



Vulnerable Children and Youth Studies

An International Interdisciplinary Journal for Research, Policy and Care

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/rvch20>

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Melinda S. Kavanaugh , Franclo Henning & Andre Mochan

To cite this article: Melinda S. Kavanaugh , Franclo Henning & Andre Mochan (2020): Young carers and ALS/MND: exploratory data from families in South Africa, Vulnerable Children and Youth Studies

To link to this article: <https://doi.org/10.1080/17450128.2020.1837409>



Published online: 21 Oct 2020.



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Young carers and ALS/MND: exploratory data from families in South Africa

Melinda S. Kavanaugh^a, Franco Henning^b and Andre Mochan^c

^aSocial Work, Helen Bader School of Social Welfare, University of Wisconsin-Milwaukee, Milwaukee, WI, USA; ^bConsultant Neurologist and Lecturer, Division of Neurology, Department of Medicine, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town, South Africa; ^cNeurosciences, University of the Witwatersrand, Johannesburg, South Africa

ABSTRACT

Amyotrophic lateral sclerosis/motor neuron disease (ALS/MND) remains under-resourced across much of the world, including the global south. The lack of supports for ALS/MND is underscored, given the barriers to care, stigma associated, and need for intensive, 24-hour care, primarily provided by family, including vulnerable children and youth, 'young carers'. With little information of the care experience in ALS/MND in South Africa, this study sought to explore family characteristics and identify caregiving experiences and need of young carers in families living with ALS/MND.

Using an exploratory mixed-methods approach, participants (N = 40) from 20 families, were recruited from the two ALS/MND clinics in Cape Town and Johannesburg areas. Separate audiotaped interviews with adults living with ALS, adult caregivers and young carers were conducted.

Young carers, both genders, ages 9–19, provided care up to 50 or more hours per week, including administering medications, toileting, and feeding the person with ALS/MND, with the majority reporting no training. Stigma, fear and lack of knowledge about ALS/MND limited how families discussed both ALS/MND and care provided by young carers. Families highlighted transportation barriers, and inconsistent access to care across regions. Parents identified emotional support, and in-home help to alleviate the burden of care on youth, acknowledging reliance on young carers due to cost of care. Young carers identified the need for education and people their age to talk to about ALS/MND.

Results highlight the complex needs and interaction among families living with ALS/MND in South Africa. Data support the development of targeted support and education programs to address the need for culturally relevant interventions for families and their young carers living with ALS/MND.

ARTICLE HISTORY

Received 27 May 2020
Accepted 9 October 2020

KEYWORDS

young carer; family caregiver; ALS/MND

Background

The burden of care for non-communicable, neurological disorders is steadily increasing in low to middle-income countries (LMICs), yet remain under-resourced compared to

communicable disorders (Chin & Vora, 2014). Limited resources create a heavy burden for patients and caregivers, including those providing care for amyotrophic lateral sclerosis/motor neuron disease (ALS/MND). An isolating, stigmatizing, and debilitating disorder, ALS/MND requires intensive, 24-hour care, primarily provided by family (Chio et al., 2013; Williams et al., 2008). The already-intense burden of care might be further exacerbated in LMICs, which have fewer resources to provide accessible clinical care and address caregiver needs. Of particular interest is South Africa, an LMIC country with *fewer than 200 neurologists and only three dedicated clinics for MND*. Incidence of ALS in South Africa is approximately 1.09/100 000, with a median age of onset of 59.4 years (Henning et al., 2020), in line with the global incidence of ALS which ranges from 0.6 and 3.8 per 100 000 (Longinetti & Fang, 2019). Yet, little is known about the overall burden of ALS/MND in South Africa, specifically, the burden felt by family caregivers, many of whom may rely on children and youth for care.

