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The psychosocial needs and coping strategies of black African mothers following the birth of a child with Down Syndrome: Implications for indigenisation of SA social work practice

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CHAPTER 1: INTRODUCTION

1.1 Introduction

The birth of a child with Down Syndrome (DS) is likely to bring mixed feelings and thoughts, which may lead to various psychological and social difficulties in any person regardless of race or creed (Weihs, 1997). However, the availability of effective support systems, be it informal family support or professional intervention, will determine how people fare through the experience of giving birth to a child with disabilities. As argued by Weihs (1971:96), "the stress and strain brought about by the birth of a child with disabilities is most likely to affect both the biological parents and relationships within the family unit". The source of problems may either be the shift in family responsibilities or challenges arising from role sharing in caring for the child with disabilities as well as the resultant differential treatment of the affected child as compared to the other 'normal' children (Weihs, 1997).

Given the above background, children with disabilities as well as their families are generally considered to be at risk (Weihs, 1997). The risk may emanate from the resultant overwhelming sequence of psychosocial reactions. If these psychosocial reactions are not properly managed, they may lead to family disintegration. Either the parents of the disabled child or the child him/herself may adopt dysfunctional coping mechanisms. As such, the family unit automatically becomes potential beneficiaries of social work intervention. Forms of social work intervention will vary according to the presenting challenge, from preventative and promotive work aimed at dealing with possible problems before they arise to curative interventions necessitated by the existence of a recognised problem, either with the individual child, parents or the family as a system in relation to the child with Down Syndrome.

Historically, Western social work interventions have been made with African people (Bar-On, 2003:27). Little has been done to ascertain the relevance and appropriateness of such interventions and consequently their effectiveness (Bar-On, 2003:27).

The researcher is of the opinion that the best way of ensuring relevance and appropriateness when it comes to social work intervention is that practitioners should know and clearly understand the needs underlying the presenting problem that calls for intervention. Thus, it is essential that in an attempt to effectively and efficiently service clients, an accurate fit between methods of intervention and needs of the clients be found. It is the aim of this study to search for those needs and assess the degree of relative fit between such felt needs and professional intervention methods.

1.2 Aims of the research study

According to De Vos et. al (1998:7), a research goal or aim is a "broader, more abstract conception of the end towards which effort or ambition is directed, while objective denotes the more concrete, measurable and more speedily attainable conception of such end towards which effort is directed". The aim of this study is to explore the psychosocial needs and coping strategies of black African mothers following the birth of a child with Down Syndrome (DS) and the implications of such needs for indigenisation of social work practice in South Africa.

The specific aims of the study are as follows:

1. to establish black African mothers' needs and coping strategies following the birth of a child with Down Syndrome
2. to explore their perceptions about the handling of their needs at a formal or professional level
3. to explore how they evaluate the handling of their needs through informal support systems

4. to establish the extent to which social work intervention appears to have been informed by the needs, ideas, values and aspirations of the mothers and finally, to highlight implications of current practice for indigenisation of social work in the South African context

1.3 Rationale

The researcher previously worked with mothers of children with Down Syndrome (DS) during study towards a Masters Degree in Genetic Counselling and as such has a keen interest in matters related to DS. The researcher later worked as a social worker at a Hospital setting and continued to work with black African mothers identified as at high risk for giving birth to a child with DS. He also worked with mothers of foetuses diagnosed with other genetic abnormalities. The majority of these mothers were black African and understood little about DS and other genetic conditions. Most of them came with preconceived beliefs of varying significance about bearing a child with physical or mental handicaps.

As postulated by Fouche and De Vos (1998: 51), topics for social work research should "come from the day-to-day activities and interactions in the work situation". This for the researcher was the main source of motivation. Furthermore, current counselling models seemed largely to be influenced by foreign cultures and counselling/therapy itself seemed to be an unfamiliar practice to many black African mothers encountered by the researcher. This raised curiosity in the researcher to develop understanding about their felt needs with the purpose of contributing to the development of models of intervention that address felt needs appropriately. Little research seemed to have been done to unearth the perceptions of black Africa people about formal social support. The researcher felt strongly that social work intervention should build on and serve to strengthen people's indigenous support systems.

The second main motivation that prompted the researcher to undertake this study was the desire to map-out how black African mothers with children with congenital handicaps

such as DS cope with regard to accessing and using formal social assistance. It was hoped that an inquiry into this matter would furthermore, assist in identifying strengths and weaknesses in the usage of available social support systems (formal and informal) in helping these mothers to provide the best possible care for their children.

1.4 Anticipated value of the study

It is anticipated that the study will contribute to emerging indigenous social work knowledge in South Africa. Indigenous social work knowledge will in turn contribute to more appropriate and responsive change outcomes brought about by social work intervention. Specifically, the study will serve to highlight black African mothers' subjective coping mechanisms with regard to traumatic experiences regarding their children and it is hoped that the study will inform approaches to working with black African mothers and their families. Finally, it is hoped that the study will generally contribute to making social work more responsive and relevant to the prevailing problems and needs of the people it serves.

1.5 Underlying assumptions

Several assumptions informed the study. These were as follows:

1. Social work practice in South Africa is strongly based on theory developed in "Western" cultural contexts.
2. An over-dependence of social work on "Western" ideas bears the risk of rendering it ineffective in the face of prevailing social problems and practice demands in South Africa.
3. An understating of needs and coping strategies is a prerequisite and a basis for the development of social work intervention models.

1.7 Research methodology

1.7.1 Research Design

The researcher used a qualitative descriptive research design. A qualitative (naturalistic) approach to research uses situations or behaviours, to arrive at concrete conclusions and generalisations about them (Neuman, 1997). The reason for choice of this research design stemmed from the fact that the study focused on the generation of knowledge about a particular social phenomenon (perceptions of needs relating to parenting of children with DS) rather than testing of theory or hypotheses. Thus, what were important in the study were participants' perceptions and feelings about their psychosocial needs and their coping strategies.

1.7.2 Research sample

Eleven participants were included in this study. Seven participants formed a focus group and another four were included in individual interviews. The criterion used in selecting participants was that they should be black African mothers with a child more than a year and half old affected with DS. They should have received some social work service and currently be participating in a DS support group. The research sampling method used is described as purposive as the researcher identified particular criteria for selection of participants. The participants were recruited from existing Down Syndrome (DS) support groups affiliated to the Down Syndrome Association, Tshwane. The researcher submitted a written request for access to black mothers of children with Down Syndrome and such permission was granted (see Appendix B). A pool of potential participants was created through compiling a list of about 50-targeted parents and approached by the researcher. When the approximate number (seven group members, four individual participants, plus four participants involved in piloting) required for the research was acquired, no further participants were approached.

1.7.3 Research Tools

The use of a focus group interview was employed in addition to four individual interviews between the researcher and participants. The researcher designed two separate data collection tools, that is a semi-structured interview guide and a set of focus group prompts (see Appendices G and H). These tools were pre-tested using another smaller group of three participants of similar characteristics to the sampled group and one individual participant. It was found unnecessary to re-adjust the research tool after pre-testing.

1.7.4 Data gathering

A focus group discussion as a qualitative research technique, involves the use of 6-12 people that are brought to a central location to respond to questions on a topic of particular interest to the researcher and a "moderator", whom in this case was the researcher, facilitates the focus group discussions (Morgan, 1993:29). In this case the focus group was composed of seven participants. The researcher found it best to let the participants speak for themselves with minimal interference through employing low levels of involvement in facilitating the focus group. The main topics covered in the discussion were the following: psychosocial needs and coping strategies; evaluation of the handling of their needs at a professional level; evaluation of the handling of needs at an informal level; and the appropriateness and relevance of social work intervention to their needs and circumstances.

In addition to the focus group, four individual interviews were conducted. This allowed the researcher an opportunity to counter-act limitations of the group interview. To optimise the effectiveness and accuracy of the data collection method discussed above, a semi-structured interview guide was used during the interviews.

1.7.5 Data analysis

According to Neuman (1997), data analysis in qualitative research involves searching for patterns and recurrent behaviours in data. In analysing collected qualitative data, the researcher followed various steps in the methods for qualitative data analysis adapted from Neuman (1997). The first step is familiarisation and immersion, which means reading through, making notes, drawing diagrams and brainstorming to get an overall picture of the findings.

The second step is inducing themes, meaning to infer general rules or classes from specific instances in a bottom-up approach (Neuman, 1997). The material is perused and the organising principles that underlie the material are identified. This is contrary to a top-down approach where one uses ready-made categories and simply looks for instances fitting such categories. The third step is coding (Neuman, 1997). This involves marking different sections of data as being instances of or relevant to one or more of the researcher's themes. The researcher interchangeably used coloured marker pens to highlight pieces of text. The fourth step is elaboration (Neuman, 1997). Elaboration involves putting information in a linear sequence. The fifth and final step in analysing qualitative data is interpretation and checking which involves going back to all steps to make sense of the data (Neuman, 1997). It also involves checking for misplacement of certain texts (Neuman, 1997).

1.7.6 Limitations of the study

Firstly, participants might have given information that they thought the researcher needed rather than what was genuine. In order to counteract this limitation, the researcher included the use of interview guides, which allowed for open-ended questions and probes. Secondly, the study was aimed at uncovering subjective psychosocial needs, and some participants might have found it difficult to open up and be honest in their responses and this might have skewed findings (self-report bias) (Neuman, 1997). The researcher acknowledged that it might be difficult for participants to share openly, but

also encouraged them to share by creating a safe environment for them through assurance of confidentiality and anonymity. Thirdly, given the discrepancies in language content and the fact that the questionnaire was written in English, the translated questionnaire might have altered meaning and validity of the questions asked. However, the interview guide was piloted to confirm that it is able to deliver intended messages and evoke intended responses.

Lastly, passive participants in focus group discussions might have influenced or inhibited by active ones, while the desire of some to be polite and fit within the norm in the group might have compromised the outcomes. The researcher added four individual interviews to counteract limitations of the focus group.

