

Why carers of frail older people are not using available respite services: An Australian study

Aim: The purpose of this study was to explore the limiting and motivating factors that influence carers' use of respite services and the ability of currently available respite services to meet the needs of carers of frail older people.

Background: The development of community carer support services, their availability and usage and the common barriers that affect or impact on carers' use of community services in general and respite services in particular need to be examined to ensure they meet client needs.

Design: A qualitative descriptive approach informed by critical social theory was used to expose the inequities inherent in community services.

Methods: A qualitative examination of carer relationships with respite services was informed and guided by critical theory. Sixteen carers took part in four focus groups. A purposeful sampling strategy was adopted to engage with carers not currently using respite services. Study participants were recruited from a state-wide carer support organisation and a community service organisation in Queensland, Australia.

Results: Three themes emerged from the data: 'Commitment' characterised by reciprocity, role definition and role frustration, 'Needing Help' discussed in terms of trust, confidence in service, fear and resistance, and 'Support' discussed in relation to informal networking, misinformation and lack of knowledge.

Conclusion: This study improves our understanding of the caring role, its significance in carer's lives and how this shapes their formal service expectations and use. The findings suggest that further investigation of the factors involved in carers' service expectations and service seeking is warranted to develop a deeper understanding of how care giving influences the ways carers seek help from formal services.

Relevance to clinical practice: Service delivery changes towards a model of care which engages and promotes user control and fosters genuine participatory relations between informal and professional carers may improve uptake of respite services.

Keywords: Respite, Community, Family care, Older people, Qualitative, Nursing.

Introduction

Australian and worldwide trends indicate that the population is ageing. An ageing population places increasing stressors on health and community care as decreasing health status and capability for independent living frequently reduce in association with ageing. The majority of community support for frail older people world wide is provided by an informal network of family, friends or neighbours (Droes *et al.*, 2004, Glendinning, 2003, McGarry & Arthur, 2001). Informal carers' appearance as an identified group can be traced to an increasing awareness amongst health and social care policy makers of the significance of the informal network in enabling people with a disability and frail older people to remain in the community (Productivity Commission, 2008, Queensland Health, 2006).

In Australia it has been estimated that informal carers' provide more than 80% of support for people with a disability, including frail older people and provided a total of 1.2 billion hours of care in 2005 (Access Economics, 2005). The cost of replacing informal care with formal support services has been estimated at \$A30.5 billion (Access Economics, 2009). A need to establish appropriate support for the widespread informal network of carers' has increasingly dominated aged care policy as the proportion of frail older people in the community increases and the availability and subsequent use of institutional care declines (AIHW 2004, NCSEM, 2004, Productivity Commission, 2008).

The increased emphasis of current community service policy on enabling frail older people to remain at home (Cwealth DoHA, 2004) has been supported by a dramatic rise in funding and the development of a wide range of community service options. Substantial amounts of federal and state government funding have been channelled into carer support services over the past three years to provide respite services in a wide range of settings (e.g. in-home, day centres, nursing homes or overnight respite cottages). The two major funding sources for community respite in Australia are

the National Respite for Carers Program (NRCP) and the Home and Community Care (HACC) program.

Despite such developments, the uptake by carers' has not met expectations. For example in the State of Queensland, which has a population of over 4 million and is the third largest Australian state (ABS, 2008) examination of local service use data showed widespread under-use of Home and Community Care (HACC) funded in-home respite services throughout the State (Queensland Health, 2006). In some areas of the state in-home respite services were only used to 20% of their funded capacity and the maximum throughout the state was only 67% (Queensland Health, 2006). Nationally clients aged 65 years or over accounted for 76% of all HACC clients in 2006–07 but accounted for only 30% of total HACC in home respite hours (Commonwealth Department of Health and Ageing, 2008).

