



Mothers' Life-Worlds in a Developing Context when a Child has Special Needs

by Eve Hemming & Jacqui Akhurst

Abstract

This South African study investigates the lived experiences of a group of isiZulu mothers of children diagnosed with multiple disabilities. Data collection from regular focus group discussions proceeded with the assistance of a translator skilled in working in isiZulu and English. The phenomenological approach employed revealed the mothers' philosophical acceptance of their child's disability. Issues of concern to the women that emerged include the effects of the child's disability on their lives, the treatment options for their children, and their perceptions of the causes of the disability. The women reflect on both traditional and Western treatment options and articulate the constraints they experience as caregivers, with limited child-care facilities preventing them from finding employment, difficulties in accessing social service grants exacerbating their position, and various levels of family and community support experienced. The study underlines the need for more adequate service provision for children with special needs and their families, and for intervention programmes to be informed by an understanding of the contexts and ways of making meaning of those whose needs they are intended to serve.

Introduction

In the developing world, healthcare interventions may be undertaken by professionals of a different ethnic background from service-users, and training in 'western' models of illness and disability may not correspond with users' ways of understanding these phenomena. The world-views and meaning-making systems of the healthcare workers are thus likely to be challenged, particularly where the people with whom they work are strongly influenced by traditional belief systems and customs.

The South African healthcare system in the post-apartheid era has faced many complex challenges.

Along with the obvious and devastating effect of the HIV/AIDS pandemic on the system (Dixon, McDonald, & Roberts, 2002), the national and provincial governments have had the considerable task of shifting the provision of public healthcare and education from a discriminatory system in which the majority were neglected to a system of equal provision for all. For example, in the realm of special educational needs and disability, Naiker (1999) points to the gross disparities in the apartheid years, where the ratio of white learners in special schools was 1:62, as opposed to a ratio of 1:830 for black learners. The result of just over a decade of democracy has been a redistribution of some services; however, in many respects, people who are impoverished are still likely

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to experience difficulties in accessing service provision. Donald, Lazarus, and Lolwana (2002) report a positive correlation between poverty and challenges to both physical and mental health in South Africa. They trace the cycle of poverty and its effects, noting that “living under conditions of poverty may often actually lead to specific disabilities or difficulties in learning” (p. 205), and that inadequate service delivery for the impoverished increases the risk of disability.

Gargiulo (2006) reports that having a disabled child can have a strong psychological impact on the family dynamic. Negative responses and conflicts may be engendered, often linked to issues of acceptance, professional help and future planning. Chinkanda’s (1987) study of 80 black South African township mothers of disabled children illustrates these concerns, with the mothers experiencing social stigma, adjustment difficulties related to family, friends and community, and, in addition to the physical demands of child-care, financial constraints, and inadequate service delivery from agencies or relevant organisations.

A further factor that may have an impact on parents’ adjustments to their child’s disability relates to the way in which professionals make the disclosure, and then the so-called ‘black hole’ experienced by many as they wait for guidance regarding the support and options available to them (Hedderley, Baird, & McConachie, 2003). Shah (in Dale, 1996) asserts that, due to faulty assumptions, misunderstandings can result between parents and professionals from different socio-cultural backgrounds. Dale (1996) argues that practitioners need to be aware of the significance ascribed to disability within any particular group. Even though early intervention programmes may be available in developed countries (Heiman, 2002), in South Africa the impoverished Black family may be difficult to reach, limiting access to support and intervention programmes. Agencies providing support may also tend to focus particularly on the needs of the child; however, there has been a growing recognition of the need to have a family focus, due to the effects of disability on other family members and on the engagement between the family and the community (Gargiulo, 2006).

In South African families where there are still strong links to traditional customs and religion, some illnesses and disabilities may be accorded additional meaning, with traditional healers having an important role to play in this regard. Melato (2000) notes that

people in such communities rely on both the traditional healer and the ‘western’ medical practitioner, and certain conditions may lead to the disabled person being rejected due to various fears related to superstition (Donald, Lazarus, & Lolwana, 2002). Melato encourages practitioners to gain some understanding of African religious beliefs, which are rooted within a holistic world-view encompassing views of self, world, and the spiritual realm.

