

Annotated Bibliography

Research for Nursing Practice 3

Nursing Degree B.Sc. (Cur.) - Junior Sophister

In order to structure the annotated bibliography, the student nurse has applied the three-stage reflection model by Rolfe *et al.* (Cited by Morrissey & Callaghan 2011).

Stage 1:

The topic I have chosen from the School Research Matrix (School of Nursing and Midwifery 2013) is “promoting health equality for marginalised groups”, specifically in the

area of dementia care and service provision. My interest in this subject stems from practice, when I observed first hand the impact a new housemate with mid-stage dementia had on long-term residents with an intellectual disability (ID).

The unit housed twelve residents with moderate ID, where some of the more independent residents would come and go as they wished. However, as the new housemate was unfamiliar with his surroundings and wandering was an issue, their home suddenly became a 'locked door' policy. Environmental changes had to quickly be re-negotiated in order to facilitate the new housemates safety along with other changes. Some of the residents reacted negatively towards these and displayed behaviours indicative of being put out.

Stage 2:

Due to medical advances and improved living conditions, people with ID are surviving longer into old age. This development means that greater numbers of individuals with ID are surviving into the age of risk, and developing dementia (Swanson 2007). In the ID population it is well researched that people with Down syndrome (DS) are six times more likely to develop Alzheimer's disease. More recent research however, indicates that people with ID without DS, are as prone to developing dementia as the generic population. This increase in life expectancy has profound effects on service provision and future policy, but also an existential effect on those who share a home with a peer with dementia (McCarron & Lawlor 2003; McCarron *et al.* 2011).

In addition, the 'Time to Move on From Congregated Settings Report' (Dolan 2011), confirms that there are currently 4,000 people with ID living in residential congregated settings, where ten or more people are in shared housing. This greatly increases the likelihood that one or more ageing residents will develop dementia. It is for these reasons that I feel we need to develop a better understanding and empathy of the issues raised, in order to support relationships that are affected by the impact of living with someone with dementia. It is imperative to both nursing knowledge and to ensure best practice in service provision. It can also help to direct education around dementia for residents, and to support them in understanding why their peers/friends may develop

changes in their personality. This enhanced knowledge could help to relieve a lot of anxiety and fear that people with ID can often have around change.

Stage 3:

I carried out an initial search of the literature on CINAHL using key terms 'dementia' and 'mental retardation' (as is the terminology used in CINAHL) and 'interpersonal relations' which revealed 0 citations. I reverted to searching with 'dementia' and 'interpersonal relations', which is where I retrieved my first generic article (see Appendix One).

I subsequently searched AMED (Allied & Complementary Medicine) using 'dementia' and 'learning disability', 35 articles were retrieved and 2 articles were chosen. The emerging problem was refined and my question is: What are the experiences of individuals with an intellectual disability, who share a house with a person who develops dementia?

The three papers chosen were the best fit for my problem and the assessment criteria. Although, the main focus of my problem is on the 'experiences' of people with an ID, it was of interest to investigate the phenomena in the generic population. I wanted to see if similar themes transpired, which could help direct further study if the findings suggest that experiences do overlap. It is evident from my search that there is a lack of literature investigating the problem from an ID perspective. For this reason I have chosen one paper from the generic population and two from the ID population, to examine what experiences are explored in the research.

O'Shaughnessy M., Lee K. & Lintern T. (2010) Changes in the couple relationship in dementia care. *Dementia* 9(2), 237-258.

This study on the generic population by O'Shaughnessy *et al.* (2010) explored the experiences of spouse carers' relationships when caring for a loved one with dementia at home, and what impact these experiences have on their relationships. A qualitative interpretative phenomenological approach was used, which is congruent with the

research question in exploring the human lived experience (Parahoo 2006). Interpretative phenomenology hinges on the belief that in-depth knowledge of understanding the phenomena is invaluable to uncovering the experiences of the participants (Sorrell & Redmond 1995). It is evident that the researchers conducted an extensive literature review, which assisted in developing their questions for the study. In addition, they conducted a pilot study with two people who had an experience of the phenomena under investigation, which further shaped the questions for the main study.