Young carers

Across disorders worldwide, both male and female children and youth ‘young carers’, typically under age 19, provide the same extensive caregiving as adults such as bathing, feeding, and toileting (Leu & Becker, 2017). Young carers struggle with attending and performing well in school (Cluver et al., 2012; Siskowski, 2006), managing depressive symptoms (Cohen et al., 2012), and relating to and receiving support from non-caregiving youth (Kavanaugh et al., 2015). In South Africa, given the extensive epidemic, young carer research primarily focuses on families living with HIV/AIDS (Cluver et al., 2012; Robson et al., 2006). This research has brought much needed attention to the effects of care on young carer education, social isolation and stigma/shame associated with being a young carer in families with HIV/AIDS (Cluver et al., 2012; Lane et al., 2015). Yet, how care experiences in ALS/MND differ from those of HIV/AIDS young carers in South Africa is unclear. Given the substantial impact and family burden of living with ALS/MND (Schepelmann et al., 2010), identifying the experiences of young carers and needs of the person with ALS is critical to the development of family support programs in South Africa. This project used a mixed-methods approach to broadly explore 1) family characteristics and communication about living with ALS/MND in South Africa, and 2) describe the challenges and needs of young carers in families with ALS/MND.

Methods

Study sample

Adults with ALS/MND

Patients diagnosed with ALS/MND, over the age of 18, and living in or near the greater Cape Town or Johannesburg areas were eligible to participate. All races and ethnicities were eligible for inclusion, and all attempts were made to include families of diverse cultural and socioeconomic backgrounds. Study eligibility criteria included: 1) Adult diagnosed with ALS and over the age of 18, and 2) have a youth between the ages of 8–19 in the family who helps with care and who agrees to participate. If the person with ALS/MND wanted to participate, but could not complete the adult interview alone due to loss

of function, the patient's spouse or adult in the family assisted, with the person with ALS/MND present and engaged. All adults with ALS had an adult family member present who assisted in the interview. Adult participants provided verbal consent and verbal parental consent for youth under age 18, and youth under 18 provided verbal assent.

Young carers

Young carers were defined as a child/youth between the ages of 8–19, any gender, providing some measure of care to a family member living with ALS/MND. The study was governed by the IRB at the PI institution.

Data collection

Recruitment

Prior to interviews, clinic staff contacted patients who were thought to have a child or youth in the family. If patients agreed to participate, interviews were conducted either at the participant's home or during their clinic visit during a two-week interview period. All interviews included consent and youth assent, conducted in person, audiotaped, and professionally transcribed for accuracy. Adult and youth interviews took place at the same time and location – but in separate rooms. Interviews were semi-structured, lasting approximately 30–45 minutes. All interviews were conducted in English or Afrikaans. Yet, no participants were excluded due to language barriers.

Measures

Demographics

Age in years, any gender, level of education for both the youth and the adult with ALS/MND, income in South African Rand, presence of insurance, access to ALS/MND providers, and access to MND care with the MND Association.

Caregiving

The Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) (Joseph et al., 2009) was utilized to assess the caregiving duties and how often each was performed by the young carer in the past month ($\text{Alpha} = .78$).

School

Questions assessed using six items drawn from the U.S. national survey of young carers, evaluating how often school is interrupted by asking questions about missed homework, missed classes, tardiness, and loss of school-related social activities ($\text{Alpha} = .81$).

Qualitative analysis

Adult open-ended questions: 1) have they talked about ALS/MND and caregiving with their youth (if no, why not), and 2) what type of support they thought would be helpful for their young carers. Youth were also asked 1) what type of support would be helpful, and 2) what they knew about ALS/MND. An inductive analysis was adopted to identify themes, using the actual words of the participants. Given the lack of any data in this area,

the analysis did not rely on pre-existing coding scheme. Quotes were used to describe data at a semantic level, rather than at a latent level, given the desire to identify the participants 'explicit meanings' (Braun & Clark, 2006) of their responses, and not to interpret their underlying meanings.

Quantitative analysis

Descriptive statistics, T-tests, and ANOVAs were run to describe the sample and assess potential gender differences among young carers.

