

Older Unpaid Carers' Experiences Supporting Adults with Cerebral Palsy and Complex Communication Needs in Hospital

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Abstract Older unpaid carers provide vital support to their adult sons or daughters with cerebral palsy who have complex communication needs during hospital stays. To date, there is little research into their experiences or the impact of providing such care on the carer and other family members. Knowledge of the experiences of the older unpaid carer is needed to inform development of a) strategies for supporting older carers of adults with disability who are unable to speak in hospital, and b) other alternatives for provision of support to these adults during periods of hospitalization. Such information could be used in training health care providers to adequately care for the adult with cerebral palsy and complex communication needs when the older carer is no longer able to provide support. This review will summarize the literature relating to older unpaid carers of adults with cerebral palsy and complex communication needs in hospital, and identify directions for future research and development in the field of supporting older carers of adults with complex communication needs.

Keywords Complex communication needs · Carers · Cerebral palsy · Ageing · Hospitalization

There is a growing body of evidence that older unpaid carers of adults with cerebral palsy and complex communication needs¹ provide vital support to their adult sons and daughters in hospital (Balandin, Dew, Llewellyn, & Kendig, 2004; Balandin et al., 2001; Buzio, Morgan, & Blount, 2002; Hemsley & Balandin, 2004). When adults with cerebral palsy and complex communication needs enter hospital their older unpaid carers may spend extended periods

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¹CCN is a broad term used to describe functional outcome in communication according to skills and needs: "Some people have complex communication needs 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).

of time with them on the ward as unpaid carers. Older unpaid carers provide advocacy and support, undertake caring duties, and assist with communication in the hospital (Hemsley & Balandin, 2004). Older unpaid carers of adults who do not have a functional method for communication with nursing staff have reported feeling that they had no choice but to stay at the bedside for extended periods of time to provide reassurance and support, interpret communication attempts and speak on behalf of their son or daughter (Hemsley & Balandin, 2004). They noted that this is stressful and exhausting. They also voiced their fears for the future when they will no longer be able or available to provide such support (Hemsley & Balandin, 2004).

The work of the older unpaid carer of the adult with cerebral palsy and communication difficulties does not go unnoticed by the recipient of care or hospital staff. Indeed, both adults with cerebral palsy and complex communication needs and the nurses who care for them in hospital have stressed that presence of an unpaid carer, usually a family member or spouse, is critical to providing good health care and promoting a positive hospital experience (Balandin et al., 2004; Buzio et al., 2002; Hemsley & Balandin, 2004). Nurses have acknowledged that they lack knowledge and experience in caring for adults who are unable to speak and must rely upon unpaid carers to provide communication support in hospital (Balandin et al., 2001; Hemsley & Balandin, 2004; Hemsley et al., 2001). Despite apparent complexities in the care of these patients, few if any hospitals have policies on the care of the patient with complex communication needs (Balandin et al., 2001) and there is little information or resources available to assist unpaid carers in the time they are at the hospital (e.g., provision of meals, accommodation, safe parking, security when leaving wards late at night) (Hemsley & Balandin, 2004).

Despite a growing awareness and recognition of the important role of the older unpaid carer in hospital, to date there is little information available about the needs and experiences of the older unpaid carer in hospital, or the impact of this caring role on them as they age and their families (Hemsley, Balandin, & Sheard, 2004). Unpaid carers have reported that providing care and support in hospital for extended periods of time is “exasperating” and “horrible” (Hemsley & Balandin, 2004, p. 247). However, the impact of these often extended periods of care upon older carers’ (a) capacity to continue to provide care, (b) health, and (c) quality of life is not known. Older people have reported that concerns about the health of loved ones does impact negatively upon quality of life in older age (Gabriel & Bowling, 2004). Gabriel and Bowling (2004), conducted a qualitative study involving in-depth interviews with 80 older people aged 65 and over as a follow-up to a larger survey of 999 older people aged 65 and over. They concluded that health and functional ability, social roles and activities, and home and social supports are among six central tenets in the quality of life of older people. Participants in the study reported that concerns for the health of relatives had a negative impact on their quality of life in older age (Gabriel & Bowling, 2004). Just over a quarter ($n = 21$) of the participants said that poor health in others close to them resulted in worry about the person’s health or the burden of caring for the person through their illness, and reported that this had a negative impact on the participants’ quality of life.

