



## Resources for resilient caregiving by parents of children with schizophrenia in Swaziland: A multiple case study

Kayi Ntinda & Siphesihle Nkwanyana

To cite this article: Kayi Ntinda & Siphesihle Nkwanyana (2017) Resources for resilient caregiving by parents of children with schizophrenia in Swaziland: A multiple case study, Journal of Psychology in Africa, 27:1, 88-92, DOI: [10.1080/14330237.2016.1268298](https://doi.org/10.1080/14330237.2016.1268298)

To link to this article: <https://doi.org/10.1080/14330237.2016.1268298>



Published online: 21 Feb 2017.



Submit your article to this journal [↗](#)



Article views: 92



View related articles [↗](#)



View Crossmark data [↗](#)

## BRIEF REPORT

### Resources for resilient caregiving by parents of children with schizophrenia in Swaziland: A multiple case study

Kayi Ntinda\* and Siphesihle Nkwanyana

*Department of Educational Foundations and Management, University of Swaziland, Kwaluseni, Swaziland*

*\*Corresponding author email: [ktinda@uniswa.sz](mailto:ktinda@uniswa.sz)*

This study reports on the care-provisioning experiences of parents ( $n = 6$ ; females = 5) raising children with schizophrenia in a rural Swazi setting. The parents were individually interviewed at their homes on caregiving aspects such as burden, coping, quality of life, expressed emotions and social support of their child with schizophrenia. Data were thematically analysed. Parent carers of children with schizophrenia reported to have personal resources for resilient caregiving such as motivation for caring, and caregiving satisfaction. They perceived compassion gains from improved quality of life for their children through the caregiving experiences. Findings suggest a need for public mental health education and provision of welfare support of parents' personal resources for resilient caregiving.

**Keywords:** schizophrenia, parent carers, caregiving, resilient, positive aspects, resources, Swaziland

#### Introduction

In most countries, the care of children with severe disabilities often falls to the parents or family of the child, and often with little government support (Freedman & Boyer, 2000; MacDonald & Callery, 2007). Neuropsychiatric disorders are estimated to contribute to 4.5% of the global burden of disease (WHO, 2011). If presented with significant mental health disorders like schizophrenia, caregiving roles may carry an intensive and significant burden, as those with the condition are predisposed to behavioural difficulties from unpredictable and disruptive psychotic episodes (Awad & Voruganti, 2008; Howard, 1998; Negota & Mashegoane, 2012). Caregiver burden is about the psychological state that arises from the combination of the physical work, and the emotional and social stress that result from taking care of the patients (Dillehay & Sandys, 1990; Jungbauer & Angermeyer, 2002). Caregiving roles may require resilience when dealing with children with major mental disorders. This study sought to explore resilient caregiving experiences among rural Swazi parents of children with schizophrenia.

In Swaziland, rural living was traditionally characterised by communal living where every adult played a role in the upbringing of the children in the community. In other words, parenting in traditional Swazi settings was communal, in that every adult was expected to contribute to parenting even if they did not have children of their own (Khumalo, 2008). However, with modernisation there has been the formation of different family types which have influenced parenting practices. For example, many families in rural settings of Swaziland are presently headed by women who are single, have been divorced or widowed (Khumalo, 2008). Therefore most women's typical roles are to provide for and take care of the family, and carry out daily domestic chores. Men are family leaders who are responsible for the overall welfare

of the family by providing for their physical and emotional needs. Men are thus role models for the children, who guide by instruction and example in a traditional rural Swazi setting. Additionally, subsistence farming is common among parents in the rural Swazi setting. Taking care of the daily needs of children is the responsibility of women, including children living with disabilities.

