

CARING FOR MENTAL HEALTHCARE USERS WITH PROFOUND INTELLECTUAL DISABILITIES: APPROACHES AND OPPORTUNITIES

Grace Malapela

University of South Africa
gmalapela@gmail.com

Faniswa Mfidi

University of South Africa
mfidifh@unisa.ac.za

Sambulelwe Sibanda

University of South Africa
sibans1@unisa.ac.za

Gloria Thupayagale-Tshweneagae

University of South Africa
tshweg@unisa.ac.za

ABSTRACT

Mental healthcare users with profound intellectual disabilities are among the most disadvantaged groups in society. They experience numerous challenges which include limitations in intellectual functioning and adaptive behaviour. These limitations present challenges in their care, especially in cases where student nurses are not well prepared to meet these special needs. The purpose of this study was to provide insight into approaches and opportunities related to the care of mental healthcare users with profound intellectual disabilities by student nurses. A qualitative, descriptive, interpretive, exploratory and contextual research design was used to explore and describe opportunities and approaches in caring for mental healthcare users with profound intellectual disabilities as experienced by student nurses. Audio-taped interviews were conducted with 12 student nurses in their fourth and final year of study who were assigned to a care centre catering for people with profound intellectual disabilities. Thematic analysis as proposed by Braun and Clarke was used to analyse the collected qualitative data. Three approaches to care emerged: promotion of health and wellbeing, training in communication skills, and support for the users' dignity. One main opportunity that emerged was being caring, an attitude deeply embedded in nursing principles. Caring for care users with profound intellectual disabilities can be emotionally challenging. However, this study identified approaches and opportunities which, when explored, can assist student nurses in rendering quality patient care. This will minimise frustrations on the part of student nurses and help improve the quality of life of mental healthcare users.

Keywords: care approaches; intellectual disability; mental healthcare users; student nurses



INTRODUCTION AND BACKGROUND

Profound intellectual disability (PID) refers to situations where an individual has a developmental intellectual capacity (IQ) of less than 20 (Lambrechts, Kuppens, and Maes 2009, 623). This implies that the everyday social and practical skills of the individual differ significantly from what is normative in society (Aldersey 2012, 2). Individuals with PID are limited in conceptual skills, social skills and intellectual functioning and these limitations in skills demand an integrated approach to their care, starting with student nurses' education.

In Gauteng, South Africa, student nurses undertake a four-year comprehensive course for the Diploma in Nursing (General, Psychiatric and Community) and Midwifery, commonly referred to as R425. Student nurses are expected to render care and rehabilitation to mental healthcare users with PIDs as part of the learning outcomes, which are assessed during clinical psychiatry placement. South African Nursing Council Regulation R425 stipulates that the four-year course constitutes Psychiatric Nursing Science (PNS) for at least for two years. During PNS exposure, students are assessed on their ability to make provision for care, treatment and rehabilitation of mental healthcare users in line with the Mental Health Care Act (South Africa 2002, chapter III).

Caring for mental healthcare users with PIDs can be challenging and at most times difficult to do (Gunther and Diekema 2006, 10). The difficulty of caring for people with PIDs stems from the fact that often all activities of daily living have to be provided for by the caregiver. The difficulties are at times compounded by the addition of autism and other neurologic conditions and situations where the person is also not ambulatory (Tuffrey-Wijne 2003, 55). Research has also noted that people with PID experience a range of health inequities compared to the general public (Read and Cartlidge 2012, 23; Tyrer, Smith and McGrother 2007, 520).

In order to ensure that the healthcare needs of people with intellectual disabilities are met, key legislation has been proposed and passed by various bodies. For instance, article 25 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) emphasises the right of individuals with disabilities to have the highest achievable standard of healthcare without discrimination. Section 28 of the Constitution of South Africa (South Africa 1996) is against any form of maltreatment, neglect and abuse or degradation. It ensures that all inhabitants of South Africa are protected against any harm. Any form of maltreatment is regarded as unlawful. Further, the National Department of Health noted in the Reconstruction and Development Programme that people with intellectual disabilities are classified as being in difficult circumstances due to the complex nature of their intellectual disability.

Problem Statement

There are profound issues of improper care of people with intellectual disability in healthcare settings. Shortcomings in the way the treatment is delivered have been

documented, for example lack of information on the patient, lack of awareness and knowledge regarding people with disabilities, as well as lack of interest in the proper care and treatment of people with learning disabilities (Michael 2008). Limited training in specific health areas is of great concern and could be responsible for the indifferent attitude and care of the staff (Webber, Bowers, and Bigby 2010, 155). Student nurses are at the stage of learning about their profession and if they are not properly educated or oriented on the specialised care needs of PID, then there are likely to be profound challenges and shortcomings when they care for people with intellectual disabilities.

