

Respite services for older persons and their family carers in southern Sydney

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Abstract

This localised study focuses on the availability; suitability and utilization of respite care services for families caring for older relatives in southern Sydney, NSW, an issue identified by the first author in the course of her employment as a community nurse. Respite care services were examined from the perspective of family carers (N=18), referring health professionals (N=18), respite referral services and respite care providers (N=9). The data was obtained from semi-structured in-depth interviews, surveys, and focus group discussions. Apart from the respite referral services all participants identified access to and utilization of respite care were constrained by actual and perceived limitations in service availability, referral processes, service flexibility and quality of care outcomes. Recommendations for improving access include re-evaluation of the centralised referral system, establishing more effective communication processes between all three groups and other health staff, and introducing focused aged care education for respite care staff.

Key words

Respite care, family, caregivers, health services for the aged

Word count: 4,081

Introduction

Anecdotal evidence from health service providers and the first author's clinical observations in one metropolitan area health service indicate there are on-going problems embedded in current respite service provision for frail older people and their family carers. Opportunities to access flexible or unplanned respite care are issues of concern for these family carers, as they are not always able to predict their need for respite. As carers are unlikely to utilize respite care unless they have an immediate or anticipated need, there is no definable pattern to their request for respite services. They are also reluctant to utilise respite service unnecessarily in consideration of its value to others with greater need.

These observations provided the impetus for the study. The pilot for this study indicated that access to all forms of respite care was the main concern of carers and referring health staff. Therefore, the aim of the study was to assess availability, suitability and utilisation of respite services for older people living in the first author's area of practice, located in the southern region of Sydney. The anticipated outcome was to provide respite services with recommendations on how to improve carers' access to these.

As the first author is a novice researcher, she was mentored by the second and third authors under the auspices of the Health and Ageing Research Unit one day a week for one year, thereby allowing her to maintain her clinical position during the study period. This situation limited the scope of the study in terms of the timeframe and the study aims, design and sample selection.

Supporting literature

Informal carers' issues have gained prominence on a number of fronts in recent times (Askham 1998; Ageing & Disability Department 1999). According to the ABS 1998 Disability, Ageing and Carers Survey, of the 2.3 million people in Australia

providing caring assistance for family and friends, 450,900 have primary caring roles. 36 percent of primary carers are located in NSW with 21 percent over the age of 65 (Ageing and Aged Care Division 2002). A nationwide survey and consultation with various stakeholders of respite care including carers, care-recipients, respite service providers, and government bodies revealed the need for increased flexibility and availability of community based respite to accommodate individualised needs (Rhys Hearn et al. 1996). In view of these findings the Commonwealth allocated almost \$73 million for 2001-2002 to the National Respite for Carers Program (NRCP) (Ageing and Aged Care Division 2002).

There is abundant literature on the subject of respite care for families at a state and national level (Brodaty & Gresham 1992; Hanson, Tetley & Clarke 1999; Ashworth & Baker 2000; Chappel, Reid & Dow 2001; Cox 1997; Smyer & Chang 1999), particularly for those caring for a person with a dementing or other neurodegenerative illness (Murphy 1999). Research has identified informal carers' needs and respite service availability and that service utilisation is neither uniform (Leong, Madjar & Fiveash 2001), nor meeting the demands of all groups (Braithwaite 1998; Zarit, Gaugler & Jarrott 1999). For example, there is virtually no access to suitable respite care for adult relatives with a mental illness or an intellectual disability (Brodaty & Gresham 1992; Burke, Chenoweth & Newman 2001; Jeon 2002; Sane Australia 1998).

Carers identify access to unplanned respite is an important factor in determining their ability to continue in this vital role, particularly when the challenging behaviours associated with cognitive impairment become overwhelming (Murphy 1999; Leong, Madjar & Fiveash 2001). Since family carers generally lack information about respite care and the range of services available to them, they are unaware of their right to access unplanned respite care, for example when they need time-out, or become ill

(Ageing & Disability Department, NSW Health 1999; Leong, Madjar & Fiveash 2001).

This becomes evident when considering the number of residential respite services accessed. In 1999-2000 of the 676,011 approved high care (Nursing Home) respite bed days, only 50.25% was utilised. Of the available 805,130 low care (Hostel) respite bed days, the uptake was 74.40%. In 2000 the total utilisation rate for all types of residential respite care was 63.80% (Ageing and Aged Care Division. 2002).

