

THE EXPERIENCES OF ADULTS WITH CEREBRAL PALSY DURING PERIODS OF HOSPITALISATION

Amanda Buzio, RN, GradDipClinTeach, Post Basic Neuroscience Certificate, is a Professional Development Advisor at The Spastic Centre of New South Wales, Australia

John Morgan, Consumer Liaison Officer (Retired), The Spastic Centre of New South Wales, Australia

Diane Blount, The Spastic Centre of New South Wales, Australia

ACKNOWLEDGEMENTS

This project was supported by a seeding grant from the Research Centre for Adaptation in Health and Illness, a collaborative research centre between the University of Sydney and the Central Sydney Area Health Service.

The researchers gratefully acknowledge the advice and support provided by Karen Willey, Research Consultant, Research Centre for Adaptation in Health and Illness.

Accepted for publication April 2002

Key words: cerebral palsy, disability, hospitalisation, experience

ABSTRACT

People with cerebral palsy may have a range of disabilities that can result in daily dependence on others to meet some or all of their basic and more complex care needs. The aim of this New South Wales research was to examine the experiences of adults with cerebral palsy during inpatient admission to a number of public hospitals. A self-selected sample of 31 adults with cerebral palsy completed a questionnaire that collected information related to their disability-specific needs and how well these were addressed by nursing staff during admissions to hospitals. Analysis of the data revealed that many respondents felt hospital staff had limited knowledge and skills of caring for people with cerebral palsy, resulting in their basic care needs not being adequately addressed during periods of hospitalisation. Changes in nursing assessment, continuing education and discharge planning are recommended to address these issues.

INTRODUCTION

When a patient enters the public hospital system, it is generally acknowledged that responsibility for providing holistic care that meets the patient's individual needs remains with the hospital. However, people with disabilities often have disability-specific care needs necessitating assistance from a carer or family member on a daily basis. When these people enter the hospital system, it is perhaps unclear who is responsible for meeting these needs as there may be no clear guidelines for hospital staff to specifically address these issues.

Anecdotal evidence from clients of The Spastic Centre of New South Wales, Australia, with cerebral palsy or similar disabilities, suggested that staff in NSW public hospitals lacked knowledge and experience when caring for people with disabilities, particularly those with severe disabilities who have no verbal communication. Specifically, the issues raised by clients and carers included:

- Hospital staff lack of knowledge and skills in caring for patients with cerebral palsy.
- A common lack of pre-admission or admission planning by hospitals for the disability-specific needs of the patient and the extra workload involved in his/her care.
- Inadequate discharge planning which often did not investigate current at home support services or assumed that existing support services would be adequate to care for the patient post-discharge, regardless of the change in care needs.

These factors were reported as often resulting in communication difficulties between patients and hospital staff, lack of understanding of the patient's physical limitations, inability of hospital staff to meet the nutritional and hygiene needs of the patient and confusion over the ongoing care requirements of the patient after discharge.

Cerebral palsy is defined as a group of non-progressive, but not unchanging, disorders of movement relating to

damage to, or lack of development of, the developing brain (Mutch et al 1992). Along with its many associated conditions it often reflects a variety of disabilities, including physical, sensory and intellectual, and in this way may be considered representative of a wide range of disabilities. Many adults with cerebral palsy now live in the community independently or are supported by paid carers or family members with their daily care needs.

LITERATURE REVIEW

A search of the literature revealed a number of published articles dealing directly with hospital care of people with disabilities. A survey of the experiences of patients with physical disabilities and nurses in acute hospital wards in England (Atkinson and Sklaroff 1987) revealed that many nurses felt they had inadequate training and experience to care for patients with disabilities in this setting. This study also showed that improvement in communication between nurses and patients would facilitate the nursing assessment of patients with disabilities during admission to the ward. Dewing (1991) states that nurses in acute-care settings may be unaware of the special needs of patients with physical disabilities. She argues that initial assessment of their special needs and preparation for discharge are essential components of the nursing care plan if nurses are to start the process of meeting their needs in the acute care setting.

