Article

Psychosocial Experiences of Family Caregivers of Children with Intellectual Disabilities in Alice, Eastern Cape, South Africa

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Abstract

In this study, we explored the psychosocial experiences of family caregivers of children with intellectual disabilities in the rural town of Alice in the Eastern Cape, South Africa. We intended to uncover the psychosocial well-being of family caregivers of children with intellectual disabilities. We adopted qualitative research methods. Snowball sampling was employed to recruit 15 family caregivers of children with intellectual disabilities in Alice. The age of the family caregivers ranged from 20 to 65. All the participants were black people and included both males and females. The data were collected through face-to-face semi-structured individual interviews. We analysed the data using thematic analysis. The study findings indicate that family caregivers of children with intellectual disabilities experience the caregiving process negatively in the various aspects of life. These aspects include social, personal, financial, emotional and health aspects. Also, the caregiving process carries a heavy burden. In light of the findings, we conclude that there is a need for the continuous rendering of comprehensive psychosocial support services to family caregivers of children with disabilities. It is recommended that social workers empower family caregivers of children with intellectual disabilities so that they can function effectively in their communities. Furthermore, the government needs to reinforce existing policies that support these psychosocial services.

Keywords: psychosocial; experiences; family caregivers; intellectual disability; children

Introduction

Tulachan et al. (2014) assert that worldwide the mental health of children and adolescents has not received enough care as compared to that of adults. According to the South African Children’s Act (RSA 2005), a child is any person who is under the

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age of 18 years. Ever since ancient times, children with infirmities, be they psychological or somatic, have been subjected to scorning, mockery, anxiety, demonisation, intolerance, isolation and social and economic demotion (Yeager 2011). Such practices took place all over the world (Tulachan et al. 2014). Drawing from our experience, in the past children with intellectual disabilities would be locked up by their family members who could not cope with caring for them and who were ashamed of them in public. Furthermore, according to Mendenhall and Mount (2011), scorning, isolation and anxiety adversely affect not only children with intellectual disabilities but also their family caregivers. Caregiver strain may be evident in all parts of parents' lives, including in their work, psychological and somatic health, and social and family relations.

It is in response to these psychosocial experiences that we embark on this study. The aim of the study is to explore the psychosocial experiences and well-being of family caregivers of children with intellectual disabilities in the rural town of Alice in the Eastern Cape. Following a discussion on the theoretical framework and the literature review, the methods used will be presented. This is followed by a presentation of the five themes that emerged from the analysis and the conclusions and recommendations.

Theoretical Framework

This study was underpinned by the social model of disability. This model was established by the Union of the Physically Impaired Against Segregation in 1976 to examine disability at different levels including the family environment, the community and societal relationships. The social model of disability understands disability as an experience shaped by the surroundings in which a person lives (McNair and Sanchez 2008). Action is therefore needed for social change as a fundamental intervention. The social model of disability theorises that if societal issues are dealt with, the issue of disability will not be evident, despite the fact that the impairment exists. The social model seeks to eliminate societal barriers by advocating the rights of people with disabilities in education, jobs, and access to health facilities and services (Kayama and Haight 2014). The societal barriers such as discrimination have been found to impede the progress of family caregivers and care beneficiaries when trying to access these services (McNair and Sanchez 2008). By eliminating societal barriers, caregivers would therefore be able to cope with and manage the caregiving process better; hence the use of this model.

Psychosocial Experiences of Family Caregivers

Family caregivers of intellectually disabled children encounter various issues such as caregiver burden (Suiter and Heflinger 2011), stress (Bingham 2017), feelings of loneliness (Ahmann 2013), isolation, being unappreciated and uncared for (Mendenhall and Mount 2011), anger and frustration, shame and embarrassment (Mhaule and

Ntswane-Lebang 2009), stigma and labelling (Iseselo, Kajula, and Yahya-Malima 2016), discrimination (Davis 2011), and economic factors (Friedemann-Sánchez and Griffin 2013).

Caregiver Burden

Families may experience the diagnosis of a mental condition of their child as a burden. This is often stated as caregiver strain or as objective and subjective burdens (Suiter and Heflinger 2011). A major factor of the objective burden of raising a child with a mental condition is the financial burden (Suiter and Heflinger 2011). The subjective burden, on the other hand, can be understood as the emotional pain, humiliation, and mental distress connected to caring for the family member (Hinshaw 2005). Mendenhall and Mount (2011) highlight the way in which the stress related to caregiver strain can affect numerous areas of the family caregiver's lives, including their own emotional condition, physical well-being, employment, social life, and family relationships.

