

In this issue:

Access to rehabilitation services:
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a dementia

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rehabilitation setting: a staff
needs assessment

Implications of caregiving

Autonomic dysreflexia occurring
in persons with multiple sclerosis:
a case report and review of
available literature

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Contents

Editorial	2
Access to rehabilitation services: a 'fair go' for individuals living with a dementia	5
Archiving <i>JARNA</i>	7
Providing palliative care in a rehabilitation setting: a staff needs assessment	8
Implications of caregiving	15
Autonomic dysreflexia occurring in persons with multiple sclerosis: a case report and review of available literature	25
Guidelines for submission of manuscripts to <i>JARNA</i>	26
Book review Beyond Stroke: Living Independently with One Arm	27
Australasian Rehabilitation Outcomes Centre	28



Editorial

Rehabilitation is everyone's business

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In this editorial, I return to one of my favourite chestnuts: rehabilitation is everyone's business. I continue to make this claim over and over again in my presentations and writing, because I know it to be true from my own clinical practice but also from my studies and observations of everyday life. I am writing about it here because there is growing support for this way of thinking and I want to draw your attention to this.

In saying that rehabilitation is everyone's business, I am saying more than my long-held view that rehabilitation belongs in every nurse's toolkit (Pryor, 2002). I am saying that every person, regardless of whether they are a health professional or not, every person in their work roles and their personal life has the capacity to enable rehabilitation. Unfortunately, it is also true that every person can be a barrier to rehabilitation. When rehabilitation is understood as everyone's business, rehabilitation as a co-production (Pryor, 2014) really comes to life.

In 2014, I introduced the notion of rehabilitation as a co-production in an editorial on the principles of rehabilitation. I explained principles as "the determining characteristics or essential qualities that serve as the foundation stones for the delivery of rehabilitation care whenever and wherever patients need it" (p. 2) and presented the principles of rehabilitation as follows:

Values-guided, person-centred enablement of
person-environment congruence using goal-directed,
strengths-based co-production

In relation to co-production I said:

Within the context of rehabilitation service delivery, rehabilitation is a co-production between patients, their family and friends, and the treating clinicians. Rehabilitation is not done by one person to another.

All members of the team have strengths. Clinicians use their expertise to guide and support patient work (Pryor & Dean, 2012).

Patients share the significance they assign to their situation with clinicians. Family and friends are potential sources of a wide range of inputs to the co-production. Seek and capitalise on the strengths of each person on the rehabilitation team. Also capitalise on the research evidence to guide the co-production of rehabilitation (Pryor, 2014, p. 2).

Like my earlier work on 'rehabilitative milieu' (Pryor, 2000, 2010), this explanation makes explicit some of the people who are commonly known as enablers of rehabilitation. There are, however, many many more people who also have this potential.

While there has been a growing body of scholarship about rehabilitation as a health strategy, understanding of rehabilitation as everyone's business has been slow to gain traction. This is disappointing given that on the international stage community-based rehabilitation (CBR) has been around for a long time.

Boyce and Lysak (2000, no page number) explain that "the concept of CBR emerged, in tandem with primary health care (PHC), in the 1970s" and "the intention of the WHO's original CBR model was efficient delivery of 'low-tech' rehabilitation services". The early CBR programs aimed to address the needs of higher than expected numbers of people with disabilities in developing countries (Helander, 2000). These programs had "to a very large extent been inspired by professionals from the industrialised West" and as such were a form of clinical rehabilitation. However, by the mid-1970s, it was clear that for the developing world these "conventional types of [rehabilitation] services" needed "substantial changes" (Helander, 2000, p. 1).



"In the late 1980s and early 1990s, there was a dramatic shift internationally, which saw the human rights of people with disabilities emerge as a community development issue" (Boyce & Lysak, 2000, no page number). This shifted the focus of CBR away from "the established professional-focussed systems to people-oriented ones" (Helander, 2000, p. 3) and community development.

Currently, CBR is defined as:

... a multisectoral approach working to improve the equalization of opportunities and social inclusion of people with disabilities while combating the perpetual cycle of poverty and disability. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services (WHO, 2016).

Boyce and Lysak (2000, no page number) explain that "a community development approach integrates a disability perspective into every facet of community activity, from childhood education to nutrition, from agriculture to sanitation, and from family planning to income-generating enterprises". Thus, with CBR there is a change away from "a telescopic-lens focus" on people with disability to "a wide-angle lens focus" on society as a whole (Krefting & Krefting, 2002, no page number).

Concerns have been raised that the adoption of this "social model" might ignore the clinical rehabilitation needs of people with disabilities (Thomas & Thomas, 2003, p. 12). However, if contemporary CBR programs are, as the Working Group on CBR (1997, no page number) notes they should be, "multi-sectorial (or multi-disciplinary)", they will provide "assistance in all of the areas that are central to improvement of the quality of life of people with disabilities". This specifically includes "appropriate health, education, vocational and social services" (ILO-UNESCO-UNICEF-WHO, 2002, p. 1). As such, disability is mainstreamed, that is, it is "an issue to be considered in all programming, rather than a stand-alone thematic issue" (United Nations Economic and Social Council, 2008, p. 7). Mainstreaming disability is underpinned by an understanding of rehabilitation as everyone's business.

Appreciation of the relevance of CBR for the developed world has been slow to develop, but this is set to change. I am taking this opportunity to raise the CBR flag, because the National Health Service (NHS) England (2016) is now formally

positioning rehabilitation as everyone's business. Like several nursing commentators (for example, Dittmar, 1989 and Pryor, 2001), they reinforce that rehabilitation is "a philosophy of care that helps to ensure people are included in their communities, employment and education" (National Health Service England, 2016, p. 5).

The NHS document rightly situates the person as playing a key role in their rehabilitation, but it also says so much more. With parallels to CBR, the NHS identifies "parks, cycle paths, outdoor gyms, swimming pools, leisure facilities, scouts/guides, play areas, smart phone apps etc." and "structured peer support" (p. 13) as major contributors to rehabilitation.

To inform your understanding of rehabilitation as everyone's business, I encourage you to take a look at the NHS (2016) document. But more importantly, I urge you to take a look into CBR. The following source is a good place to start:

World Health Organization. (2010). Community-based rehabilitation. Retrieved on June 24, 2016 from http://apps.who.int/iris/bitstream/10665/44405/7/9789241548052_health_eng.pdf

Understanding of rehabilitation as everyone's business is central to every nurse's clinical effectiveness because as Lena Plaisted said almost 40 years ago:

Rehabilitation requires all healthcare professionals to possess, and act upon, an awareness of how what does and does not happen today affects the person's desired tomorrow (Plaisted, 1978).

At a more personal level, individual and community wellbeing is enhanced when we all possess, and act upon, an awareness of how what does and does not happen today affects a person's desired tomorrow.

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Call for Expressions of Interest

JARNA Editor-in-Chief

The ARNA National Committee is calling for expressions of interest from individuals interested in taking on the voluntary role of *JARNA* Editor-in-Chief.

The current Editor-in-Chief has announced her intention to resign after four years in the role at the 2016 ARNA AGM in October. Early notice has been provided to enable a supported handover.

JARNA is a peer-reviewed journal published three times a year. As the official Journal of ARNA, *JARNA* seeks to enhance the expanding knowledge base for nursing practice through the publication of information pertaining to rehabilitation nursing and rehabilitation in 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.

The Editor-in-Chief is supported by an experienced Editorial Board and the production of *JARNA* is supported by Cambridge Publishing using the ScholarOne online manuscript management system.

Questions about the role of *JARNA* Editor-in-Chief can be directed to either Julie Pryor, the current Editor-in-Chief [editor@arna.com.au] or Terry Wells, the ARNA National President [president@arna.com.au].

**Written expressions of interest will be received by Terry Wells, the ARNA National President
[president@arna.com.au].**



Access to rehabilitation services: a 'fair go' for individuals living with a dementia

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Introduction

Similar to other Western countries, approximately nine per cent of Australians aged over 65 are living with a dementia and for those aged over 85 the prevalence rate rises to up to 30 per cent. As the ageing population increases, the prevalence of dementia will increase (Guideline Adaptation Committee, 2016). It is doubtless an important healthcare issue. In the past 10 years, since the Australian Government published its first National Framework for Action on Dementia and the nomination of dementia as a National Health Priority, dementia care has achieved never imagined improvements. Dementia-specific research and educational initiatives by the Dementia Collaborative Research Centres and Dementia Training Study Centres achieved unprecedented hope for consumers, family carers and clinicians about the new opportunities to improve the wellbeing and quality of life of individuals living with a dementia, and their family carers.

Lay perceptions about dementia and attitudes towards caring for those living with a dementia have also improved in all communities. Having said this, there is still much work to be undertaken to further improve the daily lives and care experiences of individuals living with a dementia, family carers and practitioners who provide dementia care (Isbel & Jamieson, 2016). One area where a bold change could be made is to adopt a more explicit rehabilitative model of dementia care. Over 10 years ago the eminent dementia care researcher, Professor Mary Marshall, dedicated a text to the rehabilitative approach in dementia care (Marshall, 2004). Today, this approach remains

on the periphery of best practice and is mainly part of innovative models of dementia care rather than integrated into the everyday practices of aged care or rehabilitation services. The purpose of this editorial is to outline what the Australasian Rehabilitation Nurses' Association (ARNA) could offer individuals living with a dementia, family carers and dementia care.

Evidence to support rehabilitation approaches in dementia care

We know that rehabilitation outcomes for individuals are determined by a range of external factors, including the experience and knowledge of rehabilitation clinicians, policies and funding models. This is particularly true for individuals living with a dementia who are more susceptible than other population groups to the effects of external factors. It is sad to say, but regularly individuals living with a dementia face negative attitudes about their potential to benefit from rehabilitation services. An access equity issue exists and individuals living with a dementia are denied services. This is despite evidence which clearly demonstrates that individuals living with a dementia experience positive rehabilitation outcomes. We do not have to search far to locate systematic reviews demonstrating the positive effects of rehabilitation interventions for individuals living with a dementia and their family carers. The type of rehabilitation interventions reported included cognitive 'brain training' activities, physical activity programmes, assistive technologies, modifying physical care environments, personalised 'real-life goal setting', psychosocial/psychological interventions, a telephone support line, problem-solving activities and family carer education.



Do policies support the implementation of a rehabilitation model for dementia care?

Policies supporting the implementation of rehabilitation in dementia care are uncommon. One troubling example is the Australian Commonwealth Government Transitional Aged Care (TAC) programme (Department of Health, 2015). TAC funds short-term care to optimise the functioning and independence of older people after a hospital admission when they would otherwise be eligible for relocation into residential accommodation. The TAC programme can prevent relocation into residential accommodation after a hospital admission but also requires clients to commence planning of long-term care needs. The Aged Care Assessment Teams (ACATs) are the gatekeepers for this service through an assessment to determine eligibility for the TAC programme. Rehabilitation clinicians also contribute to the TAC programme because their referral of individuals to TAC is required to trigger the ACAT assessment. The contribution made by rehabilitation clinicians to enabling individuals living with a dementia to achieve their rehabilitation goals could be enhanced by increasing the number of referrals they make to ACAT. For this to happen, rehabilitation clinicians need to adopt a more positive attitude about how well individuals living with a dementia can meet their rehabilitation goals.

