

Unmet health and rehabilitation needs of people with long-term neurological conditions in Queensland, Australia

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What is known about this topic

- People with neurological conditions may have a normal life expectancy.
- There is a firm trend of people with neurological conditions living and receiving care in the community.
- While many policies and rehabilitation models endorse reasonable and necessary health and rehabilitation, these services are likely to be inadequate.

What this paper adds

- Insight into the health and rehabilitation services perceived as satisfactory for a diverse sample of people with neurological conditions (i.e. acquired brain injury, multiple sclerosis, Huntington's disease, motor neurone disease, spinal cord injury).
- Insights from the voices of participants regarding their specific unmet health and rehabilitation needs.
- Prompts for better integration of disability, health and rehabilitation services with a particular emphasis on the supportive rehabilitation stage.

Abstract

The survival and life expectancy rates of people with traumatic and degenerative neurological conditions are increasing, sometimes up to several decades. Yet compared to the general population, people with a disability continue to experience poorer health and are at greater risk of developing secondary health problems and facing barriers to services they require. These trends have significant implications for provision of health and rehabilitation services. In this study, the adequacy of health and rehabilitation services provided to people with long-term neurological conditions and their unmet needs were explored from the perspectives of individual users, their nominated family members and key service providers. A qualitative research design with maximum variation sampling was used. Data were collected from semi-structured interviews with 65 participants comprising 25 long-term care service users, nominated family members or friends ($n = 22$) and care service providers ($n = 18$) in Queensland, Australia. All service users needed assistance with usual daily activities, and 22 were wheelchair dependent. The hours of funded personal care ranged from 2 to 201 hours per week. Data were analysed using framework analysis. Participants generally perceived that specialist medical and hospital services were adequate and satisfactory. They valued supportive health and rehabilitation professionals and receiving client-centred physical rehabilitation. However, the majority of participants ($n = 17$) had perceived unmet needs for physical rehabilitation ($n = 14$), other health or rehabilitation services ($n = 10$) or counselling ($n = 6$). Community-based physical maintenance rehabilitation was often perceived as inadequate, costly or inconveniently located. Participants highlighted the importance of personal and family counselling and information provision at time points such as diagnosis. The findings contribute to the limited international evidence on the gaps in health and rehabilitation services for people with neurological conditions receiving lifetime care services in the community. A continuum of integrated rehabilitation services to minimise avoidable impairments, optimise independence and functioning, and sustain quality of life is warranted.

Keywords: degenerative condition, interviews, long-term care, neurological condition, qualitative, rehabilitation

Introduction

Survival rates for people with long-term neurological conditions such as acquired brain injury (ABI), spinal cord injury (SCI), motor neurone disease (MND), multiple sclerosis (MS) and Huntington's disease (HD) have increased, sometimes up to several decades. Many people with disability may have a normal life expectancy and require 20–50 years of care (Senate Community Affairs References Committee 2005, Middleton *et al.* 2012). The life expectancy for people with MS has been estimated at 20 years and, in one US study, approximately one-third required some form of home-care assistance (Buchanan *et al.* 2010). Yet, the health of people with a disability and their access to health and rehabilitation services to promote health are ongoing concerns (McDermott *et al.* 2007, World Health Organization and The World Bank 2011). Compared to the general population, people with a disability are at a higher risk of developing secondary health problems and face physical, financial, attitudinal and competency barriers to healthcare (World Health Organization and The World Bank 2011). With much more empirical work required to understand the diverse healthcare needs of people with disability, this paper focuses on people with long-term neurological conditions.

The health and social inequities experienced by people with long-term neurological conditions are being addressed in many countries through disability reform. The UK Department of Health introduced The National Service Framework for Long Term Conditions to provide a continuum of integrated long-term care and support of people living with neurological conditions (DH 2005). Recently, the Australian government has introduced a National Disability Insurance Scheme (NDIS) to address criticisms about funding shortfalls, inefficiencies, inequities and lack of choice and certainty for people with disability (Productivity Commission 2011). The Scheme, supported by an increase in the Medicare levy, provides insurance cover for all Australians in the event of significant disability (Commonwealth of Australia National Disability Insurance Scheme 2013). Eligible individuals will have a blend of funded supports via the NDIS, based on what is *reasonable and necessary*, informal supports and other mainstream supports (Hawkins 2013). For adults with long-term neurological conditions living in the community, this is likely to include a complex mix of disability support and health and rehabilitation services (Foster *et al.* 2012, Gridley *et al.* 2013).

Access to the appropriate and equitable mix of care is not straightforward. A UK study on the

experiences of people with MND found that difficulties of access were due to unclear entitlements, lack of information and professional attitudes (Hughes *et al.* 2005). In the United States, significant access delays and high levels of unmet health needs are also evident among adults with disability (Henning-Smith *et al.* 2013). In Australia, poor integration across disability, health and rehabilitation systems intensifies access problems (Senate Standing Committee on Community Affairs 2007, National Disabilities and Carer Council 2009). A study on community service needs of people with MND found that as many as 43% experienced gaps in rehabilitation and respite, although the percentage for each service was not stated (Ng *et al.* 2011). Likewise, in the example of ABI, gaps in the continuum of care are evident across health and rehabilitation (Ta'eed *et al.* 2013), although compensation or other private sources can facilitate access in the private sector (Ta'eed *et al.* 2013). Other access pathways have arisen via the introduction of the Medicare Chronic Disease Management initiatives which subsidise the cost of allied health services provided in the private sector (Haines *et al.* 2010), though there are ongoing concerns about equity (Foster *et al.* 2008, Cant 2010).

The mismatch between accepted models of rehabilitation and the needs of people with long-term neurological conditions can also be a significant barrier to achieving the appropriate mix of care. Accepted models of rehabilitation place a greater emphasis on rehabilitation to achieve optimal independence to enable discharge to the community; less on maintaining function beyond discharge and resettlement (Foster *et al.* 2007, Simmonds & Stevermuer 2007, New & Poulos 2008, Okawa *et al.* 2009, Patterson *et al.* 2010). Yet, rehabilitation for people with acquired disability and progressive conditions can maintain the health of this group by ameliorating disability (Agrawal & Mitchell 2005) and avoiding functional decline, preventable contractures and pressure ulcers (New & Poulos 2008).

