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Differences in satisfaction ratings of carer-respite services between carer types: results of a Western Australian evaluation

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Abstract *Respite care offers caregivers a temporary relief from the duties of their caring role. This study examines whether caregivers' satisfaction ratings of the agencies that coordinate respite care services vary according to their relationship to the care-receiver. 177 clients of the Australian Red Cross Carer Respite Centres in Western Australia were surveyed by telephone to determine their satisfaction levels with the information and referral services they received. Those caring for children – although expressing a generally high level of satisfaction - indicated significantly lower levels of satisfaction than other carer groups on two specific criteria: the initial provision of information and the ability of the centre to cater to all their needs. It is recommended that service providers, health practitioners and researchers alike pay close attention to different carer types in the design, implementation and evaluation of respite programs.*

The importance of providing respite services to caregivers is becoming acute in societies where the primary responsibility for looking after disabled and frail persons is increasingly being undertaken in community settings or by friends and relatives. In 2003 there were 474,600 primary carers in Australia (Australian Bureau of Statistics, 2004), with a 1998 survey finding that 43 per cent caring for a partner, 24 per cent for a parent and 22 per cent of a child (Australian Bureau of Statistics, 2002). Respite care is intended to provide carers with temporary relief from their role as carers – to give them a 'break' from their duties for the purpose of rejuvenation and time to attend to their own needs before resumption of their caring duties.

While the benefits of respite care are disputed by some (e.g., McNally, Ben-Shlomo & Newman, 1999), there is a general view that respite care improves the ability of carers to cope with their caring role, even if the degree of such improvement has been shown in some studies to be relatively minor (Kosloski & Montgomery, 1993; Zarit, Stephens, Townsend & Greene, 1998). The benefits of respite care have been highlighted in various carer satisfaction surveys, which have shown strong support for respite care services amongst various carer groups (Berry, Zarit & Rabatin, 1991; Milne, Pitt & Sabin, 1993). The use of carer satisfaction surveys are a widely used method for evaluating the effectiveness of

health care services (Bauld, Chesterman & Judge, 2000). While there is increasing interest in identifying the factors that underlie satisfaction levels within specific carer groups (e.g., Simon, Little, Birtwistle & Kendrick, 2003), there has been little attention paid to the matter of variable satisfaction levels *between* carer groups.

In fact, little attention has been paid in respite studies to differences among carer groups generally (McNalley et al, 1999; Montgomery & Williams, 2001). Carers are generally aggregated into the one general category – that of ‘carer’ – with no distinction being made, for example, between those caring for spouses, those caring for parents and those caring for children. When it comes to determining the benefits of respite care and satisfaction of services received, such understanding of differences among carer groups is fundamental to ensuring that respite services are catering to all carers effectively, as it cannot be assumed that all carers have similar needs.

There is, in fact, strong evidence that carers have quite different needs based upon their relationship to the care recipient. A 1999 survey of primary caregivers in Australia found that 39 per cent of parents caring for a child required respite care, compared to 16 per cent of those caring for a partner and 22.6 per cent of those caring for a parent (Australian Bureau of Statistics, 2000b). It has been shown that carers of children face special demands that are in some important ways distinct from the needs for those caring for parents or spouses (Halpern, 1985; Marc & MacDonald, 1988). Parents caring for children with a disability experience greater problems in finding affordable special child care services, maintaining employment and drawing on social support (Litt, 2004; Fewell, 1993; Heymann, 2000; LeRoy, Harrison & Johnson, 2000; Lukemeyer, Meyers & Smeeding, 2000). An Australian Bureau of Statistics (2000a) report concluded that parents providing care were those who were most adversely affected financially by their caring role, with 37 per cent reporting an increase in financial costs and 23 per cent a substantial decrease in income as a result of caring.

To what extent, then, do differences in the relationships between carer and care-recipient correspond to differences in the level of carer satisfaction with respite services? Determining the answer to this question is important in terms of evaluating the effectiveness of current respite care programs. One of the aims of the National Respite for Carers Program (NRCP) in Australia is to ensure that the specific needs of primary caregivers are taken into account by Carer Respite Centres (CRCs), which serve as a central access point by providing information about respite services and arranging the delivery of respite care. The present study sought to evaluate the Australian Red Cross’s CRC program in Western Australia as a means of identifying whether different carer groups are equally satisfied with the services provided.

