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COVER PAGE

**Caring for People with a Mental Disability at Home: Australian Carers'
Perceptions of Service Provision**

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Caring for People with a Mental Disability at Home: Australian Carers' Perceptions of Service Provision

Abstract

This study investigates carer perceptions of the adequacy of assistance received by comparing two populations: those with a mental disability and those with a physical disability in Australia by using data representing 12.5% of the total population. This very large sample provides robust evidence for the study's findings. Of those caring for individuals with severe core disabilities, 21.6% of those with a mental disability compared to only 8.3% of carers of those with a physical disability reported inadequate service assistance. Greater involvement of consumers and their families in health care service planning will provide opportunities to deliver more appropriate services and enhance equities within this sector.

Introduction

In 1992, Australia extended the deinstitutionalisation process by moving the focus of care of people with a mental disability¹ from hospitals to the community. The following year, the Burdekin Report (Human Rights Commissioner's Report) and later in 2000 the Carers of People with Mental Illness Project (MHCA, 2000) drew attention to resource inadequacies for people with a mental disability in the wider community. Lamb and Bachrach concluded in 2001 that deinstitutionalisation has failed to realise its potential benefits because of the difficulty people with a mental disability have faced in accessing appropriate community resources (Lamb & Bachrach, 2001). More recently, the Palmer Inquiry (2005) into immigration, detention and mental health services, announced a crisis exists in Australia in the provision of care for people with a mental disability.

Today, the perception among service users and providers is that the health care system continues to remain limited in its effectiveness and accessibility to non-institutionalised people with a mental disability (Groom, Hickie, & Devenport, 2003). Informal carers, 'on the ground' formal service providers and other stakeholders have expressed dissatisfaction in the current support arrangements for carers (MHCA, 2000).

¹ Several terms used in the paper are clarified in text box 1.

National trends from project findings suggest that services from a range of Government funded programs (Home and Community Care Program (HACC), the Commonwealth/State Disability Agreement (CSDA), the Supported Accommodation Assistance Program (SAAP), and the Commonwealth National Respite for Carers Program) have excluded individuals with a mental disability and their carers. These service barriers are created through eligibility criteria and they exist within a background of complex and diverse needs that are not adequately understood by many community support agencies (Groom et al., 2003; MHCA, 2000). This exposes people with a mental disability to a range of risks, and threatens the effectiveness of in-home care.

A mental disability significantly interferes with a person's thinking and ability to socially integrate. This emotional state limits the individual's ability to achieve goals, cope with the normal stresses of life and work productively (MHCA, 2000). The Mental Health Council of Australia (2004) estimates that 3-4% of Australians experience severe mental disorders that substantially reduce their capacity to participate fully in community life. Mental disability is the fifth most expensive disease group (8.2% of total health expenditure) (AIHW, 2005).

The Australian government's emphasis on home-based care in recent years has led to informal care (i.e. unpaid care and support) by family and friends becoming an increasingly important source of support (Beilharz, Considine, & Watts, 1992; Courtney, Minichiello, & Waite, 1997; Kendig, McVicar, & Reynolds, 1992; Queensland Health, 2004; Victorian Parliament, 1997). Indeed, the majority of care is provided by informal carers (MCHA, 2004; Williams & Doessel, 2001). Although planning for services in the home care setting requires an understanding of carer availability, social and community support, little is known about informal carers, particularly those that care for people with a mental disability (Lefley, 1996; Williams & Doessel, 2001). An understanding of the role of informal carers will better assist health organisations and policy makers in implementing strategies that work in partnership with family and friends to improve the wellbeing of care recipients and their carers.

The duties of these informal carers often involve behavioural management issues and liaising with the legal and criminal justice systems as well as assisting with the activities of daily

living (Williams & Doessel, 2001) Studies have shown that caring for a relative with a mental disability is burdensome and stressful (Donaldson & Burns, 1999; Holmes & Deb, 1998; Laidlaw, Falloon, Barnfather, & Coverdale, 1999; Williams & Doessel, 2001). This may explain the sublevels of effective and consistent care faced by those suffering from chronic mental disability (Blecher, 1993; Holmes & Deb, 1998). Such inadequacies in care places people with chronic mental disability at risk of homelessness and criminalisation and this in turn impacts upon the community.