This paper examines the health and rehabilitation needs of people with acquired neurological conditions in the Australian context at a time of significant reorganisation of the disability support system. In particular, the aims were to: (i) examine the adequacy of medical and rehabilitation services provided to users of lifetime care from the viewpoint of those most directly involved and (ii) contribute to policy and service delivery developments about health and rehabilitation services for people with acquired neurological conditions. In this case, adequacy refers to the extent to which funding and the type and level of services currently received are perceived to be appro-

appropriate and reasonable to meet identified needs. To that end, the intention was to also explore the valued aspects of current care arrangements and satisfaction with service provision and service access. The research questions were:

- 1 What funded and unfunded health and rehabilitation services are received by adults with acquired disabilities due to long-term neurological conditions? How adequate and satisfactory are the health and rehabilitation services provided to this group from the perspective of service users, significant others and care service providers?
- 2 What, if any, are the areas of unmet need for this population?

This study forms part of a larger 3-year research project which examined lifetime care for adults with acquired disability and high care needs in Queensland. The larger project encompassed three policy and service delivery studies: (i) mapping of service delivery through interviews with key stakeholders and online survey data from 69 service delivery informants (Foster *et al.* 2012); (ii) the financing, management and co-ordination of lifetime care, particularly personal care and domestic assistance (Foster *et al.* 2012); and (iii) the present study which complements the second study by focussing specifically on health and rehabilitation services.

Methods

The research was designed in the qualitative research tradition to explore and interpret the participants' experiences and perceptions of the research topic (Snape & Spencer 2003). After informed consent was obtained, data were collated from 65 individual interviews organised around 25 service users, their nominated family member or friend, and care service providers during 2010. Ethical approval for the research was gained from the relevant university ethics committee [2009001282]. The study was conducted in accord with the priorities and principles of the National Disability Research and Development Agenda (2011).

Participants

With the assistance of the research Reference Group and Industry Partners, a purposive sample of 25 individuals with acquired disability and high care needs was recruited from within South East Queensland. Recruitment was purposive to explore: (i) a diverse sample of disability and needs, including need for specialised services; (ii) the lifetime care arrangements and experiences of those people with sudden onset

disability (e.g. ABI, SCI) and those with progressive conditions (e.g. MS, MND, HD); and (iii) those groups with high care needs (e.g. ABI, MS) who have traditionally been at high risk of transfer to residential aged care facilities. Recruitment also aimed to include individuals with a range of ages, geographical locations (urban, rural and regional), differences in location of support (own home and residential care) and variations in sources of funding (compensation and no compensation). Recruitment ceased when the sample was judged to meet criteria for a purposive maximum variation sample (Patton 2002).

Demographic and residential details and information about funded care and domestic assistance for the 25 care service users are provided in Table 1. The sample included six participants with ABI, three with HD, three with MND, eight with MS and five with SCI. The 25 service user participants included 14 males and 11 females aged 20–66 with a median age of 52 years. Sixteen lived in their own accommodation (privately rented, mortgaged or owned) and nine of the sixteen lived with family members who provided some lifetime care; five lived in subsidised public housing and nine lived in fully supported accommodation, including three in an aged care facility. All service users had 24-hour attendant or on-call emergency care and required assistance with instrumental activities of daily living (e.g. household cleaning, meal preparation, laundry). Twenty-two were wheelchair dependent, three were mobile and two with walking aids or assistance.

With consent and where available, one family member, friend or informal carer, and one care service provider of each service user participant were also recruited. There were 22 nominated family and friends (coded F) who provided some care or support to a service user. This group comprised nine spouses (five wives and four husbands), four daughters, three mothers, two male friends, one sister, one aunt, one neighbour and one carer. Among the 18 nominated service providers (for 22 service users) were several with healthcare qualifications (e.g. clinical nursing, social work) and others had backgrounds as carers. Job titles for the care service providers (coded CSP) include care service provider manager, service co-ordinator, residential support co-ordinator, senior support worker, community care manager and case manager.

Data collection

A semi-structured interview guide enabled two interviewers to address similar topics in-depth while suiting each participant's situation. For the larger study, the interview guide comprised a series of

Table 1 Care service users' demographic, residential and funded care details

Participant	Gender	Age	Residential situation	Funded hours of care per week
ABI_01	Male	48	Share unit in facility	7 for medication and monitoring
ABI_02	Female	52	Own room in facility	10 PC
ABI_03	Female	38	Share house in facility	10 PC, 10 CA, monitoring
ABI_04	Male	37	Home with carer support	30 PC
ABI_05	Male	20	Home with family, carers	201 PC
ABI_06	Male	47	Home with family	Reduced from 60 to wife's care
HD_01	Male	61	Aged care facility	All PC, monitoring
HD_02	Female	66	Aged care facility	All PC, monitoring
HD_03	Female	47	Home with daughter	27.5 PC and CA
MND_01	Male	57	Home with carer support	All PC – self-funded
MND_02	Male	63	Home with wife, children	18 PC
MND_03	Male	44	Home with wife, children	10 PC
MS_01	Male	52	Home, daughter nearby	2 PC
MS_02	Female	55	Home with husband, son	All PC from funded spouse carer
MS_03	Female	51	Home, with carer support	28 PC and IADL
MS_04	Female	59	Aged care facility	All PC
MS_05	Male	56	Home with wife	7.5 PC
MS_06	Female	44	Share unit in facility	10 PC and IADL
MS_07	Female	58	Share unit in facility	10 PC
MS_08	Male	48	Share unit in facility	70 PC and IADL
SCI_01	Male	57	Home with wife, children	50 PC
SCI_02	Male	20	Home with mother, brother	47 PC
SCI_03	Female	47	Home, with carer support	55 PC and IADL
SCI_04	Female	60	Home with carer support	21–25 PC and IADL
SCI_05	Male	54	Home with carer support	189 PC