It is possible that the combination of the older carer’s own aging and aging of the adult son or daughter with life-long disability impacts negatively upon the health and quality of life of older carers. Adults with life-long disability (e.g., cognitive impairment) have a higher incidence of health problems than people without disability (Beange & Lennox, 1998; Beange, McElduff, & Baker, 1995; Kapell et al., 1998). Adults with cerebral palsy often experience an age-related decline in function (Strauss, Ojdana, Shavelle, & Rosenbloom, 2004) and health (Klingbeil, Baer, & Wilson, 2004). At the same time, the older carer also is likely to be facing a decline in functioning and health associated with aging (Australian

Institute of Health and Welfare, 2003, 2004). Thus, at a time when they themselves are aging and at increased risk of developing age-related disability (Australian Institute of Health and Welfare, 2003), older carers of adults with cerebral palsy and complex communication needs may have to confront the combined impacts of a) increased concern over the health of the person they care for; and b) increased demands and stresses associated with caring in hospital.

Knowledge of the hospital experiences of the older carers of adults with cerebral palsy and complex communication needs is urgently needed to ensure that adequate supports are in place to enable them to either continue to provide care into older age or to pass on the caring role to others. Such information is critical for development of hospital and disability service policies, procedures, and training programs designed to ensure positive health outcomes for the patient with cerebral palsy and at the same time to minimize the negative impact of the hospitalization on the older carer. Such knowledge will also assist in developing alternatives for provision of future care when the older unpaid carers are no longer alive and provision of care falls to others including family members and disability services.

Unpaid carers of people with cerebral palsy: Providing support in hospital

Unpaid carers of children in hospital

Older unpaid carers of adults with cerebral palsy and complex communication needs usually have extensive experience in providing care gained over the lifespan of the adult with disability and may have experienced the stress of having a son or daughter hospitalized many times. Children with cerebral palsy have reduced health related quality of life in relation to severity of their disability (Vargus-Adams, 2005) and are frequently hospitalized for a range of interventions (Raina et al., 2005). Indeed, parents of children with and without disability are encouraged to be with their children as much as possible during periods of hospitalization (Alsop-Shields & Mohay, 2001; Livesley, 2005). They provide support and comfort to the child and assist in care, and their presence helps to avert the negative impacts of separation anxiety, isolation or loneliness on the child (Alsop-Shields & Mohay, 2001). The value of their presence is recognized by hospital staff and the parents are supported in their caring role through provision of accommodation options and facilities within the hospital ward (Robinson, Oxnam, Kelly, Broadbent, & Dillon, 1993). Despite such provisions, recent research has indicated that parents of children with multiple disabilities and complex communication needs experience difficulties in developing working relationships with hospital staff related to the child's disability (Kearney, Nagy, Wright, & Firkins, 2001). For these parents a period of hospitalization is a very stressful time. Hayes and Knox (1984) interviewed 40 parents of children with multiple disabilities about their hospital experience and noted that they needed to adapt their usual parenting roles to caring in hospital, become familiar with the hospital setting, and negotiate their caring roles on the ward. The authors postulated that much of the parental stress arising during hospitalization could be accounted for by the differences in understanding of the parent's role on the ward by the nursing staff and the parent.

Parent perceptions of hospital staff's knowledge and experience in working with people with disability may also contribute to their stress in hospital. Parents have reported that hospital staff have negative attitudes to disability, and lack knowledge and experience in disability (Kearney et al., 2001; Robinson et al., 1993). Kearney et al. (2001) interviewed fifteen mothers and two fathers of children with severe and multiple disability (communication, physical, and intellectual disability) about their hospital experiences and used grounded

theory to analyse the conversational in-depth interviews. The parents reported experiencing practical problems in provision of care, with nursing staff misinterpreting the children's behavior and lacking expertise in caring for children with physical disability. As a result, parents perceived a lack of safety and security for their children in the hospital. These parents believed that nursing staff were not comfortable in interacting with children with disability, particularly those with a communication disability. Some parents reported that they felt they were *expected* to stay with their children at all times; others believed that their children were not receiving adequate monitoring, particularly at nighttime (Kearney et al., 2001).