According to a survey by Thomas (1999), people with a disability report barriers to health care which include limited physical access to hospitals and inappropriate staff attitudes and behaviours towards them. Health professionals' misconceptions about disability may lead to further disablement and a failure to accommodate the person's individual needs. Scullion (1999) noted that some people with disabilities are dissatisfied with their contact with health care professionals. Personal accounts and research support the opinion that health professionals may consider the needs of people with disabilities of lower priority compared with those of able-bodied patients, resulting in this group receiving a lesser quality nursing service than other people.

A report by Royal Melbourne Hospital on nursing children with disabilities in an orthopaedic acute care hospital setting in Victoria (Robinson et al 1993) identified that the needs of children with disabilities and their families were not being met during periods of hospitalisation. It was noted that children with disabilities were surrounded by health professionals whose primary focus was the technical and medical aspects of their management. During their hospital stay, these children required skilled and informed nursing care which focused equally on orthopaedics and disability. However, the authors felt that this was rarely achieved. Inadequate information about the basic needs of the child, their habits and routines, was obtained on admission to the ward and nursing hand-overs failed to include information about the child's disability-specific needs. This resulted in nurses facing great challenges when trying to provide basic

nursing care, often resulting in inappropriate and inadequate care (Robinson et al 1993).

A number of studies examining the general health care of people with disabilities refer to the problems that they face when accessing health services in general. In a study of residents with intellectual disabilities in Sydney, Beange (1996) identified that this minority population received substandard community health care. Adults with intellectual and other disabilities frequently suffer medical problems that remain undiagnosed, primarily because of lack of familiarity with and knowledge of disability specific health issues by health practitioners (Cathels and Reddihough 1993; Beange 1996; Lennox et al 1997; 1998). In their study of the current health status of adults with cerebral palsy, Balandin and Morgan (1997) received a number of responses detailing a lack of faith and even disgust in the medical profession because, in some instances, it was felt that doctors had no knowledge of cerebral palsy.

Information related to the current state of general care provided by hospitals in Sydney reveals that people with disabilities may not be the only group to experience difficulties obtaining adequate hospital care. People without disabilities who have had recent experiences as patients in public hospitals also report that hospital care is not meeting their needs. Scotford (1999) describes a recent experience in a teaching hospital in Australia as chaotic and distressing, 'dangerous to health and lacking in humanity' (Scotford 1999, p.138). As one of a roomful of bedridden patients, she felt isolated and neglected as the over-stretched and disorganised hospital system failed her in her time of need. This experience included prolonged waiting for call bells to be answered, clumsy and disorganised nursing and a lack of routine in relation to medication, personal care and mealtimes.

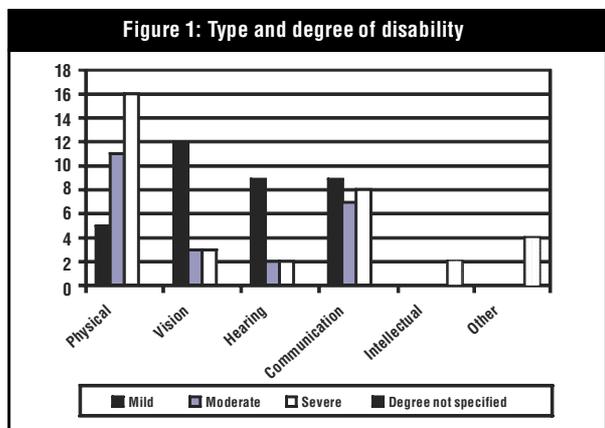
Aspinall (1999), in a personal account to the editor, also reflected on a recent hospital stay in a large teaching hospital, citing economics and staffing difficulties as leading to an erosion of patient care. She observed that patients with complex care needs, requiring longer hospital stays, placed stress on the nursing and medical environment and that deterioration in patient care was an important issue, requiring urgent attention. It is a concern that able-bodied people who can speak for themselves report such negative experiences of their stays in hospital, highlighting further the need to explore the impact on people with disabilities, particularly as they often have difficulty communicating.

METHOD

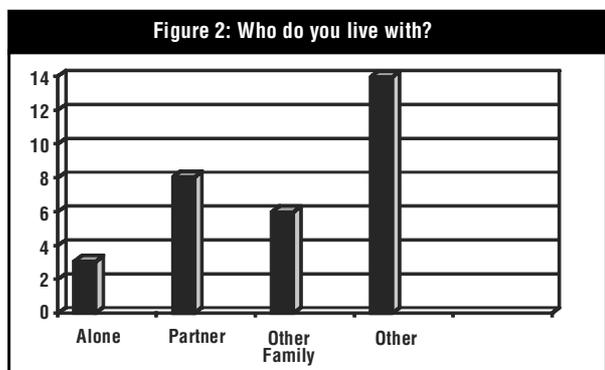
Ethics approval and support for this project was obtained from The Spastic Centre of New South Wales Ethics Committee. As the researchers and participants were employed at and/or clients of The Spastic Centre, the granting body deemed this approval acceptable and no ethics approval was sought from the Research Centre for Adaptation in Health and Illness, The University of

1. Demographic data

- 58% (18) of respondents were male.
- 97% (30) of respondents were aged 20-59 years, with one respondent aged over 60 years.
- All respondents had cerebral palsy with varying type and degree of disabilities (figure 1). These included physical, visual, hearing, communication and intellectual, as identified in the *Disability Services Act, NSW (1993)*. Respondents identified their type and degree of disability based on personal knowledge or awareness. Medical diagnosis was not requested. Moderate to severe physical disability was reported by 84% (26) of respondents, with the majority also reporting at least one other type, in particular communication disability, 77% (24).



- 87% (27) reported that they required some level of paid carer assistance on a daily basis, ranging from one to more than six hours per day.
- Level of education, in all cases, was below university level, with only 13% (4) reporting education at a TAFE level.
- Living situations are represented in figure 2. 45% (14) of respondents lived with people other than family and only 10% (3) lived alone.

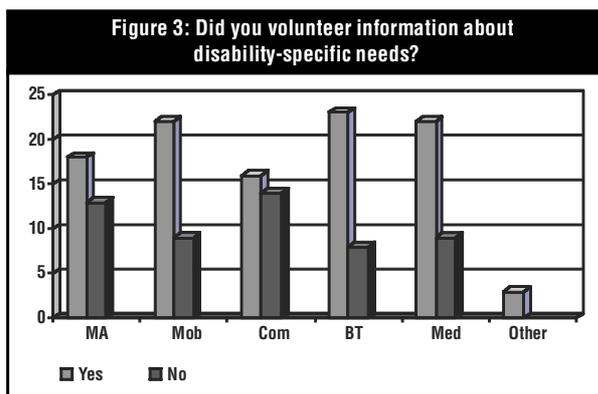


2. Level of care required

Many respondents (n=16) reported multiple admissions to hospital within the previous two years, indicating that the experiences reported were based on two or more admissions. Respondents were asked about their disability specific needs, whether they volunteered this information to staff and whether this information was requested

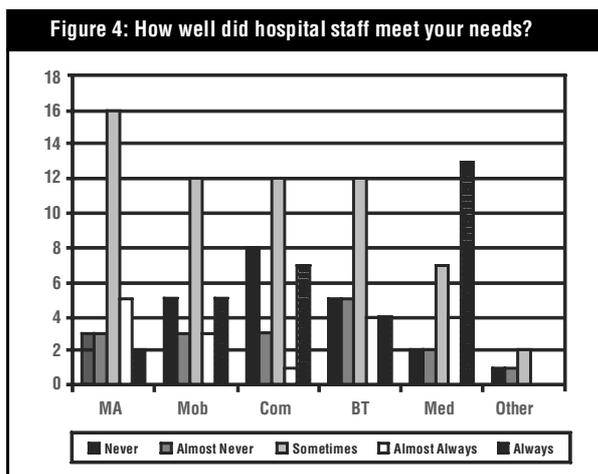
by hospital staff. Disability-specific needs were classified into six categories; Mealtime Assistance (MA), Mobility Assistance (Mob), Communication (Com), Bathing/Toileting (BT), Medication (Med) and Other (O), indicating that the person had special needs in these areas as a result of their disability. Other reported disabilities included sleep apnoea, epilepsy and multiple disabilities.

On admission to the ward, all respondents reported they volunteered information about at least one of their disability specific needs to hospital staff (figure 3). Many provided information about all needs, particularly those people with communication disabilities, as this information was required before hospital staff would know how to communicate with the person. This information was sometimes conveyed verbally by the individual or their carers but many respondents also reported providing written information of their care needs. However, only 23% (7) of respondents reported being asked by hospital staff for information about their disability-specific needs, as part of the admission process.



3. Level of care received

Respondents were asked to indicate how well they felt hospital staff met their disability-specific needs during hospitalisation. A 5 point Likert scale was used to obtain the level of response, ranging from 1 (never) to 5 (always). Where no assistance was required, these questions were left blank or marked N/A. Responses indicated that the majority of respondents (>60% in all disability categories except medication) felt these needs were never, almost never or only sometimes met by hospital staff (figure 4).



Some respondents found staff response when called or buzzed unacceptably long often resulting in the person feeling neglected and unimportant. Some respondents felt an inadequate number of staff and staff shortages may have contributed to the care able to be provided. Some respondents stated that their care was often left until paid carers or friends arrived to take over, or that hospital staff only provided assistance if no visitors were present. Two respondents reported having to rely on other patients for assistance with meals.

When asked how hospital staff could have better met these needs, three main themes emerged from the responses:

- increased staff knowledge of cerebral palsy;
- increased skills required to care for people with disabilities; and,
- increased staff patience when caring for people with cerebral palsy.

For example:

Taking time for the person with CP to relay the message they're trying to get across; staff to listen when person with CP tells them the best way to assist.

Not all respondents in the study were unhappy or dissatisfied with the care they received in hospital. For example:

They certainly looked after me; I found the staff...very well advised and I had no problems

13% (4) reported receiving a high standard of care and were very impressed with the facilities and resources available, indicating some staff within the public hospital system are familiar with the care needs of people with cerebral palsy and are competent in providing this care.

4. Staff knowledge

87% (27) of respondents felt that hospital staff had some degree of knowledge and/or skill deficit when caring for people with cerebral palsy. Hospital staff, particularly nurses, were often perceived as ignorant of how to provide appropriate care to a person with cerebral palsy. For example:

They had no/very little idea, were asking house staff all the time; most staff don't know much about cerebral palsy...the condition is a mystery and so are the needs.

As a result of this over 60% (19) of respondents chose to rely on the assistance of either family and friends or paid carers (or both) to provide basic care for them during their hospital stay.

5. Staff attitude

Examination of respondents' perceptions of the attitude of hospital staff towards people with a disability elicited mixed responses. Comments were both positive and negative but some respondents felt that a positive staff attitude did not always result in them receiving quality care during their stay in hospital. For example:

The hospital staff were mostly pleasant but they just didn't have a clue about people with cerebral palsy and they seemed as though they did not want to know either.

6. Communication

Hospital staff were often reported as not having the time or patience to listen to or read specific instructions from the patient or their carers. Respondents who had a communication disability often stated staff needed to allow more time for them to communicate.

There was a positive correlation between people who were unable to communicate verbally and dissatisfaction with the care received. Of the 15 respondents in this group, all reported they were not specifically asked about their disability needs on admission to hospital.

However, all but one provided this information, in writing, to hospital staff anyway. Despite this, all of the respondents who were unable to verbally communicate, reported some degree of difficulty in getting hospital staff to meet their basic needs. All respondents in this group who utilised augmentative communication devices (such as comic symbols or electronic talkers), stated staff did not attempt to utilise these whilst trying to communicate with the patient. These people were therefore restricted to yes/no communication with hospital staff during their entire stay in hospital, remaining dependent on the staff to guess what they were trying to say.

7. Physical environment

Other themes emerged from the responses, including lack of resources and physical restriction of environment. Lack of hoists or appropriate seating meant some respondents were restricted in their mobility, often confined to the bed for their entire stay, even though they were well enough to get up. 35% (11) of respondents indicated they had difficulty physically accessing the hospital environment, mainly due to slippery floors or limited access in bathrooms and bedrooms. This made mobilisation within the hospital environment dangerous or difficult, although one respondent reported having trouble getting into the hospital from the car park.

8. Discharge planning

55% (16) of respondents reported some degree of discharge planning by the hospital prior to discharge. This ranged from asking the person if they would cope at home to arranging community nurse follow up. The remaining 45% (15) of respondents indicated that discharge planning was not discussed with them during their stay. Whilst this was not always seen as an issue, some respondents indicated the hospital had assumed that the carers at home were able to take over care. In some instances, this caused problems for the respondents at the time of discharge or after they had returned home.

DISCUSSION

The results of this study are consistent with the reviewed literature and indicate that some adults with

cerebral palsy have negative experiences when admitted as a patient to a public hospital. People with moderate to severe communication disabilities appear to experience more difficulties than those with milder disabilities in obtaining holistic nursing care as they are often not offered the opportunity to clearly communicate with staff.

The Disability Services Act (DSA) NSW (1993) states that people with disabilities have the right to ensure their specific needs are met. When related to hospital care, this can be interpreted to mean that a person with a disability entering the hospital system is entitled to expect their disability-specific needs will be met as part of the overall service delivery. Some NSW area health services employ disability advisors to advise on general disability issues in an attempt to comply with this *Act*. However, as their role is not in the clinical setting, information may not be provided to staff who are providing direct clinical care. This study suggests the need for increased awareness of cerebral palsy and disability issues amongst clinical staff working in public hospitals to ensure the requirements of the *DSA NSW (1993)* are met.

The *EQuIP Guide* (ACHS 1998) contains standards and guidelines for The Australian Council on Healthcare Standards (ACHS) Evaluation and Quality Improvement Program. This document is used to guide all health organisations, including public hospitals, in meeting the requirements of accreditation. Contained within the guide, Standard 2.2 Patient/Consumer Rights, Responsibilities and Ethical Issues, includes 'access to appropriate, equitable care; personal dignity; participation in planning and decisions regarding their care...' (ACHS 1998, p.3). Based on the results of this research, it could be argued that some public hospitals are not properly meeting the requirements of this accreditation standard when providing services to people with disabilities.

It is interesting to note that only a small number of respondents were questioned about their disability during the admission process. Possibly some hospital staff felt embarrassed or awkward addressing these issues so directly. Although not demonstrated by this study, nurses and doctors routinely obtain information about allergies and past medical history when admitting patients to hospital. These issues are clearly seen as impacting on the patient's care and therefore require careful investigation. It is clear that if a person is admitted to hospital for routine surgery but also has a disability, particularly a moderate to severe disability, they will require more support and therefore more nursing hours than a person without a disability admitted for the same procedure. However, if recognition of these greater care needs does not occur on admission, the need for more nursing hours will also not be recognised resulting in inadequate staffing levels. Such inadequate levels of staffing have clearly been identified as a factor influencing patient care (Aspinall 1999; Atkinson and Sklaroff 1987; Robinson et al 1993; Scotford 1999).

While lack of knowledge of cerebral palsy and disability issues may explain the reported inadequate care,

this should not be an issue when specific information is provided to assist hospital staff. It could be argued that the information supplied may be inappropriate or difficult to understand or that hospital staff have insufficient time to read the information. Clearly there is a need for collection and utilisation of concise, standardised documentation of disability-specific needs on admission to hospital.

It is well established that adequate discharge planning results in decreased length of stay and readmission rates (Evans and Hendricks 1993). Chadwick (1998) advocates that discharge planning should begin at initial assessment, should be coordinated between both medical and nursing staff and should include a discharge summary sheet sent home with the patient to ensure follow up instructions are adhered to. This study did not investigate the process of discharge planning implemented by the hospital in any detail. However, it did demonstrate that only half of the respondents reported discharge planning as part of their care. This lack of discharge planning sometimes caused problems for the respondents, and indicates a need to improve the practices within hospitals when caring for people with cerebral palsy.

Gething (1992) reports that health professionals' attitudes can influence the quality of service provided to people with disabilities. In her study of nurses' attitudes toward people with disabilities, Gething observed that nurses in Australia displayed a significantly more positive attitude toward people with disabilities than the general population. Of the 17 respondents in our study, who felt hospital staff had positive attitudes towards people with disabilities, 13 also reported inability of these staff to completely meet their basic care needs, suggesting, in this instance, positive attitudes did not necessarily ensure holistic nursing care.

LIMITATIONS OF THE STUDY

Limitations of the study included the small sample size, the mix of reported disabilities and not eliciting the type of medical discipline, ward or area that the respondents were admitted to. The sample was also self-selective and, therefore, may not be truly representative of the cerebral palsy community. People who had negative experiences in hospitals may have been more motivated to join the study.

The breakdown of disability types reported by respondents indicates that not all disabilities were equally represented in this study. People with intellectual and psychiatric disabilities may have experiences that have not been captured in this study.

During the development of the questionnaire careful consideration was given to asking respondents to identify the hospitals related to their experiences. However, it was considered that this may have been too controversial. Respondents were from different regions across Sydney. Assuming they accessed their local public hospital, the experiences reported should be representative of different hospitals in different areas.

RECOMMENDATIONS

Public hospitals have a responsibility to ensure all patients receive care that meets their individual needs, including disability-specific needs. In so doing, hospitals must acknowledge that increased resources may be required to ensure equality of service for patients with disabilities and higher levels of need.

The nursing admission process should include a comprehensive history with details of any disability-specific care requirements so the need for extra resources is recognised and addressed as soon as the patient enters the system. For patients entering the system as a routine or booked admission, this process could be commenced during pre-admission planning. Once obtained and documented in the patient's file, all relevant staff should be advised to read this information and utilise it when planning and providing care. The time spent researching and reviewing this sort of documentation will often result in time saved when providing clinical care to the patient. This information can also be useful when planning for the patient's discharge to ensure, where necessary, appropriate community services are accessed and continuity of care occurs after the patient leaves the hospital environment.

Continuing education for hospital staff should also include training and support to ensure all staff are aware of the issues for people with disabilities and competent in addressing their care needs. No longer are people with disabilities restricted to disability-specific wards. A variety of different resources are available to educate and skill hospital staff in caring for people with disabilities. The Disability Awareness Package, 2nd Edition (Gething et al 1994) was designed to equip health service providers so that they can provide more appropriate and effective services for clients with a disability. Disability organisations, such as The Spastic Centre of NSW, can also provide information and training to generic services to assist them when providing services to their clients with disabilities. Staff who are responsible for professional development in hospitals are encouraged to utilise these resources and strategies to address the skill and knowledge deficit that is reported in this study. Further research investigating public hospital nursing staff's experiences, perceptions and knowledge of caring for people with cerebral palsy would also be beneficial in clarifying the issues of concern for nurses.