Results

Family demographics

Twenty families participated in the study, equally divided between the Cape Town and Johannesburg areas. Adults with ALS, as shown in Table 1, ranged in age from 30–56, and were predominately male ($n = 18$). Participants self-identified as black ($n = 5$), colored ($n = 10$), and white ($n = 4$), were largely low income (less than R50 000 (rand) per year), and diagnosed less than 4 years earlier ($n = 16$). As shown in Table 2, youth participants ranged in age from 9–19, almost equal male ($n = 11$) and female ($n = 9$). The majority had been caring for less than a year ($n = 11$). Young carers provided care up to 50 or more hours per week. No significant gender differences were identified in the type of care task, underscoring the broad engagement among all youth. The overwhelming majority of youth in both identified genders considered themselves caregivers ($n = 16$). The majority reported no caregiving training ($n = 13$).

Caregiving tasks

Shown in Table 3, youth keep their family member company ($n = 18$), help their family member dress ($n = 15$), administer medications ($n = 14$), and assist with toileting ($n = 10$), and transferring ($n = 13$).

School issues

As shown in Table 4, youth struggled to concentrate in class ($n = 13$), were frequently absent from school due to caregiving ($n = 7$), and were often unable to do their school-work due to care ($n = 7$).

Access to care

Participants almost equally reported receiving ($n = 9$; 45%) and not receiving ($n = 11$) care from the MND Association, with the majority of those not receiving care from the Gauteng (which includes Johannesburg) province ($n = 9$). Barriers to care included the lack of own transport ($n = 7$), car not wheelchair accessible ($n = 4$), inability to pay for a taxi or rental car that can accommodate a wheelchair ($n = 3$), and the inability to be moved ($n = 4$).

Family communication about ALS/MND

Over half of the adult participants stated that they had discussed ALS/MND with their youth ($n = 11$). Those who had not talked about it described the desire to not 'concern',

Table 1. Descriptive characteristics of persons with ALS

	N (%)
<i>Patient Variables</i>	
Age	
30–35	1
36–40	2
41–45	6
46–50	6
51–55	1
56 +	4
Gender	
Female	2
Male	18
Race/ethnicity	
Black	5
White	4
Colored	10
Other	1
Income	
Less than R50 000	12
51 000–100 000	1
More than 100 000	7
Length of time diagnosed with ALS/MND	
0–1 years	6
2–4 years	10
4–6 years	2
6+ years	2
Receive care from MND Association	
Yes	9
No	11
Care received from MNDA	
Durable equipment	8
Technology	1
Visits from care coordinator	6
Calls from care coordinator	7
Newsletter	5
Those not receiving care from MNDA – Care needs identified	
Medications	4
Equipment	3
Transportation	7
Financial support	4
Basic information about MND	5
Exercises	3
Seen in ALS/MND clinic	
Yes	9
No	10
Barriers to access care in MND clinic	
No car	7
Could not be moved	4
Taxi will not hold chair	4
No money for gas	2
Care from Hospice	
Yes	3
No	17
How pay for care	
Medical aid	6
Disability grant	3
Family provides money	4
Out of pocket	3
Not charged	3

Table 2. Descriptive characteristics of young carers

	N (%)
<i>Youth Variables</i>	
Age	
9–12	5 (25%)
13–15	8 (40%)
16–19	7 (35%)
Gender	
Female	9 (45%)
Male	11 (55%)
Person with ALS	
Mother	2 (10%)
Father	16 (80%)
Grandfather	2 (10%)
Race/ethnicity	
Black	5 (25%)
White	4 (20%)
Colored	10 (50%)
Other	1 (5%)
Length of time caregiving duties (in years)	
0–1 years	11 (55%)
2–4 years	8 (40%)
5 + years	1 (5%)
Hours per week care for parent	
1–10	1 (5%)
11–20	3 (15%)
21–30	5 (25%)
31–40	4 (20%)
41–50	4 (20%)
More than 50	3 (15%)
Consider self caregiver	
Yes	16 (80%)
No	4 (20%)
Consider self primary caregiver	
Yes	6 (30%)
No	14 (70%)
How much responsibility do you have?	
A lot	6 (30%)
Some	11 (55%)
Almost none	3 (15%)
Ever receive training or guidance in care tasks	
Yes	7 (35%)
No	13 (65%)

‘worry’ or ‘scare’ their youth with details ($n = 6$), while others assumed the youth would ‘not understand’ ($n = 3$) it regardless.

