

The potential burden experienced by South African caregivers of children with severe intellectual disability



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Background: Physical, financial, social and emotional demands placed on caregivers caring for their children with severe intellectual disabilities (CWSID) could lead to high levels of burden.

Aim: This study aimed to evaluate the potential level of burden experienced by South African caregivers and aimed to identify possible contributing risk factors for increased levels of caregiver burden.

Setting: Online and community parent support groups.

Methods: This quantitative survey design study utilised data from 218 South African caregivers of CWSID. Both descriptive and inferential statistics were used for analysis. Family is the main support for 67% of participants.

Results: Moderate to severe levels of caregiver burden were reported. No definite links between potentially contributing demographic risk factors and the overall level of caregiver burden were found. Caregivers of CWSID need to receive the required support from an early stage in the child's diagnosis to decrease potential caregiver burden and improve quality of life (QoL).

Conclusion: Implications on intervention and prevention practices could inform the creation and implementation of a protocol to avert increased caregiver burden. Future research could be conducted to determine the implications of intervention towards CWSID and their family to decrease caregiver burden.

Contribution: The study provided insight into the burden experienced by caregivers of CWSID. This is in line with the journal as it further proves how vulnerable CWSID are and the support they should be receiving from professionals.

Keywords: Burden Scale for Family Caregivers (BSFC); caregiver burden; parent support; severe intellectual disability; quality of life; survey.

Introduction

Children with severe intellectual disabilities (CWSID) require extensive support throughout their life span (Beadle-Brown et al. 2019). Typically, this level of support falls solely on the primary caregivers of CWSID. These primary caregivers may experience burden because of the continuous support of their children's physical, financial and emotional needs (Rathee et al. 2019). This high incidence of support in caring for their CWSID may negatively impact caregivers upholding a balanced lifestyle (Gallego et al. 2017). An unbalanced lifestyle may cause continuous high levels of stress and increased burden on caregivers that might harmfully influence the quality of care they provide to their CWSID (Hou et al. 2017). It was reported by Grau et al. (2015) that increased stress and burden was observed in caregivers who chronically care for individuals with disabilities.

High stress levels and continuous demands on caregivers to support their CWSID could lead to depressive tendencies, such as increased anxiety and decreased quality of life (QoL) (Javalkar et al. 2017). The latter proves to be more prevalent among caregivers of CWSID (Crnic et al. 2017). In a study carried out by Peng et al. (2022) it was found that burden was increased in caregivers of CWSID leading to higher stress levels on multiple levels of daily functioning. Burden does not only impact caregivers on an emotional level but also on an economic or financial level leading to

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further levels of increased stress (Netemeyer et al. 2018). In the framework developed by Abidin (1995), caregiver-related stress is indicative of dysfunctionality within the child-caregiver system, particularly the caregiver's functionality (Woodman et al. 2016). Abidin's framework embraces facets of personality and pathology, including the caregivers' subjective feelings regarding their parental investment and confidence. To ensure caregivers' well-being, healthcare practitioners should, prior to intervention, recognise the potential impact that the environment may have on caregivers, and subsequently, their CWSID (Garris & Weber 2018). The impact of stress and burden on caregivers of CWSID shows that caregivers are influenced on multiple levels and that all these areas should be observed when assessing the full impact of burden (Garris & Weber 2018). Thus, burden could influence the caregiver's overall QoL (Cohen et al. 2015). The World Health Organization Quality of Life (WHOQOL) Scale assesses multiple areas including physical health, psychological health and level of independence and is a valuable scale to utilise to determine the impact of burden on the caregiver (World Health Organization [WHO] 2012).

Previously, to guarantee well-being, emphasis was placed on addressing the disorder using the medical model (Kahonde et al. 2018). However, this notion is no longer widely accepted as many healthcare practitioners realised that well-being and resilience could rather be associated with positive changes within healthcare services (Crnic et al. 2017). Recent research has supported the use of the social model as an approach to intervention and led practitioners to value the importance of including the family as a unit into intervention in order to holistically aid the child's development and well-being (Schlebusch et al. 2017).

Bronfenbrenner's (2005) bio-ecological systems theory incorporates the child's environment and all facets of their daily life and suggests that the child's development is dependent on the relationship between all systems involved. It was found in a study by Mkabile et al. (2021) that caregivers of CWSID experience high levels of stress that influence not only on one facet but on multiple levels of daily living, such as cultural and religious levels, emotional levels as well as economical levels. Thus, when looking at the child's development, the inborn characteristics of the child, their caregiver, as well as the influence of the environment should be taken into consideration in intervention (Bennett et al. 2017). The well-being and development of the family unit could thus be influenced by any change or instability within one or more of these systems (Van der Mark et al. 2017).

