

Are Supportive Services Meeting the Needs of Australians With Neurodegenerative Conditions and Their Families?

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Abstract / Objective: To identify the needs for supportive care/palliative care services of people in Australia with four neurodegenerative disorders—motor neurone disease, multiple sclerosis, Parkinson's disease, Huntington's disease—and the needs of their families; and to determine the extent to which existing supportive and palliative care services models meet these needs. **Design:** A mailed self-administered questionnaire to individuals with the four neurodegenerative diseases and their carers, in Western Australia, Victoria, and Queensland, using stratified proportional sampling from membership lists of the disease associations. **Participants:** A total of 503 patients and 373 carers responded, representing a response rate of 25.6% and 19.0%, respectively. Exclusion criteria included those who had been recently diagnosed, and those too sick or disabled to participate. **Results:** As patient dependency increased and more support was needed, both patients and carers exhibited higher distress symptoms and a poorer quality of life. Those who received more tailored services and more palliative care services were the most satisfied. The results highlighted the need for tailored and flexible models of care for these groups with unique care requirements. **Conclusions:** This is the first empirical evidence of the needs and services used by these patient groups in Australia, and will form the basis for future developments of palliative and supportive care services for people with these four neurological conditions.

Résumé / Objectifs : Identifier les besoins, en soins palliatifs et en services de soutien, des personnes atteintes de quatre types d'affections de nature neurodégénérative—trouble du neurone moteur, sclérose en plaque, maladie de Huntington et maladie de Parkinson—de même que les besoins de leur famille. Déterminer dans quelle mesure ces modèles de soins et de soutien répondent aux besoins de ces personnes. **Méthodologie :** Nous avons posté un auto-questionnaire aux personnes atteintes de l'une de ces affections et à leur soignant. Ces personnes qui habitaient les régions de l'Australie-Occidentale, de Victoria et de Queensland, ont été choisies à partir des listes de membres de ces quatre associations selon un échantillonnage proportionnel stratifié. **Participants :** Un total de 503 patients

et 373 soignants ont retourné le questionnaire, ce qui représente un taux de participation de 25.6 % et 19.0 %. Étaient exclues les personnes dont le diagnostic était très récent et celles qui étaient trop malades ou trop handicapées. **Résultats:** Au fur et à mesure que l'état de dépendance des patients augmentait, et par le fait même leurs besoins de services de soutien, on dénotait alors, tant chez les patients que chez les soignants un plus haut niveau de symptômes de détresse et une diminution de la qualité de vie. Par ailleurs ceux qui bénéficiaient de services de soutien adaptés à leur état et de soins palliatifs appropriés étaient ceux qui étaient les plus satisfaits. Les résultats soulignent la nécessité de créer des modèles de soins plus flexibles et mieux adaptés aux besoins particuliers de ces groupes de patients. **Conclusions :** C'est la première étude empirique à mettre en évidence les besoins et les services particuliers de ces groupes en Australie, elle servira de base pour développer les futurs services de soutien et de soins palliatifs pour les patients atteints de ces maladies.

INTRODUCTION

People living with neurodegenerative conditions, such as motor neurone disease (MND), multiple sclerosis (MS), Parkinson's disease (PD), and Huntington's disease (HD) face many long-term challenges because these diseases are progressive, with no known cure, and the lifespan is limited and with long periods of dependency (1). Service provision for people with neurodegenerative diseases involves many agencies and departments across acute, community, and social services. These include home care, acute care, rehabilitation, respite, and residential and palliative or supportive care. However, services are often seen to be fragmented, communication is poor, goals are often not shared, early symptoms are not effectively detected, and there is an unacceptable delay in gaining access to services (2-4).