Methodology

Edith Cowan University researchers and ARC staff collaborated in designing a telephone survey to measure the extent to which the CRCs had met the core objectives of the ARC Carer Respite Program in Western Australia. In particular, the survey focussed on levels of satisfaction among carers regarding the quality of services received. The survey was intended for clients of the ARC Carer Respite Centres who had accessed the service between January 2003 and June 2003 and who were over the age of 20 years. There were 1919 clients who matched the selection criteria. A random sample consisting of one in every five of these clients was developed and implemented using the ARC database, resulting in a sample list of 337 clients. These clients were contacted via phone and invited to complete a questionnaire during a four-week period in August 2003.

Demographic details and utilization rates of respite services were obtained from the client database. The questionnaire sought information on barriers to utilization of services and the level of carer satisfaction based on five 'global measures' (Bauld et al., 2000, p.318): the provision of initial information; promptness in dealing with requests; helpfulness of staff members; ability to meet all their needs; and the ability to take into account *specific* needs/situation/difficulties.

Of the 337 ARC clients who were selected, 160 listed clients (47.5%) did not participate in the study, due to factors such as inability to recall utilisation of the service, incorrect contact details, death of care recipients, duplicated information, carers being away or carers simply refusing to participate. This left 177 respondents who successfully completed the telephone-based survey. There was a slight but significant bias towards female participation in the study (36.4% of male clients participated in the study compared to 56.7% females). However, there was no significant association found between rate of participation and carer group ($\chi^2 (2, N = 309) = .19, p = .91$), and therefore the underrepresentation of males in the study is not deemed to be problematic in terms of the objectives of the current study.

Results

DATABASE FINDINGS

The main carer groups in the sample were parents caring for a child (44.1%), spouses caring for a partner (36.7%) and offspring caring for a parent (13.6%). The remaining 5.6 per cent were caring for a relative or friend. The characteristics of the three main carer groups who participated in the survey are summarised in Table 1, which were derived from the ARC database prior to administering the survey.

	Parent	Spouse	Offspring
Proportion of respondents	44.1% (N = 78)	36.7% (N = 65)	13.6% (N = 24)
Percentage of female carers	94.9%	72.3%	91.7%
Age of carer	82% (< 51yrs)	84.6% (> 50yrs)	91.7% (40-71yrs)
Age of care recipient	83.3% (< 21yrs)	92.3% (> 50yrs)	87.5% > 70yrs
Mean years of caring	13.2 (SD = 10.3)	4.5 (SD = 2.5)	5 (SD = 3.3)

Table 1. Profile of Respondents based on Relationship to Care Recipient

There is a significant association between gender of care provider and carer group ($\chi^2(2, N = 167) = 15.5, p < .001$), which is moderately strong (Cramer's $V = .31$). Between the three groups, parent carers have a higher-than-expected number of females (adjusted residual = 3.2), while spouses have a higher-than-expected number of males (adjusted residual = 3.9). There is an approximately 3:1 ratio of female to male carers among spouses, which is considerably higher than the (approximately) 11:1 ratio among offspring caring for parents and (approximately) 19:1 ratio among parents caring for children.

There is also a significant association between age range and carer group ($\chi^2(4, N = 167) = 62.6, p < .001$), which is moderate in strength (Cramer's $V = .44$). Specifically, parents caring for children tend to belong in the younger 21-40 age range (48.7%) and middle 41-60 age range (42.3%), offspring caring for parents tend to belong in the middle 41-60 age range (62.5%), and those caring for spouses tend to belong in the older 61+ age range (62.3%). Not surprisingly, there is also a significant association between the age ranges of care-recipients and carer groups ($\chi^2(6, N = 167) = 163.80, p < .001$, Cramer's $V = .70$). Specifically, parents tend to care for children under the age of 21 years (83.3%), spouses tend to care for partners over the age of 60 years (67.7%), and children care exclusively for parents who are older than 60 years (100%).

The correlation between caregiver age and a specific care recipient age group is reasonably strong ($r_s = .76, p < .001$). Further, there is a significant difference between carer groups based on the length of time that respondents have been in their caring role ($F(2,121) = 16.65, p < .001$), with parents being those who, on average, have been in their caring role the longest (13.2 years) – almost three times longer than spouses and over two-and-a-half times longer than offspring (with the difference between spouses and offspring not significant).

An additional item of information provided from the ARC database records relates to the condition of recipients, which is summarised by carer group in Table 2.