A transdisciplinary therapeutic approach to intervention is required to address the overall well-being of CWSID and their caregivers (Patel et al. 2018). It is evident that caregivers of CWSID require extended support to ensure overall well-being (Modula 2022). In a low and middle-income country (LMIC) like South Africa, therapeutic services are costly (Gallego et al. 2017) and may not be readily accessible (Capri et al. 2018; Modula 2022). There still seems to be inconsistency concerning the accessibility of services, the income of middle-class people and the disadvantaged

majority in South Africa (McKenzie et al. 2013). In South Africa majority of families currently still live without accessible specialised services (Modula 2022). Persons with severe intellectual disabilities in South Africa echo this inequality as vulnerable and disregarded community members (Simplican 2019) who are neglected by healthcare practitioners and the community (Modula 2022).

To improve this inequity among this community, families of CWSID may face challenges or be unable to receive adequate support services (Sabella & Suchan 2019). Subsequently, the lack of services could lead to increased caregiver burden (Ng & Rhodes 2018).

In an attempt to address the direct or indirect influence of the various systems on the child's well-being, healthcare practitioners moved from a client-centred to a family-centred intervention approach (Anaby & Pozniak 2019). Within the family-centred approach, the caregivers receive support from healthcare practitioners to improve their care for their child with a disability (Cross 2018). In other words, to obtain unity and wellness within the family unit, the aim of intervention when working with caregivers of CWSID should include addressing the potential level of burden caregivers may experience as well as stress management (Woodman et al. 2016).

In a recent research conducted in LMICs, namely Malawi (Masulani-Mwale, Kauye & Gladstone 2018) and Ethiopia (Tekola et al. 2022), the authors confirmed that caregivers face daily challenges such as poverty, crime, lack of emotional and social support and the absence of adequate service provision. The studies by Modula (2022) and Makombe et al. (2019) confirmed that South African caregivers have similar experiences as their Malawian and Ethiopian counterparts, but with further complexities, such as multilingualism and multiculturalism. In another study performed by Mkabile et al. (2021), it found that caregivers of CWSID experience exacerbated levels of stress in their daily lives including severe sadness, financial difficulties and social isolation. These additional complexities could further challenge caregivers to access suitable support services that could exacerbate the level of caregiver burden (Sabella & Suchan 2019). What remains to be determined is the potential risk factors that could lead to increased levels of caregiver burden. Therefore, this study firstly aimed to ascertain the potential level of caregiver burden of South African caregivers with CWSID to enable healthcare practitioners to acknowledge caregiver burden by taking it into consideration during intervention planning. Secondly, the study intended to determine potential demographic risk factors that could increase further burden experienced by caregivers. It is hypothesised that South African caregivers of CWSID experience high levels of burden because of caring for their children.

Method

This study employed a quantitative survey design (Creswell et al. 2017). The benefits of choosing this design include that the findings are objective, which eliminates the possibility of bias (Creswell & Creswell 2018). The study design also provided complete anonymity for all participants.

Data collection procedure

The data collection procedure comprised two separate parts. Firstly, the questionnaire was contextualised to ensure reliability and validity and secondly, the questionnaire was applied. Upon ethics approval (HUM026/1019) and permission from the relevant authorities, participants were recruited from caregiver support online platforms for South African parents and one community parent support group in Gauteng, South Africa. The community support groups' administrators contacted caregivers via email to determine if they were interested in participating. The questionnaire was distributed online and in hard copy and in both cases, the participants gave informed consent before completing the survey.

Participants

The aim was to recruit at least 200 South African caregivers of CWSID through community or online support groups, which is, according to Leedy and Ormrod (2015), an appropriate sample size for a survey design. Criteria for caregivers to participate included that they had to be:

- of South African nationality or reside in South Africa during the time of data collection (February 2020 – May 2020), as the aim of the study was to present the potential level of burden experienced by South African caregivers;
- raising and caring for at least one child with severe intellectual disabilities who received a diagnosis from a paediatric neurologist or clinical or educational psychologist that correlates with the diagnostic criteria of The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V);
- literate in English or isiZulu, as the questions posed required reading in one of the said languages.

A total of 218 caregivers who met the inclusion criteria participated in the study. These participants represented all nine provinces of South Africa. Most of them (58%; $n = 125$) resided in Gauteng province with only one (0.5%; $n = 1$) participant being from the Free State province. Refer to Table 1 for more detail regarding the biographical information of participants.

Materials and equipment

Caregivers were provided with either paper-based (i.e. for caregivers affiliated to community support group) or electronic copies (i.e. for caregivers affiliated to online support group) of the letters of informed consent and the questionnaires. These documents were available in two official South African languages, namely English and isiZulu. English is the most common language of learning (Stoffelsma 2019), and isiZulu is spoken by 25% of the South African population. It was found that the greater population of the African language speaking population also speaks isiZulu (Statistics South Africa 2018). The isiZulu questionnaire was translated from the English version using a vigorous blind-back translation method to ensure the questions' reliability remains intact.

TABLE 1: Biographical information of participants ($N = 218$).