1.8 Ethical issues

1.8.1 Introduction

The research and its tools including ethical issues were explained to all respondents prior to their participation in the research. All participants signed a consent form (see appendices E and F). The interviews were tape-recorded and such tapes were destroyed immediately after the analysis of collected data was completed. Ethical clearance was obtained from the Human Research Ethics Committee (MEDICAL) of the University of the Witwatersrand (Appendix A) and permission was obtained from the Down Syndrome Association of Tshwane to complete the research (Appendix B)

De Vos et al. (2002: 62) outlines some of the common ethical issues that researchers need to pay attention to as including among others “harm to participants, informed consent, deception, violation of privacy, actions and competence of the researcher, cooperation with collaborators, release or publication of findings and the restoration of participants. The researcher took all these issues into account.

1.8.2 Potentially emotions-provoking study

The nature of this study compelled participants to relive their emotionally charged experiences, and this might have evoked emotional reactions of varying significance. The researcher, as a qualified social worker undertook to exercise considerable caution and be observant in order to detect such reactions and take appropriate steps, which were to include among other things referral to relevant support services where necessary.

Arrangements were made with the Support Group Coordinator as well as the Down Syndrome Association to provide relevant assistance if the need arose. None of the participants involved in the study seemed to experience any of the above-mentioned emotional reactions during the interview and therefore none were referred for counselling.

1.8.3 Respondents' right to informed consent

Participation in this study was voluntary and participants received relevant information (Appendices C and D) about what the study entailed based on which they decided to participate in the study. Non-participation in the study did not in any way disadvantage the potential participants. Similarly participation was not rewarded in any form. Participants reserved the right to withdraw from the study at any stage of the research process at their own discretion. The interviews were recorded and to obtain permission to do this, participants were given a consent form to sign regarding to participate with or without the tape recording. None of the participants expressed objection to either participation or tape recording (Appendices E and F).

1.8.4 Confidentiality of personal information

All information received direct or indirectly about potential and confirmed participants was not used for any purpose other than the research project and was at all times treated as private and confidential. Given the nature of the rationale, the researcher viewed it as

an ethical issue in this study to ensure that findings of the study are published to shed light on issues relating to the indigenisation agenda.

1.9 Definitions of terms used in the study

Down Syndrome: "A common chromosome abnormality found in children, characterised by mental retardation, heart defects, distinct facial features and an increased susceptibility to leukaemia and early onset Alzheimer's disease" (Harper, 1998:36). "The chromosomal abnormality in DS involves the presence of three chromosomes at the site of chromosome 21 instead of a pair, hence the name trisomy 21" (Harper, 1998:36).

Chromosomes: "rod-like structures that contain genetic material" (Mueller and Young, 1998:11)

Coping: Defined as "consistently changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person" (Burchardt et al. 1997:6)

Support Groups: "A forum for sharing common experiences and problems" (Cunningham and Sloper, 1985: 19)

Indigenisation: Refers to "appropriateness of theories and practice, as well as values, norms and philosophies, which underlie a professional practice" (Osei-Hwedie, 1993). The birth of these theories and practices must be indigenous sources. It is to lead to development practices based on the needs of people, their culture and economic landscape (Osei-Hwedie, 1993). Midgeley (1983: 170) defines indigenisation as " appropriateness, which means professional social work roles must be appropriate to the needs of different countries and social work practice".

Indigenous models of Social Work practice: Refers to "models inherently belonging to a people or place and so conjures up images rooted in history" (Bar-On, 2003: 26).

2. CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The main aim of this study is to explore the psychosocial needs and coping strategies of black African mothers following the birth of a child with Down Syndrome. The manner in which black mothers cope with the psychosocial implications of Down Syndrome (DS) presents a crucial window into how they manage similar or related psychosocial experiences. Thus, a thorough study of the needs and how mothers cope with the experience of giving birth to a child with DS, while supported through informal and formal support systems, provides an important opportunity for the researcher to establish how their needs could have been best met through Social Work intervention. Thus, in uncovering the felt needs and coping strategies of mothers, the researcher is able to draw implications for the indigenisation agenda of Social Work in Africa.

Down Syndrome as a condition will be discussed in this chapter as well as its incidence and prevalence in South Africa. The chapter will also cover current prevention and management approaches to the condition in South Africa as well as its impact on the individual (mothers) and families. The discussion on the impact of the condition will include a focus on social work intervention with mothers and their families. Such a discussion will culminate in a focus on the debate around indigenisation of social work in Africa. A review of the indigenisation debate will also be presented.

2.2 Down Syndrome

Down Syndrome (DS), also known as trisomy 21 in cytogenetics (study of human chromosomes) is known to be the most common genetic, chromosome abnormality found in children (Mueller and Young, 1998). It was earlier refereed to as Mongolism as children with DS look like people from Mongolia with their up-slanting palpebral features or features of the eyes (Leshin, 2000).

It is characterised by mental retardation, heart defects, distinct facial features and an increased susceptibility to leukaemia and early onset Alzheimer's disease (Gardner and Sutherland, 1989; Harper, 1998; Rees and Jones, 1977). It affects one in 650 to 700 individuals world-wide (Gardner and Sutherland, 1989; Mueller and Young, 1998).

The chromosomal abnormality in DS involves the presence of three chromosomes at the site of chromosome 21 instead of a pair, hence the name trisomy 21. The maternal risk for giving birth to a child with DS increases with maternal age and the risk is higher at an advanced maternal age (AMA), that is any age above 35 years (Gardner and Sutherland, 1989; Mueller and Young, 1998; Rees and Jones, 1977). Thus, the maternal age related risk for DS is lower at age 20 (1/1734), but higher at age 35 (1/386) (Harper, 1998).

In the black African context, this situation is exacerbated by the fact that older women tend to have children than younger women (Christianson, 1996). This is contrary to the Western context where more younger women tend to have children than older women, resulting in a higher total of DS births to younger women (70-80%) and only (20-30%) of children with DS born to mothers above the age of 35 (Leshin, 2000). DS usually occurs sporadically and the recurrence risk is usually as low as 1% (Gardner and Sutherland, 1989; Mueller and Young, 1998; Harper, 1998).

Individuals with DS are able to survive to their 4^{th}-6^{th} decade of life with good medical and social care, while others die in the first year of life, usually due to heart problems (Leshin, 2000). Heterogeneity is one of the remarkable aspects of DS (Mueller and Young, 1998). Individuals with DS exhibit a wide variety of clinical features. For example, the range of mental retardation among children with DS is very broad and the degree of developmental delay varies significantly (Mueller and Young, 1998). Similarly, some babies with DS (40%) are born with cardiac defects while others are not (Mueller and Young, 1998).

2.3 Down syndrome in South Africa

Similar to worldwide incidences, Delport documented an incidence of 1.33 per 1000 live births in a Pretoria urban hospital (Christianson, 1996). On the other hand, Venter recorded a figure of 2.09 per 1000 live births in a rural hospital (Christianson, 1996). Furthermore an incidence of 1.8 per 1000 Down Syndrome live-born was recorded by Kromberg in 1992 at Johannesburg hospital, Chris Hani Baragwanath Hospital and the surrounding areas (Kromberg et al, 1992).

The incidence of Down Syndrome (DS) in the black African population has previously been largely unrecognised due to under-diagnosis. Kromberg et al.(1992) postulated that DS is at least as common in the South African black population as in any other group. Kromberg et al. (1992) proposed an incidence of 1 in 600 births, which was later supported by Christianson (1996). No particular association has been found between DS susceptibility and any particular ethnic group or geographic region (Christianson, 1996). However, incidence could be increased in populations from lower socio-economic groups, mainly due to lack of education and non-usage of contraceptives and prenatal diagnosis (Christianson, 1996). Furthermore, most parents of children with DS in South Africa are found in areas with limited access to appropriate specialist medical facilities to provide accurate information on prevention and management (Kromberg and Zwane, 1993).

2.4. Prevention and management of Down Syndrome

According to the department of health (2001), DS is listed as one of the four congenital conditions on the national health department's priority list. The prevention of DS can be done at various levels such as primary, secondary and tertiary levels. Primary prevention for DS is aimed at giving information to people, particularly potential mothers, about DS so as to prevent its occurrence (Department of Health, 2001).

It is the author's view that Social Work can play a significant role in this case through its community work approach. A screening test known as maternal serum triple screen can also be used as a primary prevention measure for DS (Kromberg and Zwane, 1993). It identifies pregnancies at high risk for certain foetal abnormalities including DS (Kromberg and Zwane, 1993).

Secondary prevention involves initiatives such as the provision of genetic counselling to all pregnant women of advanced maternal age, which is any age above 35 years (Department of Health, 2001). It includes voluntary pre-natal diagnosis and selective termination of pregnancy for affected foetuses (Department of Health, 2001; DS Bulletin, 1998). The South African constitution guarantees women the right to selective termination of pregnancy at specified gestational ages of their pregnancies for reasons within those identified as permissible (Choice of termination of pregnancy Act, 1996). Firstly, a pregnancy can be terminated at 12 weeks for any reason on the mother's request. Secondly, a pregnancy can be terminated between 12 and 24 weeks if it is perceived as having a negative medical, psychosocial impact on the mother, and after that it can be terminated if it will result in the birth of a child with serious medical problems and poses a threat to the mother's life (Choice of termination of pregnancy Act, 1996).

Tertiary prevention for DS involves managing the condition through initiatives such as neuro-developmental therapy (physiotherapy and occupational therapy) and the provision of social support to parents as well as dissemination of the right information to the broader community to clear myths and stereotypes (Department of Health, 2001). The above has been proven to have the potential to improve the level of management and care for the child (DS Bulletin, 1998). Attempts at integrating children with DS to mainstream education are being tried with some successful examples, despite a fierce criticism from those that are cynical about the initiative (DS Bulletin, 1998). Medical management initiatives such as cardiac transplant and thyroid hormone supplementation for children with DS have been shown to be essential in prolonging the lives of children with DS (Department of Health, 2001). However, most parents cannot afford such procedures and they are not routinely offered in public hospitals.

While the constitution makes provision for the right to selective termination of pregnancy, it has been observed through the media and mass demonstrations that the pro-life sections of the population, arguing on religious, cultural and moral grounds, continues to express strong sentiments against such constitutional provision (Department of Health, 2001). As a result, the researcher maintains that, the availability of medical procedures for prenatal detection and termination of affected pregnancy does not stand as an adequate preventative measure for the occurrence and recurrence of congenital conditions like DS. Thus, a great deal of secondary and tertiary prevention will continue to be necessary.