Stress

Caregiving of a child living with a mental condition may be extremely stressful and time-consuming. The stress process model proposes that life events may result in unpleasant changes in caregivers' roles. As the pleasant features of self-concept of the caregiver fade, stress may occur (Raina et al. 2004). Bingham (2017) expresses that family caregivers of children with intellectual disabilities experience the caregiving process as stressful, predominantly when they also have to take care of other responsibilities such as household chores. Coetzee (2016) argues that many South African family caregivers are exposed to additional stressors that are not as common in better-resourced countries, partly owing to less structural support for caregivers and children with disabilities. Feeling overwhelmed, discouraged and displeased with their work can add to feeling stressed for some family caregivers of children with intellectual disabilities (Coetzee 2016).

Feelings of Loneliness

Family caregivers may feel incapable to relate to other parents and frequently feel alone when experiencing challenging emotions such as helplessness or devastation (Ahmann 2013). This feeling of loneliness can be exacerbated by having less time to spend with friends owing to meetings at school or other increased activities to meet their child's needs (Ahmann 2013).

Furthermore, family caregivers who are adolescent siblings of children with intellectual disabilities may experience feelings of loneliness owing to other people's preconceptions about their siblings with intellectual disabilities (Bingham 2017). In addition, in South Africa, some caregivers may feel that their caregiving role is unappreciated (Bingham 2017). Geiger (2012) shows how at certain times family caregivers needed to feel supported, nurtured and understood to be able to offer warmth and care to the children for whom they are caring.

Isolation

Family caregivers of children with intellectual disabilities face social isolation. Caring for a child with a mental condition requires a substantial amount of time from the family caregiver (Beresford, Croft, and Adshead 2007). The study by Beresford, Croft, and Adshead (2007) found that all the respondents in their sample revealed that most of their time was spent taking care of their children with disabilities. When the respondents were asked to respond to the issue of social isolation, they all said that they were now isolated from the community friends and relatives and that they no longer had time for socialising because of the time spent with their children. Friends had become few and not all relatives were supportive (Beresford, Croft, and Adshead 2007).

Anger and Frustration

Anger and frustration may also emerge as part of the emotional experiences of family caregivers. Some caregivers may feel frustrated and angry with the government for not providing the necessary support services to help them care for their family members with intellectual disabilities (Mhaule and Ntswane-Lebang 2009). Family caregivers of children with intellectual disabilities may also experience anger and frustration towards both the recipients of their care and health professionals (Sandy, Kgole, and Mavundla 2013). These family caregivers may attribute their frustration to regularly having to deal with challenging behaviours of their children with mental conditions.

Shame and Embarrassment

Some family caregivers may feel ashamed of the intellectually disabled children for whom they care (Mhaule and Ntswane-Lebang 2009). They may express feelings of embarrassment or shame. As a result, they may not talk to other people about their intellectually disabled children and at times may not attend community gatherings owing to the fear of having to talk about their intellectually disabled children (Mhaule and Ntswane-Lebang 2009). According to Ruini and Fava (2004), these family caregivers have impaired self-acceptance.

Stigma, Labelling and Marginalisation in the Community

The mental condition of a child may lead to various psychosocial issues such as diminished quality of life for their family members and greater marginalisation for the intellectually disabled child and their caregiver (Iseselo, Kajula, and Yahya-Malima 2016). The family caregivers of children with intellectual disabilities may at times voice feelings of being stigmatised since they associate themselves with children with intellectual disabilities (Iseselo, Kajula, and Yahya-Malima 2016). Taking from Lazarus' (1966) theory of stress and coping, the family caregiver may not experience stress because of caring for an intellectually disabled child, but because of the response of the family caregiver's community. Labelling and scorning by the community may lead to stress. According to Ruini and Fava (2004), these family caregivers may develop impaired positive relationships with others owing to the stigma and marginalisation.

Economic Factors

A systematic review of research conducted in the United States, Canada, and Europe suggests that caregivers with poor health are at the greatest risk of quitting the labour force, working reduced hours, and reducing their earnings (Friedemann-Sánchez and Griffin 2013). Research has discovered the economic consequences of caregiving in the Global South. One of the few studies examined the ability of working parents in Vietnam to care for their children and found that 63 per cent of parents, most of whom were women, lost their income or promotions or had difficulty retaining their jobs as a result of caregiving (Friedemann-Sánchez and Griffin 2013). These studies propose that in developing countries, the caregivers, especially women, encounter lower income, fewer resources, and more financial suffering (Friedemann-Sánchez and Griffin 2013).