Living with a disability in Swaziland presents major challenges, especially for children and women. Having a disability leads to rejection and isolation from experiences or activities that are part of typical development, thus making the children more susceptible to violence and abuse (Eide & Jele, 2011). Furthermore, children living in rural areas are the most vulnerable to disablement and HIV and AIDS due to limited facilities for early detection, diagnosis and support, which in turn accelerate the degree and harshness of the disablement (Eide & Jele, 2011; Mavundla, 2015). Thwala, Ntinda, and Hlanze (2015) reported parents of children with mild disabilities in a rural area of Swaziland to experience elevated levels of stress from caregiver roles. These elevated stress levels may be associated with caregiver burden from the physical demands of the carer role and the related financial challenges. Caregiving for patients with mental disorders are mainly the responsibility of the families of the individuals with the mental disorders in most developing countries. Caring for children with schizophrenia may come with unique carer roles for parents and family (Singer, Biegel, & Ethridge, 2009; Talley & Crews, 2007).

Resilience is a positive psychological concept, emphasising human strengths that enhance mental wellness and optimal functioning, and not the weaknesses and malfunctioning (Kotze & Kleynhans, 2013; Seligman & Csikszentmihalyi, 2000). Resilience might have an explanatory value in understanding how parent carers of children with schizophrenia cope with the caregiver burden. Examining the caregiving strengths of parents

of children with severe disabilities avoids a deficit-only perspective that focuses on the family burden of care.

Most studies are about experiences of caregiving for parents of children with physical and/or cognitive disabilities, but not those caring for children with psychotic disorders. The present study explored the lived experiences of parents of children with schizophrenia and the resources they use for resilient caregiving of children with schizophrenia in a rural setting of Swaziland. The study was guided by the following research questions: 1) What are the lived experiences of parents of children with schizophrenia?; and 2) What are the resources for resilient caregiving experiences among parents of children with schizophrenia in rural Swaziland?

## Method

### Research design

A multiple case study approach (Yin, 2014) was adopted for the study because it enabled the authors to explore differences within and between cases. A multiple case study design is an empirical inquiry that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used. It was selected for this study whose goals were to determine the lived experiences of parents of children with schizophrenia and the resources they use for resilient caregiving of children with schizophrenia in rural Swaziland.

### Participants and setting

Parents caring for children with schizophrenia were recruited through a non-probability technique called snowballing. Snowballing involved having a parent caring for a child with schizophrenia interested in participating in the study recommending another parent who would be interested in taking part in the study until a sample of six parents was reached.

The six parents (females = 5) raising children with schizophrenia in a rural setting in Swaziland fell into the age range 46 to 56 years (see Table 1). All the participant parents were the children's biological parents. Most mothers were single and unemployed. There were five children living with schizophrenia. The average age of the schizophrenic children was 16. The average age at the time of diagnosis was approximately 8 years. There were two female children living with schizophrenia in the sample.

### Procedure

Permission to conduct the research was granted by the Swaziland Ministry of Health and Social Welfare. The parent carer of children with schizophrenia individually consented to the study. The parents were informed of the aim and procedures of the study. They were also informed of the option to withdraw if they wished to do so, without penalty. Data were de-identified and no individual names were used to identify participants to ensure anonymity.

### Data collection

The parents reported their demographics (age, marital status, age of child when first diagnosed, child's age). They responded to individual interviews on the resilient aspects of caring for their sick children in the following domains: burden of care, coping, quality of life, expressed emotions and social support of their child with schizophrenia. Interviews were conducted in SiSwati, the first language of the participants, by a trained research assistant. Interviews were tape recorded. Audio recordings were transcribed and translated into English using forward the translation procedure (ASDE, 2009). Each interview lasted approximately 45 minutes.

### Ensuring study trustworthiness

Credibility and trustworthiness of the data were established through "member checks" (Guba & Lincoln, 2005), or by going back to participants to clarify the accuracy of responses to questions by domains of caregiving such as burden of care, coping, quality of life, expressed emotions and social support of the child with schizophrenia. The member checks enabled any discrepancies of meaning from the language translation to be resolved.

### Data analysis

Data were thematically analysed using the procedure suggested by Babbie (2007). The method involves reading through the data (answers to open-ended questions and transcriptions of the interviews) several times to deduce overall sense, underlying meanings and patterns of relationship (Babbie, 2007; Schurink, Fouche, & De Vos, 2011). These patterns translated into themes from the data.