There are other issues at play when considering this situation. Family carers are very cautious about utilising respite services that they consider detrimental to the health and well being of their relative (Askham 1998; Koslowski, Montgomery & Youngbauer 2001). This is particularly the case when the carer's desire to participate in care planning decisions is rebuffed by service providers (Walker & Dewar 2001), and also when their ill relative does not comprehend the carers' need for respite and is reluctant to receive these services (Clarke & Finucane 1995). Although previous research confirms these findings (Australian Bureau of Statistics 2000; Braithwaite 1998; Aged and Community Care Division 1996; Murphy 1999), anecdotal evidence from health care professionals suggests that local health authorities do not necessarily refer to accessible data which assists them in planning for improving respite care access. This study bridges this gap for the southern region of Sydney and thereby, provides the local area health providers with important insights to this issue.

Research methods

This was a qualitative study, employing interviews, surveys and focus group discussions, operating concurrently over a 12-month period. Permission to conduct the study was gained from the local health services research ethics committee. A combination of purposive and random sampling was used to obtain data on respite care access in southern Sydney from the perspectives of family carers, referring health professionals, respite service providers and respite referral centres.

Validity and reliability issues

During the pilot phase the surveys, interview schedules and focus group discussion questions were trialed with a small number of service providers, family carers and health professionals. Face and content validity for the surveys, interview and focus group questions were established through discussion with a panel of expert health care clinicians and literature reviews. Data collection and the initial coding were conducted by the first author to insure consistency of data, and then the second and third authors reviewed categories and their relationships.

Research participants

Family Carers

Random sampling was used to recruit 18 consenting family members who were the main carers for older people with chronic, degenerative diseases, and who were clients of community health services in southern Sydney. 83% were female aged 49 to 86 years with the majority being over 70, in caring roles from less than 1 year to 45 years. The care recipients, aged 62 to 95 years, suffered from dementia, Parkinson's disease, stroke, trans ischaemic attacks, cardiovascular disease, hypertension, deafness, blindness, glaucoma, arthritis, poor mobility, urinary incontinence and Paget's disease. The majority of carers did not enjoy good health, citing heart problems, arthritis, hypertension, chronic tiredness, Meniere's disease, backache, diabetes and depression.

Health professionals

The 18 consenting health professionals included eight nurses, six doctors, two social workers, one occupational therapist and one physiotherapist. Sixteen were Australian born and 14 were female. They all had wide exposure to aged clients and provided carers with referrals to respite care through acute, community and residential facilities, the Aged Care Assessment Team (ACAT), or General Practice. Fifteen had a wide range of health care experiences other than the field they were currently involved in.

Service Providers

Nine consenting staff represented four southern Sydney respite service providers and two respite referral centres. They included two service managers, two coordinators and five staff. Experience in respite care service ranged from two to 15 years. Three participants had experience in acute health care, family planning, disability services, community nursing and administration. The respite services included in-home, day centre and residential aged care; funded by either or both state and Commonwealth governments or voluntary agencies with no government funding. Staff levels and skill mix within the services were variable, with only two maintaining staff education programs specific to the needs of the older person with a cognitive impairment. The two state and commonwealth referral centres operated. as centralised referral systems for southern Sydney.

Research instruments

Surveys, in-depth interviews and focus group discussions were used in this study.

Surveys were administered to General Medical Practitioners (GPs) who returned them to the researcher in a reply-paid self-addressed envelope.

Family carers were administered coded demographic surveys at the time of interview.

Semi-structured interviews were conducted individually with family carers in the privacy of their own homes. Interviews lasted approximately 45 to 90 minutes. Two medical specialists and a residential facility senior manager were also interviewed privately since they could not participate in the focus group discussions.

Semi-structured focus group discussions of approximately 1½ hours were held with the health professionals and service providers in private meeting rooms or offices in their own facility.

Table 1: Questions asked of the four participant cohorts

<i>Surveys with GPs with closed and open ended questions</i> <ul style="list-style-type: none">• Perceptions of unplanned respite care?	<i>Semi structured interviews with family carers</i> <ul style="list-style-type: none">• Tell me about your experiences as a carer?• How has this role impacted on your life?
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<ul style="list-style-type: none"> List types and names of available respite services Who else organises unplanned respite care? Referral process used? Issues and problems arising when organising respite care? Suggestions for improvements? Any further comments? 	<ul style="list-style-type: none"> What do you understand by respite care services? How often and for what reason have you used in home or residential respite care services? How did this service help you and your relative? Have you used other types of respite services? How can these services be improved to meet the needs of carers? Is there any other aspect of respite you wish to discuss?
<p>Focus group questions with health professionals</p> <ul style="list-style-type: none"> What is your perception of respite services available in the Area? What are the issues concerning unplanned in home or residential respite? How are carer needs ascertained? How do you organise respite services for carers? What are your experiences with respite service providers? How can respite services can be improved? Anything else you wish to discuss regarding respite care? 	<p>Interview questions for service providers</p> <ul style="list-style-type: none"> Please outline the organisational structure of your service Briefly identify your service objectives How do you achieve these objectives? Can you tell me how your service is funded? What is your understanding of the needs of carers? Please outline the selection criteria when providing respite care? What are your experiences when dealing with carers seeking respite care? Are there issues and problems surrounding unplanned in home or residential respite care? How can unplanned respite care be improved? Any other discussion or comment on unplanned respite care?

