

The role of community nurses for people with learning disabilities: working with people who challenge

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Abstract

The locus of care for people with learning disabilities has transferred from institutional to community-based services. Increasingly people who have learning disabilities and additional challenging behaviours live in community settings. Spearheading the care for these people are community nurses for people with learning disabilities. This study aimed to explicate the role of these nurses in their day-to-day work with people who challenge. Using grounded theory methodology, 22 nurses were selected by theoretical sampling and interviewed. An analytical story and theoretical framework that emerged from the grounded data is presented. It is suggested that this framework has utility for practice.

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1. Introduction

The term ‘learning disabilities’ is used here to describe people who have a significant impairment of intelligence combined with impairments in social functioning. Synonymous terminology such as developmental disabilities, mental retardation or intellectual disabilities has also been used to refer to this group of people (Northway and Jenkins, 2003). Many people with learning disabilities have, and are continuing to move from long stay institutional care where they previously resided to community based living options. Among such individuals are a significant number of people with

learning disabilities who additionally present with challenging behaviours (Zarkowska and Clements, 1987; Emerson, 2001). When these behaviours are severe in nature they can create difficulties that limit individual’s opportunities to break free from institutional dependence. Emerson (1995, p. 44) defines severe challenging behaviour as

culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities.

Slevin (1995) in an analysis of challenging behaviours among people with learning disabilities suggests these behaviours present a major challenge for nurses and members of caring families.

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National policy and social change in most developed countries dictate that the locus of care of people with learning disabilities is transferring to the community. Valuing People, A New strategy for people with Learning disabilities for the 21st Century (DoH, 2001) suggests that community living and inclusion be a human right of this population. Community services should strive to achieve this and nurses for people with learning disabilities can make significant contributions, for example in relation to health facilitation the report states learning disability nurses will be well placed to fulfil this role (DoH, 2001, p. 63). However, challenging behaviour among this client group is one of the greatest threats to the success of community care (DoH, 1993, Mansell Report; DoH, 2001, Valuing People). Lowe et al. (1996) propose that the closure of long-stay hospitals has created an expedient requirement for community-based services to meet the needs of people with learning disabilities who have challenging behaviours. As the care for people with learning disabilities transfers from institutional to community care, nurses who represent significant numbers of the service providers for this client group have the potential to make major valued contributions to meeting this challenge (Mobbs et al., 2002; Slevin, 2004). The nurses who provide this supporting service in the country where the study was undertaken are community nurses for people with learning disabilities (CNLD). Parahoo and Barr (1996) report that support for people with challenging behaviours is one of the most frequently reported reasons for referral to CNLD services. A number of other studies support this finding (Stewart and Todd, 2001; Border, 2002; Mobbs et al., 2002). In the UK region where this study was undertaken Slevin (2004) found that among the total 1985 clients on the CNLD combined caseloads, 550 (28%) were reported to have challenging behaviours. This phenomenon is an internationally recognised challenge (Borthwick-Duffy, 1994; Joyce et al., 2001; Salovita, 2002).

1.1. Role ambiguity

According to Perry and Perry (1997) status is a position that an individual occupies in society and 'role' is the acting out of the status each of us is given i.e. the behaviours, prerogatives and assumed responsibilities attached to the status. Within the confines of a hospital or institution roles are less ambiguous than within the context of community settings, and additionally hospital-based nurses roles are often medically orientated. Clarke and Cody (1994, p. 41) suggest that 'nursing theory-based practice is not feasible in institutions where medical orders overshadow all other disciplines'.

CNLD operate in multilayered communities and their role or what they actually do for people with learning disabilities is not always perceptible. It is suggested by

Kay (1995) that learning disability nurses are relatively under active in researching their practice. There are reasons for this, for example the tacit and often intangible nature of what these nurses do for clients, which some refer to as invisible care (Parrish and Sines, 1997). The idea of 'invisible care' is not unique to learning disabilities nursing, Kirby and Slevin (1992) suggest it exists to an extent in all branches of nursing. The concept of the 'intuitive practitioner' also suggests an indiscernible element in nursing care provision (Benner, 1984; Benner and Tanner, 1987). Kitson (1987, p. 328) has referred to this as nursing's 'Achilles heel' and she suggests the need to demonstrate the therapeutic value of nursing interventions. Birchenall et al. (1993), commenting on learning disability nursing, suggest that failure to clearly define roles has 'misled many to consider that an untrained workforce... would do the job as effectively'.

In view of this ambiguity the present study aims were to investigate the roles of community nurse for people with learning disabilities when caring for clients, and their carers, when the client is a person who indulges in challenging behaviours. While previous literature has explored the overall role of CNLD there is a dearth of research on the role of these nurses caring for people with learning disabilities who have challenging behaviours in community settings. The method utilised to conduct the study was therefore a grounded theory approach.

2. Methodology

Methodology (the study of methods) is about the underpinning philosophical assumptions of a study and not only description of methods. The difference is succinctly stated by Mautner (1997, p. 352) 'methodology is *about* method, and not the same as method'. While there is an increasing use of qualitative approaches in nursing research, nurses who use these approaches often fail to explicate the traditional methodologies that encapsulate the methods they use (Baker et al., 1992; Walters, 1995). In the present study the approach used was 'grounded theory' which is philosophically associated with symbolic interactionism. Symbolic interactionism is synonymous with the Chicago school of sociology and the perspectives of Mead (1934) and Blumer (1937). The approach is based on three main premises about life meanings and interactions:

1. Individuals act towards others on the basis of how they perceive life meanings for other persons and for their self.
2. The meanings acted upon are based on interactions and communicative expressions between and among individuals.

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