Demographic characteristic	<i>N</i>	%
Age ($N = 216$)		
< 20	1	0.5
21–30	17	7.9
31–40	97	44.9
41–50	65	30.1
51–60	26	12.0
> 60	10	4.6
Qualification ($N = 218$)		
Gr 12 (NCS)	76	34.9
Diploma	52	23.9
Bachelor's Degree	34	15.6
Other	40	18.3
None	16	7.3
Financial support (grant) ($N = 214$)		
Yes	91	42.5
No	123	57.5
Monthly income ($N = 205$)		
< R10 000	77	37.6
R10 000–R20 000	56	27.3
R20 000–R40 000	42	20.5
> R40 000	30	14.6
Number of dependents ($N = 216$)		
One child	68	31.5
Two children	80	37.0
Three children	47	21.8
Four children	12	5.6
Five or more than five children	9	4.2
Number of dependents with special needs ($N = 211$)		
With special needs	110	52.1
Without special needs	101	47.9
Province of origin ($N = 217$)		
Gauteng	125	57.6
Limpopo	3	1.4
Western Cape	31	14.3
Eastern Cape	13	6.0
Northern Cape	2	0.9
North-West	9	4.1
Mpumalanga	9	4.1
KwaZulu-Natal	24	11.1
Free State	1	0.5

NCS, National Curriculum Statement.

The questionnaire consisted of two sections: Section A aimed to gather demographic information of caregivers as well as the current level of support they are receiving; Section B focused on the Burden Scale for Family Caregivers (BSFC) to elicit the possible level of burden experienced by caregivers (Graessel et al. 2014; Grau et al. 2015). The BSFC is an assessment evaluating subjective burden among caregivers (Grau et al. 2015). It consists of 28 closed-ended questions that provide the participant with a four-point Likert scale (0 = strongly disagree, 1 = disagree, 2 = agree, 3 = strongly agree). This scale evaluated the level of caregiver burden experienced by participants. Refer to Appendix 1 for the questionnaire.

Quality criteria

The quality criteria, reliability and validity, of the instrument are considered first before the data analysis section, as the instrument has to be shown to be reliable and valid before it can be applied in practice. Later, in the Data analysis section,

it is explained that an exploratory factor analysis (EFA) was conducted to explore the underlying factor structure of the instrument and in the Results section, it is shown that five factors were extracted; however, here, we only consider the fact that there were five factors extracted, which are used to establish construct validity and internal reliability.

Validation of material

An expert panel, consisting of seven experts knowledgeable on severe intellectual disabilities (SID), were asked to validate the questionnaire's content. This was carried out for two reasons: firstly, to establish content validity and, secondly to ensure that the questionnaire was culturally appropriate for South African caregivers of CWSID. The years of experience of the expert panel ranges from 5 to 15 years working with CWSID either as a speech therapist ($n = 2$), a medical doctor ($n = 1$), a psychiatrist ($n = 2$) or an occupational therapist ($n = 2$). Their qualifications ranged from a medical (MBCbB) degree ($n = 1$), a bachelor's degree in occupational therapy ($n = 2$), a master's degree in speech-language therapy ($n = 1$), a master's degree in augmentative and alternative communication ($n = 1$) and master's degrees in psychology ($n = 2$). One recommendation from the expert panel was to add a question that specifically asks what support systems are available to caregivers and, accordingly, this question was added to the questionnaire and analysed.

Construct validity was established by establishing convergent and divergent validity. Convergent validity involves that items belonging to the same factor correlate more strongly than items belonging to different factors; these correlations are referred to as within-factor correlations. On the other hand, discriminant validity involves that items belonging to different factors correlate less strongly than items belonging to the same factor; these correlations are referred to as cross-factor correlations. For conciseness, not all correlations are shown as it produced a 27×27 matrix (see Table 2 for the number of items extracted during the EFA); however, items belonging to the same factor correlated more strongly than items belonging to different factors, establishing construct validity.

Reliability of material

Cronbach's alpha coefficients were run to establish internal reliability of the questionnaire (see Table 2) and a value above 0.7 indicates good internal consistency (Bonett & Wright 2015).

Table 2 shows that although the Cronbach's alpha coefficients for Factor 1, Factor 2 and Factor 3 are above 0.7, the Cronbach's

TABLE 2: Cronbach's alpha coefficients for the five factors extracted from the exploratory factor analysis.

Factor	Cronbach's alpha coefficient	Number of items
1. Personal strain on the caregiver	0.900	11
2. Inter- and intra-personal implications of care	0.778	4
3. Capabilities of caregiver	0.730	6
4. Perceptions of caregiver towards care and CWSID's expectation	0.649	4
5. Sacrificing QoL of caregiver	0.537	2

CWSID, children with severe intellectual disabilities; QoL, quality of life.

alpha coefficients of 0.649 (Factor 4) and 0.537 (Factor 5) are below 0.7, which is not acceptable (Field 2018). Following the recommendation of Briggs and Cheek (1986) for assessing the internal consistency when there are few items, the inter-item correlations between the items of Factor 4 and Factor 5 were checked, respectively. All correlations between the items were between 0.2 and 0.4, which suggests that the internal consistency is reasonable (Briggs & Cheek 1986). In conclusion, the BSFC questionnaire is reliable within a South African context, except for one question (Question 8) where it is recommended that further investigation be performed as to why this question does not work within a South African context. Overall, as the BSFC questionnaire showed reliability, the BSFC score was calculated using the steps provided by Grau et al. (2015).