Given the fact that the issue of selective termination of pregnancy is a sensitive one with potentially grave psychosocial implications on the parents, the intervention of a social worker can be of benefit to the parents. Government's undertaking to integrate genetic services into primary health care is still at its infancy stage. A large proportion of the population has no basic knowledge of genetic conditions, or access to genetic clinics (Department of Health, 2001).

It is the researcher's observation that, where services exist in the form of genetic counselling, it is offered in the narrowest sense that does not utilise the holistic, eco-systemic approach to social services and is not offered as an integral part of the public primary health system. The training of nurses and other allied medical professionals such as genetic counsellors serves to further create an unnecessary duplication of psychosocial services already in existence in the hospital setting.

In compliance with the need for a holistic approach to social service delivery, most of the Hospitals in South Africa have put in place all necessary support services to achieve a holistic approach in total patient care and this includes the integration of health care social workers who are charged with the responsibility of helping patients deal with the psychosocial implications of their medical condition (Department of Health, 2001). Thus, this in the researcher's view poses the challenge to Social Workers in Health care to

acquire appropriate knowledge in various medical specialties that they work in, such as genetics in primary health care so as to begin to develop relevant intervention models that can help curb the burden of psychosocial and financial cost of raising a child with Down Syndrome.

While, the Department of Health (2001) acknowledges that inter-disciplinary integration of services is essential to foster appropriate client appraisal, it has not effectively utilised this approach in its inception. The researcher has reviewed processes that led to the development of the policy guidelines for the management and prevention of genetic disorders; birth defects and disabilities (Department of Health, 2001) and noted that meetings of the ad hoc committee that produced the above document had been mainly dominated by medical practitioners and had wittingly ignored the role of other allied medical disciplines such as social workers, psychologists, physiotherapists and occupational therapists. As a result, the document failed to put forward a strategy that utilises existing structures and resources in the health care setting and instead seek to create new specialised services that appears to be far from realistic given the current pressing health needs.

The researcher furthermore argues that the government is already over burdened with pressing needs to respond to the devastating effects of the HIV/AIDS pandemic and would not afford to cater for a separate cadre of specialised counsellors in the health care sector. The above assertion is supported by the fact that, genetic counsellors are not currently part of the public primary health care system as the guidelines wishes it to be. Where they are available, they practice privately, and various laboratories that provide testing for genetic conditions employ some. Therefore, in order to maximise successes in integrating genetic services into primary health care, social workers currently practising in the health care sector should play an active role in addressing the psychosocial needs of affected individuals.

2.5. Effects of Down Syndrome on the individual and family

The identification of an abnormality in a child is a shocking and traumatic experience for parents (Hsia et al, 1997:31). As a result, parents react with dismay on hearing that their newborn child possesses an abnormality. Down Syndrome (DS) is one of the few conditions associated with mental retardation where the diagnosis can be made shortly after birth (Hsia et al, 1997). The birth of a child with DS does not only create a financial, social and medical burden for the individual or family, but also places fiscal strain on the state, as the child will need social assistance in the form of a disability grant, special school, regular medical attention, in some cases major surgical operations, as well as institutionalisation where there is serious disability (Department of Health, 2001). The Department of Health (2001), estimates that on average the cost of caring for a child with DS can amount to about R15 000 - R20 000 for basic medical care. Where necessary, an additional once-off cost of R50 000 can be incurred for a heart operation (Department of Health, 2001).

The mother‘s expectations, self-concepts, and self-esteem can be shattered on learning that “she possesses a stigma, a deeply discrediting attribute, which may disqualify the individual from full social acceptance” (Hsia et al, 1997:31). As argued by Hsia et al (1997:31), having a child with DS, a genetic disorder is particularly stigmatising because it involuntarily deprives the individual of a socially valued role under circumstances that reflect unfavourably upon his/her capacity for the role. The lost role of parent of a normal child may be one that the individual had previously attained or desired. In most cases, the stigma is not only directed at the child, but also at the parents. Boswell (1974:34) argues that not only are the handicapped children stigmatised, but also the whole family feels downgraded when other people look at the child with a sense of pity.

As pointed out by various scholars, when people are faced with tragic news or events, specific needs arise and they adopt various coping mechanisms, but follow through a similar process (Hsia at al, 1997). The initial reaction of parents and family members to

the diagnosis of Down Syndrome is shock (Hsia et. al, 1997). Elisabeth Kubbler-Ross (1969) developed a five-stage model for understanding the grieving process of death and dying. Similar principles and stages can thus be used to understand the way in which people cope with different traumatic events and losses in their lives, including how families cope with the birth of a child with a handicapping condition such as Down Syndrome.

According to Kubbler-Ross (1969), the stages in death and dying are as follows:

1. Denial and isolation is a temporary defence that is probably inevitable and necessary for family members to cope with the condition.
2. Anger occurs when denial can no longer be maintained. It is replaced by feelings of anger, rage, envy and resentment. Contrary to denial, anger is the most difficult stage for family members to cope with. It is related to feelings of helplessness and the loss of control of one's life.
3. Bargaining involves an attempt to postpone the inevitable. Most bargains are made with God, but can also be made with caregivers.
4. Depression occurs when the family can no longer deny the condition
5. Acceptance is the phase when the family accepts the condition.

Individuals and families' needs and coping strategies can thus be understood as an ongoing process. Each stage of the condition poses its own developmental tasks and psychosocial demands that require different attitudes and changes from a family. The way the family conceptualises the condition, and its cause will form part of their cognitive representation of the condition. This will in turn shape how they respond emotionally and behaviourally to information about the condition (Marteau and Senior, 1997). It has been suggested that there are five core components to illness representation: beliefs about the cause of the disease, identity, time-line, consequences and cure (Marteau and Senior, 1997).

The belief about the cause of the disease may included among others, the fact that it might had been God's wish, whilst others particularly, family and close relatives may attribute it to witchcraft as well as punishment by ancestors for unacceptable personal conduct of parents. The identity of parents is also important, as it will influence how they cope with the condition. People of different identities will respond differently to similar needs and challenges, hence the need to tailor intervention strategies accordingly. The time-line or duration of the disease or condition is also very important. Some diseases are short-term and therefore have minimal psychosocial impact, while long-term and chronic conditions will have significant influence on psychosocial state of individuals and families. For instance, DS as a condition requires that roles and responsibilities of parents and siblings be restructured to accommodate the child with DS for the rest of his or her life. Long-term care plans need to be formulated. Similar to time-lines the consequences and availability of cure for the disease becomes an important variable in determining the reaction of persons involved. If consequences are less serious and the condition could be cured, the resultant psychosocial impact becomes minimal. However, where cure is unavailable and consequences are devastating as in DS, the significant others and those directly affected have far reaching psychosocial issues to deal with.

Marteau and Senior (1997) suggest that there is cultural diversity in the beliefs about the cause of illness, In Western culture; illness is often attributed to diet, weight, smoking, heredity, stress and a lack of exercise. In non-Western culture, violations of interpersonal norms, violations of the demands and expectations of social roles, the emotions involved in such transgressions (for example, envy or jealousy), violation of moral and religious taboos, and the weather, types of food and various states of one's blood are all thought to cause illness (Marteau and Senior, 1997). Taylor (1996) documented several social effects of illness, which include among others: alcoholism, delinquency, cruelty and neglect of children, and family disintegration. Kromberg and Zwane (1993), noted that African families with a member who has a genetic condition may not present to health services because of traditional beliefs and practices, which may include stigmatisation of individuals affected.

Furthermore, Marteau and Senior (1997), discuss the causal attributes given by family members to make sense of a life-threatening illness. He suggests that explanations that invoke blame within families and hold individual members responsible for the illness, severely compromise functional coping and adaptation for the family. Furthermore, close relatives, neighbours and friends may tend to pity, ignore or actively avoid the family with a child affected with a genetic condition (Lea and Foster, 1990:218).

It is difficult to obtain all accurate and representative picture of the distress experienced by black African families with a child affected with Down Syndrome, because research in this area has largely been confined to first World countries (Kromberg and Zwane, 1993). Furthermore, research has been largely focused on medical issues and little attention has been paid to psychosocial aspects and complex family dynamics associated with the birth of a child with Down Syndrome (Kromberg and Zwane, 1993).

2.6 Forms of support

Given the above background, it is clear that parents of children with DS will need long-term professional psychological and social support. The medical practitioners may refer parents to the social worker for social assistance or parents may reach-out for social support in the form of a disability grant, institutionalisation or and professional support to help them provide the best possible care for their child (Fort Cowles, 2000).

The social worker in a health care setting is a skilled professional equipped with skills to help people deal with the psychosocial implications of illness and any medical condition (Fort Cowles, 2000). Methods used include among others; individual and family therapy; group therapy and community development. Work with individuals and families are often done to help clients come to terms with the impact of the medical condition at a personal and family level. Intervention may focus on helping individuals find functional ways of managing resultant emotional reactions as well as behavioural and environmental changes to adapt to the presenting medical condition (Fort Cowles, 2000).

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Group therapy is facilitated by a social worker with individuals infected or affected with a similar medical condition in a group context. This method provides an opportunity for sharing of views and experiences as well as a normalising experience for members (Morgan, 1993: 65). Social work with groups may take different forms, ranging from closely monitored and controlled, to self-directed groups by members themselves (Morgan, 1993:65). In coping with the psychological and social implications of giving birth to a child with disabilities, families may benefit from a support group. As pointed out by Paritzky (1986: 97) self-help groups are valuable and appropriate sources of practical and emotional support for families affected by a genetic condition. Bernardt (1986) also emphasise that peer counselling by someone who has faced a similar crisis and has dealt positively with them, is also appreciated by families affected by a genetic condition. Bernardt (1986: 137) further stresses "support groups …provides an opportunity for parents to experience a natural growth towards advocacy and the care given to the handicapped". From the foregoing statement, it is clear that the benefits of belonging to a support group are not limited to the child but extend to those involved in the caring of the child.

