain support programs for caregivers. This could include grants for mental health services, respite care, and community support initiatives.

Government through the Ministry of Health should offer direct financial assistance to caregivers, such as grants, subsidies, or stipends, can help alleviate the economic burden of caregiving. This assistance might cover costs associated with medical care, transportation, home modifications, or daily living expenses, making it easier for caregivers to provide the necessary care without compromising their financial stability.

The Ministry of Health with the support of other stakeholders should allocate funding to develop comprehensive online portals, help lines, and other information resources that guide caregivers to the support and services they need. This can include creating materials in multiple languages and formats to ensure accessibility for all caregivers, regardless of language proficiency or disability.

The government should invest in technological solutions that support caregivers. This might involve developing telehealth services for remote consultations, mobile apps for managing care schedules and medical information, or innovative assistive devices to help care recipients with daily tasks.

Legislation for caregiver support:

There should be a legislation that can formally recognize the role of caregivers, affirming their importance and the challenges they face. This recognition can pave the way for more targeted support programs and resources.

Laws should be made to mandate the provision of specific types of support for caregivers. This might include financial assistance, such as tax credits or direct subsidies; access to healthcare services for caregivers themselves; and funding for respite care, which offers temporary relief from caregiving responsibilities.

Legislation should provide employment protections for caregivers, ensuring they do not face discrimination or job loss due to their caregiving responsibilities. This can include the right to request flexible working arrangements, protection against unfair dismissal, and entitlements to caregiver leave, similar to parental leave policies.

Laws that require that caregivers have access to training and educational resources to help them provide the best possible care should be enacted. This could include training in specific medical or behavioral management techniques relevant to the needs of the individuals they care for.

Legislating for caregiver support, governments should ensure that support services are not only available but are also accessible to all caregivers, regardless of their location, income, or the specific needs of the individual they care for.

Promoting inclusive policies:

Promoting inclusive policies means creating and implementing policies that recognize and cater to the diverse needs of all caregivers, regardless of their background, identity, or circumstances. There should be a policy which should include provisions for language translation services to ensure that non-English speaking caregivers have equal access to support programs.

A policy that might address the specific needs of low-income families by providing financial assistance or subsidies for caregiving supplies and services should be developed.

Changing eligibility criteria for programs, adjusting how services are delivered (such as offering virtual support groups to accommodate those who cannot attend in person), or ensuring facilities are accessible to caregivers with disabilities could remove barriers that prevent certain groups of caregivers from accessing support.

Ensuring that the voices and perspectives of diverse caregivers are included in policy-making processes. This can help to ensure that the policies developed are truly reflective of the needs of all caregivers, not just a subset.

8.6.2 Nursing practice:

Integrating caregiver assessments:

A brief screening tool should be developed. Thus, screening should be conducted on caregivers during regular attendance at the specialised clinic with their children with DD. The screening will be able to identify at-risk caregivers and refer them to the appropriate unit for appropriate services and support.

Offering direct support and referrals:

Nurses should be equipped to offer direct support to caregivers and make referrals to specialized support services. This includes counselling, support groups, and respite care.

Adopting family-centered care approach:

Nurses should embrace a care approach that considers the needs and well-being of the entire family, not just the child with a developmental disability. This includes educating caregivers about managing stress and accessing support services.

Equipping caregivers:

Well-structured information should be provided for caregivers at every stage of the disease trajectory, before, during and after diagnosis. The information should be simple yet explicit. The information document could be developed in English and translated into several Ghanaian languages. The essence is to reach out to majority of caregivers regardless of their educational status.

8.6.3 Nursing education

Incorporating caregiver support into curricula:

The nursing curricula should include comprehensive training on the needs of caregivers, the impact of caregiving on their well-being, and strategies for supporting them.

Focusing on communication skills:

Student nurses should be taught effective communication strategies that will enable nurses to engage with caregivers empathetically, providing them with the support and information they need.

Promoting interdisciplinary learning:

The curricula should be designed such that it fosters interdisciplinary learning that includes social work, psychology, and other fields relevant to providing holistic support to families of children with developmental disabilities.

8.6.4 Nursing research

A larger sample size should be used and a randomised control trial can be utilised. Randomised control trials provide the strongest evidence for treatment efficacy. It is likely to minimise allocation and selection biases.

Follow-up studies should be conducted. To be able to determine the maintenance of the changes that an intervention or support programme produces on outcomes, it would be appropriate to do a follow-up.

Budgeting allocation from internally generated funds should be made available at institutional levels, or district health funds as seed amount to fund research on children with DD; or there should be application of waivers for ethics fees or create stakeholder engagement opportunities for family caregivers in child health care delivery.

8.7 CONCLUSION

The purpose of this study was to develop a psychosocial support programme to improve the well-being of caregivers of children with DD in Ghana. This is the first study done in Ghana that developed a psychosocial support programme based on exploring the experiences and needs,

conducting a scoping review, and integrating the results. Overall, guided by the MRC framework, 20 items were generated for the Support Programme, which was referred to as the CaWELLIS Programme. The 20-item CaWELLIS programme was further divided into six modules, namely: information about DD, caregiver and stress, managing stress, managing challenging behaviour, equipping the caregiver and caregiver self-care. The CaWELLIS Programme which was run face-to-face over a period of six weeks, demonstrated that the general well-being of the caregivers of children with DD improved. The primary outcome of the study, stress, was observed to have reduced significantly after the programme was piloted, as indicated on the DASS [Stress], a subjective measure of stress. On the contrary, the cortisol level, an objective biomarker of stress, did not show any statistically significant difference after the support programme, though differences existed between scores. The other secondary outcomes [burden, anxiety, depression, somatic symptoms and social support] showed improvements after the CaWELLIS programme and the differences between the pre- and post-test scores were significant. In conclusion, the context-specific CaWELLIS programme, has demonstrated great prospects in improving the well-being of caregivers and should be considered an effective programme to support the well-being of caregivers of children with DD.

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APPENDICES

Annexure A: Caregiver Well-being Improvement Support [CaWELLIS] Programme

INTRODUCTION

Even though caregivers provide care with an open heart for the child, caring for a child with disability may impact negatively on the caregiver. Consequently, caregiving negatively affects the care recipient (children with developmental disabilities [DD]) well-being as well. In short caring for the caregivers directly improves the quality of care provided to the child. The child with DD does not need just any care but quality care from caregivers and this can only be achieved when the wellbeing of caregiver is

PURPOSE OF THE MANUAL

Globally, the prevalence of developmental disabilities is high and the problem is even more prominent in developing countries including Ghana. The systems and structures are such the informal caregiver who has a close relation with the child is the one who takes over the caregiving role in instances where a diagnosis of DD is established. The health of the child with DD largely relies on the well-being of the caregiver. There are a lot of training or support programmes or interventions globally designed for caregivers of children with DD especially where there is enough evidence suggesting the well-being of the caregiver is compromised as a result of the caregiving role. Majority of these training or support programmes or interventions were developed for use in developed countries and some have been applied in developing countries. Previous studies have highlighted the need to contextualize such trainings or support programmes or interventions to get the best out of them. Thus, this psychosocial support programme has been designed to provide support to the caregivers of children with DD attending the Neurodevelopmental Clinic at the Korle-Bu Teaching Hospital in the Greater Accra Region of Ghana. The psychosocial support programme comprises of 6 main modules, these modules were specifically designed to address various needs of caregivers identified through the

phenomenological interviews and scoping review [details of in chapter five] including informational, social support, psychological/emotional, and physical needs. The structure of the Psychosocial Support Programme and how the various contents were arrived at is described in chapter six.

OBJECTIVES OF THE PSYCHOSOCIAL SUPPORT PROGRAMME

The objectives of the CaWELLIS Programme for Caregivers of children with DD were:

1) To provide information for caregivers regarding DD which will help demystify the myths and stereotypes associated with DD.
2) To educate caregivers on the mechanism of stress, its physical emotional, cognitive impact on the caregiver.
3) To provide caregivers strategies on management of stress.
4) To equip the caregiver with role performance skills that will assist them in caring for the child with DD.
5) To equip caregivers with skills to identify and manage behavioural problems associated with children with DD.
6) To empower the caregiver to deal with guilt, self-blame, stigma and identifying social resources to help in caregiving.

FACILITATION METHODS

Caregiver active participation as participants is the basis of the training. To ensure this, teaching techniques such as individual participation, large and small group discussions, group work, brainstorming be used. To ensure that caregivers are able to participate actively, the following will be ensured:

a) The facilitator should make a conscious effort to establishing rapport with the participants.
b) The environment of the caregivers should be therapeutic. The learning environment should be quiet, free from destruction, quiet, one that the caregiver feels respected, relaxed and learning something that is relevant to him/her. The environment must be friendly, informal and humorous. This will decrease any form of anxiety and make participants relaxed.

c) The environment should allow with active involvement of the caregivers in the interaction. The facilitator should make sure that everyone is given a chance to actively participate and engage. Moreover, the caregiver should be provided chance to ask questions without fear of embarrassment. Asking questions is a good opportunity for the facilitator to clarify their misconceptions and emphasize key points.
d) The facilitator should incorporate a range of teaching strategies. Strategies such as individual participation, brainstorming, group discussion should be adopted by the facilitator to enhance effective teaching and learning.

RESOURCES TO BE USED

- Maker
- Laptop
- Projector
- Markers
- White board
- Chairs

DEFINITION OF KEY TERMINOLOGIES

Caregiver: caregiver means the person who is mainly responsible for the day to day care spending an average of 8 hours with the child with DD and has not received any formal training in terms of managing such conditions.

Developmental Disability: developmental disability means any condition that affects the child's ability to manage physical, learning and behaviour. It includes Cerebral Palsy (CP), Autism Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Intellectual Disability (ID) and Down Syndrome (DS).

Child: a child is described as person between the ages of 5 and 14 who have received a diagnosis of DD specifically ID, CP, ASD, ADHD and DS.

Psychosocial support programme: It is a programme designed for caregivers of children with developmental disabilities to improve the physical, psychological and social well-being. The Figure 1 outlines the CaWELLIS programme

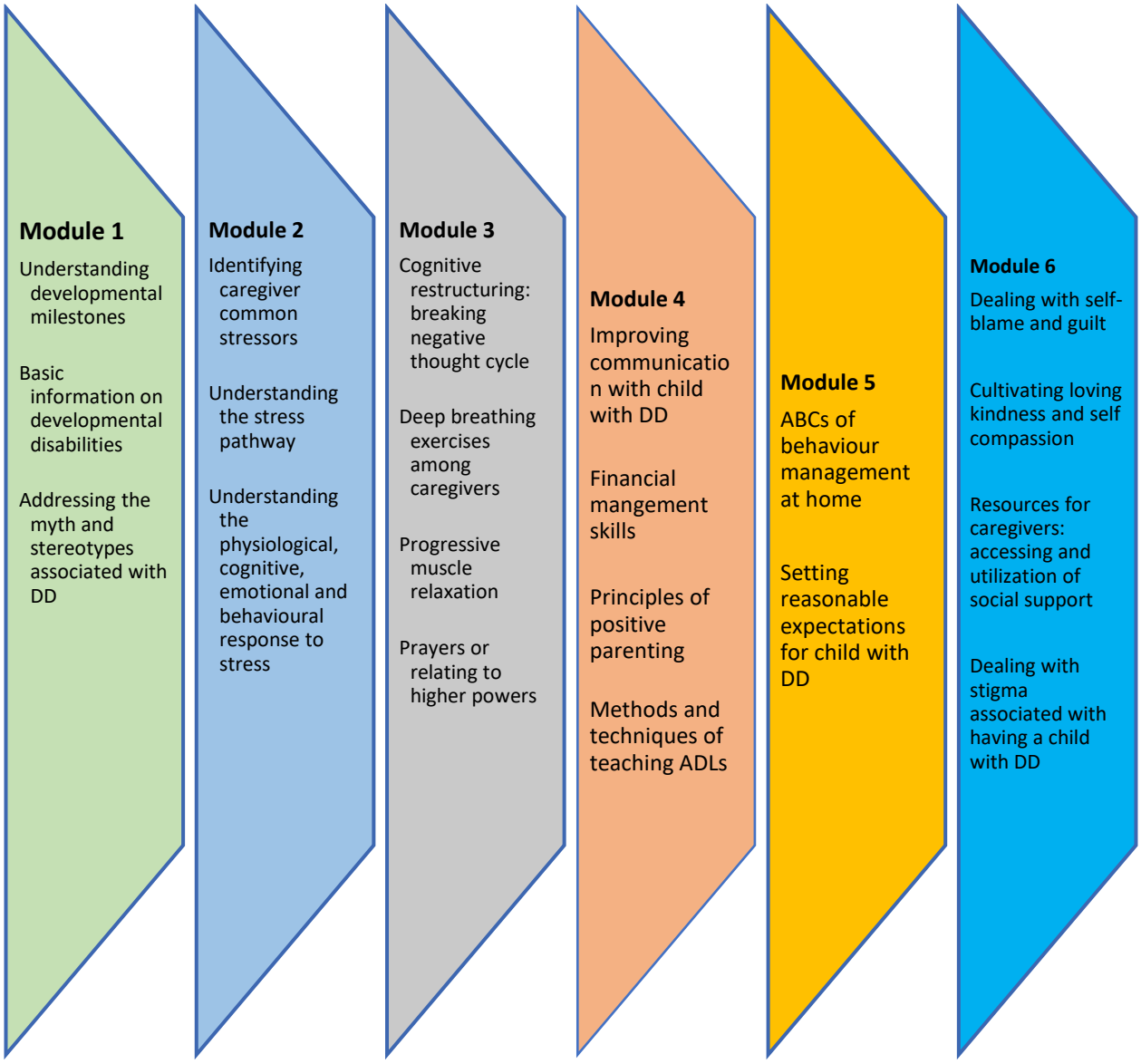

Figure 1: Outline of CaWELLIS Programme

Source: Field data, 2022

MODULE ONE: INTRODUCTION AND INFORMATION ON DEVELOPMENTAL DISABILITIES

Learning point for Module 1

Module 1 is organized in three sessions. In the first session, you will be introduced to the support programme. The second session will discuss developmental milestones and red flags of development in children. The third session will also explain the concept of developmental disabilities, risk factors and interventions available. The last session will discuss myths and stereotypes about developmental disabilities.