Although there is recognition that hospital experiences are stressful for parents of children with disability, it is not known what influence, if any, previous hospital caring experience in earlier years have upon caring experiences in adulthood, or what carers learn about providing care in hospital during repeated occasions of care. Such information is relevant to a better understanding of the unpaid carer's perceptions of their role and the development of strategies so that others may provide optimum care when the older unpaid carer is no longer able to fulfill a caring role in hospital.

Unpaid carers of adults with life-long disability in hospital

There is some evidence to suggest that parent involvement in care does not reduce, and may even increase, when the person with disability enters adult wards. When people with disability move from pediatric to adult wards, their parents often continue to attend the hospital to perform many duties traditionally performed by nurses on adult wards (e.g., mealtime assistance, transfers, personal care, toileting, bathing, and showering) (Atkinson, 1992; Dewing, 1991). The rationale for this increased involvement (compared to involvement of relatives of adults without disability) is (a) presence of disability and the resulting increase in dependence upon others for core activities of daily life (mobility, communication and self-care); and (b) nursing staff do not have time to meet the need for support in these activities. In a study addressing attitudes of nursing staff to people with learning disabilities in hospital, Slevin and Sines (1996) reported that nurses appreciated unpaid carers being present to assist with care because it removed the need for the nurse to interact directly with the person in hospital. In a personal narrative account of her hospital experiences with her daughter Kathy, who had severe and multiple disabilities, Fitton (1994) noted a perceptible change in the care provided when Kathy moved from the pediatric to the adult ward in the hospital. Fitton reported that she felt an increased responsibility for care and that she needed to spend increasing amounts of time at the hospital because of her daughter's difficulties in communicating with hospital staff. Fitton assumed all but medical care of Kathy while she was in hospital, and took on many roles normally carried out by hospital staff. The impact on the older carers of taking on increasing roles in care in the hospitalization of adults with cerebral palsy and complex communication needs, and the effect of this upon their continued ability to provide care immediately after discharge from hospital, is not known. Nevertheless, we do know that poor communication is a factor in poor discharge planning (Armitage & Kavanagh, 1998; Efraimsson, Sandman, Hydén, & Rasmussen, 2004) and that communication problems including failed communication between staff and patients costs hospitals in USA between \$17 and \$29 billion a year (Aubato, 2004).

A unique role in care?

Assumption of nursing tasks, rather than relinquishing care to hospital staff, may differentiate carers of adults with cerebral palsy and complex communication needs from carers of other

adults, who do not necessarily attend the hospital with the intention of providing care, and who may use the period of hospitalization as an opportunity for gaining some respite from caregiving responsibilities (McKay, North, & Murray-Sykes, 1983). In a study investigating the effect on carers of hospital admissions of elderly people hospitalized with respiratory illness, McKay et al. (1983) reported that some carers of older people welcomed hospital admission as it relieved them of some of the pressures of caring at home. Simpson, Scotern, and Vincent (1995) reported similar findings in a survey of carer satisfaction with hospital quality of care for adults with dementia. Half of the 40 participants, all carers of adults with dementia, reported positively on the hospitalization of the person for whom they cared. The reduced caregiving responsibilities during the period of hospitalization allowed them to rest. Although one of the participants mourned the necessity of the separation associated with hospitalization he noted that without some rest he could not continue providing care. These older carers of adults with dementia, unlike the older unpaid carers of adults with cerebral palsy and complex communication needs (Fitton, 1994; Hemsley & Balandin, 2004), perceived that hospital staff were suitably qualified to provide adequate care for their relative, and to meet their special care needs. Consequently they were able to relinquish or suspend their primary care responsibilities to hospital staff, and during this time enjoy a respite from care. They experienced rejuvenation in their capacity to provide care after discharge that enabled them to meet the demands of caring for the relative with dementia. Such research highlights the potential emotional and psychosocial benefits to the carer, and also the care recipient (after discharge) of being ready, willing or able to relinquish or transfer care of the person in hospital to hospital staff. However, unpaid carers who have held responsibilities for the adult with cerebral palsy's health and wellbeing over his or her lifetime may have greater difficulty in entrusting care of the person to hospital staff, particularly as they get older.