Social work with communities in a health care setting in the author's view would be aimed at raising awareness and mobilising community support for prevention of specified medical condition, treatment, care and support of those infected and affected by the medical condition. This method is necessary to deal with stigmatisation of patients and their families (Kuse,1997). Finally, numerous informal support systems exist in each family and community context. These include among others, the role of the extended family network, cultural and traditional belief systems and practices. Some communities will have various forums creating to assist people in need (Kuse, 1997). The social worker may tap on to these support systems whenever possible and necessary.

2.7 The origin of the social work profession

According to Bar-On (2003), Social work as a profession originally developed in the United States and Britain and later exported to other countries of the World around 1915. In line with other professions, the then founding academics in the field of Social Work identified and developed "standardised 'scientific' occupational techniques which, at least until the advent of post-modern thought, invariably meant that they were taken to be universal and so could not be differentiated" (Bar-On, 2003: 27). Arguably, despite this "search for order, it undoubtedly failed to understand and hence to consequently construct appropriate interventions for the complex, vague and largely unconscious structures of many of social work clients' socially embedded experiences" (Bar-On, 2003:27)

Bar-On (2003: 27) argues that since the inception of Social Work in the early 1900's, no systematic comparative studies were undertaken to examine the application of Social Work techniques in different societies. Despite, the lack of scientific evidence, distinguished scholars have continued to comment on the relevance or more commonly the irrelevance of Western-developed social work to non-Western countries since the 1950s' (Bar-On, 2003:27). This debate has been labelled the "indigenisation" debate.

2.8 Indigenisation of social work practice in the black African context

2.8.1 Introduction

Indigenisation on the one hand, refers to a process of ensuring appropriateness of theories and practice, as well as values, norms and philosophies that underlie practice (Osei-Hwedie, 1993). The birth of these must be indigenous sources. It is to lead to development practices based on the needs of people, their culture and economic landscape (Osei-Hwedie, 1993). Midgley (1983: 170) defines indigenisation as " appropriateness, which means professional social work roles must be appropriate to the needs of different countries and social work practice". In addition to this, practice must also follow societal procedures, norms, ideas and practices. Thus, indigenisation also translates into practice, which acknowledges the socio-cultural context (Midgley, 1983).

On the other hand, another group of scholars have emerged to call for the development of Africa's own brand of social work, "indigenous" models of social work practice. This according to Bar-On (2003: 26) refers to "physical and social traits inherently belonging to a people or place and so conjures up images rooted in history". This will consequently require differentiated models of practice in different countries. These debates in the researcher's view need to be addressed as they concern the end product of social work intervention and the means towards the end needs to be tailored appropriately to effect the desired end. Thus, the extent to which the intervention of a Social Worker may be effective in any given case will "depend heavily on the degree of congruence between the worker's approach and the client's frame of reference as defined by their socio-cultural backgrounds" (Osei-Hwedie, 1997:41). The lack of fit between the worker's approach and the client's frame of reference may undermine the effectiveness of the helping process and breed role confusion on the part of the client and the social worker (Kuse, 1997).

2.8.2 Comparative analysis of black African social life and social work practice.

As Kuse (1997:20) argues, one of the contributory factors to the confusion of the professional role of social work in black communities is "the adoption of the value base of social work in its pure form from the American societal value system". For instance, Kuse (1997:20) highlights "social work's belief in the worth and dignity of the individual, the right of the individual to determine his/her own destiny and recognition of the individual's potential, regardless of colour, creed or national origin to govern himself and others in a democratic society". Thus, from the foregoing description of conventional social work, one realises that the emphasis seems to be on the individual. On the contrary, for Africans the situation is somehow different. Tshabalala (1991) postulates that individual concerns are subordinate to group interests in the African cultural context. Whatever Africans do is based on group efforts, hence the support of the extended family throughout Africa.

Van Der Walt (1990:37) postulates “the spirit of communalism is inherent in traditional African cultures as opposed to the Western emphasis on individualism in Western cultures. Furthermore, traditional African communities view duties towards the community as paramount, hence the believe that “all children in the community are children of all adults in the community i.e. ‘my child is your child’” (Van Der Walt, 1990:37). An individual without his or her social relations is unthinkable in traditional African societies, hence the belief that “We are, therefore I am” as described by Van Der Walt (1990: 37).

The clan name system is also another form of group support and group cohesiveness. Whenever there is festivity or a crisis in most African families, families belonging to the same clan pool their resources both in cash and in kind (Tshabalala, 1991). Tshabalala (1991) supports this group emphasis by indicating some of the basic values of black South Africans. They are: importance of the family; of the group; respect for elders; fear of God; as well as a deep commitment to sustaining meaningful community life through shared produce; problems and sorrows (Ubuntu). Therefore, it appears that group consciousness; group cohesiveness is a central characteristic of the African society.

Most black African ethno-cultural practices are based on values and philosophies that conflict with conventional Western values and philosophies underpinning counselling as a process (Kuse, 1997: 21). “Such values are inherent in the traditional patriarchal family system, the philosophy of keeping family matters within the family and not to open up for strangers, the traditional beliefs in ancestral powers and witchcraft” (Kuse, 1997: 21). Furthermore, Kuse (1997) argues that, the African beliefs in sympathy militate against empathy in counselling. Congenital abnormalities and mental retardation is perceived largely as either a curse or a result of witchcraft in most of the black ethnic cultures. Therefore, such factors are crucial in any form of psychosocial intervention if positive outcomes are to be accomplished. Such factors will to a greater extent determine how couples react to the birth of a child with DS.

A study conducted by Ryke, Ngiba and Strydom (2003:139), shows that the traditional cultural practices of black African people to keep their elderly persons with them remain a stumbling block to getting them to utilise the provision of institutional care by the government. It was found that black African people prefer utilising their extended family systems instead of institutional care on the basis of their belief of "not throwing away" their elderly people (Ryke; Ngiba and Strydom, 2003:139).

As shown by Van Der Walt (1994:97), strong bonds with the extended family are emphasised in African cultures as opposed to the belief in looser bonds with a nuclear and mobile family in Western cultures. Van Der Walt (1994) describes an elderly person as a source of knowledge, a valued adviser, capable of laying down rules on the running of families and also an important resource for training and educating communities on healthy living and child rearing. Furthermore, Van Der Walt (1994) also points out that most of these elderly persons are traditional birth attendants and traditional health practitioners. This is a very important observation as it directly relates to how families with a handicapped child will manage the condition. The role of elderly persons and the extended family network cannot be ignored.

2.8.3 The indigenisation challenge for African social work practice

Social workers and other human service professionals have long been questioning the appropriateness and effectiveness of First World theory and practice within the African context (Kuse, 1997; Bar-On, 2003; Osei-Hwedie, 1993). Within Social work as a profession, authors have highlighted the biggest challenge facing social work practice in Africa as being that of the need for proper indigenisation of the models. This need has necessitated a search for social work practice that can promote the type of development that both practitioners and client systems can understand, and relate to and this search has led to the emergence and analysis of concepts such as indigenisation (Osei-Hwedie, 1993). As stated earlier, the biggest challenge for social work is to search for social work practice models that can promote the type of development people can understand, afford, relate to and control (Osei-Hwedie, 1996). Indigenisation should lead to practices that

stem from indigenous development, based on the needs of the people, ideas, and aspirations that societies develop, know and manage (Osei-Hwedie, 1996).

Midgeley (1993) outlines factors that make current social work in the Third World problematic and thus unsuitable to effectively respond to prevailing conditions. Social work's dependence on Western ideas reduces its effectiveness in the face of prevailing social problems and the demands of practice. Given the above background, the research study will seek to identify the felt psychosocial needs of black African parents and therefore draw conclusions on how such needs could be effectively met through various forms of appropriate social work intervention.

2.9 Conclusion

Down Syndrome (DS) is a condition associated with both physical and mental handicap. It is a common condition in the South African black population and is on the priority list of the National Department of Health. Amongst common prevention options is selective termination of pregnancy, which has been strongly opposed by many on religious, cultural and moral grounds. The literature that examines the impact of giving birth to a child with a handicap on mothers, suggests that giving birth to a child with DS, may evoke a series of psychosocial reactions that, if not properly handled may lead to both psychological and social disintegration. The literature highlights a general lack of fit between social work practice and the needs of black Africans. The situation is attributed to the adoption and over-dependence on western values and practice approaches.

The reason for the discrepancy is that there are numerous socio-cultural and traditional practices that underlie the norms and value system of black Africans that conflicts with practice approaches imported from Western forms of helping. Such areas of conflict include among others the emphasis in African cultures on collectivism versus individualism in social work; the support for a patriarchal male dominated power relations and secretiveness of family matters within an extended family network versus a liberal power sharing and open nuclear family systems in social work. The literature

highlights the biggest challenge for social work in Africa as being to search for practice models that can promote the type of development that people can understand, afford, relate to and control.

3. CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 Research design

This study was mainly qualitative, since the researcher ‘s aim was to explore participants’ subjective needs following the birth of a child with Down Syndrome (DS). According to Neuman (2000:133), qualitative descriptive research utilises in-depth qualitative data such as people’s subjective thoughts, perceptions, feelings and behaviours to present a picture of the specific details of a situation, social setting or relationship. The researcher selected this approach because he was interested in exploring the in-depth and subjective information regarding the psychosocial needs of black African mothers following the birth of a child with DS. Furthermore, as a social scientist, the researcher was not interested in any genaralisable and conclusive outcome, but open-ended outcomes that could point to some of the subjective views on the topic investigated.

The research design as stated above was descriptive as the research seeks to describe in detail the felt needs of mothers. The study sought to help the researcher gain more insight into the nature of needs and coping strategies of black African mothers. The reason for choice of such a research design in this study stems from the fact that the study focuses on the generation of knowledge about a particular social phenomenon (perceptions of needs) rather than testing of theory or hypothesis. Thus, what were important in the study were participants’ perceptions and feelings about their psychosocial needs.