CONCLUSION

This project was undertaken in response to personal reports and anecdotal evidence from clients of The Spastic Centre of NSW and their families and carers. The results support these reports and are consistent with the reviewed literature, indicating that some people with

cerebral palsy do not receive holistic care that meets their disability-specific needs when admitted to public hospitals.

Hospitals are responsible for ensuring all the needs of their patients are met, including those with disabilities. There is a need to improve hospital staff knowledge and skill when caring for people with cerebral palsy. Lack of hands-on resources and poor staffing levels will also impact on the level of care able to be provided. Concise history taking on or before admission to hospital and ensuring on-going utilisation of this information will assist hospital staff when attempting to meet the disability-specific needs of patients with cerebral palsy. Consistent discharge planning will assist in the continuity of this care back into the community. Addressing these issues at the local and area level will assist hospital staff to develop the skills required to provide the holistic care that adults with cerebral palsy deserve.

REFERENCES

- Aspinall, D. 1999. A patient's room with a view. *The Lamp*. Dec/Jan. 56(11):24.
- Atkinson, F.I. and Sklaroff, S.A. 1987. *Acute Hospital Wards and the Disabled Patient*. London: Royal College of Nursing, UK.
- Australia. Department of Health. 1998. *The EQUiP Guide*. Sydney: Australian Council on Healthcare Standards Evaluation and Quality Improvement Program.
- Australia. NSW Government 1993 Disability Services Act. No.3. NSW Government Information Service.
- Balandin, S. and Morgan, J. 1997. Adults with cerebral palsy: What's happening? *Journal of Intellectual & Developmental Disability*. 22(2):109-124.
- Beange, H. 1996. Caring for a vulnerable population. *Medical Journal of Australia*. 164:159-160.
- Cathels, B.A. and Reddihough, D.S. 1993. The health care of young adults with cerebral palsy. *Medical Journal of Australia*. 159:444-446.
- Chadwick, A. 1998. Discharge planning: Are we meeting the needs of our patients? *Australasian Journal of Neuroscience*. 11(4):8-11.
- Dewing, J. 1991. Physically disabled people in acute care. *Nursing Standard*. 5(22):37-39.
- Evans, R.L. and Hendricks, R.D. 1993. Evaluating hospital discharge planning: A randomised critical trial. *Medical Care*. 31(4):358-370.
- Gething, L. 1992. Nurse practitioners' and students' attitudes towards people with disabilities. *The Australian Journal of Advanced Nursing*. 9(3):25-30.
- Gething, L., Cahill, L., James, M., Redmayne, G. and Reynolds, F. 1994. *The Disability Awareness Package: 2nd edition*. Sydney: The University of Sydney.
- Lennox, N., Cook, A. and Diggins, J. 1997. Caring for adults with intellectual disabilities. *Modern Medicine of Australia*. May:79-88.
- Lennox, N.G., Diggins, J.N. and Ugoni, A.M. 1997. Barriers and solutions to the general practice care of people with an intellectual disability. *Journal of Intellectual Disability Research*. 4:380-390.
- Mutch, L.W., Alberman, E., Hagberg, B., Kodama, K. and Perat, M.V. 1992. Cerebral palsy epidemiology: Where are we now and where are we going? *Developmental Medicine and Child Neurology*. 34:547-555.
- Robinson, A., Oxnam, C., Kelly, S., Broadbent, J. and Dillon, M. 1993. A study into nursing children with disabilities in an acute care context: The 3W disability awareness group research report. Melbourne: The Royal Children's Hospital.
- Scotford, N. 1999. Humbug, health and humanity: A patient's tale of care in a public teaching hospital. *Australian Health Review*. 22(4):135-138.
- Scullion, P. 1999. Conceptualising disability in nursing: Some evidence from students and their teachers. *Journal of Advanced Nursing*. 29(3):648-657.
- Thomas, S. 1999. How healthcare professionals can become disability aware. *Nursing Standard*. 13(27):20.