Five participants were selected for the main study through the local Alzheimer's society. Although not stated in the paper, it is clear that this is a purposive sample as the participants were purposely selected for their subjective knowledge of the phenomena. The sample size is appropriate, as it allows for the in-depth inquiry required for this approach and enhances the richness of the data (Gerrish & Lacey 2010). The aim of the paper is clearly outlined, and the method of interviewing participants using semi-structured interviews is consistent with the methodology. The use of open-ended questions on the pre-determined topics according to Polit & Beck (2010) allows the interview to be more flexible and encourages the participants' to talk more openly.

The findings of the research uncovered four main themes that were interwoven. The spouse carers' experiences revealed oscillation between loss of relationship; loss of identity and their own needs being overwhelmed; lack of connectedness to their partner and community; and uncertainty about the future. Despite these overarching feelings, a strong sense of attachment remained. Furthermore, peer support groups were reported to be of great comfort and allowed for information sharing and a sense of connectedness to be re-established between carers' (O'Shaughnessy *et al.* 2010). The clinical implications of the findings, demonstrate the need for services to provide professional support and to not overlook the inherent needs of carers' when the focus can all too often be on the individual with dementia.

This interpretative phenomenological study is a good fit for the research and the methodology used also supports the question. A clear audit trail using appropriate procedural and ethical rigour is described, which demonstrates the plausibility of the research process (Ryan *et al.* 2007). However, a key aspect of interpretative

phenomenology is not mentioned; that of the researcher and interviewer participating within the interview process together (Sorrell & Redmond 1995). This aspect may have occurred but there is a lack of clarity within the study regarding this issue. This may have lead to deeper insights being obtained by the process and thus enhancing the credibility of the study.

Lynggard H. & Alexander N. (2004) 'Why are my friends changing?' Explaining dementia to people with learning disabilities. *British Journal of Learning Disabilities* **32**, 30-34.

This paper focuses on addressing the underlying factors associated with individuals who have an ID, and are confused with regards to their housemates' development of dementia and associated unusual behaviours. The methodology employed was broadly based on Psychosocial Interventions. This model is participatory, reflective and educational, and is most often used to facilitate stress management, problem solving and stress reduction in adverse living conditions (Lynggard & Alexander 2004).

The aim of this study was to create opportunities for the participants to develop an understanding of dementia. The study included four participants who had an ID, and who lived with two housemates who had developed dementia. This appears to be the inclusion criteria, although the study lacks clarity on this issue. However, clearly these participants had an experience of the phenomena, which was the focus of this paper. The method outlined within the study, involved the participants meeting for a group session once every week over a six-week period. Each session discussed various aspects of cognition that were affected by dementia. The focus was on using simple games, exercises, feedback and role-play to aid the participants understanding of the changes their housemates were going through (Lynggard & Alexander 2004).

Prior to the educational group sessions, stage one of the study involved discerning the participants comprehension levels and experiences of dementia, to establish a baseline of their knowledge. Feedback from the participants at the end of each session provided the researchers with knowledge on how to proceed with the subsequent sessions, by gaining levels of understanding. Stage two of the study involved re-interviewing the participants

one month after the sessions (Polit & Beck 2010). The emerging themes from the interviews suggested that, each of the participants understood that their peers unusual and sometimes frustrating behaviours were due to their illness/dementia. Furthermore, there was a clear emergence of empathy and an improvement in their understanding for their housemates' cognitive decline.

There is no mention of establishing rigour within the study. However, in this regard the focus was on a participatory methodology. This was ensured by constant feedback from the participants after each session, which subsequently informed future sessions. Ethical approval was not referred to, which is surprising given the vulnerability of the group participating in the project and that it is a standard research procedure (Ryan *et al.* 2007). The authors acknowledge that they lack a clear research approach, which in turn affects the studies ability to evaluate the interviews with participants and the independent assessment of the project.

This study, although not based on research methodology, correlates with the phenomena that peer support groups and education can help develop understanding and reduce stress and anxiety in people with ID. The outcome of this type of participatory methodology demonstrates that services need to provide accessible information and address problems that can occur between housemates, thus improving their living environment and quality of life. Despite these weaknesses, it is clear that this project could be generalised into other settings, and a clearer research focus would strengthen the trustworthiness of the findings (Ryan *et al.* 2007).

Forbat L. & Wilkinson H. (2007) Where should people with dementia live? Using the views of service users to inform models of care. *British Journal of Learning Disabilities* **36**, 6-12.