Purpose of Study

This qualitative study sought to gain insight into the approaches and opportunities related to the care of mental healthcare users with PIDs by student nurses.

Research Objectives

The objectives of this study were:

- To explore and describe the experiences of fourth-year nursing students in caring for mental healthcare users with PIDs
- To identify and recommend best approaches for caring for mental healthcare users with PIDs.

Definition of Key Concept

Profound intellectual disability refers to the deficits in general mental abilities (IQ below 20) which impair functioning in comparison to a person's age and cultural group by limiting and restricting participation and performance in one or more aspects of daily life activities, such as communication, social participation, functioning at school or at work, or personal independence at home or in community settings (APA 2012, 1).

RESEARCH METHODOLOGY

This was a qualitative, descriptive, interpretive, exploratory and contextual study to explore opportunities and approaches in caring for mental health care users with PIDs using the thematic analysis approach of Braun and Clarke (2006, 77).

Setting

The study was conducted in the Gauteng province of the Republic of South Africa in a rehabilitation care centre for children and adolescents with PIDs.

Population and Sample

The study population comprised all (fourth-year) student nurses in Gauteng. Twelve fourth-year nursing students were purposively recruited to participate in the study. The principal investigator (RGM) explained the objectives of the study to the care centre management and to all fourth-year nursing students. The criteria for inclusion were that participants had to be in their last year of training (fourth year), willing to participate, have worked or are currently placed in the care centre and have no mental health diagnosis.

Ethical Consideration

Approval was sought and granted by all bodies responsible for research and these were the Higher Degrees Ethics Committee of the Department of Health Studies at the University of South Africa and the national Department of Health, South Africa. Permission was also sought from and granted by the authorities of the rehabilitation care centre. The principal investigator explained the objectives of the study to all potential participants. The participants gave written informed consent to participate in the study. Confidentiality was assured by not using the participants' real names or any information that could be traced back to the participants. The right to withdraw from the study at any phase was continuously emphasised.

Data Collection Procedure

Interviews were conducted in a private room to ensure privacy. All interviews were done on different weekend days at a time agreed upon by the principal investigator and the participants. They were audio-taped with the participants' permission. The interviews started with a broad statement: "Please tell me about your experiences in caring for adolescents and children with PIDs". Follow-up questions included: "Could you tell me what in your opinion would be the best approach of caring for people with PID? Tell me about opportunities that can be derived from the approaches suggested?" Data collection continued until no new information emerged. Data saturation was actually realised with the eighth participant, but interviews continued up to the twelfth participant.

Data Analysis

Thematic analysis was used to analyse the data collected. Each interview was transcribed verbatim and reviewed for analysis using thematic analysis (Braun and Clarke 2006, 77). Three approaches to caring for people with PID emerged, namely the promotion of health and wellbeing, training in communication skills, and support for their dignity. One main opportunity emerged, namely caring, which was embedded in the principle of caring as it defines a nurse.

Trustworthiness

Trustworthiness was assured in this study by having the second and third authors independently coding similar transcripts to confirm the emergent themes. The first author also did member checking with the participants, who were asked whether what had been noted down was an accurate account of their responses. The data collection was done only by the first author to ensure consistency.

RESULTS

Demographic Characteristics

The results represent the responses from the interviews with the 12 participants who all had equal opportunity to care for mental healthcare users with PIDs during their clinical placement at the care and rehabilitation centre where the study was conducted. All the respondents answered all the questions asked in the interviews. The majority were female (83%; n = 10). The respondents' ages ranged from 21 to 50. Most of the respondents (83%; n = 10) had no prior experience of working with people with intellectual disabilities.

Table 1: Demographic profile of participants

Criterion	Characteristics	Frequency	Percentage
Gender	Female	10	83
	Male	2	17
Ethnic group	White	0	0
	North Sotho	5	42
	South Sotho	1	8
	Ndebele	2	17
	Swati	1	8
	Zulu	1	8
	Tswana	1	8
	Tsonga	1	8
Ages	21–30	6	50
	31–40	4	33
	41–50	2	17
Level of training	4 th year of training	12	100
Marital status	Single	7	58
	Married	3	25
	Divorced	1	8
	Widower	1	8
Religious denomination	Christian	12	100

Personal encounter with individuals suffering from intellectual disability in the community	Any contact/experience prior to clinical placement	2	17
	No contact prior to clinical placement	10	83

Experiences in Care

Caring for mental healthcare users with PIDs takes place within a complex historical, social, economic, political and cultural context. Participants noted the need for a change in mindset and incorporated three approaches to caring for mental healthcare users PIDs: promotion of health and wellbeing, training in communication, and support for their dignity.