Previous studies examining respite services have predominantly viewed the subject from the perspective of users of respite services, but large numbers of carers' have never used or ceased to use respite services. A review of over sixty national and international journal articles, policy documents and organisational reports identified three recurring themes regarding community service use in general. These included the service recipient or carer having limited knowledge of service availability (e.g. Ballantyne *et al.*, 2005, McDonald & Zetlin, 2004, Sandler, 2006), frustration in accessing and being assessed for services (e.g. Brodaty *et al.*, 2005, Lindeman & Newman, 2006, Winslow, 2003) and acceptability (e.g. Kellett & Mannion, 1999, Milligan, 2003) and quality of service (e.g. Gilmour, 2001, Hanson *et al.*, 1999).

This study emerged in response to a long-term under-use of in-home respite services in a non-government community service organisation. The study sought to identify why under-use was occurring and how to address the situation. The main aims were to establish how carers' identify

with formal community services, in particular respite and any benefits or limitations of such services in assisting them to maintain their caring role.

Methods

A critical approach provided the theoretical perspective. Critical theory is a tradition of thinking, as opposed to a specific research methodology, that emerged from the Institute of Social Research in Frankfurt and is associated with academics across a range of disciplines (Cheek *et al.*, 1997, Crotty, 1998, Held, 1980). Critical Theories main assumptions hinge on the need to expose and change the restrictive and oppressive nature of societies social systems and/or culture and through doing so give voice to the disempowered (Cheek *et al.*, 1997, de Laine, 1997). This approach was deemed important in making visible the needs of carers' of frail older people in terms of what assists them to continue to care in a home setting and giving a voice to a commonly perceived disempowered group.

Participants

A purposeful sampling approach was adopted to engage with carers' who could talk about the phenomenon under study from personal experience. Carers' were asked to participate in the study if they met the following criteria, they were providing support to a frail older person to assist them to remain at home, had a minimum of three days per week direct contact with the person being cared for and were not currently using respite services. A total of sixteen carers' who met these criteria participated in the study. The majority of participants (n=13) were recruited from a state-wide carer organisation and a small number of additional participants (n=3) were recruited from a non-government community service organisation. The participant group were predominantly female (n= 11), consisted of mostly spousal carers (n=9), aged between 60 – 69yrs (n= 8), were resident carers (n=15) and had been caring for more than two years (n=12).

Data Collection

Attempts to access carers' did not commence until ethical clearance had been given by the University Human Research Ethics Committee. The study was brought to the attention of the carers' by the regional Carer Services Officers and registered nurses, they outlining the study and its purpose to those of their current carers groups or individual clients who met the study entry criteria. Interested carers' were contacted and invited to participate. The purpose and process of the study were explained as well as potential risks and benefits of the study. Participants were invited to sign an informed consent proforma which assured them that information shared was anonymous and confidential and that they were free to withdraw their participation at any point during the study.

Focus groups, two in the Queensland state capital of Brisbane and one each in a coastal and a regional city provided a forum for the carers' to express their views on respite services. The different focus group locations were chosen to encourage information rich descriptions through a variety of views and demographics of participants. The focus groups lasted between one and half and two hours.

The research aim and related literature guided the focus group questions. The questions sought to establish carers' knowledge, previous and current use of formal services, in particular respite services and an understanding of services they considered would assist them. Each focus group was recorded and transcribed verbatim.

Data Analysis

The focus group questions assisted in identifying initial categories and provided the structure to assist with an in-depth analysis of each session. Data analysis commenced by critically questioning the reason for respite services, is it to assist carers' with a role they wish to maintain? Are respite services or formal services in general providing support for carers' in an acceptable manner? What are the carers' saying about the services they have used or would like to use? Once major themes

started to emerge the process of theorising with reference to established critical theory (Cheek *et al.*, 1997, Crotty, 1998) in the field of carers' and respite service use was followed by incremental development of the focus group data (Morse & Field, 1995).

