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The experiences of secondary caregivers of children diagnosed with intellectual disabilities

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ABSTRACT

Secondary caregivers of children diagnosed with intellectual disabilities in Gauteng have experiences of caring for children diagnosed with intellectual disabilities. The experiences needed to be explored. The study aims to explore and describe the experiences of secondary caregivers of children diagnosed with intellectual disabilities. The study was conducted in Gauteng province, South Africa. Three Municipalities of Gauteng were covered. A qualitative-exploratory-descriptive and contextual research design was adopted, using a non-probability purposive sampling technique to select participants. Data were collected using semi-structured individual interviews. Twenty participants were interviewed. Data analysis was done, using Content data analysis and ATLAS. it. Findings were verified with an independent co-coder. Challenges of caring and unmet needs of secondary caregivers were identified. Challenges found are lack of training on intellectual disability, lack of resources, staff shortage, emotional trauma, lack of parents' support, victimisation and threats, lack of communication by management and staff exploitation, leading to financial struggle. Identified unmet needs are the need for training, the need for adequate resources, the need for staff increases, the need for parents' involvement in caring, the need for improvement in communication by managers, the need for emotional support and the need for salaries increase, incentives and Performance Management Development System (PMDS). The study provided insight to what secondary caregivers are going through when caring for children diagnosed with intellectual disabilities, and what needs should be addressed for secondary caregivers.

1. Introduction

Secondary caregivers of children diagnosed with profound intellectual disabilities have experiences of caring that are not explored. Larkin, Henwood, and Milne, (2019) define secondary caregivers as people who have parental responsibility for children but are not parents who are identified as primary caregivers, and their roles involve helping children with activities of daily living, and mostly assisting with impairments related to disability, disease or mental disorder. Duties of secondary caregivers are further unpacked by Larkin, Henwood, and Milne, (2019), and include managing medications, talking to doctors on behalf of a child, helping to bathe or dress a child, feeding a child, changing nappies, playing with a child, and providing stimulations to a child. Regarding the American Association on Intellectual and developmental disabilities (AAIDD), Ogunfolaju (2020) explains intellectual disability as a significant sub-average intellectual functioning associated with concurrent impairments in adaptive behavior manifested during the developmental period, and the manifestation includes difficulty with general mental abilities, which impacts the intellectual functioning, practical functioning, and social functioning. Children's Act of South Africa (2005) defines a child as a person under the age of 18 years. Therefore, children diagnosed with intellectual disabilities are those under the age of 18 years and have difficulties with intellectual, practical, or social functioning.

A study by Kent, Burgess, and Kilbey, (2018) indicates that intellectual disability is measured in terms of the Intelligence Quotient (IQ) test, and further states that the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5TH)* classifies intellectual disability as mild, moderate, severe, and profound, wherein children with mild intellectual disability have an IQ of 50–55, those with moderate disability have an IQ of 35–40, those with severe disability have an IQ of 20–25, and those with profound disability have an IQ of below 20. It is therefore clear that

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children with profound intellectual disabilities require total care due to the severity of intellectual, practical, and social functioning. It is, thus, no doubt that caring for children of such a nature can be very challenging. Fernández-Ávalos et al. (2020) affirm that secondary caregivers have experiences related to caring for children diagnosed with profound intellectual disabilities. Such experiences are often negative and affect caregivers' psychological, social, and physical well-being. There is a gap in implementing policies, programmes, and services aiming at supporting secondary caregivers, hence negative experiences (Capri et al.,2018). In South Africa, about 6%-9% of secondary caregivers have been referred to mental health care practitioners due to negative experiences associated with caring. South Africa has nine provinces, with Gauteng being the smallest province of them all, but having the highest population of about 15, 888 million and the highest number of children with intellectual disabilities, ranging from difficulty in communicating, difficulty in walking, difficulty in remembering and concentrating, and difficulty in self-care (Statistic South Africa 2021). It is against this background that there was a need to explore the experiences of secondary caregivers of children diagnosed with intellectual disabilities in Gauteng province.

