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**'What Motivates Individuals in a Community to Respond to the Strain
of Responsibility Experienced by Some of its Members by the Particular
Response of Respite?'**

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Project Title:

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'What Motivates Individuals in a Community to Respond to the Strain of Responsibility Experienced by Some of its Members by the Particular Response of Respite?'

Abstract

The research question is posed in order to provide insight into the motivation for, and the experience of, respite care from the perspective of the carer. It also seeks to uncover the values underpinning the motivation behind the desire some people have to become 'respite' carers for children. The research project was conducted through JewishCare's Family to Family Respite Care program. The research project seeks to estimate and understand the values inherent in such respite carer families. Through this study the research will gain an appreciation of the existing respite care program and extrapolate the value of such a program to the wider community. It aims to raise awareness of the value inherent to individuals in participating in such programs as respite care. Respite care is designated as short-term relief for those who are caring for family members or others who have significant needs. Respite care provides a family, a family member or a full-time primary care-giver a short-term break from their care commitments.

Keywords: *respite care, families, motivation, values, altruism, empathy, caring.*

Background

Part of the breadth and almost boundless diversity of human experience, the offer of respite is encompassed in the full nature of caring as a human interaction (McCamant, 2006). Since the very first families created communities the offer of respite to others has existed. Someone offered to take in a child for a short time to give someone else a break. Respite care as a service has to be seen within the development of the welfare state. Prior to World War II most care that would now be termed as 'respite' was informally arranged in the family or the extended family ("<http://www.health.gov.au>"). Domestic assistance or 'home help' services tended to emerge later. In Australia there are families who have a need for help in the specific area of respite. There can be many reasons for this. Large, geographically close family networks, which were once a great source of support, are no longer the norm for most people (

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["http://www.acoss.org.au"](http://www.acoss.org.au)). Increase in the number of women in the work force, high rates of divorce, child rearing outside of marriage, and an overall decline in marriage and remarriage challenge the paradigm of the nuclear family (Bures, 2009). Support is limited as family units have become smaller and there is an increased social mobility because people often move for employment. This has led to many people being socially isolated in their communities. In addition to this, many families, who are in need, are often less likely to ask friends or relatives to help out. They may be full-time carers of a child, adult or an elderly person who has special needs ranging from disability, mental illness, or aged care issues. Or they may simply be parents who have a need for respite because the ongoing strain of responsibility for their own child is too great for them to manage. Respite care can be provided on a regular, planned basis, or in an emergency or crisis situation.

JewishCare

JewishCare is a major provider of non-residential services to the Sydney Jewish community. Each year JewishCare provides a wide range of services that help some 4,000 people. These services are targeted at the aged, people with a disability, families and youth in crisis, and people with mental health issues. JewishCare currently operates a small Foster Care/ Respite, Program which offers services for children. It is known as *Family-to-Family* (["http://www.jewishcare.com.au"](http://www.jewishcare.com.au)). The program has been running since 2002 and was the first respite care service in Sydney for Jewish children. It provides short-term care for children between the ages of 0-16 whose families feel they need a short-term break from being the primary carer of the child. What makes this service different and unique is that it offers respite to families with needs in a wide range of areas.

- Single parent families and families who are isolated due to lack of extended families or community support.
- Families who are struggling to meet the financial and emotional needs of their children.

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- Families who have experienced a situation of child abuse or domestic violence, mental illness, disability and or behavioural problems (["http://www.jewishcare.com.au"](http://www.jewishcare.com.au)).

Research Aim

The aim of the research project is to provide insight into the motivation for and the experience of respite from the perspective of those offering care. It also seeks to explore caring and values underpinning family and community support in the area of respite care. Through this study the research will gain an appreciation of the existing respite care program and extrapolate the value of such a program to the wider community. It will raise awareness of the value inherent to individuals in participating in such programs as respite care.

Literature Review

The literature review looked at the areas of respite care, motivation, values, and caring.

Respite care as a form of social support was first identified in the literature as 'an unmet need' twenty years prior and continues to be 'problematic' (Beresford, 1995; Gravelle, 1997, cited in MacDonald and Callery, 2003, p279). In an overview for government of all of the programs available in the ACT, Enduring Solutions (2002) found services should achieve living and service delivery arrangements that are: the same or as close as possible to general community norms and patterns; appropriate to the age and cultural background of their users; and that involve the least restriction to their rights and opportunities (pp67-68). Smyth and Eardley (2008) cite a study of foster caring in NSW, by McHugh et al., (2004), which 'found urgent needs for carers in all areas of fostering' (p16).

Respite programs offered around the world were investigated to see if there was a link to research and to see the differences in the programs. There were few if any links to research. In December of 2006, the federal Lifespan Respite Care Act was passed by United States Congress to coordinate community-based respite care services for family caregivers of children and adults with special needs (Lifespan Respite Care Act (PL 109–442), 2006 cited "<http://www.gotoskn.info>"). Cramer and Carlin (2008) released in the UK results of a survey of respite care, again for disabled or those with mental illness. In Glasgow the approach is broader with respite offered for children: because the parents are receiving support in attempting to overcome substance or alcohol misuse; parental illness or ill-health; a family or parent coping with difficult circumstances such as bereavement or separation; or simply first-time parents who need support in caring for their child ("<http://www.glasgow.gov.uk>"). This was the scheme that closely matched JewishCare's Family to Family Respite Care program ("<http://www.jewishcare.com.au>").

In this project caring as a value was researched because the very act of offering respite makes public individual values. In a paper by Paoletti (2002), caring is seen as 'bound to feminine identity' and 'is conversationally constructed as a feminine practice' with connotations both moral and emotional (p814). According to Paoletti (2002), caring practices are bound to feminine identity and make a contribution to moral worthiness. For Fischer (2006), values shared within one's culture reflect social norms whereas individuals tap more into personal preferences and personal values. The value of caring is passed on through parental influence and this study seeks to assess if this is indeed strongly internalized as a cultural norm. Values lie at the core of the diverse world of human behaviour and are expressed in every human decision and action. According to Keigher (2000), they represent basic convictions of what is right, appropriate or desirable, and motivate social behaviour.

Motivation is defined as 'a set of interrelated beliefs and emotions that influence and direct behaviour' (Wentzel, 1999; see also Green, Martin, and Marsh, 2007, 2008a, 2008b, in press cited in Martin and Dowson, 2009, p328).

Motivation is underpinned by relational dynamics with motivation by internal factors referred to as intrinsic. According to attribution theory, individuals attribute causes to events depending on the way they cognitively, affectively, and behaviourally respond (Martin and Dowson, 2009, p333). In reference to the research topic it is important to include these intrinsic motivators as they indicate a deeper level of motivation to consider in an analysis of the data. Motivation is intimated in the language from the semi-structured interviews conducted in this project. Altruism and empathy in some form are possibly strong motivators for those who offer respite care. According to Eisenberg (1991) Batson and Shaw define altruism as 'a motivational state with the ultimate goal of increasing another's welfare' so empathy is 'the sole motivation for altruism' (p128). It has even been seen as a genetic trait, *a trait for behaving altruistically to others who share this trait* (Humphrey, 1997, p207). Rushton (1991) sees it as innate with empathy learnt from parental care (p142). People can be expected to favour their own group or community in altruistic acts according to 'genetic similarity theory' (Rushton, 1991, p143). According to the 'empathy-altruism hypothesis', altruistic behaviour occurs regularly and frequently but requires 'an empathetic emotional response within the potential helper' (Batson, 1990, cited in McCamant, 2006, p337). Although altruistic motives are not specifically expressed in the interviews, the findings of this study indicate strong support for this hypothesis. The questions did not specifically mention any values or motivations as spontaneous responses were sought.

Methodology

Narrative Analysis is the methodology chosen for this research project as 'a narrative inquiry approach is seen as a preferred way of exploring social

phenomena' (such as respite care) (Stanley, 2008, p435). It is a qualitative and interpretative methodology with data drawn from semi-structured, face-to-face interviews. For Pellico and Chinn (2007), narrative is seen as a rich ground from which 'to develop new insight and new knowledge' (p58).

The methodology involved textual analysis of the taped interviews. The methodology examines the tacit knowledge conveyed in the narrative, how it can enable sense making, and how it constructs identity as put forward by Mitchell and Egudo, (2003). Narrative methodology is particularly suited to preserve the unique richness of self-narrative especially if the interviewing technique is non-intrusive. The justification for using this methodology is succinctly explicated in the following quote:

'Stories told within their cultural contexts to promote certain values and beliefs can contribute to the construction of individual identity or concept of community.' (Mitchell and Egudo, 2003, p7).

For Stanley (2008), from this narrative method insights can be gathered not only about differences in cultures but also about the validity of cultural dimensions and the extent to which the dimensions play a contextual role. Perceiving connections between stories is analytically most appropriate when such stories 'belong together' in the research context itself. Thus the focus is on how individuals or groups make sense of events and actions in their lives 'through examining the story, and the linguistic and structural properties' (Riessman, 1993, cited in Mitchell and Egudo, 2003, p8).

Thematic analysis was used in reference to Riessman's (2004*b*, cited in Bryman, 2004, p412) model which places the emphasis on what is said in the interview. 'Value' words were extracted from all of the interviews and compared for similarity and difference. The themes of 'caring', 'sharing', 'community' and 'social conscience' were anticipated. Unexpected and different

themes might also emerge. Thematic shifts in the interview were taken into account and the changes of speaker were examined because they might indicate changes of theme and importance. The analysing of stories that are linked together because of an involvement in the same pursuit (respite care) enrich the researcher's interpretational work in perceiving tacit connections that may be applied to supporting respite care as a social phenomenon to the wider community.