To ensure external reliability, a pilot study was conducted, recruiting 10 South African caregivers who met the selection criteria to complete the questionnaire and provide feedback regarding the accuracy of the questions. All participants reported that they were satisfied with the content of the questionnaire and that it seems to be of worth for caregivers to address their daily challenges and needs. As such, no changes were made to any questions after the pilot study.

Data analysis

The Statistical Package for Social Sciences (SPSS) v 26 was used for all statistical analyses. An EFA, using a principal component analysis (PCA) with Varimax (with Kaiser Normalisation), was conducted to explore the underlying factor structure of the instrument.

The Shapiro-Wilk test was used to detect differences from normality (Field 2018) and because this p -value is less than 0.05, the BSFC score differs from normality and, accordingly, non-parametric tests were used. To determine whether there is a significant association in the BSFC score in terms of demographic information (e.g. age, qualification level, income level), various inferential statistics were computed depending on the type of demographic variable; the Kruskal-Wallis (KW) test, Spearman correlation and Point-biserial correlation were used.

Ethical considerations

No data collection commenced before ethics approval, from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria (HUM026/1019). All participants were informed about the purpose of the study and that they may exit the study at any time without any negative consequences. Anonymity and confidentiality could be ensured as the researchers did not meet any participant face-to-face and any identifiable information was removed.

Results

Factor extraction

An EFA, using a PCA with Varimax (with Kaiser Normalisation), was conducted to explore the underlying

factor structure of the instrument. To determine if collected data were suitable for conducting an EFA, the Bartlett's test of sphericity and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) were applied (Field 2018). Both assessments yielded evidence that dimension reduction could be conducted (KMO = 0.913; *p*-value for Bartlett's test < 0.001) and that data were suited for EFA (Hutcheson & Sofroniou 1999). After investigating the eigenvalues, six factors were extracted (see Table 3); however, the last factor only had one item loading significantly onto it (Question 8: 'Away from the caring situation I can switch off'), and this factor was dropped as it is not desirable to have a factor with only one item. Following this, an investigation was carried out to check whether Question 8 couldn't be placed with another factor; however, as it didn't load significantly onto any of the remaining factors, the item was dropped. The highest factor loadings in Table 3 are indicated in bold, and where the factor loadings were negative, the items were reverse-scored before the results of the statistical analyses were conducted.

Next, the sub-scales were considered. As the Likert-scale items were coded as 0 = strongly disagree, 1 = disagree, 2 = agree, 3 = strongly agree, a score lower than 1.5 indicates that the respondents were in disagreement with the statements, whereas a score above 1.5 indicates they tended to be in agreement with the statements. For Factor 1, the mean (*M*) equalled 1.95 with a standard deviation (*SD*) 0.59 and because the mean is above 1.5, the respondents were in agreement

that they took personal strain as caregivers. For Factor 2, *M* = 1.83 and *SD* = 0.70 and since the mean is above 1.5, respondents were in agreement that there were inter- and intra-personal implications of care. For Factor 3, *M* = 1.87 and *SD* = 0.51, indicating that the respondents felt that they were in agreement they were capable as caregivers. For Factor 4, *M* = 0.79 and *SD* = 0.56, showing levels of disagreement with statements such as they feel that they are being forced into the caregiving situation. Finally, for Factor 5, *M* = 2.02 and *SD* = 0.68, indicating that respondents in agreement that they are sacrificing a great deal of the QoL being a caregiver.

Possible risk factors

Non-parametric tests were used to identify whether there are significant associations between the BSFC score and the demographic factors to determine possible risk factors. The demographic variable, level of education, is treated as a nominal variable (and not ordinal) as 40 respondents answered 'other', which could not be ordered. Accordingly, the KW test was used to explore differences between nominal categories, and it showed no significant differences (KW = 5.382, *p*-value = 0.250) in the BSFC score for the different categories of qualification. Table 4 displays the correlation between the demographic factors (which are binary, ordinal and continuous) and the BSFC score caregiver burden. As seen from Table 4, the *p*-values are greater than 0.05; therefore, results from this study indicated no significant correlations

TABLE 3: Results from the exploratory factor analysis.