In a city in the South African province of KwaZulu Natal, a number of concerned professionals became increasingly uncomfortable with the inequitable provision of services for children in need of diagnosis and treatment for severe disabilities. They therefore grouped together to form the Child Development Resource Centre (CDRC), linked to a non-governmental organisation, to provide services for such children on a time-limited basis. Children identified in hospitals or doctors’ surgeries as having multiple physical, sensory and intellectual disabilities are referred to the multi-disciplinary team at the CDRC for diagnostic procedures and the planning of initial intervention programmes. The team also assist the parents of the children to gain better support and educational provision. The underpinning philosophy of the team is based on a systemic view of the child (Bronfenbrenner, 1977), which strives to intervene at multiple levels and to involve parents/caregivers in the process. Psychologists’ involvement in this project was motivated by the question of how to “remain relevant and contribute to the profession by pioneering and reinventing praxis responsive to social change” (de la Cancela, Alpert, Wolff, & Dachs, 2004, p. 156).

Trainee psychologists from a nearby university became involved in the work of the CDRC, providing diagnostic and intervention services, as well as evaluating the work of the centre. One of the authors of this paper thus spent part of her internship at the centre, and, due to her background in special educational needs provision and her commitment to the involvement of parents in children’s treatment programmes, proposed this study, under the other author’s supervision.

In undertaking a study utilising a phenomenological design, it is necessary to identify the assumptions the researcher might be taking into the arena. The use of the systems theory framework was one of the strategies employed in this regard, where features of the micro-, meso-, exo- and macro-systems were described, as outlined above. This form of

'bracketing' was employed as a means of limiting the possibility of the findings being influenced by prior learning and bias on the researcher's part (Pietersen, 2002). An interpretive research approach was chosen because it enables researchers to articulate their frames of reference, as well as striving to better understand the individuals' interpretations of the world around them (Cohen, Manion, & Morrison, 2000).

Method

Participants

The participants in this study were Zulu-speaking mothers of disabled children, who travelled from an underdeveloped peri-urban area into the city to attend the CDRC over a number of months. The mothers were living in an area where rapid urbanisation had exceeded the capacity of local government to provide basic housing and services, and they experienced cramped living conditions (often sharing a single-roomed home), limited income and few material possessions. The unemployment rate in the area is high, with many people dependent on handouts from others. Ten mothers participated in seven focus group sessions. Their children, aged 2 to 8 years, had been diagnosed with learning disabilities as well as some form of physical disability and/or visual or auditory impairment. Since the mothers had limited education and were not fluent in English, a trained Zulu/English-speaking staff member at the CDRC assisted with translation.

Procedure

The mothers, who were present at the CDRC whilst their children were receiving therapeutic interventions, were given information about the proposed study, and agreed to participate in the process. The researcher, translator and mothers arranged a schedule. The mothers consented to the dialogue being recorded for research purposes, and were promised anonymity. Seven fortnightly sessions of approximately one hour each were conducted.

The focus group method was selected both as a suitable means of communicating with the mothers (since some of the mothers had limited literacy) and as a potential way of strengthening peer support through the shared process. Focus groups have gained in recognition and popularity as a research procedure in which data is collected through group interaction on the topic of interest (Krueger, 1994; Morgan, 1997). Focus groups provide an opportunity for participants to voice attitudes and opinions, and to

share experiences and perspectives, and have the advantage of enabling information to be collected in a limited period of time. The topic may differ from session to session, with group interactions offering potential synergy not experienced in individual interviews. The focus group dialogues were recorded on audio-tape.

Process

The transcribed data appeared to be suited to analysis by means of the phenomenological psychological method. Kruger (1979) notes the need for researchers to approach the material with the attitude of getting "the world to disclose itself to one in all its manifestations and complexity" (p. 113). Information is gathered through dialogue, in which the participants' interactions with their world unfold. This method was chosen because it offers both the researcher and the reader the opportunity to better grasp the perspectives of the mothers, by attempting to view the world through their eyes. The research process offered the women the opportunity to articulate their perceptions and their life-views. The data was collected by means of "an informal, interactive process ... utilis[ing] open-ended comments and questions" (Moustakis, 1994, p. 114). The aim of the process is to describe the focal phenomenon as accurately as possible, and offers an opportunity to move beyond culture-bound preconceptions (Moran, 2000).