One way to achieve this change, is for rehabilitation clinicians to expand their everyday practice to include dementia-specific rehabilitation interventions. Unfortunately, the TAC guidelines do not actively support an expansion of their expertise to dementia care. Rather, caution is implied when reference is made to referring individuals living with a dementia to ACAT because “the cognitive abilities of a person with dementia may fluctuate from day to day and so the extent of the person’s dementia may not be evident at the initial assessment”. Conversely, we need to acknowledge that hospital environments are disabling and cause negative consequences for individuals living with a dementia. Given the opportunity, individuals living with a dementia will show great improvements in their rehabilitation outcomes post-discharge when the disabling effects of the hospital are eliminated. Rehabilitation clinicians could contribute more to dementia care by demonstrating transformation of attitudes and make more referrals to TAC for individuals living with a dementia.

Non-physical outcome measures

In Australia, the current emphasis on the Functional Independence Measurement (FIM) (Australian Rehabilitation Outcomes Centre, 2016) for funding rehabilitation services is intrinsically discriminatory for individuals living with a dementia

because the main focus of the FIM is physical health outcomes. The FIM has no meaningful inclusion of psychological health and cognitive outcomes. This omission is neglectful for individuals living with a dementia since we know that their psychological health is inextricably linked to the promotion of independence and functional capacity. Ignoring these non-physical outcome measures results in funding of services which simply address physical health problems. TAC guidelines themselves mention the value of implementing cognitive therapies for individuals living with a dementia but we see little of this in practice. Implementation of cognitive therapies remain limited to ‘demonstration sites’ or small-scale research. These gaps in the outcome measure need to be addressed to ensure rehabilitation services including cognitive and psychological health interventions can be funded.

Goal-orientated care

An alternative way to measure outcomes (and fund services) is to deliver a rehabilitation service focused on goal-orientated care. This approach works well for individuals living with a dementia. Within a goal-orientated approach, clients (including the support of the family carers as necessary) develop their own goals. In a goal-orientated service the effectiveness of rehabilitation interventions are measured by achievement of individualised goals. One practical tool, known as the goal attainment scale (GAS), developed in the UK and demonstrated by the authors (Aged and Dementia Health Education and Research, 2016), describes working with clients to develop their individualised goals. The GAS tool includes a scoring system which is individualised for clients but can also be easily used by service providers to measure the effectiveness of rehabilitation interventions. The implementation of the GAS tool creates wins for individuals living with a dementia who are enabled individualised goals and clinicians who can objectively measure non-physical health outcomes.

Where to from here?

In Australia and the USA, the competency models for rehabilitation nursing provide clear explanations about how rehabilitation nurses can work in partnership with clients, family carers and all members of the healthcare multidisciplinary team to deliver effective rehabilitation nursing (Association of Rehabilitation Nurses, 2014; Australian Rehabilitation Nurses’ Association, 2004). These rehabilitation models could be applied in dementia care. In Australia, however, an inherent challenge exists in Government guidelines, such as the TAC programme, which authorises practitioners to use their judgement about whether an individual living with a dementia will benefit from a rehabilitation



service without first trialling the intervention. Where else, in a healthcare world driven by the need to deliver evidence-based healthcare, would we see a policy authorising practitioners to use their judgement for a specific population group. Clearly, in Australia, individuals living with a dementia experience discrimination within rehabilitation services. ARNA has the potential to challenge this inequality by promoting and facilitating the use of its competencies across rehabilitation services.

ARNA could also contribute to this reversal of fortune by advocating for a rehabilitation approach to be adopted within dementia care. Occupational therapists attempted to address this issue within their profession and undertook a survey to explain current barriers for occupational therapists delivering effective dementia care (Bennett, Shand & Liddle, 2011; McGrath & O'Callaghan, 2014). They found an over-emphasis on assessment, rather than implementation of interventions, was preventing occupational therapists from contributing more positively to the lives of individuals living with a dementia and family carers. Reflecting on the documentation within healthcare services and service accreditation processes it would be no surprise if a survey of rehabilitation nursing also found a similar lack of focus on implementation of interventions. The occupational therapy survey stopped short of seeking out solutions. An ARNA survey could add questions to generate ideas to implement rehabilitation interventions within dementia care.

There is a long way to go before we achieve a 'fair go' in rehabilitation for individuals living with a dementia. This editorial addressed issues in hospital and community settings but there is also a role for ARNA to lobby policy makers for an extension of rehabilitation into residential accommodation. There is unequivocal evidence about the positive effects of rehabilitation on the physical and psychological health of individuals living with a dementia in residential accommodation. We need more investment from clinicians, service providers and policy makers to

increase the presence of rehabilitation care for individuals living with a dementia across all care settings. There is evidence and tools demonstrating how to implement rehabilitation interventions in dementia care. Now we need innovative strategies to achieve implementation of these so we can contribute to the wellbeing and quality of life of individuals living with a dementia, and their family carers.

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Archiving JARNA

Did you know that *JARNA* used to be called the *ARNA Bulletin*? Do you know when the first *JARNA* was published?

We are creating an archive for *JARNA* and the *ARNA Bulletin* so we can preserve ARNA's history and answer these questions.

Our plan is to have two sets of hard copies and then scan these to develop two sets of electronic copies – one to be kept in the ARNA office and one to be kept with the *JARNA* Editor.

**We are asking for your help. If you'd like to donate to our collection, please contact Lisa Street
Tel: 0429 960 591 Email: lisamjstreet@hotmail.com**



Providing palliative care in a rehabilitation setting: a staff needs assessment

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Abstract

Background: Rehabilitation is aimed at maximising a person's ability to live well and as independently as possible within their circumstances. However, when a patient's condition deteriorates, health care professionals working in rehabilitation may be required to adopt a more palliative approach to care and need to be prepared for this to optimise quality of life and relieve suffering.

Aims and objectives: This study aimed to identify the multidisciplinary health care team members' education and support needs in providing palliative care at an outer metropolitan in-patient rehabilitation facility.

Methods: An exploratory study which used a mixed-method approach. A structured survey was administered to all clinical staff, and 58 completed surveys were returned. Subsequently, three focus group discussions were conducted where a summary of the survey results were presented and discussed by 22 survey respondents.

Results: In the survey, participants reported confidence in managing patients' physical care and providing support, though indicated the need for more education and support in palliative aspects of care. The focus group discussions uncovered challenges associated with the integration of palliative approaches to rehabilitative care that included: identifying when and how care transition occurs; and the skills and strategies needed to provide optimum care to the patient across this continuum.

Conclusion: The study highlights the challenges rehabilitation health care professionals encountered in providing palliative care. To ensure that patients receive optimal care, participants stressed the importance of a supportive environment, adequate resources and being equipped with appropriate knowledge and skills.

Keywords: Palliative care, end-of-life care, staff development, rehabilitation, education needs.

Introduction

Palliative care is a service extended to patients with malignant or non-malignant conditions living with life-limiting illness as well as for the frail elderly. The increased need for palliative care has seen health care professionals working in non-palliative care settings become more involved in providing such care to patients, especially when their health deteriorates (Palliative Care Australia, 2015).

Rehabilitation is generally aimed at maximising a person's ability to live as well and as independently as they can within their particular circumstances. This can involve restoring a person's level of functionality and wellbeing to that enjoyed prior to an illness and/or enabling positive adaptation to loss of function or ability. The process of rehabilitation usually involves a therapeutic, multidisciplinary team, can be for an extended period of time and is often undertaken across a number of different settings (Marx,



2005). In these ways, rehabilitation has many similarities to the provision of palliative care (McIlpatrick & Carson, 2013; Chasen, Bhargava & MacDonald, 2014).

Population ageing and the growing prevalence of co-morbidities suggests that greater numbers of patients may, at some point along their care continuum, require more palliative approaches, to enable optimal functioning and experience the best quality of life, through the exercise of choice within the limitations of their disease, its treatments and life expectancy (Australian Institute of Health and Welfare, 2015). Increasingly, palliative approaches to care may be required by patients admitted to rehabilitation facilities and involve members of the rehabilitation team.

The implementation of palliative, symptom-driven care in the early stages of a person's illness does not replace diagnostic work up. However, it can provide patients and their families with care that optimises quality of life and relieves suffering. This is important especially for people whose ill health is secondary to an advanced, underlying symptomatic condition (Boockvar & Meier, 2006). Providing palliative care at a rehabilitation setting can be challenging for health care professionals, especially when this has not been the focus of care for the patient (Selman *et al.* 2007; Selman *et al.* 2011; Pinnock *et al.* 2011). Inadequate and inappropriate end-of-life care such as poor symptom management, patients dying in a non-preferred place, and lack of opportunity for patients and their families to discuss issues surrounding death and dying, can contribute to a "poor quality" death and place additional stress on families and staff (Burgess, Braunack Mayer, Crawford, & Beilby, 2013; Fadul *et al.* 2009).

Further research is needed to identify the issues and challenges faced by health care professionals in rehabilitation settings, and to develop strategies to provide palliative care that is both timely and appropriate to the patients' needs. This article reports on a study which was conducted at an in-patient rehabilitation facility in Victoria, Australia. The primary aim of the study was to explore the health care professionals' perception on the provision of palliative care in a rehabilitation setting and their learning needs in this area.

Method

The study was conducted at a 69-bed outer metropolitan rehabilitation facility. The hospital provided neurological, cardiac, orthopaedic, movement disorder (including Parkinson's disease) and reconditioning programs. An exploratory, cross-sectional design was used that involved a survey and focus

group techniques. A letter of invitation and a structured self-administered anonymous survey was sent to all 150 health care professionals engaged in the provision of direct patient care at the facility.

The survey consisted of five sections. The first section sought demographic information about participants including gender, profession and recent experience in providing palliative care. The next three sections contained items drawn from *The Palliative Care Evaluation Toolkit* published by the Centre for Health Service Development at the University of Wollongong (Eagar *et al.*, 2004). The items selected were designed to be applied to palliative care providers and drew on original work attributed to Weismann *et al.* (1998, cited in Eagar *et al.*, 2004). They could be applied to assess change in participants' knowledge and attitudes before and after a palliative education session or, as in the current study, be used to collect baseline information as a needs assessment for workforce development. In each section, participants were asked to respond by ticking a box on a Likert-type scale, that best represented their view on each item.

The first component consisted of 12 questions and aimed to assess participants' confidence when interacting with patients/families and various aspects of patient management. A four-point scale was applied to each item and provided participants with a choice ranging from "Need further basic instruction" to "Confident to perform independently". The next section ascertained views about death and dying, had 10 items, each with a five-point response scale that ranged from "Agree strongly" to "Disagree strongly". The third section assessed attitudes towards palliative care and comprised 15 items that asked participants to respond using a five-point scale that ranged from "Strongly agree" to "Disagree strongly". The final section listed nine palliative care topics that participants could nominate for future education plus space for additional "other" topics.