	ADHD	Frail age	Disability	Mental Illness	Not stated
Spouse	1.5%	53.8%	38.5%	4.6%	1.5%
Offspring	0%	91.7%	8.3%	0%	0%
Parent	6.4%	0%	85.9%	7.7%	0%
PROPORTION	3.6%	34.1%	56.3%	5.4%	0.6%

Table 2. Condition of care recipient by carer group

Parents predominantly looked after a care recipient with a disability, ADHD or mental illness, while offspring tended to look after those who were frail aged. Most spouses looked after a partner suffering from frail age, but many were caring for a partner with a disability.

In terms of the number of times clients accessed the CRC in the six month period, there was no significant association between carer groups ($\chi^2(8, N = 167) = 12.14, p = .15$). In other words, no carer group accessed the CRC more frequently than any other group (although it should be noted that clients are limited to four weeks respite assistance in any three-month period).

SURVEY FINDINGS

Half of respondents (50%) indicated that they experienced ‘a barrier’ of some sort in accessing respite services. The presence of a barrier was greatest amongst parents (56.4%), followed closely by offspring (54.2%) and then spouses (40.6%). However, there was no significant association between experience of barriers and carer group ($\chi^2(2, N = 166) = 3.70, p = .157$). Keeping in mind that each respondent was able to indicate a multiple number of barriers, we can note the following results. For spouse carers, the most common barrier was fees (14.1%), followed by lack of information (9.4%) and lack of choice (9.4%). For offspring carers, their main barriers were fees (20.8%) and a waiting list for services (20.8%), followed by lack of information (16.7%). For parents, the main barrier was a lack of choice (19.2%), followed by lack of information (18.0%) and funding for services (16.7%).

The results for the question asking about the quality of initial information on respite services are provided in Table 3.

	Very good	Good	Average	Poor	Very Poor	No Response
Spouse	61.5%	24.6%	4.6%	1.5%	3.1%	4.6%
Offspring	37.5%	54.2%	8.3%	0%	0%	0%
Parent	46.2%	16.7%	19.2%	10.3%	3.8%	3.8%
PROPORTION	50.9%	25.1%	12.0%	5.4%	3.0%	3.6%

Table 3. Rating of initial information provision by carer group

When the data for ‘good’ and ‘very good’ are aggregated into the category of ‘above average’, 86.1 per cent of spouses and 91.7 per cent of offspring indicated overall satisfaction compared to a relatively lower 62.9 per cent of parents. On this basis, the data were reclassified into above average (i.e. overall satisfaction) and an average-or-lower rating. While ratings of the quality of initial information provided by the CRCs were quite positive across the carer groups, there was a significant association ($\chi^2(2, N = 161) = 15.49, p < .001$) between ratings and carer group, which was moderately strong (Cramer’s $V = .31$). Spouses were particularly associated with an above average rating (adjusted residual = 2.8) and parents were particularly associated with an average-or-below rating (adjusted residual = 3.9).

The results for the question that related to promptness in responding to requests were more even across carer groups, with no significant association between responses identified ($\chi^2(2, N = 162) = 1.54, p = .46$). Table 4 summarises the results for this item.

	Very good	Good	Average	Poor	Very Poor	No Response
Spouse	79.0%	12.9%	4.8%	0%	1.6%	1.6%
Offspring	66.7%	33.3%	0%	0%	0%	0%
Parent	66.7%	26.7%	5.3%	0%	0%	1.3%
PROPORTION	71.4%	22.4%	4.3%	0%	0.6%	1.2%

Table 4. Rating of promptness in response by carer group

Helpfulness of staff also failed to produce a significant association ($\chi^2(2, N = 162) = 3.90, p = .14$). The results are shown in Table 5.

	Very good	Good	Average	Poor	Very Poor	No Response
Spouse	79.0%	16.1%	3.2%	1.6%	0%	0%
Offspring	83.3%	12.5%	4.2%	0%	0%	0%
Parent	70.7%	14.7%	13.3%	0%	0%	1.3%
PROPORTION	75.8%	14.9%	8.1%	0.6%	0%	0.6%

Table 5. Rating of staff helpfulness by carer group

There was, however, a significant association between the rating of the CRC to meet all the carer's needs and carer group ($\chi^2 (2, N = 162) = 21.75, p < .001$), which was moderate in strength (Cramer's $V = .37$). The results are shown in Table 6.