Research Methodology

Research Approach

We adopted qualitative research methods to understand the psychosocial experiences of family caregivers of children with intellectual disabilities.

Research Design

An exploratory research design, which elucidated and defined the nature of the problem, was followed.

Research Paradigm

We employed the interpretive phenomenological approach as the paradigm to explore the personal meaning and lived experiences of the research participants in this study.

Population

The study population included family caregivers of children with intellectual disabilities in Alice in the Eastern Cape.

Sampling

We used snowball sampling (a non-probability strategy). For recruitment, we relied on referrals from primarily sampled participants to other people believed to be sharing the same characteristic under study. The age of the family caregivers ranged between 20 and 65 years. All the participants were black, but other demographics were different.

Demographic Profile of Research Participants

Table 1 presents the demographic profile of the 15 participants.

Table 1: Demographic profile of the participants

Pseudonym	**Age**	**Gender**	**Language**	**Marital status**	**Level of education**	**Socio-economic background**	**Type of housing**
A	55	F	X	W	NWTS	CDG	RDPH
B	40	F	X	MD	PE	CDG	SH
C	50	F	X	S	NWTS	CDG	RDPH
D	60	M	X	MD	NWTS	OAG and CDG	SH
E	35	F	X	S	PE	CDG	SH
F	55	F	X	S	PE	CDG	RDPH
G	43	M	X	S	SE	CDG	RDPH
H	43	F	X	MD	SE	CDG	RDPH
I	65	M	X	W	NWTS	CDG and OAG	RDPH
J	53	F	X	S	NWTS	JE and CDG	SH
K	65	F	X	MD	NWTS	OAG and CDG	RDPH
L	20	F	X	S	SE	CDG	RDPH
M	30	F	X	S	SE	CDG	RDPH
N	25	F	X	S	SE	CDG	RDPH
O	25	F	X	S	PE	CDG	RDPH

M: male, F: female
X: Xhosa
S: single, MD: married, W: widow or widower
NWTS: never went to school, PE: primary education, SE: secondary education, TE: tertiary education
CDG: care dependency grant, OAG: old age grant
SH: shack, RDPH: reconstruction and development programme house

Table 1 indicates that a minority of the family caregivers (3) were between the ages of 60 and 65, 6 were between the ages of 40 and 55, and a further 6 were between the ages of 20 and 35. This means that the youth were under burden of having to take care of their siblings more than the other age groups. Drawing from the work of Erikson, these participants fall in the last three developmental stages and they might experience failure in achieving their developmental tasks (Sacco 2013).

Most caregivers (12 out of 15) were females. That might stem from the fact that females are socially regarded as primary caregivers. This associates females with caregiving of children in society. Xhosa-speaking people dominate Alice and this is confirmed in that all the research participants were Xhosa speaking. The marital status of the participants varied significantly: one participant was a widow, one a widower, four were married, and the remaining nine were single. Most participants (6) have never been to school and four dropped out of primary school. Only five participants had secondary education, but they did not finish their courses. This demonstrates that the participants of this study were poorly educated and many were illiterate. All the participants come from low socio-economic backgrounds, were unemployed and relied on the care dependency grant. A few of the participants relied on both the old age grant and the care dependency grant for their upkeep. Most participants (11) lived in RDP houses, and only four lived in shacks.

Data Collection Instrument

The data were collected using face-to-face semi-structured individual interviews to gather and probe more data from the participants.

Data Analysis Technique

We analysed the data through thematic analysis, classifying and describing both hidden and obvious ideas of the research participants.

Ethics

Regarding the issue of ethics, firstly, we obtained ethical clearance from the Research Ethics Committee of the University of Fort Hare (LUP011SMMA01). We read the informed consent form to the participants and translated it into their vernacular language where necessary. The participants then gave consent to partake in the study and signed the informed consent form. Moreover, we ensured that the dignity of all the participants was respected through ensuring that they were not discredited or undermined. Similarly, we explained to them that they may withdraw their participation at any given time, should they want to do so. Likewise, confidentiality was assured, where we explained that no information would be divulged and no real names of the participants would be revealed. Lastly, we avoided any form of harm towards the participants and promoted their welfare by putting them first in the research.