Currently, few palliative care services provide care to populations others than those with cancer, and only a small percentage provide care to patients with neurological conditions, heart failure, end-stage respiratory diseases, stroke, or other chronic diseases (5). It is reported that much of what has been learned about palliative care for people with cancer is applicable to those with other diseases. Although some aspects of symptom management may be slightly different, the expertise in developing models of care, working as a team, allowing patients to determine the care agenda, supporting carers, dealing with the psychosocial implications, managing the dying process, and caring for the bereaved are likely to apply (6-10). Some clinicians have recommended that involvement in palliative care services should occur early, anticipating a person's needs well in advance of deterioration, and assisting with later stage symptoms and psychosocial issues (11).

Yet, when faced with the expansion of palliative care into nonmalignant disease, the palliative care movement seems cautious, perhaps daunted by the notion of providing care to a wider range of patients (12). As a consequence, many families of individuals with these diseases may not be usual recipients of palliative care services. Evidence is emerging that the supportive care needs of these people and their carers are extensive and may be linked to negative changes in quality of life (13-16). However, little is known about these supportive care needs, particularly from the point of view of the people with these diseases and their carers (17-19). The objectives of this study were, therefore, to:

- identify the needs for supportive care/palliative care services of people in Australia with MND, MS, HD, and PD, and the needs of their families; and
- determine the extent to which existing models of supportive care/palliative care services meet the needs of patients and their families.

METHODS

A self-administered questionnaire was posted to 1,962 individuals with the four neurodegenerative diseases (referred to as patients) and 1,962 carers in Western Australia, Victoria, and Queensland. Surveys were distributed through the four associations for motor neurone disease, multiple sclerosis, and Parkinson's and Huntington's diseases in the three states. No names or addresses were provided to the research team. A stratified proportional sampling method was used and the number of people

to receive the survey from each association in each state was set at 200. The associations were asked to exclude any person or family who had recently been diagnosed, or those too sick or disabled to participate.

Data collection was designed to allow participants to complete the survey within 30 minutes. Patients and carers completed a demographic questionnaire, questions about service use support needs, and a quality of life index (20). Patients then completed the Symptom Assessment Scale (SAS) (21) to measure symptom distress, the Hospital Anxiety and Depression Scale (HADS) (22) to screen for anxiety and depression, and the Patient Satisfaction with Care questionnaire (23). Carers completed the General Health Questionnaire (GHQ) to screen for psychiatric disorders (24), and FAMCARE scale which measures family satisfaction with care (25). The protocol was pilot-tested with 87 patients and carers. Respondents were asked to rate the questionnaire for content validity; an assessment of the internal consistency of the questionnaires included in the protocol was performed. Internal consistency reliability was estimated using Cronbach's alpha coefficient, with all estimates exceeding 0.70, the recommended criterion for acceptable reliability (26): amount of assistance needed (patients 0.96, carers 0.97); importance of services (patients 0.80, carers 0.97); SAS (0.80); HADS (0.83-0.86); patient satisfaction with services (0.88); GHQ (0.76-0.91); FAMCARE (0.71-0.91).

The statistical package SPSS 11.5 was used for data analysis, and included use of descriptive statistics to summarize the sample according to demographic characteristics, financial impact of the disease, living and caring arrangements, disability profile, health status support needs, service use, and satisfaction with services. Content analysis was used to group responses to open-ended questions into common themes. Cluster analysis was undertaken to identify groups within the patient and carer populations that shared similar characteristics.

RESULTS

Demographic Characteristics

A total of 503 patients and 373 carers responded, representing a response rate of 25.6% and 19.0% respectively (Table 1). The majority of respondents lived in metropolitan areas (70%). The PD respondents were more represented than the other three groups (34% of patient

38% of carers) and the HD respondents were the least represented (10% of patients, 15% of carers). Two-thirds of carers were female, half of the patients were male, and the mean age of carers and patients was about 60 years. Less than a quarter of respondents were still in paid employment, and 60% relied on social security for their living. More than two-thirds of patients

and carers reported making adjustments to their living environment as a consequence of the disease and 34% of patients and 44% of carers had to self-fund these adjustments (Table 1).