### Findings and discussion

The themes that emerged from data were: 1) motivation for caring for the children with schizophrenia; 2) caregiving satisfaction; 3) improved quality of life for the children

**Table 1.** Participant parents demographic characteristics

Participant's identification	Parent's age	Parent's sex	Marital sex	Employment status	Child's age	Child's sex	Age of child when first diagnosed with condition
#1	46	Female	Single	Unemployed	21	Female	10
#2	52	Male	Married	Security guard	19	Female	8
#3	42	Female	Widowed	Unemployed	12	Male	6
#4	56	Female	Single	Unemployed	20	Male	8
#5	45	Female	Single	Teacher	16	Male	9
#6	50	Female	Married	Unemployed	19	Female	8

Note. Participating parents were Swazis (Africans), and the biological parents of the children living with schizophrenia

with schizophrenia; 4) parents need for greater social support resources; and 5) need for information resources and education on schizophrenia, including behaviour management. These are considered next.

### **Theme 1: Motivation for caring for the children with schizophrenia**

Most of the parents (4; 67%) reported that schizophrenia improved the relationship with their children. They spoke about how positive their children were and this gave them the energy to go on. This is what one parent had to say:

*She becomes happier when I am closer or next to her and pays attention to what I have to say and I also do the same to her utterances; this makes me care even more* (Participant #1, mother, 46 years old, single, unemployed).

The finding of this study suggests motivation for caring for a child with schizophrenia is a positive aspect despite the adjustment needed for caring. This finding seems to be in agreement with findings by Halterman and Montes (2007) who reported that mothers of children with schizophrenia were motivated and able to cope as well as mothers of children free from the psychiatric illness.

### **Theme 2: Caregiving satisfaction**

Some parents (3; 50%) reported a sense of satisfaction in caregiving even though they explained the violence and aggression as the worst aspects of caring for a schizophrenic child. Participant mothers described a sense of satisfaction in caregiving as they were actively involved in the child's life. The following are illustrative statements from some of the parents regarding caregiving satisfaction.

*I think I feel good, happy and sleep at night even though I have a big job of taking care of my mother who is over 90 plus. I have a daughter to think about. I am very happy to be taking care of my daughter* (Participant #6, mother, 50 years old, married, unemployed).

*It is the will of God that I have a daughter like this. I can't treat her different from my other children. I am so grateful that I can take care of her now. But I worry what will become of her when I die. Will her brothers and sisters take care of her? I don't know if they will manage like I do especially that we have no money to buy many things we need* (Participant #1, mother, 46 years old, single, unemployed).

This seems not to be in support of the findings by Howard (1998), and Negota and Mashegoane (2012) that impoverished situations of participants brought about feelings of despair and isolation for mothers who cared for their severely disabled children at home. However, parents would have concerns about the future of their children in their physical absence with mortality or other causes.

### **Theme 3: Improved quality of life for the children with schizophrenia**

All participant mothers (5; 83%) in this study reported improved quality of life for their children due to their caregiving. They experienced improved relationship

quality with their children in terms of family and friendship. For example, participants observed:

*Even though I lost my job due to the child illness there was no one to take care of her. I am happy that I can spend time with her and this makes her happy and we are closer now* (Participant #1, mother, 46 years old, single, unemployed).

*I spend a lot of time with my son. I am not working but I have enough time to look after him, give food and arrange for his bathing something I feel is good for him and he does not appear dirty and uncared for* (Participant #4, mother, 56 year old, single, unemployed).

The carer mothers reported to sacrifice their free time and professional life to take care of their children.

*Looking after my son is very important to me. I had to leave my job when I could not get anyone to help me with looking after him. Even my own relatives refused, but I do not regret leaving the job, even though things are difficult, now we eat, we are managing* (Participant #3, mother, 42 years old, widowed, unemployed).

