In this issue:

Professional standards for nursing practice: How do they shape contemporary rehabilitation nursing practice?

Spinal cord injury and long-term carers: Perceptions of formal and informal support

Comparison of dependency scores to assess resource allocation for patients with spinal cord injuries

Carer legislation, policy support initiatives and future implications

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# ARNA

Australasian Rehabilitation Nurses’ Association

Volume 20 Number 1 – April 2017

The Official Journal of the Australasian Rehabilitation Nurses’ Association

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Published three times a year by

Cambridge Publishing

a division of Cambridge Media

10 Walters Drive

Osborne Park, WA 6017

Web: www.cambridgemedia.com.au

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ISSN 1440-3994

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Editorial

Being professionally active

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In this edition of JARNA both this editorial and the guest editorial focus on professional matters relating to registration as a nurse in Australia. Both look at professional standards for nursing practice. While this editorial looks more broadly at being professionally active, in the guest editorial Murray Fisher raises questions about how well professional standards shape contemporary rehabilitation nursing practice in Australia.

I chose my topic, being professionally active, as I prepared for the recent NSW/ACT chapter study day in Canberra. I was being professionally active and enabling others to be professionally active. So what do I mean by being professionally active? In my case I was preparing to speak at the study day, but as the chapter treasurer I was also assisting with the organisation of the study day. Most were being professionally active by attending the study day and a smaller number were presenting.

Being professionally active is a requirement of registration as a registered or enrolled nurse in Australia. This requirement is spelled out in various documents from the Nursing and Midwifery Board of Australia (NMBA), collectively referred to as standards for practice. Practising within these standards is mandatory.

For example, in the registered nurse (RN) standards for practice (NMBA, 2016a) standard 3 is “maintain the capability to practice”; it states “RNs are responsible for their professional development and contribute to the development of others” (NMBA, 2016a, p. 3). Examples of specific criteria for this standard include: “uses a lifelong approach for continuing professional development of self and others” and “actively engages with the profession” (p. 4).

In the enrolled nurse (EN) standards for practice (NMBA, 2016b) standard 10 is “engages in ongoing development of self as a professional” (NMBA, 2016b, p. 7). Two indicators of particular relevance are: “10.2 recognises the need for, and participates in, continuing professional and skills development in accordance with the NMBA’s Continuing professional development registration standard” and “10.3 identifies learning needs through critical reflection and consideration of evidence-based practice in consultation with the RNs and the multidisciplinary healthcare team” (p. 7).

In the continuing professional development (CPD) registration standard (NMBA, 2016c) the requirement for every RN and EN to engage in 20 hours CPD per annum (plus an additional 10 hours for nurse practitioners) is explained. In the accompanying guidelines (NMBA, 2016d), the aim of CPD is explained as enabling “nurses and midwives to maintain, improve, and broaden their professional knowledge, expertise and competence to meet their obligation to provide ethical, effective, safe and competent practice” (p. 1). It goes on to say that “research shows that CPD is more effective when it involves planning and reflection. You will get most benefit from your CPD activities by planning your learning goals and the activities to meet these goals, completing your CPD and then recording reflections on your learning” (p. 1). Consequently, the importance of identifying your CPD requirements and developing a learning plan is stressed.

This point led me to wonder how many nurses develop a learning plan each year and how ARNA might assist individuals to action their plans. In February this year, three study days were run by ARNA chapters across the country involving a total of 168 attendees (see Table 1 for a summary).

While we cannot know how these study days might fit with the learning plans of individual nurses, the requirements for documentation are relevant for everyone. To assist with this the NMBA provides a template for an evidence record, which details the information to be documented (see http://www.nursingmidwiferyboard.gov.au/Registration-and-Endorsement/
Audit.aspx). This is supported by a sample template in an accompanying fact sheet (NMBA 2016e), which contains some very helpful examples.

The NMBA is very clear that “all evidence should be verified, and it must demonstrate that the nurse or midwife has:

- identified and prioritised their learning needs, based on their self-reflection and evaluation of their practice against the relevant competency or professional practice standards;
- developed a learning plan based on identified learning needs;
- participated in effective learning activities appropriate to their learning needs; and
- reflected on the value of the learning activities or the effect that participation will have on their practice.

The format of this evidence is not defined by the NMBA and may take many forms. You should keep evidence of CPD activities completed, such as:

- certificates of attainment and/or attendance; and
- notes from self-directed CPD activity such as a literature review, case study or journal articles. Any notes submitted should provide a comprehensive summary of the key points of the review and reflect the learning from the activity” (NMBA, 2016d, p. 3).

At the recent NSW/ACT study day in Canberra, attendees were encouraged to keep not only their certificates of attendance but their study day programs as well as evidence supporting the claim of having participated in CPD.

Furthermore, there are clear requirements about keeping these records. “You must keep records of your CPD activities for at least five years from the date you completed the CPD. All CPD records must be available for audit or if needed by the NMBA as part of an investigation arising from a notification (complaint)” (NMBA, 2016d, p. 3).

The requirement for every RN and EN to engage in 20 hours of CPD per annum, to keep detailed records and evidence of these activities is mandatory and the possible consequences of not meeting the CPD standard are explained as follows:

- The National Law establishes possible consequences if you don’t meet this standard, including:
  - the NMBA can impose a condition or conditions on your registration/endorsement or refuse an application for registration/endorsement or renewal of registration, if you do not meet a requirement in an approved registration standard for the profession (sections 82, 83 and 112 of the National Law);
  - a failure to undertake the CPD required by this standard is not an offence but may be behaviour for which health, conduct or performance action may be taken by the NMBA (section 128 of the National Law); and
  - registration standards, codes or guidelines may be used in disciplinary proceedings against you as evidence of what constitutes appropriate practice or conduct for registered nurses and/or midwives (section 41 of the National Law)" (NMBA, 2016c, p3-4).

In writing this editorial I have drawn information from five different NMBA publications to highlight the importance the NMBA places on nurses in Australia being professionally active. In conclusion, I encourage you to consider how professionally active you are and how you can enable or facilitate others to be professionally active.

References


In this editorial I draw on my experience as a member of the Nursing and Midwifery Council of NSW (NMC) and as a researcher in the area of standards for nursing practice, the latest being a member of the research team to revise the 2016 Registered Nurse Standards for Practice (Cashin et al., 2017). As a member of the Nursing and Midwifery Council of NSW, it is clear to me that some nurses are not au fait with how the standards of professional practice and codes of conduct apply to their individual practice. In a recent review of the literature conducted by KPMG for the NMC (2016), it is evident that professional standards promote safe, patient-centred practice; however, health professionals have widely varying levels of knowledge and understanding of standards and the regulatory system that governs their practice. It is these insights that have led me to write this editorial.

In order to understand how these standards and codes are used for registration and regulation purposes you need to have a basic understanding of the regulatory system for the health professions in Australia. It is the NMBA, through the Health Practitioner Regulation National Law, that has the responsibility to develop professional standards (approved by the Ministerial Council), codes and guidelines for nurses and midwives, and it is the Board’s responsibility through the Australian Health Practitioner Regulation Authority (AHPRA) to register nurses (enrolled and registered nurses, and nurse practitioners) and midwives and through the Australian Nursing and Midwifery Accreditation Council (ANMAC) set accreditation standards and accredit courses that lead to registration. The National Board, with the assistance of its state and territory boards, make decisions regarding notifications (complaints) and registration.
of individuals. Both Queensland and NSW have a co-regulatory system where in Queensland it is the Health Ombudsman and the NMBA State Board, and in NSW it is the Nursing and Midwifery Council in conjunction with the Health Care Complaints Commission (HCCC), that regulates nurses and midwives through the management of notifications regarding the health, performance and conduct of nurses and midwives.

The primary purpose of the regulation of nursing and midwifery practice is to ensure the safety of the public. Through the management of notifications the regulatory bodies, including the NMBA and its state and territory boards, as well as the Health Ombudsman in Queensland, and the NMC and the HCCC in NSW, can impose conditions on individual nurses’ and/or midwives’ practice or suspend registration to ensure the safety of the public. The standards for professional practice and codes of conduct provide the benchmark for which nurses’ and midwives’ practice and behaviour is assessed for registration and regulation purposes, and applies to all fields and contexts of nursing practice.

The standards for professional practice and codes of conduct provide the benchmark for which nurses’ and midwives’ practice and behaviour is assessed for registration and regulation purposes, and applies to all fields and contexts of nursing practice.

So where do standards for specialist nursing practice (such as the Rehabilitation Nursing Competency Standards for Registered Nurses) fit? It is unclear as to how standards for specialist nursing practice are being used. Such standards are primarily developed by specialist nursing organisations to define the role and scope of practice of the specialist nurse in a particular field of practice, for example, the Competency Standards for Specialist Palliative Care Nursing Practice (Canning et al., 2005) and the Competency Standards for Specialist Critical Care Nurses (Dunn et al., 2000).

The Rehabilitation Nursing Competency Standards for Registered Nurses were first published by the Australasian Rehabilitation Nurses’ Association (ARNA) in 2003 following a substantive validation project. It is claimed that the purpose of the Rehabilitation Nursing Competency Standards is to “facilitate the development of rehabilitation nursing practice at both an individual and system level” (ARNA, 2003, p. 5). At the personal level, it was envisaged that the competency standards would provide a framework for professional development, guiding individual professional learning and reading. At the system level, it was hoped that the standards would inform clinical performance reviews and management, and inform curriculum development.

Since the publication of the Rehabilitation Nursing Competency Standards for Registered Nurses, there has been an absence of research that evaluates the effectiveness of the standards in achieving its purposes. Whilst there is anecdotal evidence that nurses within the rehabilitation specialty find the standards helpful, there is no published evidence as to how these standards influence the development of rehabilitation nursing practice. How, if at all, individual nurses use the standards for professional development is unclear. Similarly, there is no evidence as to how the standards influence specialist nursing curricula. In addition, the standards do not reflect contemporary change in the delivery of rehabilitation services, with the changing nursing skill mix, with more enrolled nurses and assistants in nursing and fewer registered nurses. It is now time to consider standards that acknowledge the contribution varying levels of nurse make to nurse rehabilitation outcomes.

In light of the recent revisions of the professional standards developed by the NMBA, it is time for ARNA to revise their specialty competency standards, especially in light of the lack of evidence of their contemporary use and to realign the specialty standards with the professional standards for registration. Key questions that I believe could guide the revision of the standards include:

- Are the current Rehabilitation Nursing Competency Standards for Registered Nurses applicable to contemporary rehabilitation nursing practice?
- What, if anything, is missing from or is redundant in the current standards?
- How are the current standards being used?
- Do the current standards meet their intended purposes?
- How do the Rehabilitation Nursing Competency Standards for Registered Nurses integrate with the registered nurse standards for practice? Is there overlap?
Should standards be developed to reflect the levels of nurse (registered nurses, enrolled nurses and assistants in nursing) that work in rehabilitation?

The methodology used to revise the Rehabilitation Nursing Competency Standards could include, but should not be limited to: literature reviews to examine contemporary rehabilitation nursing practice; surveys of key stakeholder groups including consumer representative groups, service providers and clinical experts; focus groups of expert panels; ARNA member consultation survey; and a validation study using participant observation.

Nursing standards for practice play a pivotal role in defining the nurse’s scope of practice, regardless of the context within which nurses work. All nurses who are registered with AHPRA must meet the standards for practice. Whilst I believe the Rehabilitation Nursing Competency Standards for Registered Nurses have served the specialty well over the past decade, especially in defining the registered nurse role and scope of practice in the specialty field, it is now time to reconsider the current standards in light of contemporary rehabilitation nursing practice.

References
Spinal cord injury and long-term carers: Perceptions of formal and informal support

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Abstract
The grounded theory study from which this paper is drawn explored the experiences of partners and other long-term family carers living with, and supporting, a person with a spinal cord injury over long periods of time. Eleven (11) female carers with between eight and 33 years of living with, and supporting, a family member with a spinal cord injury were purposively recruited to the study.

The study identified a number of key issues for long-term carers in this context. In this paper, the focus is on the extent to which long-term family carers perceived they were supported by health and social services. Findings revealed a significant need for practical and lifestyle assistance, including formal respite from familial and/or caregiving responsibilities when needed. Participants also sought out a range of health and social care services to address the loneliness, isolation, grief and loss, all of which can be involved in this experience. Participants revealed that their caregiver needs are usually not recognised by health service staff, and most expressed a desire for more recognition from health professionals for the important role they play in supporting the independence of the person in their care. The study also identified that participants tended to be more reliant on informal networks of support for practical assistance and other support. Findings on the experience, perceptions and support needs of family carers of people with lifelong disability provide valuable information of great relevance to rehabilitation practice.

Keywords Long-term carers, spinal cord injury, support needs.

Introduction
Although there is considerable research focus today on the role of the informal care provider (Australian Institute of Health and Welfare, 2013:323) there has, to date, been little research interest in the experiences of long-term family carers of people with spinal cord injury. This paper focuses on findings from a research project which has explored the experiences and perceptions of the availability of support for caregivers in this context. Family carers today are considered essential to the health care system (Australian Bureau of Statistics, 2012); however, according to this and other studies, formal support services for this group of caregivers are not adequate and do not reflect recognition of the significant contribution they make in this long-term context.

Background
Australian (Booth & Kendall, 2007; Foster, Amsters, & Carlson, 2005; Middleton et al., 2008) and international research (Arango-Lasprilla et al., 2010) has reported that people with spinal cord injury and their carers continue to experience significant unmet
needs for assistance and information (Holland & Blood, 2008; Meade, Taylor, Kreutzer, Marwitz, & Thomas, 2004). This has been confirmed in research findings from other caregiving contexts. McPherson, Kayes, Moloczij, & Cummins (2014) note that the contribution that informal carers make is “crucial” for sustainable health services overall (p. 418), but that carers report difficulties with regard to “giving” to and “receiving” from health care providers, information about formal services (McPherson et al., 2014, p. 423). McPherson and colleagues (2014) note that health and social service providers often render the situation of informal caring more difficult when, on the one hand, they seem to assume that family carers have the ability, time and willingness to care, but, on the other, they do not recognise or respect the expert knowledge of those same family carers. This approach disregards the personal circumstances of each carer, and the extent to which they may need support in order to sustain their caring role (McPherson et al., 2014).

Meade et al. (2004, p.151) found that, in the short term, within the first 76 days of an injury in this context, informal caregivers rated their own need for emotional support much less highly than their need for medical knowledge relevant to the caregiving situation. Anderson and colleagues (2013) have identified unmet needs related to information, respite services and other support services. Others have identified a strong relationship between the social support available to caregivers of people with spinal cord injury, their life satisfaction, and their mental health (Rodakowski, Skidmore, Rogers, & Schulz, 2012; Sheija & Manigandan, 2005), with one study noting that social support relieves carer depressive symptoms (Chandler, Kennedy, & Sandhu, 2007). Evidence further suggests that some of the negative psychological consequences which informal carers may experience can be mediated by planned interventions such as peer support programs (Sheija & Manigandan, 2005).

To date, little is known about the experiences of long-term informal carers in this context in Australia, and most international research in this area focuses on the first five years post injury. This study set out to address this gap in knowledge, particularly focusing on the experiences and needs of family members providing active support over long periods of time to loved ones with spinal cord injury.

Methodology

A grounded theory methodology was used to conduct the study, as this design was deemed the most appropriate for the research focus, given that little was known about family carers providing active support over long periods of time. The grounded theory method (GTM) seeks an interpretative understanding of data rather than reporting abstract generalisations (Charmaz, 2011, p. 482). Such a design is relevant to health and caregiving research, as an important principle of the constructivist GTM is to take into account the peculiarities of time, space and situation (Charmaz, 2011). The GTM is a well-accepted methodology for caregiving research and it has been used extensively by scholars to develop inductive theories of caregiving (Wuest & Hodgins, 2011). Theoretical conceptualisations of participant experiences were developed in this study, but the focus in this article is on one aspect of the study, namely, carer support needs and perceptions of support.

Theoretical conceptualisations of participant experiences were developed in this study, but the focus in this article is on one aspect of the study, namely, carer support needs and perceptions of support.

Study aim and research question

The aim of the study reported here was to explore long-term family carers’ perceptions of how they are currently supported by health and other community-based social services. The following research question was developed from this aim: What are long-term family carers’ perceptions of how they themselves are supported by health and other community-based services?

Consent

Ethics approval was gained from the University of Sydney, NSW, and reciprocal ethics approval was given by Western Sydney University. Participation in the study was voluntary and all participants were provided with a Participant Information Statement and required to sign a Participant Consent form, which confirmed their informed consent to voluntarily participate in the study (McIlfatrick, Sullivan, & McKenna, 2006). The study protocol conformed to the National Statement on Ethical Conduct in Human Research 2007 (Updated May 2015).

Setting

The setting for the study was the geographical area of NSW, Australia, specifically within a parameter of 300 km from the Sydney metropolitan area.

Participants

A variety of key Australian spinal cord injury and carer organisations published the participant recruitment invitation online and eleven (11) female participants were recruited to the study. Purposive sampling was used (Creswell, 2009) to access information-rich participants, and individuals were recruited based on specific criteria. Eight spouses, two mothers
and one sister were recruited over an 18-month period. The majority of participants had lengthy life experience living with, and supporting, a family member with a spinal cord injury. Only two of the 11 participants had less than 10 years’ experience of informal caring in this context (five and eight years respectively). Four participants had between 10 and 20 years’ experience, and five participants had between 25 and 33 years of informal caring experience supporting their family members.

The 11 participants were aged between 32 and 69 years, and most (10 of the 11) supported loved ones with cervical or high thoracic (T4 or above) injuries. Nine of the participants had dependent children, mostly younger than 10 years, and four participants supported individuals with very high medical and caregiving needs. Fifty per cent of participants knew their loved one before the injury, and the others (all spouses) met and started their families after the family member’s injury was well established, which was usually following a previous accident as a teenager or young adult. Participants were given, and referred to, by pseudonym names to protect their privacy from the very beginning of data analysis in all written accounts.

Inclusion criteria
Participants were required to be 18 years of age or over, to identify as living with, and actively supporting, a person with a spinal cord injury for five years or more, and able to understand and communicate in English. This was a doctoral study which could not accommodate the provision of interpreters.

Data collection and analysis
Data collection methods included in-depth interviews extending from 45 minutes to over three hours, a focus group discussion and an online research blog for participants to write reflections over a period of 10 weeks. Interviews were audio-recorded and transcribed verbatim. Field notes describing the paralanguage and non-verbal cues were also added to the transcriptions as annotations to further explain the context of each interview setting. This was consistent with a technique of “intensive interviewing” (Charmaz, 2014, p. 58). The focus group discussion was also fully transcribed, and all data (interviews, focus group transcript, blog transcript) were read and re-read several times before using the computer program NVivo (versions 8, 9, 9.3 and 10) to manage the data. A constant comparison method was used to analyse the data for emergent themes. Data analysis, in line with the GTM, was conducted concurrently with ongoing data collection, and data saturation was reached with 11 participants.

Findings
This study set out to explore family carers’ experiences of providing support to their family member, and also to explore their perceptions of support available to them in their carer role from both formal and informal services. The study has identified that the support participants provided to their own family members was long-term and therefore needed to be sustainable. It was aimed towards supporting their family member’s independence, even if full independence was not possible. The active support they provided to their family member with a spinal cord injury facilitated, among other things, participation in familial activities. They regularly modified family routines or activities so they could be performed more easily by the injured family member, and negotiated ways that shared activities could be enjoyed with their loved one. The study also adds to what is known about the extent and the impact of caring involved in this context, with participants regularly reporting fatigue and significant responsibilities, and a clear need themselves for more targeted support.

Overall, this study revealed that when family carers talk of receiving support themselves to manage their lives and caring responsibilities, they draw a distinction between receiving practical assistance, and receiving emotional support. Both practical assistance and emotional support may come from formal sources such as health services or health personnel, and from informal sources such as from others in a similar situation, or from close friends, extended family and neighbours.

Formal support
Participants in the study reported receiving limited personal assistance and little emotional support from health and social service providers, although they had ongoing, frequent contact with a variety of different health services. The majority of participants spoke of many hospitalisations post-injury where they had taken the opportunity to seek further practical assistance and/or emotional support for themselves while their loved one was receiving care, but usually without success.

The lack of practical assistance, for example, was particularly evident when participants discussed their loved one’s experiences of being discharged from hospital without appropriate support measures in place to manage their care needs at home. It seemed to them that service providers assumed they would be able to manage the situation even though, particularly in the early stages post injury, they had no relevant experience of caring for someone with such high-level care needs. This situation was similar for most participants, regardless of the length of time since the injury, indicating that little has changed for carers in this context over the past 20 years. In the past, these experiences were common. Only limited information regarding living with, and supporting, the person with the injury was provided at the time of the initial injury. Participants explained how they were left to manage by themselves:
In the more recent past, Meg explained that this lack of practical assistance continues. She recalled one experience, less than seven years ago now, but over 15 years after her husband’s initial injury, which had potentially dire consequences for herself, and the health of her unborn child:

I was [heavily] pregnant. They discharged him … and he physically couldn’t get himself into bed. … [Our child] came five weeks early, and I really blame that ‘cause I was lifting him … I had no choice. … When they discharged him, I said, “I am heavily pregnant. How am I going to get him into bed?”

Meg feels that the health professionals she dealt with at the time did not see it as their responsibility to ensure her husband’s discharge into the community was appropriately supported and managed. This is surprising, given that this situation was relatively recent, indicating that discharge planners were not recognising the need to organise appropriate ongoing support for a person living in the community with a significant disability or their main carer. Often, it is assumed that the family carer will be able to manage alone.

Several participants in this study identified some formal services as unhelpful because information and advice received from experts turned out to be inaccurate. Some participants even described some professional advice as “stupid”. This included suggestions of major home or car alterations that would clearly be difficult to achieve, or perhaps were well beyond the scope of the family budget. Frequently, these recommendations were not appropriate to the personal circumstances of the carer and the person with the injury:

The … hospital said, “Oh you can’t put such and such in there [the car].” … And a friend … who had a brother in a wheelchair … said, “Oh that’s shit!” He said, “Give me the car” and … he took our car and he brought it back the next day … had them [wheelchair restraints], all in and … [put in] a ramp. (Tracey)

Other participants had similar experiences. Anne had supported her husband who worked full time but was reliant on her ongoing assistance to enable him to maintain his independence, for three decades. She recalled professional suggestions that seemed “ridiculous” and included “… putting railings in the shower [when] in the commode … he was never going to be able to stand up” and “… lots of things that weren’t necessary”. Sophie, who supported a son with high caregiving needs explained a situation where the advice from formal services seemed inappropriate since the rest of the family had to occupy the family space. She recalled the advice of an occupational therapist: “Her suggestion was to knock the … wall out between his [Son’s] bedroom and the bathroom … and … it was our only bathroom … so you’d have this big gap”. Participants’ experiences of gaining practical assistance from formal organisations such as hospitals and other community-based services were negative. Eventually, as explained later, informal networks of family and friends became more important as a reliable source of practical assistance.

The need to be heard and recognised

Many of the participants in this study could be described as “hidden carers” (NSW Health, 2007; NSW Department of Family and Community Services, 2012). These were carers who, for example, did not qualify for carer benefits as they worked full time and did not want to cease paid employment. However, due to this, they had not been legally recognised as an important member of their partner’s support network, even though they were often providing full assistance. Some participants noted that they were rarely consulted by health professionals, presumably because health privacy laws require staff to work with the client or patient (if they are without cognitive impairment), rather than with others, including family members. Nevertheless, our participants felt this neglect strongly, given the critical role they felt they were fulfilling in supporting their family member to be safe and active.

There was strong evidence in the data to indicate that participants generally perceived that health professionals do not credit them with holding valid information which would be helpful for care planning. In their capacity as informal family carers, participants perceived negativity in the attitudes shown by some health professionals:

My sister … got pneumonia … so they transferred her to [hospital] … They didn’t believe me when I told them about her bowel regime. … They told me that it … couldn’t
Long-term family carers in this study expressed a sense of disappointment and frustration with formal health services. They felt health professionals could improve their collaboration with any informal carers they came across in their practice.

Health services and safety

Participants reasonably expected their loved ones to be kept safe at all times when in the care of health service providers, and, although a taken-for-granted assumption is often made about hospitals ensuring physical and psychological safety for patients, participants reported safety concerns. Several carers in this study reported that having their family member in a non-spinal injury unit within general hospitals in NSW (often as a result of secondary complications from the injury) was particularly challenging. This was because they had concerns for that person’s safety. The need to intervene themselves to ensure that safety is articulated by Carmel, who recalls a chilling memory of a past hospitalisation where, if not for her own actions, her husband may not have survived the incident. Her intervention was life-saving, although her husband was under the direct care of formal care providers in a general hospital setting:

He was in the room one up from the nurses’ station. I walked past them. They were all chatting about their weekend. I walked in, and he was choking. He was laying on his back and he had vomited, and he was choking! I sat him up. I pushed the button. I tried to have a bowl over him, pushed the button, calling out! No one came for 20 minutes! (voice tone and pitch rises)

Participants wanted to be assured that their family member was kept physically and emotionally safe, and some were distrustful of formal services due to their past experiences. Brenda explained her perceptions of the disempowering attitudes of health professionals when her partner is admitted for frequent medical care:

There’s too many times when we have doctors and nurses walk into a room, and because they see [Partner] the way he is [with physical limitations] they automatically assume they know ... his routine better than he does, and they know how to position him better than he does.

Long-term family carers negotiate their caring support with their loved one, and in consultation with them; however, five of the eleven participants reported a problem with care provision from formal health services. The distrust they feel with health services, or individuals who work within such services, often arises when they perceive a lack of interest or attention to individual needs on the part of the professional they are observing, or trying to communicate with.

Active support

Active support describes how family carers integrate caring actions within a family context.

Family carers provided active support to facilitate healthy family relationships and to enable the person with the injury to participate in all family activities where it was possible to do so. Participants described a range of active daily support activities. For some participants, elements of personal caregiving were identified as crucial to the comfort and wellbeing of their family member. For others, enabling safety, dealing with access issues, and sharing social time were part of the diverse spectrum of active support.

Because of the high level of active support required in the case of all participants in this study, their need for respite arrangements and more practical assistance is high. Janice outlined the different activities of support she provided on a daily basis:

... all those little incidental things I am constantly doing ... running around ... grabbing his shoes ... filling his car with petrol ... I do ... all the shopping, all the cleaning, 99% of the cooking ... [If] the kids have got parent-teacher interviews coming up at school ... it will be me that contacts the school, and makes [access] arrangements.

Supervising and caring for young children is another area where there is often a need for active support. There are some physical limitations that a person with a thoracic (mid to upper back) spinal cord injury has when it comes to activities involving the safety and supervision of young children. All participants pointed out that neither they, nor their partners, took any risks which could potentially compromise their children’s safety. Participants negotiated responsibilities with the co-operation of their partners who, as people living long-term with spinal cord injury, understood their own physical limitations in relation to managing their own children. Thus, inevitably, there were additional responsibilities which family carers undertook with regard to co-parenting. According to Fiona, “one of the … things that is really hard as a parent is … I can’t leave [Partner] with them [the children] on his own ’cause they can quite easily get into strife. ... so many of my friends [laughs] can just have a morning off and ... leave the kids behind, and have coffee with their girlfriends … and if I do that, I have to get someone in to help … “
Potentially, additional parenting responsibilities can lead to physical fatigue, and the need for a degree of respite, as well as assistance with childcare, has been identified in this study. Caregiving respite, and assistance with childcare, has been identified as a key support need in this context for spousal carers.

**Emotional support from formal service providers**

Study participants who had provided support for over 20 years reported either a complete lack of emotional support from professional services in the early years, or, a service provided which did not meet their needs. Hannah, for example, recalled no emotional support from formal service providers being offered to her or her parents during her sister’s initial hospitalisation, or at any time afterwards. Participants all expressed a desire for more targeted and ongoing emotional support and follow-up from health services, both at the time of injury, and, perhaps more importantly, at regular periods afterwards. Over time, it seems this situation has not improved:

> That’s been our experience all the way along with hospitals. … They don’t ring you. … Surely somebody there could spare five minutes and ring … and say, “How are you doing?” a week later. … But there’s nothing {emphasis}. You leave hospital and that’s it. (Meg)

Many participants expressed a need for emotional support in the form of formal counselling to assist them in developing and maintaining some personal boundaries, particularly in relation to caregiving, and they all actively sought out this formal support. Several participants had accessed counselling from a range of formal services. Ellen, for example, had “been seeing a psychologist for about five years … pretty much weekly … [to] help be able to have … boundaries … and just say, ‘I can do this much and that’s all I can do.” Ellen disclosed that she had suffered severe anxiety and sleep deprivation.

General practitioners were often the first line of contact for participants, followed by psychologists, and, on occasion, case managers from spinal-specific services. Participants had to seek out formal support themselves as it was not usually offered, but they recognised their own needs and acted on this, even though this necessitated them becoming “patients” themselves.

**Informal support**

Social, as distinct from professional or formal support has been found to have a strong positive association, with reports of higher quality of life for both the person with the injury (Sherman, DeVinney, & Sperling, 2004) and their family members (Sheija & Manigandan, 2005; Rodakowski et al., 2012). Negative social interactions and poor social integration were the two strongest factors associated with caregiver depression in a recent study (Rodakowski et al., 2012, p. 569).

**The need for medical knowledge and practical support**

The category of social support which was reported as most significant in this study was medical information obtained from informal care networks. Perhaps surprisingly, it was members of those informal networks who were the most helpful when it came to being able to access complex medical information. For instance, friends with medical knowledge were often called on by participants to assist them with medical problems and also with resolving lifestyle problems. Anne, a carer for 33 years, draws attention to the long-term, informal, practical assistance offered by her close neighbour, a medical practitioner, who supported them for some years: “We had a surgeon live next door up until … a few months ago, and I called on him quite often … if … [Partner] really got sick [and] he couldn’t get out of bed.” (laughs)

Tracey, the mother of a young adult son, also explained the circumstances under which she accessed neighbours with medical expertise in preference to seeking advice from health professionals, for whom she felt a deep distrust, a feeling that was shared by some of the other participants as outlined earlier:

> “I have a girlfriend who is a nurse and her husband is a doctor, and when we first came home [from the hospital], we were on their doorstep … ringing up … “What do we do? What do we do!” … They know if I ring up … something’s urgent …”

As well as seeking assistance and advice from neighbours and friends with medical skills, participants also called upon informal networks for other types of practical assistance, although they were mindful of intruding on the time commitment of others or inconveniencing them in other ways. Ellen acknowledged the assistance of a close neighbour whom her partner could call with an emergency alarm when she (Ellen) was away from the family home:

> “If I’m going somewhere … [Partner] uses an emergency system to ring her in the middle of the night [and if] he needs [anything] she’ll come over, and let herself in the back door with a torch.”

Brenda identified the assistance given by a regular taxi driver, who, while providing a formal service, is not expected to deliver the degree of support that he does provide. “He knows how to put [Partner] into bed … and … He is huge, bald, and if you say anything, he will deck you!” This practical support enables Brenda and her partner to occasionally socialise with friends for an evening.
Medical knowledge and the need to remain competent to identify and address any immediate health situations was identified as a need in this study, yet, surprisingly, the need was often met by friends and community members with medical expertise rather than by formal health professionals. In addition, participants described situations where caregiving support was given by complete strangers, who then became friends, as their support was invaluable to meeting the needs of their family members with injuries.

**Emotional support and social isolation**

Participants in this study had varying experiences of receiving emotional support from extended family members. Several spoke of a lack of emotional support from immediate relatives. Some participants had good family support, and others had experienced the antithesis of what they considered supportive. Carmel, for example, was open about her lack of extended family assistance. She reported a complete lack of practical assistance and emotional support, even when she did seek it from her extended family. “We haven’t got any support from family. Absolutely none … except from our son … I’ve got five brothers and four sisters, and … well there’s seven of them [in Partner’s family]”. Participants sought assistance and support from family, friends and neighbours and there is a wide variation in how they experienced this informal support, particularly with regard to extended family and friends.

The research blog for this study enabled participants to share some of their experiences with each other, and several wrote about the sense of social isolation they experienced because of their perceived lack of emotional support:

> We have overcome many obstacles and challenges but the burden has grown greater in some ways. It seems most people just get used to the idea of my husband in a wheelchair, and then forget the impact it has on our lives. … I often feel invisible. … We carers put … up with a lot of stuff for not much reward, and always overshadowed by the one with the actual disability. … If nothing more, it has been comforting to see there are fellow carers out there facing the same feelings of frustration and irritation at the lack of understanding or acknowledgement. [Research Blog: Five participants combined data, 2012]

Many participants described receiving emotional support from informal peer networks – in other words, people who were in similar situations. Participants in this study described peer support as consisting of empathic, interactive contact, either directly or indirectly, with people who share a similar life context. Several long-term carers highlighted the important, accurate and realistic information that they received informally from families or individuals in the same situation as themselves. Fiona explains that peer support can address the feeling of “being on your own”. She commented:

> Support can be provided in little ways by knowing others who are in the same situation, ‘cause that’s one thing, especially when I was dating [Partner]. … I didn’t know anyone who was in this situation. It’s the sort of feeling of being slightly on your own, and not quite knowing …

**Peer support**

The development over time of peer networks of various kinds is identified in this study. For long-term carers, informal peer support networks often began when their family member was originally in hospital immediately post-injury. Several participants spoke of ongoing associations that they and their partners had with people in similar situations. Anne explained that the connections her husband had made when he was first hospitalised still existed three decades later. Participants also used online social media and other available technology to participate in anonymous support groups, which, to some extent, met their perceived needs for emotional and information support. They discussed both receiving and also offering peer support online. Fiona mentioned providing information and advice about monitoring the potential for fatigue and exhaustion in this context to others in similar situations. Some participants highlighted the need for peer support to be flexible because of the time limitations of caregiving for people with high support needs, and most referred to the value of communicating with others in similar situations. According to Brenda:

> It would be good to have a bit more support … at times. Just … people in my situation … so you could get together and … talk … and it doesn’t actually have to be about what we are doing … It’s just to have an outside relief because … I really don’t have anyone. … I am sort of the only “carer” in the group …

This study found that, while there are often well-established peer support networks available for the person with the spinal cord injury, there are few, if any, established peer support networks for long-term informal carers in this context. If they did have peer support, it appeared to be unplanned and spontaneous rather than occurring on a frequent basis. Peer support for long-term family carers is generally limited to online and anonymous networks, or incidentally through interest and sporting activities. Thus, it is not surprising that some participants in this study experienced a strong sense of isolation and invisibility.
Discussion

This study demonstrates that long-term family carers often have unmet needs for practical assistance and support. The study also reveals that there is very little emotional or social support available in the wider community for carers in this context, including from health and community-based social services. In addition, participants have expressed a desire for further recognition from health professionals of the important role they play within the broader caregiving network.

Long-term family carers supporting a person with a significant disability have a need for practical and lifestyle assistance, including formal respite from familial and/or caregiving responsibilities. They would appreciate regular respite from their active support role, and occasional practical assistance with childcare, domestic and home maintenance activities. The finding that a significant burden is experienced as a result of lack of assistance and social support for themselves, including lack of available respite, is consistent with findings from international research on spousal caregivers with two to 12 years’ experience in this context (Dickson et al., 2012:251), and caregiving over longer periods of time, namely from five to 20 or more years (Gajraj-Singh, 2011; Post et al., 2005; Rodakowski, Skidmore, Rogers, & Schulz, 2012).

Participants in this study would also welcome better access to formal emotional support services. They are extremely concerned about the safety of their loved ones when hospitalised, and they resent the lack of recognition by health professionals of their expertise in relation to the care and support they provide to their family member, and the significant contribution they make to health and social care more broadly.

These findings build on limited extant knowledge from other research (Arango-Lasprilla et al., 2010; McPherson et al., 2014; Holland & Blood, 2008; Meade et al., 2004). As noted earlier, previous studies have emphasised that there are significant gaps in knowledge about long-term family carers of people with spinal cord injury, although international work on the experience of spinal cord injury itself has now identified needs related to information, respite services and other support services (Anderson et al., 2013). Other studies focusing on caregiving over longer periods of time – from five to 20 or more years (Gajraj-Singh, 2011; Post, Bloemen, & de Witte, 2005; Rodakowski et al., 2012) – have identified the significant burden experienced as a result of lack of assistance and social support, including lack of available respite care opportunities. Certainly, community-based services, including domestic services, can empower a person with a spinal cord lesion to live independently (Galvin, 2004). Participants in this study felt that they, too, could be more empowered with access to effective, targeted health and social support services.

Participants in this study have also highlighted their experience of loneliness and social isolation. Most of the participants had never before been asked about their experiences as long-term family carers, and they had rarely had the opportunity to discuss these issues; partly due to a respect for upholding the privacy of their family member, but also because of the level of responsibility involved, which can limit their opportunities for external social connection. Most participants felt that formalised peer support would be helpful in providing emotional support, and they were also willing to provide this support themselves to others in similar situations.

Limitations of the study

This study was limited by the absence of the male carer voice. The study was open to all long-term family carers of people with spinal cord injury, but as it happened, no male participants were recruited. The qualitative nature of the study means that the findings are not generalisable, and the scope of the study was such that it was not possible to recruit participants from beyond a 300-kilometre radius of Sydney. Only two participants were recruited from rural areas. Despite these limitations, given the small population of people affected by a spinal cord injury overall, this study has provided rich information which complements and builds on existing work in this area.

“...the qualitative nature of the study means that the findings are not generalisable, and the scope of the study was such that it was not possible to recruit participants from beyond a 300-kilometre radius of Sydney...”

Conclusions and recommendations

Long-term carers of people with spinal cord injury have a need for regular external assistance to manage home and domestic tasks, particularly in the early years of parenting children. They also have a desire to be heard and to have their expertise recognised, particularly by health professionals. There is no doubt that family carers perceived that they need more practical assistance and emotional support from health services themselves over the long term to assist them to strategically manage their complex situations. There is a significant need for formalised and flexible peer support for long-term family carers. Rehabilitation health professionals, particularly, should listen carefully to the caregiving advice and the experience of family carers. Further research attention to this area may uncover strategies to further support them. Findings may then enable families to achieve ongoing and lifelong sustainability, despite challenges which may frequently arise.
Acknowledgement

The authors wish to acknowledge, and thank, the Australasian Rehabilitation Nurses Association (ARNA) who generously funded this arm of the study with an ARNA National Research Grant awarded in 2012.

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National Statement on Ethical Conduct in Human Research 2007 (Updated May 2015). The National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors’ Committee. Commonwealth of Australia, Canberra


Comparison of dependency scores to assess resource allocation for patients with spinal cord injuries

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Abstract

Introduction
Appropriate nursing resource allocation is essential to ensure optimal care for patients suffering a spinal cord injury. Nursing hours per patient are currently determined by the number of allocated staff per shift, with distribution for patient care based upon patient numbers rather than patient acuity.

The aim of this pilot study was to compare patient dependency scores using the Functional Independence Measure (FIM) and the Northwick Park Dependency Scale-Hospital (NPDS-H) and to evaluate if data from these tools could be used to determine optimal resource allocation.

Methods
This prospective pilot study used convenience sampling and was completed in a tertiary hospital spinal injuries unit (SIU). FIM and NPDS-H tools were used to score patient dependency and compared to the nursing resources allocated. There were no changes to usual allocation of nursing staff during this period.

Results
Data were collected from October 2015 to January 2016. Scores were determined using the FIM and NPDS-H for 60 patients and scores for the FIM ranged from 41 to 110 and for the NPDS-H 2 to 59. Nursing resources allocated ranged from 3.3 to 17.7 nursing hours per day. There was strong correlation between the FIM and NPDS-H scores. The Pearson correlation coefficient between nursing hours and the FIM and NPDS-H was −0.18 and 0.37 respectively.

Conclusion
The NPDS-H scores better reflected the nursing resource allocation for the patient population. The use of the NPDS-H could be utilised as a tool to determine dependence of the patient population within a spinal injuries rehabilitation unit and assist in the allocation of nursing resources.

Keywords Rehabilitation, nursing dependency, dependency scoring, spinal cord injury.
The need for rehabilitation following an SCI has been well documented (Turner-Stokes, 2007) but the dependency and the patient care requirements are not always agreed upon. Nursing resource allocation is reliant on a number of factors including levels of nursing experience, team dynamics, patient acuity and attitudes towards rehabilitation. Evaluation of patient dependence is also subjective according to the nurse in charge of the shift (Lowe, Santamaria, Tacey, & Rowe, 2015). A tool is required in the assignment of nursing resources to best meet the individual patient needs within the patient population. Levels of patient dependency can be measured using the Functional Independence Measure (FIM) (The Uniform Data System for Medical Rehabilitation, 2008). The FIM shows the burden of care needs, but cannot be utilised to determine the number and skill mix of the staff required to meet the clinical care needs within a given patient population (Turner-Stokes et al., 2010). Patient dependency can also be measured using the Northwick Park Dependency Scale-Hospital (NPDS-H), which provides an assessment of care and nursing needs within a rehabilitation setting and is sensitive to the complex care needs of the patient population (Svensson, 2012).

The aim of this research was to compare the FIM and the NPDS-H patient dependency scores and to evaluate if data from these tools could be used to facilitate allocation of nursing resources. Association between patient factors and scores would also be used to determine the feasibility of a larger study to determine the optimal resource allocation based upon patient acuity, with data from this pilot study used to provide benchmarking to evaluate future changes to the units’ model of care and staff resource allocation.

Methods
An observational pilot prospective study was conducted over a four-month period between October 2015 and January 2016.

Ethics
Human research ethical approval was granted to conduct the study, approval number HREC/15/QPAH/560. All data was de-identified at source and conformed to the National Statement on Ethical Conduct in Research involving Humans (2007) by the National Health and Medical Research Council of Australia.

Participants and setting
The study was conducted in a 40-bed spinal injury unit (SIU) and included all inpatients between the ages of 18 and 100 with the exception of patients readmitted to the unit and non-spinal patients.

The SIU is part of the Queensland Spinal Cord Injuries Service, a statewide service that has been established to assist individuals with an SCI in achieving their maximum physical, social and psychological potential across their lifespan (Service Profile SIU Division of Rehabilitation, 2015). The unit is located within the campus of the Princess Alexandra Hospital, detached from the main building but has ready access to all medical services. At the SIU the journey through rehabilitation may differ for each individual patient but the primary aim remains the same: to maximise independence within the context of their individual goals, environment and level of injury (Queensland Spinal Cord Injuries Model of Care, 2012). Currently within the SIU the model of care utilised incorporates an allocation of staff to patient ratio. While there is a difference between acute- and rehabilitation-patient to staff ratios, ratios are based upon numbers and not dependency of the patient population within a given pod. The acute care pod is made up of a six-bed ward configuration with a single isolation room that has a staffing-to-patient ratio of 1:2, while the rehabilitation pods are comprised of eight to 10 patients with predominantly a 1:4 ratio of staff-to-patient. The calculation of ratio only incorporates licensed workers that are enrolled and registered nurses, while non-licensed staff such as assistants in nursing (AINs) are excluded. While this ratio forms the basis of staff allocation there is always the ability of the senior nurse in charge to request more staff if there is a clinical justification.
Outcome measures
The outcome measures utilised were the FIM score, the NPDS-H score and the attributed hours of nursing staff.

FIM tool
The FIM is a basic indicator on the severity of disability. Patients’ functional ability changes throughout the rehabilitation process and the FIM tool is able to track those changes. The FIM tool comprises 18 items for assessment against a seven-point scale, where the higher the score for any given item the more independent the patient is with task completion. Total score with a FIM tool ranges from 18 to 126. The FIM tool looks at both motor and cognition components of functional independence.

While the FIM is applied in many areas such as Canada, Australia and many parts of Europe (Turner-Stokes, 2012) the FIM administration requires training and credentialling. There are only a few nursing staff within the SIU that maintain a FIM credential.

NPDS-H tool
The NPDS-H tool provides an assessment of patient care needs. It is an ordinal scale incorporating activities of daily living, safety awareness, behavioural management and communication. The NPDS-H takes into account the time taken to supervise patients undertaking tasks to completion, rather than the estimated time for the task to be completed. The NPDS-H considers the benefits of effective communication between staff and patients, including the extra time required to communicate with a patient who has language or cognitive difficulties. The tool comprises four sections and is further divided into components incorporating the basic care needs, special nursing needs and inpatient assessment with total scores for the tool ranging from 0 to 100. Lower NPDS-H scores indicate greater patient independence. The NPDS-H was developed by Kings College London and is held by The North West London Hospitals NHS Trust 2014. The NPDS-H data collection tool requires no formal training with any nursing staff member able to complete the data collection tool. An example of the NPDS-H appears in Appendix 1.

Attributable nursing hours
For deliberation and review of the nursing hour resources currently utilised throughout the SIU, an analysis spreadsheet was developed. This spreadsheet allowed for the allocation of the resources and the skill mix of the staff pre-allocated to a ‘pod’ to be calculated to provide an overall hours per patient per day. The analysis incorporated all clinical nursing staff for the day; it did not include the nurse unit manager, clinical nurse consultant or nurse educator as they are not allocated to directly care for set patients.

The distribution of nursing hours identified two distinct groups and was dichotomised accordingly into categories at 12 hours, with Group 1 less than 12 nursing hours and Group 2 greater than or equal to 12 nursing hours.

Factors of interest
Other factors of interest included patient demographics including: age, sex and length-of-stay in the unit. Length of stay was taken from the date of admittance to the unit until discharge or duration of hospitalisation at study end (Jan 2016). Patient American Spinal Injury Association Impairment Scale (AIS) classification was also noted for all patients. The AIS is a multi-dimensional approach to categorising motor and sensory impairment in individuals with an SCI. The AIS is classified into categories A, B, C, D or E. This ranking is based on the Frankel scale and classifies individuals from “A” which is a complete SCI to “E” which comprises normal sensory and motor function (Eng & Chan, 2013). While complete AIS data was collected, for this analysis data were categorised into three levels of injury; categories included injury levels at C1–C6, T1–T9 and T10 and below.

Data collection
All data were collected by two trained clinical nurses with experience working with spinal cord-injured patients receiving rehabilitation. One of these clinical nurses had FIM credentialling and completed all FIM assessments. Data were collected on the same day of the week on a fortnightly schedule, with data collected randomly during the day when documentation could be visualised. The nursing hours per patient per day data were collated on the day following FIM and NPDS-H data collection to allow a comprehensive 24-hour assessment.

Data analysis
Patient demographic descriptive statistics including frequencies and percentages were reported. Non-normal distributed demographic data including age on admission to the SIU and length of stay were categorised into clinically significant groups, and medians calculated.

NPDS-H and FIM scores were normally distributed; therefore mean scores with 95% confidence intervals (CIs) were calculated according to patient demographics and categories of patient-allocated nursing hours. The Pearson correlation coefficients
and p-values for statistical significance (at the $p = 0.05$ level) between the FIM and NPDS-H scores and also for each scale score with nursing hours were reported.

**Results**

Data were collected from 62 patients between October 2015 and January 2016, with an average of seven dependency score assessments completed for each patient. During the period of data collection there were two patients who had English as their second language; data were collected using an interpreter, but due to unreliability of data, were omitted from analyses.

A total of 247 dependency scale assessments were analysed and the allocated nursing hours for patients during this assessment nursing shift ranged between 3.3 and 17.7 hours (median 7.6).

The median age of patients was 51 (range 19 to 81) years, and approximately two-thirds were men (Table 1). Higher dependency scores (low FIM scores and high NPDS-H scores) were found for patients with cervical SCI than those with lower SCI and also for those with longer length of stay in the unit. The median length of stay from admission to discharge or at study end (January 2016), for the 60 patients was three months.

Almost half the patients ($n = 26, 43\%$) had a C1–C6 impairment level.

Scores for the FIM ranged from 41–126 and the NPDS-H from 2–60, with mean FIM score of 66 (95\% confidence interval [CI] 58–73) and NPDS-H of 37 (95\% CI 37–43), completed during shifts with 14.5 or more nursing hours allocated (Table 2).