Results

Three themes emerged from the focus group data, 'Commitment', where the carers' shared information on their caring role which embodied reciprocity, role definition and role frustration. 'Needing Help' discussed in terms of experiences that elicited mistrust, a lack of confidence in service and resulted in fear and resistance. 'Support' characterised by informal networking, possessing misinformation and a lack of knowledge of current community aged care services. Each of these themes is described in more detail below and direct quotations are provided as supporting evidence. Three key issues, empowerment, improving knowledge and access and entry, were identified as the carers' experiences and understanding of the community aged care sector were revealed.

Commitment

Commitment was characterised by three sub themes. Participants considered that *Reciprocity* had a major part to play in them accepting or considering a caring role. As indicated in the following quotation carers' saw their role as an opportunity to reciprocate the care and support they had previously received from their care recipient or would expect to receive if the situation were reversed:

I feel it's my job to look after him and he would do it for me too.

However, the majority of participants referred to the impact their caring role had had on their life particularly in relation to their own ill health, loss of social life and lack of sleep:

He is up all night. I don't get much sleep either, because when he gets out of the bed he's giddy and I'm frightened he's going to fall, so, you know, I'm sort of up and you're watching him all the time.

The all encompassing nature of the caring role and the isolation created by the role was shaped by situations where participants felt they no longer had friends who visited socially:

You just don't have the time to go and see people and some people aren't willing to accept an elderly person as being there with you if they come to visit. So they just drop off, you know.

For the majority of participants interpreting and defining their caring role (*Role Definition*) was important. More than one carer saw their role as an intermediary between support services and the care recipient due to the care recipients poor English:

Mum finds it hard to communicate with the lady [Personal Care Worker]...she's New Australian so she doesn't speak English.

Length of time caring was also strongly associated with the role of 'expert carer'. The 'expert carers' during the course of the focus group reiterated that they were managing and that others could too if they used similar strategies or learnt particular skills which they willingly shared:

[Suggestion for] the ladies today [trying to get] their husbands to go [to a nursing] home for respite care and say 'look, at the meeting today there was ladies there that their partners or their husbands had been into [residential] respite care and they thoroughly enjoyed it, you know, just try it for a day'... 'if you're not happy, you know. But just to go and see because there's lots of things go on there'. They do enjoy it after a while. I mean I know it's telling little white stories but I think that we do have to do that for the benefit of ourselves at times.

One participant who had cared for her husband for several years spoke at length about the strategies she had used to get her previously resistant husband to accept residential care:

I would plan the arrangements for him to into the nursing home and didn't tell him of course until the day before and then I would go and say 'that was the nursing home they've got a spare bed would you like to go in? They thought you might like to come in'. Because someone else said it, it was fine! So of course he would go and I'd go off and have a holiday.

Role Frustration emerged from discussion and was described in terms of the challenges and difficulties experienced in every day caring:

...he is up all night. I don't get much sleep either, because when he gets out of the bed he's giddy and I'm frightened he's going to fall, so, I'm sort of up and you're watching him all the time.

...we have our bad days too... You know he jumps down your neck like that when you least expect it

Participants did not directly state that they experienced burden or strain in their role but did discuss tasks that they found overwhelming or challenging. Care recipient traits the participants found particularly frustrating or challenging included irritable behaviour, repetitive questioning and paranoid behaviour often displayed with dementia:

I go to the shop and when I come home he said 'why you go to work? We don't need the money, we're OK' I say 'you think I went to work?' He said 'Yeah you leave since this morning and come back now it's late, its six o'clock'. I said 'I don't go out every day, I go just when I need and do shopping, do doctor, do this, do that and we need somebody to do this'.

The majority of participants expressed frustration regarding the excessively bureaucratic processes they were required to negotiate to access basic necessities for their caring role and how time consuming this had been for them:

I do have a disability parking permit, which took forever to get...I would have liked it a lot earlier, that's one point was really very annoying, when I really, really, really needed it, I didn't have it.

...and the forms you've got to fill out, the forms drive you absolutely round the bend!