ABI, acquired brain injury; HD, Huntington's disease; MND, motor neurone disease; SCI, spinal cord injury; MS, multiple sclerosis; PC, personal care; IADL, instrumental activities of daily living/domestic chores; CA, community access; hours of funding for IADL are only stated when they were inseparable from PC hours.

questions to elicit experiences and perceptions on four main topics: (i) current lifetime care arrangements; (ii) co-ordination and management of lifetime care; (iii) appropriateness and adequacy of lifetime care; and (iv) perceived areas for improvement in lifetime care. Some example questions were as follows: *tell me about your current care arrangements; how adequate is the funding and type and level of care received to meet needs; how suitable is the current care to maintain desired routines and lifestyles; how predictable and secure are the current care arrangements; are there occasions when you or your family have to pay personally for care to meet needs; how important is choice in determining care arrangements; what specific needs are not being met; what improvements would you want in your current care arrangements.* Personal and demographic data were also collected. Participants' responses relating to health and rehabilitation services specifically were extracted from the transcripts and collated for separate analysis. For the larger study, participants were interviewed on average for 1 hour at a place they nominated, generally their home or workplace. In eight instances, the family member was present with consent to assist participants who fatigued easily or to supply supplementary information. The interviews

were recorded and transcribed verbatim. Participants were ascribed a unique participant code which protected their identity.

Data analysis

The five-stage thematic framework approach to policy research (Ritchie & Spencer 1994, Ritchie *et al.* 2003, Pope *et al.* 2006) was used to analyse data. The intention with the analysis was to explore and integrate three perspectives, that is, individual users, family members and care service providers. Data addressing the research questions were coded, categorised for each of the 25 service users in tables and word documents, and then analysed using constant comparison of each question and response. Initially, the perceptions and experiences of the family member and the care service provider were compared with those of the service user. The latter two participant sub-groups generally confirmed or extended the data from individual users. Any similarities and discrepancies in the data were noted and progressively recorded as researcher's memos. Next, data from users with the same disability were compared before data across all participants were compared.

Table 2 Types of health and rehabilitation services being received by 25 servicer users

Service	Participants
Regular health consultation and monitoring including GP	20
Medical specialist consultation	
Specialist other than psychiatrist (e.g. neurologist)	12
Psychiatrist	5
1–4 specialist outpatient clinics annually for HD, MND, SCI	11
Allied health*	11
Physiotherapy	3
Hydrotherapy monitored by a physiotherapist	3
Combined AH consultation or services	6
Fitness programme monitored by fitness trainer	1 with ABI
Equipment funders and maintainers (e.g. wheelchairs, hoists, shower chairs)	
Queensland's government Medical Aids Subsidy Scheme (MASS)	16
Insurers	2
Disability-specific organisations (no charge, loan, low-cost purchase)	5 with MND or MS
Service user, family and friends	14

GP, general practitioner; HD, Huntington's disease; MND, motor neurone disease; SCI, spinal cord injury; ABI, acquired brain injury; MS, multiple sclerosis; AH, Allied Health; OT, occupational therapy.

*Allied health funding sources included government funded, disability specific organisations, private practice.

Analysis and interpretation were aided by reflection on each participant's context and statements about the meaning of services to them, recorded as researcher's memos. A range of expressions and the associated feelings and actions were interpreted as levels of satisfaction or dissatisfaction in services. Words such as 'content', 'happy', 'lucky', 'I like', 'it is good to' and 'she's great' were interpreted as satisfaction. Words such as 'dissatisfied', 'unhappy', '[he] voiced one complaint' and 'we were ill-informed' were interpreted as dissatisfaction. The findings were reviewed regularly by the research team to clarify and confirm interpretations. Strategies to increase rigour included: (i) triangulation of data sources for each service user; (ii) open-ended questioning by interviewers; (iii) frequent discussion by research team members from three professional backgrounds; (iv) regular presentations to and discussions with a reference group representing funders and interested parties, including people with a disability; (v) use of researcher memos to ensure transparency of analysis; and (vi) consideration of all divergent views.

Data were progressively synthesised into a series of reports which ensured that the emerging health and rehabilitation sub-themes were fully supported with representative quotes and examples.

From the analysis, preliminary descriptive themes were identified: valued health and rehabilitation choices; satisfaction and dissatisfaction with health and rehabilitation providers and services; and unmet health and rehabilitation needs. These descriptive themes were interrogated further with

reference to the research questions to elicit the types of health and rehabilitation services received (first research question), and the main themes relating to adequacy and satisfaction (first research question) and unmet needs (second research question). Three themes emerged as follows: (i) meeting and exceeding expectations; (ii) falling short of expectations; and (iii) lacking health and rehabilitation services.

Findings

Following a description of the types of health and rehabilitation services received, the three main themes are presented below with reference to the research questions and complemented by supporting evidence in Tables 2–4 and Box 1.

What types of health and rehabilitation services were received

Table 2 presents the numbers of service users receiving different types of health and rehabilitation services. The majority had their health monitored on a regular basis by a general practitioner, and attended annual reviews at specialist outpatient clinics and/or were seen by other medical specialists. Less than half of the participants received allied health or rehabilitation services. In 14 of the 25 cases, servicer users, family and friends contributed to the high cost of equipment provision and maintenance and/or to home modifications indicating substantial overlap between the two groups. For example, SCI_01's

Table 3 Satisfaction with health and rehabilitation providers and services

Provider or service	Participants
General practitioners	MS_02, MS_03, HD_01, SCI_02, SCI_03 (<i>n</i> = 5)
Medical specialists (public or private)	MS_05, HD_01, ABI_05, SCI_03, MS_06 (<i>n</i> = 5)
Physiotherapist/physiotherapy	ABI_03, MS_02, MS_03, MS_06 (<i>n</i> = 4)
Other individual providers	Occupational therapist (SCI_03),* psychologist (SCI_03), social worker (ABI_06F), mental health worker (HD_01) (<i>n</i> = 4)
Teams that support client and family	MND_03, HD_01, SCI_05 (<i>n</i> = 3)
Teams that communicate effectively	MS_03, ABI_05, MS_06 (<i>n</i> = 3)
Driving rehabilitation	ABI_06 (<i>n</i> = 1)
Home modification advice	MND_03 (<i>n</i> = 1)
Weekly massage from naturopath	MS_03 (<i>n</i> = 1)
Dementia facility services	HD_02F (<i>n</i> = 1) [†]
Intensive therapies (home)	ABI_05 (<i>n</i> = 1) [‡]
Wheelchair accessible services	MS_05 (<i>n</i> = 1)

ABI, acquired brain injury; HD, Huntington's disease; MND, motor neurone disease; SCI, spinal cord injury; MS, multiple sclerosis.