3.2 Research methodology

3.2.1 Sampling

The sampling method used was purposive as the researcher identified particular criteria for participants (Neuman, 2000). As argued by Neuman (2000:151), “it is their relevance to the topic rather than their representation which determine the way in which people to be studied are selected”. The criteria used for selecting participants were that they should

be black African mothers, with a child above a year and half old affected with DS, who are members of a support group and have received social work intervention. This sampling method is also referred to as 'target sampling' by De Vos et. al (2002: 195). De Vos et. al (2002:195) defines this form of sampling as "a non-probability sampling method done without any randomisation". This method was used because there were known groups of black mothers with children with DS currently participating in an active support group. The participants had all received some form of service from a qualified social worker. The participants were recruited from existing DS support groups affiliated to the Down syndrome Association, Tshwane. The researcher submitted a written request for access to black African mothers of children with Down syndrome and such permission was granted (see Appendix B). A pool of potential participants was created through compiling a list of about 50-targeted parents and approached by the researcher. When the approximate number (seven group members, four individual participants, plus four participants involved in piloting) required for the research was acquired, no further participants were approached. The research and its tools including ethical issues were explained to all respondents prior to their participation in the research. All participants signed a consent form (appendix C; D; E; and F).

3.2.2 Data collection

3.2.2.1 Introduction

A focus group discussion was employed with seven participants in addition to four individual interviews. The researcher designed two separate data collection tools, which is a semi-structured interview guide (appendix G) and a set of focus group prompts (appendix H). A major advantage of using an interview guide is that it allows personal contact between the researcher and the participants and most importantly, the researcher has an opportunity to probe and seek clarifications where necessary (Grinnell, 1993).

These tools were pre-tested using another smaller group of three participants of similar characteristics to the sampled group and one individual participant. Grinnell (1993)

stresses that pre-testing or piloting the research instrument can give a true indication of how well the participants would understand the questions in the actual study. It was found unnecessary to re-adjust the research tool after being pre-tested.

3.2.2.2 Focus group

According to De Vos et al. (2002), a focus group as a data collection method refers to group discussions organised to explore a specific set of issues such as people's views and experiences around a particular issue. The idea of the group being focused stems from the fact that it involves some kind of collective activity where members share a similar type of experience. A focus group interview as a qualitative research technique, involves the use of six to twelve persons brought together to a central location to respond to questions on a topic of particular interest to the researcher. The discussions are facilitated by a "moderator", who in most cases would be the researcher (Morgan, 1993:29).

The most important factor that distinguishes a focus group as a data collection tool from other forms of group interviews is that of the use of group interaction as research data. The choice for the above data collection tool was motivated by the fact that the study was aimed at uncovering people's perceptions and focus groups are known to be very useful in investigating issues such as people's thoughts, but most importantly, they excel at uncovering why participants think as they do (De Vos et al. 2002). This is because, participants do not only share with the group what their views and experiences are, but are often encouraged by other group members to explain the reasons for holding such views. Further advantages of using a focus group as a research tool include among others, the fact that participants can react to and build on the responses of other group members (De Vos et al. 2002). It provides data from a group of people more quickly than interviewing individuals. Thus, focus groups are less costly than individual interviews (De Vos et al. 2002).

However, as in any other research tools, the use of a focus group is not immune to limitations and disadvantages. Firstly, facilitation of a focus group requires a different skill than ordinary individual interviews (Morgan, 1993:30).
The facilitator has to be sensitive to group dynamics and such dynamics are in themselves an important source of data. A particularly dominant group member may bias the results if such a dynamic is not modified appropriately. The open-ended nature of the responses may make interpreting results very difficult. Furthermore, group responses may be affected by the size and composition of the group (Morgan, 1993:30). Lastly, the researcher as interviewer may influence the responses of the group members. However, despite the foregoing limitations, focus groups appear to be the most preferable rich source of qualitative data, though not easy to use.

The focus group was composed of seven participants. According to Morgan (1993), the usual conclusion in determining the group size is to use “moderate sized” groups, which is somewhere between six to ten participants. Smaller groups demand greater contribution from each individual, while in larger groups, there is a possibility of “social loafing”, that is each individual participates less because the group as a whole can carry the discussion (Morgan, 1993). On the basis of the foregoing, the researcher adopted the moderate size and involved seven participants in the focus group interview.

According to Morgan (1997), the most preferable approach in facilitating a focus group discussion is nondirective, which he calls a “self-managed group”. It is highly recommended by several scholars that low levels of moderator involvement should be adhered to in exploratory research. Such an approach appeared to be appropriate for this study on the basis that, the aim of the research was to learn something from the participants. Thus, the researcher found it best to let the participants speak for themselves with minimal interference through employing low levels of facilitator involvement.

The main topics covered in the interview were the following: their psychosocial needs; their evaluation of the handling of their needs at a professional level; their evaluation of

the handling of their needs at an informal level and lastly; the appropriateness and relevance of social work intervention to their needs and circumstances.

3.2.2.3 Individual interviews

In addition to the focus group, four individual interviews were conducted. Interviews were conducted at participant's homes and each took 45 minutes to an hour. This allowed the researcher an opportunity to counter-act limitations of the group interview. To optimise the effectiveness and accuracy of the data collection method discussed above, an interview guide was used during the interviews.

3.3 Data analysis

According to Neuman (2000), data analysis refers to a process of searching for patterns in data; recurrent behaviours; objects or a body of knowledge. In analysing collected qualitative data, the researcher followed various steps in the methods for qualitative data analysis adapted from Neuman (1997)**.** The first step was familiarisation and immersion, which involved reading through, making notes, drawing diagrams and brainstorming to get an overall picture of the findings.

The second step was inducing themes, which involved inferring general rules or classes from specific instances in a bottom-up approach. The material was perused and the organising principles that underlie the material were identified. This is contrary to a top-down approach where ready-made categories are used and simply looks for instances fitting such categories.

The third step was coding. This involved marking different sections of data as being instances of or relevant to one or more of the researcher's themes. The researcher interchangeably used coloured marker pens to highlight pieces of text. The fourth step followed was elaboration. Elaboration involved putting information in a linear sequence.

The fifth and final step in analysing qualitative data in this study was interpretation and checking which involved going back to all steps to make sense of the data. It also involved checking for misplacement of certain texts.

3.4 Limitations of the study

Given the fact that the researcher used interviews (individual and focus group), participants might have been selective in disclosing information as anonymity cannot be guaranteed as the researcher saw the participants.. Participants might have given information that they thought the researcher needed rather than what was genuine. As argued by De Vos et al. (2002: 305), though valid, interviews are generally perceived as the weakest data collection methodologies because of the fact that participants are likely to provide the researcher with the 'official account'. In order to counteract this limitation, the researcher made use of interview guides, which allowed for open ended questions and probes. Through reflections and probing for further information, the researcher was able to obtain more depth in the data.

The study was aimed at uncovering subjective psychosocial needs, and some participants might have found it difficult to open up and be honest in their responses and this might have skewed findings (self-report bias). The researcher dealt with this limitation by first acknowledging that it might be difficult for participants to share openly, but also encouraging them to share by creating a safe environment for them through assurance of confidentiality and anonymity. All participants were given information about the study and the kind of questions they were going to be asked. They had to sign a consent form for participation. In addition during the interview process, the researcher referred frequently to the research ethics.

The interview guide was written in English and translated according to respondents' language. Given the discrepancies in language content, the translated questionnaire might have altered meaning and validity of the questions asked. However, the interview guide

was piloted to confirm that it is able to deliver intended messages and evoke intended responses.

A general weakness of focus groups as a method of data collection as postulated by De Vos et al. (2002: 319), is that often passive participants are influenced or inhibited by active ones, while the desire of some to be polite and fit within the norm in the group or what he calls ‘forced compliance’ might have compromised the outcomes. The researcher added four individual interviews to counteract limitations of the focus group.

4. CHAPTER 4: PRESENTATION AND ANALYSIS OF FINDINGS

4.1 Demographic details

Table1. Summary of participants' characteristics

CATEGORY	DESCRIPTION	PARTICIPANTS No.	%
Religion	Christian	5	46%
	Traditional	3	27%
	Unspecified/no affiliation	3	27%
Occupation	Clerical	2	19%
	Domestic	1	9%
	Farm-worker	1	9%
	Unemployed	3	27%
	Pensioner	1	9%
	Professional	3	27%
Marital status	Divorced	1	9%
	Married	5	46%
	Single	4	36%
	Separated	1	9%
Ethnic group	Ndebele	2	18%
	Tswana	5	46%
	Pedi	2	18%
	Xhosa	1	9%
	Venda	1	9%
Current age of mother	20-30 years	1	9%
	30-40 years	2	18%
	40-50 years	5	46%
	50-70 years	3	27%

4.2. Emotional and social needs.

4.2.1 Initial disclosure of information

Firstly, most participants felt that they had needed to better understand Down Syndrome as a condition. Therefore they needed information about the condition to be given to themselves and their families. Almost all of the participants highlighted the fact that they

were not happy with the manner in which the disclosure of bad news about their child's condition had occurred.

According to the participants, no proper counselling was provided, but mothers were told that they had given birth to a child with some medical problem. Participants pointed out that because of the shock that came with the disclosure of bad news, anything else that was said afterwards was not properly internalised. As a result, they remained ill informed about the condition even after various medical and allied professionals had spoken to them

They knew that their child had a problem, but could not understand clearly what the problem was and therefore they were not in a position to even explain the situation properly to their families. Most of them were told alone by the Doctor or Nurse that their child has DS. All participants expressed how they had wished in vain for their family members to have received accurate information in order to accept the situation and provide mutual support to each other as a family unit.

It is a generally held perception among the participants that giving information to mothers alone instead of the mother and father and/or another family member places a huge burden on the mother to have to give the news to the other members of the family.

"The in-laws need to understand the situation better, but are never involved in the process," said one of the participants.

The participants reported that, if other family members are not involved, the mother automatically becomes the middle person to relay information to the family and is often met with stigmatising attitudes and shifting of blame to the mother.

4.2.2 Practical needs and resources

Participants felt that in addition to the need for information about the condition, they also needed general information on the rights and entitlements for the child with DS. Parents needed to know what the rights of the children are with regard to the various services they need.