Most patients reviewed were allocated less than 12 hours of nursing care ($n = 212, 86\%$) (Figure 1).

There was a strong negative correlation between the FIM and NPDS-H scores, which was statistically significant, $r = –0.75, p <0.001$ (Table 3). A strong negative correlation between scores indicates that as one score increases the other score decreases.

*Table 1: Patient demographics ($n=60$), with corresponding observations and mean scores for the NPDS-H and the FIM*

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Number of patients</th>
<th>Number of observations</th>
<th>FIM*</th>
<th>NPDS-H*</th>
</tr>
</thead>
<tbody>
<tr>
<td>18–39</td>
<td>18 (30)</td>
<td>75 (31) 101 (41)</td>
<td>67.5 (22.1) 75.9 (19.1)</td>
<td>26.3 (12.0) 23.4 (11.1)</td>
</tr>
<tr>
<td>40–59</td>
<td>25 (42)</td>
<td>70 (28)</td>
<td>70.9 (14.6) 29.1 (12.9)</td>
<td></td>
</tr>
<tr>
<td>60 +</td>
<td>17 (28)</td>
<td></td>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number of patients</th>
<th>Number of observations</th>
<th>FIM*</th>
<th>NPDS-H*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>40 (67)</td>
<td>167 (68)</td>
<td>71.3 (19.1) 25.6 (12.4)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>20 (33)</td>
<td>80 (32)</td>
<td>73.2 (19.4) 26.6 (11.5)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of injury</th>
<th>Number of patients</th>
<th>Number of observations</th>
<th>FIM*</th>
<th>NPDS-H*</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1–C6</td>
<td>26 (43)</td>
<td>105 (43)</td>
<td>62.6 (17.7) 28.9 (11.4)</td>
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</tr>
<tr>
<td>T1–T9</td>
<td>21 (35)</td>
<td>100 (40)</td>
<td>77.3 (16.0) 25.2 (12.7)</td>
<td></td>
</tr>
<tr>
<td>T10 – below</td>
<td>13 (22)</td>
<td>41 (17)</td>
<td>82.5 (19.9) 20.0 (9.8)</td>
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<table>
<thead>
<tr>
<th>Length of stay* in days</th>
<th>Number of patients</th>
<th>Number of observations</th>
<th>FIM*</th>
<th>NPDS-H*</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–89</td>
<td>8 (13)</td>
<td>86 (35)</td>
<td>78.1 (22.6) 21.5 (12.9)</td>
<td></td>
</tr>
<tr>
<td>90–149</td>
<td>13 (22)</td>
<td>62 (25)</td>
<td>71.5 (19.5) 27.1 (13.1)</td>
<td></td>
</tr>
<tr>
<td>150 +</td>
<td>39 (65)</td>
<td>99 (40)</td>
<td>66.9 (13.7) 28.9 (9.4)</td>
<td></td>
</tr>
</tbody>
</table>

*a FIM: scores range 18–126; high score suggests greater patient independence

bNPDS-H: scores range 0–100; low score indicates greater patient independence

cLength of stay calculated from day of admittance until discharge or end of study (7 January 2016)
The correlation coefficient between nursing hours and the FIM and NPDS-H was $r = -0.18$, $p = 0.004$ and $0.37$, $p < 0.001$ respectively which indicated that there was limited negative correlation between nursing hours and FIM and a weak positive correlation between the NPDS-H and nursing hours.

### Discussion

In this observational pilot study a patient population was targeted to investigate the relationship between the NPDS-H and FIM and the allocation of nursing hours. We found that there was a strong negative correlation between the NPDS-H and the FIM. We also found that the NPDS-H had a greater correlation with the allocation of nursing hours than the FIM score.

We found that patients with higher level SCI had greater dependency scores. These patients were routinely allocated more nursing hours, suggesting that the scales may both be suitable indicators for high-dependency patients. It has been shown that patients with high-level SCI AIS scores have high needs for hospital admission and upon discharge (Lifetime Care and Support, 2007).

In a previous study undertaken in 2010 by Turner-Stokes and colleagues, which compared FIM and NPDS-H (Turner-Stokes et al., 2010) it was highlighted that there were a number of factors that can impact upon the scores derived and although scores may be similar they should not be automatically regarded as equivalent. Turner-Stokes et al. (2010) indicated a major factor of these differences may be due to the FIM being completed by therapy staff and the NPDS-H by the nursing staff, while in this project scores for both measurement tools were completed by nursing staff members, reducing measurement bias.

Another important factor is the issue of time pressure and the need to have patients ready for their first morning appointment.

### Table 2: FIM and NPDS-H mean scores (n=247 reviews)

<table>
<thead>
<tr>
<th>Allocated nursing hours</th>
<th>Number of patient reviews</th>
<th>FIM score(^a) Score range (18–126) Mean score (95% CI)</th>
<th>NPDS-H(^b) Score range (0–100) Mean score (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–6.9</td>
<td>96</td>
<td>74.1 (69.7–78.5) 23.8 (21.4–26.1)</td>
<td></td>
</tr>
<tr>
<td>7–9.9</td>
<td>118</td>
<td>72.3 (69.2–75.4) 24.5 (22.6–26.4)</td>
<td></td>
</tr>
<tr>
<td>10–14.4</td>
<td>10</td>
<td>61.3 (52.3–70.3) 35.5 (27.1–43.9)</td>
<td></td>
</tr>
<tr>
<td>14.5 +</td>
<td>25</td>
<td>65.6 (58.0–73.1) 37.2 (37.1–42.6)</td>
<td></td>
</tr>
<tr>
<td>&lt; 12</td>
<td>212</td>
<td>73.1 (70.5–75.7) 24.2 (22.7–25.7)</td>
<td></td>
</tr>
<tr>
<td>≥ 12</td>
<td>35</td>
<td>64.3 (58.4–70.2) 36.7 (32.2–41.2)</td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) FIM: high score suggests greater patient independence

\(^b\) NPDS-H: low score indicates greater patient independence

Table 3: Correlation matrix of NPDS-H, FIM and nursing hours

<table>
<thead>
<tr>
<th>FIM(^a)</th>
<th>NPDS-H(^b)</th>
<th>Nursing hours(^c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIM</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>NPDS-H</td>
<td>-0.7597</td>
<td>1</td>
</tr>
<tr>
<td>≤ 0.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing hours</td>
<td>-0.1832</td>
<td>0.3702</td>
</tr>
<tr>
<td>0.0039</td>
<td>&lt;0.000</td>
<td></td>
</tr>
</tbody>
</table>

Pearson’s correlation coefficient and statistical significance

\(^a\) FIM: high score suggests greater patient independence

\(^b\) NPDS-H: low score indicates greater patient independence

\(^c\) Nursing hours: Number of nursing hours attributed to patient at time of score assessment
(Turner-Stokes et al., 2010). It can also be understood that the experience level of staff involved in caring for the patient can influence the outcome, as a less experienced staff member may not know when to stand back and allow the patient to achieve a task independently (Turner-Stokes et al., 2010).

Patient perception about what constitutes rehabilitation can also be a challenge, as the patient may only see the time spent with allied health professionals such as physiotherapists and occupational therapists as rehabilitation while being with nurses allows patients to have a more passive approach to rehabilitation as nurses provide care. (Turner-Stokes et al., 2010). Rehabilitation for patients following an SCI is about gaining their independence and as nurses are available 24 hours a day they are pivotal in care delivery to maximise functional improvements (Williams, Harris & Turner-Stokes, 2007).

It is well recognised that the nursing resources required on a morning and evening shifts are different to those required on a night duty shift (Romito, 2006). Allocation of resources needs to be related to the patient needs rather than the floor plan, which is common practice. A limitation of our study was that data was only collected on the morning shift due to staff availability and budget constraints. Results may have been different with afternoon collection of data when patients are routinely fatigued from a day of rehabilitation.

“**A limitation of our study was that data was only collected on the morning shift due to staff availability and budget constraints**”

The FIM is considered the ‘gold standard’ for activities of daily living (ADL) assessment, but as achievements can be small in this patient population, dependency gains are not always well reflected with ADL measurement. The NPDS-H has shown a more accurate measure in the severely disabled or the patient population requiring more care (Svensson & Sunnerhagen, 2012; Flynn, Heinzer & Radwanski, 1999). Changes within the skill mix of the staff can also impact upon the ability of the patients to maximise their independence. When non-licensed staff such as AINs are available to assist with unit-related activities such as restocking, cleaning and housekeeping, then licensed workers can best utilise their time to meet the ongoing needs of the patient. Patient needs may include being engaged in education for the patient and/or significant other, consolidation of activities and tasks learned in therapies, for example dressing practice as well as attending meetings in relation to ongoing care or discharge planning (Flynn, Heinzer & Radwanski, 1999; Williams, Harris & Turner-Stokes, 2007). It is also noteworthy that it cannot be assumed that basic care needs can be met by non-licensed staff, it is at times necessary to have highly qualified staff provide the care to patients that have complex care requirements or challenging behaviours to ensure both the needs of the patient are met as well as the organisation.

The SIU utilises AIN team members to assist the registered nurse to achieve a variety of patient care-related activities under direct supervision, but with the limitation of morning shift allocation when the workload is the most demanding.

This study was too small to allow for individual patient factors to be addressed such as the stage of rehabilitation or ward placement. Only 36 of the 60 patients sampled were discharged.

The aim of the rehabilitation team is to assist the patient to achieve their personal goals and maximise independence, thereby enhancing their quality of life. While this is an overarching component of the model of care, the ongoing work is to further look to the nursing allocation and resource management. This project did not ascertain quality of life as a component but if any future work was to be completed it would be advantageous to incorporate a quality of life measure utilising one of the already available tools.

**Conclusion**

This project was seen as the first step in a larger project to look at redefining the model of care utilised within the SIU. The current model of care incorporates an interdisciplinary approach to rehabilitation. This allows for collaboration, teamwork and goal planning with the patient and significant others being considered an integral component of the team. This work has presented useful information and pilot data to progress to a much larger study.

**Acknowledgements**

I would like to acknowledge the support from my colleagues within the SIU completing this initial investigation into patient dependency scores. I also wish to acknowledge the support provided from the Nurse Practice Development Unit. I would also acknowledge the work completed on the formation and evaluation of the Northwick Park Dependency Score-Hospital and the corresponding approval granted for its use in this project.
### Appendix 2

#### 6.1. EATING

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mealtime supervision / assistance 0</td>
<td></td>
</tr>
<tr>
<td>2. Able to eat independently</td>
<td></td>
</tr>
<tr>
<td>3. No need for assist / feeding / feeding aid</td>
<td></td>
</tr>
<tr>
<td>4. No need for assist / feeding / feeding aid</td>
<td></td>
</tr>
<tr>
<td>5. Needs help with eating / feeding / feeding aid</td>
<td></td>
</tr>
<tr>
<td>6. Needs help with eating / feeding / feeding aid</td>
<td></td>
</tr>
<tr>
<td>7. Needs help with eating / feeding / feeding aid</td>
<td></td>
</tr>
</tbody>
</table>

#### 6.2. DRINKING

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mealtime supervision / assistance 0</td>
<td></td>
</tr>
<tr>
<td>2. Able to drink independently</td>
<td></td>
</tr>
<tr>
<td>3. No need for assist / drinking / feeding aid</td>
<td></td>
</tr>
<tr>
<td>4. No need for assist / drinking / feeding aid</td>
<td></td>
</tr>
<tr>
<td>5. Needs help with drinking / feeding / feeding aid</td>
<td></td>
</tr>
<tr>
<td>6. Needs help with drinking / feeding / feeding aid</td>
<td></td>
</tr>
<tr>
<td>7. Needs help with drinking / feeding / feeding aid</td>
<td></td>
</tr>
</tbody>
</table>