Supporting quotes and context:

*SCI_03 is very satisfied with her [agency] occupational therapist of whom she said, 'she is just brilliant', and with a [hospital] occupational therapist who made her a hand splint although she did not have to take her referral.

†HD_02F is very satisfied that his wife, in a high-care dementia ward, is provided with health, dental, podiatry and hairdressing services, and also continence pads for which they previously paid. 'You don't have to even go anywhere you know and in the high-care they get extra services as well' (HD_02).

‡Since coming home, ABI_05 was receiving 'intensive' physiotherapy, speech pathology and occupational therapy three times a week from the insurer and that she 'could be there virtually 24 hours a day [and] we could do things say twice a day if we wanted to do it, ... [and] we could plan our own times for his meal or his rest or whatever'. ABI_05F had noticed the improvement in ABI_05's abilities.

supporters set up a website to raise funds locally, interstate and overseas for an electric lift, a hoist, a ramp and bathroom modifications for him. SCI_01 said that:

The community rallied behind and friends and family. And so like the money for the lift, we had to come up with \$14,000.00. I mean we didn't have that.

How adequate and satisfactory were health and rehabilitation services?

Theme 1: meeting and exceeding expectations

The first theme related to services meeting or exceeding participants' expectations. Participants expressed satisfaction with several aspects of health and rehabilitation providers, and services that they perceived displayed certain positive characteristics and met or exceeded expectations (see Table 3). The role of families and friends appeared less important to satisfaction with health and rehabilitation services as these services were provided primarily by professionals. Overall, participants were satisfied with the professionalism, advocacy and care, with particular praise directed towards individuals, teams and services with the following characteristics: (i) pleasant, friendly and knowledgeable (SCI_02, SCI_03); (ii) prepared to visit (HD_01F, SCI_02, SCI_03); (iii) thorough in their

holistic care plan or service delivery (MS_05, SCI_02); and (iv) 'approachable' and 'kind' (SCI_03). Health professionals who advocated strongly for their clients with insurers were also highly regarded (e.g. the social worker and psychiatrist who supported ABI_06F and MND_01 respectively). However, satisfaction with access to services was more specific to: (i) responsiveness to expressed needs ('...they helped me out with physiotherapy' ABI_03); (ii) the scope and intensity of service received; and (iii) access to preferred services. In some cases, access to more intensive or greater hours of care was linked to greater satisfaction, but this was conditional on perceived needs being met. The ability to access private care was an important distinction in access to more intensive and also preferred services, though this was more pronounced in personal care rather than health and rehabilitation services specifically. Nevertheless, specific services such as equipment (MND_01), medical specialists (HD_02) or therapy services (MS_06, ABI_02) were sometimes purposively self-funded to avoid delayed access, or to meet preferences for services. However, this was associated with mixed feelings due to the precariousness of personal financial situations and 'the frustration of the jumping through the hoops in the system to get something' (MND_01).

Table 4 Dissatisfaction with health and rehabilitation providers and services

Providers or service	Participants
Adequacy or style of nursing	ABI_06F, MS_07, MS_07F, MS_08,* ABI_05F, SCI_05F (<i>n</i> = 6)
Inaccessible GP, X-ray, AH services	MND_03, SCI_02, SCI_03, SCI_05F, MS_05,† MS_07 (<i>n</i> = 6)
Delayed, inappropriate, limited	AH ABI_06F, MS_03,‡ MS_07,§ SCI_05 (<i>n</i> = 4)

GP, general practitioner; ABI, acquired brain injury; HD, Huntington's disease; MND, motor neurone disease; SCI, spinal cord injury; MS, multiple sclerosis; AH, ???.

Supporting quotes and context:

*MS_08 was not satisfied that the [agency] nurse who 'should attend him for bladder care has not visited yet' and consequently, he had to go to hospital for this care.

†MS_05 had changed his GP. MS_05F stated, 'that doctor shopping wasn't so much confidence in the man, it was trying to get a wheelchair into the doctor's office'. Accessing an X-ray was an additional problem for MS_05.

‡MS_03 was not satisfied with the 2-month delay for her [hospital] occupational therapist to attend to her wheelchair modification which made her feel 'closed-in'.

§MS_07F was dissatisfied that MS_07 who 'gets lots of spasms' does not get physiotherapy to relieve them and does not accept that the carers cannot stretch the spasm for occupational health and safety reasons.

Theme 2: falling short of expectations

In contrast to the first theme, participants (*n* = 15) also indicated many areas where health and rehabilitation services fell short of their expectations. Dissatisfaction was mainly linked to delays in accessing services or limited access to desired services, or in some cases, the attitudes of service providers (see Table 4). Noticeably, a perceived mismatch between regularity of nursing care and need (MS_08), restrictions on the scope of aids and equipment (MND_02, MND_03), or lack of expected level and type of therapy (SCI_03, ABI_01, ABI_02) were associated with reports of inadequacy and general dissatisfaction. It was also evident that dissatisfaction was associated with a perception that public funding did not cover what participants regarded as necessary therapy to improve or maintain health and function, and for a number of participants, other affordable options were lacking (SCI_02, SCI_03, MS_07).

There was some overlap between participants who were satisfied and dissatisfied with health and rehabilitation services. Of the 14 who expressed satisfaction, all disability groups were represented, and half of them also expressed some dissatisfaction. Of the five who only expressed dissatisfaction, three were family members of participants with ABI, MS or SCI. Some participants expressed satisfaction or dissatisfaction with one or more aspects of a service, which was consistent with findings for the other sub-themes.