2. Material and methods

2.1. The design

A qualitative-exploratory-descriptive and contextual research design was adopted. The design enabled the researchers to obtain information directly from secondary caregivers, thus understanding the challenges experienced and the unmet needs of caregivers. The design was in line with the explanation of qualitative-exploratory-descriptive and contextual research design by Burns and Grove (2016), who affirms that it allows full investigation of the nature of the phenomenon, including the way it manifested. The design further assisted researchers in gaining an understanding of the real-world context as it is experienced by the participants (Pelzang & Hutchinson, 2018). The design therefore assisted researchers in obtaining a detailed account of secondary caregivers' experiences as lived.

2.2. The setting

The study forms part of a doctoral study of a corresponding author, whose title is a support programme for caregivers of children with intellectual disability in Gauteng province, South Africa, hence the setting in Gauteng province. The province was chosen due to its highest population and highest number of children diagnosed with intellectual disabilities, plus the highest number of secondary caregivers of children diagnosed with profound intellectual disabilities who receive services from mental health care practitioners. Gauteng province has three metropolitan municipalities, namely, Johannesburg, Tshwane, and Ekurhuleni. All three metropolitan municipalities were covered. For accessibility purposes, the study was confined to six mental health care institutions with the highest number of children and secondary caregivers, within the three municipalities, both in governmental and non-governmental institutions. Mental health care professionals of the study are social workers, auxiliary social workers, psychotherapists, and psychologists.

2.3. The participants

The study adopted a purposive, non-probability sampling approach. Participants were secondary caregivers of children diagnosed with profound intellectual disabilities, who had experiences of caring and could share their experiences of caring for children with intellectual disabilities. Simple random sampling was used to select participants; therefore, each one had an equal chance of being included. Some of the selected secondary caregivers were previously referred to mental health care practitioners due to difficulty in coping. The authors recognise that there could be a possibility that the results that were obtained could have been impacted by the previous exposure to trauma for those participants who previously suffered, as evidenced by the referral to mental healthcare practitioners. However, the participants could not have been excluded because they provided rich information about the study. A total of 40 caregivers in the three metropolitan municipalities were approached and requested to participate in the study as they met the inclusion criteria for participation. Due to voluntary participation, only twenty secondary caregivers agreed to participate. Those who refused to participate gave various reasons such as not feeling comfortable, not having time to come to the venue for interviews, and being scared that they would be targeted by their managers in the future should they participate, Because participation was voluntary, their decision not to participate was respected. Inclusive criteria were secondary caregivers who were known to the institutions and had experience of more than two years in caring. All participants were over eighteen years of age and gave voluntary consent to participate. All secondary caregivers who were below eighteen years of age were excluded since they could not give voluntary consent. Furthermore, caregivers with experience of less than two years were also excluded. Before the interview and signing of consent forms, the study purpose, risks, and benefits were explained to participants, and permission to audiotape the interviews was obtained.

2.4. Data collection

Semi-structured individual interviews were used to collect data. The corresponding author collected data. Interviews were conducted in a neutral quiet place agreed by both the participant and the researcher. Participants were individually asked the following questions: What are your experiences of caring for children diagnosed with intellectual disabilities? What according to you can be done to support you in caring? Participants were allowed to share information with minimal interruptions, whilst information shared was audiotaped. The duration of interviews ranged between fifteen and fifty minutes, and no interview exceeded fifty minutes. Data were collected until data saturation, which occurred on participant number fourteen. However, all twenty participants were interviewed.

2.5. Data analysis

Analysis of data was done using content analysis and ATLAS.ti. This form of analysis assisted the researcher in extracting the essential meaning of the topic from the verbal and written versions of the recorded data, separating them into constituent concepts and arranging them into themes, sub-themes, and categories (Aveyard & Goodman, 2017). The researcher listened to the tape and transcribed data. Each transcript was done separately. Non-verbal cues such as tone of voice, eye contact, body movement, and posture were observed and documented. Transcripts were read and reread, and further coded into categories, using open coding. ATLAS.ti software was used to help identify clusters of concepts. Codes were reviewed, revised, and combined into themes and sub-themes, which were further presented cohesively. For confirmation, a co-coder was used, who also followed the same process of data analysis. A meeting was convened between the researcher and a co-coder to discuss and verify identified themes and sub-themes, and where there were disagreements, a thorough discussion was conducted, and consensus was reached on the final themes and sub-themes.