In the successive group meetings, the researcher explored themes related to coping and attribution of meaning, working from the present to the past within an increasingly retrospective time frame, in order to elicit more holistic accounts of the mothers' life-worlds. It was hoped that this would contribute to the development of an environment of trust, as well as establishing an outlet for collective catharsis. The responses to the open-ended questions and subsequent questioning for clarification are included under relevant headings in the findings set out below. Stones (1988) notes the importance of respondents' verbal fluency and ability to communicate their feelings, thoughts and perceptions in relation to the topic; whilst this criterion held true in the mothers' first language, the authors recognize the use of translation as a major limitation of this study. Since the researcher was not fluent in isiZulu, the groups were conducted in both isiZulu and English, with a translator as intermediary; care thus had to be taken that the mothers' accounts were recorded as accurately as possible.

Following the process outlined by Van der Mescht (1996), the initial data analysis focused on the descriptive, with the temptation to categorise the data suppressed until a more holistic sense of the women's experiences began to emerge. Then the content of the group discussions was coded into Natural Meaning Units (Stones, 1988), and categorised into essential themes, with the process aimed at identifying and distilling the lived experiences of the mothers. This third, descriptive step (Polkinghorne, 1989) forms the basis of the following section. In order to capture the richness of the data, it was decided to include excerpts of the transcribed translations of the mothers' words.

Findings

Emerging themes were synthesised into the four main headings below, with the mothers' words, as reported in the third person by the translator, presented in italics.

Effects of Having a Disabled Child

The mothers reported that their lives had been profoundly affected by the birth of their disabled child. They found their role demanding, and their caring for the child had financial consequences. Their relations with others were also impacted, and they felt the need for support from family, community and professionals. The lack of access to welfare grants and the unavailability of child-care facilities were further concerns.

Conflicting Role and Financial Demands

A prevalent early theme was the demands of the child, which impacted on the mothers' lives in a variety of ways. These included the amount of time they spent with their child limiting time for other activities, including housework. Some noted concerns about the effect of the time spent with the child in leading to the child becoming increasingly dependent on them.

"The child cries until the mother takes attention. She can't leave the child with anyone else."

"She feels that the child could not make progress at a place without her, as the child depends and relies on her too much."

Some mothers expanded by noting that the child's dependency had led to perceptions of the child becoming spoilt, but this was countered by the

acknowledgement that the child was only able to progress if tended to by the mother.

"She is commenting ... that she has to be with the child, as the child is only improving because she is always there."

The emotional impact of the child-rearing was clear, and some mothers reported that the time-consuming nature of the role led to feelings of sadness or despondency:

"She feels, 'What can I do?' Because of the child, everything seems dark and that nothing else can happen, because the child is so time-consuming."

"She is sad ... as she has to neglect the most basic duties due to the demands of the child."

Financial constraints added to the problems experienced by the mothers. The caregiving role led directly to the mothers not being in a position to be employed. One mother also reported that leaving the child would be painful for her. Some wanted to find employment, but were unable to seek it, due to the demands of child-care. Moreover, most added that, if they found employment, they could not leave the child with anyone else, leading to dilemmas such as:

"She can't leave the child with anyone else; on the other hand, she has to go and look for a job."

"At the moment she is looking for a job, but if she finds a job, then she can't leave the child."

For some, the unemployment of their spouses exacerbated the financial problems arising from being a caregiver to a disabled child. The mothers' feelings of conflict thus became apparent, with their devotion as primary caregivers juxtaposed with their need to make a contribution towards their families' financial needs. The essence of this tension appears to be a core factor contributing, for some, to a sense of helplessness.

Difficulties in the process of obtaining a state monetary grant for the child added to the mothers' financial burdens. Most reported what they believed were unnecessary delays in procuring the grant for their child.

“These other mothers all say that they have difficulty with finance, as they do not work and they ... just have to wait for it [the grant] to help them.”

Waiting appeared to be a common experience for the mothers, in the form of, for example, passively waiting for grant support, and seeming to accept that this waiting was part of daily existence.

Need for Support Systems

The helpfulness of others and the need for support from others was conveyed. With regard to their partners, a few mothers reported that their spouse made a positive contribution, whilst some, in contrast, reported limited support being contributed by the spouse. Examples of the contrasting experiences are:

“ ... fortunately the father of the child is supportive of everything ... in each and every thing, they are working hand-in-hand.”

“She gets little support from the father – he is elsewhere.”

Varied levels of other support were experienced: two of the mothers were widowed, thus having no spousal support, whilst some received support from other family members. Some mothers reported a lack of support from the paternal family, while others received support from both maternal and paternal families:

“She gets some support from the family, parents and siblings, as she is not married and gets little support from the child’s father.”