What are the areas of unmet needs?

Theme 3: lacking health and rehabilitation services

The third theme related to a perceived lack of health and rehabilitation services. Despite identifying services which met and exceeded expectations and

existing services which did not meet expectations, for 17 of the 25 service users, there were perceptions that health and rehabilitation services were inadequate to meet needs. In five of the fourteen instances, the service user identified the need, and in six additional instances, a family member/friend or CSP also independently corroborated a need identified by the service user, while in the remaining three instances, a participant other than the service user identified the need. Service users, family, friends and care service providers frequently noted more than one area of unmet health and rehabilitation needs (see Box 1 for quotes regarding unmet needs). Affordability, geographical accessibility and availability of competent providers were factors contributing to unmet needs. The other substantial area of unmet need concerned the provision of personal care services and is addressed in another paper (reference withheld).

Physical maintenance therapies were the largest area of perceived unmet rehabilitation or healthcare need (*n* = 14). In five of the 14 instances, the service user identified the need; in six additional instances a family member/friend or CSP also independently corroborated a need identified by the service user; and in the remaining three instances a participant other than the service user identified the need. The average age for participants needing physical maintenance was 49.6 years (cf. average age of 52 years for all service users).

Physical maintenance therapies for which participants perceived a need encompassed physiotherapy and other physically based programmes, including hydrotherapy, fitness sessions, exercise and massage designed or monitored by a physiotherapist or a personal trainer. Service user, family and caregiver

Box 1 Illustrative quotes and contexts from participants regarding unmet needs

Physical maintenance

ABI_03: said '...I'd also like some sort of funding for some exercise and fitness things that I do'

At 52 years, MS_01 said that he needed 'more regular hydrotherapy' to maintain his abilities

SCI_02F and SCI_02 said that SCI_02 needs 'vital' physiotherapy once or preferably twice weekly. SCI_02 said that he needed a 'workout' to 'maintain' his body, and that 'as a young man I think that is important'

SCI_02F stated that she wants 'an ongoing commitment to that client's health from not just going to their GP but looking at things like the physiotherapy; looking at their bone density; looking at fertility issues for younger people, women and men, whether they want a family; looking at their psychological health'

Other allied health and medical or dental services

ABI_02 wanted occupational therapy for upper limb management including splinting, and said of her left arm, 'I've got to get it moving'

ABI_04F wanted regular speech therapy for ABI_04 because 'he can get a little bit slurry because he hasn't talked to anyone properly over the weekend'

ABI_05CSP said ABI_05 and his family need an additional room built to house his equipment as a place for the 24-hour personal carers to take a break away from the family spaces. ABI_05CSP said '...we got [name], an occupational therapist who specialises in major mods, her to come in with her associate, [name], to design and provide us with a floor plan of an appropriate space that would give him a bedroom that was suitable to him for the long term, plus a bathroom, plus a carer's room with kitchenette, rehab area and equipment storage, because currently his equipment is stored in the hallway or shuffled around the house'

ABI_06F said that ABI_06 needs an 'activity officer' to co-ordinate his activities and accompany him to woodworking classes. He needs someone to accompany him to a social group and remind him that he has met people before

MS_01 needs a stronger ramp for his van. MS_01 said, 'I have just got a ply-wood ramp that I run up into the back of the van, but it is a little bit awkward and I'm just a bit over the weight'

SCI_02 needed to access a dentist, but SCI_02F said that 'our ordinary dentist is a bit loath to look at him in his chair because he knows that dysreflexia is a bit of a scary thing that they're not trained to deal with, noting that dysreflexia during dental and other surgery can potentially be fatal for people with SCI'

SCI_05F expected more for her father: 'And when we came home, we were told that there would be support systems in the community that we could access and use and OTs that would be there when we needed them. We've seen none of this'

Counselling

SCI_03 said, 'There is not a lot out there to tell you what to do and where to go', and with reference to people with recent traumatic injury she said that 'everyone's heart is just broken'

GP, general practitioner; ABI, acquired brain injury; SCI, spinal cord injury; MS, multiple sclerosis.

participants consistently proposed that physical maintenance therapies were needed once weekly, or twice weekly for some younger service users. Several participants, concerned about the physical deterioration of the service users, specified that physical therapy goals should include: (i) the maintenance or improvement of standing and walking ability (three with ABI and one with MS); (ii) stretching muscles that were stiff or in spasm (three with MS); (iii) strength and fitness (one with ABI and one with SCI); and (iv) addressing balance and back pain (one with HD).

Ten participants identified that other health and rehabilitation services were needed, including occupational therapy (two with ABI, one with SCI), dental care (one each with HD, MS, SCI), speech pathology (two with ABI), on-site nursing (MS_07, MS_08), visiting podiatry (MS_07), psychology (SCI_03), surgery for a prolapsed bowel (SCI_01) and regional urology consultation (MS_07).

In response to questions about unmet need, participants identified barriers to accessing existing health and rehabilitation services, recapping on some issues alluded to previously. Several participants (e.g. ABI_02, MS_07, SCI_02, SCI_03, SCI_04) wanted visit-

ing therapy and other health services (e.g. podiatry) at affordable prices in a location they could easily access. Three other participants (ABI_03, MS_02, HD_03) cited the cost as the reason that they could not access some services. For SCI_03, travelling to a private physiotherapist for a 1-hour session could mean a 4-hour commitment, including time transferring into the car and driving, as well as the cost of fuel and parking. Two participants with MS (MS_01, MS_07) found that unqualified carers were not permitted to provide muscle stretching to relieve pain and stiffness or cut toenails because of occupational health and safety concerns.

