

People with Severe and Profound Intellectual Disability: Nurse Carer Experiences in a South African setting

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Abstract

We explored nurse carer experiences with people with severe and profound intellectual disability in a care and rehabilitation centre in South Africa. Informants were a convenience sample of 10 nurses (females = 7; males = 3; mean years of service = 7.8, SD = 4.8 years). They completed an unstructured interview on their care provision experiences. The data were thematically analyzed using Tesch's method of open coding. Findings resulted in the following themes to characterise the nurse carer experiences: compassion, person-centered care and importance of parent involvement. Compassionate and person-centered care is fundamental to the establishment of a therapeutic relationship between nurse carers and people with severe and profound intellectual disability.

Keywords: Institutional care and rehabilitation, profound intellectual disability, severe intellectual disability, intellectual disability nursing.

Introduction

From childhood years, people with intellectual disabilities have impaired cognition and difficulties in conceptual, social, and practical areas of living (American Psychiatric Association, 2013). They often are able to learn simple daily routines and do simple self-care activities, but require supervision in social settings. They need care to support activities of daily living (Boat & Wu, 2015). Caring for people with developmental disabilities relies on a professional facilitative process that includes both the individual in need of support and the environment in which this person lives (Doody et al., 2014).

Caring for people with intellectual disabilities can be both rewarding and also stressful and challenging (Gray-Stanley & Muramatsu, 2011; Hickey, 2014; Petner-Arrey & Copeland, 2015). For instance, caregivers report a sense of self-fulfilment looking after people with intellectual disability (Capri & Buckle, 2015:173; Doody, Markey, & Doody, 2013). However, they also report increased levels of burnout from the demands from their carer roles (Lahana et al., 2017). Studies are needed on nurse carer experiences in low resource service setting like in South Africa to inform practices in similar developing country care provider settings. This exploratory study sought to explore nurse carer experiences with people with severe and profound intellectual disability in a care and rehabilitation centre in South Africa.

About 0.05 to 1.55% of people have severe to profound intellectual disability (McKenzie, Milton, Smith, & Ouellette-Kuntz, 2016). The prevalence rate in South Africa is estimated at 3.6% to 5% (Uys & Middelton, 2014). Intellectual disabilities can co-occur with mental illness, medical problems and challenging behaviours (Matson & Cervantes, 2013), increasing the burden of care. For instance, between 5 and 15% of people with intellectual disability present with challenging behaviour including self-injury, aggression and stereotypic behaviour for which they require intensive supervision. In addition, people with severe and

profound intellectual disability are prone to medical problems including obesity, osteoporosis, cardiac conditions, hearing and vision impairment, epilepsy, endocrine problems (especially thyroid disease), skin anomalies, oral and dental issues, musculoskeletal deformities, bowel and bladder problems, and gastro-esophageal reflux disease (Gentile, Cowan, & Smith, 2015).

The context for service for health carer providers to people with intellectual disability can be challenging from lack of organizational support, marginalisation of intellectual disability care work (Capri & Buckle, 2015) and constant changes in service provision paradigms (Doody, Slevin, & Taggart, 2012). This is in addition to the challenges associated with the behavioural and medical management of their charges (Willems, 2016). For these reasons, employment turn over can be high among carers of people with intellectual disability.

Care and rehabilitation centres in South Africa are authorized by the Mental Health Care Act (17 of 2002). The head of the national department designate health establishments which serve as care and rehabilitation centres and determine the nature of the services to be provided. Care and rehabilitation centres may conduct assessments of intellectual abilities and provide care, treatment and rehabilitation services to persons with severe or profound intellectual disability. These centres are staffed by mental healthcare providers such as nurses, psychologists, psychiatrists, occupational therapists and social workers.

Since the centre under study experienced a high turnover of nurses at the time of the study, the present study focused on the carer experiences of nurses. The study was guided by the following question: What are the lived experiences of caring for patients with severe and profound intellectual disability?

Understanding nurses' lived experiences in caring for patients with severe and profound intellectual disability in institutional settings in South Africa may aid in keeping nurses working in demanding environments.

Method

Population and sampling

We purposively selected 10 of 129 nurses who worked in the care and rehabilitation centre in a rural area in South Africa. Five registered nurses, four enrolled nurses and one assistant nurse (females = 7; males = 3) participated in the study. Their nursing experience ranged between four and 20 years of caring for people with mental disabilities.

Data collection

We asked the following central question: "What are your experiences of caring for patients with severe and profound intellectual disability?" We also kept field notes to clarify responses to the interview questions. In addition, we audio-recorded the interviews for a reliable record.