Given that inadequate care impacts on the community as well as the individual, an understanding of the care resources within the community setting is imperative in the development of effective health strategies and programmes that arise in an environment of deinstitutionalisation.

Several studies have documented a positive relationship between informal care and perceptions of unmet need by professionals (Holmes & Deb, 1998; Shaw & Dorling, 2004; Weiss, Gonzalez, Kabeto, & Langa, 2005). Broe (2002) found disability predominantly predicted unpaid support and community service use.

In this paper, we examine carers' perceptions of the assistance they receive from health services. Comparisons are drawn between the assistance to carers of people from two populations – those suffering a mental disability and those with a physical disability. Based on the data collected from the Australian Survey of Disability, Ageing and Carers (ABS, 2003), the investigation involves non-institutionalised main recipients of care, aged 15 years and over with either a profound or severe disability, and their primary carers. Since individuals with profound and severe disabilities are the most likely candidates for institutionalisation an understanding of the carers of this group will provide a better understanding of the success of the deinstitutionalisation process from the point of view of individuals and their families. Perhaps more importantly, however, such a comparison would provide a basis for negotiation with policy makers when prioritising the allocation of health care resources.

Methods

This study is based on the analysis of data for approximately 12.5% of the Australian population obtained through the Survey of Disability, Ageing and Carers (SDAC), 2003. This survey, conducted throughout Australia in the months of June to November 2003, covered people in both urban and rural areas in all states and territories. Trained interviewers collected the household component of the data survey. Where possible, a personal interview was conducted with people identified as either disabled, aged 60 years and over, and those providing care to people with disabilities or the aged (ABS, 2003).

The study population was confined to the main recipients of care and their primary carers. This ensured that carers with disabilities were not included in both populations. For weighting purposes, the 2003 SDAC was benchmarked to the estimated population at 30 June 2003, based on results from the 2001 Census of Population and Housing. The ABS applied the weightings data collected from the household sample of 36088 persons to estimate the total population with the selected characteristics. These figures are treated as population figures.

For comparison, care recipients and their primary carers were split into two populations, mental disabilities (N=38999) and physical disabilities (N=235991). Consistent with the summary findings reported by the ABS (2003), the mental and physical categories were derived from the main disabling condition variable (ABS, 2003).

The research was approved by the Griffith University Ethics Committee. The authors of this paper have no known conflicts of interest and all certify responsibility for its content.

Results

The aim of this study is to investigate and compare the perception of the adequacy of assistance received by carers of two groups, those with a mental disability and those with a physical disability. The statistics are presented for the weighted population.

Non-institutionalised Care Recipients

Comparison of the care recipient populations, mental and physical, is presented in Table 1. Of those reporting mental disability as the main disabling condition, males outnumber

females (1:0.88). Compared to the physical disability group (42.6%), a greater proportion of the mental disability group (71.4%) are aged between 15 and 65 years.

INSERT TABLE ONE HERE

A fall back carer is a person identified by the primary carer as taking responsibility for care should the primary carer become unavailable (ABS, 2003). A fall back carer is not a formal provider. Fewer of those with a physical disability reported the existence of a fallback carer compared to those with a mental disability: 34.7% of people with a mental disability reported a fall-back carer residing in the same household compared to only 13.3% of other care recipients. The greater proportion of parents caring for people with a mental disability, 38.3% compared with 7.3% for people with a physical disability, partly explains the difference (refer Table 2).

Primary Informal Care Givers

Primary informal carers of people with disabilities are typically younger than 65 years of age, female and receive a government pension. The analysis supports previous studies (Holmes & Deb, 1998; Winefield & Harvey, 1994) that those with a mental disability are more likely to be cared by parents. Those with a physical disability tend to be cared by a spouse or partner.