As part of the survey, participants were also invited to join a focus group discussion and, if interested, to submit their contact details for follow-up. To preserve anonymity, this was done independently of their return of the completed survey. The researcher contacted the participants who indicated their interest in being involved and then allocated them to one of three groups according to their preference. At each focus group, the researcher presented a summary of the findings of the survey which provided the basis for discussion.

Fifty-eight completed surveys were returned (39% response rate) and simple descriptive statistics applied to quantifiable data.



For this sample, the survey instrument demonstrated an overall strong internal reliability of 0.76 (Cronbach's alpha). The three palliative care toolkit components: "confidence with interactions and aspects of patient management", "views about death and dying" and "attitudes towards palliative care" demonstrated alpha coefficients of 0.92, 0.56 and 0.57 respectively.

The focus group discussions were attended by a total of 22 participants with seven or eight in each. Each session lasted 40–60 minutes and provided opportunities for participants to engage with each other and provide more detailed commentary on the findings and issues raised by the survey results. The focus group discussions were audio-recorded and later transcribed using a professional transcription service. The researcher then checked the transcripts with the recordings to ensure accuracy. Focus group data were analysed thematically. The study was approved by St John of God Health Care research ethics committee and conformed to the National Statement on Ethical Conduct in Research involving Humans by the National Health and Medical Research Council of Australia.

Results

The majority of survey participants were female and most worked full-time. Nursing was the largest single profession represented (71%) and close to a quarter (24%) were allied health professionals (Table 1). Most (84.5%) of the participants rated their knowledge of palliative care as "general knowledge only", though many had received some "on the job training" (40.3%) or had participated in a "short course" (24.1%) on palliative care. Whilst palliative care is not necessarily core business or frequently required within a rehabilitation facility, 75.9% of respondents indicated that they had provided some level of palliative care to patients at the facility in the previous 12 months.

Participants indicated that, overall, they were quite confident in managing patients' symptoms of nausea/vomiting, constipation, dyspnoea and pain. They also felt confident "supporting the patient or family member when they become upset". They were less confident, though, in managing "terminal delirium", discussing "different environmental options" for dying "patients", and in "answering patients' questions about the dying process". In the focus group discussions, participants stated that they generally found it easier to manage physical rather than emotional aspects of care, though some felt that they did require more education on the management of larger dosages of analgesics and the use of sedation.

Responses to the section "views about death and dying" tended to indicate positive attitudes toward death, and a degree of comfort with "caring for a dying patient" and "talking to families about death". This contrasts somewhat with responses to other items about these topics, and suggests that participants could be "comfortable" with an aspect of care, though not necessarily "confident" when required to manage the area.

Responses to items within the "Attitudes towards palliative care" section highlighted participants' recognition of the importance of providing adequate pain relief to patients, discussion and talking about death and dying, and the rights of patients to determine their own advance care needs. Participants generally declared positions on these issues consistent with contemporary, patient-centred views on the role of health care workers in providing palliative care (Palliative Care Australia, 2015).

For the focus group discussions, survey findings were collated as frequency tables of responses to each item. Written comments were also summarised and distributed to participants for more in-depth discussion and included topics prioritised for continuing education sessions (Table 2). The focus groups provided an opportunity for participants to discuss the survey

Table 1: Characteristics of survey participants (n=58)

Variable	f (%)
Gender	
– Male	4 (6.9)
– Female	54 (93.1)
Profession	
– Nursing	41 (70.7)
– Physiotherapy	5 (8.6)
– Medicine	3 (5.2)
– Speech pathology	2 (3.4)
– Pastoral care	2 (3.4)
– Occupational therapy	1 (1.7)
– Dietician	1 (1.7)
– Allied health (unspecified)	1 (1.7)
– Allied health assistant	1 (1.7)
– Missing	1 (1.7)
Employment status	
– Full-time	35 (60.3)
– Part-time	16 (27.6)
– Casual	7 (12.1)



findings, normalise and validate their views, and to raise issues and amplify any concerns that may have been masked by the summarised survey results such as very strong or minority views etc. Four themes emerged from these discussions: *dimensions of care*; *understanding transition*; *proficiency in care delivery*; and *strategies to optimise care*.

Table 2: Priority topic areas for further education

Planning for the transition to palliation (DNR orders, advance directives, decision-making capacity)
End-of-life care communication skills (giving bad news, talking with family members, discussing prognosis and treatment options)
Symptom management (terminal delirium, intravenous hydration and/or non-oral feeding, pain assessment and management)
Spirituality and cultural aspects of end-of-life care

Dimensions of care

Participants described caring for patients requiring palliative care as “something very daunting for many people” (P10, 932) and can be “very draining” (P11, 1016), especially for those with little experience in the area.

Often a number of our caregivers are young and may not have been touched by the experience of death in any way, shape or form. Even within their own personal lives or anywhere else. And there are some people who are very well equipped, irrespective of their age. But I think we do need to be mindful, particularly with our staff who've not had even the life exposure let alone the work exposure. (P9, 1036)

Participants found the role to be demanding as care frequently included both patients and their families. Moreover, when health care professionals had more than one patient confronting end-of-life care issues, this further increased anxiety levels on the ward. Nevertheless, one participant, reflecting a sentiment also expressed by others, regarded the provision of such care as a privilege.

... this is my personal view, what a privilege it is to be able to embrace it [palliative care] and change, you know, if we're able to ... You're dealing with care not here in rehabilitation but it is at the end of the continuum. (P1, 579)

Although the caring experience can be emotionally draining, participants emphasised the need for clinicians to respond to a changed prognosis and adopt a more palliative approach to

care when required. This often involved a transition for them and the patient.

Understanding transition

Participants described the need to reduce the intensity of rehabilitation and to re-orientate the goals of care when a patient's condition started to deteriorate. Changing this focus of care required health care professionals to make a personal transition, and to acknowledge and accept that patients may need different interventions to optimise comfort and wellbeing.

Participants argued that both patients and families needed to be prepared for and, where possible, eased into the change to a more palliative approach and that this needed to be planned for by the team in a patient-centred way. This included explaining the reason for palliative care referral; providing options that are available, and the opportunity for patients to work towards and achieve particular goals in their rehabilitation plan that were relevant to their priorities and quality of life.

Nevertheless, participants reported that the initial discussion about the imminence of death with patients and families was a difficult topic to raise, and one that could be very challenging. Participants said that health care professionals needed adequate knowledge, exposure and experience to be confident and comfortable when raising and discussing issues around death and dying.

I think obviously death and dying is an extremely sensitive topic and it's a really difficult one to broach at times, because you don't want to come across potentially as being the person who put the elephant in the room ... But once that elephant is out in the room, then the conversation ... I think a way to approach it is: how can we make people more comfortable talking about what is potentially, giving people knowledge, giving people confidence and comfort? Giving people experience and exposure ... [is] an option but if you've never had that exposure before you're probably going to continue to step away from it. (P9, 948)

In addition, participants stressed that health care professionals needed to understand that patients and families needed time to grieve, and to work through a range of emotions such as anger and denial before coming to terms with and accepting a palliative approach to care.



The family was not going to – I think they were in denial, too. Yeah. The wife was going through cancer treatment herself. Well, she kept coming and, “Oh, he is not eating. He’s not drinking. Can you see if he’s ... he’s not even moving out of bed.” But she still insisted that he has to get up and go to the toilet, so where do we stand? How do we convince them? (P15, 2087)

Participants said that part of making this transition meant that advance care plans or directives needed to be established, so that when a patient’s condition further deteriorated, all members of the health care team and family understood and accepted this approach to care, and had a clear plan to follow. Participants also commented that, often, it was unclear who should initiate discussion with the patient and family and to then take responsibility for developing the plan for care. They felt that discussion about resuscitation and life support measures, for example, was not necessarily restricted to any professional discipline, though believed this did require an open, collaborative, team approach.

It’s hard to work out sometimes who to initiate the DNRs [do not resuscitate] because the nurses will talk to the doctors and suggest you know: this, this and this. And then the family wants this and then who takes the reins? And then you might end up waiting two weeks, while this patient is slowly getting worse and worse before certain medical professionals extract digits and get – you know – and it’s hard to know whether or not it’s the nurses who have to start to push and push. Or whether or not it’s the family who need to come in. (P3, 237)

This transition in care required health care professionals to be skilled and knowledgeable in aspects of palliative and end-of-life care to help patients and their families through this difficult and often distressing period.

Proficiency in care delivery

Participants reported that as discussing death and dying with patients and their families wasn’t a norm, they found it to be challenging for a number of reasons:

For a lot of older people it’s really a taboo subject. They don’t want to discuss it. They don’t want to talk about it or just don’t want to go there. (P16, 1667)

Whilst some indicated that they would prefer to delegate discussion about death and dying to other team members like the pastoral care worker, they recognised the need to be skilled communicators and comfortable in discussing sensitive topics.

I think as a caregiver to be able to understand that dynamic and be responsive to what everyone needs, that is a demanding role, but I think picking up cues and being able to go “Okay, that’s where that person’s at, that’s where that person’s at, that’s where that person’s at”, takes a huge skill to do. (P9, 1007)

For participants, having an appropriate repertoire of skills and being proficient in using them included the ability to manage patients’ severe symptoms. They stressed the importance of pain management, and that it was not uncommon for palliative care patients to be ordered very high doses of analgesics.

And I would agree with that, in the palliative care environment, the amount of pain relief and drug relief that is given is much larger than what acute nurses and rehab nurses are used to. So it does take a little bit of getting your head around. (P2, 146)

This could sometimes present as an issue. One participant described their discomfort:

We had a patient that was having cancer and was palliative and we were giving some morphine. With my experiences I never had a patient who was given morphine now and again, now and again each time. This time I was balking, I couldn’t even look after that patient; I even asked to change the patient because I couldn’t look after the patient and understand all those things. So it would be great if we can get some more information on pain management and whatever. (P7, 66)

Participants emphasised the importance of being confident and proficient in a range of skills to ensure that patients were provided optimal care and suggested a number of strategies to support this.

Strategies to optimise care

Participants stressed that having adequate resources was important to optimising the delivery of palliative care. This included infrastructure, such as single rooms with adequate facilities for both patients and their families. One participant recalled:

Well, it should be that the patient should be able to go into a single room. Like this gentleman, he was in a shared room. His condition deteriorated, but he was still in a shared room. It was just that the other gentlemen with the patient actually went home on the day that this man passed away. But up until that, he was in a shared



room. So for the patient that went home, it was very uncomfortable, because there were no rooms available. And for the family who visited that relative, it was very difficult for them, because they were coming into a room with another patient who was quite ill. (P13, 1248)

In addition, appropriate staffing levels that allowed health care professionals to spend more time with patients and their families was seen as vital. Participants stated that having policies and procedures on what to do when patients were referred for palliative care such as protocols on symptom managements was important to guide clinical care.

They emphasised the importance of regular education and training, and also suggested that identifying palliative care “champions” or more experienced staff who were trained in palliative care that they could contact when needed, would be very beneficial. Participants also suggested education sessions/seminars on coping with grief and loss; the role of allied health in end-of-life care; discussing resuscitation orders; and bereavement counselling to help them manage patient care more effectively.