Data analysis

Participant numbers were small, therefore only coded descriptive demographic and service-related data from the questionnaires were analysed for frequencies.

Qualitative data (individual interviews, focus group discussions and open ended questionnaires) were content analysed for themes, using Collaizzi's (1978) coding and classifying technique. Once the themes were integrated, the description of these was returned to the study participants for validation and any new pertinent information incorporated.

Key findings

Thematic analysis presented rich and systematic information about the caring experience, the context of respite service provision and access from the perspective of family carers, referring health professionals and respite service providers.

However, the key findings in this paper focus specifically on their perceptions of respite care availability, suitability, and utilisation.

Table 2: Availability of Respite Services

Participant Cohort	Knowledge of respite	Issues identified
Family carers	<ul style="list-style-type: none"> little knowledge of respite availability and scope 	<ul style="list-style-type: none"> demand for respite is greater than availability.

		<ul style="list-style-type: none"> • Inadequate access to centre-based, occasional overnight and weekend respite • not familiar with types of respite available
Health professionals	<ul style="list-style-type: none"> • unplanned respite available in emergencies (family crisis, a death in the family or carer's illness) and to a limited extent for social events • except for GPs and acute care staff aware of the scope and usefulness of respite services in southern Sydney region • understand the referral processes required 	<ul style="list-style-type: none"> • demand for respite is greater than availability • Inadequate access to centre-based, occasional overnight and weekend respite • poor access for carers of older people with a cognitive impairment. • poor access to emergency respite • unable to inform carers of emergency or unplanned respite because of limited supply • GPs and acute care staff have poor knowledge of respite, appropriate referral mechanisms, the complex, lengthy and detailed processes required and the context of the family's situation. • GPs and acute care staff often do not refer carers for respite
Respite Services	<ul style="list-style-type: none"> • overlook the fact that carers have poor knowledge of respite 	<ul style="list-style-type: none"> • demand for respite is greater than availability • arbiter unplanned respite for carers in emergencies • allocate respite according to need and position on waiting list

Participants' suggestions for improving carers' access:

- Providing more respite services of all types, including volunteer respite programs for centre based services
- Clearer communication and dissemination of verbal and written information between health professionals, service providers and carers
- Forwarding carer resource information regularly to General Practitioners via the GP newsletter
- Improved remuneration for better educated field workers
- Regular monitoring of centre based waiting lists and attendance records, to address the take-up rate of vacancies when cancellations occur.

Table 3: Suitability of Respite Services

Participant Cohort	Features of suitable respite services	Issues relating to suitability of respite services
Family carers	<ul style="list-style-type: none"> • meet a range of needs, flexible, • provided in a timely fashion • quality care delivery • ease of access • suitable field worker knowledge, skills and attitudes 	<ul style="list-style-type: none"> • long waiting times for residential and centre-based respite • existing services not meeting need for respite at short notice • limited times and days of operation of centre based respite • cost of residential services too high • necessity to book residential respite long in advance • insufficient transport for centre-based respite • staff unskilled for in-home and residential respite • not adequately meeting client's needs
Health professionals	<ul style="list-style-type: none"> • meet a range of needs, flexible, • provided in a timely fashion • quality care delivered. • ease of access 	<ul style="list-style-type: none"> • long waiting times for residential and centre-based respite
Respite services	<ul style="list-style-type: none"> • meet a range of needs, flexible, • provided in a timely fashion • quality care delivered. • ease of access • suitable staff numbers and skills 	<ul style="list-style-type: none"> • long waiting times for residential and centre-based respite • carers requesting short stay residential respite, requiring lengthy paperwork for staff • residential service structures (eg., staffing) limit potential to meet clients' and carers' needs • limited ability to realise greater independence and social skills with respite clients • unable to inform and educate carers about community-based counselling services

Recommendations for improving suitability of respite services:

- Maintain and enhance case management and brokerage models whereby individual client and carer needs are more easily identified and addressed
- Improve availability of out-of-hours respite, such as occasional overnight or weekend stays
- Provide greater education for field workers to cope with the increasingly complex needs of clients being managed in the community
- Require field workers to assist carers when preparing relatives for respite care
- Increase staff numbers and skills in managing people with cognitive impairment

- Provide direct telephone access between family carers and residents accessing residential respite