Aging and changes in demand and capacity to provide unpaid care in hospital

Aging of the adult with cerebral palsy

Adults with cerebral palsy are now living longer (Rapp & Torres, 2000; Strauss et al., 2004); consequently, the care responsibilities of family members and other carers will also continue for longer. Increased longevity in the adult with cerebral palsy is associated with a decrease in functional skills in the later life (Crichton, Mackinnon, & White, 1995). In fact, these age-related changes may be seen at an earlier age in adults with cerebral palsy than in people without disability (Balandin & Morgan, 1997, 2001). Although cerebral palsy is a non-progressive disorder (Mutch, Alberman, Hagberg, Kodama, & Velickovic, 1992; Scherzer, 2001), some researchers have suggested that people with cerebral palsy may experience a decline in function and health, and an associated increase in support needs as early as 30 years of age. (Andersson & Mattsson, 2001; Balandin & Morgan, 1997; Overeynder, Turk, Dalton, & Janicki, 1992; Strauss et al., 2004). This decline in function may become more pronounced as the person with cerebral palsy gets older. Strauss et al. (2004), in studying the functional deterioration and life expectancy of adults with cerebral palsy, examined 904 adults with cerebral palsy aged 60 and above. Strauss et al. noted a marked decline in this group of adults' functional skills, particularly in mobility and self-care, especially in late adulthood. Klingbeil et al. (2004) presented a comprehensive review of studies on people aging with a disability, including 28 studies relating to people aging with cerebral palsy. The authors described a range of physical impacts of aging with cerebral palsy. They concluded that functional deterioration in adults with cerebral palsy could arise "as a consequence of a life-long of

abnormal movements, altered postures, immobility, chronic medication consumption, and poor nutrition” (p. S69) and was also associated with conditions commonly accompanying cerebral palsy (e.g., epilepsy, intellectual disability and communication disorders). Klingbeil et al. (2004) commented that such changes may not be anticipated, and can result in increased dependence in care and changes in role of the person and their carers. As a result of any deterioration in function or health of the adult with cerebral palsy, the older unpaid carer must cope with increasing caregiving demands as they and the person they care for age. Indeed, these older carers may be faced with an increasing burden of care at a time when they themselves are feeling the effects of aging, experiencing the onset of age-related illness or disability (Australian Institute of Health and Welfare, 2004) and consequently having a reduced capacity to provide direct support to the person for whom they care.

Aging of the older unpaid carer

Older carers of adults with cerebral palsy and complex communication needs face a number of challenges in continuing to provide care in hospital as both they and the adult they care for grow older. Trends in the increasing age of the general population are reflected in the increasing age of carers and of the recipients of care. Like other older people in the general population, older carers of adults with disability are more likely than younger carers to experience age-related disability that result in severe or profound restriction in activities of daily life² (Australian Institute of Health and Welfare, 2003). Pickard, Shaw, and Glendinning (2000) commented that older carers are more likely than other carers to have age-related illness. Indeed, in Australia in 1998, 9% percent of primary carers over the age of 65 reported a severe or profound restriction in a core activity³ of daily life (Australian Institute of Health and Welfare, 2004). Such restrictions in skills and activities could in turn restrict the older carer’s ability to continue to provide care into the future.

Quality of life and caring into older age

Onset of age-related illness or decline in function might reduce the older carer’s capacity to meet the increased physical and other demands of providing assistance to the adult with cerebral palsy, and increase their susceptibility to stress associated with caring (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998). Therefore, older carers may be ill equipped to take on extra caregiving responsibilities associated with supporting sons or daughters in hospital. Also, the need to provide care in hospital is likely to occur at a time when the older carer has fewer sources of support. Like other older people, these carers have a gradually diminishing network of support through retirement, moving away from a familiar area, or the illness or death of spouses, relatives or friends (Gabriel & Bowling, 2004). In a national survey on quality of life in older age, older people reported that feeling useful, being active and volunteering to help others was associated with an increase in quality of life (Gabriel & Bowling, 2004). However, feeling worried or responsible for family members, particularly those in poor health, contributed negatively to their quality of life in older age (Gabriel & Bowling, 2004).

²Daily activities include communication, mobility and self-care, occupation, leisure and domestic tasks (Australian Institute for Health and Welfare, 2003).