2.6. Trustworthiness and integrity of the study

Five testing criteria were observed: credibility, dependability, confirmability, transferability, and authenticity. Credibility was attained by verbatim transcription of interviews, the use of a co-coder, triangulation by using semi-structured individual interviews, and taking field notes. Dependability was attained through the description and

application of the research methodology, audit trial, and the use of an independent co-coder. Confirmability was attained by ensuring that the findings are not shaped by the researcher's bias, motivation, or interest, hence the researcher ensured that the data represent the information that participants provided. Transferability was attained through the thick description of the research methodology and triangulation. Authenticity was attained by ensuring that the report conveyed the feelings and tone of participants.

Ethical approvals were given by the North-West University Health Research Ethics Committee (NWU-HREC, Ref: NWU-00462–20-A1), the Director of Health, and CEOs of the six mental health care institutions in Gauteng province. Managers in the six institutions acted as mediators. Furthermore, researchers attended an ethics workshop to ensure an understanding of research ethics. Participants 'names were not used, but codes were assigned, for example, P-B.

3. Results

The participants were between twenty-eight and fifty-four years of age and were a mixture of males and females. Of the twenty participants, only one female was a professional nurse, and all nineteen were care workers. The number of years of caring was between four and fourteen. Two themes emerged, namely, challenges experienced by secondary caregivers and unmet needs of secondary caregivers. The two themes have sub-themes.

3.1. Challenges experienced by secondary caregivers

Lack of training on intellectual disability, lack of resources, staff shortage, emotional trauma, lack of parents' support, victimisation and threats, lack of communication by management, and staff exploitation, leading to financial struggle, are sub-themes. The first sub-theme, lack of training on intellectual disability, affirms that caring for someone diagnosed with intellectual disability requires extensive training. Without training, it becomes very difficult and frustrating for a person to perform and provide quality care, and further destroys the emotional being of a person. One participant said: *"We were not given any training on intellectual disability. They just allocated us to work, even though they knew that we did not do training about intellectual disability. This made us not provide proper care to the children"* P-P. Another frustrated participant said: *"I had to take the child to the hospital on my third day after employment. I did not know how to handle the child. The management was aware that I did not know anything, but they did not care"* P-H. The expectations of management created low self-esteem and a sense of unworthiness. The second sub-theme is the lack of resources. Resources are necessary for healthcare institutions. Inadequate or lack of resources results in poor quality of care. Participants said: *"Cot beds are broken, and children can fall. Lack of resources compromise provision of quality of care for these children"* P-B. *"There are no nappies, toiletries, sheets, and blankets. Wheelchairs are not fit for children. There are no splints to support children, we use pillows, and this defeats the purpose. Bathrooms have no lights. There are no lifting devices to assist in lifting the children. Children are getting poor quality of care"* P-J.

The third sub-theme is staff shortage. *"Physiotherapists see children once a month because they are not enough, hence children are deformed"* P-M. *"We don't have doctors. One caregiver takes care of thirty-seven children. How will quality care be accomplished?"* P-D. Emotional trauma is the fourth sub-theme, which is further aggravated lack of counselling after the loss of a child through death. *"It is very traumatic to see a child dying under your care because you became helpless to prevent the incident. Even when the child has passed on, you do not get counselling. We are expected to soldier on and continue to work normal"* P-N. *"We are emotionally affected; it is difficult and painful. It is sad because management does not even care. We are traumatised"* P-G. In dealing with emotional trauma, participants had to suppress their emotions by pretending that things are normal, through prayers, or resorting to spirituality. *"We just hang in there because there is nothing we can do. Some of us ask for strength from God by praying. We always have a morning session of prayer before we commence work."* P-D.