The burden of care is linked to reduced quality of life and can negatively influence the health and functioning of caregivers (Cummins, 2001; Jungbauer & Angermeyer, 2002; Singh & Prajapati, 2012; Wai-chi Chan, 2012). Although stress from caregiving is likely even with external support (Bloch, Szmukler, Herrman, Benson, & Colussa, 1995; Cassidy & O'Callaghan, 2001; Thara, Kamath, & Kumar, 2003), it was not overwhelming to these Swazi mothers. Their compassionate care and concern was a major personal resource as caregivers.

In Swaziland, the Ministry of Health and Social Welfare oversees all disability issues, including those of children. The Ministry has a national disability unit that is responsible for disability issues in the country. The purpose of the unit is to promote significant improvements in the quality of life for persons with disabilities across the country (MoHSW, 2000). The Federation Organization of People with Disabilities [FODSWA] is a national mother body for people with disabilities in Swaziland established in 1993 (Lang, 2008). The Parents of Children with Disabilities in Swaziland [PCDSWA] is an affiliate member of FODSWA which aims at promoting the dignity and rights of children with disabilities. The major limitations of disability organisations in Swaziland include lack of organisational capacity, which limits functionality, and lack of funding to promote the organisation's agenda.

### **Theme 4: Carer parent need for greater social support resources**

Most participant parents (3; 50%) reported a need for social support and indicated that they received no emotional and financial support from significant others such as spouses, family members, close relative or friends. Below are example statements from participant parents:

*I have no relatives to help us. They don't even want to see us close to them at all, but they are there. They just changed when I give birth to this child as our*

*relationship was fine before (Participant #5, mother, 45 years old, single, employed).*

*I am not home with our daughter because I am working, but my wife is there to take care of her. Our relatives they do not want to even come close saying we are with a bad spirit which can go to them (Participant #2, 52 years old, father, married, employed).*

The carer parent need for increased social support from family and friends is consistent with the findings by Negota and Mashegoane (2012). Furthermore, there is evidence to link lack of social support to psychological strain on caregivers (Feinstein, Melnyk, Moldenhouer, & Small, 2001; Gona, Mung'ala-Odera, Newton, & Hartley, 2010; Schofield, 1998; Thwala, Ntinda, & Hlanze, 2015). In rural Swazi communities, there is an expectation for care assistance by extended family, which might mitigate the burden of care of the primary parent care provider.

#### **Theme 5: Need for information resources and education on schizophrenia, including behaviour management**

Participants in the study indicated the need for information resources such as knowledge on managing the condition, including the distressing symptoms and behaviour. The following are illustrative statements from the parents.

*At first when this sickness started I didn't know what it was and what helped me was when I took him to the hospital. I don't know when it will come but now I have the experience even though I still need more information on how to handle it (Participant #5, mother, 45 years old, single, employed).*

*When these attacks happen he is usually with a lot of strength and I cannot hold him alone. One time he broke the door of the house during an attack. I wish I knew what to do about this this sickness. So far there seems to be no answer (Participant #4, mother, 56 years old, single, unemployed).*

They feared being harmed by their children during acute aggressiveness phase of the illness. Participant parents were not able to cope with stress and anxiety related to their new caregiving roles, handling unpredictable aggression and disruptive behaviour by their child charges.

*All I can say is that you have to always make sure that he is in a safe place because it can come any time. I sometimes worry for if he grabs me during the attack because of the power he has and he hurts me at times (Participant #3, mother, 42 year old, widowed, unemployed).*

These needs for information support are consistent with those reported by previous studies (Jones, 1996; Maurin & Boyd, 1990; Negota & Mashegoane, 2012). Mental health services in Swaziland are generally managed by nurses. The National Psychiatric Centre is exclusively committed to mental health (WHO, 2011). Additionally, two general hospitals have functional psychiatric units and capacity to admit severely affected mental health patients (WHO, 2011). Mental health is a component of the primary health care system. Actual treatment of severe mental disorders

is not available at the primary level. It is unclear what parent education on psychiatric illness these public health facilities provide.