Procedure

The study was approved by the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria (reference 368/2013) and the management of the rehabilitation and care centre. Participants signed informed consent before being interviewed. The nurses completed the interviews at their places of work.

Data saturation was reached after the eighth interview during which no new themes emerged. We conducted two additional interviews which did not yield any new themes. We identified participants with sequential numbers, rather than using the names of participants, to ensure confidentiality.

Data analysis

Data were qualitatively analysed using open coding. The transcribed interviews were analysed by the first author and an independent coder to identify themes that answered the research question (Creswell, 2014). We stopped theme extraction once categories became repetitive with no new information coming from further interviews (Polit & Beck, 2017).

Results

Three themes emerged from the data, namely: compassionate caring, person-centered care, and importance of parental involvement. These themes are elaborated on below. To the extent possible, we substantiate our findings with verbatim quotations, and informant number.

Theme 1: Compassionate care

Nurses described their experience of caring for people with severe and profound intellectual disability to involve being loving and accepting towards their charges. For example, the nurses observed:

...I will take care of them and love them as my children... (P#3, registered nurse)

As someone who dedicated his whole life to helping other people there is nothing much I can do except to be with these kids and make them feel loved... (P#4, enrolled nurse)

...[with] passion [I] understand them, [and] I know their needs and then furthermore [I] know when they are in pain or they are experiencing something that is not usual from them... (P#10, enrolled nurse)

...my relationship with [then] counts a lot because ifunderstanding what their needs are (P#3, registered nurse)

One of the nurse carers reported a spiritual awakening for her carer role:

...I wish God to make some miracles for them, it saddens me a lot [about their lives]. (P#4, enrolled nurse)

The relationships between people with intellectual disability, carers and nurses should be based on respect and support (Taua 2015). Nurse carers need to have adequate therapeutic skills to care for disabled patients effectively (Morrissey & Callaghan, 2011).

Theme 2: Person-centered care

Nurses spoke of the need to individualize care for each of the people with severe and profound intellectual disability. For example, some of the nurses said:

...we must [provide care] to make sure that [each of them] feels comfortable [and] not feel alone ... (P#3, registered nurse)

...we must patient with each of theme ... (P#8, registered nurse)

...because we must treat them with love, we must understand... (P#9, registered nurse)

...[each of them]is special and ... needs more time with you... (P#10, enrolled nurse)

Even if the person doesn't talk, but to touch, touching is the most important thing to the patient... (P#9, registered nurse)

...if aggressive, [they may be due for] medication...give them medication and they do well ... (P#8, registered nurse)

...if aggressive, [and] you start talking to them calmly and it helps. (P#9, registered nurse)

Nurses need to focus on behavioural indicators and interpret non-verbal communication to identify asymptomatic signs of ill-health and the needs of the patient with intellectual disability (Doody, Markey, & Doody, 2013; Taua, 2015). Nurses need to be respectful and non-judgmental while carefully considering the reasons for challenging behaviour (Hutchins

& Prelock, 2014). Understanding these reasons can help to develop realistic, proactive and responsive interventions (Crotty, Doody, & Lyons, 2014). Policy and supportive interventions should aim to reduce patient aggression and prevent or manage the associated emotional exhaustion that may negatively affect staff (Hensel, Lunskey, & Dewa, 2014).

Theme 3: Importance of parent/guardian involvement

Nurses considered parent/guardian carer support important. The following quotations are illustrative:

...if the parent come in and you explain to them nicely and talk to them, this is what happen to your child, sometimes they will understand, sometimes they don't... (P#7, enrolled nurse)

...[some] parents ...just dump their children here and then they give you the incorrect telephone number, if you phone tomorrow the telephone is changed... (P#3, registered nurse)

Most of ...the families ...don't came to visit, some don't have families especially those who has been here for a very long time, we don't know the whereabouts of the families... (P#9, registered nurse)

I have been working here I don't even know a single parent... it feels like they are abandoned. (P#3, registered nurse)

Doody, Markey, and Doody (2013) identified family support and input as fundamental to care provision. Family members and healthcare professionals should thus be able to communicate effectively. Unfortunately, some parents cannot face or accept the responsibility of taking care of a child with intellectual disability as explained by the nurses in this study. Parents may reject their children and leave them at institutions to avoid embarrassment and escape their disturbing behaviour. As a result, nurses become the primary

caregivers and assume the emotional and physical burden of caring for children with intellectual disability (Vassos, Nankervis, Skerry, & Lante, 2013).

Compassionate and person-centred care is essential to facilitate a therapeutic relationship between nurse carers and people with severe and profound intellectual disability. This is all the more important when parents are unable to act as primary caregivers and nurses have to fulfil this role. Career staff should receive training and support to improve current practice and to prevent burnout.

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