At the end of this module, the caregiver will be able to:

- Identify the purpose of the CaWELLIS programme.
- Explain developmental milestones and red flags associated with development.
- Describe DD, its risk factors, interventions and associated myths.

SESSION ONE: INTRODUCTION, WELCOME AND DISCUSSION OF EXPECTATIONS

Establishing rapport and building trust is one of the many steps to organizing a successful psychosocial support programme for caregivers of children with DD. The facilitator should therefore make a conscious effort to establishing rapport with the caregivers. To achieve this, the facilitator should:

BOX 1: Introduction, welcome and expectations

i. Ask one of the participants volunteer to lead the participants in singing a common song after which he/she shares a word of prayer with the group.

ii. Officially welcome participants to the support programme and express gratitude to the participants for making time to be part of the programme.

iii. Introduce himself/herself and the other non-participants present. The introduction should not be too elaborate. Ideally, your name and the role you will be performing during the programme is enough. Giving too much information about yourself at this stage may create a barrier between you and the participants.

iv. Give a brief background of the programme informing participants of the rationale and the structure of the programme.

v. Ask participants to introduce themselves, then can mention only their first names or the preferred name they would like to be addressed with during the programme. Other information during the introduction could be the duration of caring for the child with DD.

vi. After the introduction, create small groups to be utilized for the small group discussion session and the group exercises.

vii. Inform participants of their role in the support programme. They are also to share their rich experiences.

viii. Ask participants of their expectations for and fears of support programme. If possible, let each participant talk about their expectations and fears individually.

ix. Ask participants to tell you their reason(s) for attending the workshop and then inform them that the psychosocial support programme is to equip them as caregivers of children with developmental disabilities with knowledge and skills that is aimed at improving the performance of their caregiving role and their overall well-being.

x. Ask participants to select the ground rules that would guide them. They are to select the rules themselves so that each and every one will feel bonded. Setting ground rules will ensure other things do not take the time needed to perform the various sessions so that all activities/sessions could be achieved within the stipulated time frame.

xi. Conclude this session by expressing how excited you and your team of facilitators are about the workshop and your hope that the expectations of everyone would be addressed by the end of the programme.

SESSION TWO: UNDERSTANDING DEVELOPMENTAL MILESTONES

Developmental milestones are described as goals which a child is expected to accomplish during maturation from infancy into childhood. In other words, developmental milestones are things that are expected to be done by most children at a certain age. Developmental milestones usually provide some clues about the child's developmental health. Thus, if a child is able to reach certain milestones at the typical age, it gives the impression that the child is developing as expected. Usually if a child reaches a milestone early, it may not be a cause for concern because that child may be ahead of children of the same age. On the contrary, if a child is not reaching milestone or reaching them at a very later age, it can be an indication that the child may have developmental delay. Milestones are essential in tracking and explaining a child's behaviour and development. The developmental milestones have been classified into certain domains including: social/emotional, language/communication, cognitive (learning, thinking, problem solving), and movement/physical. Table 1 summarizes the developmental domains:

Table 1: Developmental domains

Domain	Key development
Language/communication	Th domain involves following directions and speaking so others understand what they're saying. The domain focuses on how children are able to express their needs and share what they are thinking, as well as understand what is said to them.
Cognitive	The domain focuses on how children are able to learn new things, think and solve problems. It also involves how children are able to explore their environment to make things out and form conclusions. It also includes "academic" skills like counting and learning letters and numbers.
Movement/ Physical	This domain focuses on how children use their bodies. It considers gross and fine motor skills. Physical milestones include gross skills like rolling over unassisted and crawling unassisted. Fine motor skills including holding a crayon and using utensils. Large group of muscles are used for gross skills whilst small muscle groups for fine motor skills. The gross motor skills include sitting up, standing, crawling and walking. Fine include grasping a spoon, drawing shapes and picking up small objects.
Social and emotional milestones	The domain focuses on the child being able to gain a better understanding of the emotions of others and their own emotions as well as social expectations.

Source: **(**Centre for Disease Control and Prevention, 2022)

RED FLAGS IN DEVELOPMENT

In order to recognize DD early, these are the red flags a parent or a care giver can look out for. These covers impairment in social interaction and communication, gross motor, fine motor and language development. The red flags are described in table 2 below:

Table 2: Reds flags that caregiver of children with DD should look out for

Developmental domain	Red flags
Social interaction and communication development	Avoids eye contact with others Lack of reciprocal social smile Inability to communicate using pointing, facial expressions, and gestures Poor attention or inability to stay focused on an activity Focuses on unusual objects for extended periods or observes them from unique angles Does not seek love and approval from a caregiver or parent Lack of sharing interest or enjoyment with others Preference to play alone and withdraws or spends time 'in a world of his own'. Does not respond to his/her name being called Gets unusually frustrated when trying to do simple tasks Dislikes hugs, kisses, cuddles and close physical contact
Behaviour and personality development	Unusual motor mannerisms, e.g., hand flapping, spinning, staring into space, or tiptoeing Difficulty to cope with change or abnormal reaction to a change in routine Displays aggressive or uncooperative behaviours Is significantly overactive or oppositional for his age Displays temper tantrums or violent behaviours daily Shows unusual attachments to toys, objects, or parts of objects Does not play with the toys in a way they are designed for
Hearing and language development	Does not startle to loud noises Resists loud sounds, e.g., hand dryers by covering hands over ears Talks in a very loud or incredibly soft voice Seems to have difficulty responding when called from across the room Does not make sounds in response to others after 12 months Has difficulty understanding simple sentences after 3 years of age Fails to develop sounds or words that would be appropriate at his/her age Cannot chew or choke on food or drink. Little variation in tone, intonation, pitch, or rhythm of speech
Gross motor development	Has a floppy or limp body posture compared to other children of the same age Has stiffness in arms and or legs Reduced movements of arms or legs Uses one side of the body in preference to the other, especially under 18 months Is very clumsy or poorly coordinated when compared with peers of the same age Difficulties in keeping balance while sitting, walking, playing or frequent falling

Fine motor and vision development	Turns tilts or holds head in an unusual position when trying to look at or follow an object Seems to have difficulty finding or picking up small objects dropped on the floor Has tremor in limbs Rubs eyes frequently Closes one eye when trying to look at distant objects Brings objects too close to eyes to see One or both eyes appear abnormal in size

Source: Gada (2012)

Activity 1: Observation

For this activity, you need to go to a place where young children congregate (e.g., a playground). Unobtrusively observe the children in terms of their development. Compare their abilities with the abilities of the other children, and with the list of developmental milestones from the lesson after you estimate their chronological age. Do all of the children appear to be on track? Do you notice any who might be somewhat delayed? After observing for 45 minutes, jot down your observations and impressions in a diary (do not take notes while watching the children, because this may make parents understandably nervous).

***To have a group discussion on observations before beginning next module

SESSION THREE: BASIC INFORMATION ON DEVELOPMENTAL DISABILITIES

What are developmental disabilities?

Developmental disabilities are not considered as single condition but rather as a group condition which linger on throughout life usually as a result of an impairment leading to certain challenges mainly learning behaviour and self-care. The term is usually applicable to conditions that exhibit functional limitations in at least three of the following domains; self-care, receptive and expressive language, learning, mobility, self-direction, independent living or economic self-sufficiency.

What are the risk factors of developmental disabilities?

The risk factors contributing to DD are described in Table 3 below:

Table 3: Risk factors of DD

Risk factor	Description
Nutritional deficiencies	Nutritional deficiency of the mother and child during the early stages of development. For example, iodine deficiency is associated with intellectual impairments. One risk factor for low birth weight babies is malnourished mother. This is a strong indicator for mild ID.
Infection	Infections in any form can affect the developing nervous system of a foetus and damage it. Such damage can lead to DD.
Toxins	Toxins such as lead, mercury, nicotine could increase the risk of DD. For example, strong association has been established between CP and mercury. There is also a strong link between intellectual disability and developmental delay and carbon disulphide, lead, mercury and nicotine.
Birth outcome	Preterm births and Intrauterine growth restriction/ retardation are associated with increased risk of DD.
Poverty	Poverty is identified as a risk factor of DD because it increases the risk of inadequate access to education and health care, unsafe working conditions, polluted environments and lack of access to safe water and sanitation.
Complication	Complication during pregnancy, child birth and postnatal period could increase the risk of DD. For example, prolonged labour can lead to foetal distress leading to lack of oxygen which could lead to disabilities like Cerebral Palsy

Types of developmental disabilities

The most common types of developmental disabilities in Ghana are Autism Spectrum Disorders, Cerebral Palsy, epilepsy, down syndrome, intellectual disabilities, attention deficit hyperactivity disorder. Types of DD are described in Figure 2.

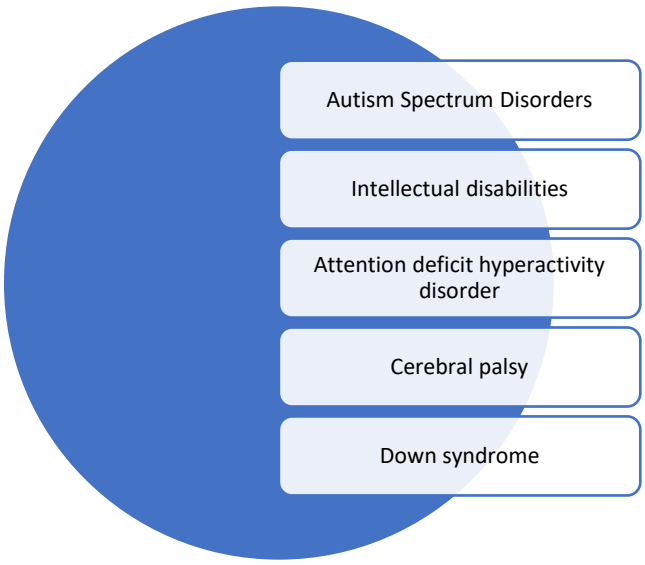

Figure 2: Developmental disabilities

What are the interventions to prevent developmental disabilities?

There are several interventions that can be done to prevent DD includes:

a) **Genetic counselling**: It can be done for the parents-to-be. During the process, family history is analyzed and the chances of a genetic condition occurring is discussed thoroughly. If chances of a genetic condition recurring are high, the management, further testing and coping is discussed.

b) **Prenatal care and advice to the mother**: Since the health of the mother is directly linked to that of the child, the mother is advised to like avoid certain lifestyle, substances and foods that could be harmful to the foetus. These include drinking of alcoholic beverages, smoking, taking drugs like marijuana.

c) **Prenatal nutrition**: The nutrition of the mother is very important. Deficiency in certain nutrients could have negative consequences on the developing foetus. For example, folic acid deficiency is linked to neural tube defect.

d) **Perinatal care:** Measures should be put in place that delivery is done by skilled personnel leading to a safe delivery of the baby. Oxygen deprivation, forceps delivery and breech birth have to be avoided or administered carefully.

e) **Vaccination of child**: Vaccination helps prevent certain diseases like measles, meningitis. The schedule should be followed.
f) **New born screening**: The new born can be screened to help identify the problem early and measures can be taken to reduce the impact of the disability.
g) **Injury prevention**: Childhood injuries are often common. Injuries which have the potential of causing disabilities should be avoided as much as possible. The environment should be kept safe.
h) **Adequate child nutrition**: During early childhood caregivers/parents should be advised to provide proper nutrition to the child. All food nutrients including carbohydrate, proteins, fats, vitamins, minerals etc should be available in meals provided for children.

SESSION 4: MYTHS ABOUT DEVELOPMENTAL DISABILITIES

Myths are widely held beliefs which are usually false but majority of people still believe they are true. Some common myths associated with DD and their corresponding facts are described in Table 5:

Table 5: Common myths about DD with their associated facts

Myths	Facts
Developmental disabilities can be outgrown or it is temporal	They are chronic and linger on throughout life
DD is a contagious disease	DD is not contagious. Various factors interplay to lead to the onset of DD
DD is mental illness	Its nature is neurological and it is not the same as mental illness. A person with DD may develop below the average mentally and may have trouble with learning or adjusting to the environment but they can learn. Appropriate intervention and education can lead them to a fulfilling life.
Caused by sins of previous generations.	Not caused by the sins but caused by impairment.
People with disabilities are unable to contribute meaningfully to society.	People with disabilities are able to contribute meaningfully to society.
People with disabilities are contagious or bring bad luck. People often shun those with disability because they believe associating with them would cause ill fortune or misfortune to them. Sometimes pregnant women avoid encountering children with developmental disabilities because they have the perception that their unborn children may be affected. Parents of children who are not disable feel that if their children without disability associate with those who have disability in the same classroom.	People with disabilities are neither contagious nor bring bad luck.
The bodies of children with DD have special magical powers which makes them target for all forms of abuse.	Children with developmental disabilities do not have magical bodies. Their bodies are just like any other human being

Source: (ACC Special Needs Education, 2018)

MODULE 2: THE CAREGIVER AND STRESS

Learning point for Module 2

In this module, the participants will go through three sessions. The first session will help caregivers in identifying common stressors. The second session will let caregivers understand the physiology of stress. The third session will look at how stress affects the caregivers' emotion, behaviour, thoughts.