Table 3: Utilisation of Respite Care Services

Participant Cohort	Experiences in utilising respite services	Issues associated with utilising respite services
Family carers	<ul style="list-style-type: none"> • utilised all forms of respite • two-thirds frequently used planned centre-based respite services • residential respite used Infrequently for longer periods • respite referral services inefficient and not always user-friendly • many carers were denied access to necessary respite by respite referral services 	<ul style="list-style-type: none"> • negative experiences of in-home respite because of inadequate staff levels, knowledge and skills • positive experiences with Centre-based respite • future use related to client's desire to access respite, or resistance to respite • post-respite adjustments/ reactions in clients difficult for carers to manage • will not access respite referral service unless desperate • some prefer to make direct contact with respite services
Health professionals	<ul style="list-style-type: none"> • respite referral services inefficient and not always effective • referral process undertaken by health staff duplicated by referral services • not all GPs familiar with accessing respite services for patients/clients 	<ul style="list-style-type: none"> • carers often neglect own needs as they did not feel staff were able to provide individualised client care • carers do not benefit from respite if not used as time-out for themselves, or if outcomes for clients are negative • phone interview of carers by referral services inadequate and iniquitous • many carers denied access to necessary respite by respite referral services
Respite services	<ul style="list-style-type: none"> • referral for respite streamlined and efficient 	<ul style="list-style-type: none"> • staff do not encourage carers to participate in care planning during residential respite • carers do not benefit from respite if not used as time-out for themselves, or if outcomes for clients are negative • not aware carers have difficulties in accessing respite referral services

Discussion and conclusion

As with most respite care research, all participants recognize that caring for an older person with a cognitive impairment commands a central place in the lives of family carers and gradually reduces their health and well-being unless suitable respite is accessed sufficiently (Askham, 1998; Braithwaite, 1998; Murphy 1999). Similarly, while the carers in this study did not command good health and had responsibility for relatives with many co-morbidities which required a great deal of physical and emotional support, their main concern was in maintaining their relative's safety and well-being when accessing any form of respite care (Ageing & Disability Department, NSW Health 1999). To achieve positive outcomes, it is critical that respite services are well equipped with more skilled and trained staff (field workers) who can deliver the quality of care while the care recipients are in respite care (Cox 1997; Hanson, Tetley & Clarke 1999). This requires service providers to offer better training for their staff to cope with complex care needs of clients, in particular when providing in home respite as indicated by the study participants.

There is agreement between the three participant cohorts in this study that it is rare to find short-notice or unplanned respite places available in day centre, in-home, and residential facilities, and if available, they are difficult to access. This is problematic, as this form of respite is regarded as most likely to assist carers when they most need it to maintain their own health and wellbeing. However, since neither referring health professionals nor respite service providers make mention of the limited availability to carers, it is unlikely carers will request unplanned respite, even in times of crisis. As identified previously (Leong, Madjar & Fiveash 2001), if carers understand that emergency respite is only available when they suffer a serious illness or need hospital treatment, they will continue to ignore their own needs and their deteriorating health, well-being and coping ability.

It is interesting that both referring health professionals and carers identified the referral processes to be one of the barriers to respite access, yet the respite service providers were unaware of this and in fact, viewed the centralised process to be working effectively. Clearly communication between all three cohorts and feedback of study findings to the referral services is needed to realise timely access. While stressing decisions are made to ensure equity of access, a claim of most respite services (Aged and Community Care Division 1996), it appears that this process serves to deny health professionals' experience and expertise in making informed judgements about carer need, and ignores many carers' pleas for help.

As with other research (Braithwaite 1998; Clarke & Finucane 1995; Murphy 1999) carers will not access respite services which appear to impact negatively on the client, despite their own needs and this is understood by referring health professionals and some of the respite service providers. However, service providers maintain the status quo, claiming the ultimate goal of services is to meet the needs of carers, while at the same time acknowledging they cannot meet all of the carers' expectations, nor all of the client's needs. While this dichotomy signals a major barrier to service uptake, the acknowledgement by service providers that improvements are necessary in terms of staff preparation and flexibility of delivery, it is at least one step further in the change process.

Despite the rich data gained from the three participant groups using multiple methods, the limitations of this study are the small sample size and exclusion of carers who could not communicate in English. Nevertheless, the comprehensiveness of data indicates that the overall sample of the study was adequate and appropriate in identifying key issues with respite care in southern Sydney for English speaking participants. Future research will be necessary to identify these same issues for non-English speaking populations.

This study provides important new data explaining the reasons for inadequate respite service access by carers in one local health area in Sydney. Replicating this study with other health areas would assist in identifying whether the findings are specific only to this region or whether they reveal widespread issues of concern for carers in accessing respite services within current policy. These findings can facilitate improved aged care policy directions and influence the way that respite referrals are made and services provided. In embracing evidence based clinical practice and commitment to continuous quality improvement, the study was an important vehicle for achieving positive client care outcomes through identification of local needs. In addition, the study provides an opportunity for others to compare these findings with respite service policies, provision and outcomes in their own regions. r

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