Trustworthiness

We adhered to the five elements of trustworthiness, namely, credibility, dependability, transferability, confirmability and authenticity. Credibility was ensured through the triangulation of data collection methods, namely semi-structured individual interviews with 15 family caregivers and a focus group discussion with professionals dealing with mental health. However, this article only focuses on the data collected from the caregivers. Dependability was achieved through rich and detailed descriptions of the data procedure and site selection. Transferability was assured by producing detailed and rich descriptions of contexts, with the intention to give readers detailed accounts of the structures of meaning which developed in a specific context. These understandings can be transferred to new settings in other studies although they cannot be generalised owing to the small number of participants who took part in the study. As far as the confirmability is concerned, the findings of this study could be confirmed by a similar study. The use of triangulation of methods of data collection in this study assisted in reducing bias. Authenticity was ensured through inclusion of the verbatim quotes of the research participants in the findings.

Research Findings

Having discussed the demographics of the participating family caregivers, this section is dedicated to the thematic analysis of the data. Thematic analysis is one of the qualitative instruments used to analyse themes that emerged during the data collection process. Table 2 presents the themes and subthemes that emerged from the questions the researcher asked the participants. This is followed by a presentation of the findings.

Table 2: Themes and subthemes

Themes	Subthemes
Social experiences	• Labelling that is encountered by family caregivers from the community • Family caregiver's relationship with the family and the community
Financial experiences	• Financial support for living • Financial support from the family and the community at large to family caregivers • Financial support during emergencies
Personal experiences	• Experiences of the caregiving process as an individual • Life goals achievement during the caregiving process • Balance between caregiving process and personal activities
Emotional experiences	• Feelings about caregiving for a child with an intellectual disability • Bond between the family caregiver and the child with intellectual disability
Health experiences	• The well-being of the family caregivers • History of illness of the family caregivers • Measures that were taken by those who suffered the illnesses

Social Experiences

Social experiences were one of the persistent themes that emerged during the individual face-to-face interviews with the family caregivers.

Labelling Encountered by Family Caregivers from the Community

Most of the participants (13) confirmed that they were being labelled by the community. Referring to Lazarus' (1966) theory of stress and coping, the caregiver may not experience stress because of caring for a mentally challenged child, but because of the response of their community in the form of labelling and scorning. The following are their submissions with regard to the issue of labelling:

> I am said to be caring for a dumb child. (C)

> In social gatherings, I become a joke for taking care of the child. They usually state that I am not man enough. (D)

In contrast, one participant stated the following:

> Not really for me, labelling is usually posed to the child with an intellectual disability. (A)

The above excerpts are supported by Iseselo, Kajula, and Yahya-Malima (2016) who discussed the greater marginalisation and labelling of the mentally challenged child by the community. Another participant mentioned the following:

> It is just hearsays that I am dumb even myself. (B)

Family Caregiver's Relationship with the Family and the Community

The minority of participants (4) stated that they had healthy relationships with their families but not with the community. Most participants (11), however, mentioned that they did not have healthy relationships with either their family members or the community members. Two participants said the following:

> I relate a little well with the family, the big issue lies with the community members themselves as they stigmatise us. (E)

> I must concede that we do not relate well. (F)

Ruini and Fava (2004) reported that unhealthy relationships with families and communities are common among caregivers. Conversely, drawing from the theory of psychological well-being, formulating enduring and constructive relationships with others plays a pivotal role in building the communities (Hills 2015).

Financial Experiences

Financial experiences was the second theme that frequently emerged during the interviews with the caregivers.

Financial Support for Living

Most participants (11) mentioned that they lived on the disability grants of the intellectually disabled children they were caring for. Some added that they also lived on their old age grants and some on their piecework earnings. This statement is maintained by Friedemann-Sánchez and Griffin (2013) that in developing countries caregivers, especially women, encounter lower income, fewer resources, and more financial suffering. The following narratives of the participants confirm this:

> We depend to the disability grant of the child I care for as I am not working, neither getting any grant. (A)

> There is no other form of financial support except the child’s disability grant and the child support grants of my grandchildren. (C)
>
> I receive financial support from the old age grant from the government and from my granddaughter’s disability grant. (I)
>
> I depend on piece jobs and the child’s disability grant. (J)