Across all three focus groups, participants emphasised that peer support and understanding from colleagues was critical in assisting them to provide palliative care. This included creating an environment in which practitioners felt safe to seek help from colleagues. They reported that when debriefing sessions were held, they found them very beneficial, especially where they felt safe to share feelings and ask questions. It was suggested that this be done regularly throughout the process of providing palliative care as well as at the end of the patient’s life.

And perhaps have that environment where you feel protected that it’s okay to say: “Look, I am out of my depth” or “don’t have a lot of experience,” but you feel comfortable to say this. Rather than to say “You know I absolutely know what to do” because you don’t want them to say that you don’t ... I can then ask all these questions or confirm that without having the “You should know that” response. Because this doesn’t happen a lot, I do need to check in and see that I’m on the right path, and just that coach-mentoring sort of ... and feeling safe to do that. (P9, 1292)

Participants in this study said that providing palliative care can be daunting and emotionally draining at times, though emphasised that healthcare professionals needed to be confident and knowledgeable in providing this care.

Discussion

The findings of the current study highlighted several challenges health care professionals working in a rehabilitation setting faced when providing palliative care to patients. Participants agreed that discussions about end-of-life issues should be initiated early and not left until curative treatment options had been exhausted, though reported that it was often unclear when and who should take responsibility for initiating these discussions with the patient and their family. Similar to the finding in the current study, others have also highlighted that the timing of a palliative care approach in the course of the patient’s illness was often ambiguous, and that there can be great difficulty in identifying that point when a transition to a palliative care approach is appropriate, especially for patients with a non-cancer diagnosis (Bekelman *et al.* 2009; McIlfatrick 2007; Pinnock *et al.* 2011).

Fadul *et al.* (2009) and Selman *et al.* (2007) observed that health care professionals faced challenges in making a transition to palliative care. This can be especially difficult where there has been an unpredictable disease trajectory; a focus on curative aspects of care; patients not wanting to identify themselves as having a terminal illness, as well as a lack of appropriate physical facilities and education of staff (Hudson *et al.* 2006; Selman *et al.* 2007).

Participants indicated they lacked confidence in discussing matters such as the dying process, resuscitation (or DNR) requests, and a patient’s wishes after death, though most were quite confident in managing patients’ severe symptoms. However, pain management could sometimes be a dilemma for those not accustomed to administering such high doses of opioid-based analgesics. Such discomfort is not unusual, though, as Philips, Salamonson and Davidson (2011) proposed, the use of pain assessment tools can enable pain assessment to become a more objective process, and assist in reducing the impact of individual values and beliefs on decision making. Participants stressed that education was vital in helping health care professionals alleviate their concerns, understand the importance of pain management in palliative care, and to provide care confidently.

A study by Street, Love and Blackford (2005) found that health care professionals’ lack of resources and demands of a busy unit prevented them from supporting families, when and in ways they needed to. In this study, participants indicated that appropriate resources such as an adequate mix of appropriately trained staff, a supportive environment and organisational culture in which practitioners felt safe and secure to ask questions, as well as physical infrastructure were needed to be put in place to support more effective and person-centred palliative approaches to care.



This study found the exercise of survey data feedback to participants useful, and helped authenticate the information collected. Allowing respondents to review their collated results provided an affirmation of shared experiences, needs and concerns. The subsequent focus discussions provided an opportunity for a consensus to be developed on strategies that could improve patient care at the hospital. The discussions also allowed dissenting or different opinions to be aired, and these topics to be explored in a constructive way.

This study was limited to one particular rehabilitation facility though was well informed by the relatively high proportion of respondents who indicated they had provided palliative care in the previous 12 months. Whilst this may not be characteristic of other facilities, it is likely that a changing and ageing demographic will impact the type of care that will need to be delivered to patients admitted for in-patient rehabilitation in the future.

Conclusion

Whilst a rehabilitation hospital is focused on providing rehabilitation services, there are occasions when palliative care needs to be delivered to patients. To provide optimal patient care, participants indicated that a decision to transition to a more palliative approach to care needed to be made explicit, and be undertaken in consultation with all stakeholders. Care should be adjusted according to patient needs, and in ways that provides them with the opportunity to prioritise and achieve their own rehabilitation goals which may change over time. Participants indicated that easing patients and their families into palliative care can be challenging, and required them to be equipped with knowledge and skills to support them through their journey. This included management of symptoms such as pain and being able to communicate issues relating to terminal care. Participants stressed the importance of a supportive environment, and the need for adequate resources such as infrastructure and staffing to provide a holistic approach to care and that training and education was an important part of this.

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Implications of caregiving

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Abstract

Many and varied implications of caregiving have been reported in the literature. Caregiving has been associated with both negative and positive impacts and researchers have acknowledged the need for a greater understanding of the total caregiving experience. This paper is the first in a series of papers examining the complex and diverse reactions to caregiving within the context of a narrative review of the literature. The paper concludes that the consideration of the diverse, individual and complex experiences of caring for a relative or friend may assist health care professionals to identify at-risk carers and appropriate carer support needs.

Keywords: Caregiving, carers, experience

Globally, the support and involvement of family members and friends (carers) in rehabilitation units has been recognised as significant. The provision of care and support from carers is also important in supporting people to live independently in the community following rehabilitation (Bookman & Harrington, 2007; Huber, 2005; World Health Organization, 2002). The implementation and cost-effectiveness of community care upon discharge from rehabilitation often relies on caregiving support to navigate and negotiate an often complicated health care system (Coleman, Parry, Chalmers & Min, 2006) and coordinate and facilitate a complex network of community resources, which are often supplied by multiple service providers (Australian Institute of Health & Welfare, 2008; Productivity Commission, 2011; Sussman, 2009).

The impact of caregiving on physical and mental health, specifically burden, depression and anxiety reduces the capacity of carers to provide the level of care required and has been established as a factor for rehabilitated patients returning to acute care and/or entering residential care (Kuzuya *et al.*, 2011; Senate Community Affairs References Committee, 2005; Spillman & Long, 2009). Therefore, carers' physical and mental health has become an important issue in rehabilitation nursing and research (Pickard, 2004). A concern for carers' health and

wellbeing and an understanding of the impact of caregiving in the context of rehabilitation nursing, will provide information on the provision of appropriate support to carers which may influence their capacity to maintain and continue their role and level of support.

Many and varied implications of caregiving have been reported in the literature. Caregiving has been associated with negatively impacting on carers' physical and mental health (Scuffham, Synnott, Turkstra & Hegney, 2010), general wellbeing (Horner & Boldy, 2008), family and social context (Davey & Szinovacz, 2008) and education and employment opportunities (Berecki-Gisolf, Lucke, Hockey & Dobson, 2008; Covinsky, Eng, Lui, Sands, Sehgal, Walter & Wieland, 2001; Pinqart & Sorensen, 2003). In contrast, the provision of care to family members and friends can be a rewarding experience (Koerner, Kenyon & Shirai, 2009). Positive caregiving experiences reportedly delay the institutionalisation of a care recipient (Cohen, Gold & Shulman, 1993). Researchers have acknowledged the need for a greater understanding of the total caregiving experience to facilitate and promote the positive benefits of caregiving (Carbonneau, Caron & Desrosiers, 2011; Cohen, Colantonio & Vernich, 2002; Pinqart & Sorensen, 2004).



This paper is the first in a series of papers examining the implications of caregiving and variables associated with caregiving. Following a definition of caregiving and the term carer, this paper provides an overview of the implications of providing care to a family member or loved one.

The complex and diverse reactions to caregiving will be discussed within the context of a narrative review of the literature with a particular focus on care burden, depression and anxiety.

Definitions

Whilst there is no scientific definition of the term caregiving, it generally implies the provision of care above and beyond what is usually considered normal (Liu & Gallagher-Thompson, 2009). Caregiving includes assistance with personal activities of daily living (ADLs) and instrumental activities of daily living (IADL), which ranges from supervision to assistance with personal care, mobility, communication, through to practical and financial assistance. However, the provision of care is not always task-orientated and often includes emotional support and interaction with various health care services and systems. Caregiving can be transitional or long-term.

Caregiving is often an extension of a close, mutually supportive and continuing relationship (Fine & Glendinning, 2005) and can be motivated by obligation, emotional commitment or a sense of responsibility (Hirst, 2005). Caregiving is a distinct role involving “a complex process where the outcomes relate directly to the individual’s perception of their experience as well as the appraisal of their ability to meet the demands presented by the caregiving experience” (Coleman, Parry, Chalmers & Min, 2006, p. 96).

A carer is a person who provides unpaid care and support in a non-professional manner to a family member or friend with a disability, mental illness, chronic condition, terminal illness or who are frail (Carers Australia, 2008). Carers assist people with physical, mental, personal, social and often spiritual wellbeing so that they can maintain their independence and continue to live in the community, often in their own home (Aggar, Ronaldson & Cameron, 2012). In terms of policy and health care practice, carers have been perceived as a resource providing support, a collaborator who works with the formal care network, and as a co-client with their own needs (Pickard, 2001; Twigg & Atkin, 1994).

Global and international organisations and various national research reports often use the term “informal carer”. The national associations that represent carers in Australia and the United Kingdom suggest that the preferred term is carer (Lloyd, 2006). Whilst in the United States of America, Canada and several European countries, “caregiver” is the selected term. However, many people who are providing care to a family member or friend do not identify as carers or caregivers, particularly if they do not perceive their caregiving activities as a burden.

The ‘language of relationships’ when describing the provision of care to a family member or friend may be more appropriate (Goberman-Hill & Ebrahim, 2006), as family carers in particular are more likely to identify their caregiving activities within their familial role (Henderson, 2001; O’Connor, 2007). Wife carers, in particular, accept caregiving as part of their spousal responsibilities (Stalker, 2002). Interestingly, the word carer does not translate into many other languages, because it is often a natural role or extension of commitment for many cultures (Stalker, 2002; Sung, 2001). The provision of care does not generally rely upon the support of a single family member or friend (World Health Organization, 2002); however, it is usually one person who takes on the responsibility of the primary carer role (Seltzer & Li, 2000).

Implications of caregiving

Caregiving and the carer role are gaining interest and increasingly being included in health care research and policy. However, the majority of caregiving research has focused on disease-specific populations such as stroke and dementia, making it difficult to generalise the results (O’Reilly, Connolly, Rosato & Patterson, 2008; Stoltz, Uden & Willman, 2004). There is debate about the intensity of caregiving within specific disease populations (Bertrand, Fredman & Saczynski, 2006; Draper, Poulos, Poulos & Ehrlich, 1996; Kim & Schulz, 2008; Ory, Hoffman, Yee, Tennstedt & Schulz, 1999). More specifically, that dementia caregiving is more challenging and demanding than any other (Bertrand *et al.*, 2006; Joling, van Hout, Schellevis, van der Horst, Scheltens, Knol & van Marwijk, 2010). Butterworth, Pymont, Rodgers, Windsor and Anstey (2010) surveyed a large population sample of carers and found that ‘substantial caregiving’ significantly impacted on carers’ mental health, regardless of the care recipients’ condition.