The fifth sub-theme is the lack of parents 'support. When parents do not visit their children in institutions, it affects healthcare providers and the children themselves. *"Parents do not visit". It is like they have dumped their children here. If parents were visiting their children, they could have brought better food for children because institutions do not provide a balanced diet for children. Their diet does not have proteins or vitamins, it is only carbohydrates, hence children have lost weight"* P-K. The sixth sub-theme is victimisation and threats. According to participants, they are victimised when raising their dissatisfactions to their managers and further receive threats, intimidations, and ill-treatment. *"When we talk, we receive threats to be fired. We are being intimidated and ill-treated for raising our dissatisfactions. Nobody wants to be a union representative because we are afraid to be fired. The slightest mistake that you make, you, you receive threats".* The next sub-theme is lack of communication by managers. *"Management does not communicate with us, they do not include us in parents' meetings, they do not involve us in planning, or even ask us how we can improve the service"* P-H. *"They even sent important information through WhatsApp, forgetting that we dot earn a decent salary that will enable us to buy smartphones that have WhatsApp"* P-G. *"The last time we had a meeting was three or four years back"* P-O. The last sub-theme is staff exploitation, leading to financial struggle. When staff is not paid well, it amounts to exploitation. *"We are working but we are struggling because we are earning so little. Life is so difficult. We are breadwinners, but we are unable to feed our families"* P-H. *"The salary that we get is very low. We are not even provided with salary advice; therefore, we do not even know exactly how much our salary is, or how much are we supposed to earn"* P-R. *"We do not get bonuses. There is no Performance Management Development System (PMDS)"* P-P.

3.2. Unmet needs of secondary caregivers

Sub-themes are the need for training, the need for adequate resources, the need for staff increases, the need for emotional support, the need for parents' involvement in care, the need for improvement in communication by managers, and the need for salary increases, incentives, and Performance Management Development System (PMDS). The first sub-theme, the need for training, is crucial to ensure that staff members become competent. *"They need to send us for training so that we can learn more about intellectual disability and how to take care of children. Training will empower us on how to handle children, and further boost our morale and self-confidence" P-A,* P-K, P-T. The second sub-theme, a need for adequate resources, is a necessity in every healthcare institution. Lack of, and dysfunctional resources frustrate health care providers and even compromise the quality of care. *"We do not have resources such as special wheelchairs, monkey chains, suitable chairs for children to sit, machines that assist us during lifting of children, and disposable nappies. They need to order medical equipment required to provide quality care to the children"* P-K. Another participant cited the negative impacts of dysfunctional equipment *"Available lifting machines are broken and cannot function well, compelling us to lift children without machines. Lifting has now injured us; we are constantly presenting with backaches. The towel nappies that they use for children make them develop nappy rashes. They must request more funding to order equipment"* P-O. The third sub-theme, the need for staff increases, is a requirement in any healthcare institution. *"I wish they could employ more staff so that we can manage to provide quality care for children. Staff must also include multidisciplinary team members such as caregivers, nurses, doctors, physiotherapists, occupational therapists, and dieticians".* The fourth sub-theme is the need for emotional support. Participants pleaded for emotional support from management and the Department of Health. *"I wish the Department of Health could ask us how we feel, and even provide us with a programme that will address our emotional wellness. We need emotional support. We thank God that you came, and we are hopeful that you will communicate this to the department"*

P-J. *"We are going through a lot, and we wish we could have someone that we can talk to"* P-S. Parents 'involvement in caring is the fifth sub-theme. A person admitted to a healthcare institution requires the love and support of family members. This enables a patient not to be bored or stressed and to have rapid improvement in his or her health condition. Parents 'love, support, and appreciation for children when in a healthcare institution is important. Therefore, if parents do not visit, the healing process becomes delayed. Furthermore, during visits, parents can bring along meals that they know their children love and enjoy, thus making children happy. *"Parents do not visit their children, and this is very sad because when they visit, they bring joy to children and can even bring better food. The department needs to contact parents and encourage them to visit their kids. These kids miss them"* P-F.

The sixth sub-theme is the need for improvement in communication by managers. Communication is an important tool in any institution, and lack of communication is very frustrating. *"I wish management could speak to us more and allow us to speak without victimising us so that we can be able to raise our concerns"* P-G. Participants further recommended regular meetings between themselves and management. They believe that effective communication can lead to service delivery improvement. *"They need to involve us in planning meetings and ask us how we can improve the service"* P-T. The seventh and last need is the need for salary increases, incentives, and Performance Management Development System (PMDS). According to participants, both intrinsic and extrinsic motivators are necessary. They believe that salaries increase, incentives and PMDS will motivate them. According to participants, there is a need for re-visitation and revision of policies addressing salary increases, incentives, and PMDS. *"Performance Management Development System (PMDS) should be used to motivate us. Some managers use PMDS to punish us, which is wrong"* P-K. *"Our salaries must be increased because we work hard, yet we earn peanuts. The salary that we are getting cannot sustain us. We must also be given bonuses at the end of a year"* P-Q.

