

DECLARATION

I declare that “Perceived Benefits and Burdens encountered by relatives caring for persons on long term Haemodialysis in Johannesburg,” is my own work. It has never been submitted for any other degree or examination to any other University. All references used have been acknowledged by means of referencing.

SIGN

Student	Shingai M Kuture
Supervisors	Ms Hilary Thurling Dr Gayle Langley

DEDICATION

This work is dedicated to all people with Chronic Renal Failure as well as to my father Tamuka Mbira Kuture and my mother Marianna “Milly” Kuture, for their continued support and dedication. I would not be where I am today, if it was not for your support. To my daughter Dudzai Taona-dadiso Kuture, this one is for you, my child.

ACKNOWLEDGEMENTS

I wish to acknowledge my heartfelt and sincere gratitude and appreciation to:

- All participants who took part in this study. Without them this study would not have been possible.
- My supervisors; Ms Hilary Thurling and Dr Gayle Langley, for their patience and guidance throughout this study. I am truly fortunate to have been supervised by them.
- Mrs Chirwa; for assisting me with the statistics and for her patience.
- My colleagues; Rosemary “Rosy” Phillpotts and Isaac Seopa for their support, understanding and encouragement.
- Fresenius Medical Care; for allowing me access to their dialysis units and their patients.
- The following doctors; Roger Phillips, Nerissa Manthri, Shoyab Wadee and Vhaktang Rekhiviashivilli, for allowing me access to their patients.
- The nursing staff from all the three dialysis units who participated in this study. Thank you for your understanding, friendliness and encouragement.
- My brothers and sisters Dumezweni, Mazvitireni, Dudzai and Tamuka, for all the support, love and encouragement you have given me over the years, I am proud to be your little sister.
- My friend; Patience Chiloane for all her love, encouragement and sisterly advice.
- My forever loving Father Jehovah for his love and blessing.

ABSTRACT

Perceived benefits and burdens encountered by relatives caring for person on long-term haemodialysis in Johannesburg.

This study examines the perceived benefits and burdens of family members caring for persons on long term Haemodialysis. The caregiver burden scale by Elmastahl, Malmeberg and Annerstedtl (1996) was used for the purposes of the study.

The participants were selected by Census (total) sampling. The sample consisted of family caregivers who were 18 years and above who were selected from three haemodialysis units in Johannesburg. Permission to conduct the study was requested and granted from all relevant authorities. One hundred and fifty questionnaires were distributed amongst the three haemodialysis units of which seventy nine participants responded to the study.

Data were analysed using the statistical package STATA version 12. Demographic data and the caregiver burden scale were analysed through frequency counts, percentages and graphs were constructed from the collected data and analysed. Cross tabulations, using Fisher's exact test were performed to determine the relationship between the demographic information and factors of the caregiver burden scale. The results are presented in the form of tables and graphs. Semi structured questionnaire with an option for elaboration were analysed using content analysis to enumerate a deeper understanding of the perceived burdens and benefits of caring for a person on Haemodialysis.

Findings from the study concluded that family caregivers have encountered both benefits and burdens when caring for a person on Haemodialysis. The following factors have emerged namely demographics which include age, gender, relation to patient, highest education level, employment, ethnicity and duration of care and the factors surrounding general strain, isolation, disappointment, emotional involvement and environment. The factors, whether good or poor, are not always a predictor of perceived benefits and burdens of caring for persons on long term haemodialysis. The overall caregiver burden score, inclusive of all factors, showed a median score of 46.59% of all family caregivers' experienced burden in caring for their relative on haemodialysis. Health education and support for the family caregivers proved to be a need in improving and reducing the caregiver burden. Caregiver health is quickly becoming a public health care issue that requires a more focused attention

from health professionals, policy makers and caregivers themselves to ensure the health and safety of those dedicating their lives to the care of their relatives on haemodialysis.

TABLES OF CONTENTS

	PAGES
Declaration	I
Dedication	II
Acknowledgement	II
Abstract	III
List of tables and figures	IV

LIST OF TABLES AND FIGURES

	PAGES
Table 1 :Stages of Chronic Kidney Disease	2
Table 3.2 :Research instrument responses	20
Table 4.1 :Demographic information of the family caregivers	33
Fig 4.3.1 :General Strain %	35
Fig 4.3.2 :Isolation %	36
Fig 4.3.3 :Disappointment %	37
Fig 4.3.4 :Emotional Involvement %	38
Fig 4.3.5 :Environment %	39
Table 4.4 :Cross Tabulation of demographic and caregiver burden scale	42
Fig 4.6.1 :Question 1	45
Fig 4.6.2 :Question 2	46
Fig 4.6.3 :Question 3	47

