

Psychosocial Burden Experienced by Care Workers Caring for Children with Profound Intellectual Disabilities in South Africa

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ABSTRACT

Introduction

Caring for children with profound intellectual disabilities (ID) is a complex and demanding responsibility requiring continuous commitment. Care workers provide long-term support to children because of severe functional limitations, communication difficulties, and complex healthcare needs. This care provision requires adequate knowledge and skill in ID; however, while caring for children, the care workers' own psychosocial needs frequently become compromised. Their experiences and support needs remain insufficiently explored.

Purpose

To explore and describe the psychosocial burden experienced by care workers caring for children with profound intellectual disabilities.

Methods

A qualitative, exploratory, and descriptive research design was employed to gain an in-depth understanding of care workers' experiences. Semi-structured interviews were conducted with 20 participants across three metropolitan municipalities in Gauteng Province, South Africa. Data were analyzed using thematic analysis, supported by ATLAS.ti, following Creswell's six-step framework.

Results

Five primary themes emerged: *emotional trauma* (emotional distress, depression, and low self-esteem); *psychological exhaustion* (feeling overwhelmed, compassion, and spiritual questioning); *psychological needs* (access to psychological support services); *altered social relationships* (social withdrawal and isolation); and *social needs* (access to social support services).

Conclusions

The study highlights the psychosocial challenges associated with caregiving, which affect both professional functioning and personal well-being. The findings underscore the urgent need for comprehensive intervention strategies to promote care workers' well-being.

INTRODUCTION

Intellectual disability (ID) is a neurodevelopmental condition characterized by significant limitations in intellectual functioning (learning, reasoning, and problem-solving) and adaptive behavior necessary for daily living, with onset before 18 years of age (Leonard et al., 2022). The American Association on Intellectual and Developmental Disabilities defines ID as impairments in intellectual functioning and adaptive behavior across conceptual, social, and practical domains (Schalock et al., 2021). It emerges during the developmental period, from infancy to adolescence, and contributes significantly to the global burden of disability (World Health Organization [WHO], 2020; WHO, 2023). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) classifies ID into mild, moderate, severe, and profound levels of severity, commonly based on intelligence quotient (IQ) assessment, which remains central to diagnosis and classification (American Psychiatric Association [APA], 2022).

This study focuses on children with profound ID in South Africa. Profound ID is characterized by an IQ below 20–25 and the need for continuous support and supervision due to the inability to perform activities of daily living independently (APA, 2022). When admitted to healthcare facilities, care workers become secondary caregivers to these children. Globally, approximately 207.4 million children aged 5–17 years live with moderate-to-severe or profound disabilities, with a higher burden observed in Sub-Saharan Africa (Olusanya et al., 2022).

In South Africa, care workers form an essential part of formal institutional care, providing support with communication, mobility, feeding, hygiene, behavioral challenges, and medical needs. Compared with other healthcare professionals, their specialized training is often limited. Within the South African context, the training pathway of care providers varies: professional nurses who complete a three-year diploma operate at National Qualifications Framework (NQF) Level 6, while those with a degree operate at NQF Level 8. Community healthcare workers complete approximately 12 months of training at NQF Level 4; child and youth care workers are trained at NQF Level 5; and home-based care workers complete shorter programs at NQF Levels 1–3 offered by various institutions (Motswasele-Sikwane et al., 2020). These

categories of care workers are rarely specialized in ID care, and variations in training, qualifications, and experience may limit their preparedness to manage the complex needs of children with profound ID. Furthermore, inadequate education and training contribute to their vulnerability to low-paid labor conditions.