Needing Help

Participants were very selective about accepting assistance. The majority of carers' in the study accepted that they needed some assistance to care for their care recipient but expressed concern regarding the trustworthiness and quality of support available from others including both family and formal community aged care services. Whilst some participants relied on and were appreciative of the support provided by family members, frustration was expressed with regards to their ability to grasp simple instructions, for example with medication assistance:

If I left her [mother] with any of the family members I didn't think that they were doing it right, you know, I knew she wouldn't be dead when I came home but I just knew that there would be trouble with the pills and troubles with this and troubles with that...there would be a settling down period when I came back.

This raises the question that if carers' are unable to trust their own family members to care for the care recipient why would they consider receiving care from a stranger?

Confidence in services was expressed in terms of the negative impact of formal services.

Consistency of formal care staff was highly valued by the majority of participants, in particular those who were caring for a care recipient with dementia or particularly resistant to formal services.

They were upset when formal service providers did not give their preference for known care workers a high priority:

...one day it would be a girl then a man and initially when he needed someone to give him a shower, the look on his face when he'd got to know the first nurse or lady and then another one came and she was only sixteen or eighteen...oh gosh! So had it been the same one, you know, the initial shock of having someone else to do it [help in the shower] and then the change from week to week and this sort of thing...so that [consistency] is important.

The majority of participants who received, or had previously received, formal services had become resigned to the fact that workers changed frequently, often at short or no notice, for no apparent reason and they were required to accept the consequences of the changes which usually involved renewed resistance from the care recipient. One participant provided an example of poor practice in-home formal service provision for her palliative husband that highlighted the participant's feelings of resignation and the limited communication that existed between carer and service provider:

...they [Community Service Provider] would only come twice a week [to shower spouse]. I mean you can't have them there twenty-four hours a day, I understand that, but you're a bit weary. They only allot you a certain time, if it's not enough you can't do much else [said with resignation].

Fear and Resistance was expressed in terms of concern regarding the diminution of their caring role by acceptance of formal service. In some instances participants felt that they should be coping with their caring responsibilities and weren't entitled to services:

...I feel so guilty that I'm not doing it [family members house cleaning & shopping] and the lady there [formal carer], she thinks 'Oh god you could be doing it rather than me'.

They were embarrassed that they needed support and felt obliged to justify, sometimes at great length, their care recipients' need for additional support and their own difficulties in meeting the need.

Support

Support was discussed in terms of participants' reliance on *Informal Networking*. When discussing their use or non-use of community services all of the participants referred at some point to the informal support structures they relied on and how they assisted them to accomplish their caring role. Due to limited formal service availability or acceptability some participants relied on their informal network to supplement the formal services they received:

...I had to rely on other people because they [Community Service Provider] would only come twice a week.

Most participants preferred to concentrate on maintaining their informal network in preference to re-establishing themselves with formal service providers. Some did not feel the need to know about or access formal services, as their support network was sufficient for their needs and was convenient and accessible.

Misinformation related to anecdotal information received from the informal network on formal services. There was a common perception amongst participants that community aged care services, particularly in-home and centre based respite services, are predominantly focused towards or required by individuals with dementia or those with an intellectual disability:

...the old lady who lives next door to us is the same age as Mum, her family took her down to a day respite centre one day years ago and she said it was awful, it was all people with Alzheimer's and really badly disabled people and stuff like that ... she just found it awful for the six hours or so she was there. So Mum said to me 'Don't you ever do that to me!'

They considered the activities provided during respite periods to be, on the whole, limited and demeaning.

The final sub-theme related to the participants *Lack of Knowledge* of how to access accurate information on the community aged care service structure and formal support services. Carers' expressed frustration when relaying how and where they had been able to access information and the difficulties they had experienced. Almost all participants' described lack of knowledge of general community services and difficulty in navigating the formal aged care support system as issues of concern and frustration to them:

I'm sure you've all been through the thing, there are services out there but you never know where they are.

...every one service that a carer requires they've got to go through a long process.