This article explores the experiences of service users' who have, or live with someone who has dementia. It proposes that by attaining individuals' understandings of dementia, it can enhance service provision and ensure best practice when delivering services and care to people with ID. The introduction to this paper is well laid out, and illuminates the challenges that are faced in delivering effective care as people with ID age.

Although not clearly stated, the research design is within the qualitative mode, using a mix method approach. The study also lacks clarity on how the participants were recruited. According to Gerrish & Lacey (2010), criteria for sample selection regarding the ethnographical element of the study should be explicit which it is not. Nonetheless, it is apparent that in total there were 16 participants, 8 of whom had experiences of living with someone with dementia (these formulated the focus group) and 8 participants who had a diagnosis of dementia (involved in the ethnographic part of the study). However, of the 8 participants taking part in the ethnographic study, only 2 participants experiences were reported. This was due to the progressive nature of dementia, which impacted on their ability to participate in the study (Forbat *et al.* 2007).

The interviews were taped and transcribed and analysed using thematic analysis which organised developing themes and patterns from the interviews (Forbat *et al.* 2007). Rigor was supported in some of the study by describing aspects of an audit trail. A second researcher who analysed the transcripts supported the rigor of the analytic process. However, a major component of rigor is to provide evidence of how the researcher represents the participants' experiences (Ryan *et al.* 2007). Another important aspect is confirming that the interviews of the participants' experiences are typed verbatim. These should then be returned to the participants to confirm that it is a true reflection of their interview. The study lacks this important aspect and therefore the trustworthiness of the study has been impacted. The researchers could have enlisted the help of an advocate for the service users', which would enhance the credibility of the study (Parahoo 2006).

The main themes that emerged from the study of those living with a peer with dementia were; their lack of understanding around dementia; the sense of loss for a friend who was forgetful and confused; the increased amount of time staff spent looking after the person with dementia, and concerns of what will happen to their friends in the future.

Although the sample size is small, the researchers recognise that substantial claims cannot be made. However the experiences uncovered, highlight that there is an obvious need to develop service provision when individuals with ID develop dementia. It not only

affects the person with dementia, but also significantly impacts on the living environment of those sharing a house.

References:

Dolan P. (2011) *Time to Move on From Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings*. Health Service Executive, Dublin.

Forbat L. & Wilkinson H. (2007) Where should people with dementia live? Using the views of service users to inform models of care. *British Journal of Learning Disabilities* **36**, 6-12.

Gerrish K. & Lacey A. (2010) *The Research Process in Nursing*, 6th edn. Wiley-Blackwell, Oxford.

Lynggard H. & Alexander N. (2004) 'Why are my friends changing?' Explaining dementia to people with learning disabilities. *British Journal of Learning Disabilities* **32**, 30-34.

McCarron M. & Lawlor B. (2003) Responding to the challenges of ageing and dementia in intellectual disability in Ireland. *Aging and mental health* **7**, 413-417.

McCarron M., McCallion P., Fahey-McCarthy E. & Connaire K. (2011) The role and timing of palliative care in supporting persons with intellectual disability and advanced dementia. *Journal of Applied Research in Intellectual Disabilities* **24**, 189-198.

Morrissey J. & Callaghan P. (2011) *Communication Skills for Mental Health Nurses*. Open University Press, McGraw Hill, Maidenhead.

O'Shaughnessy M., Lee K. & Lintern T. (2010) Changes in the couple relationship in dementia care. *Dementia* **9**(2), 237-258.

Parahoo K. (2006) *Nursing Research: Principles, Process and Issues*, 2nd edn. Palgrave Macmillan, Hampshire.

Polit D. & Beck C. (2010) *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*, 7th edn. Lippincott Williams and Wilkins, Philadelphia.

Ryan F., Coughlan M. & Cronin P. (2007) Step-by-step guide to critiquing research. Part 2: qualitative research. *British Journal of Nursing* **16**(12), 738-744.

School of Nursing and Midwifery (2013) *Research Strengths* <http://www.nursing-midwifery.tcd.ie/research/strengths/> Retrieved 7th February 2013.

Sorrell M. & Redmond G.M. (1995) Interviews in qualitative nursing research: differing approaches for ethnographic and phenomenological studies. *Journal of Advanced Nursing*. **21**(6), 1117-1122.

Swanson K.A. (2007) Dementia and co-morbidities: an over-view of diagnosis and management. *Journal of Pharmacy Practice* **20**, 296-317.

Appendix One:



