

Young people with brain injury in nursing homes: not the best option!

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Abstract

We discuss the growing needs for appropriate accommodation for young people with acquired brain injury by exploring the accommodation of young people with brain injury in nursing homes. While the actual number is not clear, it is certainly expected to grow. Reviewing the literature and drawing on clinical experience exposes how nursing home becomes an option for these people. We argue that this should not be an option for this typically young male population, and give some suggestions for more appropriate accommodation.

Introduction

Advances in medical management and rehabilitation have brought about increases in survival rates and life expectancy of people following injury or illness (Rosenthal 1999, Whenman, West, Johnson & Cifu 1999). Rehabilitation after acquired brain injury, however, can be a very slow process that continues long after discharge from the inpatient rehabilitation setting (Kaplan 1991). Suitable accommodation for the slow to recover person appears to be limited in Australia. Families faced with the overwhelming feelings of taking a person home sometimes see the nursing home as their only option (Brain Injury Association of NSW 2000).

There are approximately 370,000 people in Australia who have sustained a brain injury (Brain Injury Association of NSW 2001a). More than 160,000 of these people have been severely affected and require some form of personal assistance or supervision with everyday living (Brain Injury Association of NSW 2001b) and this number is growing. In New South Wales (NSW) it is estimated 45,067 people will sustain a brain injury each year (Brain Injury Association of NSW 2001b). Many of these, especially those who have sustained a traumatic brain injury will be young males, typically aged 15 to 29 years (Fortune & Wen 1999).

The purpose of this paper is to draw attention to the growing need for appropriate accommodation for young people with acquired brain injury. After a brief explanation of acquired brain injury, we will discuss the number of young people with brain injury living in nursing homes, and explain how nursing home becomes an option. Finally, why nursing home should not be the option will be discussed.

What is acquired brain injury?

Acquired brain injury (ABI) is a collective term used to describe brain injury sustained as a result of traumatic or non-traumatic events. It is "injury to the brain, which results in deterioration in cognitive, physical, emotional or independent functioning" (Department of Human Services 1994 pp 29). Traumatic brain injury (TBI) is caused by an external event such as a blow to the head, a fall, or as a result of a motor vehicle accident. Non-traumatic brain injury is caused by an internal event such as a cerebral vascular accident, infection or hypoxia (Brain Injury Association of NSW 2001b).

Problems associated with acquired brain injury are many and varied. These include decreased attention and concentration, memory impairment, agitation, confusion, behaviour difficulties such as reduced ability to manage anger, communication difficulties due to receptive or expressive aphasia, difficulty swallowing, reduced co-ordination and balance, and muscle weakness or paralysis (Gatens & Hebert 1996; Label 1997; McKinlay & Watkiss 1999). Any combination of these difficulties can severely limit a person's ability to function independently in the community.

How many people with brain injury live in nursing homes?

The answer to this question is far from clear. However, recent reports shed some light. Furthermore, the fact that this information is recent and that it has originated from government departments (Ageing and Disability Department, Commonwealth Department of Health and Aged Care, Australian Institute of Health and Welfare) as well as community welfare groups (Brain Injury Association of NSW and the Melbourne Citymission) indicates a growing interest in accommodation for people with ABI.

No national estimate could be found for the number of younger people (ie, under 65 years) with ABI who live in nursing homes in Australia. However, the Ageing and Disability Department suggests that in 1996 in NSW, 570 people with ABI aged 20 to 65 years were in nursing homes (Cited in Brain Injury Association NSW 2001c). In 1998 in Victoria, 89 young people with ABI, 61 of whom are aged between 45 and 59 (Stringer 1999) were living in nursing homes. It has also been predicted that in Victoria "a further 40 long term placements into nursing homes will take place over the following 18 months" (Stringer 1999 pp 4).

Less formal data was also collected in 2000 in a study of the accommodation support needs of people with ABI in NSW. The Brain Injury Association of NSW surveyed eight services that provide support to people who have ABI (Brain Injury Association of NSW 2000). One hundred and twenty nine people were identified who lived in supported accommodation. These included 106 in nursing homes, five who were "long stay residents of local hospitals", 14 in "institutions", three in "inappropriate support in hostel care" and one "living in a boarding house that may close soon" (Brain Injury Association of NSW 2000). Regardless of the source, there is no doubt that the accommodation of young people with ABI in nursing homes in Australia is not an isolated occurrence.

How does nursing home become an option?

Return to pre-injury or illness accommodation in the community is not always an option, because of the wide range of problems associated with ABI and its 'slow-to-recover' nature. The duration of the accommodation crisis lengthens, because many people are young males with a normal life expectancy (Fortune & Wen 1999).