#### 6.3. ENTERAL FEEDING (Dietary history or Nasogastric tube)

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Enteral feeding/ nutrition/ nasogastric tube</td>
<td></td>
</tr>
<tr>
<td>2. Needs help to set up feeding/ nasogastric tube</td>
<td></td>
</tr>
<tr>
<td>3. Needs help to take feeding/ nasogastric tube</td>
<td></td>
</tr>
<tr>
<td>4. Needs help to manage gastric function / nasogastric tube</td>
<td></td>
</tr>
<tr>
<td>5. Needs help to set up feeding / nasogastric tube</td>
<td></td>
</tr>
<tr>
<td>6. Needs help to take feeding / nasogastric tube</td>
<td></td>
</tr>
<tr>
<td>7. Needs help to manage gastric function / nasogastric tube</td>
<td></td>
</tr>
</tbody>
</table>

#### 6.4. SKIN PRESSURE RELIEF

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Able to relieve pressure independently</td>
<td></td>
</tr>
<tr>
<td>2. Needs help to relieve pressure / pressure area</td>
<td></td>
</tr>
<tr>
<td>3. Needs help to maintain pressure area</td>
<td></td>
</tr>
<tr>
<td>4. Needs help with skin protection / pressure area</td>
<td></td>
</tr>
<tr>
<td>5. Skin broken or broken, needs to relieve pressure area</td>
<td></td>
</tr>
<tr>
<td>6. Skin broken or broken, needs to maintain pressure area</td>
<td></td>
</tr>
</tbody>
</table>

#### 6.5. BEHAVIOUR

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General and socially appropriate</td>
<td></td>
</tr>
<tr>
<td>2. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>3. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>4. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>5. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
</tbody>
</table>

#### 13. SAFETY AWARENESS

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Fully oriented, aware of personal safety</td>
<td></td>
</tr>
<tr>
<td>2. Able to communicate basic needs with others</td>
<td></td>
</tr>
<tr>
<td>3. Able to communicate basic needs with others</td>
<td></td>
</tr>
<tr>
<td>4. Able to communicate basic needs with others</td>
<td></td>
</tr>
<tr>
<td>5. Able to communicate basic needs with others</td>
<td></td>
</tr>
</tbody>
</table>

#### 15. COMMUNICATION

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Able to complete basic needs with a little help</td>
<td></td>
</tr>
<tr>
<td>2. Able to communicate basic needs with a little help</td>
<td></td>
</tr>
<tr>
<td>3. Able to communicate basic needs with a little help</td>
<td></td>
</tr>
<tr>
<td>4. Able to communicate basic needs with a little help</td>
<td></td>
</tr>
<tr>
<td>5. Able to communicate basic needs with a little help</td>
<td></td>
</tr>
</tbody>
</table>

#### 19. BEHAVIOUR

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General and socially appropriate</td>
<td></td>
</tr>
<tr>
<td>2. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>3. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>4. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>5. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
</tbody>
</table>

#### 20. BEHAVIOUR

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General and socially appropriate</td>
<td></td>
</tr>
<tr>
<td>2. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>3. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>4. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>5. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
</tbody>
</table>

---

**SECTION 2: SPECIAL NURSING NEEDS**

**ADD ON FOR EACH OF THE BELOW (if applicable)**

### 6.1. HYGIENE

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Able to maintain personal hygiene</td>
<td></td>
</tr>
<tr>
<td>2. Able to maintain personal hygiene</td>
<td></td>
</tr>
<tr>
<td>3. Able to maintain personal hygiene</td>
<td></td>
</tr>
<tr>
<td>4. Needs help with personal hygiene</td>
<td></td>
</tr>
<tr>
<td>5. Needs help with personal hygiene</td>
<td></td>
</tr>
</tbody>
</table>

### 6.2. MEAL TIME

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Able to maintain mealtime</td>
<td></td>
</tr>
<tr>
<td>2. Able to maintain mealtime</td>
<td></td>
</tr>
<tr>
<td>3. Able to maintain mealtime</td>
<td></td>
</tr>
<tr>
<td>4. Needs help with mealtime</td>
<td></td>
</tr>
<tr>
<td>5. Needs help with mealtime</td>
<td></td>
</tr>
<tr>
<td>6. Needs help with mealtime</td>
<td></td>
</tr>
</tbody>
</table>

### 6.3. NURSING CARE PLAN

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Able to maintain nursing care plan</td>
<td></td>
</tr>
<tr>
<td>2. Able to maintain nursing care plan</td>
<td></td>
</tr>
<tr>
<td>3. Able to maintain nursing care plan</td>
<td></td>
</tr>
<tr>
<td>4. Needs help with nursing care plan</td>
<td></td>
</tr>
<tr>
<td>5. Needs help with nursing care plan</td>
<td></td>
</tr>
<tr>
<td>6. Needs help with nursing care plan</td>
<td></td>
</tr>
</tbody>
</table>

### 6.4. SKIN CARE

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Able to maintain skin care</td>
<td></td>
</tr>
<tr>
<td>2. Able to maintain skin care</td>
<td></td>
</tr>
<tr>
<td>3. Able to maintain skin care</td>
<td></td>
</tr>
<tr>
<td>4. Needs help with skin care</td>
<td></td>
</tr>
<tr>
<td>5. Needs help with skin care</td>
<td></td>
</tr>
<tr>
<td>6. Needs help with skin care</td>
<td></td>
</tr>
</tbody>
</table>

### 6.5. BEHAVIOUR

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General and socially appropriate</td>
<td></td>
</tr>
<tr>
<td>2. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>3. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>4. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
<tr>
<td>5. Needs help to manage behaviour / social isolation</td>
<td></td>
</tr>
</tbody>
</table>

---

**SECTION 3: IN-PATIENT NURSING NEEDS**

**Task if applicable**

### 1. TRACHEOSTOMY MANAGEMENT

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No tracheostomy care / management</td>
<td></td>
</tr>
<tr>
<td>2. Maintenance of tracheostomy care / management</td>
<td></td>
</tr>
<tr>
<td>3. No additional time from qualified staff</td>
<td></td>
</tr>
<tr>
<td>4. Additional time for qualified staff</td>
<td></td>
</tr>
<tr>
<td>5. Additional time for qualified staff</td>
<td></td>
</tr>
</tbody>
</table>

### 2. WOUND DRESSING OR PROBLEMATIC STOMA DRESSINGS

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No wound dressing / ostomy management</td>
<td></td>
</tr>
<tr>
<td>2. Simple dressing, does not require qualified staff</td>
<td></td>
</tr>
<tr>
<td>3. Qualified dressing / ostomy management</td>
<td></td>
</tr>
<tr>
<td>4. Qualified dressing / ostomy management</td>
<td></td>
</tr>
</tbody>
</table>

### 3. NUTRITION (including intravenous fluid, enteral feeding etc)

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No fluid restriction / nutrition / enteral feeding</td>
<td></td>
</tr>
<tr>
<td>2. Maintenance of fluid restriction / nutrition / enteral feeding</td>
<td></td>
</tr>
<tr>
<td>3. Additional time from qualified staff</td>
<td></td>
</tr>
<tr>
<td>4. Additional time for qualified staff</td>
<td></td>
</tr>
<tr>
<td>5. Additional time for qualified staff</td>
<td></td>
</tr>
</tbody>
</table>

### 4. PATIENT AND OR FAMILY REQUIRE PSYCHOLOGICAL SUPPORT FROM WARD STAFF

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No additional psychological support required</td>
<td></td>
</tr>
<tr>
<td>2. Additional psychological support required</td>
<td></td>
</tr>
<tr>
<td>3. Additional psychological support required</td>
<td></td>
</tr>
<tr>
<td>4. Additional psychological support required</td>
<td></td>
</tr>
</tbody>
</table>

---

**SECTION 4: BASIC CARE NEEDS**

**SECTION 2: SPECIAL NURSING NEEDS**

**SECTION 3: IN-PATIENT NURSING NEEDS**

---

**UK ROC v1.0.01**

**NPSH v1.05H, Page 4 of 6**

_Last updated September 2012_
**1. SOCIAL ACTIVITIES (SPORTS)**

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. No restriction to sports own church</td>
<td>1</td>
</tr>
<tr>
<td>b. Needle-sport application (eg, tennis) can be applied by one person, from known and reliable source</td>
<td>2</td>
</tr>
<tr>
<td>c. Additional sport supervision (eg, tennis) can be applied by one person, from known and reliable source</td>
<td>3</td>
</tr>
<tr>
<td>d. No restriction to sports own church</td>
<td>4</td>
</tr>
<tr>
<td>e. Needle-sport application can be applied by one person, from known and reliable source</td>
<td>5</td>
</tr>
</tbody>
</table>

**2. POSTURAL MANAGEMENT (IN BED OR CHAIR)**

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Needs to maintain own position</td>
<td>1</td>
</tr>
<tr>
<td>b. Needs one person or help from one to maintain posture, position for 1 to 3 times in 24 hours</td>
<td>2</td>
</tr>
<tr>
<td>c. Needs one person or help from one to maintain posture, position for 4 to 7 times in 24 hours</td>
<td>3</td>
</tr>
<tr>
<td>d. Needs support for 4 to 7 times in 24 hours</td>
<td>4</td>
</tr>
</tbody>
</table>

**3. INTERCURRENT MEDICAL/SURGICAL PROBLEM**

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Intermittent medical/surgical problem</td>
<td>1</td>
</tr>
<tr>
<td>b. Requires skilled nurses in usual care</td>
<td>2</td>
</tr>
<tr>
<td>c. Requires a review of vital signs or specific intervention by a qualified nurse less than 24 times a day</td>
<td>3</td>
</tr>
<tr>
<td>d. Requires a specific intervention by a qualified nurse more than 2 times a day</td>
<td>4</td>
</tr>
</tbody>
</table>

**4. MEDICATION (Frequency/amount of medicine) to take by mouth only**

<table>
<thead>
<tr>
<th>Days a week</th>
<th>Depending on medication</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>3</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>1</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

**5. Do they require support from a nurse or trained carer**

<table>
<thead>
<tr>
<th>Description</th>
<th>Support</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Supplementation</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>b. Pressure lifting/wound dressing</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>c. Special nutrition (eg, insulin injections)</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

**6. Frequency of care**

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Fistula care</td>
<td>1</td>
</tr>
<tr>
<td>b. Wound care</td>
<td>1</td>
</tr>
<tr>
<td>c. Special medication</td>
<td>1</td>
</tr>
</tbody>
</table>

**7. ON-TO-ONE SPECIALISING**

<table>
<thead>
<tr>
<th>Description</th>
<th>Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Needs one-on-one support</td>
<td>1</td>
</tr>
<tr>
<td>b. Needs two-on-one support</td>
<td>2</td>
</tr>
<tr>
<td>c. Needs three-on-one support</td>
<td>3</td>
</tr>
</tbody>
</table>

**SECTION 4: CARE NEEDS ASSESSMENT**

**1. STAIRS**

<table>
<thead>
<tr>
<th>Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Can go up and down stairs at home</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>b. Can go up and down stairs with assistance</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>c. Can go up and down stairs without assistance</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

**2. MAKING A SNACK/MEAL (at home)**

<table>
<thead>
<tr>
<th>Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Can make a snack</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>b. Can make a meal</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

**SECTION 5: SPECIALIZED SERVICES**

<table>
<thead>
<tr>
<th>Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Library</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>b. Shopping</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>c. Laundry</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
Carer legislation, policy support initiatives and future implications

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Abstract

There is a concern for carers’ health and well-being, particularly in terms of their ability to maintain their caregiving role, and the level of support for the care recipient. It is well known that the provision of appropriate and flexible support to carers may also influence their capacity to continue to provide care in a familiar and caring environment. This review paper, the third in a series, provides an overview of Australian carer legislation and policy initiatives to support carers, a brief summary of global perspectives and future caregiving implications.

Carer legislation and policy support initiatives

The health of a carer, and their ability to continue in the caregiving role, has been established as a factor for a care recipient being rehospitalised and/or entering residential care (Spillman & Long, 2009). As a result, the cost to the economy of carers’ mental and physical health, general well-being, socio-economic status and their productivity or contribution to the economy, has become an important issue in health legislation, policy and research (Access Economics, 2015). In Australia, the Commonwealth Government acknowledges carers’ contributions through respite programs, counselling services and financial support (Carers Australia, 2008; Commonwealth of Australia, 2009a).