Whilst providing care to a family member or friend has been reported as a positive and rewarding experience (López, López-Arrieta & Crespo, 2005), the responsibility and sense



of obligation placed on carers has been described as a great burden (Carretero, Garcés & Ródenas, 2007; Carretero, Garcés, Ródenas & Sanjosé, 2009; Garcés, Carretero, Ródenas & Sanjosé, 2009). Carers are often required to learn to deal with complicated treatments and medications (Travis, McAuley, Dmochowski, Bernard, Kao & Greene, 2007), monitor medication side effects and provide symptom management (Henderson & Caplan, 2008; Pearson, Inglis, McLennan, Brennan, Russell, Wilkinson, Thompson & Stewart, 2006). Many carers experience a significant decline in their own physical and mental health, as well as a negative impact on their employment and education prospects, their financial position, and their ability to participate in social and community life (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995; Brodaty, Green & Koschera, 2003; Cummins, Hughes, Tomin, Gibson, Woerner & Lai, 2007; Heitmueller & Inglis, 2007; Muller & Volkov, 2009; Pinquart & Sorensen, 2007; Robison, Fortinsky, Kleppinger, Shugrue & Porter, 2009; Schulz & Beach, 1999; Schulz & Martire, 2004; Sorensen, Pinquart & Duberstein, 2002; Xue, 2011; Yin, Zhou & Bashford, 2002). Carers generally have poorer physical and mental health and wellbeing than non-carers (Butterworth *et al.*, 2010; Pinquart & Sorensen, 2003), especially if the demands of care are high and the carer has been providing many hours of care and/or has been providing care for a long time (Butterworth *et al.*, 2010; Cummins *et al.*, 2007; Gonzalez, Polansky, Lippa, Walker & Feng, 2011; Hirst, 2005; Nankervis, Waxman, O'Hara & Burbidge, 2002).

Overall, carers are considered an at-risk group (Schulz & Martire, 2004). In particular, people who care for adults with cognitive or physical disabilities are more likely to experience health problems (De Frias, Tuokko & Rosenberg, 2005) and a significant reduction in years lived in a good state of health (Nepal, Brown, Ranmuthugala & Percival, 2008). Providing care is a risk factor for mortality (Schulz & Beach, 1999). Kurtz, Kurtz, Given and Given (1995) and more recently Christakis and Allison (2006), established that the mortality rates increased for spouses, particularly post hospitalisation.

Carers are more likely than the general population to report chronic conditions such as arthritis, diabetes, asthma and cardiovascular disease (Gill, Jury, Avery, Warmington, Stacey & Taylor, 2008; Lee, Colditz, Berkman & Kawachi, 2003) and to experience chronic pain and report an injury (Cummins *et al.*, 2007). Caregiving has also been linked to increases in blood pressure (King, Oka & Young, 1994), psychiatric symptoms (Spector & Tampi, 2005), compromised immune system,

altered response to influenza vaccinations, slow wound healing (Kiecolt-Glaser & Glaser, 2001), a high risk for fatigue and sleep disturbances (Jensen & Given, 1993), increased blood sugar levels (Cannuscio, Jones, Kawachi, Colditz, Berkman & Rimm, 2002), and altered lipid profiles (Vitaliano, Echeverria, Yi, Phillips, Young & Siegler, 2005). There have been recent developments in the association between the chronic stress of caregiving with impaired endothelial function and a link to increased cardiovascular disease in older carers (Mausbach, Roepke, Ziegler, Milic, von Kanel, Dimsdale, Mills, Patterson, Allison, Ancoli-Israel & Grant, 2010). Women who report their caregiving role as stressful and also have metabolic syndrome indicators have been found to have a declining walking speed and therefore a high risk of health decline (Fredman, Doros, Cauley, Hillier & Hochberg, 2010).

Carers also tend to have increased health risk behaviours, for example, smoking and a high use of prescription drugs (Beach, Schulz, Yee & Jackson, 2000), and they often neglect their own health care needs (O'Connell, Heslop & Fennessy, 2010; Schulz & Beach, 1999). Burton, Newsome, Schulz, Hirsch & German (1997) found carers did not get enough rest and exercise, were more likely to forget to take their own medication and rarely fully recuperated from illness. These serious adverse consequences of caregiving generally increase as the care recipient's disability increases (Given, Given, Stommel & Lin, 1994; Yee & Schulz, 2000).

Carer burden

Carer burden is traditionally a multidimensional broad term representative of a negative concept affecting health, financial situation, social life, self-esteem (Gaugler, Davey, Pearlin & Zarit, 2000; Nijboer, Triemstra, Tempelaar, Sanderman & van den Bos, 1999a; Pearlin, Mullan, Semple & Skaff, 1990) quality of life (Chappell & Reid, 2002) and grief response (Robinson-Whelan, Tada, MacCallum, McGuire & Kiecolt-Glaser, 2001; Schulz, Boerner & Herbert, 2008). Generally, carer burden is a heightened reaction to the demands of caregiving and the inability of the carer to adapt or employ coping strategies (Garlo, O'Leary, Van Ness & Fried, 2010). Carer burden has been described as affecting the carer's ability to provide care, which can ultimately result in the institutionalisation of the care recipient (Given, Given, Stommel, Collins, King & Franklin, 1992; Halm, Treat-Jacobson, Lindquist & Savik, 2006). However, research has also demonstrated that institutionalisation of the care recipient does not necessarily decrease or improve carer burden. Rather,



elements of institutionalised burden often replace home care burden (Aneshensel *et al.*, 1995).

The most illustrated cause of carer burden has been care recipient characteristics (Quine, Helby, Cameron & Lyle, 1994; Sherwood, Given, Given & von Eye, 2005), particularly behavioural problems (Tooth, Russell, Lucke, Byrne, Lee, Wilson & Dobson, 2008). The physical health of care recipients, their functional abilities and hours spent caregiving have also been demonstrated to predict carer burden (Baronet, 1999; Bartolo, De Luca, Serrao, Sinforiani, Zucchella & Sandrini, 2010; Chenier, 1997; Pinquart & Sorensen, 2003; Saunders, 2008). Significantly high levels of carer burden have been associated with the care recipients' high degree of dependency for ADLs (Comans, Currin, Brauer & Haines, 2011; Garcés *et al.*, 2009; Garlo *et al.*, 2010).

A population study in Britain conducted by Hirst (2005) and also supported by Garcés and colleagues (2009), found burden was directly related to intensity or level of care, and women suffered more than men. van Exel, Brouwer, van den Berg, Koopmanschap and van den Bos (2004) found carer burden strongly related to the number of caregiving tasks performed rather than the amount of time spent caregiving. Several other caregiving studies suggest task difficulty impacts on carer burden (Bakas, Austin, Jessup, Williams & Oberst, 2004; Bakas & Burgener, 2002; Hughes, Giobbie-Hurder, Weaver, Kubal & Henderson, 1999). The carers' age, gender, employment status, residence and relationship with the care recipient, including carers' perceived sense of guilt are other reported variables associated with carer burden (Chan & Chui, 2011; Gonyea, Paris & de Saxe Zerden, 2008).

Social support has featured in several studies investigating carer burden. Whilst considerable involvement in caregiving activities limits social interactions (Ranmuthugala, Nepal & Brown, 2009; Utz, Carr, Nesse & Wortman, 2002), it is argued whether carer perceived social support rather than received social support correlates more strongly with carer burden. Goode, Haley, Roth and Ford (1998) found that a lack of social support resulted in carer burden. Similarly, the importance of social support in reducing carer burden has been acknowledged (Chiou, Chang, Chen & Wang, 2005; Pohl, Given, Collins & Given, 1994; Savage & Bailey, 2004). However, Chapell and Reid (2002) suggest there is no correlation between social support and carer burden and Smerglia, Miller, Sotnak and Geiss (2007) established that social support did not improve adjustment to

stressful caregiving. Chang, Brecht and Carter (2001) agree, and add, that the size of one's social network does not positively impact on carer burden. Rather, the quality and relevance of the social network to a carer's situation appears to predict carer burden (Chiou *et al.*, 2005; Scharlach, Li & Dalvi, 2006).

Carer depression

Depression is a predictor of higher morbidity and mortality rates in carers (Lee *et al.*, 2003; Schulz & Beach, 1999) which can ultimately influence a carer's ability to provide caregiving support (Choi & Bohman, 2007; Evans, Bishop & Haselkorn, 1991; Segal, Qualls & Smyer, 2011). Carer depression has been reported to result in anorexia, fatigue, exhaustion and insomnia (Beach, Schulz, Williamson, Miller & Weiner, 2005; Gaugler, Kane, Kane & Newcomer, 2005). The relationship between carer burden and depression in the literature is mixed. High levels of burden have been found to influence carer depression scores (Clyburn, Stones, Hadjistavropoulos & Tuokko, 2000; Hirst, 2005; Sherwood *et al.*, 2005), whereas other researchers have found carer depression predicts carer burden (Tsai & Jirovec, 2005).

Carer depression is the most common negative outcome of providing care (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003; Gallicchio, Siddiqi, Langenberg, Baumgarten, Gallicchio, Siddiqi, Langenberg & Baumgarten, 2002; Given, Given, Stommel & Azzouz, 1999; Nijboer, Triemstra, Tempelaar, Mulder, Sanderman, & van den Bos, 2000; Schulz, VisinLainer & Williams, 1990; Spector & Tampi, 2005), affecting nearly half of all carers (Alexopoulos, 2005; Cummins *et al.*, 2007; Lu, Austrom, Perkins, Bakas, Farlow, He, Jin & Gamst, 2007), particularly adult children (Coe & Van Houtven, 2009). Wives who are carers have been described as experiencing more anxiety and depression than do husbands who are carers (Hirst, 2005).

Independent predictors of carer depression include financial status (Robison *et al.*, 2009), hours spent caregiving (Aggar, Ronaldson & Cameron, 2010a; Tsai & Jirovec, 2005; Lieberman & Fisher, 1995; Yates, Tennstedt & Chang, 1999), care recipient functional ability (Covinsky, Newcomer, Fox, Wood, Sands, Dane & Yaffe, 2003; Kurtz *et al.*, 1995) and depressed mood (Izawa, Hasegawa, Enoki, Iguchi & Kuzuya, 2010; Kurtz *et al.*, 1995) and carers' functional ability (Chung, Pressler, Dunbar, Lennie & Moser, 2010), poor family dynamics (Siminoff, Wilson-Genderson & Baker, 2010) and stressful life events (Tsai & Jirovec, 2005). Carers with poor self-efficacy (Zeiss, Gallagher-



Thompson, Lovett, Rose & McKibbin, 1999) and self-esteem are more susceptible to depressive symptoms (Aggar, Ronaldson & Cameron, 2011; Li & Seltzer, 2003).

Care recipient falls (Kuzuya, Masuda, Hirakawa, Iwata, Enoki, Hasegawa, Izawa & Iguchi, 2006), care recipient depression levels (Izawa *et al.*, 2010), unsatisfactory rehabilitation outcomes (Evans *et al.*, 1991) and recent hospitalisation (Given *et al.*, 1999) have also been associated with depressive symptoms in carers. Given, Stommel, Given, Osuch, Kurtz & Kurtz (1993) also suggest that a change in care demands rather than the amount of care provided, results in poor carer mental health. Pioli (2010) further postulates that it is the carers' 'sense of control' that mediates psychological health.