Item	Factor loading					
	1	2	3	4	5	6
BSFC10: Sometimes I don't really feel like "myself" as before.	0.759	0.171	-0.041	0.143	0.127	-0.047
BSFC24: I feel I should take a break.	0.749	0.313	-0.111	0.111	-0.181	0.128
BSFC3: I often feel physically exhausted.	0.706	-0.088	-0.115	-0.124	0.305	-0.016
BSFC20: The care takes a lot of my own strength.	0.685	0.328	0.116	0.149	0.238	-0.084
BSFC4: From time to time, I wish I could "run away" from the situation I am in.	0.657	0.255	-0.295	0.104	0.089	0.196
BSFC18: I have had to give up future plans because of the care.	0.606	0.339	-0.059	-0.065	0.299	-0.200
BSFC16: My health is affected by the care situation.	0.597	0.216	-0.215	0.235	0.119	-0.210
BSFC6: I have enough time for my own needs and interests.	-0.585	-0.116	0.357	0.271	-0.050	0.182
BSFC21: I feel torn between the demands of my environment (such as family) and the demands of the care.	0.571	0.507	-0.053	0.184	0.155	0.007
BSFC1: I feel fresh and rested in the morning.	-0.518	-0.006	0.331	-0.001	-0.078	0.428
BSFC5: I miss being able to talk with others about the care.	0.510	0.254	-0.211	-0.089	0.294	0.188
BSFC26: My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care.	0.327	0.705	-0.211	0.112	0.187	-0.036
BSFC23: I have problems with other family members due to the care.	0.142	0.696	-0.059	0.174	0.247	-0.008
BSFC27: I feel sad because of the fate of the person I am caring for.	0.401	0.562	0.005	-0.129	0.014	-0.112
BSFC25: I am worried about my future because of the care I give.	0.468	0.544	-0.179	0.000	0.165	0.004
BSFC15: I feel I have a handle on the care situation.	-0.213	-0.016	0.663	-0.194	-0.295	0.050
BSFC28: I can take care of other daily obligations to my satisfaction in addition to the caregiving.	-0.349	0.011	0.654	-0.024	-0.174	0.120
BSFC17: I am still capable of feeling really joyful.	-0.336	-0.067	0.628	-0.108	0.030	-0.133
BSFC19: It doesn't bother me if outsiders are aware of the sick person's situation.	0.203	-0.257	0.534	-0.307	0.053	-0.060
BSFC11: The care I give is acknowledged by others.	0.041	-0.453	0.502	0.053	0.252	0.217
BSFC9: It's easy for me providing the necessary nursing care (washing, feeding etc).	-0.243	-0.128	0.478	-0.203	-0.249	0.280
BSFC7: Sometimes I feel that the person I am caring for is using me.	0.055	0.055	-0.134	0.767	0.131	0.185
BSFC14: The wishes of the person I am caring for are reasonable in my opinion.	-0.020	0.081	0.125	-0.753	0.171	0.213
BSFC13: I feel like being forced into this caregiving situation.	0.340	0.234	-0.122	0.595	0.137	0.136
BSFC22: I feel I have a good relationship with the person I am caring for.	0.198	-0.098	0.408	-0.420	0.049	-0.179
BSFC12: Since I have been a caregiver my financial situation has decreased	0.164	0.261	-0.083	-0.005	0.721	-0.109
BSFC2: My life satisfaction has suffered because of the care.	0.445	0.187	-0.169	0.045	0.574	0.064
BSFC8: Away from the caring situation I can switch off.	0.018	-0.089	0.007	0.105	-0.031	0.767

BSFC, Burden Scale for Family Caregivers.

Note: The highest factor loadings are indicated in bold, and where the factor loadings were negative, the items were reverse-scored before the results of the statistical analyses were conducted.

TABLE 4: Correlation between BSFC score and each of the demographic factors.

Demographic factor	N	Correlation	p-value
Age of participant	216	-0.069	0.315
Number of children	216	-0.063	0.359
Participant's annual income	205	0.093	0.184
Number of children with special needs	211	-0.055	0.429
Participants is a grant recipient	214	0.022	0.749

BSFC, Burden Scale for Family Caregivers.

between the level of burden and the demographic variables as possible risk factors.

Discussion

This study aimed to determine the level of caregiver burden experienced by caregivers of CWSID and it was hypothesised that there would be no statistically significant correlation between the BSFC score and the demographic variable under consideration. It further aimed to identify any possible demographic risk factors that might influence the level of caregiver burden. The results obtained during the study will be discussed according to these aims of the study.

Caregiver burden

At least 76% of the study participants experienced high levels of caregiver burden due to caring for their CWSID. Caregivers' QoL may potentially be influenced by the level of caregiver burden (Cohen et al. 2015; Crnic et al. 2017) and could cause caregivers to experience depressive tendencies, and decreased QoL (Javalkar et al. 2017). As mentioned, caregivers of CWSID experiences increased burden to those caring for typically developing children as CWSID depend primarily on their caregivers for extensive support – financially, emotionally and physically (Cohen et al. 2015). Therefore, the researcher used the WHOQOL and compared the aspects of the WHOQOL with the factors found in the study. The WHOQOL evaluates the following areas: psychological health, physical health, environment, social relations, level of independence and personal beliefs (WHO 2012). Bronfenbrenners' bio-ecological systems theory can be linked to the WHOQOL as the latter identifies areas of concern, and the bio-ecological systems theory identifies on which level or in which area the caregivers receive support (Bronfenbrenner 2005). When focusing on the bio-ecological system theory, high levels of stress in the microsystem may not influence higher levels within the bio-ecological systems, but lack of support from the exosystem could lead to further stress experienced by the caregiver (Purnima & Frongillo 2018). This finding is supported by a study in the United States of America, that found that caregivers of CWSID experience burden in a multitude of areas, such as emotional burden, financial burden, social burden and physical burden (Cohen et al. 2015).