INSERT TABLE TWO HERE

Table 2 documents greater burdens among carers of people with a mental disability. For instance, of this group, 29.5% (receives assistance and needs further assistance, 19.1% and does not receive assistance and needs assistance, 10.4%) reported inadequate assistance in their role as carer. This compares to 17.4% of other primary carers. Also a greater proportion of carers of people with a mental disability reported a change in their physical and emotional well-being due to their caring role (36.5%) compared to other primary carers (26.1%).

Inadequate Assistance

There is consensus within the literature that disability type and disability status impacts on the level of care provided to individuals. Table 3 presents carers' perceptions of assistance by disability type and disability status. Disability status consists of those restricted in their core activities, either profound or severe. Across the disability type and status categories, again a greater proportion of carers of those with a mental disability reported inadequate or unmet assistance compared to carers of those with a physical disability. Specifically, within the profound category, 33.6% of carers of those with a mental disability reported inadequate assistance, compared to 23.5% of carers of those with a physical disability. The gap widens for carers of people with severe disability status: 21.6% of carers of people with mental disabilities report unmet assistance compared to 8.3% of other carers.

INSERT TABLE THREE HERE

Clearly there are differences between the needs of recipients of different age groups, with young people in particular having very different care needs from people who are older.. The data presented in Table 3 is segregated by age (refer Table 4) to explore this issue further. Among the older age cohorts of people with a mental disability, a greater proportion of their carers report inadequate assistance compared to the carers of people with physical disabilities. This is most pronounced within the profound disability group where reports of inadequate assistance are concentrated among the highest age groups.

INSERT TABLE FOUR HERE

Discussion

The Carers of People with Mental Illness project (MHCA, 2000) and later the Out of Hospital, Out of Mind project (Groom et al., 2003) drew attention to resource inadequacies for people with a mental disability living within the community. This study investigated and compared the perception of assistance received by carers of those with either a mental or physical disability. A case exists for the implementation of strategies that work in partnership with family and friends to improve the circumstances of those with a mental disability and their carers.

Carers of people with a mental disability were more likely to report the existence of a fall back carer residing in the same household but 29.5% of them still felt that they received inadequate assistance in their caring role, compared to other primary carers (17.4%). Although informal care assistance may have been adequate, as suggested by the availability of a live-in fall back carer, formal services were not. This is supported by reports that 21% of care recipients with a mental disability received inadequate respite care, a major formal service, compared to 13% of other care recipients(ABS, 2003).

The Mental Health Council of Australia (2000) asserts that if formal service delivery for consumers operated at the levels expected within the National Standards for Mental Health Services (Commonwealth of Australia, 1997) little difference should exist in the resources available to people who are mentally or physically ill. This study has measured equity in terms of perceived need rather than finite resources and concludes that an inequitable distribution of resources exist, with primary carers of people with a mental disability experiencing greater burdens in care. We offer two possible explanations for the reported differences in the level of assistance received: 1. People with a physical disability have greater access to formal services; 2. Access to formal services between the two disability groups is similar, but the families of people with a mental disability require either a greater amount of resources or different types of resources. Both explanations may be relevant. It seems evident that greater or different demands may be experienced by informal carers of people with mental health issues and it may no longer be appropriate to consider carers' needs between the two groups as homogenous.

The veracity of this reasoning cannot,, however, be identified here and this is a limitation of the study. Data limitations precluded an investigation of the extent of unmet need for assistance. This study was confined to care recipients aged 15 years and older with a profound or severe disability and their primary carers. Investigations of people experiencing moderate to mild disabilities provide further research opportunities. An understanding of the reasons for the perception of inadequate assistance is important for both policy makers and service providers.. It points to the need to involve consumers of services much more closely in resource identification and planning at a local level as well as further research to establish national/international data.