When adults were asked if they talked about caregiving, almost half stated that they had discussed care with their youth ($n = 11$), in the words of a father, to make sure his daughter ‘was ok while doing care’. Those who had not talked about care ($n = 9$) stated that they often avoided it to ‘keep things normal’, or in the words of one father, ‘[care] is just what to do as a family, you take care of each other. Why talk about it?’ The majority stated that they relied on youth for care because they are unable to pay for other or outside care ($n = 13$).

Need for youth support

Parent view

The majority of parents ($n = 12$) wanted some form of emotional support and acknowledgement for their children, specifically around being a caregiver. Exemplary quotes from

Table 3. Caregiving tasks performed by young carers

Task	N	%
Grocery shopping	15	75
Cook meals by yourself	9	45
Help parent with appearance	15	75
Help parent undress/dress	15	75
Help parent eat	12	60
Help administer medications	14	70
Help parent toilet	10	50
Help parent bathe	7	35
Help to wipe mouth or with drooling	12	60
Assist with respiratory equipment	2	10
Interpret, sign or other communication	7	35
Help with range of rotation or therapy	11	55
Keep parent company	18	90
Help parent walk	13	65
Help parent transfer	13	65
Help parent write	9	45
Help parent make phone calls	14	70
Talk to doctor for parent	6	30
Work part-time	3	15
Pay household bills	1	5
Take care of siblings	13	65

fathers highlight this, stating, *'I want them to feel like people care about them, and not only me'*, while another father said, *'they need time with friends who know us, but she doesn't have it'*. Additionally, many parents (N = 12) saw a need for caregiving assistance, with one mother saying she wanted someone to *'help [her daughter] with the actual care so she can be a child'* while another parent highlighted the need for assistance for both the child and himself, saying *'I want someone to show them how to lift me, so he don't hurt us both'*.

Youth view

Youth participants clearly want support. When asked, they preferred in-person programs (n = 11) over online support (n = 6). Few participants indicated a desire for an overnight retreat (n = 5), out of concern as to who will care for their family member with ALS/MND in their absence. When asked if they wanted more people their age to talk to about ALS/MND, almost all (n = 18) stated that they wanted it, but did not have it as exemplified by one 13-year-old female who said *'no one I know understands what this does to me'*.

Information about care and ALS/MND

The majority of young carers stated that they did not have enough information about ALS/MND but wanted more information (n = 17). This information included specific information on how the disease progressed (N = 11), what were specific symptoms (n = 9) and how the care would change over time (n = 7).

Discussion

Living with ALS/MND is complicated, requiring time, communication, and support for all family members. Yet many of the families in this study had few supports or access to the care they needed. Data from this study showed access to care is hampered by transportation barriers and the ability of families to lift, move, and transport their loved one, a point that cannot be underscored enough given the clear reliance on children and youth to engage in care, in a deeply engaged way. As reflected in data from across the globe (Leu & Becker, 2017), young carers in this study are engaged in a variety of care tasks, including those typically assumed to be the purview of adults, such as medication management, bathing, and toileting. A critical finding is the fact that both identified genders engaged in care tasks, with males participating in care traditionally thought to be the purview of females (bathing, toileting and dressing). These results, while small, identify the potential for less gendered care ethic in young carers, as opposed to adult caregiving where females have long been identified as the primary caregiver, regardless of country.

Youth in this study received little training in the often complicated care they provide. Additionally, these youths have limited information about ALS/MND, progression, and symptoms, potentially stymieing their ability to process and develop skills as the disease progresses – particularly critical for a fast-moving disease like ALS/MND. For young carers, confidence improves when they are provided training and skills by professionals who understand the disease and its progression (Kavanaugh et al., 2019; 2020). Moreover, developing skills and having access to professional resources also offers a unique opportunity to engage the parents who are struggling with how to discuss the disease and care with their child.