One woman reported earlier support that had progressively diminished and eventually been lost:

“She says that the paternal family did accept the child, and the maternal family was fine. But when the condition became conspicuous at one year, the paternal family rejected her and the child. Then the father ... died, and then her own mother died, so the maternal family also ceased to give support.”

This mother became tearful at this point, as she reflected on her losses, and on the impact of diminishing support from family members. The theme

of death of partners or other family members also became evident. One mother reported that, due to being widowed, her need for a relationship with a new partner was constrained by having a disabled child:

“ ... what is difficult for her is that, sometimes, she feels that one day she has to have ... a relationship ... as the father [of the child] passed away. And this seems difficult for her ... to search for another relationship, because ... she has to spend most of the time with the child.”

Since some families can give only limited support, the wider community may also be an important support system. Most mothers reported that they welcomed support, acceptance and understanding from the community, and that lack of support could be hurtful. A number of other mothers had experienced people asking hurtful questions, and commenting on the child’s condition, for example:

“ ... with this mother, the community ask, ‘What’s wrong with the child?’ and that frustrates her.”

“This mother says that the community say nothing - they just look at her and spread rumours which are not true. She hides the child, as she does not know what they are expecting her to do.”

Thus the mothers have experienced varied reactions from community members, which impact in differing ways, leading to feelings of anger, shame and uncertainty.

Service Delivery Issues

Most mothers reported that they had sought assistance from various agencies, and had then been referred to the CDRC. The mothers’ main needs from a service delivery agency were to gain knowledge, while some expressed their need for support from other mothers.

“She would like more knowledge to help the child, for example the child is not sleeping well at night and is crying.”

“She says that she seeks support from the other mothers ...”

Some mothers reported that their children had benefited, and that they were assisted by the

knowledge, training and support received from, in particular, the CDRC:

"... she sees improvement in the child since coming to CDRC."

"... the child is now developing and she is doing lots of things she could not do before. ... Lots of information and help that she got from the training here at CDRC ... has helped her. She sees ... differences and developments in the child."

A few mothers reported inadequate service delivery or support from other agencies, especially with respect to disclosure of the child's disability. Some mothers experienced insensitive communication and a seeming lack of empathy from healthcare workers with regard to their feelings.

"She took the child to the hospital. They told her the child had had a birth injury. She was shocked and cried."

The mothers' daily lives were impacted by having no access to appropriate child-care facilities for children with profound disabilities, as well as problems with transport and accessibility.

"She and some of the other mothers ... say that they have looked up and down and they haven't found a place like this in town, and it is too far for some of them. It is difficult to find what they are looking for."

"She says that there are lots of disabled children in her area, and ... the mothers mention things like transport and financial problems. Maybe the child is big and heavy, and the mother cannot carry the child. And the transport to fetch and carry the child [from day care] is a problem ..."

Some mothers sought schooling for their children, but reported that most schools catered for children with a specific disability in one modality, and not for multiple disabilities. The mothers' frustrations with an unhelpful school system are recorded:

"Since last year the mother has been looking for a place. They say, 'If the child is blind, it is fine.' But, because the child is physically disabled, she can't find a place."

So she tried another place. They said, 'If the child is physically disabled, it is fine.' But she can't help herself She can't sit properly and she is also blind, so she does not fit there."

Some mothers reported that a boarding facility for their child would be preferable, but that the facilities would have to be conducive to the child's ongoing development. One mother reported that her child's conduct was seen as inappropriate for child-care, which created an added factor of concern.

"She says that she cannot put the child in a crèche, due to the child's inappropriate behaviour The teachers complained, as in the school the child destroyed the property and the books."

A few mothers were concerned about the costs of a live-in facility, and would be reliant on a grant to cover the costs. The mothers differed in opinion regarding the use of a potential grant, whether only to fund the child's upkeep, or to enable parental visits as well. Whilst most agreed that the quality of child-care was a prime focus of their needs, some mothers felt that such a facility would not suit them in respect of either their need to monitor their child in regards such as eating habits and health, or their personal need to be close to the child.

"... she is saying that, actually, she does not like to take the child away from her, but ... she is mostly concerned about the day care centre, a place where most of the time she can be with the child ..."

The above discussions highlighted the devoted, attached role of the mothers. In respect of their concerns about the suitability of child-care facilities for their child, high quality care and stimulation were a priority.