³Core activities are defined as being communication, mobility and self-care (Australian Institute for Health and Welfare, 2004).

Preparing for the future

While making efforts to meet the physical demands of caring in later life, older carers experience anxiety that they will be unable to provide care (Heron, 1998). Increasing responsibilities in providing support in hospital may be accompanied by uncertainties as to who will carry on such support in hospital when the older carer is no longer alive (Hemsley & Balandin, 2004). Carers may make informal arrangements but service providers may not be aware of what supports are in place and future support for the person with a disability may be fragmented (Bigby, 2000).

Further research is needed to explore the impact on the older unpaid carer or their families of changes associated with aging, the onset of age-related disability, and any decreasing capacity in the older unpaid carer to meet care needs as they and the recipient of care get older. Such information will be useful in helping older unpaid carers plan for the future when they may not be able to provide such support in hospital, and may avoid the need for crisis intervention by already stretched services. Like older parents of adults with intellectual disability, older unpaid carers of adults with cerebral palsy and complex communication needs (Bigby, 1997, 2000) may need support to formalize arrangements for the future when they are no longer able to provide support in hospital and to let others know about these arrangements.

Conclusions

It is apparent that older unpaid carers of adults with disability who are unable to speak cannot and do not rely solely upon the health care system to adequately care for their adult sons or daughters in hospital (Fitton, 1994; Hemsley & Balandin, 2004). Nurses themselves perceive that they cannot adequately care for a person with disability who is unable to speak without support from an unpaid carer familiar with the person's method of communication (Hemsley et al., 2001). When the person with cerebral palsy who is unable to speak enters hospital, unpaid carers often step in to meet the person's support needs, carrying out caring duties usually carried out by hospital staff and assisting them in communication (Balandin et al., 2004; Buzio et al., 2002).

Although there is growing recognition of the importance of unpaid carers who provide support in hospital, little is known of the patterns of care, the type of care or support provided or the impact upon them of providing such support in older age (Hemsley et al., 2004). To date, there has been limited exploration of how provision of care and support in the hospital setting impacts on the life of the older unpaid carer, or the consequences if he or she is unable to be present in the hospital. Without such information, it is difficult to determine ways to support older carers, either in continuing to provide care in the hospital, or in passing on this role to other carers or to hospital staff. Such information is urgently needed to inform development of alternatives for provision of support for adults with disability who are unable to speak in hospital, and to ensure that health care providers have the skill to provide adequate care after the parent is dead or too frail to provide care.

If older carers are to provide care and support in hospital over time, it is critical that they have effective avenues for support to enable a continuation of care into older age. In addition, it is important that alternatives for provision of care in hospital be developed as caregiving demands increase, and when the older carer is no longer able to provide such assistance in the hospital. Consideration also needs to be given as to how best to continue to meet the surviving adult with cerebral palsy's increasing hospital support needs after the death of the

parent. In addition, older unpaid carers provide vital support to their adult sons and daughters in hospital and relieve the burden of care of nursing staff. Therefore, development of policies to provide guidance to hospital staff and unpaid carers in their role in the hospital setting would be helpful for all concerned in this caring experience.

Directions for future research

Further research into the experiences of older carers of adults with cerebral palsy and complex communication needs is urgently needed to explore a) the nature of the experience for the older carer, and changes in this over the lifespan; b) the roles and strategies the older carer adopts in providing support in hospital; c) whether and how older carers are supported in fulfilling such a role through provision of training, policies and guidelines that relate to their role and to adults with complex communication needs in hospital; d) strategies for passing over their expertise to others in preparation for the future; and e) whether and how they may assist in addressing barriers to communication in hospital. Knowledge of the communication experiences and roles of older carers will also help improve communication and health care outcomes for people who are unable to speak in hospital, in clarifying how best to support both the person with complex communication needs and staff in communicating in hospital. It will also inform the development of hospital policies to ensure that those with complex communication needs are not disadvantaged or discriminated against during a hospital stay. Furthermore, such information could be applied to alleviate difficulties commonly encountered by other unpaid carers and all staff who interact with people who cannot speak in hospital. This knowledge would help ensure that the period of hospitalization is as stress free as possible for all concerned and ultimately may lead to better health outcomes for the person with cerebral palsy and complex communication needs. It is important to have a holistic understanding of the environmental, emotional, social and work related pressures that may arise in the context of hospital care.