Six participants identified that supportive counselling was needed at critical stages of adjustment to stressful life events or life-threatening conditions, including: (i) more information about the course of recovery following a traumatic brain injury and what to expect (ABI_06F); (ii) information about MS and how to cope with it as this may have enabled her family to 'handle it' rather than 'walk away' (MS_04F); (iii) advice on how to deal with the stress of having a husband with a fatal condition and four children living at home (MND_02F); (iv) assistance to

cope with many losses (i.e. physical, financial, family, work, relationship) (ABI_01F); (v) support when being first told the course of MND and his longevity (MND_01); and (vi) from discharge, individualised support and help to find resources (e.g. occupational therapist and psychologist) (SCI_03).

Discussion

Adequacy of health and rehabilitation services

In relation to the first aim, this study has found that although the participants were satisfied with many aspects of health and rehabilitation services received, there are some clear areas of unmet need. Based on the viewpoints of 65 participants, general medical practitioner (GP) and specialist medical services for users of lifetime care and support services are adequately provided in a timely way, although some medical and dental services were not readily available for people with SCI because of the high risk of an adverse event. Another Australian study found that people with MND and their caregivers concurred that full specialist medical care was received at the specialist clinic from which they were recruited (Ng *et al.* 2011). Overall, participants were also satisfied with the professionalism, advocacy and care demonstrated by health professionals. This finding is consistent with the findings in a study of patients with long-term neurological conditions in the United Kingdom in which most participants were satisfied with the professionalism and understanding of the health professionals they encountered (Peters *et al.* 2013). Noticeably, in our study, approximately a quarter ($n = 6$) were not satisfied with the style or adequacy of nursing they received in the community. These findings affirm the findings of one US study which found that among family caregivers, there were high levels of satisfaction with the medical services accessed by the person with MS, but a small majority (54.8%) were dissatisfied with home health nursing they received (Buchanan *et al.* 2010). Given that the lack of accessible nursing services could necessitate hospital admission, it is important that community-based nursing services are well integrated into models of care for people with long-term neurological conditions.

Although service users accessed a range of allied health services and equipment, ability to self-fund sometimes meant a more timely or adequate level of service, though not necessarily more satisfaction. The general sentiment was that the scope of services provided and funded by the government and disability organisations should be more responsive to needs.

The findings are consistent with views expressed in the two largest Australian states, Victoria and New South Wales, about the inadequacy of provision of aids, equipment or home modifications to patients not covered by compensation (New & Poulos 2008). These combined findings, from the three most populous Australian states, raise issues of equity and social justice for people with traumatic and degenerative conditions who do not have the capacity to pay or who are not eligible for compensation. Likewise, in a US study, only a fifth of informal caregivers were dissatisfied with the home health, rehabilitation services and mobility/assistive aids provided by health insurance for people with MS, while over 80% expressed dissatisfaction with home modifications (Buchanan *et al.* 2010). Taken together, these findings suggest that if care in the home is to remain a viable option for many family caregivers, there needs to be consideration of the subsidies and/or eligibility for the provision of costly aids, equipment and home modifications.

The perceived inadequacies in provision of and access to physical maintenance therapies, other allied health services and counselling services in this study to some extent are unsurprising. The findings are consistent with a UK survey of 211 people with complex neurological disability 6 months after discharge from hospital (Turner-Stokes *et al.* 2013). This UK study also found a significant shortage of rehabilitation, social care and equipment, although needs for medical/nursing care and accommodation were generally met. Another UK survey of people with rare neurological conditions (including HD and MND) found that although they received some rehabilitation, they had poorer access to health and social care services than they needed (Calvert *et al.* 2013). Moreover, previous research in Australia with people with SCI (Foster *et al.* 2005) found that people living in residential facilities often had no on-site medical practitioners and few or no allied health services. Moreover, services of health professionals (e.g. social work, medical, physiotherapy) were also needed in the home either for caregivers or the individual with SCI. In another Australian study, 14% of people with MND and 19% of caregivers perceived that the service users required increased therapy (physiotherapy, occupational therapy, social work or psychology) with the caregivers more likely to perceive that psychological supports were needed (Ng *et al.* 2011). Although these authors cautioned that caregivers have been found to overestimate the psychosocial impact of MND and MS, they concluded that multidisciplinary rehabilitation (such as the provision of assistive technology) was needed to improve quality of

life, reduce hospitalisation and improve the function of people with MND receiving care in the community (Ng *et al.* 2011). The Australian governments have been urged to adopt and fund a national rehabilitation strategy which better integrates rehabilitation with other sectors of health, including disability services (Australian Rehabilitation Alliance 2011). However, an integrated model of care, particularly under the NDIS, will be dependent on 'structural enablers' such as joint interdisciplinary planning processes and pooled funding models (Williams 2012) and more so, a consensus about what is considered *reasonable and necessary* in terms of the scope and level of publicly funded health and rehabilitation services.

Contribution to policy and service delivery developments

The second aim of this study was to contribute to policy and service development in the area of health and rehabilitation services for people with long-term neurological conditions. The findings of the current study resonate with the proposals of the Australian Rehabilitation Alliance (2011) and the UK National Service Framework for long-term conditions (DH 2005). These organisations strongly contend that rehabilitation is reasonable and necessary for people with long-term neurological conditions requiring lifetime care to sustain quality of life and maintain function and independence. Rehabilitation can prevent new and further functional loss and sustain optimal functioning and independence (Australian Rehabilitation Alliance 2011). Participants in this study appear to be at a double disadvantage in the current policy environment. First, they required ongoing or intermittent rehabilitation which is an underfunded resource, even for patients in acute care and primary care (New & Poulos 2008). Second, service delivery is based on models of rehabilitation which require demonstrated functional improvement to continue to receive a service and which overlook the prevention of further impairment and maintenance of quality of life.

Evidence to support the efficacy of rehabilitation for people with long-term neurological conditions requiring lifetime care is however equivocal. On the one hand, community-based rehabilitation can maintain physical function and health in clients with disability and frail clients (Patterson *et al.* 2010). Furthermore, the results of a randomised control trial of the effectiveness of physical rehabilitation for 3611 older people in long-term care (average age = 82 years) showed improvements in strength, flexibility and balance (Forster *et al.* 2010), suggesting

that physical rehabilitation can be effective for people with complex long-term care needs and diminished prospects of full recovery. On the other hand, a study of programmes for people with long-term neurological conditions failed to demonstrate improvements in function or on measures of health and well-being (Elsworth *et al.* 2011). These studies indicate that the outcomes of rehabilitation designed for people with long-term neurological conditions requiring lifetime care need to be carefully researched.