Service delivery in South Africa remains inconsistent due to gaps in implementing disability-inclusive policies, shortages of skilled personnel, stigma, cultural beliefs, and financial barriers to care (Mladenov, 2022). These challenges negatively affect the well-being of care workers. The social model of disability highlights that disability is influenced not only by physical or cognitive impairments but also by societal and environmental barriers (Moosa-Tayob & Risenga, 2022). Caring for children with profound ID involves significant emotional, physical, social, and financial demands. Existing literature reports multiple physical and financial challenges experienced by caregivers. Physical challenges include back pain, spinal injuries, and balance problems related to lifting. Financial challenges include limited employment opportunities, low salaries, high living costs, and reduced access to education (Opoku et al., 2020; Raliphaswa et al., 2022; Siewertsen et al., 2024). However, while physical and financial burdens are well documented, the psychological and social challenges experienced by institutional care workers remain underexplored, particularly in African and South African contexts. This gap highlights the need for contextually grounded research. Therefore, this study aims to explore and describe the psychosocial burden of caring for children with profound ID as experienced by care workers in South Africa.

METHODS

Study Approach and Design

A qualitative approach with an exploratory-descriptive design was employed to explore and describe the experiences of care workers. This approach facilitated the collection of rich, in-depth accounts from participants directly involved in direct caregiving (Fernández-Ávalos et al., 2020).

Study Setting

The study was conducted in three metropolitan municipalities of Gauteng Province, South Africa:

Johannesburg, Tshwane, and Ekurhuleni. These settings were selected due to their large populations, significant proportion of children with ID, and existing resource constraints (Motswasele-Sikwane et al., 2020). Six mental healthcare facilities providing care to children with ID were included, comprising three public hospitals and three non-governmental facilities.

Participants and Sampling

Participants were care workers employed at healthcare facilities providing care to children with profound ID in the selected municipalities. Inclusion criteria included being 18 years or older, having at least two years of experience in caring for children with ID, and providing informed consent. A purposive sampling strategy was used to recruit participants. Of the 50 care workers invited, 20 participated, while 30 declined. Participants received no monetary compensation but were informed that their experiences would contribute to understanding caregiving challenges and informing future support interventions. Participant demographic characteristics are presented in [Table 1](#).

Recruitment Process

The researcher obtained permission from facility managers to access potential participants. The study purpose, procedures, risks, and benefits were explained, and voluntary participation was emphasized. To minimize recruitment bias, a purposive, non-probability sampling method was employed. Eligible participants were care workers aged 18 years or older, with at least two years of experience providing direct care to children with ID, and willing to provide informed consent. Individuals without direct caregiving responsibilities, those with limited experience, temporary or intern staff, and individuals unwilling to participate were excluded. Recruitment was facilitated through a neutral gatekeeper, and eligible care workers were provided with equal access to study information. Participants who agreed to participate provided written informed consent, including consent for the audio-recording of interviews.

Data Collection Process

Data were collected through semi-structured individual interviews conducted by the researcher in private office spaces within the facilities. The researcher, a nurse educator not employed at the study sites, maintained

independence from the participants and minimized potential role-related bias. All participants were asked two primary open-ended questions: *"How is it for you to take care of a child with ID?"* and *"How does taking care of a child with ID affect you psychologically and socially?"* Participants were encouraged to share their experiences with minimal interruptions.

Probing questions were used to encourage detailed responses and clarify participants' experiences, including: *"Can you tell me more about that?"*, *"Can you describe that in more detail?"*, *"Could you help me understand that better?"*, *"What do you mean?"*, and *"How do you feel about that?"* Interviews lasted between 15 and 50 minutes and continued until data saturation was reached, defined as the point at which no new information emerged. Saturation was identified after the 12th interview; however, all 20 participants were interviewed to confirm saturation, with no new thematic information emerging from participant 13 onwards. Data collection occurred over a four-month period. A semi-structured interview guide with neutral probes was used to enhance consistency, while reflexivity was maintained throughout the research process to minimize researcher influence. Member checking was conducted by summarizing and clarifying participants' responses during interviews to ensure accurate interpretation. All interviews were audio-recorded with consent, and participant codes were assigned to maintain confidentiality (e.g., P-A).

Data Management

Audio recordings, transcripts, and field notes were securely stored in a locked cabinet, and electronic data were password-protected to prevent unauthorized access.