At the end of this module, the caregiver will be able to:

- Identify stressors associated with caregiving
- Gain knowledge on the pathway of stress
- Gain knowledge on the impact of stress

SESSION 1: UNDERSTANDING THE CONCEPT OF STRESS AND STRESSORS

Stress is a household word and everyone is familiar with it. To a certain extent, we do need stress to function optimally as people. Stress is a way the body tries to maintain homeostasis, a bid to protect itself. Factors affecting the homeostasis of the body could be internal or external. Stress thus can be conceptualized as responding to demands which could be physical or emotional. An individual's available resources are used in dealing with stress, when the demands of a particular situation exceed the resources available than stress will be experienced.

Types of Stress

Stress can be described in three types and it is described in figure 3.

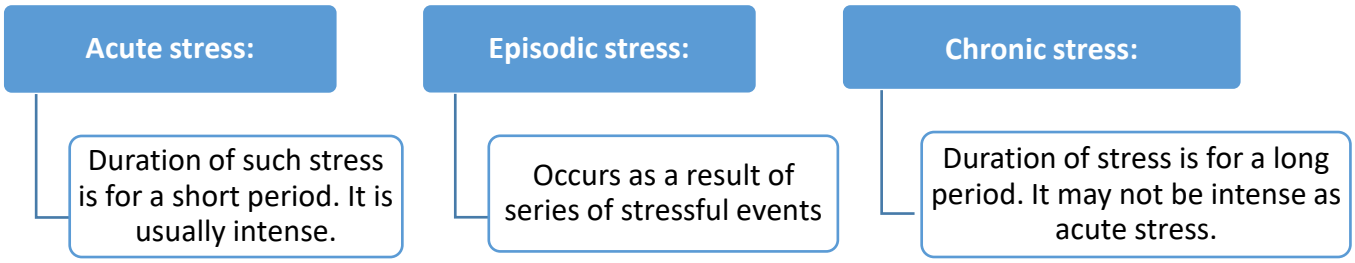

Figure 3: Types of Stress

Identifying common stressors

Activity 2: Brainstorming

- Lead participants to brainstorm the activities that generates stress for them
- Points raised by the participants should be discussed
- Those, that are not highlighted should be introduced by the facilitator and discussed with the participants

a) **Performance of ADL:** Assisting the child with ADL like feeding, bathing and toileting is stressful and may be due to the fact that some children with DD may have problems with chewing, swallowing and drinking. Thus, caregivers may exhaust of a lot of energy in accomplishing these tasks and may be time consuming.
b) **Seeking treatment/frequent medical needs:** Stress may be generated as caregivers would have to visit the hospital frequently for a child with DD than a typically developing child

because the former may have to access different forms of treatments and therapies to ensuring that they the well-being is improved. Having to do so in a low resource country may be more stressful for the caregivers as such specialized facilities may not be adequate and getting access to the few available one can be more stressful.

c) **Dealing with problem behaviour:** Challenging behaviour like aggression, SIB, stereotypical behaviour, hyperactivity can be difficult to deal with. Having to intervene with an unwanted behaviour every now and then can be stressful. Some of these behaviours may pose danger to the child with DD or others making it a herculean task for the caregiver to ensuring such dangers are minimized or even avoided.

d) **Balancing caregiving with other roles:** Caregivers typically may not only be a caregiver but may have other roles from other statuses which may cause role strain. This may create stress as the caregiver will have to allocate time to perform all the other roles leading to stress.

e) **Uncertainty about the future of the child:** Caregivers worry about the condition of the child with DD whether the condition will improve or not. Sometimes the caregivers are worried about who will take care of the child when they are not around.

f) **Challenges with communication:** Caregivers challenge of communicating effectively with the child with DD is one common source of stress. Trying to figure out the specific needs the child wants to communicate can be a challenging task for the caregiver.

g) **Lifting difficulties:** Having to lift the child can be stressful. Some may have to be carried around in cases where assistive devices are not readily available because caregivers cannot afford and even in instances where they can be afforded structural limitations may force caregivers to carry the children with disability from place to place and may increase stress levels.

h) **Unmet educational needs:** It is the goal of every caregiver that their children receive some level of education. Children with DD usually do not have equal opportunities especially in developing countries where special schools are few, expensive or not close to the homes of the children. Those who get the opportunity to join the mainst4ream educational system have their peculiar challenges as caregivers often have negative feedback from teachers and other parents about the negative feedback about the challenging behaviours of the children.

SESSION 2: UNDERSTANDING STRESS PATHWAY

The changes that occur in response to stress are collectively referred to as stress response. It usually involved the nervous and endocrine systems. When a threat is perceived, the hypothalamus is activated.

a) **Firstly,** it causes the activation of the autonomic nervous system (ANS). The sympathetic system of ANS is responsible for fight or flight response. Epinephrine and nor epinephrine are released which causes changes like heart rate increase, pupil dilation, reduction of digestive activities, vasodilation of arteries throughout working muscles and vasoconstriction of arteries throughout non-working muscles. The parasympathetic assist in conservation of energy and relaxation of the body.

b) **Secondly**, it leads to the stimulation of the Hypothalamic Pituitary Adrenal (HPA) axis thereby releasing a hormone called Corticotrophin Releasing Hormone (CRH). Adrenocorticotropin Hormone (ACTH) is released from the anterior pituitary gland which occurs in response to CRH. This stimulates the adrenal cortex to release glucocorticoids and mineralocorticoids. Energy is released by the glucocorticoids by converting glycogen into glucose in a process called glycogenolysis. Energy is again released by breaking down of fats into fatty acids and glycerol in a process called lipolysis. Other functions of corticoids include: suppression of appetite and immune system. Mineralocorticoids on the other hand promotes retention of Na^+ and elimination of K^+. Blood pressure increases as a result of increased blood volume. The adrenal medulla also released epinephrine and norepinephrine to reinforce that of the sympathetic nervous system.

c) **Thirdly**, there is the secretion of Arginine Vasopressin specifically, Antidiuretic Hormone (ADH). ADH main role is the regulation of fluid loss through the urinary tract. Through the process of reabsorption. Additionally, cardiac output increase or blood vessel constricts which leads to increased blood pressure causing energy distribution to organs which need it most. Growth hormone is also released to increase the glucose and fatty acid concentration. Thyroid hormone also increased the overall metabolic rate or basal metabolic rate (BMR). Figure 4 below describes the stress response pathways.

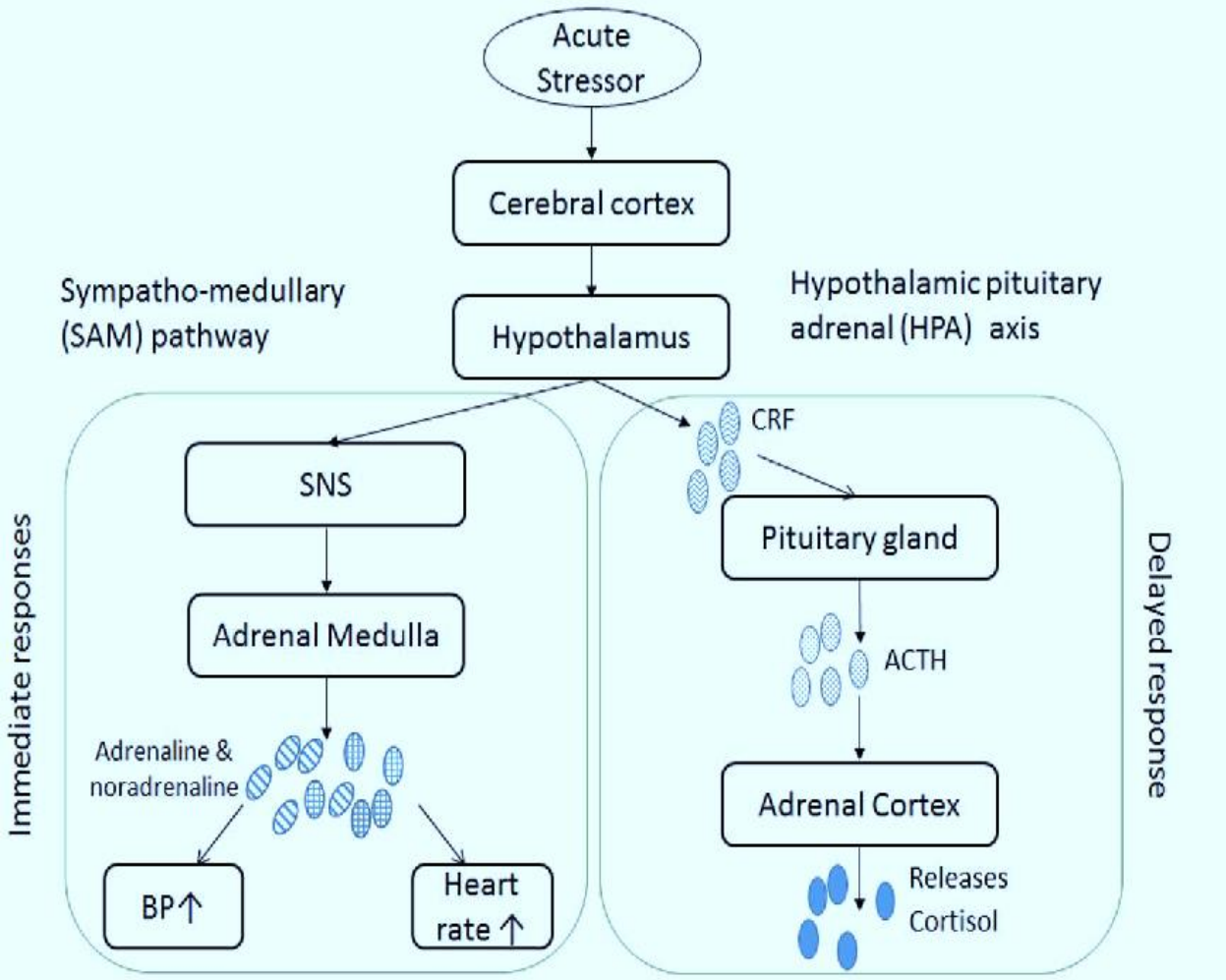

Figure 4: Stress response pathways

Source: (Antoun *et al.*, 2017)

Abbreviations: ACTH = Adrenocorticotropic hormone; BP = blood pressure; CRF = Corticotropin releasing factor; SNS = sympathetic nervous system; TPR = total peripheral resistance.

SESSION 3: UNDERSTANDING THE RESPONSE TO STRESS

Activity 3: Small group discussion

- Create small groups of 8 to 10 participants using random mix.
- Let them discuss how they feel and behave when they are stressed up.
- Let them identify what is similar among them and the differences among their experiences.

Stress response could be emotional, behavioural, cognitive. Figure 5 below describes the response of the body to stress.

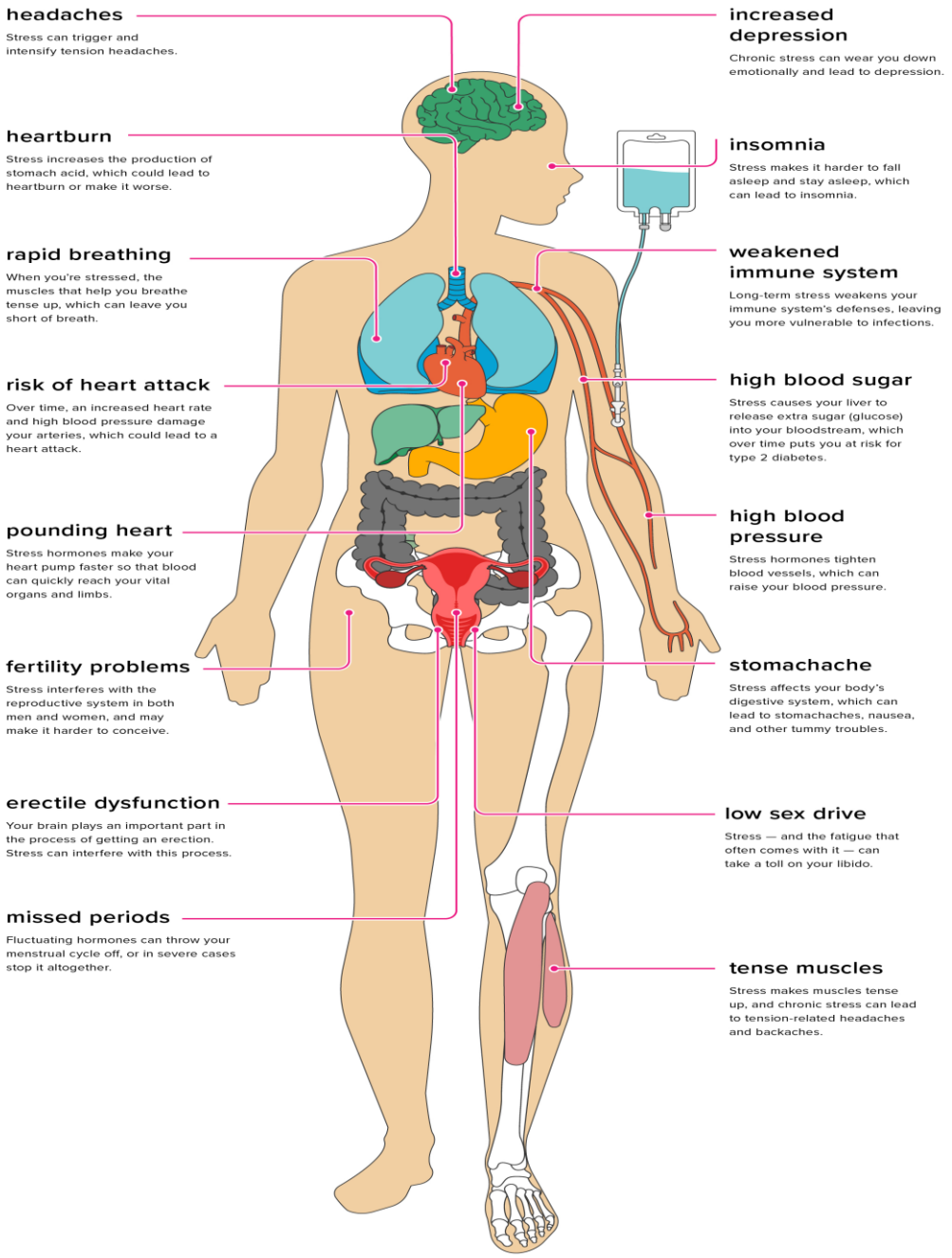

Figure 5: Response of the body to stress

Source: (Pietrangelo, 2017)

MODULE 3: MANAGING STRESS

Learning point for Module 3

This module is organized into four sessions. The session one will focus on identifying negative thought cycle and how to restructure negative thoughts. The session two and three will take caregivers through deep breathing exercises and progressive muscle relaxation respectively. The last session will focus on prayer and relating to higher power.