Support Needs

The amount of assistance needed with activities was ranked from 1 (no help needed) to 4 (help

Table 1 / FREQUENCY AND PERCENT DISTRIBUTION OF DEMOGRAPHIC CHARACTERISTICS OF PATIENTS AND CARERS, FINANCIAL IMPACT OF DISEASE, AND CARING AND LIVING ARRANGEMENTS (absolute numbers in parentheses)

	Information from patients' surveys	Information from carers' surveys
Total number of respondents	503	373
response rate	25.6% (total=1,962)	19.0% (total=1,962)
MND respondents in study	24% (119)	28% (105)
MS respondents in study	32% (162)	19% (71)
PD respondents in study	34% (174)	38% (141)
HD respondents in study	10% (48)	15% (56)
State of residence		
Western Australia	32.4% (159)	29.2% (107)
Victoria	37.3% (183)	39.9% (146)
Queensland	29.9% (147)	30.1% (110)
metropolitan area	70% (345)	68.3% (250)
rural area	30% (148)	31.7% (116)
Gender and age		
male	50.7% (255)	33.9% (126)
female	49.3% (248)	66.1% (246)
mean age of patient (yrs)	60.8 (SD=14.06)	63.0 (SD=13.60)
mean age of carer (yrs)	60.2 (SD=13.26)	61.0 (SD=13.34)
Current source of income (multiple responses)		
paid employment	15% (73)	23% (83)
social security	60% (296)	60% (218)
superannuation payments	21% (102)	18% (66)
investments/insurance	6% (29)	15% (57)
other	2% (8)	2% (8)
Impact of disease on work/employment		
gave up job/retired early	36.4% (177)	22.7% (82)
reduced hours at work	8.6% (42)	10.2% (37)
no change in hours at work	6.0% (29)	11.6% (42)
already retired	37.4% (182)	44.3% (160)
other	11.5% (56)	11.1% (40)
carer gave up work to care	28.1% (70)	-
Living arrangements		
patient has a carer	72.5% (359)	-
patient lives alone	15.2% (75)	4.8% (18)
patient lives with family	76.3% (384)	-
carer lives with patient	-	85.3% (318)
patient lives in residential care/nursing home	7.7% (39)	9.7% (36)
patient has other living arrangement	0.8% (4)	0.2% (1)
Relationship to patient		
carer is husband/male partner	51.4% (188)	30.6% (114)
carer is wife/female partner	33.1% (121)	51.7% (193)
carer is other family member	13.7% (50)	14.7% (55)
carer is not family related	1.9% (7)	2.9% (11)
Adjustments to living environment (multiple responses)		
moved to better suited home	38.6% (34)	21.1% (74)
moved closer to services	3.4% (3)	3.7% (13)
made renovations	17.0% (15)	38.3% (134)
moved to residential care	6.8% (6)	8.9% (31)
no changes made	34.1% (30)	28% (98)
Source of funding for adjustments (multiple responses)		
self-funded	34.4% (165)	43.5% (153)
Health Department	12.3% (59)	17% (60)
Veterans' Affairs	2.7% (13)	3.7% (13)
other (Department of Housing, Housing Commission, local council, friends & family)	10.2% (49)	10% (35)

needed all of the time). The tasks that patients needed most assistance with (mean 2.3, SD 1.3–mean 2.7, SD 1.3) and carers were frequently providing (mean 3.0, SD 1.2–mean 3.3, SD 1.0) are listed in Table 2.

The patients did not indicate high-needs levels of dependence with personal tasks. Rather, their need for assistance focused on accessing community activities and other administrative tasks. The services most frequently received by patients, confirmed by carer report, were community rehabilitation, home care, and respite.

When asked to rate from 1 to 4 (1=not important, 4 =very important) the importance of support services to help them manage, four were rated highly by both carers (mean 3.0, SD 1.1–mean 3.3, SD 1.0) and patients (mean 2.6, SD 1.2–mean 3.3, SD 0.9) (Table 2).