Families find themselves in an unenviable situation when they see placement in a nursing home as the last resort. Sutker (1993) explains families have usually exhausted all other possibilities and have often endured personal, social and economic stress in the process, making the final decision with great reluctance. Nursing home becomes an option for a range of very common reasons. These include limited accommodation options for young people with ABI, family and carer burden, limited respite for families, financial constraints, and ageing carers.

Firstly, accommodation specifically designed to meet the needs of young people with ABI is limited in Australia (Ramsey & Hilson 1995; Fortune & Wen 1999; Brain Injury Association of NSW 2001c). Ideally, these services will have a rehabilitation and community reintegration focus, and cater for the lifestyle of younger people (Bishop & Kent 2000).

Secondly, family and carer burden are common sequelae of ABI. Patients are often discharged to the care of family, given that 60% of hospital separations for people with ABI are aged 15 to 64 years (Fortune and Wen 1999). As a consequence, the burden of care shifts from the health care system to the family. This is often to the detriment of these new and usually inexperienced carers. These caregivers experience burden that is both objective and subjective. Chwalisz (1992 pp 190) explains that objective burden includes changes in the patient's personality and behaviour, as well as "financial strain, changes in routine, changes in living conditions, and changes in social activities", while subjective burden relates to the "caregiver's negative reaction resulting from the presence of objective burden".

Gervasio and Kreutzer's (1997) study of 116 families illuminates the reality of caregiver burden. They concluded that "... family caregivers of people with TBI feel alienated, isolated, overwhelmed, and mentally preoccupied" (Gervasio and Kreutzer 1997 p14). Other studies show similar negative experiences for family carers (Florian & Katz 1991; Kruetzer, Marwits & Kepler 1992). Of note is Allen, Linn, Gutierrez and Willer's (1994 pp 44) finding that "cognitive disability and social behaviour problems have greater association with burden than do injury severity or physical disability". It is the cognitive, behavioural and personality changes, common sequelae of brain injury, that are likely to have the greatest negative impact on families and caregivers (Florian & Katz 1991; Kruetzer, Marwits & Kepler 1992; Douglas & Spellacy 1996; Fortune & Wen 1999), as they are key contributors to the isolation that these families report.

Clinical experience confirms that social isolation for the person with the brain injury and their carers is problematic. Friends taper off when the person is discharged from hospital. The person with ABI often does not have the ability to maintain social contacts and requires someone else to initiate the interaction. Support for the person with ABI is often limited to their immediate contacts because families are often overwhelmed by the provision of physical care and the lifestyle adjustments this demands. Opportunities for support for the family are frequently considered secondary to the needs of the injured person. Given the significant role that social support plays in coping and adaptation (Kaplan 1991; Mengal, Marcus & Dunkle 1996), these findings are concerning for the person with ABI and their carers. While it is an individual's perception of support that is paramount in coping, opportunities must be available for this support to be experienced (Gervasio & Kreutzer 1997). The availability of appropriate and timely respite services could facilitate these opportunities.

Limited respite for families, however, is the third reason why nursing home becomes an option. Respite provides temporary support to a person with specialised needs, to give families and caregivers relief from the responsibility of providing care. There is a consensus that ongoing support for the families and caregivers is vital (Florian and Katz 1991; Chwalisz 1992; Hall, Karzmark, Stevens, Englander, O'Hare & Wright 1994; Douglas & Spellacy 1996; Gervasio & Kreutzer 1997; Perlesz, Kinsella, & Crowe 1999). However, clinical experience suggests services offering respite are difficult to access if the person with ABI has challenging behaviour. It seems ironic that, while the philosophy of respite services is based on prevention of family breakdown and reduction of institutional care (Chan & Sigafos 2000), services do not accommodate those families who are potentially at greatest risk.

Fourthly, financial constraints may make nursing home a more affordable option. Gething (2001) reports that, while people with disability are reluctant to look at nursing homes as an accommodation option for the long term, issues such as finances and the expense of home supports could make living at home an unaffordable option. Compared to living in a nursing home, community care is expensive.

Finally, the inevitable ageing of carers who are typically parents, spouses or siblings makes nursing home an option as the burden of care becomes too great (Stanton 1994; Mengal, Marcus & Dunkle 1996; Stringer 1999; Gething 2001). Caregiving is stressful even in the ideal situation, although this is magnified for carers who are ageing and are faced with changes in their own health and physical ability (Mengal, Marcus & Dunkle 1996). Parents, spouses, and siblings have the added burden of worrying what will happen to their dependent child, spouse, brother or sister when they are no longer able to provide the care or when they die (Mengal, Marcus & Dunkle 1996).