By the end of this module, the caregiver will be able to:

- Establish the relationship between thoughts, mood and behaviour
- Identify negative automatic thoughts
- Gain knowledge on how to break negative thought cycle.
- Learn to relax their muscles and release immediate stress using deep breathing exercise and progressive muscle relaxation

SESSION 1: COGNITIVE RESTRUCTURING-BREAKING NEGATIVE THOUGHT CYCLE

Cognitive restructuring is a group of therapeutic techniques that help people notice and change their negative thinking patterns. When thought patterns become destructive and self-defeating, it's a good idea to explore ways to interrupt and redirect them. That's what cognitive restructuring can do. The steps involved in cognitive restructuring is described in figure 6.



Figure 6: Cognitive Restructuring process

Below the cognitive restructuring steps are described in detail:

STEP 1: THE SITUATION

Identifying the situation which causes upset is the first step of the process and the ability to do so is very important as it sets the stage for the other stages. The situation could be any event that triggers or causes changes in our mood and such situations may be actual events or thoughts about future events. You do not need to write exhaustively on the situation, you just need to describe it briefly. *Example of the situation may include thinking about your child living with disability for life, your child not being able to perform ADLs etc.*

STEP 2: THE FEELING

Step 2 focuses on the feeling experienced during the situation. Each situation and the feeling which will be strongest. You may experience more than one feeling in the situation but you should concentrate on the most upsetting feeling. In instances where more than one feeling is very strong, work on one feeling first, followed by the other. The common feelings include: fear or anxiety, sadness or depression, guilt or shame and anger. *Example: Feeling sad for having a child with developmental disability*.

STEP 3: THE THOUGHT

Step 3 focuses on your thoughts about the situation described in 1. Write down all your upsetting thoughts and choose the one that causes you most distress. Classify the thought by choosing which category of unhelpful thinking style it belongs. It could belong to more than one problem thinking style. Do NOT choose any, if you are unsure. *Example: I take responsibility for having a child with developmental disability. This is really my fault and no other person.* Unhelpful thinking styles are described in figure 7 below:



Figure 7: Unhelpful thinking styles

Source: (PsychologyTools, 2014)

STEP 4: EVALUATE THE THOUGHT

Step 4 involves the process of evaluating the upsetting thought in a careful and objective manner as possible for accuracy and appropriateness. You need to gather all the possible evidence that supports your thought as well as those that does not support your thought, or suggests it may be inaccurate. Consider as many reasons as you can for why your thought might not be correct. There are several ways of gathering evidence against the thought identified in step 3.

a) One of the ways is to check if you categorized the thought into a particular category of problematic/unhelpful thinking style (described in figure 6 above). If you did, then you believe the thought is inaccurate. You can then proceed to ask yourself why you believed an inaccurate thought.
b) Another way of identifying evidence that does not support the thought is to ask yourself questions that may help you look at the situation and your thought differently. Some good questions to ask in identifying the evidence are described in box 3:

BOX 2: Strategies for identifying evidence

i. Is there another way of looking at the situation?
ii. Is there an alternative explanation for what happened?
iii. How would someone else think about the situation?
iv. Is my concern based more on how I feel than the actual facts in the situation?
v. Am I placing unrealistic and unobtainable standards on myself that I would never expect other people to achieve?
vi. Am I overestimating how much control and responsibility I have in this situation?
vii. What would be the worst thing that could happen if my fear were true?
viii. Am I not considering everything I can do to deal with the problem or situation?
ix. Am I thinking that because a low-probability event happened to me, that it is very likely to happen again to me?

Example: "I take responsibility for having a child with developmental disability. This is really my fault and no other person". This falls under personalization. Since it falls under unhelpful thinking style, then it is not accurate.

STEP 5: MAKE A DECISION

The final step focuses on making a decision on the thought. You need to decide whether your thought is accurate or inaccurate, based on all the evidence you gathered in step 4. The characteristics of the evidence you need to gather is described in box 3.

BOX 3: Considering evidence for a thought

Is it objective?

Is it based on facts?

Is it strong?

Is it not be based on feelings?

Is it not based on beliefs?

After deciding whether the thought is accurate or not, you then take action, depending on your decision. If you concluded that the evidence does not support the thought, then you come up with a new and more accurate thought to replace your old inaccurate thought. New and more accurate thoughts are almost always associated with a reduction in distress compared to the original, inaccurate thought.

Example: The decision is that based on the evaluation from step 4 that the thought was an unhelpful thinking style, the thought is inaccurate. Evidence is that developmental disabilities may be attributed to multiple risk factors.

New thought to replace the old thought is that "I cannot be blamed for my child's disability, the risk factors for developing developmental disabilities is multiple.

SESSION 2: DEEP BREATHING EXERCISE

Definition of deep breathing exercise

Deep breathing is also known as diaphragmatic breathing. Deep breathing a technique based on the principle that integration of the mind and body leads to some form of relaxation. The technique requires participants to contract the diaphragm, slowly inhaling and exhaling. Deep breathing appears to amplify blood oxygen levels, massages the inner organs located in or close to the abdomen.

Reminder

- Identify a place to do your breathing exercise. It could be in your bed, on your living room floor, or in a comfortable chair.
- Don't force it. This can make you feel more stressed.
- Try to do it at the same time once or twice a day.
- Wear comfortable clothes.

Deep breathing exercise steps

The steps involved in deep breathing is simple. The first step involves positioning yourself in a comfortable position. The second step involves support your head and knees. The third step involves taking in deep breath through your nose while placing you hand on your abdomen. The next step involves exhaling from your mouth. Repeat the process. The steps involved is described in Figure 8 below:



Figure 8: Deep breathing exercise steps

Source: (St. Joseph Health, 2021)

SESSION 3: PROGRESSIVE MUSCLE RELAXATION (PMR)

What is Progressive Muscle Relaxation?

Progressive muscle relaxation is a form of relaxation technique based on the practice of tightening or tensing a set of muscle group at a time which is then followed by relaxation, thus, the tension in the muscles is released.

Helpful hints

- Set aside some time to perform this exercise. You can begin with about 15 minutes to 20 minutes.
- Find a place to perform the exercise. Ideally, the environment should be free from distraction. Turn off your phone or put it on silence to avoid distractions.
- The technique can be done while seated or lying down
- Wear comfortable clothing and remove your footwear.
- Keep focus and remain attentive throughout the process.
- Move in a sequence that works for you

The process of Progressive Muscle Relaxation [PMR]

PMR involves three forms, tension and relaxation, quick tense and release and relaxation only as described below:

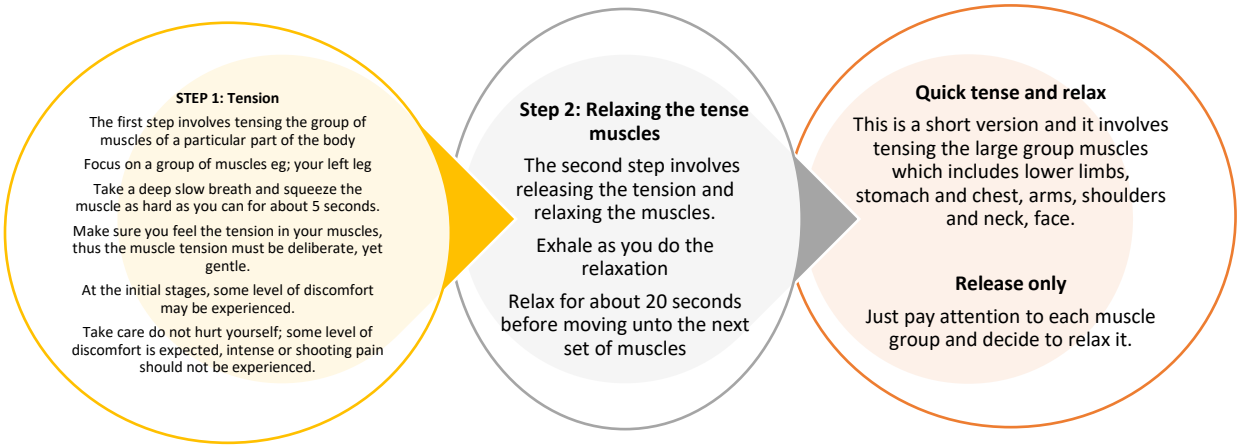

Figure 9: Tension and relaxation response

The table below is a description of how to tense the muscles of the body.

Table 6: Steps of Progressive Muscle Relaxation

Step	**Progressive Muscle Relaxation**	
	Parts	**Exercise**
1	Hand and forearm	Make a fist with your hand
	Upper arm	Bring your right forearm up to your shoulder to "make a muscle"
2	Forehead	Raise your eyebrows as high as they will go, as though you were surprised by something
	Eyes and cheeks	Squeeze your eyes tight shut
	Mouth and jaw	Open your mouth as wide as you can, as you might when you're yawning
	Neck	Be careful as you tense these muscles. Face forward and then pull your head back slowly, as though you are looking up to the ceiling
	Shoulders	Tense the muscles in your shoulders as you bring your shoulders towards your ears
	Shoulder blades/back	Push your shoulder blades back, trying to almost touch them together so that the chest is pushed forward
	Chest and stomach	Breathe in deeply, filling up your lungs and chest with aair.
	Hips and buttocks	Squeeze your buttock muscles
3	Upper leg	Tighten your thigh
	Lower leg	Do this slowly and carefully to avoid cramps. Pull your toes towards you to stretch the calf muscles
	Foot	Curl your toes downwards

Source: (Ramasamy *et al.,* 2018)

SESSION 4: PRAYERS OR RELATING TO RELIGIOUS PRACTICES

Caregivers are to set aside at least 10 minutes thrice a week to pray to any higher power. To make this effective, they are to document when, where, for how long and the mood after the prayer exercise.

MODULE 4: EQUIPPING THE CAREGIVER TO PERFORM ROLES

Learning point for Module 4

In this module, the participants will go through four sessions. The first session will assist the caregivers with skills and techniques they can employ in teaching ADL. The second session will focus on effective communications skills. The third session will focus on identifying resources available to support in the caregiving process. The fourth session will look at financial management skills.

At the end of this module, the caregiver will be able to:

- communicate effectively with the child with DD
- recognize who is helpful and who can support.
- manage their finances effectively.
- equip caregivers on how to manage their time effectively.

SESSION 1: METHODS AND TECHNIQUES OF TEACHING ACTIVITIES OF DAILY LIVING

The basic ADLs or physical ADLs are those skills required to manage one's basic physical needs, including personal hygiene or grooming, dressing, toileting, transferring or ambulating, and eating. Children with DD usually have challenges performing certain activities of daily living. This may be because of slow or impaired physical development, difficulty in understanding or following directions, lack of awareness, easily getting frustrated or acting out when it does not, no desire to learn or accomplish tasks, cognitive or memory challenges, weak motivation, weak imitation skills. The methods and techniques of teaching ADLs include:

(a) Stimulus control: Stimulus control is the phenomenon of a stimulus increasing the probability of a behaviour (operant response) because of a history of that behaviour being differentially reinforced in the presence of the stimulus. In other words, stimulus control is basically learning to pay attention to things that we identify in the environment (discriminative stimuli) that give us information about the effectiveness of our behaviour: what behaviour is likely to be effective or ineffective, under which conditions, and what does that behaviour give us (reinforcement or punishment). Therefore, in the presence of those stimuli we are likely to respond differentially. Stimulus control is a term used to

describe situations in which a behaviour is triggered by the presence or absence of some stimulus. Before teaching a skill, identify the stimuli that will prompt behaviour. To prompt children to wash their hands, a stimulus can be dirty hands or a routine of washing hands before a meal

(b) Chaining and task analysis: Breaking complex task/bels into steps can help simply learning process. For example, brushing teeth includes finding a toothbrush, toothpaste and cup. Then it involves putting toothpaste on the brush, brushing the bottom teeth, brushing the top teeth, rising, cleaning the brush, putting all the equipment away properly. Another example may include getting dressed. This can be broken up into taking a shirt off the hanger, removing the pyjamas, putting on the shirt, buttoning the shirt etc

(c) Prompting: Prompts can be delivered verbally, modelled and guided through physical behaviour. Example touching a child's elbow can prompt the child to pick up a toothbrush.