"…How do we move the child to school"?
"…How do we prepare the child for work and how to get the child to work"?
"…Where to get developmental stimulation and therapy for the child"?
"…How to go about getting a disability grant or care dependency grant if necessary"?
"… Where to get psychological support as mothers and guidelines on how to look after their children"?

One of the participants mentioned that a schoolteacher told her that her child would only qualify for a grant after he had reached the age of 18yrs.

"*…. The need arise immediately after birth and has to be provided for, for better growth and development of the child"*
"... How does one begin to satisfy such needs without the provision of necessary social security support"?

After knowing and understanding the condition, participants wanted to give the best care to the child and needed support with that as well. All participants expressed a need to give their child with DS the best possible care. They expressed their heart-felt adoration of these children. Most of them experienced their child with DS as having certain unique qualities that other children do not have. They described them as:

"Ba a bereka" (they are hard workers).

"They are neat and want to keep the house neat, you see him with a broomer, cleaning cutleries, cleaning the yard, doing all in the house chores"

"Ga se bana ba baratang dintwa, babotho" (They are peaceful kids and have good personalities)

"They are very sweet and peaceful, that is one thing that made me hesitate to take him to school. I looked at the children and thought about how rough they are and my sweet child and said no"

4.2.3 Participants' emotional reactions and ascribed meaning

All mothers confirmed that the experience was very stressful for them, particularly the first few months of learning that their child has DS. They reported that it was not easy for them to come to terms with the experience, but it got better as time went by. Some mothers reported that it was so painful that they felt like crying, but they could not cry, as it is a taboo in their culture to cry for a person while the person is alive. Crying for a person is only permissible when mourning the death. There is also a belief among black Africans that crying for a living person may lead to the person dying prematurely.

As pointed out by various scholars, when people are faced with tragic news or events, specific needs arise and they adopt various coping mechanisms, but follow through a similar process (Hsia at al, 1997). The initial reaction of parents and family members to the diagnosis of DS was shock (Hsia et. Al, 1997). Elisabeth Kubbler-Ross (1969) developed a five-stage model for understanding the grieving process of death and dying. The researcher is of the view that, similar principles behind these stages can be used to understand the way in which people cope with different traumatic events and losses in their lives, including how families cope with the birth of a child with a handicapping condition such as Down Syndrome.

When asked about how they had coped, some explained that they had used their belief in God and pastoral counselling as a coping strategy while others had tended to use traditional healers; prophets; close family members and friends for support. None of the

mothers mentioned formal support systems as a resource that they considered useful in helping them cope with their situation.

There was a general consensus on the need to be secretive about the condition of the baby. Some reported that they became secretive as a way of managing stigma, while others needed to first learn to come to terms with the experience before exposing it to the public. Kuse (1997:21) highlighted some of the inherent values and philosophies of black Africans as including "the philosophy of keeping family matters within the family and not to open up for strangers and traditional beliefs in ancestral powers and witchcraft" However; they all confirmed that they are currently very open about their children's condition. They all expressed a passionate need to go out and educate other people about the condition.

Mothers demonstrated courage and determination to face challenges associated with having a child with DS. They all acknowledged that it is not easy, but that it is worthwhile persisting. They generally perceive it as a 'Gift from God'. One of the respondents stated the following:

"Joo…go tsere nako go amogela, Gago easy. Mara ngwana wa gago ke wa gago, ke mpho ya modimo'' Interpreted as *'it took time to come to terms with the experience, its not easy, but one eventually accept as it is a gift from God'.*

Most mothers asserted that, their love for the child and their acceptance of the child as a gift from God kept them going. As argued by Lea and Foster (1990), deep religious convictions influence parental adjustment to the mentally handicapped child, particularly with regard to how parents interpret and understand the presence of handicap in the family. Other participants reported that they had consoled themselves by comparing their child with other children they met that do not receive adequate stimulation as theirs and consequently tended to be far backward in their developmental milestones. In view of such situations they considered themselves lucky.

Most importantly, most participants in the study continued normally with reproductive activities. No significant gaps in child bearing were noted in all subjects that could be linked to the incidence of the birth of a child with Down Syndrome. The uninterrupted sequence in reproductive activities amongst mothers confirms the capability of mothers to accept the situation and move on normally. The findings of this research study showed no decline in reproductive activities. However, the researcher acknowledged the fact that this was a small sample to conclude on this matter, but it is notable as it demonstrated the ability of mothers to accept the incidence of the birth of a child with DS and move on. This is contrary to the findings of studies conducted in other countries. Tips et, al (1963) found that the birth of a child with DS to 24 Oregon, USA families was so traumatic that reproduction ceased in these families. Similarly, Ando (1978), confirming earlier work of Ando and Tsuda (1978) found that reproductive activity of Japanese mothers of children with DS had declined significantly after the birth of a child with DS when compared with mothers of normal children matched on the basis of age.

4.3 Formal support systems or Social Work intervention

The general perceptions of participants regarding social work intervention is that it partly addressed some of their needs, while leaving significant other needs unattended. Firstly, participants reported that social work intervention received was focused mainly on addressing practical needs such as assistance with social grants. Thus, none of them received adequate psychosocial support. Consequently, their needs had not been addressed at that level through professional intervention. However, they resorted to other avenues such as self, family and friends to help cope with the situation.

Secondly, intervention was not holistic. The individual targeted was either the mother or the child and the two were targeted depending on the nature of their presenting challenges. For instance, if the mother presented with lack of proper accommodation for the child, the social worker would work towards addressing such a problem. If the child needs institutionalisation in the social worker’s view, he or she would work towards getting the child an appropriate institution.

Thirdly, treatment and care options came as prescriptions to mothers from social workers The forms of assistance given were mainly logistical aids such as assistance with care dependency grants and placements of children in institutions. Some participants were advised during the process of applying for a care dependency grants to place their child with DS in an institution. Participants could not understand why they should place their child with DS at an institution. For instance, one participant expressed the following sentiments:

" I asked my self and them, for what good reason must I take my child to Sizanani when I am alive and my child is healthy and fresh"

There seemed to be a generally negative attitude towards institutionalisation amongst the mothers. Similar to an African proverb that says: "Tlou ga e imelwe ke mmogo wa yona" Literally interpreted as "An elephant cannot be burdened by its own body" Meaning that it is a divine responsibility of parents not institutions to look after their children. As shown by Ryke, Ngiba and Strydom (2003:139) "traditional cultural practices of black African people to keep their elderly persons with them remain a stumbling block to getting them to utilise the provision of institutional care by the government". It was found that black people prefer utilising their extended family systems instead of institutional care on the basis of their belief of "not throwing away" their people (Ryke, Ngiba and Strydom, 2003:139). In other words, children cannot be regarded as burdens for parents. This conviction provides positive reinforcement in helping mothers to accept and cope with their child with DS.

Lastly, intervention was focused on the individual. Furthermore, it was commonly felt by participants that, mothers are left to go through the grieving process unsupported. Most participants expressed their wish for interventions that are family focused as most of their problems begin in the family and extend outside to the community. They seemed to be understanding and accepting of a community based stigmatisations, but expressed great disappointment at misconceptions and labelling coming from inside the family, which

sometimes if not properly modified and contained, may lead to a complete disintegration of the family system. No attempt had been made by Social Workers to engage the entire family system and the extended family. Van Der Walt (1990:37) stresses "the spirit of communalism is inherent in traditional African cultures as opposed to the Western cultural emphasis on individualism." Furthermore, traditional African communities view duties towards the community as paramount, hence the belief that "all children in the community are children of all adults in the community- 'my child is your child'" (Van Der Walt, 1990:37). The above provides opportunities for sustaining change efforts and should be encouraged in the researcher's view. Furthermore the researcher noted that although there is a trend towards individualism amongst African people due to Western influences, the communal life style carries more benefits for black African people.

The participants expressed their appreciation of an opportunity to belong to a support group and efforts of the multi-disciplinary team that assist them on an on-going basis including nurses, physiotherapists, Doctors and Social Workers. They all stressed that the support group itself assist them to deal effectively with challenges they encounter in their lives.

4.4 Family reactions and ascribed meaning by other informal support systems

When asked how their informal support systems or family had reacted to the birth of a child with Down Syndrome (DS), the responses of participants were varied. Most of the participants were satisfied with the support they had received from their close family members (elders, partners and siblings). They felt that close family members were supportive and loving towards their child with DS. They had never felt that their child with DS was unfairly treated or stigmatised by anyone at home.

However, some participants reported that they had serious problems with their extended family members gossiping about the cause of the condition. Some extended family members, particularly the in-laws, had attributed the condition to being a curse by ancestors, while some attributed it to witchcraft by envious family members. Participants,

who experienced these sentiments from extended family members, described the experience as having a negative impact on their ability to cope and effectively manage their situation.

Literature demonstrated that "relatives, neighbours and friends may tend to pity, ignore or actively avoid the family" (Lea and Foster, 1990:218). The study revealed that almost all participants (100%) were unhappy about the reactions of their neighbours and community at large. They reported that, their child with DS was adversely stigmatised by the community. The community gave them negative labels such as calling the children "Zodwas". The children were reported to being isolated and not perceived as part of the normal pool of children in the community. The participants felt that they were generally perceived by the community as being "cursed" for deviating from cultural norms. The following responses bear's testimony:

Babang bana ba ba badirile di tsheisa. Ke gore o kree motho o mogolo, ge ngwana a feta, ono ra ngwana o are "Zodwa.." Le bese ya bona e bitswa bese ya dizodwa. Skolo sa bona se sespecial akere ke Zodwa. Interpreted as *'Some people have turned our kids into laughing stocks, you find an adult person calling a child with DS, Zodwa, even their school bus is called Zodwas' bus. Just because their special school is called Zodwa'*

It appears that the stigma is not only directed to the child, but also to the parents. Boswell (1974) argues that not only are the handicapped children stigmatised, but also the whole family feels looked down upon when other people look at the child with a sense of pity. Participants described the situation as messy and unpredictable. Labelling and stigmatisation, self-pity and mockery resulted from such engagement, particularly with the extended family and other external parties such as friends and neighbours. In Attridgeville, the children with DS are labelled Zodwas, emanating from the name of the special school they attend which was named after a community nurse who established the special school (Zodwa).