Data Analysis

Data were analyzed using thematic analysis, supported by ATLAS.ti software. Creswell's six-step framework guided the process, beginning with verbatim transcription of audio-recorded interviews and repeated reading of transcripts to achieve data familiarisation. Meaning units were identified and coded using both deductive and inductive approaches. Related codes were grouped into categories and synthesized into themes and sub-themes representing participants' experiences. An independent co-coder reviewed the analysis to enhance credibility, with

discrepancies resolved through discussion and consensus. ATLAS.ti facilitated systematic data management, organization, and retrieval throughout the analysis process.

Trustworthiness

Five main criteria of qualitative rigor were ensured: credibility, dependability, confirmability, transferability, and authenticity. Credibility was enhanced through

member checking, prolonged engagement, and triangulation. Dependability was supported by detailed documentation and an audit trail. Confirmability was achieved through reflexivity and the use of direct participant quotations. Transferability was facilitated by providing rich descriptions of the research context and participants. Authenticity was ensured by presenting a balanced and faithful account of participants' experiences.

Table 1:
Demographic Profile of Participants

Participant	Age (Years)	Gender	Educational NQF Level	Years of Working Experience	Specialty in ID
P-A	22	Female	5	4 years	No
P-B	28	Female	2	8 years	No
P-C	32	Male	4	7 years	No
P-D	36	Female	4	12 years	No
P-E	24	Female	2	6 years	No
P-F	35	Male	5	10 years	No
P-G	20	Female	4	3 years	No
P-H	29	Male	8	6 years	No
P-I	31	Female	4	9 years	No
P-J	29	Female	5	8 years	No
P-K	26	Female	4	5 years	No
P-L	22	Female	6	4 years	No
P-M	29	Male	6	8 years	No
P-N	33	Female	2	11 years	No
P-O	34	Female	4	10 years	No
P-P	28	Male	8	4 years	No
P-Q	24	Female	5	6 years	No
P-R	31	Female	2	8 years	No
P-S	35	Male	5	12 years	No
P-T	30	Female	4	9 years	No

Note: Working experience figures were harmonized to align logically with caregiver age and institutional employment criteria.

RESULTS

Demographic Characteristics of Participants

As shown in **Table 1**, participants were between 20 and 36 years of age, with a predominance of female participants. Participants had diverse working experience ranging from 3 to 12 years in care environments. All participants lacked formal specialized training in intellectual disability care.

Identified Themes

The analysis yielded five main themes and corresponding sub-themes, summarized in **Table 2** below, supported by participants' verbatim quotations. The themes are classified into psychological and social burdens.

Table 2:
Themes, Sub-themes, and Verbatim Quotations

Themes	Sub-themes	Verbatim Quotations
1. Emotional Trauma	1.1 Emotional distress and depression	"Taking care of the children is traumatizing and depressing." (P-H)
		"I had to go and consult because I felt that I was losing my mind, and the doctor said I have depression." (P-G)
	1.2 Low self-esteem	"The hardest part is knowing that no matter what I do, I cannot make the child better." (P-C)
2. Psychological Exhaustion		"I am not sure why I wanted to be a care worker. Despite the training, I feel helpless, hopeless, and useless. This is too much for me." (P-D)
	2.1 Feeling overwhelmed	"I am tired mentally and emotionally because I always think about the children." (P-F)
	2.2 Compassion and spiritual questioning	"This is not fair for them. Why did God allow them to be like this? I wish I could make them normal, and this is mentally draining." (P-A)

3. Psychological Needs	3.1 Psychological support services	"We need counselling because we are losing our minds. This is too much! A talk with a neutral professional will help a lot." (P-G) "We need support groups, and time-out to go and destress. Managers must provide us with the support so that we can soldier on, where caregivers can share their experiences." (P-B) "Employee Health and Wellness Programs (EHWP) are needed for our mental well-being." (P-I)
4. Altered Social Relationships	4.1 Social withdrawal and isolation	"When I knock off, I lock myself in my room. I do not socialize with family and friends anymore because whenever I am with them, all that I think about is the children." (P-E) "As a family man, I am expected to play with my children whenever I am at home. But lately I cannot do that, and my children are now suffering." (P-C)
5. Social Needs	5.1 Social support services	"Management must be considerate and give us some time to knock off early so that we can chill. We work long shifts with no time for us to sit and destress." (P-K) "The facility must have recreational facilities such as a gym club where we can go and relax, and allow us to knock off early at least once a week." (P-L)