(d) Using pictures/ visual guide: The visual guide that can be used by caregivers include photos or clip art style images of each step in the process. The child then follows the step by step process in the picture or visual guide and attempts to do same.

(e) Video modelling: Many children with disabilities prefer visual learning styles and one of the things that helps is video. The video could highlight the right way of performing the task or even the wrong way of performing the task. Video modelling is a mode of teaching that uses video recording and display equipment to provide a visual model of the targeted behaviour or skill. Types of video modelling include basic video modelling, video self-modelling, point-of-view video modelling, and video prompting. Basic video modelling involves recording someone besides the learner engaging in the target behaviour or skill (i.e., models). The video is then viewed by the learner at a later time. Video self-modelling is used to record the learner displaying the target skill or behaviour and is reviewed later. Point-of-view video modelling is when the target behaviour or skill is recorded from the perspective of the learner. Video prompting involves breaking the behaviour skill into steps and recording each step with incorporated pauses during which the learner may attempt the step before viewing subsequent steps. Video prompting may be done with either the learner or someone else acting as a model.

SESSION 2: IMPROVING COMMUNICATION WITH CHILDREN WITH DD

Communication between caregiver and children with DD is usually impaired. Several strategies have been instituted to improve communication. When communication is improved, the stress experienced by the caregiver may decrease. Strategies for improving communication among caregivers include:

(a) Learn to connect with the child: The child with DD feels that you support, accept and acknowledge their presence. Regardless of their communication skills the caregivers should make effort to connect and communicate with them.

(b) Use non-verbal communication/ and gestures: Communication could be either verbal or non-verbal. In stances where a child is verbal, the caregiver. To improve the communication skills in children with, the caregiver can use gestures which can help them in understanding the message that is being put across and it includes pointing, nodding and use of focused eye contact. To enhance comprehension of these gestures, caregivers may be required to prolong the gestures or exaggerate them most especially at all initial stages when it is being introduced.

(c) Do not make assumptions: The caregiver should not assume for the child with DD. The caregiver should be willing to ask questions in instances where they do not understand what the child is trying to communicate. In trying to assume, the caregiver may get it wrong.

(d) Be patient: Children with DD have their likes, dislikes, feelings, beliefs and dreams which should not be sublimely overlooked because they are disabled. It may appear frustrating but it is key in developing effective communication skills with the child.

(e) Use concrete language: For the child with DD to get a better understanding, it is important to use concrete language over vague or open language. Open or vague language usually could be interpreted differently, but when the language is not concise with unclear wording it makes it abstract and caregivers might get frustrated.

(f) Practice story telling with picture card: Read books aloud to the child or tell stories. Using picture cards. The use of visual guide and pictures during communication makes communication easier for the child with special needs. Using flashcards, pictures usually challenge memory. When the child learns to link still pictures with words, they are able to translate that learning into the real world. However, caregivers are cautioned not to use

pictures with a very busy background, rather the pictures should have single items. As the child with DD progresses with the learning, more challenging pictures can be used

(g) Provide choices: Children with DD have choices. Too many choices could be overwhelming for them and get them confused, however, the caregiver in bid to improving their communication skills of child with DD, the caregiver should provide a few options or choices maybe 2 or 3. One of the easiest ways out is to provide the child with 2 choices, one that is liked and the other that is disliked. Then, the child should be given the opportunity to choose. Doing so, improves encourages them to communicate since they have 2 or 3 options to choose from. Additionally, they feel independent to make for themselves choices.

SESSION 3: FINANCIAL MANAGEMENT SKILLS

Managing finances adequately could reduce the stress an individual face. Taking care of a child with DD is expensive because they have various needs which requires financial resources. Additionally, the caregiver's job may be affected because of caregiving hence, the income may be low. This may increase the stress levels of the caregiver.

a) Time your purchases: Purchases of items are less expensive during some seasons. Most perishable goods in Ghana are seasonal. Buying them during those periods decreases cost and saves money. Make a list of items you would like to purchase before going for shopping, this is likely to prevent impulse buying.

b) Create/draw a financial plan or budget monthly: Gather all financial statement including receipts, invoices and other records. Calculate your income for the month, if there are multiple sources of income, put all them together. Determine fixed and variable expenses. This can be done by looking at your expenses within the last 3 to 6 months. Total your monthly income and expenses. Make adjustment to expenses, if the expenses exceed your income. Creating the budget should be guided by your monthly spending habits, as well as your monthly take-home pay. Your lifestyle and spending habits should also be considered when creating a budget. Budget should be created in such a way that you can keep. Budgets should encourage better habits not vice versa. Budgeting helps you to avoid overspending that may occur through impulse buying.

c) **Monitor spending/Scrutinize expenses:** Do not purchase because you would like to please anyone or because you feel compelled. Expenses which can wait or may not be needed immediately can be cut off. Know the differences between your needs and wants. Though wants add up to you comfort and improves the quality of life, they are things one can hold on and do later. You have to be diligent in making sure that you spend less than you earn and not vice versa.

d) **Involve entire household:** Involving everyone in the household let them understand the financial situation and may not make unnecessary demands that will add to the financial strain. Additionally, they will learn to be economical with whatever resources that is provided at home.

e) **Start investing:** Look for avenues to invest. You do not need huge sums of money before you can invest. With the little you have you can invest. Consider investment opportunities that has minimal risks. Investing helps you to secure your future and that of your child with developmental disabilities.

f) **Avoid debt:** One of the surest ways to achieve this is to make sure you follow your budget. Also avoid impulse buying and concentrate on your needs not wants. Wants can be delayed, thus, if it is not a need but wants, then overlook till you are more financially stable before getting it. Because when you are not financially stable and you decide to purchase your wants, you may make the payments in instalments and end paying more

g) **Get other source of income:** One of the easy ways of generating other sources of income is by relying on the skills. It is important, such jobs will not be too time consuming because, already, the caregiving role takes time. Avenues that can be looked at includes online shopping etc

SESSION 4: PRINCIPLES OF POSITIVE PARENTING

Positive parenting is a parenting principle that assumes children are born good and with the desire to do the right thing. It emphasizes the importance of mutual respect and using positive ways to discipline. The positive parenting approaches focus on teaching proper future behaviour instead of punishing past misbehaviour.

(a) Attachment: Attachment has been described as a deep, secure emotional bond which is very important for every child. The bonds that are created between children and their primary caregivers positively influences their resilience, ability to regulate emotions and figure relationships. Children who are unable to build such bonds especially at the early stages may later on in life develop behaviour problems. Children are likely to misbehave when they feel disconnected from their caregivers. When they feel connected, they naturally would want to do things to please them, hence, behaviour is usually improved. When attachment is developed very well, they develop the feeling of safety, which provides them the opportunity to grow and learn appropriately. Additionally, it makes guiding and correcting them much easier for the caregivers. Caregivers usually have genuine influence in the presence of strong attachment which is better than forced compliance. To have this kind of attachment, development of trust is important.

(b) Respect: Children need respect from their caregivers. Therefore, caregivers need to learn to respect the body and dignity of their children. This can be done by consciously making a decision not to hit the child, yell or cause any type of pain or harm during training or teaching them. Also, the child's personhood needs to be respected and this can be achieved through providing them space to explore and develop at their own pace. Caregivers also need to respect the uniqueness of the child's spirit by honouring them.

(c) Proactive parenting: Caregivers are not required to wait until a particular problem arise before making efforts to teach the children the boundaries & skills which are required to manage that particular issue or challenge. Caregivers need to be able to deal with their emotions and then thoughtfully respond when a problem arises. Thus, caregivers should always have a planned action and avoid any form of impulsivity. This will help in addressing potential problems before they escalate to become more serious problems.

(d) Empathetic leadership: Caregivers should understand the children's needs and be able to relate to them in such a manner that they feel, heard and understood. That notwithstanding, the boundaries that have been set should still be held unto

(e) Positive discipline: Discipline and punishment are often used interchangeably. However, the two concepts are distinct with different goals, thus, discipline is not punishment. The goal of punishment is to inflict some form of suffering on the individual and the suffering is to defer the individual from repeating such behaviour in the future. On the other hand,

discipline's goal is to teach an individual to learn to control not only their impulses but behaviour as a whole, to learn new skills, to fix mistakes and find solutions. In punishment, these are absent, new ways of doing things are not looked at. It is always necessary for the caregiver to acknowledge the wrong behaviour or actions of the child but instead of hitting, screaming, yelling or threatening the child to put a stop to the behaviour, the emphasis should be on teaching them to do it well. Thus, positive discipline makes the children accountable as the caregiver teaches them how to own up and fix their mistakes. The child is able to develop or acquire the necessary skills and tools to be able to do well in the near future as discipline focuses on their capabilities not their mistakes.

MODULE 5: MANAGING BEHAVIOUR PROBLEMS

Learning point for Module 5

Module 5 comprises of four sessions. Session, one focuses on antecedents, behaviour and consequences of behaviour management. Session two emphasizes on the strategies of dealing with problem behaviour. Session three deals with the steps involved in behaviour management. Session four focuses on setting reasonable expectations for the child with DD

By the end of this module, the caregiver will be able to:

- Know the antecedents and patterns of problem behaviour.
- identify effective ways of dealing with problem behaviour
- Know the steps involved in managing behaviour
- identify ways of setting reasonable expectations for the child with DD

SESSION 1: ANTECEDENTS BEHAVIOUR AND CONSEQUNCES OF BEHAVIOUR MANAGEMENT

Antecedents

Antecedents could be described as a proceeding event, condition or cause. Factors to look for when determining antecedents:

- When does the behaviour usually occur? Example specific time of time, after lunch etc
- Where does the problem behaviour usually occur? Example classroom, home.
- Who is present when the behaviour problem occurs? Example playmates
- What activities or events precede the occurrence of the problem behaviour?
- What do other people say or do immediately before the problem behaviour?
- Does the child engage in any other behaviour before the problem behaviour?
- When, where, with whom and in what circumstances is the problem behaviour least likely to occur?

Behaviours

To manage behaviour successfully, the first step to take is to identify the behaviour of interest. Three key characteristics should be evident about the behaviour, it should be specific, observable

and measurable. Behaviour is said to be specific when each one is clear on what is expected. Behaviour is observable when there is a consensus that behaviour occurred or not. Behaviour is measurable when it can be quantified. Behaviours which are not specific or observable or measurable are difficult to describe. When behaviours are poorly described, it becomes difficult to initiate any meaningful plan to help.

Behaviour can be appropriate or inappropriate. Appropriate behaviours include:

- Eye contact
- Using words or gestures to get objects or to get attention
- Waiting quietly
- Using toys and objects nicely
- Sharing with others
- Following instructions

Inappropriate behaviours are referred to as problem behaviours. The characteristics, types and functions of problem behaviour is described below:

Problem behaviour characteristics

- Behaviour is not appropriate for the child's age
- Behaviour is not acceptable by the society
- Behaviour may be harmful to self or others
- Behaviour may interfere daily lifestyle or activities

Types of behaviour problem

- Violent and distributive behaviour, example tearing of books
- Temper tantrums, example screaming or rolling on the floor
- Self-injurious behaviour example banging of head
- Repetitive behaviour example flapping hands
- Odd behaviour example laughing or talking to self without reasons
- Hyperactive behaviours example unable to sit at a particular place for a required time.
- Rebellious behaviour, example does not obey command.
- Fears, example being fearful of a particular place, person, animal and object.

Functions of problem behaviour

- Sensory: provides sensory experiences, behaviour seems good to do
- Escape: Removes undesired activities or interaction
- Attention: Provides access to people or interactions
- Tangibles: Provides preferred items or activities

Consequences

The results that naturally follow a behaviour which could be positive or negative. It's really just the outcome of the behaviour. The consequence might be something that someone does in response to the behaviour, or it may be the child escaping from a situation. Recording antecedents, behaviour and consequences is described in Table 7:

Table 7: ABC Chart

Date/time	Antecedents	Behaviour	Consequences

SESSION 2: BEHAVIOUR MANAGEMENT TECHNIQUES

a) **Change the antecedents:** The antecedents trigger certain behaviours if the triggers are identified in relation to a particular problem behaviour, then those behaviours can be managed if by avoiding or changing those factors which may include a particular situation, settings, persons, sudden change in routine among others.

b) **Extinction:** Behaviour which are reinforced are likely to be repeated and vice versa. In extinction, a problem behaviour which was initially reinforced is no longer reinforced, thus reinforcement is withdrawn. Thus, if attention was paid anytime the problem behaviour occurred, now the behaviour is ignored. It however important that steps should be taken to replace the inappropriate behaviour otherwise another problem/ inappropriate behaviour

may replace it. Extinction burst where there is an initial increase of behaviour following reinforcement. The caregiver must not give in by reinforcing otherwise it will worsen the intensity of the problem behaviour.

c) **Time out from positive reinforcement:** It is simply referred to as time out. Time out is a procedure in which a child is placed in a different, less-rewarding situation or setting whenever he or she engages in undesirable or inappropriate behaviours. Timeout withdraws the opportunity for a child to access positive reinforcement for a short period of time if he or she demonstrates challenging behaviours. Timeout can involve the removal of a reinforcing item for a short amount of time, or the child can be removed from a reinforcing activity or situation. Timeout from positive reinforcement should only be used for children with DD whose challenging behaviour serves to gain attention or to gain access to an item/activity. It is not effective for behaviours used to escape an activity, avoid a task, or escape attention from someone. Use timeout from positive reinforcement when the setting/area/activity that the student is being removed from has a high level of reinforcing qualities. Typically, time-out is used in tandem with positive discipline techniques.

d) **Functional communication training**: Behaviour may occur for a particular function or purpose. The purpose of a behaviour may be seeking attention or to be given a tangible item or for something to be stopped or discontinued. In instances like this, the child needs to be taught how to use appropriate means of communicating in serving words or signs in demanding what they want. If the child's problem behaviour is because he/she wants attention, the caregiver can teach the child to use a sign or to say "please come here". Also, if a child is behaving in such a way to escape from a task that is presumed to be difficult, the caregiver can teach the child to learn to say "please help me" or "please I need help".

e) Use of reinforcement: They can increase or maintain a set behaviour. They are also known as reinforcers. The caregiver would have to identify reinforcer. You can make a list of the reinforces by asking yourself certain questions. What does your child like? To do? To eat? To look at? To play with? To do when alone?