At a policy and service level, the counselling needs of individuals over the course of disability also warrant attention. Counselling for people with disabilities and their families can provide support and achieve emotional adjustment (Australian Rehabilitation Alliance 2011). One Canadian study (Dryden *et al.* 2004) and one Dutch study (van Loo *et al.* 2010) found that there was a need for increased psychosocial support to counter the higher rates of depression found in people with SCI. The prevalence of depression among people with MS (Buchanan *et al.* 2010) and traumatic brain injury (Tsaousides *et al.* 2013) has also been noted.

The introduction of Australian social insurance schemes in health, rehabilitation and disability services can lead to systemic change and provide funding to eligible people (Dyson & Canobi 2011). The UK National Service Framework for long-term conditions highlighted the need for adequate rehabilitation facilities, timely provision of equipment and well-integrated and coordinated health and social care services (Thomas *et al.* 2010). A review halfway into its 10-year introduction identified that community interdisciplinary rehabilitation teams for people with neurological conditions provided access to physiotherapy, occupational therapy, speech and language therapy and neuropsychology with as few as 16%–23% requiring ongoing services with intermittent reviews (Bernard *et al.* 2010). In Australia's case, while the NDIS represents an opportunity for substantial change, it will require structural mechanisms to support close integration between disability and health and rehabilitation services. Moreover, it will require clarity in policy as to the rights and entitlements of people with disability to access specific health and rehabilitation services.

Limitations

A number of issues may impact on the transferability of findings from the study to other contexts. Although people with long-term neurological conditions in the developed world may share many health and rehabilitation needs, the healthcare systems, policies on

service delivery and available services and resources may vary between countries and even between Australian states. The study aimed for a maximum variation sample; however, differing numbers of participants with each condition were recruited. Nevertheless, where the study is consistent with findings from other contexts, the similarities have been noted.

Conclusion

This study adds to the limited evidence based on the provision of health and rehabilitation services to people with long-term neurological conditions requiring lifetime care. The findings highlight the enduring challenges of achieving the appropriate mix of disability support and health and rehabilitation services for people with long-term neurological conditions. Importantly, the findings point to the need for a more discernible integrated care pathway to address the complex needs of this population and to overcome inadequacies in the current system.

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Declaration of interests statement

The authors declare that they have no competing interests.

References

- Agrawal N. & Mitchell A. (2005) The national service framework for long term neurological conditions. *British Medical Journal* **330**, 1280–1281.
- Australian Rehabilitation Alliance (2011) *The need for a national rehabilitation strategy: working towards a clear and united rehabilitation strategy for Australia*. [Draft Position Statement dated August 10, 2011]. Available at: <http://afmr.racp.edu.au/index.cfm?objectid=0F7AE593-9D8B-CDD1-A2096977C34069AA> (accessed on 17/2/2012).
- Bernard S., Aspinall F., Gridley K. *et al.* (2010) *Integrated Services for People with Long Term Neurological Conditions: Evaluation of the Impact of the National Service Framework*, Final Report, SPRU Working Paper No. SDO 2399. Social Policy Research Unit, University of York, York. Available at: <http://php.york.ac.uk/inst/spru/research/summs/ltnc.php> (accessed on 4/5/2013).
- Buchanan R., Radin D., Chakravorty B.J. *et al.* (2010) Perceptions of informal care givers: health and support services provided to people with multiple sclerosis. *Disability and Rehabilitation* **32**, 500–510.
- Calvert M., Pall H., Hoppitt T. *et al.* (2013) Health-related quality of life and supportive care in patients with rare long-term neurological conditions. *Quality of Life Research* **22**, 1231–1238.
- Cant R. (2010) Today's profession: views and practices of private practice dietitians re Medicare Chronic Disease Management. *Nutrition and Dietetics* **67**, 77–83.
- Commonwealth of Australia National Disability Insurance Scheme (2013) Available at: <http://www.ndis.gov.au/> (accessed on 27/6/2013).
- DH (2005) *The National Service Framework for Long Term Conditions*. Department of Health: London. Available at: <https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions> (accessed on 12/5/13).
- Dryden D.M., Saunders L.D., Rowe B.H. *et al.* (2004) Utilization of health services following spinal cord injury: a 6-year follow-up study. *Spinal Cord* **42**, 513–525.
- Dyson M. & Canobi S. (2011) A long term disability care and support scheme for Australia: opportunities for disability sector reform. *Asian Social Work and Policy Review* **5**, 138–144.
- Elsworth C., Winward C., Sackley C. *et al.* (2011) Supported community exercise in people with long term neurological conditions: a phase II randomized controlled trial. *Clinical Rehabilitation* **25**, 588–598.
- Forster A., Lambley R. & Young J.B. (2010) Is physical rehabilitation for older people in long term care effective? Findings from a systematic review. *Age and Ageing* **39**, 169–175.
- Foster M., Amsters D. & Carlson G. (2005) Spinal cord injury and family caregivers: a description of care and perception of service need. *Australian Journal of Primary Health* **11**, 91–101.
- Foster M., Fleming J. & Tilse C. (2007) Council of Australian Governments' (COAG) initiative for young people with disability in residential aged care: what are the issues for acquired brain injury? *Brain Impairment* **8**, 312–322.
- Foster M., Mitchell G., Haines T. *et al.* (2008) Does Enhanced Primary Care enhance primary care? Policy-induced dilemmas for allied health professionals. *Medical Journal of Australia* **188**, 29–32.
- Foster M., Henman P., Fleming J., Tilse C. & Harrington R. (2012) The politics of needs-based entitlement: perspectives on a proposal for a National Disability Long-term Care and Support Scheme in Australia. *Social Policy and Society* **11** (3), 331–343.
- Foster M., Henman P., Fleming J., Tilse C., Allen S. & Harrington R. (2012) ARC Linkage Lifetime Care Research Report: A study of financing and management of lifetime care and support for adults with acquired disability and high care needs in Queensland. School of Social Work and Human Services, The University of Queensland: Brisbane.
- Gridley K., Brooks J. & Glendinning C. (2014) Good practice in social care for disabled adults and older people with severe and complex needs: evidence from a scoping review. *Health and Social Care in the Community* **22** (3), 234–248.
- Haines T.P., Foster M.M., Cornwell P. *et al.* (2010) Impact of Enhanced Primary Care on equitable access to and economic efficiency of allied health services: a qualitative investigation. *Australian Health Review* **34**, 30–35.