Varying Attributions of Causality

As the topics for discussion moved further back in time, the mothers made sense of the cause of their child's disability in different ways. Some mothers showed full acceptance of their child's disability, whilst others had become accepting because they could not change the situation:

"These two mothers are just convinced that their child was a gift from God. And so, whatever the doctor, or whoever, can say,

they just take it as 'okay'. That's the first emotion that comes to them, is that they accept it as a gift from God."

"She says that even if it was the doctor's fault, it is fine, because the child is disabled and there is nothing else that can happen. Or, if she took some medicine when she was pregnant, which was wrong for the child ... she is accepting the child as it is, because there is nothing else that can happen after that."

The above quotation alludes to potential medical causes or human error as related to the child's condition. One mother believed that her child's disability was the midwife's fault.

"She just believed on what the doctor told her; that, because the child lacked oxygen during the time of birth, she thinks it was the midwife's fault for not giving her oxygen for those couple of hours before the birth, because she has, like, asthma."

A variety of other opinions were expressed about potential causes of the child's disability, such as mothers' emotional stresses, premature birth, a possible curse, and heredity.

"... she believes ... it might be the worries ... when she was pregnant ... about how her family were going to treat her and who was going to support her, because just after falling pregnant, the father disappeared ... and she was worried how she was going to cope with this child, while she was still unemployed."

"She is saying that at first she believed that she got the child at seven months [prematurely], but the second idea is that ... she got 'umego' [a curse]. ... She is convinced it is a curse, because her first baby died after five days and last year she had a miscarriage."

"She says what seemed to be the cause of her child's disability, ... it's something that is an inheritance ... because ... the father of the child started to walk and talk at the age of three, so ... she is convinced that ... the child will also start walking and talking at this stage."

From the above, it is apparent that the mothers experienced an array of responses, including acceptance, blaming of others, being resigned or having hope.

Diversity of Treatments Explored

Since these mothers live at the intersection of traditional meaning systems and westernised approaches, they spoke of the diversity of treatment options explored. Most mothers reported pursuing Western medical treatment for their children. Some mothers reported having received medical support for their child through a hospital, while others had consulted a doctor or a therapist.

"She took the child to ... hospital at three months. The white doctor explained to her that the child was injured at birth and that it was not a curse."

"She said that the child was given physiotherapy at [...] for her severe spasticity. The child was also on medication for fits, but they have stopped now."

Some mothers had therefore been given information, and others had accepted other medical treatments. Some mothers reported that they had been influenced through media exposure to go the Western route; however, a number of the mothers had consulted a traditional healer. The variety of different healers available to the mothers is evident in the following excerpts:

"She took the child to the traditional healers because of 'indiki' [curse] ... on the child. The ancestors labelled the child and special 'muthi' [medicine] has to be used for the 'Indiki child'. It's like the ancestors want you to do something to make amends for something that was not done correctly."

"She took the child to the traditional healer The ancestors said that she must go to the father's family, and not stay with her maternal family. This was apparently the reason for the child's disability and possible 'indiki'."

Some mothers reported taking the child to the *Inyanga* [herbalist], whilst others reported taking their child to the *Sangoma* [spiritual diviner]:

“She went to the Inyanga. He said that when she was pregnant ... she was cursed not to have children, and that is why the child is disabled ... but after that the child still could not walk or talk ...”

“She took the child to the Sangoma ... He told her that she was cursed The curse was that the child should die before birth, but the child survived the ‘indiki’. He gave the mother special ‘muthi’ for the child This costs about R500. A goat is slaughtered, plus the cost of the ‘muthi’, plus presents ...”

“These three mothers said that they believe in prayer, and they will believe in everything to help the child ... and, they see the Sangoma as a link between themselves and God.”

One mother reported taking her child to a healer who used both traditional and Christian belief systems.

“Then she took the child to the Sangoma-cross-Sayoni. He is like a prophet with a Traditional-Christian dimension. He said that the child did not need to be treated for Indiki, but was a ‘gift from God’.”

The above excerpts reveal the extent of the mothers’ search for a cure for their child, and the time and costs entailed. One mother reported feeling disappointed, because she was told by the Sangoma to slaughter a goat at first the maternal, and then the paternal, home. This was time-consuming and costly (R700 for two goats), and there had been no improvement in the child. Some mothers reported feeling pressured by family members to pursue the traditional route, while some mothers reported having opted for a combination of both healing options for their children. It was apparent that the older generation continued to influence the younger generation to retain ties with traditional medicine.