SESSION 3: STEPS IN BEHAVIOUR MANAGEMENT

Problem behaviour using ABC can be managed in five steps described in figure 10:

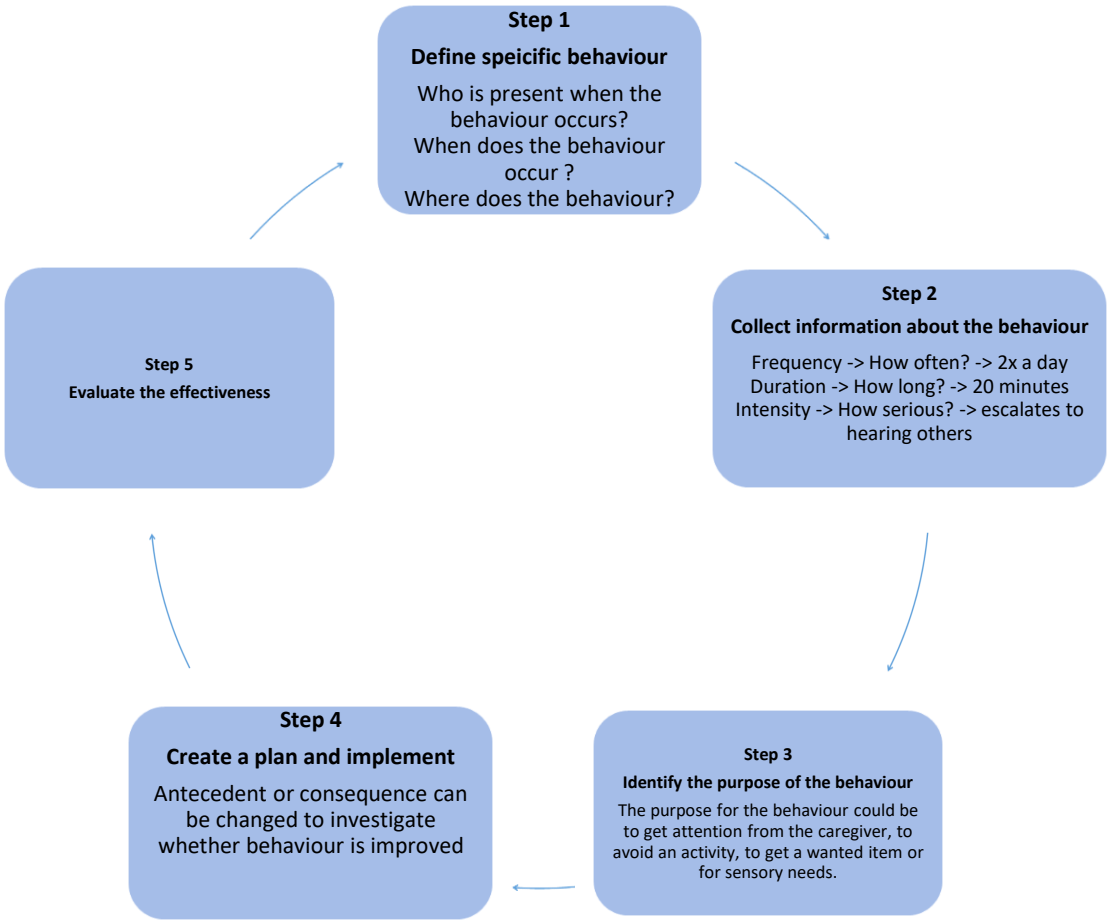

Figure 10: Steps in behaviour management

SESSION 4: SETTING REASONABLE EXPECTATIONS FOR THE CHILD WITH DD

Expectations that are too low or too high can be challenging for any typically developing and especially for a child with developmental disabilities.

a) **Make sure your expectations are age appropriate:** Different children develop at different pace. To be able to set age appropriate expectations, the caregiver has to know

the developmental milestones since these milestones provides guidelines of what the child can do at a particular age.

b) **Explain to your child what is off-limits:** Let your child know what they can do and what they cannot. It may be a difficult task at the onset trying to explain to them certain things they cannot do or have.

c) Give your child some control: Children are not always capable of making decisions for themselves, so parents generally do this for them. That in mind, children also need to feel like they get to make some on their own choices. If you are not creating opportunities for them to do this when you go out, it is not realistic to expect their cooperation with your decisions.

d) Evaluate your expectations: Change any expectations that you think your child cannot meet and set them up with expectations that they can meet.

MODULE 6: CAREGIVER SELF-CARE

Learning point for Module 6

Module 6 is organized into four sessions. The sessions address the issues of guilt, self-compassion, social support and stigmatization.

By the end of this module, the caregiver will be able to:

- Identify ways of overcoming self-blame and guilt
- Identify ways of cultivating loving kindness and self-compassion
- Identify resources available for caregivers: accessing and utilization of social support
- Identify ways dealing with stigma associated with having a child with DD

SESSION 1: DEALING WITH SELF-BLAME AND GUILT

Definition of guilt

A painful feeling of self-reproach resulting from a belief that one has done something wrong or immoral.

Types of guilt

Table 9 distinguishes between two types of guilt, healthy and unhealthy guilt.

Table 9: Types of Guilt

Healthy guilt	**Unhealthy guilt**
It is proportionate	It is disproportionate
It is rational	It is misplaced and irrational
It occurs as a result of the individual's own inappropriate behaviour	The occurrence is not as a result of the individual's behaviour
The individual can be blamed about the situation	The individual is not to be blamed about the situation because they have no control over the situation
It is short-lived, with a clear course to correction	It is long lasting with no clear ways of making amends
The purpose is to guide you for future behaviours. It has a constructive quality	The purpose is to punish you. It has an abusive quality

Signs of guilt

Certain physical or psychological signs may be an indication that you are feeling guilty and these include feeling unworthy, being paralyzed by the past, having unresolved issues, struggling to forgive yourself, acting defensive and distant, feeling afraid of trying again. Figure 10 depicts the signs of guilt:



Figure 10: Signs of guilt

Source: (Cherry, 2020)

Table 10: Dealing with unhealthy guilt

Dealing with unhealthy guilt	Explanations
Be realistic about what you can control	Identity and list what you can control and what you cannot control. Disregard those you cannot control and focus on what you can control.
Use affirmations/ Affirm positive aspect of the situation	Use positive affirmations as the situation is not really your fault. Negative self-talk should not be tolerated and seek the opinions of other people. Positive: "I gave birth to a child with developmental disability because I can't control who I gave birth to and I followed all the advice during pregnancy". Negative: I'm old and older age is linked to increased risk of DD

Change perfectionism/ Challenge your own standard	The thoughts of being perfect usually will let you not focus on what you have been able to do. Rather, the refocusing your thoughts to the things you have not been able to do well or those that you have not done well enough.
Be assertive with those who seek to make you feel guilty	Some people intentionally manipulate you just to make sure you feel bad about having a child with developmental disabilities. Let people know that it is no fault of yours that you have a child with DD

SESSION 2: CULTIVATING LOVING KINDNESS AND SELF-COMPASSION

Self-compassion is where the individual develops a non-judgmental attitude towards self and treats themselves with kindness. Self-compassion is described as showing kindness towards the self, which entails being gentle, supportive and understanding rather than harshly judging oneself for personal short comings, the self is offered warmth and unconditional acceptance. To be able to achieve this, the individual must see themselves as imperfect beings. In practicing self-compassion, the individual is motivated to make the necessary changes in their life on the basis that they have a caring attitude towards themselves, and therefore seeks to lesson/decrease the suffering they are going through. This is aimed at helping the individual live happier and fulfilling life. The techniques for cultivating self-compassion includes:

How would you treat a friend?

- What will your response be to a friend who is in a difficult situation? What will you say, how will you say it and which tone of voice will you use?
- What has your response been towards yourself in situations where you find yourself in a difficult situation. What do you say to yourself and with what tone do you say it?
- What is the difference between the two responses, the one towards yourself and the one towards your friend? What is contributing to the differences between the two responses?
- What will happen to you if you respond to your situation in the same way you would respond to your friend?

Self-compassion break

In using this approach, you have to think about a situation that is causing you stress. You then go through these steps:

- This is a moment of suffering
- Suffering is part of life
- May I be kind to my self

Supportive touch

You can show care and comfort towards self by giving yourself supportive touch. Touch works by calming the individual down and ignites the feelings of safety. This is achieved through activating the parasympathetic nervous system. You can practice using

- Hand on heart
- One hand on your cheek
- Gently stroking arms with hands
- Closing your arms and giving a gentle squeeze
- Hand on your abdomen
- Gently rubbing your chest or using circular movement.

It is a simple way to be kind to yourself and can be practiced at any time.

Changing your critical self-talk

- Step 1: Identify when you are being self-critical
- Step 2: Make an effort to soften your critical self-voice
- Step 3: Reframe the observation by your inner critic

Using affirmations

Use kind words towards yourself especially when you are having negative thoughts. When you say kind words to yourself, it is like someone else saying them to you. It can offer reasonable support. Example of affirmations include

- It is ok, dear self

- You are ok
- I will be kind to myself

SESSION 3: RESOURCES AVAILABLE FOR CAREGIVERS: ACCESSING AND UTILIZATION OF SOCIAL SUPPORT

1. Assess your social support system
   Who are the people and institutions who offer you, eg spouse, parents, children, friends, other caregivers
2. Identify at least one of the above who helps you in each of the following ways.
   • Provides physical/ practical assistance
   • Provides resources and information
   • Provides emotional/psychological assistance
   • Provides a positive outlook/attitude
3. What are some of the practical reasons you have for not using relatives, friends or significant others for social support and what are some of the reasons they have for not providing you with the needed support?
4. What are some beliefs and attitudes others may have that prevent them from offering support to you?
5. What are some beliefs and attitudes you have that may prevent you from accepting or seeking support from others?
6. What steps could you take to cope with the barriers that prevent you from getting the support you need?

SESSION 4: DEALING WITH STIGMA ASSOCIATED WITH HAVING A CHILD WITH DD

Activity 5: Look at the picture and discuss what you think is happening



Figure 11: Dangers of stigmatization

Source: (Novosti, 2020)

a) Know the facts. Educate yourself about developmental disabilities.

b) Be aware of your attitudes and behaviour. Examine your own judgmental thinking, reinforced by upbringing and society.

c) Choose your words carefully. The way we speak can affect the attitudes of others.

d) Educate others. Pass on facts and positive attitudes; challenge myths and stereotypes.

e) Focus on the positive.
f) Support people. Treat everyone with dignity and respect; offer support and encouragement.

Annexure B: Semi-structured interview guide

Opening

Establish rapport

Outline purpose

Justification

Duration of interview

Background/demographics

Gender		Employment:	
Age		Number of children	
Level of education		Relationship to child with DD	
Marital status		Duration of care	
Number of caring hours per day			

Question (to follow-up each question with probes where necessary)

1. Please tell me about your experience in caring for your child with DD.

Probes:

Tell me how you came to be involved in caring for the child with DD.

Describe a typical day in caring for a child with DD at home.

Tell me about how you feel about your role as a caregiver for a child with DD.

2. Describe the needs of the child with DD that makes caregiving difficult for you?

Probes:

Is the child able to perform activities of daily living for himself/herself?

Are you able to communicate your needs to your child with DD?

Is your child with DD able to communicate his needs to you?

Is your child receiving education just like any other child?

3. In which ways have caring for a child with DD affected your life?

Probes:

How has caring for a child with DD affected your physical health?

How does caring for a child with DD affect you psychologically?

How has your social wellbeing and relationships been affected by caring for a child with DD?

Has caring for your child affected your finances?

4. What health needs do you currently have in relation to your care giving role?

Probes:

Do you have adequate information on your child's condition?

What kinds of support do you think could help you in your caregiving role?

5. How do you cope with caregiving?

Probes:

Can you tell me the specific things you do to deal with your caregiving role?