Financial Support from the Family and the Community at Large to Family Caregivers

It appears in the following citations that neither family members nor community members financially supported the family caregivers:

> As said previously that there is no other form of financial support. Thus, it is clear that there is nothing I receive from the family and community members. (C)
>
> Family members and the community have never made any of financial support upon me. (F)

Financial Support during Emergencies

It is clear in the following responses that the participants receive financial support for emergencies in different ways, although some have never been in an emergency situation. The participants expressed the following:

> I ensure that we do not use all her disability grant on food for emergence purposes as you say. (A)
>
> I borrow money from loan sharks and pay in month end when the child has received his disability grant. (G)
>
> I borrow money from loan sharks as his disability grant is not enough. (L)
>
> I would call a public ambulance in times when there was an emergence. (N)
>
> I can say that I am lucky enough not to experience any emergence regarding the health of the child, including myself. I must submit that I have never encountered any emergency regarding the child since he was born. (H)

Personal Experiences

Personal experience is another theme that frequently emerged during the individual face-to-face interviews with the family caregivers.

Experience of Caregiving Process as an Individual

All the participants declared caregiving as a burdening process. This is confirmed by Mendenhall and Mount (2011) that the stress related to caregiver strain can affect numerous areas of the caregiver's lives, including their own emotional condition, physical well-being, employment, social life, and family relationships. For example, one participant said:

> Caregiving is the most burden I have ever experienced in my entire life, because I am old myself, yet I have to look for this child who if mentally it. (I)

Life Goals Achievement during the Caregiving Process

With regard to life goals, most participants (12) who are caregiving for intellectually disabled children seemed to have given up their life goals. The 12 participants gave sentiments similar to participant K, who said:

> My focus is no longer on achieving life goals as my attention is full towards taking care of the child.

With regard to the theory of psychological well-being by Ryff and Keyes (1995), the above denotes that the participant lacks a sense of meaning in life, has few goals or aims, lacks a sense of direction, does not see a purpose of their past life, and has no outlook or beliefs that give their life meaning. Two participants indicated the following:

> I cannot put blame on caregiving. I blame myself because I would have at least achieved them in early adulthood. (J)

> God will never let me suffer, he will give me strength to achieve my goals regardless of difficult caregiving process. (M)

Balance between Caregiving Process and Personal Activities

Regarding the manner in which the participants have to strike a balance between caregiving and their personal activities, they disclosed the following divergent comments:

> I prepare her needs first, then when she is at the day care centre it when I do my personal stuff. (A)

> It becomes really difficult for me to strike a balance because I have to take full care of the child as his mother is always in the tavern drinking alcohol. (F)

The findings demonstrate that certain caregivers are able to strike a balance, whereas others cannot cope. This statement overlaps with one of Ryff's (1989) six dimensions, which is the lack of environmental mastery. This dimension asserts that caregivers may lack a sense of control over their multiple areas. These caregivers may therefore at times require help since they are not able to savour and enjoy their daily lives, as they are too busy with family activities.

> At least I am able do my personal stuff because the child is not schooling, so sometimes he assists me with other tasks like fetching water from the tap. (H)

Emotional Experiences

Emotional experiences seemed to be one of the most persistent themes that emerged during the individual face-to-face interviews with the family caregivers.

Feelings about Caregiving for a Child with an Intellectual Disability

As far as the feelings about caregiving for children with intellectual disabilities are concerned, all the participants indicated the issue of emotional instability, for example:

> I feel burdened, because it is not an easy task to take care of an intellectually disabled child alone. (D)

This shows that caregivers of children with intellectual disabilities experience the task as a burden. Their confessions are corroborated by Suiter and Heflinger (2011) that families may experience the diagnosis of the mental condition of their child as a burden. This is often termed caregiver strain or as objective and subjective burdens.

Bond between the Family Caregiver and the Child with Intellectual Disability

With regard to the bond between the family caregiver and the child with intellectual disability, unexpectedly, all the participants gave the same remarks. One of them said:

> The caregiving process may burden me, but to tell you the truth, I love him so much. (H)

This assertion confirms what Bronfenbrenner’s ecological systems theory alluded to: that parent–child bonding is quite important in shaping and developing a child (Bronfenbrenner and Morris 1998).

Health Experiences

Health experiences were also investigated and yielded the subthemes as discussed below.