Benefits of the Group

The concluding focus group evaluated the changes or shifts that had occurred during the focus group period. A number of the mothers reported feeling different, and appreciated the identification with others and a sense of mutual sharing:

“ ... she is feeling much of a difference ...”

like she has developed self-confidence to her son, after talking and sharing with other mothers about grief and the difficulties she has met Now she has got confidence of challenging even other mothers or caregivers, who are having a disabled child, about life itself, and there are many other things that you can do while having a disabled child.”

“What she is saying is that, like before, when she was at home, she used to cry and have that spirit and moaning soul of having a disabled child. Now ... after sharing the grief with other parents, she can now sit at home and say, I’m not alone. And even though she is unemployed, because of having a disabled child, that it is comforting her ... ”

Two mothers reported that, through the focus groups, they had developed friendships and support systems:

“ ... these two mothers say that, because they are living in the same area and use the same tap to fetch water, it is easy for them to meet. This mother says that when she is visiting the other mother, they get a chance to talk ... while still watching their kids.”

One mother reported “taking new steps”, while another mother reported that she had developed a sense of hope:

“She says she is also taking some new steps. From Western medicine, she is adding some little bit of traditional now.”

“She is hoping that every end of the day ... something is going to happen.”

Some mothers said that their material needs had in no way altered. Others reported being influenced by the discussions in the focus groups, with respect to pursuing new avenues for treatment, while other mothers reported remaining fixed in their treatment choices. These varied responses are shown in the following excerpts:

“ ... she has seen a lot of improvement from the programmes she got from the hospitals and the therapists and the western people.”

“She prefers the doctors ... and therapists ... because also she is seeing a lot of improvement in her child, like in terms of the child’s speech. Now her hope is on those western medical people.”

“She is marrying the concern of western medical and hospitals ... because the child does not want to drink these traditional ‘muthis’.”

Certain of the beneficial effects of the focus groups reported above were unexpected by the researcher. However, the researcher is also aware that the mothers may have become more optimistic about the benefits of ‘western’ medicine, and may subsequently be disappointed.

In summary, the findings highlight the effects of a multiply-disabled child on the life-world of the mother. The mother’s world often becomes more constrained by the child’s needs, with the mother’s time being consumed by caregiving. This has ripple effects on the mother’s capacity to seek other employment and impacts on the family income. Whilst few mothers expressed resentment about these constraints, their difficulties are compounded by a cumbersome social welfare system which leads to great difficulty in accessing grants, and a number of the mothers have limited familial support. The schooling and child-care systems also seemed inaccessible. While some mothers enjoyed community support, others reported experiences of frustration and shame in the face of family and community members’ reactions. The mothers have sought help from a variety of sources, with mixed experiences, and have also understood the aetiology of their child’s disability in varying ways.

Discussion

The experiences of the mothers were viewed in relation to their life-worlds. The mothers’ lives were deeply impacted upon by their role as caregivers. It became apparent that the multiply disabled child was an integral part of the mothers’ existence, and impacted on every facet of their lives. Despite poverty, family disintegration, unemployment, lack of resources and limited service delivery agencies, the mothers portrayed a determined caregiver role in which they pursued various treatment options for their child’s disability, and in relation to which they had adopted attitudes of acceptance. The mothers

reported experiencing pain and distress, yet they appeared to have developed their own philosophical sense of acceptance of their children’s disabilities. Whilst they faced many material and emotional challenges, along with difficult family circumstances, the mothers appeared to take a stoical approach to coping. There was little evidence of questioning, searching for a cause, or blaming others for the nature of the child’s limitations.

With regard to time in space, the mothers appeared not to be preoccupied with either a search into the past or excessive future concerns. The impact of limited material resources was reflected in the necessity to focus on daily challenges. There appeared to be little cognitive space for developing longer term planning strategies or projections for the child’s future as a disabled person who might require lifelong specialised facilities. Hope existed on a day-to-day basis of finding a cure for the child, and their expressed need for a child-care facility was primarily to facilitate paid employment. Reflections on the past were primarily rooted in cultural mores, with respect to seeking treatment or a cure. Some of this was determined by custom or through pressure from the older generation to comply with tradition. Most appeared accepting of their own explanatory constructions of the circumstances surrounding their child’s disability.