Reports of inadequate assistance were concentrated among carers of older people with profound mental disabilities. This finding also has serious policy implications. In common with other countries with ageing populations, dementia in Australia is the greatest contributor to the burden of disease due to disability and the greatest single contributor to the cost of care in residential aged care ((AIHW, 2006). In 2003, the incidence of either dementia or Alzheimer's as a main disabling condition among those cared for in private dwellings rose from 2% among those aged 65-69 years to a staggering 31.3%² among those aged 85 and over (ABS, 2003). In contrast, among the same cohort the most common main disabling physical conditions included arthritis, injuries/accidents and breathing problems (23.9%, 23.7% and 13% respectively) (ABS, 2003). Given the rising levels of dementia and Alzheimer's that are a factor of ageing populations, it is reasonable to expect that, all else held constant, the burden experienced by carers of older people with profound mental disabilities will worsen. While the deinstitutionalisation process and the ageing of Australia's population have increased the demand for informal carers, demographic changes such as declining fertility rates, increasing employment participation among women and greater proportions of older people living alone (ABS 2006a) will continue to place greater pressure on a shrinking pool of informal carers.

Policy makers must take a proactive and consumer involved approach to ensure that health resources and support services are channelled towards groups that reflect population trends and actual needs.

² The reported incidence of dementia and Alzheimer's among those 85 and over was 16.4% and 14.9% respectively (ABS, 2003b).

References

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Text Box 1**Definitions**

Several terms used in this paper are clarified below.

Mental disability: Disabling conditions include psychoses and mood affective disorders, neurotic, stress-related and somatoform disorders and intellectual and development disorders.

Severe Disability: A care recipient possesses a severe disability when sometimes they need help with a core-activity task, has difficulty understanding or being understood by family or friends, can communicate more easily using sign language or non-spoken forms of communication (ABS, 2003)

Primary Carer: A primary carer, aged 15 or over, provides the most informal assistance to the care recipient. The assistance is ongoing for at least six months and includes communication, mobility and self care (ABS, 2003)

Care Recipient: A non-institutionalised person with a profound or severe disability.

Disability: A person has a disability if they possess a limitation, restriction or impairment, that lasts at least 6 months and are restricted in everyday activities (ABS, 2003)

Profound Disability: A care recipient possesses a profound disability when they are unable to do or always need help with a core activity task in communication, mobility and self-care (ABS, 2003)

Table 1. Characteristics of Non-institutionalised Main Recipients of Care with Profound and Severe Disabilities, Aged 15 and Over, Australia, 2003

Recipient of Care		Mentally Disabled N=38999 %	Physically Disabled N=235991 %
Gender	Male female	53.3 46.7	46.5 53.5
Age	15 - 65 years 65+ years	71.4 28.6	42.6 57.4
Main source of income	Government pension/allowance	75.6	78.9
Whether fall back informal carer lives with main recipient	Yes No No carer/unknown	34.7 18.7 46.6	13.3 35.4 51.3
Disability status	Profoundly restricted Severely restricted	65.8 34.2	59.8 40.2

Source: Survey of Disability, Ageing And Carers (Australian Bureau of Statistics 2003).

Table 2: Characteristics of the Primary Care Givers of Non-institutionalised People Aged 15 and Over with Profound and Severe Disabilities, Australia, 2003

Primary Carer Profile		Mentally disabled (N=38997) %	Physically disabled (N=235990) %
Gender	Male	27.3	37.3
	Female	72.7	62.7
Age	15-64 years	78.4	62.8
	65 years and over	21.6	37.2
Main source of cash income	Government pension/allowance	59.2	64.4
Relationship to recipient	Spouse/partner	35.7	66
	Parent	38.3	7.3
	Offspring	14.1	20.7
	Friend/neighbour/other relative	11.9	6
Physical/emotional well-being has changed due to caring role	Yes	36.5	26.1
	No	55.6	67
	Not stated	7.8	6.8
Need and receipt of assistance to care for main recipient	Receives assistance and does not need further assistance	32	27.7
	Receives assistance and needs further assistance	19.1	9.7
	Does not receive assistance and needs assistance	10.4	7.7
	Does not receive assistance and does not need assistance	38.5	54.9

Source: Survey of Disability, Ageing And Carers (Australian Bureau of Statistics 2003)

Table 3: Primary carer perceived adequacy of assistance by disability status and type, Australia, 2003