The Well-Being of the Family Caregivers

We sought to understand how the health of the family caregivers was. Five participants indicated that they are experiencing health complications. The participants expressed the following:

> I feel well with no health complications. (B)

> I am diabetic, but I am still surviving. (C)

The findings show that certain participants have to look after their ill health as well as that of the children.

History of Illness of the Family Caregivers

The data indicate that certain family caregivers once suffered from different forms of illnesses. However, some had never experienced any health-related issues. Below are the comments of some of the caregivers about this issue:

> I once suffered from tuberculosis, but it was treated. (A)
>
> It is only this diabetes, nothing else. (C)
>
> I was once diagnosed with depression, but it was treated. (F)
>
> I had never experienced any form of illness. (O)

Measures that were Taken by Those who Suffered from Illnesses

With regard to the manner in which the issue of having a history of illness was dealt with, the participants indicated the following:

> I was hospitalised in a TB hospital for six full months, and it was treated. (A)
>
> I am taking its treatment to normalise it. (C)
>
> I consulted the doctor and he gave me a prescription of antidepressants to treat my depression. Fortunately, they worked and I am now fine. (F)
>
> I have not yet overcome it. I think I need professional help. (M)

This means that some of the participants had first-hand experiences of the pain of illnesses, in addition to the suffering of the children with disabilities they take care of.

Discussion of Findings

Psychosocial Well-Being of Family Caregivers of Children with Intellectual Disabilities

The study findings revealed that in Alice, South Africa, family caregivers of children with intellectual disabilities experience impaired psychosocial well-being. This finding is corroborated by that of Folkman and Lazarus (1984) which state that caregivers may cognitively interpret psychosocial stressors along a continuum ranging from no harm to harmfully affecting their well-being. This psychosocial well-being of family caregivers includes social experiences, financial experiences, personal experiences, emotional experiences and health experiences.

Social Experiences

As far as the social experiences of the family caregivers are concerned, the study findings indicated that family caregivers experience labelling by their communities. This means that community members have little respect for human dignity and the value of the children with intellectual disabilities in society. Sandy, Kgole, and Mavundla (2013) attest to the fact that family caregivers experienced stigmatisation in their societies as a result of negative attitudes and prejudices held by family and other civic associates about children with mental conditions and their caregivers. In addition, the study findings discovered that in Alice, South Africa, family caregivers encounter labelling that originates from their community, which is unbearable. It is clear that community members disregard the caregiving process. This is confirmed in a study by Iseselo, Kajula and Yahya-Malima (2016) which reported that family caregivers of children with intellectual disabilities might at times voice feelings of being stigmatised because they associate themselves with children with intellectual disabilities.

Lastly, the study findings have shown that most of the family caregivers’ relationships with their families and the community are not healthy. Only the minority of the participants shared positive relationships with their families. This shows a lack of care by the family members and the community at large. This is confirmed by what Mhaule and Ntswane-Lebang (2009) articulate that some family caregivers would experience exclusion from their spouses or other family members.

Financial Experiences

With regard to financial support and upkeep, all the research participants depended on the care dependency grant and a few on both the care dependency grant and their own old age grant. This means that all the family caregivers come from low socio-economic backgrounds. The work by Friedemann-Sánchez and Griffin (2013) states that in developing countries, caregivers, especially women, encounter lower income, fewer resources, and more financial sufferings. With regard to those caregivers who resigned from their work to take up caregiving duties, Friedemann-Sánchez and Griffin (2013) stipulate that family caregivers who leave the labour force or offer care for more than 10 hours a week rarely re-enter paid employment at the same level. This could possibly lead them to be financially burdened in the future despite their previous status.

As far as the financial support from the family and the community at large to family caregivers is concerned, all the caregivers mentioned that there was no financial support of any kind that they received. We therefore suggest that no one from either the family or the community is willing to extend good hands to family caregivers of children with intellectual disabilities. With regard to the caregivers’ financial support during emergencies, most participants stated that they depended on the care dependency grant and some said that they had never experienced any emergency. To give some light, the South African Social Assistance Act (RSA 2004) offers the care dependency grant to parents, foster parents and other primary caregivers of children who need stable care or support services owing to psychological or somatic infirmity (Rieser 2012).

Personal Experiences

Concerning personal experiences, the research findings demonstrated that in Alice, South Africa, the family caregivers considered the caregiving process a burden. Mendenhall and Mount (2011) confirm the fact that the stress related to caregiver strain can affect numerous areas of the family caregivers' lives, including their own emotional condition, physical well-being, employment, social life, and family relationships. It is apparent that caregiving is a difficult process that needs resilience.