Satisfaction With Care

On a scale of 1 to 5 (1=very dissatisfied, 5=very satisfied), patients were generally satisfied (mean 3.9, SD 0.9) with the following aspects of services: privacy during health care provision;

Table 2 / PERCENT DISTRIBUTION OF PATIENTS AND CARERS ACCORDING TO MOST HIGHLY RANKED NEEDS FOR ASSISTANCE AND IMPORTANCE OF SERVICES

	Patients	Carers
Assistance with services (% most of the time to all of the time)		
transport for appointments/shopping	56	79
housekeeping	54	77
finances/bills/accounts	44	69
attending social activities or support groups	45	60
Importance of services (% very important to important)		
information about disease	81	87
equipment for daily living	61	80
reliable and ongoing dependable support workers	59	73
financial assistance for care	57	72

being involved in decision making about their care; prior information received about care and support services; availability of healthcare workers; and the way their condition and progress were explained to them. Approximately half the patients were less satisfied with the opportunity to address their social and spiritual concerns.

The FAMCARE Scale, with values from 1 to 5 (1=very dissatisfied, 5=very satisfied), was used to assess carers satisfaction with care. Carers were least satisfied with psychosocial care, availability of respite, family conferences held to discuss the condition, and information given about managing pain. Those most satisfied were carers of patients with MND and PD.

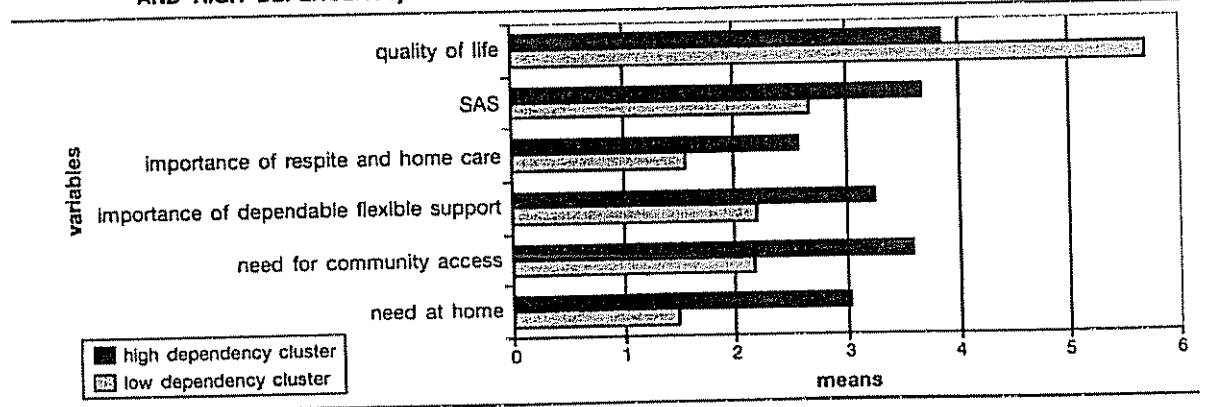
Quality of Life and Health Status

Patients and carers rated their quality of life as average (mean 5.6, SD 2.2) on a scale ranging from 0=poor to 10=excellent. MND and HD patients reported the lowest quality of life, with ratings below average. Among carers, those of MND patients reported the lowest quality of life. The symptom that caused most distress was "fatigue and tiredness", and about a quarter of patients rated a number of symptoms towards the severe end of the SAS. In particular, the HD group reported problems with concentration, communication, swallowing, and depression. A quarter of patients indicated moderate to severe anxiety and depression on the HADS scale, with the HD group exhibiting higher rates than the other groups. A quarter of carers reported having recently experienced somatic symptoms, anxiety and insomnia, and social dysfunction "rather more than usual or much more than usual".