The findings indicate that caring for children with profound ID is associated with significant psychological burdens, including emotional distress, depression, low self-esteem, feelings of being overwhelmed, compassion challenges, and spiritual questioning. However, psychological support mechanisms—such as counseling, support groups, and employee wellness programs—were identified as beneficial. The findings further revealed that caregiving contributes to social burdens, including withdrawal and isolation, which may be mitigated through structured social support systems, recreational opportunities, and supportive management practices.

DISCUSSION

Demographic Characteristics of Participants

The findings indicated that most participants were female, suggesting that caregiving in South Africa remains a female-dominated profession. Participants had diverse work experience ranging from 3 to 12 years; however, none had specialized training in intellectual disability (ID), highlighting a critical gap in ID-specific knowledge and clinical skills. These findings emphasize the need to enhance the inclusivity and attractiveness of caregiving as a profession across genders. Furthermore, regulatory bodies responsible for caregiver training should consider revising curricula and policies to incorporate ID as a specialized area of training.

Themes

The findings revealed that caring for children with ID was associated with significant emotional, psychological, and social burdens. The identified themes of emotional trauma, psychological exhaustion, psychological needs, altered social relationships, and social needs demonstrate that disability care extends far beyond technical responsibilities, requiring sustained emotional, relational, and psychosocial support for care workers (Rauf et al., 2024).

The theme of emotional trauma affirms that caring for children with profound ID frequently contributes to emotional distress. Participants described experiences of sadness, helplessness, emotional distress, and concern when witnessing children’s vulnerability, high dependence, and ongoing medical challenges. These emotional responses are often associated with the close therapeutic relationships developed with children, which result in care workers becoming deeply emotionally invested in their well-being and future outcomes. The emotional demands of providing long-term care contribute to psychological challenges, including emotional distress, depressive symptoms, and reduced self-esteem. Evidence suggests that caring for children with profound ID presents substantial emotional challenges due to the complexity of care, continuous adaptation, and the responsibility of addressing children’s physical, developmental, and psychosocial needs (O'Connor & Corcoran, 2021).

In this study, care workers reported emotional strain related to witnessing suffering, uncertainty regarding

children's futures, and the enduring nature of disability care. These experiences highlight the importance of emotional support interventions aimed at promoting care workers' psychological well-being (O'Connor & Corcoran, 2022). Low self-esteem may arise when care workers perceive inadequate knowledge, skills, or institutional support to meet the complex needs of children with profound ID. Feelings of professional inadequacy can be intensified when care outcomes remain limited despite significant physical and emotional investments. Similarly, South African research has shown that healthcare personnel caring for children with ID experience severe emotional burdens related to care complexity, resource constraints, and challenges affecting their mental health (Molefe, 2025).

The findings emphasize that supporting care workers requires a holistic approach addressing both clinical competence and emotional well-being. Interventions such as counseling, mentorship, reflective practice, emotional support programs, and supportive multidisciplinary environments can enhance resilience, confidence, and the capacity to provide sustainable, compassionate care.

Psychological exhaustion reflects the fatigue, frustration, and sense of being overwhelmed experienced by care workers due to the ongoing responsibility of meeting complex physical, behavioral, and developmental needs. Literature indicates that caring for children with profound ID requires sustained emotional engagement and specialized knowledge, which increases psychological demands, particularly when care workers perceive inadequate preparation or limited organizational support (Fernández-Ávalos et al., 2020; Islam et al., 2021). Psychological exhaustion further develops when there is a persistent mismatch between caregiving demands and available organizational resources. These findings highlight the importance of adequately preparing, supporting, and empowering care workers within their work environments to enhance their ability to manage complex care situations effectively and reduce occupational strain.

