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Breaking down barriers – the importance of good relationships

This article focuses on the key importance attributed to the quality of relationships between residents with neurological conditions and staff in long-term care settings and explores the tensions and obstacles that could make developing good relationships complicated or difficult.

Introduction

The problem of isolation for those living in long-term care facilities, especially those with severe disabilities is well documented (e.g. Hubbard et al. 2003). A great deal of work highlights how residents wish to be connected to their family and social circles, the local community and the wider world (Cooney et al. 2009) but such connections can diminish over time and staff often become the main source of social interaction (Bergland & Kirkevold, 2005). It is not surprising therefore that research highlights that residents (and their families) consider their relationships with staff (and other residents) to be critical to their well-being (Galvin & De Roiste 2005; Duncan and Morgan 1994). However, following a review of the literature Brown-Wilson (2009, p.179) highlight that there is *"a dearth of studies that examined relationships as the key focus"* and a lack of detail about quite what constitutes a positive relationship.

There is also a lack of research on the younger care-home population in general and on specialist neurological long-term care settings in particular (Winkler et al. 2010). This is important because although long-term residential care is often associated with the elderly, almost a quarter of adults receiving such care in the UK are under 65 (Department of Health 2009). Many such residents will have acquired brain injuries or progressive neurological conditions (e.g. multiple sclerosis). This is a distinct population who may have particular needs due to their likely younger age, the complexity and multiplicity of their symptoms, and their requirement for specialist care input.

This article seeks to address this gap by reporting findings from a study which examined residents' and relatives' perspectives on what is important to residents with neurological conditions and their families in rehabilitation and long-term care settings.

Method

The study was undertaken in three specialist neurological long-term care centres in England. A qualitative, multi-methods design was employed, using focus groups and semi-structured interviews (methods chosen to maximise participation adapted to the participants preferences and communication needs). Thirty three individuals participated in the study: thirteen current residents, 1 former resident and 19 relatives. The residents who spoke to us included individuals with traumatic brain injury, multiple sclerosis, stroke, motor neurone disease, and spinal cord injury, the relatives included family members of residents in vegetative or minimally conscious states.

Data collection and analysis

The research involved five focus groups and 15 interviews, totalling twenty hours of discussion which was audio-recorded, transcribed verbatim and analysed using 'thematic analysis'. Transcripts were read, and reread, and then coded by basic topic and/or concepts. The researchers identified key cross-cutting themes in the data following the procedure described in Braun and Clarke (2006).

Ethics

Ethical approval for the study was gained from Cardiff University.

In the discussion that follows names of research participants have been replaced with pseudonyms and occasionally we have changed identifying details or left quotes unattributed in order to maximize confidentiality.

Findings

One of the strongest themes that emerged from the research was the importance both residents and relatives placed on the quality of residents' relationships with staff - the following four dimensions of staff interaction with residents were highlighted as key.

Social interaction, inclusivity and friendliness

Residents valued staff (nurses, care assistants, therapy and domestic staff) being friendly and referred to the need to have someone to talk to, confide in, or feel connected to. They also appreciated personal encouragement from therapists and their ability to make therapy sessions fun and engaging. Residents reported that 'everyday' interaction with staff helped them to retain 'a sense of normality' and explained that they valued interactions with staff that went beyond the formal professional/clinical relationships.

> *You can sit and eat a meal with them or whenever they're on a break, they're not your carer but they still want to sit down and break bread with you basically and it's just really nice to sit there and talk to people that way.* (Max)

Residents' sentiments were echoed by family members and seemed especially important to those whose relative had severe neurological disabilities. Family members wanted their relative to be included in everyday conversation even if the resident could not communicate and were concerned that due to their family members' neurological disabilities they might not be included in everyday social events.

The need of residents (and expectation from relatives) for staff to care about residents emotionally was also highlighted in the research - one relative, Lois, summed this up with

the comment: *'I want staff who are going to engage at the heart not just the head'*, a point underlined by a resident, Marjorie, who declared: 'everything should be done with care by carers'.