4.5 Impact of support groups

Paritzky (1986) points out that the self-help group is valuable and appropriate source of practical and emotional support for families affected by a genetic condition. All mothers interviewed individually, asserted that they had found it beneficial to belong to a support group. They found the support group to be particularly helpful in assisting them to explore best ways of looking after their child with Down syndrome. They also acknowledged the fact that support groups go a long way in assisting them to come to terms with the psychosocial trauma created by the birth of a child with Down syndrome as it provides a normalizing experience. They reported that, through the help of the support group, their relationship with their children is improving as they are increasingly becoming more patient and understanding towards their children. Bernardt (1986) emphasises that peer counselling by someone who has faced a similar crisis and has dealt positively with them, is also appreciated by families affected by a genetic condition.

Bernardt (1986: 117) postulates that support groups for the families of handicapped provide an opportunity for parents to "experience a natural growth towards advocacy and the care given to the handicapped". This does not only benefit the child but also those involved in the caring of the child. The research findings confirmed that support groups are crucial in helping mothers cope and care for their child with mental handicap.

5. CHAPTER 5: SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This study was aimed at exploring the psychosocial needs and coping strategies of black African mothers following the birth of a child with Down syndrome (DS), in order to highlight implications of such needs for the indigenisation agenda of social work in the South African context. The study adopted a qualitative research design, purposive sample and utilised a method of a focus group of seven participants, as well as four individual interviews to collect data. The research sample was drawn from existing DS support groups in Tshwane. The analysis of collected data was done using a method for analysing qualitative data adapted from Neuman (1997). The method outlines 4 steps in data analysis; namely, familiarisation and immersion, inducing themes, coding, elaboration and lastly interpretation and checking.

The study reveals that, giving birth to a child with DS is a shocking and stressful experience. Mothers need on-going psychosocial support ranging from the individual to the family and the community needs to be educated about the condition; assistance with practical needs such as grants and stimulation of the child; as well as information about the condition. The study also shows that, in coping with the experience of giving birth to a child with DS, black mothers turn to the elders for support as well as God and in some cases traditional healers and prophets. In the light of the above needs, the researcher further found that there is a general lack of fit between the conventional professional approach to psychosocial support and understanding of needs of black social work clients. Social work intervention was perceived as being prescriptive; none-holistic; practical; and individualistic in focus. Such lack of fit results in failure on the part of professional helpers to integrate personal and family resources to the helping process.

5.2 Main findings

5.2.1 Black African mothers' needs and coping strategies

The research reveals that participants needed psychological and social support as they and their significant other family members were shocked by the incidence of the birth of a child with Down Syndrome (DS). They also needed more information about the condition to be given to them as well as their families. Secondly, the research also found that participants needed general information on the rights and entitlements for the child with DS. They needed to know what the rights of the children are with regard to the various services they need. It is found that like any other mothers, mothers of children with DS strive to give the best care to the child and require support in that regard.

The research findings show no decline in the reproductive activities of mothers following the birth of a child with DS. This points to the ability of mothers to accept the experience and move on normally. The research findings reveals that participants did experience greater levels of stress, particularly during the first few months of learning that, their child has DS. Most participants turned to their belief in God, Ancestors, elders and Pastoral counselling as a coping strategy while others turned to close family members and friends for support.

Participants resorted to being secretive about their child's condition initially as a coping strategy until they have dealt with the issue. They only opened up once they felt ready to do so emotionally. The findings shows that mothers find it difficult to deal with the experience of giving birth to a child with Down syndrome. However, the research findings also show that black mothers find ways of coping and are eventually able to come to terms with the experience within a reasonable time frame due to their strong moral standing and cultural values.

5.2.2 Handling of their needs at a formal or professional level

The findings reveals that black African mothers perceive formal support systems as partly useful in helping them cope with their situation, but not entirely helpful as it fails to impact on significant other factors in their predicaments. The research findings show that participants did not perceive professional social work intervention as essential in assisting them cope with the psychosocial implications of the birth of a child with DS, but rather as a formality in assisting them to access grants and other practical aids. Social work intervention was perceived as being prescriptive, practical, non-holistic and individualistic in focus.

The research findings shows that, support groups plays an important role in helping mothers explore best ways of looking after their child with Down syndrome and assisting them to come to terms with the psychosocial stress created by the birth of a child with Down syndrome as it provides a normalizing experience.

5.2.3 Handling of their needs through informal support systems

The findings reveal that informal support systems are an essential source of support for black African mothers, particularly with regard to psychosocial issues. Most of them depended on guidelines from their elder family members such as in laws and grand parents. However, these informal support systems are not embraced by formal interventions. Sometimes, stereotypic belief systems and handicapping attitudes are encountered with these systems such as shifting of blame to the mother due to cultural beliefs and attribution of the condition to witchcraft. In the absence of proper coordination and professional support, informal support systems become very destructive to mother's coping strategies.

5.2.4 The extent to which social work intervention is informed by the needs of the mothers

The findings demonstrated the lack of fit between what is been given as an option by the professional helper and the extent of receptivity by the client. Most participants reported that, they would have appreciated help to be extended to their families and this was not the case. The participants presented various belief systems of themselves and their families that strongly influenced their coping strategies as including among others; their belief in God, ancestors and witchcraft. Ultimately, any intervention by the professional helper becomes a fruitless endeavour that the client cannot identify with if it does not touch on such belief and value systems.

5.2.5 Implications for the indigenisation agenda of Social Work in South Africa

The discussions with participants in the sample painted a picture of a clear disparity between formal and informal systems working together towards the same goals. Mothers appeared to be at the middle of this double agenda. The on agenda being that of the family system and its traditional ways of problem solving, while on the other hand, the professional coming in from a technical, rational point of view. The two agendas seemed to have been engineered to work against each other instead of being complimentary. The above statements demonstrate the lack of fit between what is been given as an option by the professional helper and the extent of receptivity by the client. For example, it is normal practice to put children with disabilities in institutions to alleviate the demanding burden of caring for such children from their parents, while in the black African traditions, such an act is unacceptable and perceived as undesirable conduct that may annoy ancestors. Ryke, Ngiba and Strydom (2003:139) warned against institutionalisation as a an alternative care option to black African people on the ground of the belief amongst black Africans in “not throwing away” their people to institutions.

As articulated earlier, most of the black African ethno-cultural practices are based on values and philosophies that conflict with conventional values and philosophies

underpinning counselling as a process (Kuse 1997). “Such values are inherent in the traditional patriarchal family system, the philosophy of keeping family matters within the family and not to open up for strangers, the traditional beliefs in ancestral powers and witchcraft (Kuse, 1997:21).

Participants seemed to rely more on their informal ways of addressing needs as it contains an element of self-direction and ownership. The formal interventions are then seen as alien and necessary to access certain material needs such as grants and acceptance at special schools. The participants had to in one way or another involve their extended family system in these matters. They have a moral obligation and it is their responsibility as black African mothers to involve their extended family system about the incidence of the birth of a child with Down Syndrome. As pointed out by Van Der Walt (1994) elderly persons are traditional birth attendants and traditional health practitioners. This is a very interesting and significant observation as it directly relate to how families with a child with disabilities will manage the condition. The role of elderly persons and the extended family network cannot be ignored.

5.3 Conclusions

In conclusion, the researcher reconfirms earlier research findings that giving birth to a child with Down syndrome (DS) evokes immense psychological and social reactions with grave implications on the individual mother and her family. Furthermore, mothers ascribe certain meanings to the birth of a child with Down syndrome such as perceiving it as a gift from God. This helps them to have a speedily acceptance of the experience. However, negative connotations may also be equally attached to the birth of a child with DS. Some people may attribute the birth of a child with DS to either a curse by ancestors who may be unhappy with the personal conduct of parents or to acts of witchcraft. These generally held perceptions have negative impact on the mother’s ability to accept and come to terms with their experience of giving birth to a child with DS and therefore need to be modified accordingly to harness functionality within the family unit.

The cultural norms and values of black people, including principles of Ubuntu and their belief in collectivism provides important opportunities, support systems and resources that could be pooled for efficient and effective helping intervention. Failure to recognise the above renders any social work intervention fruitless. Mothers derive a great deal of strength in coping with challenges associated with the birth of a child with DS from their strong moral grounds and Ubuntu principles. The abundance of interest from the family, both nuclear and extended as well as other associates such as friends, neighbours and community at large present another platform that could add value to the helping process.

Lastly, social work practice seemed to be unpopular amongst black African people, the participants did not value the professional intervention as a necessary psychosocial healing process, but just one of the technical formalities that needed to be complied with particularly as a means to access grants and other assistance for the welfare of the child. The nature of social work intervention added to this perception, as it did not adequately address psychosocial issues of clients. They perceived social work as attending only to practical needs, as being prescriptive; none-holistic and individualistic. The above situation calls for re-examination of professional services.

5.4 Recommendations

1. Social Work practice should align itself to contextual issues of black African people. There is a need to find a fit with values and norms inherent in a particular context. The principles of Ubuntu must be embraced and cultural rituals and practices must be understood and accommodated so that clients do not perceive intervention as alien to their own coping strategies. The two need to integrate and work together for a common goal.

2. Families should be encouraged to develop their own capabilities rather than become dependant on professionals. They need to acquire the necessary knowledge and coping skills to become stronger and better able to manage and negotiate the many demands and forces that impinge on them.

3. The focus needs to fall on the family as a whole and not only on professionally identified needs. The extended family system cannot be ignored as it is part of and influences the nuclear family remarkably. Partnerships need to be built between parents, the family (extended where possible) and professionals. When knowledge skills and resources are shared, parents become even more capable through a co-operative arrangement.

4. Communication systems need to be improved and gaps within the intervention process filled. The researcher recommends better co-ordination of professional help as family will become involved with a large number of professionals, including Paediatricians, GP's, geneticists, health visitors and social workers.