The data further highlight additional needs for these youths, those of 'like' peers. Youth in this study have few peers who understand their experience, leaving them socially isolated at a time when they likely need the most support, and may struggle with being 'othered' or left out of activities with peers or school. Previous research in South Africa found students in families with illness struggled with school attendance (Gray et al., 2006), with those specifically caring for a family member with HIV/AIDS missing school, or dropping out of school to provide care (Cluver et al., 2012). While similar impacts have also been described in the U.S. (Siskowski, 2006), the potential clearly exists for more impactful outcomes in South Africa, given the developing nature of many communities still recovering from decades-long lack of access to schools. Adding care tasks to the existent struggle for adequate education may further separate groups of youth who may be starting out behind others, due to care responsibilities.

Results of this study highlight clear avenues for support, guided by young caregivers themselves, and mirrored by their family members. Perhaps most important are the needs for in-person support and education, as opposed to a preference for online support found in young carers in the U.S. (Kavanaugh et al., 2015). In the development of programming, it is critical to offer it in conjunction with respite care for the adults, alleviating the young carer's fear of leaving their loved one at home alone. Young carers in this study provide necessary care and are aware of the important role they fulfill. Thus, stepping away from that care to attend a support session, regardless of how impactful it may be for them, may not be an option without replacement care for the person with

ALS/MND. The identification of this need underscores how strongly these youths not only identify as caregivers, but place the needs of their family member over their own. Thus, any services must be developed and administered not only with the constant engagement of the families and youth, but also in a way that reflects and respects the perspective and views of the family regarding care roles and expectations. Young carer programs targeting youth living with and caregiving for adults with HIV/AIDS in South Africa have existed for years, providing youth engaged education and support in the community. Adding young carers in ALS/MND to the South African young carer data, strengthens the case that youth are engaged in care across disorders and need education, skills and support programs regardless of the disease affecting their family, including programs to help families talk about disease. Data from the adult participants highlighted that they often did not talk about ALS/MND out of fear or concern for their youth. In a country where little is known about ALS/MND, the fast progression and total disability may engender that fear, but also lead to stigma and shame in these families, only further increasing isolation and lack of care. The results of which may point to a broader discussion of how illness is perceived in communities and across cultures, and how families may benefit from culturally relevant support, provided with engagement by the community, for all members of the family.

Study limitations

This study provides initial data on families living with ALS/MND in South Africa. Given the small convenience sample, results should not be seen as generalizable across all those living with ALS/MND. Indeed, this study was a pilot to assess initial data on a very underserved and unknown population. Due to access and transportation, the study team was not able to reach more isolated and rural areas, thus limiting the sample to families known to the two clinics in Cape Town and Johannesburg, or the MND Association. How families who did not participate in the study or who live in more rural areas may differ from those who participated is unknown and will be further explored in future studies. Additionally, all interviews were available in English and Afrikaans, but none of the other nine official languages in South Africa. While no families who participated asked for another language, it is unknown how many may be living with ALS/MND, and speak any of the other languages.

Implications

With limited funds, it can be difficult to provide care and support for all families living with ALS/MND. However, this study provides a compelling case to develop targeted family support and education programs, inclusive of adults and youth, which can be delivered in the community to address the need for culturally relevant interventions for families and their young carers. The reliance of families on children and youth as caregivers should not immediately be viewed in a negative light, but rather as a way families adapt to lack of access and care. Moreover, the reliance on youth is also a sign of the need for support for the family as a whole. Professionals who engage with families should ask about youth who provide care, in order to provide critical family level support, improving the well-being of not just the person with ALS/MND, but also those who provide daily care.

Disclosure statement

Dr. Kavanaugh declares that she has no conflict of interest. Dr. Henning declares that he has no conflict of interest. Dr. Mochan declares that he has no conflict of interest.

Funding

This work was supported by the International Alliance of ALS/MND Associations.

ORCID

Franco Henning  <http://orcid.org/0000-0002-4006-8101>

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