- Hawkins M. (2013) DisabilityCare Australia making a difference. *Australian Journal of Occupational Therapy* **60**, 309.
- Henning-Smith C., McAlpine D., Shippee T. *et al.* (2013) Delayed and unmet need for medical care among publicly insured adults with disabilities. *Medical Care* **51**, 1015–1019.
- Hughes R.A., Sinha A., Higginson I. *et al.* (2005) Living with motor neurone disease: lives, experiences of services and suggestions for change. *Health and Social Care in the Community* **13**, 64–74.
- van Loo M.A., Post M.W.M., Bloemen J.H.A. *et al.* (2010) Care needs of persons with long term spinal cord injury living at home in the Netherlands. *Spinal Cord* **48**, 423–448.
- McDermott S., Moran R., Platt T. *et al.* (2007) Risk for onset of health conditions among community-living adults with spinal cord and traumatic brain injuries. *Primary Health Care Research and Development* **8**, 36–43.
- Middleton J.W., Dayton A., Walsh J. *et al.* (2012) Life expectancy after spinal cord injury: a 50-year study. *Spinal Cord* **50**, 803–811.
- National Disabilities and Carer Council (2009) *Shut Out: The Experiences of People with Disabilities and Their Families in Australia*. National People with Disabilities and Carer Council; Commonwealth Government, Canberra, ACT.
- National Disability Research and Development Agenda (2011) *Disability policy and research working group*. Available at: http://www.pda.org.au/uploads/documents_for_download/item_1_national_rd_agenda_web.pdf (accessed on 6/2/2013).
- New P.W. & Poulos C.J. (2008) Functional improvement of the Australian health care system – can rehabilitation assist? *Medical Journal of Australia* **189**, 340–343.
- Ng L., Talman P. & Khan F. (2011) Motor neurone disease: disability profile and service needs in an Australian cohort. *International Journal of Rehabilitation Research* **34** (2), 151–159.
- Okawa Y., Nakamura S., Kudo M. *et al.* (2009) An evidence-based construction of the models of decline of functioning. Part 1: two major models of decline of functioning. *International Journal of Rehabilitation Research* **32**, 189–192.
- Patterson S.A., Ross-Edwards B.M. & Gill H.L. (2010) Stroke maintenance exercise group: pilot study on daily functioning in long term stroke survivors. *Australian Journal of Primary Health* **16**, 93–97.
- Patton M.Q. (2002) *Qualitative Research and Evaluation Methods*, 3rd edn. Sage Publications, Thousand Oaks, CA.
- Peters M., Fitzpatrick R., Doll H. *et al.* (2013) Patients' experiences of health and social care in long term neurological conditions in England: a cross-sectional survey. *Journal of Health Services Research and Policy* **18**, 28–33.
- Pope C., Ziebland S. & Mays N. (2006) Analysing qualitative data. In: C. Pope & N. Mays (Eds) *Qualitative Research in Health Care*, 3rd edn, pp. 63–81. Blackwell Publishing Inc., Carlton, Victoria.
- Productivity Commission (2011) *Disability Care and Support: Draft Inquiry Report*. Productivity Commission, Canberra, ACT.
- Ritchie J. & Spencer L. (1994) Qualitative data analysis for applied policy research. In: A. Bryman & R.G. Burgess (Eds) *Analysing Qualitative Data*, pp. 173–194. Routledge, London.
- Ritchie J., Spencer L. & O'Connor W. (2003) Carrying out qualitative analysis. In: J. Ritchie & J. Lewis (Eds) *Qualitative Research Practice: A Guide for Social Scientists and Researchers*, pp. 219–262. Sage, London.
- Senate Community Affairs References Committee (2005) Community Affairs References Committee: Quality and equity in aged care. The Senate, Canberra.
- Senate Standing Committee on Community Affairs (2007) *Funding and Operation of the Commonwealth State Territory Disability Agreement*. Senate Printing Unit, Parliament House, Canberra, ACT.
- Simmonds F. & Stevermuer T. (2007) The AROC annual report: the state of rehabilitation in Australia 2005. *Australian Health Review* **31** (Suppl. 1), S31–S35.
- Snape D. & Spencer L. (2003) The foundations of qualitative research. In: J. Ritchie & J. Lewis (Eds) *Qualitative Research Practice: A Guide for Social Scientists and Researchers*, pp. 1–23. Sage, London.
- Ta'eed G., Skilbeck C. & Slatyer M. (2013) Which factors determine who is referred for community rehabilitation following traumatic brain injury? *Brain Impairment* **14**, 222–234.
- Thomas S., Davies A. & Peel C. (2010) A mid-term review of the NSF for long term neurological conditions. *British Journal of Neuroscience Nursing* **6**, 336–370.
- Tsaousides T., Ashman T.A. & Gordon W.A. (2013) Diagnosis and treatment of depression following traumatic brain injury. *Brain Impairment* **14** (1), 63–76.
- Turner-Stokes L., McCrone P., Jackson D.M. *et al.* (2013) The Needs and Provision Complexity Scale: a multicenter prospective cohort analysis of met and unmet needs and their cost implications for patients with complex neurological disability. *British Medical Journal Open* **3**, e002353.
- Williams P. (2012) Integration of health and social care: a case of learning and knowledge management. *Health and Social Care in the Community* **20** (5), 550–560.
- World Health Organization and The World Bank (2011) *World Report on Disability*. World Health Organization, Geneva. Available at: <http://www.who.int> (accessed on 4/2/2013).