	Very good	Good	Average	Poor	Very Poor	No Response
Spouse	64.6%	23.1%	6.2%	1.5%	0%	4.6%
Offspring	54.2%	45.8%	0%	0%	0%	0%
Parent	41.0%	23.1%	25.6%	3.8%	3.8%	2.6%
PROPORTION	52.1%	26.3%	14.4%	2.4%	1.8%	3.0%

Table 6. Rating of CRC's ability to meet all needs by carer group

While 87.7 per cent of spouses and 100 per cent of offspring provided a rating of 'good' or 'very good' (i.e. 'above average') for this item, only 64.1 per cent of parents provided a similar rating. In other words, one-third (33.2%) of parents rated the ability of the CRC to meet all their needs as average or worse.

The association between needs satisfaction and carer group was stronger than that between needs satisfaction and condition of care recipient ($\chi^2 (2, N = 161) = 11.17, p < .01$, Cramer's $V = .26$), indicating the primacy of the carer group as the main factor. Interestingly, there was no significant correlation between an average-or-worse rating by parents and the experience of a barrier in accessing respite services ($r_s = .20, p = .08$). There was also no significant correlation between an average-or-worse rating by parents when questioned about the ability of the CRC to meet all their needs and an average-or-worse rating by parents of the

initial provision of information by the CRC ($r_S = .14, p = .24$). Neither was there a significant difference between those parents who gave an above-average rating and those who did not, based on their length of time as a carer ($F(1,70) = .18, p = .67$).

For the question asking about the ability of the CRC to take into account their *specific* needs/situation/difficulties, there were no significant associations found ($\chi^2(2, N = 160) = 4.76, p = .09$). The results are shown in Table 7.

	Very good	Good	Average	Poor	Very Poor	No Response
Spouse	71.0%	19.4%	8.1%	0%	1.6%	0%
Offspring	62.5%	29.2%	8.3%	0%	0%	0%
Parent	49.3%	28.0%	13.3%	5.3%	2.7%	1.3%
PROPORTION	59.6%	24.8%	10.6%	2.5%	1.9%	0.6%

Table 7. Quality of CRC in considering specific needs rated by carer group

Discussion

DIFFERENCES IN CARER RATINGS

The generally high satisfaction ratings with the ARC's Carer Respite Centre services is an important outcome. The results indicate, however, that there is a significant difference between carer groups with regard to rating the CRCs in terms of their provision of initial information and their ability to meet the different needs of carers vis-à-vis different carer groups. Spouses and offspring differed only in the degree to which they were positively satisfied with the CRCs, while parents were significantly less likely to give an above-average rating. Although the majority of those caring for children were satisfied with their CRC (an outcome not to be considered lightly), it was nevertheless the case that almost one-third of parents caring for a child felt that their needs were not being positively met by the CRCs.

The reasons for the significant difference between carers of children compared to the other carer groups in relation to these two criteria could not be clearly discerned from the analysis. The fact that there were no significant differences between the groups in terms of their rating of the CRC's ability to meet clients *specific* needs indicates that the problem that parents face is primarily one of the available service options rather than that of service delivery. In other words, it would seem that the carers were satisfied with services received, and that they

were satisfied with the level of provision, but those caring for children were neither satisfied with the range of services available to meet all their needs nor the provision of information regarding available services. This confirms Cotterill, Hayes, Flynn and Sloper's (1997, p.780) view that satisfaction with services provided and satisfaction with the level of provision available tend to be two distinct components in evaluations of respite services, with positive ratings of one component not necessarily translating to positive ratings to the other.

While it would seem logical that dissatisfaction with information provision might be related to dissatisfaction with lack of respite options, the results indicated no correlation between the two. In other words, carers of children who were generally unsatisfied with the lack of service options were not more likely to be unsatisfied with the provision of information, and *vice versa*.

UNCERTAINTIES IN THE FINDINGS

It is uncertain whether the lower ratings by parents regarding the two criteria discussed are due to some degree of neglect of this carer group's needs (either by the CRCs or by health/disability services generally) or due to the general difficulties that characterise this carer group's particular situation (or to a combination of both). The fact that the condition of care recipients had no bearing in explaining the variations between the carer groups with respect to the satisfaction of all needs should not be accepted at face value. The particular type of disability and the severity of the disability were not considered as variables in the survey. Further, it may be the case that the condition of care recipients when combined with the particular life stage position of the caregiver may be important. Indeed, many carers of children with disabilities tend to face certain challenges associated with being young adults – for example, being prone to greater financial challenges, work demands and social issues compared to carers from other age groups (which is not to trivialise in any way the struggles experienced by other carer groups). None of these factors were measured in the survey.