Closure

Summarize

Maintain rapport

Annexure C: Socio-demographic questionnaire

Instructions: Please tick the option most applicable to you in the box [ ] provided

1	Age of caregiver (in years):	18-25 26-35 36-45 > 45	[ ] [ ] [ ] [ ]
2	Gender of caregiver:	Male Female	[ ] [ ]
3	Educational Background:	No formal education Primary Secondary Tertiary	[ ] [ ] [ ] [ ]
4	Socio-economic status:	Unemployed Employed	[ ] [ ]
5	Average number of caring hours per day:	2-4 5-7 8-10 10-12	[ ] [ ] [ ] [ ]
6	Duration of caregiving (in years):	>½ 2-5 6-9 > 10	[ ] [ ] [ ] [ ]
7.	Free time per day:	2-4 5-7 8-10 10-12	[ ] [ ] [ ] [ ]
8.	Age of child with DD	5-8 9-11 12-14	[ ] [ ] [ ]

9.	Gender of child	Male Female	[ ] [ ]
10.	Specific DD Diagnosis:	Intellectual Disability Attention Deficit Hyperactivity Disorder Autism Spectrum Disorder Down Syndrome Cerebral Palsy	[ ] [ ] [ ] [ ] [ ]
11.	Any underlying condition?	Diabetes Hypertension Others, specify	[ ] [ ] [ ]
12.	Which of these behaviours is applicable to you?	Smoking Drinking None	[ ] [ ] [ ]
13.	Relationship with child with DD	Mother Father Other	[ ] [ ] [ ]
14.	Marital Status	Single Married Divorced Widowed Co-habiting	[ ] [ ] [ ] [ ] [ ]

Annexure D: Zarit Burden Interview

Instructions: Please circle the response the best describes how you feel.

	Question	**Score**				
		Never 0	Rarely 1	Sometimes 2	Quite frequently 3	Nearly always 4
1.	Do you feel that your child asks for more help than he/she needs?					
2.	Do you feel that because of the time you spend with your child that you don't have enough time for yourself?					
3.	Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?					
4.	Do you feel embarrassed over your child's behaviour?					
5.	Do you feel angry when you are around your child?					
6.	Do you feel that your child currently affects our relationships with other family members or friends in a negative way?					
7.	Are you afraid what the future holds for your child?					
8.	Do you feel your child is dependent on you?					
9.	Do you feel strained when you are around your child?					
10	Do you feel your health has suffered because of your involvement with your child?					
11.	Do you feel that you don't have as much privacy as you would like because of your child?					
12.	Do you feel that your social life has suffered because you are caring for your child?					
13.	Do you feel uncomfortable about having friends over because of your child?					

14.	Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
15.	Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?					
16.	Do you feel that you will be unable to take care of your child much longer?					
17.	Do you feel you have lost control of your life since your child's illness?					
18.	Do you wish you could leave the care of your child to someone else?					
19.	Do you feel uncertain about what to do about your child?					
20.	Do you feel you should be doing more for your child?					
21.	Do you feel you could do a better job in caring for your child?					
22.	Overall, how burdened do you feel in caring for your child?					

Annexure E: DASS scale

Instructions: Please read each statement and circle a number, 0, 1, 2, or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

	Statement	**Score**			
		Did not apply to me at all 0	Applied some of the time 1	Applied a considerable degree 2	Applied to me much 3
1.	I find myself getting upset by quite trivial things				
2.	I was aware of dryness of the mouth				
3.	I couldn't seem to experience any positive feelings at all				
4.	I experienced breathing difficulty				
5.	I just couldn't seem to get going				
6.	I tended to overreact to situations				
7.	I had a feeling of shakiness				
8.	I found it difficult to relax				
9.	I found myself in situations that made me so anxious				
10.	I felt that I had nothing to look forward to				
11.	I found myself rather getting upset too easily				
12.	I felt that I was using a lot of nervous energy				
13.	I felt sad and depressed				
14.	I find myself getting impatient when I am delayed in anyway				

15.	I had a feeling of faintness				
16.	I felt that I had lost interest in just about everything				
17.	I felt I wasn't worth much as a person				
18.	I felt that I was rather touchy				
19.	I perspired noticeably in the absence of high temperature or physical exertion				
20.	I felt scared without any good reason				
21.	I felt that life was not worthwhile				
22.	I felt it hard to wind down				
23.	I had difficulty in swallowing				
24.	I couldn't seem to get any enjoyment out of the things I had				
25.	I was aware of the action of my heart				
26.	I felt down hearted and blue				
27.	I felt that I was very irritable				
28.	I felt that I was close to panic				
29.	I found it hard to calm down after something upset me				
30.	I felt that I would be thrown by some trivial but rather unfamiliar task				
31.	I was unable to become enthusiastic about anything				
32.	I found it difficult to tolerate interruptions to what I was doing				
33.	I was in a state of nervous tension				
34.	I felt was pretty worthless				

35.	I was intolerant of anything that kept me from getting on with was I was doing				
36.	I felt terrified				
37.	I could see nothing in the future to be hopeful about				
38.	I felt life was meaningless				
39.	I found myself getting agitated				
40.	I was worried about situations in which I might panic and make a fool out of myself				
41.	I experience trembling				
42.	I felt it difficult to work up the initiative to do things				

Annexure F: PHQ-15 somatic symptoms questionnaire

Instructions: Please tick where applicable.

During the past 7 days, how much have you been bothered by any of the following problems?				
		Not bothered at all (0)	Bothered a little (1)	Bothered a lot (2)
1.	Stomach pain			
2.	Back pain			
3.	Pain in your arms, legs, or joints			
4.	Menstrual cramps			
5.	Headaches			
6.	Chest pain			
7.	Dizziness			
8.	Fainting spells			
9.	Feeling your heart pound or race			
10.	Shortness of breath			
11.	Pain or problems during sexual intercourse			
12.	Constipation, loose bowels or diarrhoea			
13.	Nausea, gas and indigestion			
14.	Feeling tired or having low energy			
15.	Trouble sleeping			

Annexure G: Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement by circling the one that applies to you.

	Statement	**Score**						
		Very strongly disagree (1)	Strongly disagree (2)	Mildly disagree (3)	Neutral (4)	Mildly agree (5)	Strongly agree (6)	Very strongly agree (7)
1.	There is a special person who is around when I am in need.							
2.	There is a special person with whom I can share my joys and sorrows.							
3.	My family really tries to help me.							
4.	I get the emotional help and support I need from my family.							
5.	I have a special person who is a real source of comfort to me.							
6.	My friends really try to help me.							

7.	I can count on my friends when things go wrong.							
8.	I can talk about my problems with my family.							
9.	I have friends with whom I can share my joys and sorrows.							
10.	There is a special person in my life who cares about my feelings.							
11.	My family is willing to help me make decisions.							
12.	I can talk about my problems with my friends.							

Annexure H: Permission to conduct study at the Korle-Bu Teaching Hospital

Dear Sir/Madam,

My name is Doreen Asantewa Abeasi, a PhD student of the University of Witwatersrand, South Africa. I write to ask permission to use your facility for my research.

The study aims to develop a psychosocial support programme for caregivers of children with developmental disabilities in Ghana. The researcher will like to use the Out Patient Department of Neurodevelopmental Clinic under the Child Health Department.

The caregivers will be contacted at the clinic and the necessary information regarding the research will be provided to them. If they consent to participate in the study, depending on the phase the caregiver will be involved, the researcher will make a follow up to their homes or they will be invited at scheduled times to undergo assessments and also taken through the intervention. In the nutshell, the hospital will be the point of contact to the caregivers of children with DD and also a paediatrician confirming the diagnosis of the child.

The Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg has approved this study after thoroughly reviewing the ethical considerations outlined in this study. My ethical clearance number is [Insert HREC number]. If you have any other concern with regards to the conduct of this research, please contact the chairperson of the Committee, Professor Clement Penny either via telephone number on +27 (0)11 717 2301 or email on Clement.Penny@wits.ac.za . Otherwise, the committee secretariat can also be contacted on +27 (0)11 717 2700/1234 or Zanele.Ndlovu@wits.ac.za /Rhulani.Mukansi@wits.ac.za .

If you have any further question regarding the research please do not hesitate to contact me or my supervisor on the details provided below.

I am looking forward to a favourable response.

Yours Sincerely,

Researcher/PhD student
Doreen Asantewa Abeasi
Email: 2193368@students.wits.ac.za
Tel: +233 (0)24 280 8985

Research Supervisor
Dr. Nokothula Nkosi-Mafutha
Email. Nokuthula.Nkosi-mafutha@wits.ac.za
Tel: +27 (0)11 488 3094

Annexure I: Study information sheet-caregivers of children with disability in the qualitative phase

Dear Caregiver,

My name is Doreen Asantewa Abeasi, a PhD student of the University of Witwatersrand, South Africa. I wish to invite you to participate in my research work that aims to develop a psychosocial support programme for caregivers of children with developmental disability.

Who is a caregiver and who can participate in this study?
Caregivers are the people who are mainly responsible for the day to day care of the child with developmental disability, has not received any formal training and lives with the child. If you are a caregiver who manages and assists the child with developmental disability in their activities of daily living, I would like to invite you to participate in this study.

What is the objective of this study?
The objective of this study is to explore your experiences and health needs as a caregiver of a child with developmental disability.

What would participation in this research involve?
If you choose to participate in this study, the researcher will make a follow-up to your home on a date and time that is scheduled and agreed by you and the researcher. The researcher will conduct an interview with you and you will be required to share your experiences as a caregiver and also to describe your present health needs. The interview will be recorded which is to enable the researcher transcribe afterwards. After the interview, the data obtained from the interview will be analyzed and the researcher will present caregiver participants with the research findings. Your role will be to check and confirm if the data has been accurately captured and the interpretation truly reflect your views.

Will I benefit from participating in the study?
There are no direct benefits associated with participating in the study. However, the indirect benefit is that as a participant of this study you will be part of generating the necessary knowledge required to develop the psychosocial support programme for caregivers of children with developmental disabilities.

Are there any risk involved in participating in this study?
There are no direct risks that will be involved in participating in this study. The interview may last beyond 60 minutes and this may be a little stressful for you. In view of the above, a registered clinical psychologist will be available for counselling if the need be. The contact details are as follows:

Dr. Richard Appiah
University of Ghana, Legon
Lecturer/ Clinical Psychologist
Telephone number: +233245823866
Email: Richardappiah2010@gmail.com

Is participation voluntary and confidential?
Participation in this research is voluntary. If you volunteer to participate, you may at any point in time withdraw from the study without facing any negative consequences. With regards to data analysis, all participants will be assigned codes and the researcher will ensure that there is no data by which you can be identified or linked with.

How will the findings of the study be disseminated?
This research will be written as a doctoral thesis which will be made available through the University of Witwatersrand library's online portal. The study will also be submitted to peer reviewed journals for publication.

Has the study been ethically approved?
The Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg has approved this study after thoroughly reviewing the ethical considerations outlined in this study. My ethical clearance number is [Insert HREC number]. If you have any other concern with regards to the conduct of this research, please contact the chairperson of the Committee, Professor Clement Penny either via telephone number on +27 (0)11 717 2301 or email on Clement.Penny@wits.ac.za . Otherwise, the committee secretariat can also be contacted on +27 (0)11 717 2700/1234 or Zanele.Ndlovu@wits.ac.za /Rhulani.Mukansi@wits.ac.za .

If you have any further question regarding the research please do not hesitate to contact me or my supervisor on the details provided below.
Yours Sincerely,

Researcher/PhD student
Doreen Asantewa Abeasi
Email: 2193368@students.wits.ac.za
Tel: +233 (0)24 280 8985

Research Supervisor
Dr. Nokothula Nkosi-Mafutha
Email. Nokuthula.Nkosi-mafutha@wits.ac.za
Tel: +27 (0)11 488 309

Annexure J: Study information sheet-Experts

Dear Expert,

My name is Doreen Asantewa Abeasi, a PhD student of the University of Witwatersrand, South Africa. I wish to invite you to participate in my research work that aims to develop a psychosocial support programme for caregivers of children with developmental disability.

What would participation in this research involve?
If you choose to participate in this study, the researcher will send a draft of the psychosocial support programme to you and through consensus with other experts you provide your input. The Delphi technique will be used and two rounds of consensus building will be done. As experts, you will be required to rate each of the proposed items of the support programme on a 7-point ordinal Likert scale for acceptability, feasibility and effectiveness. You will also have an opportunity to comment on your choice of item and provide suggestions on items which should be included in the support programme.

What are the risk and benefits for participating in the study?
There are no direct risks or benefits associated with participating in the study. However, the indirect benefit is that participation offers you the opportunity to contribute to the development of the psychosocial support programme for caregivers of children with developmental disabilities.

Is participation voluntary and confidential?
Participation in this research is voluntary. If you volunteer to participate, you may at any point in time withdraw from the study without facing any negative consequences. Your expertise within the group of experts will be clearly defined (Example; psychologist, psychiatrist, nurse etc). You will be known by the other members of the panel.

How will the findings of the study be disseminated?
This research will be written as a doctoral thesis which will be made available through the University of Witwatersrand library's online portal. The study will also be submitted to peer reviewed journals for publication.

Has the study been ethically approved?
The Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg has approved this study after thoroughly reviewing the ethical considerations outlined in this study. My ethical clearance number is [Insert HREC number]. If you have any other concern with regards to the conduct of this research, please contact the chairperson of the Committee, Professor Clement Penny either via telephone number on +27 (0)11 717 2301 or email

on Clement.Penny@wits.ac.za . Otherwise, the committee secretariat can also be contacted on +27 (0)11 717 2700/1234 or Zanele.Ndlovu@wits.ac.za /Rhulani.Mukansi@wits.ac.za .

If you have any further question regarding the research please do not hesitate to contact me or my supervisor on the details provided below.