4. Discussion

The study aimed to explore and describe the experiences of secondary caregivers of children diagnosed with profound intellectual disabilities. The results revealed that secondary caregivers have challenges and needs, therefore, the discussion will be based on the two. Eight challenges as identified in the results are lack of training on intellectual disability, lack of resources, staff shortage, emotional trauma, lack of parents' support, victimisation, and threats, lack of communication by management, and staff exploitation, leading to financial struggle. Seven identified needs are the need for training, the need for adequate resources, the need for staff increases, the need for parents' involvement in care, the need for improvement in communication by managers, the need for emotional support, and the need for salary increases, incentives, and Performance Management Development System (PMDS).

Training is a necessity in the workplace because, without it, employees do not have a firm grasp on their responsibilities or duties. Employee training refers to programs that provide workers with information, new skills, or professional development opportunities (Elnagal & Imran 2018). A study by Sendawula et al. (2018:1) further affirms that training affects the quality of workers' knowledge and skills, improves the level of knowledge and commitment, promotes a positive attitude, and improves care. Lack of training outlined how frustrated caregivers were during the provision of care due to lack of training on intellectual disability. Lack of training results in a lack of knowledge, which leads to a person's unintentional ignorance (Buratti & Allwood 2019). Caring for a child who has an intellectual disability requires extensive knowledge of intellectual disability, and therefore someone cannot be an expert in such a field without knowledge and adequate training (Sendawula et al., 2018). It is for this reason that the need for training was identified by caregivers. Caregivers requested to be sent for training so that they can learn more about intellectual disability, and how to take care of children with profound intellectual disability.

Resources are necessary to provide quality care in healthcare institutions. It is the responsibility of managers to ensure that institutions are well equipped with resources through the ordering of medical equipment because a lack of such resources affects the well-being and performance of staff, and further impacts service delivery and quality of care negatively (Nielsen et al., 2017), hence found to be challenging for caregivers, making it easier for them to provide a poor quality of care. The notion is supported by Primc (2020), who said that when resources are lacking or dysfunctional, the staff is unable to perform necessary tasks or is unable to perform tasks to the intended extent. It is against the background of the provision of poor quality care that caregivers recommended that managers request more funding and order the medical equipment required to provide care to the children. The recommendation is supported by Moyimane et al. (2017), who said resources such as medical equipment are very important in the provision of care, and a shortage of such resources is a barrier to the delivery of quality healthcare services.

Adequate staff in any healthcare institution is key because it reduces workload, promotes job satisfaction, promotes the well-being of employees, increases staff morale, decreases work-related stresses and burnouts, promotes quality care of recipients of care, promotes clients'safety and positive outcomes (Nijkamp & Foran 2021). Staff shortage has been seen as a bigger challenge for caregivers during the provision of care for children. According to caregivers, there is a shortage of other multidisciplinary team members such as doctors and physiotherapists. Furthermore, there are not enough caregivers for children, thus compromising the provision of quality care. Provision of poor quality care due to staff shortage is affirmed by Ghafoor et al. (2021), who emphasized that adequate staffing in the provision of care is important because the shortage of staff compromises the provision of quality care, and enables the available staff to become exhausted, thus unable to provide the best care. It is for this reason that caregivers pleaded for the employment of more staff members such as caregivers, nurses, doctors, physiotherapists, occupational therapists, and dieticians, affirming the need for staff increase.

To promote a conducive work environment, employers must ensure that employees are emotionally supported because this assures employees that they will obtain help in regulating emotions, which in turn enhances their confidence, and further promotes the accomplishment of tasks (Pohl et al., 2022). Emotional support further boosts confidence in staff members, promotes work engagement, and boosts a person's emotional capabilities, hence the role of supervisors is critical in mitigating the adverse effects of work-related stress through emotional support for employees (Kuroda & Yamamoto 2018). A study by Shah et al. (2021: 3) highlights that a lack of emotional support encourages employees to leave their jobs due to burnout, stress, and depression. Caregivers indicated emotional trauma associated with caring for children with profound intellectual disability, which is further aggravated by a lack of counselling is a concerning health problem for caregivers. According to caregivers, it is traumatic to experience the death of a child who was under one's care, even worse when there are no counselling services for post-traumatic stress, hence caregivers resort to prayers and suppressing emotions to manage trauma. Exposure to work major work-environmental challenges may result in occupational stress, anxiety, and depression, leading to poor mental health outcomes such as emotional trauma (Magnavita et al., 2021). Emotional suppression can often be used as a coping strategy to suppress the emotional trauma that one experiences. Workers may suppress their emotions by pretending that problems do not exist (Herren & Ferrer 2021). The literature supports the view that people often use their coping strategies when experiencing traumatic situations, in a case where professional services such as counselling sessions are unavailable. However, such actions can further weaken people's capability to deal with psychological distress in the future, which will eventually lead to mental illnesses (Xi et al., 2020). To avoid this, caregivers pleaded for emotional support from management