Promoting Health and Wellbeing

The participants reportedly observed that mental healthcare users with PID did not enjoy optimum healthcare which met their complex needs. They also made the observation that the majority of mental healthcare users with PID were overweight due to their sedentary lifestyle characterised by using a wheelchair with little or minimal physical activity. Participants suggested that an integrated team of healthcare workers that included a dietician and a physiotherapist should be deployed to work with mental healthcare users with PIDs. This, they felt, would promote the health and wellbeing of these mental healthcare users. These reports are better explained by the following extracts:

Nurses can look after these clients by providing care but for them to enjoy optimal health; they will need a dietician to plan their diet and a physiotherapist who will plan their exercises regimen.

A concerted effort is needed in order to improve their health. Working with families and teaching them what to do would improve their health.

Training in Communication Skills

Participants also observed that there was minimal communication with the clients and it was often one-sided. The student nurses suggested that for mental healthcare users with PID to maintain their self-esteem, they need to be talked to and to be listened to in ways that were dignified and empowering. The teaching of communication strategies such as mouthing words and using gestures was identified as measures to assist users in communicating their needs. Nurses should be taught these skills so that they can pass them on to mental healthcare users with PID. The need for training in communication skills is best expressed by these extracts:

Every time I come to the centre I will find that one of those who were assigned to me will jiggle in her seat and make some noises until I found that it is her way of saying she is wet or needs a bathroom. All along I thought she was happy to see me. What a contradiction.

Opportunities

Opportunities for the improvement of care emerged from the approaches that the study identified. These opportunities are embedded in “caring” as the cornerstone quality for nurses. They include appropriate training for nurses in knowledge, attitudes and skills required to work with mental healthcare users with PID. Participants reported that incorporating training in special skills for working with these users with PID in their studies would better prepare them to work with these users. The participants also felt that this could even be the much-needed incentive to attract many nurses to work with these clients. Some of the views to emerge from the participants were:

We [students’ nurses] just bath them and feed them and that is all we do. We should be trained on how to educate them on social skills so that they can be more independent. We treat them like they are all the same. There is no individualism and since they cannot make any choices for themselves we are forced make choices for them.

Some of the participants alluded to the fact that with appropriate training the nurses would have the required set of skills which would likely change their attitudes to mental healthcare users with PID. This change in attitude would ensure better care for the care users and enhance acceptance of them as human beings without some limitations or prejudice.

DISCUSSION

The study has shown that proper preparation and training of students during placement is a key element in the successful discharge of their nursing duties. Caring for mental healthcare users with PID demands a concerted effort from healthcare practitioners. This position has long been advocated for by researchers and practitioners alike, as asserted by Welie (2015, 3). The shortage of staff working in centres caring for mental health users with PIDs is also well documented (Gaede and Surujlal 2011, 344). Article 25 of the UNCRPD proposes that mental healthcare users with PIDs should have access to the highest standards of health without discrimination (Welie 2015, 20). However, the study found that these users are being looked after by only a few nurses owing to staff shortages. It was also noted that not all their health needs, such as proper diet and exercise, are met as part of their care. These shortcomings were attributed to a combination of factors such as improper communication and lack of knowledge and skill in caring for people with intellectual disabilities on the part of the nurses.

Dithole (2014, 6) reports that communication is a basic need and a right of every individual, even more so those individuals that are being cared for and have a reduced capacity to communicate themselves. Communication by nurses is an integral part of care. These statements allude to the fact that every individual needs to be assisted in communicating, as it is the only means through which service users can share their needs, challenges and difficulties. This position is also shared in a review on communication by Dithole et al. (2016, 204). Participants in this study observed that while children and adolescents with PIDs have limitations in communication, there is minimal effort on the part of nursing staff to assist them with communication. Effective communication is an integral component and key indicator of a caring nurse and the main vehicle through which rapport with patients is developed and maintained. The emphasis on effective communication between nursing staff and care users to emerge from this study is in agreement with previous studies on nurse-patient communication. Effective communication underpins the ability of care users to convey their psychological and physical needs (Grossbach, Stranberg, and Chlan 2011, 46; Happ et al. 2011, 28).

It can be argued, based on the findings, that perhaps a lack of knowledge and skills in caring for people with PID is responsible for the poor communication and the general lack of interest in caring for this group of care users by nursing staff. Nursing staff have the capacity to improve their attitude and skills through tailored training in the care of mental healthcare users with PID. Knowledgeable nurses are able to provide the right care and are likely to be motivated in discharging their duties, which benefits care users. The argument can also be made that the best approach in caring for children and adolescents with PIDs is to support them in a way which promotes and maintains their dignity. Dignity or autonomy is a basic right for every individual, including those with PID (Welie 2015, 1). To have dignity or autonomy means that individuals can make their own decisions and choices. Article 12 of the UNCRD asserts this as a human right. In this study participants observed that mental healthcare users are often denied this right as there is poor facilitation for these users with PIDs to communicate their needs and wishes. However, the findings in this study are in agreement with other studies, which have highlighted that the challenges in clinical settings present an opportunity for positive experiences for the student nurses (Chambers, Thiekötter, and Chambers 2013, 106; Helgesen, Gregersen, and Roos 2016, 4).