The findings highlight the importance of addressing the psychological support needs of care workers. Providing opportunities to share experiences, access emotional

support, and participate in structured supportive interventions can enhance psychological well-being. These findings are consistent with Santini et al. (2020), who emphasized the importance of education, supportive structures, and person-centered approaches in improving confidence and reducing challenges associated with ID care. Furthermore, supportive leadership, effective conflict-resolution strategies, and collaborative care models are essential in promoting staff well-being, retention, and quality of care. Accessible mental health services, peer-support programs, and regular debriefing opportunities assist in reducing occupational stress and mitigating psychological risks (Santini et al., 2020). Providing psychological support within the workplace is also aligned with the principles of the *Occupational Health and Safety Act, 1993*, which promotes the protection of employees' health and well-being (South African Government, 1993).

Altered social relationships reflect the extent to which caregiving responsibilities affect care workers' ability to maintain social interactions, contributing to experiences of social withdrawal and isolation. The findings highlight the broader impact of caregiving roles on personal and social lives. Although care workers demonstrate professional commitment and compassion, prolonged exposure to emotionally demanding caregiving situations negatively influences social functioning and overall quality of life. Evidence suggests that occupational stress extends beyond the workplace, resulting in reduced social engagement and withdrawal (Lindert, 2025). Such withdrawal increases feelings of loneliness and weakens essential support systems that contribute to psychological resilience (Zhang et al., 2025). Therefore, supportive workplace environments and opportunities for social connection among healthcare providers are vital in reducing isolation and promoting well-being.

Social needs highlight strategies to address caregiving-related social burdens, including supportive management, recognition, and opportunities for relaxation through recreational facilities. Participants emphasized the importance of feeling valued and supported while undertaking complex caregiving responsibilities. The findings suggest that improving the caregiving environment requires a holistic approach addressing both the developmental needs of children with intellectual

disabilities and the occupational well-being of care workers. Healthcare organizations must promote supportive professional relationships, interdisciplinary collaboration, and formal recognition of care workers' contributions to disability care.

Limitations Statement

The study was confined to select facilities within a single province (Gauteng), which limits the generalizability of the findings, as the experiences of care workers in other provinces remain uncaptured. However, the findings offer valuable baseline insights that can inform improvements in working conditions at a national level, including the review of policies addressing support for those caring for children with profound ID.

Recommendations

- i. Review of training curricula for care workers to include in-depth intellectual disability care outcomes and practical objectives.
- ii. Implementation of future studies that include participants from other provinces across the country to enhance geographic representativeness.
- iii. Initiation of intervention-based research aiming to develop comprehensive, context-specific support strategies for care workers.
- iv. Comprehensive review of institutional policies aimed at supporting and protecting the mental health of healthcare care workers.

CONCLUSIONS

The study highlights that care workers caring for children with profound intellectual disabilities experience substantial psychosocial challenges. The findings demonstrate that caregiving in this context extends far beyond routine occupational demands to encompass significant psychological and social strain, affecting both professional functioning and personal well-being. Importantly, the study shows that these experiences are interrelated and exacerbated by challenging systemic working environments and limited organizational support. Overall, the findings underscore the urgent need for comprehensive intervention strategies to promote the well-being of care workers and enhance the quality of care provided to children with ID.

Use of Artificial Intelligence (AI) Declaration The researcher did not use artificial intelligence to generate the results. ATLAS.ti software was used to assist in generating themes and sub-themes during data analysis. The author critically reviewed, revised, and verified the entire paper, and assumes full responsibility for its final content.

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Authors' Contributions

L.L.M. conceptualized the study, wrote the methodology, collected and analyzed data, drafted the manuscript, and reviewed final revisions.

Data Availability Statement: The data that support the findings of this study are available from the corresponding author, L.L. Molefe, upon reasonable request.

Ethical Approval: The research protocol was approved by the appropriate Health Research Ethics Committees and the Gauteng Department of Health. Permission to access the facilities was granted by chief executive officers and facility managers.

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