Research suggests that the amount and quality of social and emotional support that caregivers receive could lead to lower levels of depressive tendencies and mental health issues, and may even reduce the caregiver's risk for mental health difficulties (Carlson & Miller 2017). The levels of burden experienced do not only affect the caregiver's mental health

but also their physical health as research has found that these caregivers are more likely to experience a variety of chronic health conditions (Lee et al. 2017).

Possible contributing risk factors

Apart from only describing the possible burden – both physically and mentally – that caring for CWSID has on the caregiver, this study also aimed to determine any possible contributing factors considering the caregiver's demographic factors. These likely impacting factors could be any combination of lack of financial stability, support structure, number of dependants or the caregiver's age that could influence the financial, emotional, social and health conditions of the caregiver as identified by the demographic questionnaire (McKenzie et al. 2013). The current study focused on the demographic factors the caregivers face on a daily basis. Included amongst these factors, social support was assessed since social and emotional support is critical for stress management and well-being of the caregivers (Nguyen et al. 2019). Apart from social and emotional support, the caregiver's financial support was identified as another potential risk factor for increased burden. This was identified as previous studies also indicated that perceived financial well-being is a predictor of overall well-being (Netemeyer et al. 2018).

Families of CWSID endure extensive financial strain because of the multitude of service needs required by these children (Modula 2022; Saunders et al. 2015). Financial burden may be because of caregivers who have to abandon their career to care for their CWSID and are, as a result, at risk of unemployment (Chou et al. 2018). Financial challenges could potentially be exacerbated by caring for CWSID without receiving a social or disability grant, as reported by 58% ($n = 123$) of the caregivers. This is also reflected in Statistics South Africa as it was found in July 2020 that 54% of South African people receive a social or disability grant (South African Social Security Agency [SASSA] 2020). Nonetheless, Modula (2022) found in her study that, although South African caregivers indicated their need for financial support (such as a social or disability grant), they were of the opinion that these grants were inadequate in meeting the basic financial needs of the families.

This study confirmed that caregivers of CWSID experience high levels of burden because of caring for their children. Not only do they experience financial burden but caregiver participants also experience burden in multiple areas of life that could influence their overall well-being and QoL (Javalkar et al. 2017; Mkabile et al. 2021). Similar trends were observed in international literature. For example, in a study performed by Thomas et al. (2018) in India, also a LMIC, it was found that the caregivers experienced emotional burden as well as an overall decreased QoL because of their financial burdens.

Bio-ecological systems theory

Participants in this study confirmed that their main social and emotional support was from family and friends. This links with Bronfenbrenner's ecological systems theory, where

the caregiver's support is found primarily in the microsystem and mesosystem (Bronfenbrenner 2005). Caregivers reported that they are not receiving professional support to aid the level of caregiver burden they experience. This lack of professional support was also confirmed by Modula's (2022) study who found that caregivers of CWSID felt unsupported and neglected by professionals (including teachers and healthcare professionals).

Research within South Africa posits that there is limited evidence-based protocol and practices for the intervention of CWSID (Courtade et al. 2015). This study aimed to identify possible risk factors by assessing these demographic factors in order to address intervention better. It should be noticed that no statistically significant associations were found between the demographic factors and the level of burden experienced by caregivers of CWSID. According to Abidin's framework (1995), the caregiver's subjective feelings regarding their parental confidence and investment should be considered. Healthcare practitioners should thus realise the impact of migrating from the medical to a social model while dealing with caregivers of CWSIDs and should acknowledge the overall well-being and QoL of the caregiver (Anaby & Pozniak 2019). Therefore, healthcare practitioners need to work as a transdisciplinary team and not in silos when providing intervention to CWSIDs and their family (Okoh et al. 2020). The input from the transdisciplinary team could potentially have a positive impact on caregivers when all team members recognise the role of caregivers within this collaborative team. Parents know their children's needs and could provide the team with useful information needed to provide the best intervention for their children (Piotrowska et al. 2017). By including caregivers within the decision-making of the intervention goals, healthcare practitioners may also be able to better understand the caregivers' level of burden as well as to identify any potential contributing biographical risk factors (Guralnick 2017).