Carers are more likely than non-carers to demonstrate poor psychological health (Cooper, Balamurali, Selwod & Livingston, 2007; Cummins *et al.*, 2007; Edwards, Higgins, Gray, Zmijewski & Kingston, 2008; Hirst, 2005; Oyebode, 2003; Pinquart & Sorensen, 2004; Savage & Bailey, 2004), particularly at the onset of providing significant care (Hirst, 2005) and immediately after caregiving has ceased (Scuffham *et al.*, 2010). The risk for developing psychological illness due to caregiving can persist even after the care recipient is institutionalised (Douglas, Daly, Kelley, O'Toole & Montenegro, 2005; Paulson & Lichtenberg, 2011; Robinson-Whelan *et al.*, 2001), particularly if carer depressive symptoms pre-placement were present (Gaugler, Mittelman, Hepburn & Newcomer, 2009).

A relatively new concept, "caregiving mastery", which is the ability of a carer to feel confident and capable in their role, has been found to moderate depression and anxiety levels (Gilliam & Steffen, 2006; Pioli, 2010).

Carer anxiety

Carer anxiety is described as a reaction to a stressful caregiving situation (Zarit, 2009). High levels of carer stress are associated with high rates of mortality (Fredman, Cauley, Hochberg, Ensrud & Doros, 2010; Son, Erno, Shea, Femia, Zarit & Stephens, 2007) and more recently to stroke risk (Haley, Roth, Howard & Safford, 2010). The relationship between carer anxiety and managing the caregiving role is unique to each individual carer (Aneshensel *et al.*, 1995). Abel (1990) suggests anxiety is intrinsic to the caregiving role. Opie (1994) further postulates that providing care is inevitably and necessarily stressful and that it is the manner in which one copes with, adapts or manages

the caregiving situation that will determine the intensity of the experience. Carers with health problems have been found to more likely suffer from anxiety (De Frias *et al.*, 2005).

There are consistent findings in the caregiving literature about the relationship between particular features of the caregiving situation and anxiety. For example, the level of physical impairment of the care recipient, the difficulty and frequency of tasks performed and care recipient behavioural problems have been found to impact on carers' physical and mental health (Aggar, Ronaldson & Cameron 2010a; Baronet, 1999), sleep patterns (Chenier, 1997; Wilson, 1990), social life (Abraham & Berry, 1992; Chenier, 1997) and employment opportunities (Havens, 1995; Masuy, 2009). Dealing with the health care system and non-caregiving family members has also been reported as stressful and provoking anxiety (Stajduhar, Martin, Barwaich & Fyles, 2005).

There is a view that long-term carers adapt to their caregiving situation and adjust to the demands of caregiving and achieve a more balanced life over time (Hirst, 2005; Tsai & Jirovec, 2005). Even so, high levels of anxiety as a result of caregiving have been related to greater depressive symptoms (Lawton, Moss, Kleban, Glicksman & Rovine, 1991). In terms of evidence to assist carers to cope with reactions to caregiving and the demands of providing care, extensive research conducted by Nolan and colleagues (Nolan & Philp, 1999; Nolan & Caldock, 1996; Nolan, Grant & Ellis, 1990; Nolan, Keady & Grant, 1995) and more recently by Aggar and colleagues (Aggar *et al.*, 2012; Aggar, Ronaldson & Cameron 2014; Aggar *et al.*, 2011; Cameron, Aggar & Kurrle 2011; Aggar *et al.*, 2010a; Aggar *et al.*, 2010b) suggest individual assessment of a carer's unique caregiving situation is necessary.

Summary

The impact of providing care, the diverse aspects of caregiving and particularly the prevalence of burden, depression and anxiety symptoms experienced by carers have been highlighted in this paper. Although some positive caregiving experiences have been emphasised, the negative effects of providing care seem to far outweigh the positive. The demands on a carer's role and personal resources have been demonstrated as predictors of carer burden, including depression and anxiety. However, Chappell and Dujela (2008) suggest that carers can experience a sense of wellbeing and life satisfaction whilst being burdened as a result of providing care. Therefore, rather than focusing on



the role of burden when examining carers' lives, the examination of a carer's experience of providing care may provide a more comprehensive understanding of the caregiving situation.

The complexity and often ambiguous reporting of caregiving experiences raises the following research questions:

1. What care characteristics and relationships impact on the caregiving experience?
2. What is the relationship between caregiving experiences and depression and anxiety in carers?

Research that examines the diverse, individual and complex experiences of caring for a relative or friend may assist health care professionals to identify at-risk carers and appropriate carer support needs.

Recommendations for practice

The inclusion of individual and ongoing carer assessments in rehabilitation nursing practice will facilitate a more comprehensive understanding of reactions to caregiving, carer perspectives and support needs and assist in the identification of at-risk carers.

The second paper in this series will examine variables associated with the caregiving experience.

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Autonomic dysreflexia occurring in persons with multiple sclerosis: a case report and review of available literature

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Abstract

Autonomic dysreflexia is a known life-threatening complication of spinal cord injury. It is a rare entity in persons with multiple sclerosis (MS), but it can occur and cases have been described in the literature. It is important that information about the presenting signs, symptoms and management of the disorder be made available to carers of, and persons with MS, to help reduce the risk of a potentially life-threatening event for persons who live with MS.

Keywords: Multiple sclerosis, autonomic dysreflexia.

Recently I attended a home visit with a community nurse who had requested advice on pressure care management for a patient with incomplete tetraplegia due to advanced progressive multiple sclerosis (MS). When we arrived at the house, Mark (pseudonym) was partially dressed and resting on his bed waiting for us to observe and advise on a sacral stage 1 pressure area. I noted that Mark was perspiring freely with flushed face and upper trunk, despite the cool bedroom. Cognitive issues were apparent; he appeared anxious and his speech was difficult to understand, but this state was not unusual, according to his carer.

After advising on a plan for pressure care management in both bed and chair, Mark's carer finished dressing him and hoisted him into his power chair for the day. I noted that at the start of the preparation for transfer, Mark's urine collection bag was empty, but nearly full by the time he was positioned in his chair, a matter of minutes later. I surmised that whilst he was lying on top of his bed, the drainage tubing from the indwelling catheter to the bag had been kinked off. After a few minutes settled in his chair, Mark's flushed appearance and sweating settled. I suspected at that point that I had witnessed an episode of autonomic dysreflexia (AD). At that time, not wanting to alarm the patient or carer unnecessarily, I did not voice my suspicion, but later advised on the importance of free urine drainage into the collection bag at all times.

AD is a known life-threatening complication of spinal cord injury in persons with an injury at or above the sixth thoracic vertebra level

(Middleton, Ramakrishnan & Cameron, 2014). Despite the cord injury, spinal reflex mechanisms remain intact and an episode of AD can present with a variety of symptoms. Cardinal signs and symptoms are headache, elevated blood pressure with flushing of skin and sweating above the injury level, due to an uninhibited sympathetic reflex response to a noxious stimulus, originating below the injury level. In Mark's case, his distended bladder was the noxious stimulus contributing to the apparent reflex response, causing his sweating and flushed appearance across his upper trunk. Due to his sensory loss, he had not verbalised discomfort from urine retention and it was only when the urine drained freely into the collection bag, that the sympathetic reflex response ceased.

When the nurse and I first arrived at the house, there was no identified need to take a blood pressure (BP) reading; with hindsight it would have been raised, if an AD episode was occurring. After the patient had been settled in his chair for 10 minutes, a routine observation BP 110/65 was recorded. Other than observing Mark's obvious changed condition following his transfer, I am unable to categorically state that this resulted from an episode of AD, as I only had the single BP reading and his altered cognition and poor speech did not alert me to whether he had a headache or not.

Later that day, I searched the literature specifically for discussion of AD in MS. There is very little, but I found two case studies (Bateman & Goldish, 2002; Kulcu, Akbas, Citci & Cihangiroglu, 2009) where individuals with MS had experienced episodes



of AD. In both studies the individuals had multiple sclerotic plaques/lesions on their spinal cords above the sixth thoracic level and, interestingly, in both cases MS was not in an advanced stage. I believe Mark, the subject of my case report, has a poor prognosis, and it is not anticipated that imaging of his spine to verify plaques/lesions on his spinal cord (which could give rise to AD) will occur.

To better inform my understanding of AD occurring in persons with MS, I contacted the nurse specialist at the local MS Clinic and the MS Connect Advisor Service for their comments. Although both services were aware of the potential of AD in MS, a search of MS consumer resources did not find any specific information on the topic.

Although pathophysiology and management of AD are well understood in the spinal cord-injured population, AD in persons with MS is a rare entity; but it is important to consider this important aetiology, which has been sparsely covered in the MS literature to date. The purpose of this paper is to heighten nurses' awareness that AD can occur in persons with MS. For instance, when a person with MS is admitted to the ward for

investigations/respite/rehabilitation or if a person with MS presents at an emergency department in a hypertensive state, AD should be a consideration to be excluded. Failure to seek the noxious stimulus as a cause could result in a life-threatening situation for the person with MS.

I concur with the referenced MS papers that presenting signs, symptoms and management of the disorder should be made available to carers of, and persons with MS.

Declaration

There is no conflict of interest to declare.

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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.

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Authorship

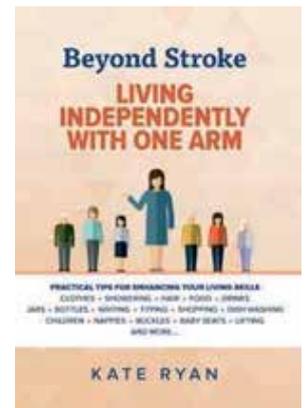
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Beyond Stroke: Living Independently with One Arm

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Kate Ryan has mastered living one-armed in a “two-handed world”, and this is evident in her book *Beyond Stroke: Living Independently With One Arm*. Designed to assist fellow stroke survivors, it is both a guide for completing daily tasks that many of us take for granted, and a practical patient education tool for health professionals.

The spiral-bound print version has 81 lie flat pages (for turning with one hand), and step-by-step instructions and pictures, to assist those with altered reading or memory skills. The A5 format and slender design also enables easy positioning for reading by the person using it. Content is organised into seven short sections: Personal Care; In the Kitchen; Opening Food Containers; Around the House; Children and Babies; Lifting Large Objects; and Recreation. Many daily tasks are included, as well as some more ‘unusual’ ones. In the Personal Care section, for example, there are detailed instructions for cutting fingernails, managing zippers and doing hair, and if you’ve ever wondered how to cut a watermelon one-handed – then page 30 of In the Kitchen reveals all!

I was especially impressed with the information in the section on Children and Babies, as we know it can be challenging to support patients (especially new mums) who live with altered upper limb function. As the mother of three-year-old twins herself, Kate’s advice is invaluable, and her practical suggestions, such as sitting beside the cot to tend to the baby, getting down on the floor with them (and tips on how to get back up again), is good advice for any new mum. Colleagues and I successfully ‘tested’

some one-handed instructions (tying shoes and swaddling a baby), and also discussed important others, including lifting small children. Many in the group felt there was nothing more important as a parent than being able to hold your child, and that as rehab nurses, helping people reconnect with life roles important to them, is more than simply ‘relearning’ physical skills – it is also about supporting them to move forward with determination, independence and dignity. For this reason, I recommend this book as essential reading for all rehab nurses (especially those starting out), and a ‘must have’ addition to any patient education library.

