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Narrative analysis of the hospital experience for older parents of people who cannot speak ☆

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Abstract

In this study eight parents aged over 60 years participated in in-depth interviews about their experiences in supporting an adult son or daughter with cerebral palsy and complex communication needs (CCN) in hospital. A narrative analysis of the interviews provided insights into the nature of the parent carer's experiences in hospital. The results are presented as an interpretation of the participants' perceptions of their roles in hospital and the impact of these upon their health and wellbeing in older age. The participants' suggestions of how to improve the hospital care experience for all concerned are included and directions for future research are discussed.

Keywords: Parents; Unpaid carers; Complex communication needs; Cerebral palsy; Aging; Hospitalization; Developmental disability

1. Introduction

Older parents often provide vital care and support to their adult son or daughter with cerebral palsy and complex communication needs[1] (CCN) in hospital (Balandin, Dew, Llewellyn, and Kendig, 2004; Balandin et al., 2001; Buzio, Morgan, and Blount, 2002; Hemsley & Balandin, 2004). Adults with cerebral palsy enter hospital more frequently than the general population and have continuing health needs that require more frequent hospitalization as they get older (Bakheit et al., 2001; Young et al., 2005). In addition, adults with CCN experience difficulty interacting with nurses in hospital and rely upon their parents and other carers to provide care (Balandin, Hemsley, Sigafoos, & Green, in press; Buzio et al., 2002). Although parents are not obliged to provide support in the hospital (NSW Department of Health, 2005), both nurses and the adults with CCN have commented on the importance of this support (Balandin et al., in press; Balandin et al., 2001).

There is a growing body of knowledge relating to the caregiving experiences of older parents of adults with developmental disability (Bigby, 2000; Grant, 1990; Grant, Nolan, & Keady, 2003; Llewellyn, Gething, Kendig, &

☆ This paper is dedicated in memory of Graham Guest, an inspiration and pioneer in the field of cerebral palsy.

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[1] CCN is a broad term used to describe functional outcome in communication according to skills and needs: "Some people have CCN associated with a wide range of physical, sensory and environmental causes which restrict/limit their ability to participate independently in society. They and their communication partners may benefit from using Augmentative or Alternative Communication (AAC) methods either temporarily or permanently" (Balandin, 2002, p.2).

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Cant, 2004) and of carers' experiences with hospital care (Driscoll, 2000; Heaton, Arksey, & Sloper, 1999; Simpson, Scothern and Vincent, 1995). Over the past two decades parents have become increasingly involved in the care of their children in hospital (Fegran, Helseth, & Slettebo, 2006; Just, 2005). There is now substantial information available on the experiences of parents of children with developmental disability in hospital and their working relationships with hospital staff (Baruch, 1981; Espezel & Canam, 2003; Hallstrom & Elander, 2004; Kirk, 2001; Phua, Reid, Walstab, & Reddihough, 2005; Ygge, Lindholm, & Arnetz, 2006). However, there is little information available about the needs and experiences of older parents who take on a caring role in hospital, the impact of undertaking this supportive role as they age (Hemsley, Balandin, & Sheard, 2004; Hemsley, Balandin, & Togher, 2007), their working relationships with hospital staff, or their hospital care experiences in the context of their narrative of care across the lifespan. It is important to redress this gap in information about older carers as poor recognition of their needs may negatively affect their health and wellbeing thus influencing their capacity to care in the future (Kersten, McLellan, George, Mullee, & Smith, 2001). This, in turn, is likely to impact negatively upon the beneficiaries of that care, their adult offspring with disability (Hemsley et al., 2007).

Providing care to adults with cerebral palsy and CCN in hospital presents a number of challenges to older parents (Hemsley et al., 2007). These parents, like their age peers, may be experiencing a decline in function and health associated with their own aging (Australian Institute of Health and Welfare, 2003, 2004). Such age-related changes may restrict their ability to continue to provide care to their adult offspring with disability and may coincide with an age-related decline in their son or daughter with cerebral palsy (Strauss, Ojdana, Shavelle, & Rosenbloom, 2004). Thus, parents may experience difficulty in meeting the demands of caring along with an increased susceptibility to stress associated with providing such care (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998; Nolan and Lundh, 1999). Additionally, older parents may experience additional stress from age-related reductions in sources of support (e.g., retirement, moving away from a familiar area, the illness or death of spouses, relatives or friends) (Gabriel and Bowling, 2004). Furthermore, the responsibility of providing support in hospital may be accompanied by uncertainty and anxiety about who will provide such support when the parent is too frail or no longer alive (Hemsley & Balandin, 2004; Heron, 1998; Llewellyn et al., 2004).

The aim of the current project was to explore the experiences of parents who provide care to an adult son or daughter with cerebral palsy and CCN in hospital. We used a narrative analysis to develop an understanding of the narrative sequence and plot of the older parents' stories of experience in hospital, and to identify (a) how parents perceived their role in the hospital, (b) what parents perceived as strategies for and barriers to performing this role, (c) the impact of providing care and support on the parent, and (d) ways to improve the hospital care experience for parents.

2. Method

Participants

Eight parents of seven adults with cerebral palsy and CCN participated in this study. Their ages ranged from 60 to 75 years with a mean age of 66 years. All the parents had provided care to an adult with cerebral palsy and CCN during a hospital stay of three or more days in the past two years. The total number of days the parents provided support to their son or daughter in hospital was 244 days with a range from 10 to 77 days and a mean of 30.5 days. The care had been provided in nine metropolitan hospitals. The participants were recruited through an organization that provides services to people with cerebral palsy. Managers at community access and accommodation services in the organization distributed an invitation to participate to all parents who had provided support in hospital to an adult son or daughter in the past two years. All who responded to the invitation to participate were interviewed. Information on the eight older participants (including their age, living situation, patterns of attendance in care and wards attended in providing care in hospital) is presented in Table 1.

Interviews

Individual, in-depth interviews were used to gather narrative data to explore each participant's experiences. The first author, a speech pathologist, conducted the conversational style interviews at the participants' homes. Each interview lasted a maximum of 2 h and was audio-taped and transcribed verbatim. A topic list that included issues highlighted in previous research into communication in hospital (Balandin et al., 2001; Hemsley et al., 2001) was also used to guide