Caring touch

Giving 'care with care' meant delivering physical treatments with gentleness and empathy. Delivering 'personal care' (e.g. washing someone) without displaying attention to, and caring for, the person could leave the resident being handled feeling distressed. One woman, who needed full assistance with all personal care, commented:

> *At night times, the carers are the ones and sometimes they frighten me by the way they grab hold of me.*

Residents also discussed their desires for gentleness and positive touch that conveyed physical affection:

> *I think touch is…, is so important. I don't mean people rolling them and wiping their bums, I mean proper love and affectionate touch, I think that's so important for people to feel like they're loved. There are lots of residents here and they don't have visitors, they don't have their families come hugging and kissing them and I think the physios, when you go down the gym and they are giving you massages, I know for me it gives me goose bumps to have hands down my back.* [Erica]

Another resident, Patrick, said simply: *'[Touch helps] just to feel human.'*

Recognition of individuality

Alongside friendliness and caring touch, residents emphasised how they wanted to be known as an individual by staff. Erica, for example, explained that she wanted to be seen as more than 'just a list of symptoms'. 'Being known' incorporated being known functionally

(i.e. staff being aware of care routines and physical abilities and limitations) but also personally (i.e. how they might feel and their likes and dislikes).

Like residents, family members also emphasised the importance of knowing the resident as an individual and understanding their different personalities and abilities. *'Adjusting to the individual is very important'*, explained one relative of a severely brain injured woman:

> *We think people with brain damage are kind of goofy sitting in a chair and you feed them and talk to them in loud simple sentences. [But] they are all so different.*

Personhood

The concern that the person 'as a unique individual' might be erased in a care setting was particularly expressed by relatives of residents with no or limited consciousness, or severely compromised abilities to communicate – indeed some worried that their relative was at risk of not being treated as a 'person' at all. Lois, for example, commented: *'when we are talking about someone [in a] minimally conscious state people too quickly side line them'* and Fran asserted that although her daughter *'can't do anything for herself and she can't express anything there is still a person in there'*.

The four themes outlined above infused residents and relatives accounts of what made for good quality care – and the research participants were often very positive about the ways in which staff managed to achieve this. However, in spite, or perhaps precisely *because*, the way staff relate to residents was so significant there were some tensions around how such interactions could play out. A 'good quality' relationship can be difficult to achieve, or complex to negotiate and it is to these interpersonal and institutional challenges that we now turn.

Some tensions and external obstacles to quality relationships

Managing relationship boundaries

Although residents placed great value on their relations with staff they were at times unsure about the boundaries and whether their feelings of friendship towards staff were reciprocated and 'real'. One resident described her relationship with staff as 'the most important part of me being here' but also commented *'I know you're not supposed to say they're your friends'* and, another resident said he found it confusing to work out whether the *'people who get you up in the morning'* are *'people who underneath care for you in an emotional way'.*

Another resident however highlighted the risks of 'over-familiarity' describing a staff member 'going too far' and making an inappropriate 'childish' gesture claiming quasi kinship:

> *We've got one carer who made me a father's day card. (Card is shown to interviewer, it has been made in paper with felt tip pen). It's going too far. A bit childish. Caring is a responsible job, really the carers have a responsible job here.*

Some relatives questioned what it meant for staff to really 'know' the person they were caring for given their lack of knowledge of the person *before* the injury. Elizabeth, for example, talked about the importance of taking into consideration how her husband had been before his brain injury - respecting him 'as an individual' meant incorporating an understanding of what he would have wanted when he had full cognitive abilities.

Institutional barriers

Aside from tensions within relationships, participants identified external elements or factors which impacted upon them. Staffing levels, the sheer amount of physical care required (suctioning, turning etc.) could mean that residents had little time or energy for relationships, and staff may be fully stretched by providing the basics. Lack of continuity

and staff turn-over could also be a threat: *'Our worst scenario would be if a manager changed'.*

Research participants also described how a lack of respect between different grades or professions could undermine the value of having a member of staff who understand, and knows the resident as a person.

> *I've had a nurse in my room and she's tried to tell a doctor something on my behalf because they feel that the doctor isn't listening to me. [But] nurses take orders from the doctors even though, say they [nurses] might perhaps know you better and the doctor just completely dismissed the nurse.*

Conclusion

This article has identified the importance of relationships with staff in long-term neurological care centres from the perspective of residents and their families in the context of the threat to relationships neurological conditions and long-term care contexts can pose. It has highlighted the value service users place on social interaction that goes beyond instrumental interaction and the importance of good communication, genuine listening, friendship (or at least friendliness), and caring touch. The research also highlighted the importance placed on recognition of individual preferences, values and beliefs and personhood. We hope this summary of our research will provide a reminder to staff in these settings about how valued and important they are to residents and stimulate discussion surrounding how best to facilitate these relationships and tackle barriers. This research highlighted many other key areas about care in neurological long-term care settings. To see the full report of this research please go to http://www.cardiff.ac.uk/jomec/resources/Long_Term_Care.pdf

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