In the author’s words, this book can “positively impact people’s lives by restoring independence and dignity in the everyday things”. I would add too, that in so doing, we free up the time (and effort) for people who may need a bit of support, to experience the things that make the life of their choosing – really worth living.

Alison New is a Nurse Educator in the Queensland Brain Injury Rehabilitation Service based in Brisbane. She has completed a Master of Clinical Rehabilitation (2009, Flinders University) and a Master of Health Science (Nursing): Clinical Education (2012, Australian Catholic University). After many years in the field of spinal injuries rehabilitation nursing, she moved to her current position, and works with staff from the Brain Injury Rehabilitation Unit and Jasmine Unit Slow to Recover (STR) Brain Injury Rehabilitation Unit in Brisbane.



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Outcomes of rehabilitation for reconditioning: falls, frailty, care service requirements – what does the national data tell us?

Between 2006 and 2015, the volume of reconditioning episodes submitted to AROC each year has steadily increased, with about 5,000 episodes reported in 2006 and 32,200 in 2015 (Figure 1).

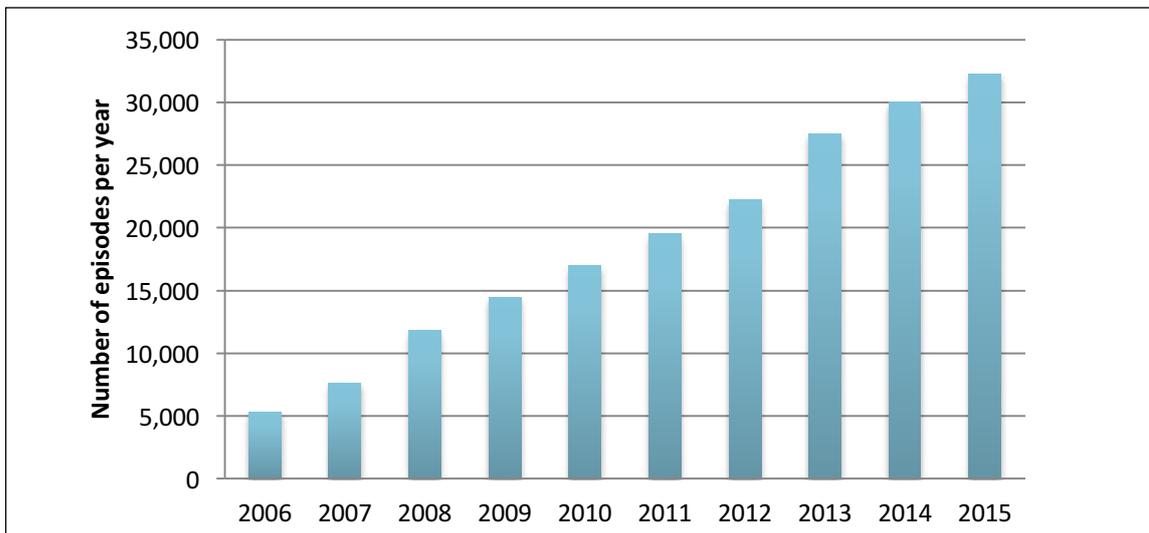


Figure 1: Growth in volume of episodes reported to AROC as reconditioning, 2006–2015

Over time, reconditioning episodes have also represented a steadily increasing proportion of the episodes submitted to AROC, just over 10% in 2006, rising to 25% in 2014 and 2015 (Figure 2).

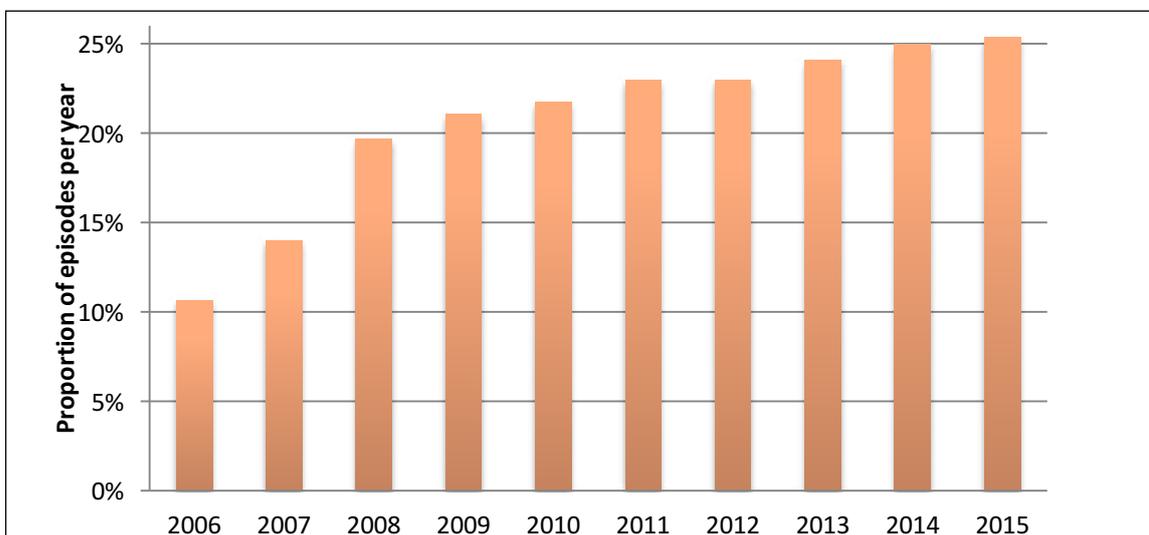


Figure 2: Reconditioning episodes as a proportion of all episodes reported to AROC, 2006–2015



The average age of patients engaging in reconditioning rehabilitation is approximately 80 years old.

The AROC dataset includes a number of data items specific to the reconditioning impairment including:

- the Rockwood Clinical Frailty Scale
- was the patient able to participate in therapy from day 1?
- has the patient fallen in the last 12 months?
- has the patient lost more than 10% of their body weight in the last 12 months?

As shown in Figure 3, some 60% of patients attending for reconditioning rehabilitation had either fallen, or experienced a significant weight loss, or were unable to participate from day 1 or had experienced a combination of these things. From AROC's perspective, it is interesting to analyse the outcomes achieved by these differing cohorts of patients.

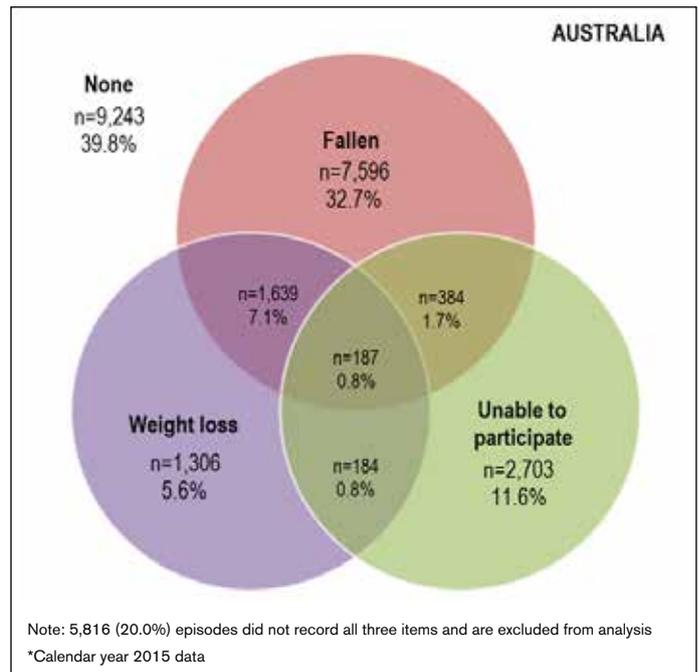


Figure 3: Summary falls, weight loss, ability to participate in rehabilitation from day 1

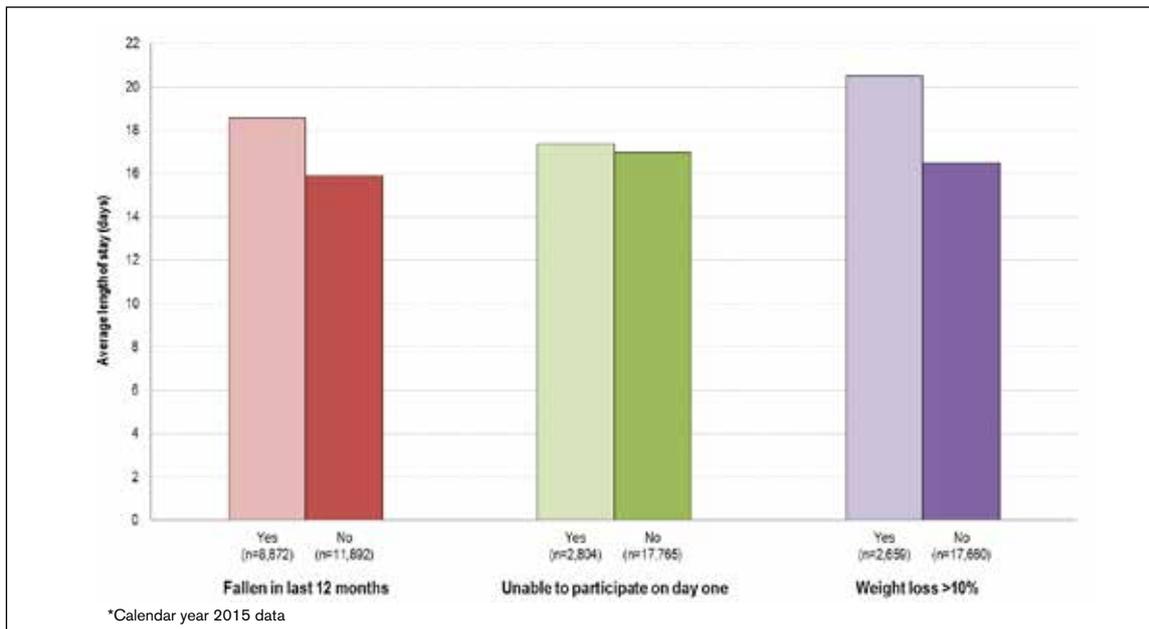


Figure 4: Average LOS by falls, weight loss and inability to participate from day 1

As Figure 4 shows, the average length of stay (LOS) of patients who had fallen in the previous 12 months or experienced a weight loss of greater than 10% was longer than that of patients who had not experienced one of these factors. About 14% of those undertaking rehabilitation for reconditioning were not able to participate on the first day, but this had only minimal impact on their LOS, compared with those who could participate from day 1.



The Venn diagram in Figure 5 shows that patients who had experienced more than one of the factors had an even longer of stay. Patients who had experienced none of the factors had an ALOS of 15.3 days; patients who had experienced one factor had an ALOS of between 16.4 and 19.4 days; patients who had experienced two factors had an ALOS of between 18.1 and 21.8 days; and patients who had experienced all three factors had an ALOS of 24.8 days.