They described the variety of methods they had used to gather information on and access to the services they required to assist them or their care recipient. The strategies they used were often convoluted and it appeared that most participants had stumbled on an entry point into the aged care system more by luck than good planning.

Discussion

All participants firmly located the socially defined physical care of the care recipient as central to their role and as such tasks that are not easily relinquished. This could be seen as one of the main reasons that respite services are refused as they effectively usurp the carer's role by removing the central character in the carer/care recipient dyad. The study findings provided insight into, how the care-giving experience impacts on awareness or acceptance of formal services, how carers' identify with formal community services, in particular respite and, whether carers' consider community

services provide any worthwhile benefits in assisting them to maintain their caring role. The following key issues were identified.

Empowerment

All of the carers' in this study showed great commitment to their caring role but it was evident that they were disempowered. By virtue of their role and its connection with disability, ageing and frailty which are firmly associated with the marginalised and disadvantaged and also through their experiences of the aged care sector. Australia's aged care sector is fragmented with multiple funding sources and service delivery providers, making it difficult for carers' to decipher and negotiate. In addition they experience frustration in their transactions with service providers when shared care is required (Ashworth & Baker, 1999, Palliative Care Australia, 2005). Family carers' are increasingly expected to assume the role of health provider for their frail or disabled family members but when formal care providers' become involved in care their professional expertise and opinions frequently dominate and dictate the care and services provided (Innes *et al.*, 2004). It is this clash of cultures and expectations that commonly form a reason for carers' to reject formal support due to the marginalised, disempowered status they are obliged to assume (Milligan, 2003, Wiles, 2003).

Aged care and carer services need to evolve to respond to current and emerging consumer groups' expectations. It is time for the traditional paternalistic model of aged care service provision to change to a culture of shared decision-making where the carer and care recipient are centrally located and not on the periphery (Clark & Spafford, 2002, Clarke, 2001, JRF, 2004). Adults from the 'Baby Boomer' generation have different expectations from previous generations. As current carers' and prospective users of aged care services they are starting to question the relevance of traditional service system and demand changes in practice (Alsop *et al.*, 2004, JRF, 2004). A paradigm shift in service focus and allocation is required. One of the main components in providing services for carers' should involve effective engagement with the carer. Recognising the carer's

knowledge of the person they care for and their abilities in their caregiving environment are as important as identifying the areas in which they require support. Winch (2006) argues that a carer defined need may not necessarily align with need as commonly identified by service providers or with service availability but is no less valid and requires a collaborative response.

The aged care sector would do well to follow the palliative care sector lead in recognising the significant value that informal carers bring to the community service sector. Palliative Care Australia has taken steps to promote the role of carers amongst formal service providers particularly with regards to empowering and supporting their role in the home palliative care team. This stance is clarified in a recent service delivery guide which states, 'The primary carer is at once an individual with their own needs, emotional and spiritual responses and a care provider, part of the team involved in supporting and caring for the patient. Recognition and acknowledgement of these dual roles will ensure that primary carers are both enabled in their caring role and cared for themselves' (PCA, 2005, pg 27).

Improving knowledge

If the aged care sector cannot afford the time and effort to empower carers' the least it can do is to effectively communicate and inform them (Ballantyne *et al.* 2005, JRF, 2004). For carer's to make an informed choice on the support they require at various points in their carer trajectory they need to gain access to information. In this study the carers experienced difficulty in finding sufficient information to establish an initial entry point. They expressed frustration with the poor quality and sporadic nature of the information they received on service types and availability as they passed through and between services.

Ballantyne *et al* (2005) found that carers' poor service knowledge and frequently expressed desire for information appears not to be related to lack of information, but more to difficulty in understanding the information provided. The participants voiced their frustration regarding the

volume and readability of the written information they were 'bombarded with' which had not improved their understanding of the range of settings that respite services were available in or the options for overnight or day services. Information dispersal strategies need to consider if and how a common language may be achieved to communicate more effectively and use a broad range of approaches to disperse the information. Of all the communication strategies the carers had encountered they cited presentations and seminars provided by service provider organisations or peak bodies as the most effective. Those that had attended them considered that they were an effective forum to receive information on specific services, provided an opportunity to ask questions about the services and also to meet with other carers and share caregiving experiences.