It can be argued that a qualitative research methodology, that explores the social and psychological aspects of the hospital experience, would be suitable to exploring these issues, and indeed to create a detailed picture of the nature of the experience for the older unpaid carer (Polkinghorne, 1995).

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References

- Aduato, S. (2004). Making the communication connection. *Nursing Management*, 35, 33–35.
- Alsop-Shields, L., & Mohay, H. (2001). John Bowlby and James Robertson: theorists, scientists and crusaders for improvements in the care of children in hospital. *Journal of Advanced Nursing*, 35(1), 50–58.
- Andersson, C., & Mattsson, E. (2001). Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion [see comment]. *Developmental Medicine & Child Neurology*, 43(2), 76–82.
- Armitage, S. K., & Kavanagh, K. M. (1998). Consumer-orientated outcomes in discharge planning: a pilot study. *Journal of Clinical Nursing Inquiry*, 7, 67–74.
- Atkinson, F. I. (1992). Experiences of informal carers providing nursing support for disabled dependants. *Journal of Advanced Nursing*, 17(7), 835–840.

- Australian Institute of Health and Welfare (2003). *Disability prevalence and trends*. Canberra: Australian Institute for Health and Welfare.
- Australian Institute of Health and Welfare (2004). *Carers in Australia: assisting frail older people and people with a disability*. Canberra: Australian Institute of Health and Welfare.
- Balandin, S. (2002). Message from the President. *International Society for Augmentative and Alternative Communication Bulletin*, 67, 2.
- Balandin, S., Dew, A., Llewellyn, G., & Kendig, H. (2004). Communicating in hospital without functional speech. *Journal of Intellectual Disability Research*, 48, 425–443.
- Balandin, S., Hemsley, B., Sigafoos, J., Green, V., Forbes, R., Taylor, C., et al. (2001). Communicating with Nurses: The Experiences of 10 Individuals with an Acquired Severe Communication Impairment. *Brain Impairment*, 2(2), 109–118.
- Balandin, S., & Morgan, J. (1997). Adults with cerebral palsy: What's happening? *Journal of Intellectual and Developmental Disability*, 22(2), 109–124.
- Balandin, S., & Morgan, J. (2001). Preparing for the future: Aging and AAC. *Augmentative and Alternative Communication*, 17, 99–108.
- Beange, H., & Lennox, N. (1998). Physical aspects of health in the learning disabled. *Current Opinion in Psychiatry*, 11(5), 531–534.
- Beange, H., McElduff, A., & Baker, W. (1995). Medical disorders of adults with mental retardation: a population study. *American Journal on Mental Retardation*, 99(6), 595–604.
- Bigby, C. (1997). Parental substitutes? The role of siblings in the lives of older people with intellectual disability. *Journal of Gerontological Social Work*, 29(1), 3–21.
- Bigby, C. (2000). *Moving on without parents: Planning, transitions and sources of support for older adults with intellectual disabilities*. New South Wales: McLennan and Petty.
- Buzio, A., Morgan, J., & Blount, D. (2002). The experiences of adults with cerebral palsy during periods of hospitalisation. *Australian Journal of Advanced Nursing*, 19(4), 8–14.
- Crichton, J. U., Mackinnon, M., & White, C. P. (1995). The life expectancy of persons with cerebral palsy. *Developmental Medicine and Child Neurology*, 37, 567–576.
- Dewing, J. (1991). Physically disabled people in acute care. *Nursing Standard*, 5(22), 37–39.
- Efraimsson, E., Sandman, P. O., Hydén, L. C., & Rasmussen, B. H. (2004). Discharge planning: 'fooling ourselves?'—patient participation in conferences. *Journal of Clinical Nursing*, 13, 562–570.
- Fitton, P. (1994). *Listen To Me: Communicating the needs of people with profound intellectual and multiple disabilities*. London: Jessica Kingsley Publishers Ltd.
- Gabriel, Z., & Bowling, A. (2004). Quality of life in old age from the perspectives of older people. In A. Walker & C. H. Hennessy, (Eds.), *Growing older: quality of life in old age* (Vol. 9, pp. 14–34). Maidenhead, England: Open University Press.
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, 42(Pt 1), 58–71.
- Hayes, V. E., & Knox, J. E. (1984). The experience of stress in parents of children hospitalized with long-term disabilities. *Journal of Advanced Nursing*, 9, 333–341.
- Hemsley, B., & Balandin, S. (2004). Without AAC: The Stories of Unpaid Carers of Adults with Cerebral Palsy and Complex Communication Needs in Hospital. *Augmentative and Alternative Communication*, 20(4), 243–258, p. 247.
- Hemsley, B., Balandin, S., & Sheard, C. (2004). Older parent carers of adults with complex communication needs and their experiences in providing unpaid care in hospital. *Journal of Intellectual Disability Research*, 48, 425.
- Hemsley, B., Sigafoos, J., Balandin, S., Forbes, R., Taylor, C., Green, V. A., et al. (2001). Nursing the patient with severe communication impairment. *Journal of Advanced Nursing*, 35(6), 827–835.
- Heron, C. (1998). *Working with carers*. London: Jessica Kingsley Publishers.
- Kapell, D., Nightingale, B., Rodriguez, A., Lee, J. H., Zigman, W. B., & Schupf, N. (1998). Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation*, 36(4), 269–279.
- Kearney, P., Nagy, S., Wright, H., & Firkins, A. (2001, 11–12 October). *These sorts of kids...* Paper presented at the Children on the margin, 8th National Conference of the Association for the Welfare of Child Health (AWCH). Powerhouse Museum, Sydney.
- Klingbeil, H., Baer, R., & Wilson, P. E. (2004). Aging with a disability. *Archives of Physical Medicine & Rehabilitation*, 85(S3), S68–73, p. S69.
- Livesley, J. (2005). Telling tales: a qualitative exploration of how children's nurses interpret work with unaccompanied hospitalized children. *Journal of Clinical Nursing*, 14, 43–50.