With reference to the mothers’ surrounding meso-systems, Dale (1996) argues that much depends on the community, society or ethnic group of which one is part. The mothers, being part of a peri-urban Zulu community, appeared to experience mixed and complex societal responses, ranging from acceptance and community support to feelings of alienation and being the focus of gossip. The mothers were often in a vulnerable position, apparently reliant on various family members, especially if the father did not play a supportive role. The mothers appeared to need to interact with the community and to feel that they played a functional societal role. The mothers appreciated the opportunity provided by the focus groups, feeling a growing sense of solidarity with the other mothers due to their shared experiences.

With regard to service delivery, agencies are usually situated in urban areas, which may be difficult and costly to reach. This project underlined the need for professional and group support in respect of the mothers’ concerns, and supports Gargiulo’s (2006) assertion that parents need information. The mothers in this study reported gaining beneficial support and

information from the CDRC.

Traditional and western philosophies appear to have impacted upon the mothers' lives, supporting Melato's (2000) findings. Whilst the post-apartheid era entitles these mothers to advocacy and empowerment with respect to the choices and opportunities (such as education and literacy, better educational facilities and medical intervention services) open to them, poverty, limited education and a lack of role models may hamper access. The change from a traditional collective approach to the opportunity for individual choice and an array of treatment options is a potential stressor for the mothers, insofar as it may lead to a sense of isolation and places more responsibility on the individual caregiver.

The mothers' adoption of 'living in the present' as a coping mechanism may be the result of a combination of political, cultural and socio-economic factors. By-products of the oppressive apartheid regime were restricted self-development and sense of agency, which created a sense of reliance on others (for financial, practical and emotional support) in contrast to being proactive. There also appeared to be limited searching for personal pleasure or material goods. Rather, there was a timeless sense of waiting for some or other external phenomenon to alleviate their circumstances.

The mothers appeared to have had few expectations. Their desires were to find a cure for their child's condition and to pursue various treatment options. They appeared to have coping skills that appeared to enable them to be resilient in the face of adversity. They seemed to live one day at a time, with the hope of some amelioration of their conditions, whilst simultaneously philosophically accepting their circumstances. Their prime needs seemed to be to belong to the world, earning an income, and to have self-esteem.



About the Authors

Eve Hemming has a Master's degree in Educational Psychology from the University of KwaZulu-Natal, South Africa. Currently a practising psychologist with the Ministry of Education, Special Education, in Auckland, New Zealand, she was formerly Principal of a special needs school in KwaZulu Natal, South Africa, having worked in the field of special needs education for thirty years. She recently completed her MA in Applied Drama, due to her enthusiasm for expressive arts as a form of therapeutic intervention. Eve Hemming is

Evaluation of the Study

One of the limitations of this study was the language barrier between the mothers and the researcher, leading to dependency on a translator fluent in English and isiZulu. Thus the mothers' words may have lost some of their original essence in the reporting. With the researcher being from a different ethnic group, it is possible that, despite her having attempted to 'bracket' her pre-conceived ideas and expectations, the questions asked may have revealed more than if the researcher had shared the mothers' world views.

There is an urgent need for day care facilities to be developed and funded for multiply-disabled children, so that mothers in this predicament may be freed to seek employment. This might promote a sense of self-worth for the mothers as contributors to the family's financial needs, and also lead to less isolation within their communities. It is clear that participation in the focus groups had some important benefits for the mothers, and this needs further follow-up and development.

In conclusion, this research was a challenging and thought-provoking experience of some moments of the mothers' life-worlds, with their responses revealing their ways of making meaning of their circumstances and coping in the face of adversity.

This study thus illustrates the need to first gain an understanding of people's contexts and ways of making meaning before imposing programmes informed by the providers' ideas of their needs. In this way, more appropriate and useful interventions might be implemented.

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happily married, with three children and four-going-on-five grandchildren, and has various creative and humanistic interests.



Jacqui Akhurst has a PhD in Psychotherapy from Rhodes University, South Africa. She is a Principal Lecturer in Psychology at York St John University in York, England. She was formerly a Senior Lecturer at the University of KwaZulu-Natal, South Africa, and worked extensively with trainee and in-service teachers, school counsellors and school psychologists. Dr Akhurst has published articles about the impact of apartheid on education and counselling, applications of Activity Theory, and peer group supervision. Her research interests are in the fields of community psychology, student development in higher education, career psychology, and adolescent mental health and wellbeing.

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