Given the strong correlations between the age of the caregiver, carer group and age of the care receiver, it would also be necessary to rule out age as the principal factor behind the variations in satisfaction ratings. Unfortunately, the manner in which carer groups cluster around different age categories (both with regard to the caregiver and care receiver) meant that it was not possible to meaningfully compare carer groups *within* age categories, and hence determine whether significant differences persisted between carer groups when age is accounted for. Nor was it possible to compare different age categories within carer groups to identify significant variables. Only a larger sample size would resolve this issue. Hence, the carer groups identified in this study could alternatively be defined by particular ages of the caregiver and/or care recipient, rather than the

relationship between caregiver and care receiver *per se*. It is quite feasible that either one, two or all three of these variables could account for different satisfaction levels between the carer groups.

Conclusion

One-third of parents surveyed rated the ability of the CRCs operated by the Australian Red Cross as average or worse. While their ratings about the respite service are positive overall, the significant difference with respect to the other main carer groups is important from an evaluative perspective, particularly when the objectives of the National Respite for Carers Program (NCRP) are considered. The NCRP guidelines for Commonwealth CRCs lists “younger people with moderate, severe or profound disabilities” as one of its five target groups (CCRC Guidelines, p.1). It also lists the aims of informing carers “about any options for support open to him or her” and of being “responsive to the diverse social, cultural and physical experiences and needs of carers and the persons for whom they care” (p.21) among the principal responsibilities for service providers. In this respect, the study indicates that there is a greater need to inform clients of the services available to them and to improve the range and type of services offered. These are important matters that CRC’s operated by the Australian Red Cross and other organisations need to consider in order to fully meet the objectives of the NCRP program.

IMPLICATIONS FOR RESEARCH, POLICY AND PRACTICE

The findings of this research serve as a reminder to service providers and medical practitioners that different carer groups have different needs and/or expectations, and that respite services – like other health care services – need to become more responsive to these needs if they are to satisfy all client groups. The results of our research suggest that health providers need to strive to further ensure the availability of respite services that are tailored to the specific needs of carers of children, and to ensure that information about these services is conveyed to this client group more effectively.

General practitioners, nurses and other health care professionals all have a role to play in ensuring that reliable service information is provided to carers, and they should not leave it to referral agencies alone to ensure that appropriate respite information is provided. The ability of general practitioners and nurses working together with referral agencies in providing information for carers has obvious advantages. Practitioners are those most often in contact with carers, and hence are in the prime position to inform clients about available respite services that can be matched with their specific needs. Referral agencies, for their part, can serve an

important role in providing up-to-date information on available services to health practitioners.

The findings are also a reminder to evaluators and researchers that different carer groups need to be clearly delineated or disaggregated in evaluation/research designs. There have been too few studies that have considered the relationship of caregivers to care recipients as an important variable in their methodology and data analysis, with the consequence being that different carer groups tend to be overtly aggregated into the general category of 'the carer' with important differences obscured.

LIMITATIONS OF RESEARCH

It needs to be stressed that the results of our research are limited to users of Carer Respite Centres, and not to the population of carers as a whole (many of whom do not receive – or even claim to need - respite care at all). Hence, the research is only relevant to the satisfaction ratings of those who have already sought information on respite services (or more specifically, those who have sought information from the Australian Red Cross), and who can be expected to already have some level of general awareness and need of such services.

The results are also limited in terms of being unable to identify the specific factors underlying the different satisfaction ratings among different caring groups. There was no attempt made in the survey design to investigate the question of why carers were or were not satisfied. This is in contrast to studies such as Nicoll, Ashworth, McNally and Newman's (2000) that explicitly set out to explore possible influencing factors on satisfaction levels (in their case, the level of social support for carers).

DIRECTIONS FOR FUTURE RESEARCH

Further research is needed that explores the defining features of each of the different carer groups and the range of needs related to their particular situation. For example, more extensive quantitative research is needed that explores variables such as age, marital status, income level, the specific disability of the child, motivations for using respite care and initial expectations. In short, there is a great need for fully disaggregated data in this regard. Such research may help identify the specific factors that distinguish highly satisfied clients from those who are less satisfied. In-depth qualitative research is also required that explores the needs and views of carers of children. Such research would enable service providers, general practitioners and other health practitioners to more fully understand and attend to the needs of this carer group and ensure that respite care services are benefiting all carer groups equally.

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