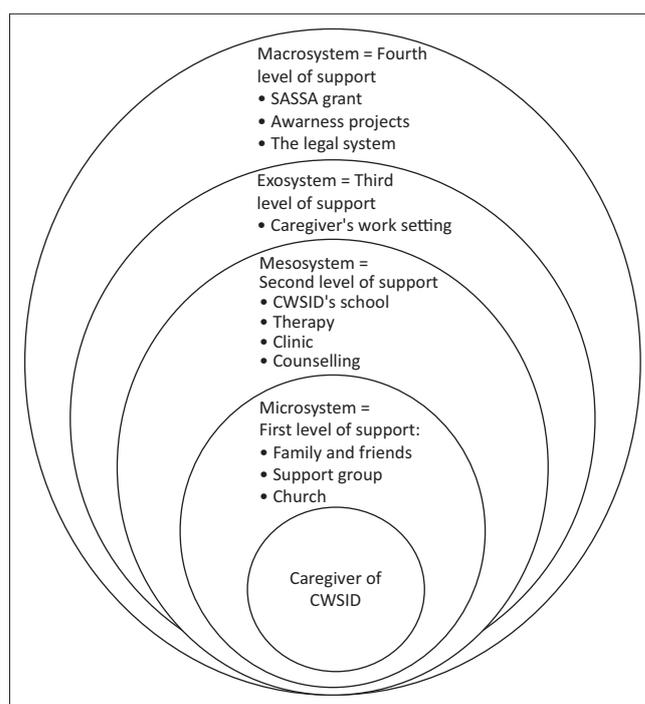
The study at hand further emphasises that caregivers of CWSID experience limited to no professional support. This needs to be addressed during intervention. To ensure optimum well-being for caregivers, support should be provided to them on multiple areas – including financial, social and emotional support (Lindo et al. 2016). Social support positively influences well-being and health and is an important part of caregiver support (Doty & Dworkin 2014). As a result of similar results found in the study in hand, existing intervention practices should be re-evaluated to improve the current procedures in an attempt to ensure decreased caregiver burden. Thus, it would be beneficial to early identify potential risk areas to increase the possibility of decreasing or even preventing caregiver burden experienced (Spencer & Harpalani 2020).

When focusing on the South African context, multiple areas could further influence burden experienced by caregivers of CWSID. For example, when applying Bronfenbrenner's bioecological systems theory (Figure 1) with the caregiver as focus of intervention, multiple systems could be

considered (Crnic et al. 2017). The microsystem (e.g. friends and family, support groups and the church community) directly influence the caregivers' ability to care for their CWSID, as well as their QoL as confirmed by this study.

The next level (mesosystem) could include the school that CWSID attend, the therapy provided by healthcare practitioners, the clinic and possible counsellors. At this level, healthcare practitioners focus on the needs of the CWSID but provide less direct support towards the caregiver themselves (Vlot-van Anrooij et al. 2020). Based on the results of this study, it is recommended that healthcare practitioners should also support caregivers of CWSID to reduce caregivers' experienced level of burden. A more hands-on approach providing caregivers with some strategies on how to care for their CWSID and themselves, should be considered.

The last three levels of Bronfenbrenner's bioecological systems theory include the exosystem, macrosystem and chronosystem (Bronfenbrenner 2005). Within the exosystem and macrosystem, caregivers receive financial support (such as disability grants) but are limited to no emotional or social support. It is, however, important to note that these system levels influence each other directly. For example, when a caregiver does not receive any social or disability grant (which would be included in the macrosystem), all other levels may be negatively impacted – causing increased stress for the caregiver. The chronosystem represents the caregiver as they move through time and also who they are or were in history (Bluteau, Clouder & Cureton 2017). Change over time should be taken into account as every individual would process and experience every unique situation differently (Lau & Ng 2014).



SASSA, South African Social Security Agency; CWSID, Children with severe intellectual disabilities.

FIGURE 1: Bronfenbrenner's bioecological systems theory as applied to the caregiver of children with severe intellectual disabilities.

Proposed intervention guidelines

Children with severe intellectual disabilities and their caregivers are also scarcely represented with regard to intervention policies put forward (Razzouka et al. 2010). Therefore, based on this as well as the results of this study, a possible intervention model is proposed to establish the collaborative intervention of a child with severe intellectual disabilities. This model includes counselling as the major facet of intervention (Stanbridge 2012) and is imperative at each level of Bronfenbrenners' biocological systems model. As a transdisciplinary team, this would mean that each healthcare practitioner would assume a role as counsellor as appropriate for their situation to increase the support provided to the caregiver (Costan et al. 2018).

After initial diagnosis of the CWSID, the educational psychologist would assign a social worker to the case as case manager (McConkey, Cassin & McNaughton 2020). The case manager will be involved with the caregiver as well as the child with severe intellectual disabilities, as per appropriate scope of practice to ensure the family's well-being in all areas of life (Cheng & Lo 2020). The case manager will be responsible for providing counselling from initial diagnosis straight through life and ensure that the child with severe intellectual disabilities is seen by all other relevant practitioners (Damianakisa et al. 2018). Both the case manager and educational psychologist will also be responsible for instilling the importance of education in the caregivers.