and the Department of Health in the form of programmes and counselling sessions that will address their emotional wellness.

There is a need for parents to be involved in the care of their children during admission. This will promote a healthy collaboration between healthcare workers and parents regarding flexibility and sharing of responsibility because parents will assume the responsibility of maintaining home-like care, whilst healthcare workers assume the responsibility of treatment-centered care. Parents and healthcare workers depend on each other's help to ensure the provision of quality care for children (Sundal & Vatne 2020). The social support of parents during the admission of their children plays a complete mediating role between childhood maltreatment and emotional intelligence, improves life satisfaction, reduces stress, and inhibits the development of mental illnesses. Furthermore, parents play the role of health promoters, role models, and educators in the lives of their children by influencing their food cognition because they socialize children in the context of food consumption by conveying learning outcomes such as norms, knowledge, attitudes, and behaviors to children (Zhao et al.,2019). Lack of parental support is a concerning issue for caregivers. Caregivers indicated that parents of children do not visit their children, and do not support them in providing care to children. This does not only affect caregivers but further impacts negatively on the well-being of children. Children do not have an alternative to what they get in a hospital, for example, if the hospital does not provide nutritious food for children, they are unable to even get them from their parents because they do not visit. When parents do not visit their children in hospitals during admission, healthcare providers become overwhelmed because they are unable to discuss issues affecting children with parents (Yee et al., 2017). The effects of parental modelling on a child's food consumption are significant. The nutritional need of a child requires collaboration between healthcare professionals and parents, which is something that is often underestimated (Kolset 2020). Therefore, if parents do not visit their children, the collaboration expected will collapse and the nutritional needs of children will suffer. Furthermore, the nutritional needs of children will become the sole responsibility of health care providers, who become overwhelmed by not knowing what to feed the child because they cannot predict the food that the child was socialized to take, thus causing stress and burnouts (Zhao et al., 2019). It is for this reason that caregivers recommended that parents be encouraged to visit their children so that they give children love and support because parental love, support, and appreciation are important for the healing process, and further provide motivation to caregivers to build strength of continuing with provision of quality care to children.

Regular and effective communication is a very crucial and significant element in an organisation. It creates collaboration within the work environment that has effects on organisational performance and decision-making (Musheke & Phiri 2021). Managers are advised to hold regular meetings with healthcare workers, in this case, secondary caregivers. This platform allows discussion of issues of healthcare delivery, problems identified or experienced, and solutions to identified problems. Managers are further advised to implement effective listening skills, without intimidating or victimising staff. In addition, managers are advised to avoid keeping secrets from staff members, especially information that is valuable to assist in the provision of quality health care delivery. A secretive communication environment that shuts people results in lost ideas and opportunities (Musheke & Phiri 2021). A study by Kuroda and Yamamoto (2018) confirms that effective communication is a key factor for workers' mental health as well as productivity. According to Min et al. (2020), ensuring sustainable employee performance means employers must be willing to listen to employees' problems and treat them with respect. Reviewed literatures therefore support the findings of the study. Caregivers expressed victimisation and threats from managers, coupled with a lack of communication. According to caregivers, there is no open line of communication between them and managers, such that the vocal caregivers are victimised and threatened when raising issues affecting them. This act by managers causes frustration and a state of hopelessness in caregivers. When employees are subjected to victimisation and threats, they are unable to raise their concerns, frustrations, and opinions on matters of the improvement of service delivery and they can be less productive and overwhelmed, and eventually become stressed and depressed (Kuroda & Yamamoto 2018). Furthermore, lack of communication by management promotes the feeling of unworthiness of employees, low staff turnover, and poor productivity. Because staff members find it difficult to raise issues with managers, they can opt to look for greener pastures or better employment, leaving a gap of staff shortage in the current employment, thus promoting poor quality care in the current institution (Narayana et al.,2018; Kuroda and Yamamoto 2018)). It is for this reason that caregivers proposed an open line of communication between themselves and managers that does not result in victimisation and threats. Managers must further involve caregivers in the planning meetings for improvement in service delivery.