People with intellectual disabilities continue to experience poor care from nursing staff. This care is characterised by negative attitudes and poor communication, attributed to a lack of training and skills on the part of nurses. There has to be continuous training of healthcare personnel in understanding the special needs of care users with PIDs. Students have been shown to take a more proactive approach to knowledge through structured learning activities (Helgesen et al. 2016, 5). There should be a compulsory component of training in the special needs and care of people with intellectual disabilities for all student nurses.

REFERENCES

- Aldersey, H. M. 2012. "Family Perceptions of Intellectual Disability: Understanding and Support in Dar es Salaam." *African Journal of Disability* 1 (1): 1–12.
- American Psychiatric Association (APA). 2012. *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. Washington, DC.
- Braun, V., and V. Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3 (2): 77–101.
- Chambers, D., A. Thiekötter, and L. Chambers. 2013. "Preparing Student Nurses for Contemporary Practice: The Case for Discovery Learning." *Journal of Nursing Education and Practice* 3 (9): 106.
- Dithole, K. S. 2014. "Nurses' Communication with Mechanically Ventilated Patients in the Intensive Care Units." Doctoral thesis, University of Pretoria.
- Dithole, K. S., S. Sibanda, M. Moleki, and G. Thupayagale-Tshweneagae. 2016. "Communication Challenges between Intensive Care Nurses and Ventilated Patients." *World Views in Evidence Based Nursing* 13 (3): 197–206.
- Gaede, R. J., and J. Surujlal. 2011. "Through the Lens of the Learner: Using Photo-Elicitation to Assess the Recreational Needs of Learners with Intellectual Disabilities." *African Journal for Physical, Health Education, Recreation and Dance* (Supplement 1): 344–355.
- Grossbach, I., S. Stranberg, and L. Chlan. 2011. "Promoting Effective Communication for Patients receiving Mechanical Ventilation." *Critical Care Nurse* 31 (3): 46–61.
- Gunther, D. F., and D. S. Diekema. 2006. "Attenuating Growth in Children with Profound Developmental Disability. A New Approach to an Old Dilemma." *Archives in Pediatric Adolescent Medicine* 160 (10): 1013–1017.
- Happ, M. B., K. Garrett, D. D. Thomas, J. Tate, E. George, M. Houze, J. Radtke, and S. Sereika. 2011. "Nurse-patient Communication Interaction in the Intensive Care Unit." *American Journal of Critical Care* 20 (2): e28–40.
- Helgesen, A. K., A. G. Gregersen, and A. K. Roos. 2016. "Nurse Students' Experiences with Clinical Placement in Outpatient Unit – A Qualitative Study." *BMC Nursing* 15 (49): 1–6.
- Lambrechts, G., S. Kuppens, and B. Maes. 2009. "Staff Variables associated with the Challenging Behaviour of Clients with Severe or Profound Intellectual Disabilities." *Journal of Intellectual Disability Research* 53 (7): 620–632.
- Michael, J. 2008. *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: HMSO.
- Read, S., and D. Cartlidge. 2012. "Critical Reflection on End-of-life Care for People with Intellectual Disabilities: A Single Case Study Approach." *International Journal of Palliative Nursing* 18 (1): 23–27.
- South Africa. 1996. *Constitution of the Republic of South Africa, 1996 (Act No. 108 of 1996)*. Pretoria: Government Printer.

South Africa. 2002. *Mental Health Act 2002* (Act No. 17 of 2002) Pretoria: Government Printer.

The Constitution of the Republic of South Africa. 1996. Chapter 2, Bill of rights.
Pretoria: Government Printer.

Tuffrey-Wijne, I. 2003. "The Palliative Care Needs of People with Intellectual Disabilities: A Literature Review." *Palliative Medicine* 17 (1): 55–62.

Tyrer, F., L. K. Smith, and C. W. McGrother. 2007. "Mortality in Adults with Moderate to Profound Intellectual Disability: A Population-based Study." *Journal of Intellectual Disability Research* 51 (7): 520–527.

United Nations General Assembly. 2007. "Convention on the Rights of Persons with Disabilities: Resolution adopted by the General Assembly, Geneva, A/RES/61/106." Accessed 2 November 2015. <http://www.refworld.org/docid/45f973632.html>.

Webber, R., B. Bowers, and C. Bigby. 2010. "Hospital Experiences of Older People with Intellectual Disability: Responses of Group Home Staff and Family Members." *Journal of Intellectual and Developmental Disability* 35: 155–164.

Welie, J. V. M. 2015. "The Search for an Ethically Sound Approach to Caring for Persons with Intellectual and Developmental Disabilities." *Journal of Religion and Society Supplement* 12: 1–7.