CHAPTER 1: INTRODUCTION TO THE STUDY

	PAGES
1.0 INTRODUCTION	1
1.1 BACKGROUND OF THE STUDY	1
1.2 PROBLEM STATEMENT	8
1.3 PURPOSE OF THE STUDY	9
1.4 AIM AND OBJECTIVES OF THE STUDY	9
1.5 SIGNIFICANCE OF THE STUDY	9
1.6 OPERATIONAL DEFINITON	10
1.6.1 caregiving	10
1.6.2 family caregiver	10
1.6.3 caregiver burden	10
1.6.4 burdens	10
1.6.5 benefits	11
1.6.6 factors family caregivers caring for a patient on haemodialysis	11
1.6.7 chronic kidney disease	12
1.6.8 end stage renal disease	12
1.6.9 haemodialysis	12
1.7 CONCLUSION	12

CHAPTER 2 LITERATURE REVIEW

2.0 INTRODUCTION	13
2.1 LITERATURE REVIEW	13
2.2 CONCLUSION	18

CHAPTER 3 RESEARCH METHODOLOGY

	PAGES
3.0 INTRODUCTION	19
3.1 RESEARCH DESIGN	19
3.2 SETTING AND POPULATION	19
3.3 THE SAMPLE	20
3.3.1 inclusion criteria	21
3.4 RESEARCH INSTRUMENT	21
3.4.1 Question 1	22
3.4.2 Question 2	22
3.4.3 Question 3	22
3.5 PILOT STUDY	23
3.6 DATA COLLECTION	25
3.7 APPROACH TO DATA ANALYSIS	28
3.7.1 Demographic information of the family caregivers	28
3.7.2 Factors affecting family caregivers caring for a patient on haemodialysis.	28
3.7.3 Relationship between the demographic information and the factors of the caregiver burden scale.	29
3.7.4 Semi structured questionnaire.	29
3.8 RELIABILITY AND VALIDITY	29
3.8.1 Ethical Considerations	31
3.9 CONCLUSION	31

CHAPTER 4 ANALYSIS OF DATA

	PAGES
4.0 INTRODUCTION	32
4.1 DEMOGRAPHIC INFORMATION OF THE FAMILY CAREGIVERS	32
4.2 DESCRIPTION OF DEMOGRAPHIC INFORMATION OF CAREGIVERS	33
4.3 RESULTS: FACTORS AFFECTING FAMILY CAREGIVERS CARING FOR THE PATIENT ON HAEMODIALYSIS	35
4.3.1 general strain	36
4.3.2 isolation	37
4.3.3 disappointment	38
4.3.4 emotional involvement	39
4.3.5 environment	40
4.3.6 overall burden score	41
4.4 RELATIONSHIP BETWEEN THE DEMOGRAPHIC INFORMATION AND THE FACTORS OF THE CAREGIVER BURDEN SCALE	42
4.5 A DESCRIPTION OF THE CROSS TABULATION OF DEMOGRAPHIC INFORMATION AND THE FACTOR OF THE CAREGIVER BURDEN SCALE	42
4.6 SEMISTRUCTURED QUESTIONNAIRE	43
4.6.1 question 1	45
4.6.2 question 2	46
4.6.3 question 3	47
4.7 CONCLUSION	48

CHAPTER 5 DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.0	INTRODUCTION	49
5.1	DISCUSSION OF THE RESULTS ILLUSTRATED IN CHAPTER 4	49
5.2	DEMOGRAPHIC INFORMATION OF FAMILY CAREGIVER	49
5.3	FACTORS OF THE CAREGIVER BURDEN SCALE	50
5.3.1	general strain	50
5.3.2	isolation	51
5.3.3	disappointment	51
5.3.4	emotional involvement	52
5.3.5	environment	53
5.3.6	overall burden score	53
5.4	CROSS TABULATION OF THE FACTORS OF THE CAREGIVER BURDEN SCALE AND DEMOGRAPHIC CATERGORY	54
5.5	SEMI STRUCTURE QUESTIONS	57
5.5.1	question 1	57
5.5.2	question 2	58
5.5.3	question 3	58
5.6	LIMITATIONS OF THE STUDY	59
5.7	RECOMMENDATIONS	60
5.7.1	Recommendations for the research	61
5.8	CONCLUSION	61

CHAPTER 6 LIST OF SOURCES

6.0	LIST OF SOURCES	63
-----	-----------------	----

APPENDICE

- Appendix A : Information letter to Haemodialysis patient.
- Appendix B : Information letter to family caregivers.
- Appendix C : Consent form for family caregivers.
- Appendix D : Questionnaire (demographic, caregiver burden scale and semi structured questionnaire).
- Appendix E : Approval from the Ethics committee.
- Appendix F : Approval from the postgraduate committee.
- Appendix G : Approval from the Fresenius Medical Care Management.
- Appendix H : Email response from Professor Saraldevi Naicker