Staff exploitation is a burning issue for participants. The staff is not well remunerated, and this is an indication of exploitation, which ultimately leads to financial struggle for caregivers. Staff members receive lower salaries that do not meet their basic needs; hence they struggle financially, and this further leads to staff dissatisfaction in the workplace. A study by Papaconstantinou (2015) revealed several factors such as unattractive salaries, lack of appreciation, and unfair policies on remunerations are the leading causes of staff dissatisfaction. Lack of rewards and appreciation which causes a financial struggle can result in stress, burnout, and depression (Auberry 2018). To attract staff, managers must recognise the staff for the hard work that they do through Performance Management Developmental System (PMDS). This will promote productivity and quality care. The notion is supported by a study by Monzoor et al. (2021), who advises that a reward management system significantly motivates workers to improve their efforts and performance. Such rewards can be in the form of salary increments, provision of incentives, and through a Performance Management Developmental System. Employees who are rewarded extrinsically become motivated to ensure that the mission and vision of the institution are accomplished and continue to become dedicated and committed to the work (Min et al.,2020), and failure of an employer to recognise and reward employees well for the good work that they perform impacts negatively on the social and psychological well-being of employees (Min et al. 2020). It is against this background that participants recommended the implementation of both intrinsic and extrinsic motivators in the form of salary increases, incentives, and PMDS, and further re-visitation and revision of policies addressing salary increases, incentives, and PMDS.

5. Recommendations

Based on the results, the study recommends massive support for secondary caregivers of children diagnosed with profound intellectual disabilities. It has been noted that the type of work that they do, is not an easy one, hence the plea for support. With support, it is anticipated that challenges experienced by secondary caregivers can be reduced, if not eradicated, therefore, their needs would have been met. Therefore, future studies aiming at developing supporting frameworks, guidelines, or programmes for secondary caregivers of children diagnosed with profound intellectual disabilities are recommended.

Future studies are necessary to include primary caregivers of children diagnosed with intellectual disabilities. This will give an idea of whether challenges and needs would be similar among primary caregivers and secondary caregivers. A future study covering all provinces of the country is recommended so that the experiences of secondary caregivers in other provinces can be known, thus indicating whether challenges and needs are similar amongst secondary caregivers in the country.

5.1. Implications for Nursing Practice

Lack of support for secondary caregivers to provide quality care is a concerning issue, especially in specialized institutions such as those admitting children diagnosed with intellectual disabilities. It is therefore necessary for all stakeholders in health care settings to ensure that caregivers are provided with training, including regular in-service training on intellectual disability. Resources, including human resources, material resources, and financial resources must be always made available. Therefore, there is a need for an increase in budget in these institutions. This will ensure the provision of quality care and improvement in conditions.

5.2. Implications for policy Development

There is a dire need for a review of policies within institutions catering to children diagnosed with intellectual disabilities because current policies do not address the needs of caregivers. The revised policies must thoroughly address support for caregivers, and further provide extensive guidelines of such support.

5.3. Implications for Nursing education

There is a need for a review of education and training curricula for caregivers. The revised curriculum must therefore include outcomes that will address the care of a child with intellectual disability. A review of the curriculum will assist in cases where caregivers are not provided with training within the institutions that they are working at.

6. Conclusion

The study aimed to explore and describe the experiences of secondary caregivers of children diagnosed with profound intellectual disabilities. The study was conducted in Gauteng province, South Africa, and twenty secondary caregivers participated. Data was collected and analysed, and results were obtained. Results revealed challenges and unmet needs of caregivers. Therefore, the results of the study could be used in future studies to address the identified challenges and needs.

7. Authors' contribution

LLM collected and analysed data. LAS and MPK did proofreading to ensure quality.

8. Disclaimer

Views expressed in the manuscript are the authors 'own and not of any official policy or affiliated agency or institution.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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