Disability status	Disability type	Perceived adequacy of assistance	% of persons
Profound	Mental	Inadequate	33.6
		Adequate	66.4
Profound	Physical	Inadequate	23.5
		Adequate	76.5
Severe	Mental	Inadequate	21.6
		Adequate	78.4
Severe	Physical	Inadequate	8.3
		Adequate	91.7

Source: Survey of Disability, Ageing And Carers (Australian Bureau of Statistics 2003)

Table 4: Primary carer perceived adequacy of assistance by disability status, disability type and age of main recipient of care, Australia, 2003

Severe Disability		Perceived adequacy of assistance			
		Adequate (N=222417)		Inadequate (N=52570)	
Age	Disability Type	% Row	N	% Row	N
15-24 years	physical	100.0%	2722	0%	0
	mental	84.6%	4336	15.4%	790
25-34 years	physical	56.3%	1845	43.7%	1430
	mental	51.7%	1096	48.3%	1023
35-44 years	physical	100.0%	10780	.	.
	mental	100.0%	824	.	.
45-54 years	physical	84.5%	12242	15.5%	2243
	mental	49.7%	647	50.3%	654
55-64 years	physical	94.9%	23959	5.1%	1294
	mental	100.0%	1809	0%	0
65-74 years	physical	92.9%	20755	7.1%	1579
	mental	0%	0	100.0%	422
75 + years	physical	91.6%	14630	8.4%	1343
	mental	100.0%	1739	0%	0
Profound Disability					
15-24 years	physical	67.6%	3543	32.4%	1701
	mental	78.9%	5604	21.1%	1498
25-34 years	physical	79.8%	2936	20.2%	745
	mental	59.9%	1565	40.1%	1047
35-44 years	physical	69.2%	4213	30.8%	1876
	mental	100.0%	1215	0%	0
45-54 years	physical	83.9%	10567	16.1%	2031
	mental	82.1%	2508	17.9%	545
55-64 years	physical	84.2%	13989	15.8%	2628
	mental	76.1%	2036	23.9%	638
65-74 years	physical	87.5%	24745	12.5%	3529
	mental	41.2%	1714	58.8%	2451
75 + years	physical	69.9%	48011	30.1%	20652
	mental	49.3%	2385	50.7%	2451

Dear Sir/madam

Please thank the reviewers for their helpful suggestions which we believe have increased the quality of our manuscript. All the revisions recommended by the reviewers have been addressed and are listed below.

Reviewer #2:

1. *The Definition Section:* As suggested a text box that includes the definitions has been inserted on page 11 of the manuscript.

2. *The Analysis:* *The authors have chosen to use only percentages to illustrate the differences between the two populations. It would be beneficial to do some simple statistical tests to determine significance and drive the point home. There are clearly statistically significant differences between the two populations...* The data presented in Tables 1 to 4 are derived from the ABS Confidential Unit Record File. Since we treated the weighted data as estimates of the population, the test of significance was not required. The very large numbers means that there are statistically significant differences. Refer to page 4, paragraph 2.

3. *The Analysis:* *Are there only two ways to break down the age groups? If you can break down the age groups further, I would do it. There are significant differences between the needs of 15 years old and 64 year olds. This may explain some of the findings. As it is now, it is too simplified.* This is a good suggestion. Table 4 segregates the population into age groups. The results on page 6, paragraph two and the discussion on page 8 adds a deeper dimension to the manuscript.

4. *The Content:* *The discussion section needs to be more thoroughly thought out and re-written. It provides a basic summary, but does not go much further. What are the implications for community mental health services? What are the policy implications? According to the study, services are not being delivered and resources are not being allocated appropriately. What do the authors think needs to be done? While you do not want the discussion to state more than what the data speak to, at least give some general ideas.* Refer to pages 7 (last sentence of paragraph 2) and all of page 8 has been revised.

There are more limitations to this study than stated in the discussion. What are they? More of the limitations of this study are discussed in the last paragraph on page 7.

The last sentence is not a good one to end a journal article on. I would revise that last paragraph completely. The last paragraph has been replaced.