- McKay, B., North, N., & Murray-Sykes, K. (1983, November 30). The effect on carers of hospital admission of the elderly. *Nursing Times*, 42–43.
- Mutch, L., Alberman, E., Hagberg, B., Kodama, K., & Velickovic, M. (1992). Cerebral palsy epidemiology: where are we now and where are we going? *Developmental Medicine & Child Neurology*, 34, 547–555.
- Overeynder, J., Turk, M., Dalton, A. J., & Janicki, M. P. (1992). *I'm worried about the future: The aging of adults with cerebral palsy*. Albany, New York: New York State Developmental Disabilities Planning Council.
- Pickard, S., Shaw, S., & Glendinning, C. (2000). Health care professionals' support for older carers. *Ageing and Society*, 20, 725–744.
- Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. *Qualitative Studies in Education*, 8(1), 5–23.
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehau, J., Walter, S. D., Russell, D., et al. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115, 626–636.
- Rapp, C. E., Jr., & Torres, M. M. (2000). The adult with cerebral palsy. *Archives of Family Medicine*, 9(5), 466–472.
- Robinson, A., Oxnam, C., Kelly, S., Broadbent, J., & Dillon, M. (1993). *A study into nursing children with disabilities in an acute care context: The 3W Disability Awareness Group research report*. Melbourne: Centre for Studies in Paediatric Nursing, Royal Children's Hospital Melbourne.
- Scherzer, A. L. (Ed.). (2001). *Early diagnosis and interventional therapy in cerebral palsy: An interdisciplinary age-focused approach* (3rd ed.). New York: Marcel Dekker, Inc.
- Simpson, R., Scotern, G., & Vincent, M. (1995). Survey of carer satisfaction with the quality of care delivered to inpatients suffering from dementia. *Journal of Advanced Nursing*, 22(3), 517–527.
- Slevin, E., & Sines, D. (1996). Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact, and graduate-non-graduate status, a comparative study. *Journal of Advanced Nursing*, 24(6), 1116–1126.
- Strauss, D., Ojdana, K., Shavelle, R., & Rosenbloom, L. (2004). Decline in function and life expectancy of older persons with cerebral palsy. *NeuroRehabilitation*, 19(1), 69–78.
- Vargus-Adams, J. (2005). Health-related quality of life in childhood cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, 86, 940–945.