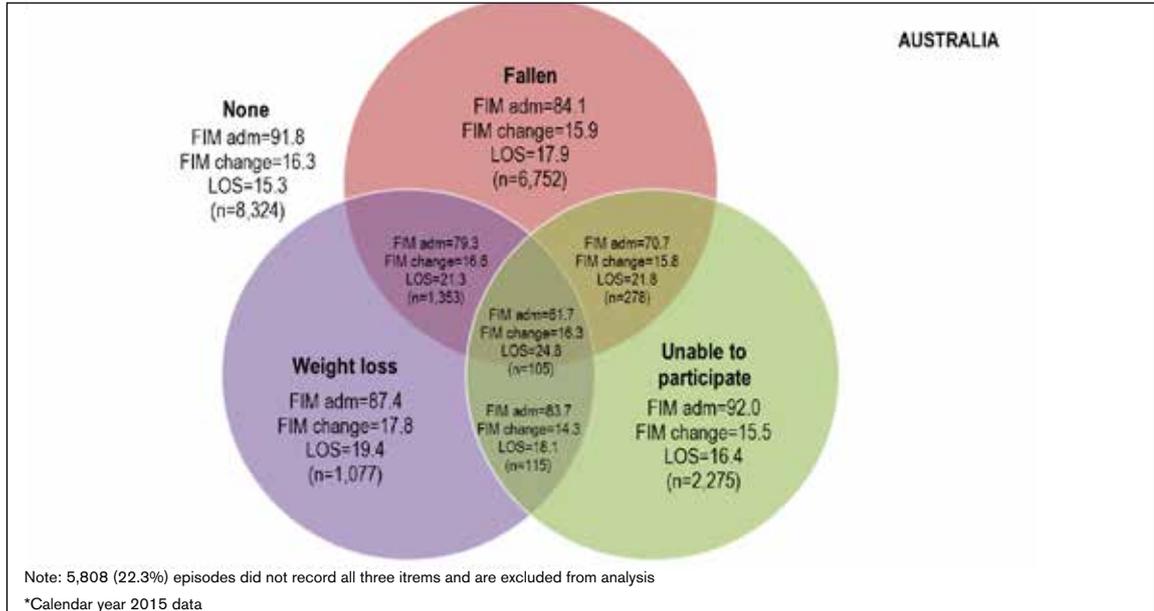


Figure 5: Summary FIM, LOS, falls, weight loss, unable to participate from day 1

The Rockwood Clinical Frailty Scale categorises patients into one of eight groups as shown below. The proportion of patients in each group for calendar year 2015 was:

very fit	1%	mildly frail	22%
well	11%	moderately frail	24%
well with co-morbid disease	21%	severely frail	5%
apparently vulnerable	16%	terminally ill	1%

AROC has analysed several factors by frailty category, including falls. Figure 6 shows the proportion of patients in each frailty category who have fallen in the last 12 months. Unsurprisingly, the proportion increases with increasing level of frailty.

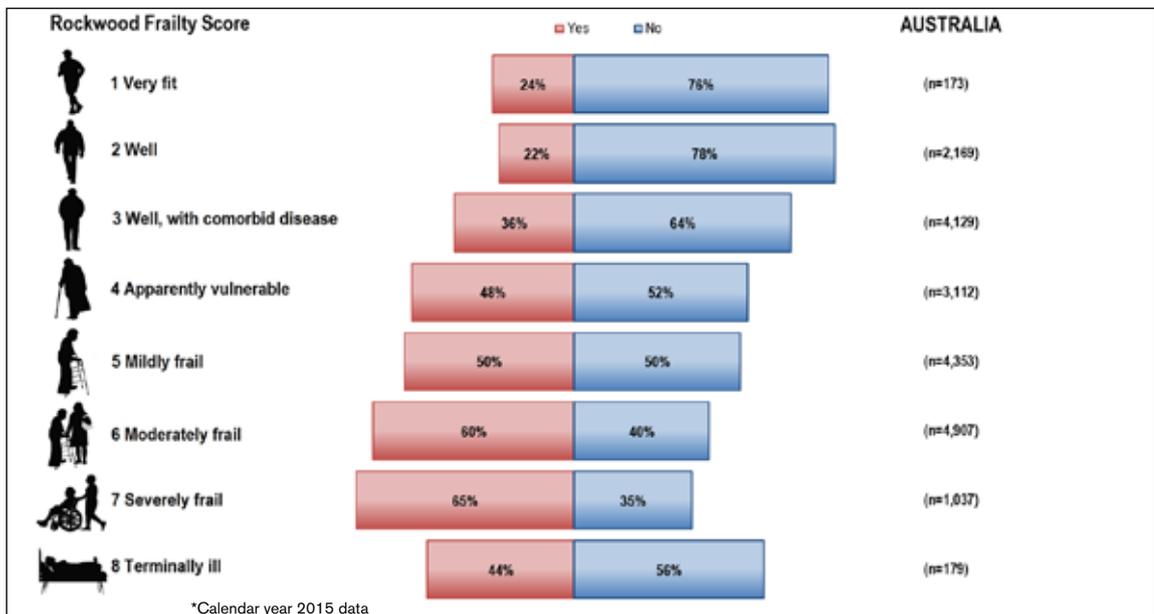


Figure 6: Falls by frailty



Figure 7 shows the average admission and discharge FIM scores by frailty category. Whilst the admission FIM decreases as frailty level increases, as does the average discharge FIM, the amount of functional gain achieved by the rehabilitation program remains fairly constant across the categories.

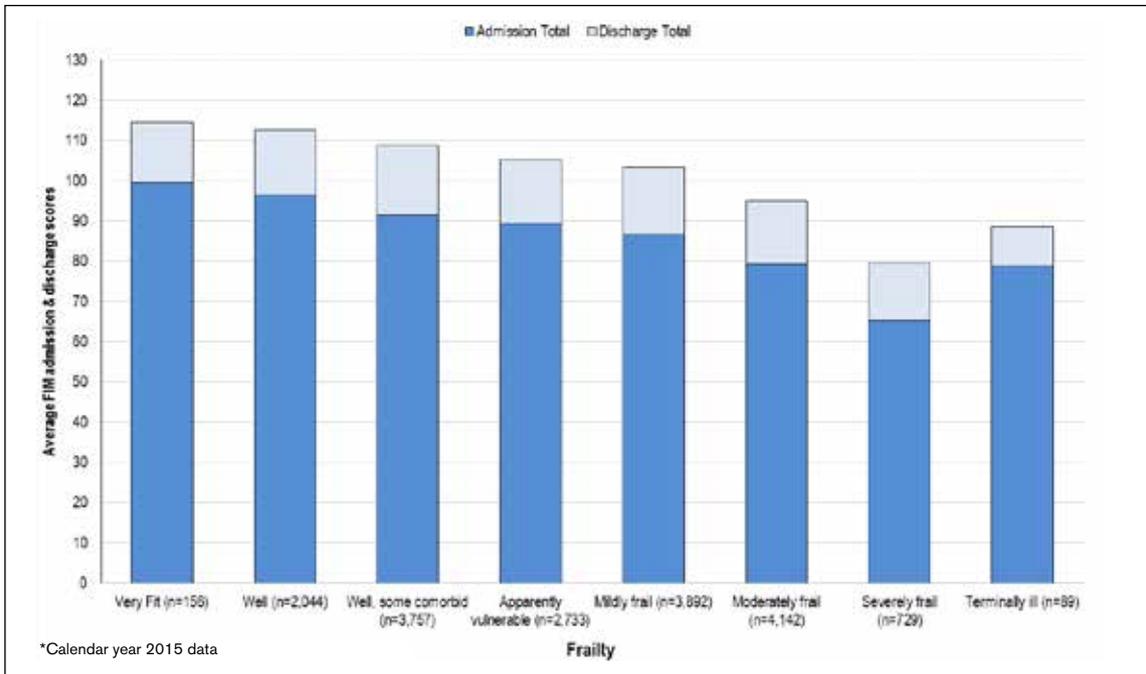


Figure 7: Average admission and discharge FIM scores by frailty

In terms of outcomes by frailty category, as Figure 8 shows, the ALOS by frailty category increases, with the severely frail cohort staying almost eight days longer than the very fit, well, well with comorbid disease and apparently vulnerable categories.

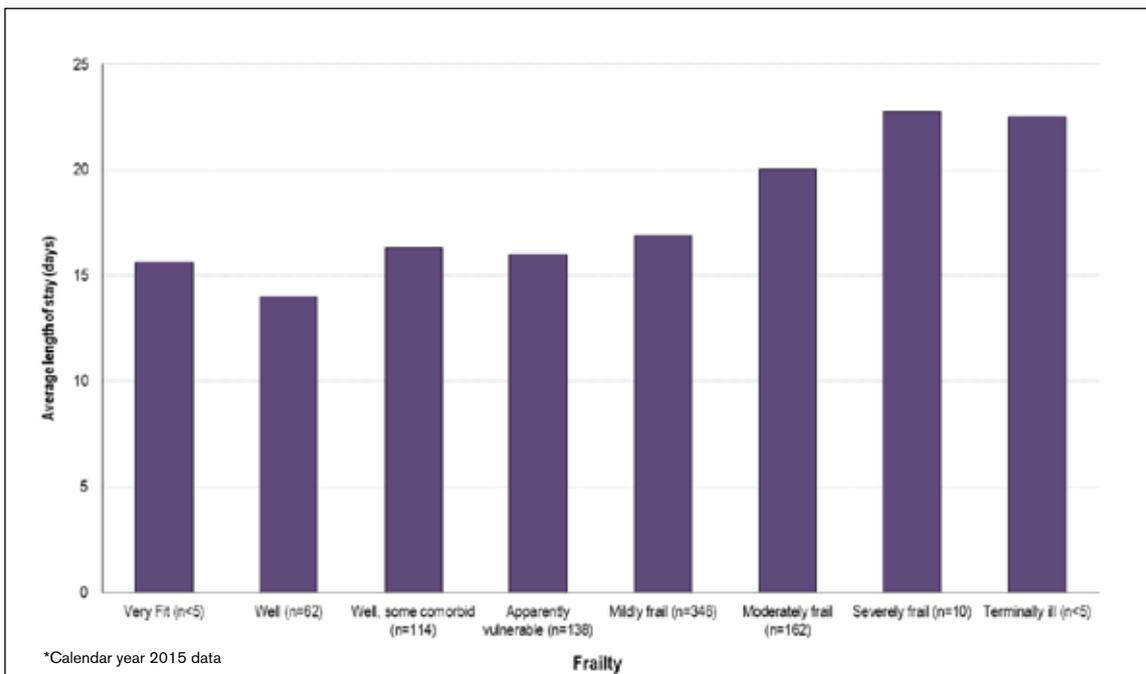


Figure 8: ALOS by frailty

In summary, reconditioning impairment-specific data items are part of the routine AROC data collection and have allowed us to divide this significant group of patients into meaningful cohorts based on their clinical pathology. The data indicates that cohorts demonstrating increasing frailty, falls and weight loss are generally associated with a reduced average admission FIM score and increased ALOS.



Guidelines for submission of manuscripts to *JARNA*

Continued from page 26

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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.

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