Overall, families face many pressures. In the presence of such adversity and little possibility of relief, nursing home becomes an option for the long-term accommodation of some young people with ABI. For many, feelings of anxiety, fear, apprehension, guilt and sadness are great when nursing home placement is considered (Sutker 1993), as they are faced with acceptance of a decision that is considered less than ideal.

Why should nursing home not be an option?

Amid "growing concern of the impact of ABI on the community" (Fortune & Wen 1999 pp 5), serious consideration of the accommodation needs of this group is overdue. The need for specialised brain injury services in Australia has been acknowledged (Fortune & Wen 1999). However, these services have largely been focused on rehabilitation following the acute phase of care. Preparation for discharge from inpatient

rehabilitation settings commonly reveals a shortage of appropriate long-term accommodation options. Nursing home, however, is not considered the ideal for young people for a wide range of reasons.

Gething (2001) reports “widespread consumer perceptions are that nursing homes do not provide age-appropriate activities for younger people with disabilities” (Gething 2001 pp 2). This is not surprising when nearly half of the 135,991 residents in nursing homes in Australia were aged 85 and over on 30 June 2000 and only 4.5% were under the age of 65 (Australian Institute of Health and Welfare 2001). Furthermore, the interests of this 4.5%, or 6,151 people, could span five decades compared to one or two decades for the more dominant elderly group.

The nursing home environment will also “provide fewer opportunities for interaction with same age peers” (Gething 2001 pp 2). This is of concern, given Kaplan’s (1991) findings in a study of social support and family cohesion for 25 individuals three years after severe TBI. He concluded that, “the less actual and perceived social support made available to the TBI survivor, the more likely the incidence of client emotional problems and rehabilitation failure” (Kaplan 1991, p366). Furthermore, given that the ultimate goal following ABI is for the person to resume the role of being a “participating and valued member of their family and community” (Fortune & Wen 1999 pp 4), this becomes increasingly difficult in the nursing home environment (Stringer 1999).

Stringer (1999 pp 4) also expresses a range of concerns about nursing home placement for young people with significant cognitive impairment and associated physical disabilities. In addition to those already mentioned, Stringer (1999), in a report for the Melbourne City Mission, adds lack of support in decision making, limited choice in day to day living, issues relating to privacy, dignity and confidentiality, as well as the potential for neglect and abuse. Furthermore, Stringer (1999) believes that rehabilitation will be compromised for the young brain injured person in the nursing home environment due to a reduction in therapy input. Gething (2001) notes that consumers share a similar concern based upon a belief that the aged care culture is in contrast to a rehabilitation culture. A rehabilitation culture means much more than therapy input. It is a process that “enables people to return to optimum function” (Pryor 1999 pp 3) and should infiltrate the whole health care system.

Most importantly, two Australian organisations particularly interested in people with ABI believe strongly that nursing home should not be a permanent accommodation option for these people. For the Melbourne Citymission (Stringer 1999) this claim is based upon the belief that “nursing homes which have a primary focus on supporting frail elderly people” have “limited capacity to meet the complex social and rehabilitation needs of young people” (Stringer 1999 pp 4). The Brain Injury Association of NSW (2001c) recommends that accommodation should be individualised and should be determined by a person’s needs and choices. They believe that young people in aged care facilities are disadvantaged because once they enter the aged care facility they are forgotten as they fall between the cracks of the community care system (Brain Injury Association of NSW, 2001c). For the Brain Injury Association, this phenomenon relates to a shift of responsibility from state to federal government, which state governments are in no hurry to rectify.

Conclusion

Attention to the accommodation needs of young people with ABI in Australia is long overdue. This paper has highlighted the need for reliable data about young people with ABI living in nursing homes, as well as the need for alternative models of care that meet the needs of these people. Given recent improvements in medical technology and rehabilitation, the long-term sequelae of ABI, and the typically young age at time of injury, the number of people with ABI in our community will steadily increase. Therefore, the problem will not go away.

The Brain Injury Association of NSW and the Melbourne Citymission (Stinger 1999) need support in their campaign to improve the quality of life and future of young people with ABI in Australia. Attention to this problem by policy makers and funders as well as workers in rehabilitation and aged care can help right the wrong that is done to the young persons with ABI in aged care settings and their families.

To complete the specialised continuum of care required by these people, accommodation that meets the needs of the young brain injured population must be provided. This should be based on a rehabilitation philosophy that includes ongoing access to therapy, community integration, age-appropriate activities and social contact, and a homelike environment. This could also have additional benefits for aged care facilities as they can focus more on their core business, the care of their elderly residents.

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