Secondly, concerning the life goals achievement during the caregiving process, many family caregivers reported that they had given up on life goals as they had to take care of the children with intellectual disabilities, which is a full-time job. Drawing from the work of Ryff (1989), these family caregivers lack purpose and meaning in life and will not gain personal growth.

On the other hand, a few still had hope that their God would never forsake them, but would give them strength to achieve their goals regardless of the difficult caregiving processes they were going through. Concerning striking a balance between the caregiving process and personal activities, most participants voiced that they first prepared for the daily needs of the children and then performed their own activities. Some participants expressed that they struggled to strike a balance, as they had to focus fully on children with intellectual disabilities. Only a few of the participants indicated that they did strike a balance as the children helped them with other tasks. Drawing from the theory of suicidal behaviour, some of these family caregivers may fail to overcome the burden of caregiving and behave in suicidal ways (Amitai and Apter 2012).

Emotional Experiences

With regard to emotional experiences, all the family caregivers expressed the feelings of being burdened by having to take care of the child with intellectual disability alone. The work by Mathye and Eksteen (2015) alludes to the fact that part of what worsened the caregivers' burden and fatigue is the lack of a break from their caring responsibilities. Secondly, with reference to the bond between the family caregivers and the children with intellectual disabilities, the findings indicated that all the participants share a strong bond with the children they were caring for despite the caregiving burden. This shows that kinship ties are not changed by one's condition. These findings prove what Bronfenbrenner and Morris (1998) pointed out that the kinship ties ought to be maintained to ensure the child's positive development.

Health Experiences

In relation to health experiences, the study findings indicated that in Alice, South Africa, most of the participants had health complications. Only a few of the participants indicated that they had no health complications. Out of that minority, two mentioned experiencing stress and chronic headaches. Coetzee (2016) endorses that when children have severe psychiatric diagnoses or behavioural problems, family caregivers may also experience more stress.

Limitations of the Study

The study could not explore other areas in Alice owing to the data saturation. The problem lies in the fact that a qualitative study could not be repeated as the elements of the original study cannot be repeated. Qualitative research deals with individuals and more emphasis is on explaining why they behave and think in certain ways.

Conclusion and Recommendations

It is evident that the family caregivers of children with intellectual disabilities undergo numerous psychosocial experiences they cannot cope with, ranging from caregiver burden, stress, loneliness, isolation, anger and frustration, shame and embarrassment, stigma, labelling and marginalisation in the community, to economic factors.

In light of the study findings, we recommend the following:

- Psychosocial interventions, life skills training, parental programmes, respite care services, and other systems of community support should be accessible to families with children with disabilities.
- Family caregivers should be empowered to function effectively in their environment as the Department of Social Development (2009) also stipulates.
- Professionals dealing with mental health, such as social workers, should raise awareness in the communities where labelling and discrimination are rife, with the intent to change the mentality of community members towards children with intellectual disabilities and their caregivers.
- Social workers should conduct family conferencing between the caregivers and their families, where the social workers will be emphasising the importance of unity and positive relationships between the family members so that they can live in harmony.
- Social workers should help caregivers with lower income to budget effectively for monthly expenses.
- Awareness programmes should be initiated to enable family and community members with adequate financial resources to help family caregivers who need financial support.
- Social workers should encourage caregivers to apply for the care dependency grant and to inform them about the processes to follow when doing so.

- Social workers should call for family conferences that will encompass the family caregiver who experiences the caregiving burden and the family members. In the family conference, the social worker should teach the family members about the importance of respite care so that the family caregivers can be assisted.
- Social workers and psychologists should initiate programmes aimed at caregivers in informing them about the importance of having life goals regardless of the permanent caregiving duty. Hope must be instilled into those caregivers who lost all hope.
- The Department of Education should build special schools for intellectually disabled children so that their caregivers can be relieved from the immense caregiving burden.
- Professionals dealing with mental health (for example, community psychologists and social workers) should conduct home visits to the family caregivers of intellectually disabled children, conduct situational analyses regarding the emotional experiences of caregivers and intervene when there is a need.
- Nurses should promote regular health check-ups among the family caregivers of intellectually disabled children. If, during the check-up, a family caregiver is found with health complications, proper treatment should be prescribed and an appropriate referral should be given.

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