Strengths and limitations of the study

To the authors' knowledge, this study is the first of its kind within the South African context. Participants were from all over South Africa, which made it a reflection of the South African context. Unfortunately, only caregivers who were part of support groups were reached; that could lead to biased results. The disadvantages of this study included the limited access to caregivers who did not have access to online support groups as the coronavirus disease 2019 (COVID-19) pandemic provided challenges to reach these caregivers in the community. By using a uniform interpretation method via the online platform, interpretative objectivity was ensured. The COVID-19 pandemic provided the study with some limitation because of limited access to caregivers.

Recommendations for future research

Research needs to be conducted regarding what possible caregiver support should be provided within a multidisciplinary intervention team. The current level of caregiver burden needs to be further studied to determine the possible causal factors and thereby identify the intervention procedures required to effectively address caregiver burden. Various factors regarding what could influence the degree of caregiver burden still required investigation. Further investigation should be carried out to fully develop the use of the BSCF

scale in a South African context, as the EFA showed that one item doesn't seem to fit with the rest; it might be as simple as rephrasing the sentence to fit South African linguistics better. It is recommended that a larger population in a global setting be targeted to ensure further generalisation.

Conclusion

It was concluded that approximately 50% of caregivers experience severe levels of caregiver burden. This study found that South African caregivers experience burden in all areas (e.g. financial, emotional, physical and social) that could influence their overall QoL. No risk factors could be identified that could potentially contribute to the level of burden experienced by the caregivers who partook in this study. It is recommended that a caseworker be assigned to each child with severe intellectual disabilities at diagnosis in order to possibly decrease caregiver burden. Further research needs to be conducted to determine possible areas of support for caregivers of CWSID.

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Competing interests

The authors declare no conflict of interest.

Authors' contributions

P.v.d.M. developed the original idea. E.J., M.I.R. and S.G. contributed to the development of the idea. M.G. assisted with the statistical analyses of the data. Interpretation of the design was done by P.v.d.M. with assistance from M.G. Critical revision of the manuscript as well as supervision of the study was carried out by E.J., M.I.R. and S.G.

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Data availability

The data that support the findings of this study are available from the corresponding author, E.J., upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

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Appendix starts on the next page →

Appendix 1

Potential burden survey (Parents with children with severe intellectual disabilities)

Section A: Demographic questionnaire

Please answer the following by indicating with an (X) or write out where applicable.

1. In what province do you reside?

Gauteng	Limpopo	Western Cape	Eastern Cape	Free State	Northern Cape	North West	Mpumalanga	Kwazulu- Natal

2. How old are you?

3. How many children do you have?

1	2	3	4	5+

4. Does any of your other children also have special needs?

Yes	No

5. What is your highest qualification?

None	National Senior certificate (gr 12)	Diploma	Bachelor's Degree	Other: Please specify

6. Who do you consider your support system?

Family	Friends	Health Care Practitioners	Only me	Other: Please specify

7. Are you receiving any grants to assist you financially?

Yes	No

8. What is your annual income?

Below R10 000 p/month	Between R10 000 – R20 000	Between R20 000 – R40 000	Above R40 000 p/month

Section B: Burden Scale for Family Caregivers

Instructions: Please tick the response the best describes how you feel.

Questions	Strongly agree	Agree	Disagree	Strongly disagree
1. I feel fresh and rested in the morning.				
2. My life satisfaction has suffered because of the care.				
3. I often feel physically exhausted.				
4. From time to time I wish I could "run away" from the situation I am in.				
5. I miss being able to talk with others about the care.				
6. I have enough time for my own needs and interests.				
7. Sometimes I feel that the person I am caring for is using me.				
8. Away from the caring situation I can switch off.				
9. It's easy for me providing the necessary nursing care (washing, feeding etc).				
10. Sometimes I don't really feel like "myself" as before.				
11. The care I give is acknowledged by others.				
12. Since I have been a caregiver my financial situation has decreased.				
13. I feel like being forced into this caregiving situation.				
14. The wishes of the person I am caring for are reasonable in my opinion.				
15. I feel I have a handle on the care situation.				
16. My health is affected by the care situation.				
17. I am still capable of feeling really joyful.				
18. I have had to give up future plans because of the care.				
19. It doesn't bother me if outsiders are aware of the sick person's situation.				
20. The care takes a lot of my own strength.				
21. I feel torn between the demands of my environment (such as family) and the demands of the care.				
22. I feel I have a good relationship with the person I am caring for.				
23. I have problems with other family members due to the care.				
24. I feel I should take a break.				
25. I am worried about my future because of the care I give.				
26. My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care.				
27. I feel sad because of the fate of the person I am caring for.				
28. I can take care of other daily obligations to my satisfaction in addition to the caregiving.				

Thank you for your time completing this survey.