#### **Limitations and conclusion**

The study was exploratory in nature and the findings as reported are at best tentative. Future studies should sample a larger number of rural parents to determine the extent to which the findings from this study could be replicated.

In conclusion, the findings of the present study suggest parent carers of children with schizophrenia to have personal resources for resilient caregiving, including motivation for care and caregiving satisfaction. Parents perceived to need social support and poverty effects alleviation. They expressed a need for information resources and education on the children's condition, including behaviour management. Parents with a positive attitude to caregiving seemed to report a higher quality of life for them and their children.

#### **References**

- Africa Scholarship Development Enterprise (ASDE). (2009). *Development of a framework for implementation of tests in Ministry of Education and Skills Development*. Botswana: Africa Scholarship Development Enterprise.
- Awad, A. G., & Voruganti, L. N. P. (2008). The burden of schizophrenia on caregivers: A review. *Pharmacoeconomics*, 26(2), 149–162. <http://dx.doi.org/10.2165/00019053-200826020-00005>.
- Babbie, E. (2007). *The Practice of Social Research* (11<sup>th</sup> edn). Belmont: Thomson/Wadsworth.
- Bloch, S., Szmukler, G., Herrman, H., Benson, A., & Colussa, S. (1995). Counseling caregivers of relatives with schizophrenia: Themes, interventions, and caveats. *Family Process*, 34(4), 413–425. <http://dx.doi.org/10.1111/j.1545-5300.1995.00413.x>.
- Cassidy, E., & O'Callaghan, H. (2001). Efficacy of psycho-educational intervention in improving relatives' knowledge about schizophrenia and reducing rehospitalisation. *European Psychiatry*, 16(8), 446–450. [http://dx.doi.org/10.1016/S0924-9338\(01\)00605-8](http://dx.doi.org/10.1016/S0924-9338(01)00605-8).
- Cummins, R. A. (2001). The subjective well-being of people caring for a family member with a severe disability at home. *Journal of Intellectual & Developmental Disability*, 26(1), 83–100. <http://dx.doi.org/10.1080/13668250020032787>.
- Dillehay, R., & Sandys, M. (1990). Caregivers for Alzheimer's patients: What we are learning from research. *International Journal of Aging & Human Development*, 30(4), 263–285. <http://dx.doi.org/10.2190/2P3J-A9AH-HHF4-00RG>.
- Eide, A. H., & Jeje, B. (2011). *Living conditions among people with disabilities in Swaziland. A national, representative study*. SINTEF A 20047. Oslo: SINTEF Technology & Society.
- Feinstein, N. F., Melnyk, B. M., Moldenhouer, Z., & Small, L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing*, 27, 547–557.
- Freedman, R. I., & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health & Social Work*, 25(1), 59–68. <http://dx.doi.org/10.1093/hsw/25.1.59>.
- Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2010). Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience? *Child: Care, Health and Development*, 37(2), 175–183. <http://dx.doi.org/10.1111/j.1365-2214.2010.01124.x>.

- Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions and emerging confluences. In N. K. Denzin & Y. S. Lincoln (eds), *The Sage Handbook of Qualitative Research* (3rd edn, pp. 1–32). Thousand Oaks: Sage.
- Halterman, J. S., & Montes, G. (2007). Psychological functioning and coping among mothers of children with schizophrenia: A population based study. *Journal of the American Academy of Pediatrics*, *119*, 1040–1049.
- Howard, P. (1998). The experience of father of adult children with schizophrenia. *Issues in Mental Health Nursing*, *19*, 339–413.
- Jones, S. (1996). The association between objective and subjective caregiver burden. *Archives of Psychiatric Nursing*, *10*(2), 77–84. [http://dx.doi.org/10.1016/S0883-9417\(96\)80070-7](http://dx.doi.org/10.1016/S0883-9417(96)80070-7).
- Jungbauer, J., & Angermeyer, M. (2002). Living with a schizophrenic patient: A comparative study of burden as it affects parents and spouses. *Psychiatry*, *65*(2), 110–123. <http://dx.doi.org/10.1521/psyc.65.2.110.19930>.
- Khumalo, T. F. (2008). Parenting and parenthood in Swaziland. In T. Maundeni, L. Lopez Levers, & G. Jacques (eds), *Changing Family Systems: A global perspective* (pp. 127–145). Gaborone, Botswana: Bay Publishing (Pty) Ltd.
- Kotze, M., & Kleynhans, R. (2013). Psychological well-being and resilience as predictors of first year students academic performance. *Journal of Psychology in Africa*, *23*(1), 51–60.
- Lang, R. (2008). *Disability policy audit in Namibia, Swaziland, Malawi and Mozambique: Final report*. London: Leonard Cheshire Disability and Inclusive Development Centre: University College London.
- MacDonald, H., & Callery, P. (2007). Parenting children requiring complex care: A journey through time. *Child Care, Health and Development* *34*(2), 207–213.
- Maurin, J. T., & Boyd, C. B. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing*, *4*(2), 99–107. [http://dx.doi.org/10.1016/0883-9417\(90\)90016-E](http://dx.doi.org/10.1016/0883-9417(90)90016-E).
- Mavundla, S. D. (2015) *Country report: Swaziland – African Disability Rights Yearbook 3*, 245–264. <http://dx.doi.org/10.17159/2413-7138/2015/v3n1a11>.
- Ministry of Health and Social Welfare [MoHSW]. (2000). *Disability profile: Swaziland*. Government of Swaziland, Mbabane: Ministry of Health and Social Welfare.
- Negota, A. J., & Mashegoane, S. (2012). Mothering children with schizophrenia in a village setting: A multiple case study. *Journal of Psychology in Africa*, *22*(2), 259–262.
- Schofield, H. (1998). *Family caregivers: Disability, illness and aging*. St Leonard, New South Wales: Allen & Unwin.
- Schurink, W., Fouche, C. B., & De Vos, A. S. (2011). Qualitative data analysis and interpretation. In A. S. De Vos, H. Strydom, C. B. Fouche, & C. S. L. Delpoit (eds), *Research at grass root: For the social sciences and human services profession* (4<sup>th</sup> edn) (pp. 397–423). Pretoria: Van Schaik.
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *The American Psychologist*, *55*(1), 5–14. <http://dx.doi.org/10.1037/0003-066X.55.1.5>.
- Singer, G. H., Biegel, D. E., & Ethridge, B. L. (2009). Toward a cross disability view of family support for caregiving families. *Journal of Family Social Work*, *12*(2), 97–118. <http://dx.doi.org/10.1080/10522150902874859>.
- Singh, P. M., & Prajapati A. (2012). Burden of schizophrenia on caregivers in Nepal. *Nepal Medical College Journal*, *15*(4), 140–143.
- Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health*, *97*(2), 224–228. <http://dx.doi.org/10.2105/AJPH.2004.059337>.
- Thara, R., Kamath, S., & Kumar, S. (2003). Women with schizophrenia and broken marriages – doubly disadvantaged? Part II: Family perspective. *The International Journal of Social Psychiatry*, *49*(3), 233–240. <http://dx.doi.org/10.1177/00207640030493009>.
- Thwala, S. K., Ntinda, K., & Hlanze, B. (2015). Lived experiences of parents' of children with disabilities in Swaziland. *Journal of Education and Training Studies*, *3*(4), 206–215. <http://dx.doi.org/10.11114/jets.v3i4.902>.
- Wai-chi Chan S. (2011). Global perspective of burden of family caregivers for persons with schizophrenia. *Archives of Psychiatric Nursing*, *25*(5), 339–349.
- World Health Organization [WHO]. (2011). *Mental Health Atlas*. Department of Mental Health and Substance Abuse, Geneva: WHO.
- Yin, R. K. (2014). *Case study research: Design and methods* (5<sup>th</sup> edn). Thousand Oaks: Sage. Publications.