5. Further research on the topic of indigenisation of social work in the black African context is also recommended.

6. Appendices

6.1 Appendix A: Ethics clearance certificate

6.2 Appendix B: Letter of permission of access from DSA

6.3 Appendix C: Participant information sheet for individual interview

UNIVERSITY OF THE WITWATERSRAND, SOCIAL WORK DISCIPLINE

PARTICIPANT INFORMATION SHEET FOR INDIVIDUAL AN INTERVIEW

Dear participant

My name is Mbazima Mathebane I am a Social work Masters student at the University of the Witwatersrand. As part of the requirements for fulfilment of my degree, I am conducting a research study on the psychosocial needs of black mothers following the birth of a child with Down syndrome. The topic of the research is as follows:

"The psychosocial needs of black mothers following the birth of a child with Down syndrome: implications for indigenisation of social work practice in the S A context".

The study aims to investigate the common needs of black mothers after the birth of a child with Down syndrome and assess if the various social work services provided are relevant and responsive to such needs.

I therefore, invite you to participate in the study. Your participation in the research would involve taking part in a one-on-one interview session with me as the researcher. The interview session will take approximately 1 hour of your time. The interview will focus on your experience and needs as a black mother, following the birth of your child with DS. To allow for effective and efficient analysis of the outcomes of the discussion, the session may be tape-recorded with your consent. You may, however, choose not to give consent for the tape recording of the interview if you wish so and the interview will be done without the tape.

Please note that your participation is voluntary. You can choose to withdraw your participation at any time, and you will not be penalised for this. Neither, will your participation in the study be rewarded in any way. All the information obtained from you will be kept confidential. None of the information received will be used for any purpose than that of the study. A copy of the research report will be given to the Down Syndrome Association in Tshwane and all participants will be welcome to read it at their own time.

The interview will be conducted by the researcher at a private place. The research study aims to explore the felt needs of mothers and as such there are no right and wrong answers that the researcher is looking for. Thus, your openness would be greatly appreciated. Please feel free to ask any questions you might have.

Thank you

Mbazima Mathebane

(If you like to ask me anything about the study in future, please contact me at: CELL- 083 574 1571 or my supervisor : Mrs L Smith (011) 717 4472/3)

6.4 Appendix D: Participant information sheet for a focus group interview

UNIVERSITY OF THE WITWATERSRAND, SOCIAL WORK DISCIPLINE

PARTICIPANTS INFORMATION SHEET FOR THE FOCUS GROUP

Dear parent

My name is Mbazima Mathebane I am a Social work Masters student at the University of the Witwatersrand. As part of the requirements for fulfilment of my degree, I am conducting a research study on the psychosocial needs of black mothers following birth of a child with Down syndrome. The topic of the research is as follows:

"The psychosocial needs of black mothers following the birth of a child with Down syndrome: implications for indigenisation of social work practice in the S A context".

The study aims to investigate the common needs of black mothers after the birth of a child with Down syndrome and assess if the various social work services provided are relevant and responsive to such needs.

I therefore, invite you to participate in the study. Your participation in the research will involve taking part in a focus group session. This is a group of 6-10 persons with similar experiences to yours, which will meet once for approximately 2 hours. The group will discuss experiences and needs of black mothers following the birth of a child with DS. To allow for an effective and efficient analysis of the outcomes of the group discussion, the session will be tape-recorded. The tapes used will be destroyed after completion of the study.

Please note that your participation is voluntary. You can choose to withdraw your participation any time, and you will not be penalised for this. Neither you're your

participation in the study be rewarded in any way. All the Information obtained from you in the group will be kept confidential by the researcher. However, please, note that confidentiality cannot be guaranteed in view of the nature of the focus group. None of the information received will be used for any purpose than that of the study. A copy of the research report will be given to the Down Syndrome Association in Tshwane, and all participants will be welcome to read it at their own time.

The researcher will facilitate the discussions and there would be no right and wrong answers. Thus your openness would be greatly appreciated. Please feel free to ask any questions you might have.

Thank you

Mbazima Mathebane

(If you like to ask me anything about the study in future, please contact me at: CELL-083 574 1571 or my supervisor : Mrs L Smith 011 717 4472/3)

6.5 Appendix E: Participant consent form for individual interview

UNIVERSITY OF THE WITWATERSRAND, SOCIAL WORK DISCIPLINE
SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT

Researcher: Simeon Mbazima Mathebane, MA Social Work Student

The psychosocial needs of black mothers following the birth of a child with Down syndrome: Implications for indigenisation of social work practice in the South Africa context.

Consent form for a one-on-one interview

I…….. (name) hereby give my full consent to participate in a research interview scheduled between myself and ……..(researcher) on a research study titled as indicated above, which involves answering questions about my emotional and social needs after the birth of my child with Down syndrome (DS), my experience of caring for and raising a child with DS and the support services I received. The interview will take approximately 1 hour.

I understand that the study aims to investigate the different needs of black mothers after the birth of a child with Down syndrome and to assess if the various social work services provided are relevant and responsive to such needs. I understand that my participation in the research will involve taking part in a one-on-one interview session with the researcher. The interview will focus on my experience and needs as a black mother, following the birth of my child with DS. I also understand that my participation in this study is voluntary. I can choose to withdraw my participation at any time, and not be penalised for this. Neither will my participation in the study be rewarded in any way. I also understand that should a need for counselling arise, I would be referred for appropriate counselling services.

All the information obtained from me will be kept confidential. I will remain anonymous in the research as a respondent. None of the information received will be used for any purpose than that of the study. A copy of the research report will be given to the Down Syndrome Association in Tshwane and I, as the respondents will be welcome to read it at my own time. The interview will be conducted by the researcher at a private venue.

…….……..…. ……
Signature of participant Date

…… ……
Witness Date

…….. …….
Researcher Date

Consent for the tape-recording of the interview

As per the information provided above,
I…….. (name) hereby further give my consent for the tape-recording of the research interview scheduled between myself and ……..(researcher).

…….……..…. ……
Signature of participant Date

…… ……
Witness Date

…….. …….
Researcher Date

6.6 Appendix F: Participant consent form for a focus group interview

UNIVERSITY OF THE WITWATERSRAND, SOCIAL WORK DISCIPLINE
SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT

Researcher: Simeon Mbazima Mathebane, MA Social Work Student

The psychosocial needs of black mothers following the birth of a child with Down syndrome: Implications for indigenisation of social work practice in the South Africa context.

Consent for participation in a focus group

I…….. (name) hereby give my full consent to participate in a focus group discussion scheduled between myself and ……..(researcher) on a research study titled as indicated above, which involves answering questions about my emotional and social needs after the birth of my child with Down syndrome (DS), my experience of caring for and raising a child with DS and the support services I received. The focus group session will take approximately 2 hours.

I understand that the study aims to investigate the different needs of black mothers after the birth of a child with Down syndrome and assess if the various social work services provided are relevant and responsive to such needs. I understand that my participation in the research will involve taking part in a one-on-one interview session with the researcher. The interview will focus on my experience and needs as a black mother, following the birth of my child with DS. I also understand that my participation in this study is voluntary. I can choose to withdraw my participation at any time, and not be penalised for this. Neither will my participation in the study be rewarded in any way. I also understand that, should a need arise for counselling, I will be referred for appropriate counselling services.

All the information obtained from the group will be kept confidential by the researcher, although confidentiality cannot be guaranteed in view of the nature of the focus group.

None of the information received will be used for any purpose other than that of the study. A copy of the research report will be given to the Down Syndrome Association in Tshwane and I, as the respondent will be welcome to read it at my own time. The interview will be conducted by the researcher at a private venue.

……..……..….	……
Signature of respondent	Date
……	……
Witness	Date
……..	…….
Researcher	Date

Consent form for the tape-recording of the group

As per the above information, I…….. (name) hereby give my consent for the tape-recording of the focus group discussion.

……..……..….	……
Signature of respondent	Date
……	……
Witness	Date
……..	…….
Researcher	Date

6.7 Appendix G: Interview guide for individual participants

UNIVERSITY OF THE WITWATERSRAND, SOCIAL WORK DISCIPLINE
SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT

INTERVIEW GUIDE

Biographical details

Participant's age		Occupation	
Age when child was born		Child's age	
Marital status		Type of social work service	
Family composition		Child institutionalised or at home	
Ethnicity		Duration in support group	

1. How did you receive the news that your child has DS?

(If necessary prompt: who, when, under what circumstances, where)

2. How did it feel?

(If necessary, prompt for reactions such as crying or other indicators of stress)

3. In your understanding, what are some of the reasons that may have led to you giving birth to a child with DS?

(If necessary prompt: a gift from God, a curse, misfortune, biological reasons etc)

4. What was your most important need after learning that your child has DS?

(Prompt: information, support from family and friends or a social worker)

5. What kind of support did you need and expect from the people around you?

(Prompt: Father of the child, family, friends, neighbours, and community)

6. What kind of support did you receive from your family?

(Prompt: Father of the child, family, friends, neighbours, and community)

7. Were you satisfied with the support you received from the people around you and your community?

8. Please describe in detail the kind of social work services you have received
(Prompts: Individual counselling, group work, support group and other admin assistance such as application for a grant)

9. What was the most helpful assistance you received from social workers?
(Probe for detail)

10. What was less helpful?
(Probe for detail)

11. Did you feel that your needs were taken into account when you received help?
(Probe for detail)

12. What could have been done better?

13. How did you end up joining the support group and what does it do for you?

14. Where are you now and according to your own evaluation, what helped you get where you are now?

6.8 Appendix H: Focus group prompts

UNIVERSITY OF THE WITWATERSRAND, SOCIAL WORK DISCIPLINE
SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT

The researcher collected the biographical information from individual group members prior to the group session as follows:

Biographical details

Participant's age		Occupation	
Age when child was born		Child's age	
Marital status		Type of social work service	
Family composition		Child institutionalised or at home	
Ethnicity		Duration in support group	

The session begun with a joining-in activity wherein, group members introduced each other to the group. Later on the group discussed ground rules, include among others, the issue of confidentiality of matters discussed in the group.

Focus Group Prompts

1. How did you receive the news?

2. What were some of your most important needs after you received the news?

3. Who did you turn to? Were there people that you would have liked to turn to, but didn't?

4. What kind of help did you get?

5. How did you end up joining a support group and what does it do for you?

6. What would the perfect services for parents of children with DS look like? (Prompt: consideration of material needs, values, cultural issues or prejudices)

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