These standardised initiatives are designed to support and assist family and friends caring for people in the community who are unable to care for themselves because of disability, mental illness, drug and/or alcohol dependency, chronic conditions, terminal illness, or frailty. The National Respite for Carers Program (NRCP) provides carers with specialised professional counselling and practical written information to support them in their caregiving roles, including Commonwealth Respite and Carelink Centres (CRCC). Practical information and information regarding services available to carers is also provided via the Australian Government’s My Aged Care and Carer Gateway websites (Australian Government, 2017a, 2017b). Carers Associations, supported by government funding, provide support, information, and referrals to carers through the Carer Line (a telephone support service), the National Carer Counselling Program (a short-term program of up to six counselling sessions), and the Young Carer Program (information, advice and support for young carers) (Carers Australia, 2017).

The Australian Government also provides two types of payments that eligible carers may access in order to support and care for a person to live in the community (Australian Government, 2017e). The Carer Payment is available to carers who provide constant care in a private home, with eligibility criteria related to income and assets, as well as care recipient characteristics. The Carer Allowance is an additional income supplement, which is neither taxable nor means-tested. Additional income support may also be available to specific groups of carers. For example, the Carer Supplement is an annual lump-sum payment to assist with the costs of caring, and the Child Disability Assistance Payment is an annual payment to assist parents with the costs of caring for a child with a disability. A summary of the carer payment structure is provided in Table 1.
The structure of the payments has been criticised as reducing workforce participation and/or the ability to work at a skilled level, because the cost for alternative care arrangements has not been considered (Task Force on Care Costs, 2007). It has been well established that carers are less engaged in the workforce than their non-carer peers. Recent Australian data emphasise that amongst the working age population (that is, 15–64 years), the labour force participation rate for primary carers (56.3%) is well below that of non-carers (80.3%) (ABS, 2015). Not only does carers’ reduced labour force participation impact household income levels, flow-on effects exist in relation to lifetime earning capacity, superannuation, asset accumulation and education opportunities (Access Economics, 2015). The Australian Bureau of Statistics (2004a) proposed that more flexible employment conditions would support carers’ capacity to maintain a caring role whilst participating in the workforce – an assertion that has been supported by many researchers, both in Australia (for example, Bereki-Gisolf, Lucke, Hockey & Dobson, 2008; Crettenden, Wright & Skinner, 2014) and internationally (Arksey & Glendinning, 2008; Chou, Fu & Chang, 2013; Pavalko & Henderson, 2006).

According to the National Employment Standards within the Australian Fair Work Act 2009, employees are entitled to a minimum of 10 days (pro rata) of paid personal/carer’s leave per annum (with the exception of casual employees). This leave can be utilised to fulfil caring responsibilities for family or household members in cases of illness, injury or other emergencies. Depending on the level of care required, carers may use all their leave entitlements in fulfilling their caring role, which leaves them with little to no personal leave to use when they themselves require time off work for illness. In addition to leave entitlements, carers have a legislated right to request flexible working arrangements (Australian Government, 2017c). Employers are able to refuse these requests based on reasonable business grounds, though there is little guidance as to what constitutes ‘reasonable’ grounds (Guidice, 2012).

Carers have featured in several recent Australian Government reports (Commonwealth of Australia, 2009b; Cummins, Hughes, Tomyn, Gibson, Woerner, & Lai, 2007; Edwards, Higgins, Gray, Zmijewski, & Kingston, 2008; Productivity Commission, 2008), resulting in the National Carer Recognition Framework (Commonwealth of Australia, 2011). The carer framework legislation acknowledged the importance of carers in society

Table 1: Carer payment schedule

<table>
<thead>
<tr>
<th>Payment</th>
<th>Eligibility</th>
<th>Current rate (as of February 2017)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Payment</td>
<td>• Provide constant care in the home to someone with a severe disability, medical condition, or who is frail aged&lt;br&gt;• Meet income and asset tests&lt;br&gt;• Live in Australia&lt;br&gt;• Meet residence requirements&lt;br&gt;• Care recipient must also meet disability, residence, and income/asset criteria</td>
<td>Max. $877.10/fortnight (single)(^1,2)&lt;br&gt;Max. $1322.40/fortnight (couple)(^1,2)</td>
</tr>
<tr>
<td>Carer Allowance</td>
<td>• Provide daily care to a person with a disability, medical condition, or who is frail aged&lt;br&gt;• Meet residence requirements&lt;br&gt;• Not means tested&lt;br&gt;• Care recipient must also meet disability and residence criteria</td>
<td>$124.70/fortnight(^3)</td>
</tr>
<tr>
<td>Carer Supplement</td>
<td>• Receive Carer Payment and/or Carer Allowance</td>
<td>Max. $600/year (lump sum)</td>
</tr>
<tr>
<td>Child Disability Assistance Payment</td>
<td>• Receive Carer Allowance for a child under 16 years</td>
<td>Max. $1000/year (lump sum)</td>
</tr>
</tbody>
</table>

\(^1\) Reported fortnightly rates include pension and energy supplements (9% of reported rates)<br>\(^2\) Carer payment rates change 20 March and 20 September each year<br>\(^3\) Carer allowance is adjusted on 1 January each year (in line with the Consumer Price Index)
through the introduction of the Carer Recognition Act 2010 and the release of a National Carers Strategy (Commonwealth of Australia, 2011). Carers’ importance in society is further reflected in state level legislation, such as the NSW Carers (Recognition) Act, which exists to recognise the role and contribution of carers to the community, and to increase awareness of their valuable contributions. The NSW Government has outlined a five-year plan which commits to improving carers’ lives (the NSW Carers Strategy 2014–2019), and other Australian states and territories have similar strategies and policies guiding principles that focus on carers’ rights, choices and opportunities (Australian Government, 2017b).

There are a number of transformative changes currently occurring across the Australian disability and aged care sectors, with many community services (including the CRCC) currently funded to provide carer support services until 30 June 2017 (Carers NSW, 2017a). These changes have significant impact on the operation and delivery of aged and disability care in Australia (Productivity Commission, 2011), the aim being to integrate or ‘mainstream’ health and care services. Key components of the system are expected to support patients and carers to navigate a previously very fragmented and complex health care system, and provide the flexibility to choose appropriate support services (Productivity Commission, 2011).

The National Disability Insurance Scheme (NDIS) represents a major overhaul to the existing system of disability support (National Disability & Insurance Agency, 2017). The NDIS aims to give people with disability and their families and carers more choice and control over their lives (Australian Government, 2017d). Since the focus of the NDIS is people with disability, carers cannot receive funded supports themselves under this scheme; however, carers can be involved in planning processes with NDIS participants, and many will still benefit from supports received by the person they care for. Further, a participant’s NDIS plan may include activities to help support the carer within their caring role. Due to the individualised focus of the NDIS, different carers will have different roles and levels of engagement based on what the NDIS participant wants, what is considered reasonable, and what the carer feels they can manage. By being included in planning processes, carers’ needs can be considered in regard to whether they are able to continue providing the same support into the future, and whether they need any assistance in doing so (Carers NSW, 2017b).

The aged care sector reforms are based on the same premise as the disability reforms, and are designed to structure the service system to support:

- Placing the person at the centre of the service system;
- Providing individuals with greater choice and control; and
- Prevention and early intervention strategies across the life course.

(Productivity Commission, 2011)

The “Living Longer Living Better” reforms provide for the move to a single gateway-based information, needs assessment and service connection point model to help people navigate the aged care system (Australian Government, 2017d). The reforms reflect that most people would, if given the choice, prefer to remain living in their own homes supported by appropriate care, rather than move to a residential aged care facility. The consumer-directed care model has been reported by carers as a more flexible and better quality service, which better meets their needs and expectations (Department of Health, 2017).

The Australian Department of Immigration and Border Protection provide carer visas for people who want to live in Australia to provide care for relatives (Australian Government, 2017f). While the provision of these visas suggests an acknowledgement of carers’ importance, eligibility criteria is strict. In order to qualify for a carer visa, the care recipient must:

- Be a relative or family member of the carer visa applicant;
- Be an Australian citizen or permanent resident, or an eligible New Zealand resident;
- Be unable to take care of themselves and need direct care;
- Have no relatives in Australia who can provide the necessary care; and
- Be unable to receive necessary care from health services.

The requirement of having no other relatives in Australia may place undue pressure on any relatives who do live in Australia, as this may render them ineligible to sponsor another relative’s visa application in order to assist with caring. Furthermore, familial sources of care may be more culturally appropriate than health services for many individuals from culturally and linguistically diverse backgrounds, yet this preference may result in barriers to the success of a carer visa application.
Global carer perspectives

Globally, carers are generally acknowledged by health care systems and policy makers as making an important contribution to community care (Hanson, Magnusson, Nolan, & Nolan, 2008). The provision of care to a frail, ageing population in particular is a global concern, with the rights of carers being widely recognised in policy and legislation (Clements, 2013; O’Reilly, Connolly, Rosato, & Patterson, 2008). While international carer policies focus on benefits, services and employment, there still appears to be overall concern in most developed countries involving carer access to support services.

In the United States of America, carers have been recognised under the Family and Medical Leave Act (1993), and the amended Federal Older Americans Act (2000) (Elmore & Talley, 2009; Feinberg & Newman, 2006). The Medicaid Waiver program and the National Family Caregiver Support Program potentially provide eligible carers with access to temporary leave from employment for caregiving activities, access to support services (counselling, respite, support groups and information services) and financial assistance (Elmore & Talley, 2009). However, eligibility criteria are strict, funding is inadequate, and discrepancy between the states limits resources and therefore consumer choice (Castora-Binkley, Noelker, Ejaz, & Rose, 2011; Feinberg & Newman, 2006; Giunta, 2010; Rozario & Palley, 2008).

Support for carers in the United Kingdom was regulated by law in 1995. The Carers Recognition and Services Act (1995) and the ensuing Acts in 2000 and 2004, provide carers with the right to request an assessment of their support needs. The Health and Social Care Act (2001) introduced carer payments and the Work and Families Act (2006) gave eligible carers entitlement to flexible working conditions; however, it is not mandatory for employers to provide flexible working conditions to carers (Arksey & Morée, 2008). The Care Act 2014 which supersedes any previous Acts, significantly reforms the way social care needs are assessed, met and paid for, and how social services are provided (Clements 2012). It also provides a way of linking assessments for carers with assessments for those they care for, and providing personal budgets and direct payments (Carers UK 2017). The Children and Families Act 2014 provides young carers a right to assessment and to have their needs met (Carers UK, 2017). The Care Act and the Children and Families Act together ensure whole family needs are met, and inappropriate caring for young people is prevented or reduced (Department for Communities and Local Government, 2007).

European countries also envisage home care as a sustainable approach to an ageing population, with family carers providing the majority of care (Bonsang, 2009). The Northern European countries are the exception, where the provision of formal support services is higher, and family carers tend to provide emotional and social support rather than domestic and personal assistance (Bonsang, 2009; Hoffmann & Rodrigues, 2010). Policies for carers in almost all European countries include respite care, although legal entitlement to respite services varies widely. Many European countries provide financial support to carers through cash benefits either paid directly to carers through a carer allowance, or paid to those in need of care, part of which may be used to compensate family carers (Eurocarers, 2017).

The New Zealand Carer’s Strategy (2008), acknowledges the challenges confronting carers and proposes the need for a strategy to support carers (Brunton, Jordan, & Fouche, 2008; Ministry of Health, 2017). The Flexible Working Arrangements Amendment (Department of Labour, 2008), provides carers in New Zealand with emergency leave from their paid employment. However, inconsistency of and poor access to the New Zealand’s carer support system, particularly respite services has been reported (Jorgenson, Parsons, Jacobs, & Arksey, 2010). New Zealand’s Carers’ Strategy Action Plan for 2014 to 2018 advocates for respite, carer wellbeing and employment opportunities (Ministry of Social Department, 2017).

The United States of America, New Zealand, Australia and many European countries report that carer support services have limited funding and choices, and no standardised assessment tool to assess carers’ needs (Arksey & Glendinning, 2007; Arksey & Glendinning, 2008; Howse, 2007; Hoffmann & Rodrigues, 2010). The United Kingdom is the exception, where carers have a legal right to an assessment of their care and support needs, and are provided information and advice about services aimed at meeting those needs (Carers UK, 2017).