Yours Sincerely,

Researcher/PhD student
Doreen Asantewa Abeasi
Email: 2193368@students.wits.ac.za
Tel: +233 (0)24 280 8985

Research Supervisor
Dr. Nokothula Nkosi-Mafutha
Email. Nokuthula.Nkosi-mafutha@wits.ac.za
Tel: +27 (0)11 488 3094

Annexure K: Study information sheet-Caregivers of children with developmental disability in the quantitative phase

Dear Caregiver,

My name is Doreen Asantewa Abeasi, a PhD student of the University of Witwatersrand, South Africa. I wish to invite you to participate in my research work that aims to develop a psychosocial support programme for caregivers of children with developmental disability.

Who is a caregiver and who can participate in this study?
Caregivers are the people who are mainly responsible for the day to day care of the child with developmental disability, has not received any formal training and lives with the child. If you are a caregiver who manages and assists the child with developmental disability in their activities of daily living, I would like to invite you to participate in this study.

What are the objectives of this study?
The objectives of this study are;

a. To conduct a baseline assessment of your burden of care, stress levels, cortisol levels, anxiety, physical health, blood pressure and perceived social support.
b. To pilot test the psychosocial support programme developed from the study on you.
c. To measure the outcomes (burden of care, stress levels, cortisol levels, anxiety, physical health, blood pressure and perceived social support) immediately after the psychosocial support programme and at 6 weeks.

What would participation in this research involve?
If you choose to participate in this study, two main data will be collected from you before and after the administration of the support programme. On the data collecting dates, you will be required to travel to an arranged setting. You will be given a socio-demographic questionnaire to provide your details like age, gender etc. Again, self-report measures of your burden of care, stress levels, level of anxiety, physical health and perceived social support will be given to you to complete. Each measure has its own instructions to guide you to complete. All the measures are Likert scale and you will be required to choose how much a statement applies to you or not. Apart from the self-report measures, your blood pressure will be measured three times during that day. Your blood samples will be collected at two different times during that day (in the morning between 7-9am and late afternoon, 3-5pm). No excess blood will be stored and used for any other study. If there is no one to leave your child with developmental disability with, you can bring him/her along and provision will be made for them. Transport fees will be covered and

meals will be provided because you may spend nearly 8 to 10 hours since the samples will be collected twice in the same day.

Will I benefit from participating in the study?
The researcher cannot guarantee any direct or indirect benefit to be obtained from this study.

Are there any risk involved in participating in this study?
There are no direct risks that will be involved in participating in this study. Blood samples that will be collected by put ting a needle in your vein and this may be a little painful. Again, the procedure can cause phlebitis, however, the procedure will be undertaken by qualified Medical Laboratory Technologists making this risk very minimal. In addition to the above, a registered clinical psychologist will be available for counselling if the need arises. The contact details are as follows;

Dr. Richard Appiah
University of Ghana, Legon
Lecturer/ Clinical Psychologist
Telephone number: +233245823866
Email: Richardappiah2010@gmail.com

Is participation voluntary and confidential?
Participation in this research is voluntary. If you volunteer to participate, you may at any point in time withdraw from the study without facing any negative consequences. With regards to data analysis, all participants will be assigned codes and the researcher will ensure that there is no data by which you can be identified or linked with.

How will the findings of the study be disseminated?
This research will be written as a doctoral thesis which will be made available through the University of Witwatersrand library's online portal. The study will also be submitted to peer reviewed journals for publication.

Has the study been ethically approved?
The Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg has approved this study after thoroughly reviewing the ethical considerations outlined in this study. My ethical clearance number is [Insert HREC number]. If you have any other concern with regards to the conduct of this research, please contact the chairperson of the Committee, Professor Clement Penny either via telephone number on +27 (0)11 717 2301 or email on Clement.Penny@wits.ac.za . Otherwise, the committee secretariat can also be contacted on +27 (0)11 717 2700/1234 or Zanele.Ndlovu@wits.ac.za /Rhulani.Mukansi@wits.ac.za .

If you have any further question regarding the research please do not hesitate to contact me or my supervisor on the details provided below.

Yours Sincerely,

Researcher/PhD student
Doreen Asantewa Abeasi
Email: 2193368@students.wits.ac.za
Tel: +233 (0)24 280 8985

Research Supervisor
Dr. Nokothula Nkosi-Mafutha
Email. Nokuthula.Nkosi-mafutha@wits.ac.za
Tel: +27 (0)11 488 3094

Annexure L: Consent form-caregivers of children with developmental disability in the qualitative phase

CONSENT FORM

Title of Project: A psychosocial support programme for caregivers of children with developmental disabilities in Ghana.

Name of Researcher: Doreen Asantewa Abeasi

I, ———————————————— hereby acknowledge that I have read thoroughly and understand the study information sheet. I have asked the necessary questions and have been answered to full satisfaction by the researcher.

I give consent for the audio recording of my interview with the researcher. I understand that this audio recording will be password protected on the researcher's computer. I also understand that the audio recording will be transcribed but my name will remain anonymous.

I understand the risks and benefits in the study. I agree that if the need arises, a registered clinical psychologist will be available to take me through counselling. I voluntarily agree to participate.

Signature		**Date**
Participant		
Researcher		
Witness		

Annexure M: Consent form-caregivers of children with developmental disability in the quantitative phase

CONSENT FORM

Title of Project: A psychosocial support programme for caregivers of children with developmental disabilities in Ghana

Name of Researcher: Doreen Asantewa Abeasi

I, _____ hereby acknowledge that I have read thoroughly and understand the study information sheet. I have asked the necessary questions and have been duly answered by the researcher. I understand that my participation in this study is voluntary and I can at any time withdraw from the study if I wish to do so.

I give consent for my blood samples to be taken during the research. I understand the risks and benefits in the study. I agree that if the need arises, a registered clinical psychologist will be available to take me through counselling. I voluntarily agree to participate in this research.

Signature		**Date**
Participant		
Researcher		
Witness		

Annexure N: Consent Form-Experts

CONSENT FORM

Title of Project: A psychosocial support programme for caregivers of children with developmental disabilities in Ghana

Name of Researcher: Doreen Asantewa Abeasi

I, _____ hereby acknowledge that I have read thoroughly and understand the study information sheet. I have asked the necessary questions and have been duly answered by the researcher. I understand that my participation in this study is voluntary and I can at any time withdraw from the study if I wish to do so.

I give consent to be part of the expert panel. I understand the risks and benefits in the study. I voluntarily agree to participate in this research.

Signature		**Date**
Participant		
Researcher		
Witness		

Annexure O: Consent form-caregivers of children with developmental disability for recording of interviews in the qualitative phase

CONSENT FORM

Title of Project: A psychosocial support programme for caregivers of children with developmental disabilities in Ghana

Name of Researcher: Doreen Asantewa Abeasi

I, ———————————————— hereby acknowledge that I have read thoroughly and understand the study information sheet. I have asked the necessary questions and have been duly answered by the researcher. I understand that my participation in this study is voluntary and I can at any time withdraw from the study if I wish to do so.

I give consent for the recording of all interviews between the researcher and myself. I agree that if the need arises, a registered clinical psychologist will be available to take me through counselling. I voluntarily agree to participate in this research.

Signature		**Date**
Participant		
Researcher		
Witness		

Annexure P: Institutional approval to conduct study at KBTH, Ghana

In case of reply the number
And the date of this
Letter should be quoted
My Ref. No. KBTH/MD/C3/21
Your Ref. No......

KORLE BU TEACHING HOSPITAL
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

20th May, 2021

DOREEN ASANTEWA ABEASI
PHD CANDIDATE, UNIVERSITY OF WITWATERSRAND
P. O. BOX 42, AGOGO

INSTITUTIONAL APPROVAL: KORLE BU TEACHING HOSPITAL-SCIENTIFIC AND TECHNICAL COMMITTEE/INSTITUTIONAL REVIEW BOARD (KBTH-STC/IRB/00021/2021

Following approval of your study entitled "A support programme to improve the well-being of caregivers of children with developmental disabilities at Korle Bu Teaching Hospital, Ghana" by the Korle Bu Teaching Hospital-Scientific and Technical Committee/Institutional Review Board.

I am pleased to inform you that institutional approval has been granted for the conduct of your study in Korle Bu Teaching Hospital.

Please contact the Head of Department to discuss the commencement date of the study.

Please note that, this institutional approval is rendered invalid if the terms of the Institutional Reviewed Board/Scientific and Technical Committee approval are violated.

Sincere regards,

Dr. Ali Samba
Director of Medical Affairs
For: Chief Executive

Annexure Q: Ethics approval from the Institutional Review Board, KBTH

In case of reply the number
And the date of this
Letter should be quoted
My Ref. No. KBTH/MD/C3/21
Your Ref. No......

KORLE BU TEACHING HOSPITAL
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

20th May, 2021

DOREEN ASANTEWA ABEASI
PHD CANDIDATE, UNIVERSITY OF WITWATERSRAND
P. O. BOX 42, AGOGO

A SUPPORT PROGRAMME TO IMPROVE THE WELL-BEING OF CAREGIVERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES AT KORLE BU TEACHING HOSPITAL, GHANA

KBTH-IRB /00021/2021

INVESTIGATOR: Doreen Asantewa Abeasi

The Korle Bu Teaching Hospital Institutional Review Board (KBTH IRB) reviewed and granted approval to the study entitled: "A support programme to improve the well-being of caregivers of children with developmental disabilities at Korle Bu Teaching Hospital, Ghana"

Please note that the Board requires you to submit a final review report on completion of this study to the KBTH-IRB.

Kindly, note that, any modification/amendment to the approved study protocol without approval from KBTH-IRB renders this certificate invalid.

Please report all serious adverse events related to this study to KBTH-IRB within seven days verbally and fourteen days in writing.

This IRB approval is valid till 30th April, 2022. You are to submit annual report for continuing review.

Sincere regards,

DR. DANIEL ANKRAH
VICE CHAIR (KBTH-IRB)
FOR: CHAIR (KBTH-IRB

Cc: The Chief Executive Officer, KBTH
The Director of Medical Affairs, KBTH

Annexure R: Approval from Scientific and Technical Committee, KBTH

In case of reply the number
And the date of this
Letter should be quoted

My Ref. No. KBTH/MS/(03)/21

Your Ref. No......

KORLE BU TEACHING HOSI
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-(
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

19th April, 2021

DOREEN ASANTEWA ABEASI
UNIVERSITY OF WITWATERSRAND
P. O. BOX 42, AGOGO

SCIENTIFIC AND TECHNICAL COMMITTEE APPROVAL
PROTOCOL IDENTIFICATION NUMBER: KBTH-STC 00021/2021

The Korle Bu Teaching Hospital Scientific and Technical Committee (KBTH-STC), on 19th April, 2021 approved your submitted study protocol.

TITLE OF PROTOCOL: "A Support Programme to Improve the Well-Being of Caregivers of Children with Developmental Disabilities at Korle Bu Teaching Hospital, Ghana"

PRINCIPAL INVESTIGATOR: Doreen Asantewa Abeasi

This approval requires that you **forward your approved document to Korle Bu Teaching Hospital –Institutional Review Board (KBTH-IRB) for the ethical aspect of the proposal to be assessed before the project can be initiated.**

This STC approval is valid till 30th December, 2021
You may, however, request extension of the approval period, or renewal as the case may be, should the study extend beyond the stated period.

Upon completion, you are required to submit a final report on the study to the STC. This is to enable the STC ensure among others that, the project has been implemented as per the approved protocol. You are also required to inform the KBTH-STC and Research Directorate of any publications that may emanate from the research findings.

Kindly note that, should the need arise, the KBTH-STC or IRB may institute appropriate measures to satisfy itself that study is being conducted according to the highest scientific and ethical standards.

Please note that any modification to the study protocol without Scientific Technical Committee (STC) approval renders this approval invalid.

Sincere regards,

Prof. G. Obeng Adjei
Chairman, KBTH-STC

Cc: The Chairman, KBTH-IRB

Annexure S: Approval of title

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

03 August 2020
Person No: 2193368
PAG

Ms DA Abeasi
Presbyterian University College, Ghana
P.O.Box 42
Agogo, Asante-Akyem
Ghana

Dear Ms Doreen Abeasi

Doctor of Philosophy: Approval of Title

We have pleasure in advising that your proposal entitled *A support programme to improve the well-being of caregivers of children with developmental disabilities in Ghana*. has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Annexure T: Ethics Approval from Human Research Ethics Committee

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R49 Ms DA Abeasi

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M201160

NAME: (Principal Investigator)	Ms DA Abeasi
DEPARTMENT:	School of Therapeutic Sciences Department of Nursing Education Medical School University
PROJECT TITLE:	*A support programme to improve the well-being of caregivers of children with developmental disabilities in Ghana*
DATE CONSIDERED:	2020/11/27
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr N Nkosi-Mafutha
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2021/06/30

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **November** and therefore reports and re-certification will be due in the month of **November** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator _____ Date _____

Annexure U: Proofreading certificate

UNIVERSITY OF CAPE COAST
COLLEGE OF HUMANITIES AND LEGAL STUDIES
FACULTY OF ARTS
DEPARTMENT OF COMMUNICATION STUDIES

Tel: 03321-30944
Email: dcs@ucc.edu.gh
Our Ref:
Your Ref:

University Post Office
Cape Coast, GHANA

20th June, 2023

Certificate of Editing

This is to certify that the doctoral thesis "A Support Programme for Caregivers of Children with Developmental Disabilities in Ghana" Doreen Asantewa Abeasi has been thoroughly proofread and edited for clarity in expression, spelling, punctuation, vocabulary and grammar.

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