Cluster Models

Cluster analysis was used to identify group within the patient and carer populations that share similar characteristics. The analysis re

Figure 1 / COMPARISON OF MEANS OF SIGNIFICANT VARIABLES OF TWO PATIENT CLUSTERS (LOW DEPENDENCY AND HIGH DEPENDENCY)



In general, carers who responded to the survey were looking after care recipients who were slightly more disabled or needing more support than patients who personally responded to the survey. Twelve percent of patients participating in the survey reported having no carer, raising implications for service provision for those living alone as the disease progresses.

The exclusion from the mail-out of people who were too sick or disabled to participate explained the under-representation of a third group, which consisted of those in the late stage of the diseases who may have been coping more with end-of-life care issues than were those included in the sample. This third group would be expected to have had much greater need of physical care and home assistance. Therefore, the assessment of palliative and supportive needs of these populations from this study's results is likely conservative.

Nevertheless, it appears that, as dependency increased and more support was needed, both patients and carers exhibited higher distress symptoms and a poorer quality of life. Moreover, the respondents had yet to confront end-of-life issues because most were still at the early stages of their disease experience. The frequency of use of palliative care services was quite low, possibly because of the early stage of the diseases, the patients' being unready to accept these services, or a lack of access to these services.

The MND group reported receiving at least twice as many palliative care services as the other groups (18% vs. an average of 7%). Carers who were most satisfied were those in the MND group and in the PD group. This could be because these carers were supported by more tailored services, (i.e., a PD specialist nurse and a special MND program were often mentioned) and received more palliative care services. Also, patients and carers in these groups may have been more accepting of a palliative care approach.

The trajectories of function and well-being over time are not the same for all fatal chronic illnesses (27). Of the three trajectories described by Lynn (27), the neurological disorders considered within this study might follow a pattern similar to that of individuals with organ system failure, where those affected may be ill for many months or even years, with occasional exacerbations, each exacerbation triggering fears of death. In contrast, the illness trajectory for individuals with a terminal cancer (the usual patient group served by palliative care) continues for a relatively long period of time with active treatment, then suddenly slopes toward death with a relatively brief palliative care phase.

An understanding of the differences between the illness trajectories is helpful in constructing service delivery models that may be more appropriate to different populations. The model of care for individuals with progressive, neurological conditions may be one that combines active rehabilitative approaches with supportive palliative services. As the illness progresses, greater emphasis must be placed on palliative care approaches that incorporate and enhanced family support.

CONCLUSIONS

Due to challenges of access to these study populations, the results are limited by the relatively low response rate and the under-representation of individuals with more severe stages of illness. Future studies would benefit from including more people with more advanced disease in order to assess the need for palliative care services. Also, functional and disability levels of patients should be assessed more objectively.

Notwithstanding these limitations, no previous study of this scale (including the first phase of the study which was qualitative) has been undertaken in Australia, with a rural/urban mix of more than 800 participants spread over three states, including patients, carers, and service providers of four neurodegenerative disorders. This study has provided the first empirical evidence of the needs and service use of these special groups, and will form the basis for future development of palliative and supportive care services for people with these four neurological conditions. The study also laid the foundation for subsequent evaluation of service provision for these populations. The results underscore the need for tailored and flexible models of care for these groups, taking into consideration their unique illness trajectories and the long-term and notable demands on carers. Lack of information about services, patient dependency, and care fatigue may delay access to appropriate supportive and palliative care services. Therefore, clinicians working with these patients and their carers need to be alert to the supportive and palliative care needs of these groups to ensure their specific needs are assessed and addressed.

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To: Allison Taylor
Subject: Re: ISSN - Urgent request!
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Sincerely,

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From: Allison Taylor <A.Taylor@exchange.curtin.edu.au>
Date: Thu, 22 Mar 2007 12:23:48 +0900
To: <marcotc@ircm.qc.ca>
Conversation: ISSN - Urgent request!
Subject: ISSN - Urgent request!

Hello

I am preparing a report for our University and urgently need your ISSN - would really appreciate your response.

Many thanks

Allison

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