Future caregiving implications

The provision of caregiving is a less costly measure than institutional placement, and the incidence of care being managed in the home with the support and involvement of a family member or friend will increase (Australian Institute of Health and Welfare, 2009). Currently, an estimated 2.7 million Australians are providing unpaid support to a family member or friend, many of whom are elderly themselves (ABS, 2015). Australian carers, for example, provide an estimated 1.9 billion hours of unpaid care to a family member or friend, with the economic value estimated
at A$60.3 billion per annum (Access Economics, 2015). In the United States of America, the economic value of carers is approximated at US$470 billion and £132 billion in the United Kingdom (International Alliance of Carer Organisations, 2017).

There is evidence to suggest that the number of carers available will not meet future demand for care. Baby boomers’ preference for aged care in their own homes, rather than residential care, also reflects the increasing demands on community aged care resources and the challenges for and importance of carers (Productivity Commission, 2008; Fine, 2014). Changes in societal obligations and responsibility have been reported to impact on carer numbers (Arksey & Glendinning, 2008). Higher rates of divorce, the trend of smaller family units, higher rates of female workforce participation, the increase in single-parent families, childless couples and unmarried adults have all been identified as impacting on the availability of carers (Access Economics, 2015). Workforce mobility and the increased options of seeking employment overseas have also led to an increase in ‘transnational care’ (Dhar, 2011), and older cohabiting partners, as opposed to married individuals, are also less likely to receive or provide care (Noël-Miller, 2010).

An increase in the educational levels of both the older population and the children of frail, older adults, has resulted in an inclination to pay for formal support services to supplement the caregiving role (Johnson, 2008), increasing the demand for paid care (Uhlenberg & Cheuk, 2008). People living alone receive fewer hours and intensity of care from family and friends, and more formal support (Wanless, Forder, Fernandez, Poole, Beesley, Henwood, & Moscone, 2006). The availability of carers in terms of their place of residence and distance from the care recipient is important. Understanding the experience of caregivers will provide information on the support needs of co-resident and non-resident carers and those providing caregiving support from a distance. This is particularly the case where existing approaches to carer support, while effective for many, are not suitable or useful for many other carers. Provision of appropriate and flexible support to carers may also influence their capacity to continue to provide care in a familiar and caring environment, especially those whose needs are not adequately met by existing service frameworks.

The fourth paper in this series will provide an overview of carer interventions and support programs that support the caregiving experience and carer well-being.

Conclusion

A concern for carers’ health and well-being, particularly in terms of their ability to maintain their role and level of support for the care recipient is important. Understanding the experience of caregiving will provide information on the support needs of co-resident and non-resident carers and those providing caregiving support from a distance. This is particularly the case where existing approaches to carer support, while effective for many, are not suitable or useful for many other carers. Provision of appropriate and flexible support to carers may also influence their capacity to continue to provide care in a familiar and caring environment, especially those whose needs are not adequately met by existing service frameworks.

References


The Australasian Rehabilitation Outcomes Centre (AROC) is the national clinical quality registry for rehabilitation medicine in Australia and New Zealand. This year AROC is turning 15 and to celebrate we thought we’d take a look back at how AROC came into being …

It all began with the development of the AN-SNAP classification …

In November 1993 the Australian Health Ministers Advisory Council endorsed a five-year strategic plan for the National Casemix Development Program. This plan established three priority areas — classification, costing and payments — and identified a series of required strategies including the determination of classification systems for rehabilitation.

From 1995 to 1997, the Commonwealth convened the National Sub-Acute and Non-Acute Casemix Committee, whose role was to achieve national agreement on the development of a classification for sub-acute and non-acute care, including medical rehabilitation. The Australasian Faculty of Rehabilitation Medicine (AFRM) was represented on this Committee.

The National Steering Committee resolved that a study should proceed (the National Sub-Acute and Non-Acute Casemix Classification Study) with the goal of establishing an agreed national classification for use by 1997–1998. The outcome was the Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP), which makes use of the Functional Independence Measure (FIM) as the standard measure of functional status for rehabilitation.

The Australian Clinical Casemix Committee subsequently endorsed the recommendation to adopt AN-SNAP as the national classification and the AFRM formally endorsed it.

Then the development of the Australian Minimum Data Set for Rehabilitation Medicine …

In 1997 the then Casemix Branch of the Commonwealth Department of Health and Family Services provided an $86,000 grant to the AFRM following a proposal by the AFRM to develop a national Australian Minimum Data Set for Rehabilitation Medicine. The final report submitted in February 1999 included the FIM as the agreed standard national outcome measure.

In March 1999 the Commonwealth Department of Health and Aged Care provided a further one-off grant of $50,000 to the AFRM. This grant allowed the AFRM to obtain the licensing contract from UDSMR in America for education, training and development of the FIM in Australia.

Meanwhile, in the private sector …

In 1999 the Private Rehabilitation Working Group (PRWG) was established by the Insurance Regulation and Quality Section of the Commonwealth Department of Health and Aged Care, with the task of facilitating the development of a nationally adopted classification system and funding models for private rehabilitation services.

The work of the PRWG, and its commissioned research by the Centre for Health Service Development (CHSD), led to the adoption of the AN-SNAP classification across the whole of the private sector and the collection of the Australian Minimum Data for Medical Rehabilitation in the private sector from 1 July 2000.

Significantly, Australia now had a uniform agreement to use the same rehabilitation classification model and data set across the majority of the public system and all private rehabilitation service facilities.

… and so the Australasian Rehabilitation Outcomes Centre was established

AROC was originally conceived as an initiative of the AFRM with the original AFRM proposal developed at the invitation of the Commonwealth. The AFRM proposed to establish a Centre that would develop a national database to be used for reporting and research with the aim of improving clinical rehabilitation outcomes in both the public and the private sectors.

The AFRM, invited by the Commonwealth to identify options for the establishment of AROC, undertook a preliminary industry
consultation to identify relevant issues and identify options. Initially, consideration was given to establishing AROC as a legal entity within the Royal Australian College of Physicians. However, the AFRM formed the view that the most viable, efficient approach to establishing AROC was for it to be managed by an appropriate external organisation. This led to the AFRM signing an agreement with the CHSD (now the Australian Health Services Research Institute – AHSRI) to manage the day-to-day operations of AROC. As such, AROC sits within the University of Wollongong (UOW) structure and has access to the University’s ethics committee.

The Commonwealth Department of Health and Aged Care agreed to fund a planning phase for the establishment of AROC. To this end, a Working Group was set up with representatives from all the stakeholder groups – providers, payers, Commonwealth and State Governments as well as the AFRM and CHSD.

With the support of its industry partners, AROC was established by the AFRM and officially commenced operation on 1 July 2002. The purpose and aims of AROC were established as, and continue to be:

- Develop a national benchmarking system to improve clinical rehabilitation outcomes in both the public and private sectors.
- Produce information on the efficacy of interventions through the systematic collection of outcomes information in both the inpatient and ambulatory settings.
- Develop clinical and management information reports based on functional outcomes, impairment groupings and other relevant variables that meet the needs of providers, payers, consumers, the States/Commonwealth and other stakeholders in both the public and private rehabilitation sectors.
- Provide and coordinate ongoing education, training and certification in the use of the FIM and other outcome measures.
- Provide annual reports that summarise the Australasian data.
- Become a research and development centre that seeks external funding for its research agenda.

### Growth of AROC since it was established

Private sector rehabilitation units were the first to submit data to AROC, having collected this data since July 2000; the first benchmark reports were based on 26,586 episodes from 73 facilities. In the 15 years since, AROC now receives more than 130,000 inpatient overnight episodes a year from 280 units from both the public and private sector in Australia as well as in New Zealand (Figure 1), and the data set has been extended to collect adult ambulatory (outpatient) and paediatric data.

AROC holds the licensing contract for education, training and development of the FIM in Australia. In 2016 AROC FIM Master Trainers ran 85 face-to-face workshops and over 5,200 clinicians credentialled or recredentialled in FIM.

Through impairment-specific and jurisdictional benchmarking workshops providers of rehabilitation are provided the opportunity to compare their outcomes with other facilities in their jurisdiction/specialty, and thereby gain insight into avenues for improvement.

AROC continues to provide a rich source of information for the Australasian rehabilitation medicine industry. In the next JARNA 15 years of AROC – part 2 will review the characteristics of rehabilitation patients over the past 10 years.
Guidelines for submission of manuscripts to JARNA

Aims and scope

Rehabilitation nursing is a recognised specialty area of nursing within Australia with a broad and expanding knowledge base. As the official Journal of the Australasian Rehabilitation Nurses’ Association (ARNA), JARNA seeks to enhance this expanding knowledge base through the publication of information pertaining to rehabilitation nursing. An equally important purpose of JARNA is to facilitate the development of ARNA members as writers for publication by providing constructive feedback to authors.

Prospective authors are asked to follow the following guidelines when compiling a manuscript they wish to submit for consideration for publication in JARNA.

Terms of submission

JARNA is published three times a year and manuscripts pertaining to rehabilitation nursing are invited. The Editor welcomes manuscripts on research, quality activities, innovative practice, education, management, case studies and any other item of interest to rehabilitation nurses. JARNA also invites new and first-time authors, with mentoring provided by the Editorial Board to assist in achieving publication standards.

All work will be sub-edited to the journal’s style. The Editor reserves the right to modify the style and length of any manuscript submitted, so that it conforms to journal format. Major changes to a manuscript will be referred to the author for approval prior to publication.

Once published, the manuscript and its illustrations become the property of JARNA, unless rights are reserved before the publication.

Authorship

All authors must make a substantial contribution to the manuscript and will be required to indicate their contribution. Participation solely in the acquisition of funding, collection of data or supervision of such does not justify authorship. All participating authors must be acknowledged as such: proof of authorship may be requested by the editors. The first-named author is responsible for ensuring that any other authors have seen and approved the manuscript and are fully conversant with its contents. If the author wishes to reproduce material subject to copyright, it is the responsibility of that author to obtain written permission from the copyright holder and to acknowledge this permission within the manuscript.

Conflict of interest It is the responsibility of the submitting author to disclose to the Editor any significant financial interests they may have in products mentioned in their manuscript before the references section.

Regulatory requirements

Research protocol Approval of protocol by the appropriate ethics committee of the institution within which the research was carried out must be stated within the manuscript.

Human investigations All work must be stated that it conformed to the “National Statement on Ethical Conduct in Research involving Humans” by the National Health and Medical Research Council of Australia, or equivalent in other countries or the Declaration of Helsinki.

Humane animal care All work involving animals must contain a statement that it conformed with the “Statement on Animal Experimentation” by the National Health and Medical Research Council of Australia or equivalent in other countries.

Manuscript types

Submitted work may take any of the following forms:

Original articles These articles should be 1500–4000 words in length and, where appropriate, may include photographs or tables.

Reviews, commentaries and discussion articles These articles should be 1000–3000 words in length.
**Case reports and opinion pieces** These articles should be 1000–1500 words in length and should ensure patient confidentiality is maintained.

**Letters to the editor** Letters will be no longer than 1000 words (but mostly shorter) and typically comment on a topic covered in a recently published edition of JARNA or on matters of key professional or clinical importance to rehabilitation nursing or nurses.

**Book and film reviews** Book or monograph reviews of no more than 500 words may be included depending on the interest to the subscribers. Books or monographs to be reviewed can be sent directly to the Editor. No books will be returned.

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JARNA is a peer-reviewed journal. All manuscripts are initially reviewed by the Editor or a member of the Editorial Board and those deemed unsuitable (insufficient originality, serious scientific or methodological flaws, or a message that is of limited interest to the audience of JARNA) are returned to the author/s, usually within four weeks. If the manuscript does not conform to the submission guidelines, the author will be asked to amend prior to peer-review.

All manuscripts are reviewed by peers with rehabilitation nursing experience for relevance, accuracy, currency, construction, flow, style and grammar. All reviewers spend considerable time reviewing manuscripts and providing feedback to authors. The length of time of the review process can vary and depends on the quality of the work submitted. Several revisions may be required to bring the manuscript to a standard acceptable for publication.

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Manuscripts should use double spacing with Times Roman 12 font and margins 2.5 cm.

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Use quotation marks for quotations of fewer than 40 words. For quotations of more than 40 words indent the quotation as a block, without quotation marks and always include the page number.

Examples of APA referencing style

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