Access and entry

Glindenning *et al* (2005) argue that the reactive culture of community services works against a preventive approach that can support carers' and delay or prevent crises. It is common practice for service provider agencies to use assessment processes as a gatekeeper function. Entry criteria and assessment processes are not generally used to empower those seeking or requiring services but as a mechanism to control and exclude. This reactive stance draws attention to a conflict between the proactive approach envisaged for respite services by policy makers and the resource administration role that service providers often see for themselves.

Consumer directed care approaches in aged care services are starting to gain credence in Australia (Bruen & Rees, 2007, Tilly & Rees, 2007). They have been shown to provide carers and those they care for with more independence, choice and control over the services they access, aspects that the carers in the study identified as important. The concept signifies a shift from traditional paternalistic models of aged care service provision to one of shared decision-making, with the carer and care recipient centrally located and actively involved in the need identifying and service allocation process (City of Melbourne Council, 2002, Clark & Spafford, 2002, Clarke, 2001, JRF, 2004)

Future Research

The findings from this study suggest a need to develop a deeper understanding of how care giving influences the ways carers' seek help from formal services. Future work on this issue should consider a wide range of perspectives, respite service consumers, policy makers and providers'. Theory alone has little power to create change. Additional critical research would bring together theory and practice as researchers work with participants towards practical outcomes and additional understanding. The researcher would facilitate participation and empowerment by increasing communication, bringing the key stakeholders together to negotiate and develop mutual understanding and consensus on strategies to address the situation. This inclusion will assist in developing a genuine partnership between professional and informal carers' thereby improving structures that provide advice and support for carers.

Limitations

The lack of cultural diversity amongst participants could be considered a limiting factor. The majority of participants came from white Anglo-Saxon backgrounds. The complex issues related to respite awareness and use by Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) carers' were not explored in this research.

Conclusions

This study improves our understanding of the caring role, its significance in carer's lives and how this shapes their formal service expectations and use. The critical approach provided the platform to expose the inequities inherent in current community service and to critically examine carer experiences of in-home respite services. The power relationships involved in community service allocation were exposed as were the structure and delivery that potentially hinder the use of such services. The findings suggest that further investigation of the factors involved in carers' service

expectations and service seeking is warranted to develop a deeper understanding of how care giving influences the ways carers' seek help from formal services. Suggested changes to respite service delivery include improving mechanisms to inform and communicate with carers' and guide service delivery changes towards a model of care which engages and promotes user control and fosters genuine participatory relations for all involved.

Relevance to clinical practice

A major strength of this study was the richness of data achieved from the focus group discussions. The study findings provided insight into, how the care-giving experience impacts on awareness or acceptance of formal services, how carers' identify with formal community services, in particular respite and, whether carers' consider community services provide any worthwhile benefits in assisting them to maintain their caring role. Three key issues, empowerment, improving knowledge and access and entry, were identified as the carers' experiences and understanding of the community aged care sector were revealed. The issues provided a platform from which to critically examine respite and community aged care services in general and an opportunity to identify appropriate methods of informing and communicating with carers' and guiding service delivery change.

Gaining an understanding of the reason behind carers' resistance is of great importance when considering why they are not using respite services, contributes to an understanding of the significance the caring role plays in carers' lives and how this impacts on their expectations and use of formal community services. A carer defined need may not necessarily align with need as commonly identified by service providers or with service availability but is no less valid and needs to be acknowledged. The findings from this research indicate that the uptake of respite services by carers may be improved by service delivery changes towards a model of care which engages and promotes user control and fosters genuine participatory relations between informal and professional carers'.

Contributions

Study design: GSS, UK, WM.

Data collection and analysis: GSS, UK, WM.

Manuscript preparation: GSS, UK, WM.

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