Project Report

After consultation with the program coordinator a list of potential participants was made. The program coordinator made the first contact with these people by telephone and email. The potential participants were sent a letter about the project which asked for an expression of interest. Upon confirmation the participants were sent an information letter outlining the research and including a consent form. It stated that the interviews were to be taped and the tapes were to be code marked only, to protect the privacy of the individual respite families. A follow-up telephone call was made to ascertain if one or both parents were available to be interviewed. A time to conduct the interview and a suitable location was also discussed. Upon agreement the participants were informed that the consent form would be collected at the time of the interview. At the time of the interview an information sheet about how the interview was to be conducted was read out. It reiterated the project's interest in their experiences in participating in the respite care program and that all responses would be kept confidential. The participants signed this document. Data was stored on the researcher's premises by the researcher in a locked filing cabinet to be kept for five years. Unauthorised individuals are not permitted access to this data. As the respite family data is coded the individuals from the interview tapes are not able to be identified.

Procedure

The participants were couples who offered respite through JewishCare's Family to Family program. Interviews were conducted at the participant's home. The participants signed a consent understanding that the interviews were to be taped. Participants were asked the questions from the semi-structured interview. In most cases, participants appeared calm during the interview process, and did not show any overt indication of being upset or distressed. They maintained a conversational interaction and the atmosphere was relaxed. Each interview was transcribed from audio-tape soon after it was completed. After transcription, the data were broken down by coding of individual concepts conveyed by the participants. This coding process organized the text into segments based on the meaning conveyed, and each segment was labeled as themes (Creswell, 2005). These occurred naturally. The interviews were compared 'for their intrapersonal and interpersonal structures' (Gagnon and Simon, 1974; Simon, 1996, cited in Fraser, 2004, p191). As the analysis proceeded, a larger organizing structure emerged. This structure was then used to organize the data into broader themes, in order to aid analysis. Throughout the analysis, effort was directed at determining the most central, or core themes. By sorting the data into each relevant theme, the categorization was complete. It was now possible to understand the key areas and further analysis revealed major themes and led to the development of the emergent findings.

Findings

JewishCare has a broad-based program that offers an insight into the application of a model of respite care to its community. According to Smyth and Eardley (2008), the availability of respite care is recognised as 'essential

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to support (primary) carers and provide them with temporary relief from the stresses of caring' (p46).

Narrative Analysis is a methodology that evidences stories as unique and individually constructed wholes. What the participants have to say provides more specific and relevant information than research assumptions or questions could.

How they heard about respite care:

1. ad in school newsletter
2. visit to synagogue
3. from daughter working in social services
4. self generated (would have gone to Department of Community Services)

'We would have gone to DOCs but then we thought having a normal foster child or respite child there would be complications with Easter Christmas so then we thought "I wonder if there is a Jewish program?"'

Training:

Training was one of the major areas of difference in this program. The respite care training is a Department of Community Services (DOCs) program (<http://www.community.nsw.gov.au>). Respite care is considered an aspect of fostering and the training received by the participants in this study qualifies them to be full time foster carers (Hayden et al., 2000).

'We had to qualify first before doing the course in DOCS it is the opposite.' The participants were interviewed twice before being accepted to do the course. It is a four to six weeks commitment depending upon where the course was conducted. 'With DOCS anyone can do the course, then they have to go through the qualifying process or screening process'. JewishCare conduct the

training annually. This necessitated one couple travelling to complete training, which evidenced their commitment. Training in the area of boundaries was strongly referenced by the participants. The program coordinator regularly followed up to ensure the best interests of the children. The amount of time spent with the child was monitored and care was taken to ensure those in the program did not usurp the power or the control of the parent.

Length of time in the program:

This extended from two years to four and a half years; every second weekend to every third weekend with one family having two children (because of family commitments) every two months. One family had a previous respite care experience with a child which did not work out. This child had Asperger's Syndrome with challenging behaviours, although the main problem was 'his mother didn't cooperate... wasn't there when we went to go and pick him up'; 'she'd hide him'; 'it became a DOCs issue'. 'But I think it wouldn't have been a binding thing over the years for the family, we wouldn't have been able to get close to him'. This same child has now been successfully cared for by one of the other participating couples for two years.

Intergenerational family values:

This was evidenced in two families where their 'parents have always been community aware' or who had been involved in the Big Brother Big Sister program. One of the participants had also been in that program as a teenager and was still in touch with her 'sister'.

Motivation:

Each couple spoke about giving back to the community because 'there are some out there who need help'. If a mother or a family is unable 'then you or

the community needs to come in and help.' It was seen as a way of giving to a child something that they missed out on 'based on the belief that I got everything that I needed as a child'. To be helpful and share a loving family experience were strong motivators across all participants. It makes them feel good to do something. 'We may as well share it with those that can benefit'. There is a 'sense of achievement' in 'doing something useful'. Altruism was mentioned spontaneously in only one interview. 'I am not sure it comes from somewhere really positive and altruistic'. Her partner did point out that (she) has a history of altruism'.

Values:

Values expressed were 'respect for each other and care'. Family values were indicated as participants considered themselves 'lucky and to be able to be brought up in a family where every need is provided and to live in a nice house in a nice suburb and so forth'. 'I would like X to feel that everyone in our life is part of her life too'. 'It is easy to write a cheque, but giving of your own time that is something different.' 'Value' words from all of the interviews were similarly expressed: 'fortunate', 'caring', 'sharing', 'loving', 'giving back', 'lucky', 'part of our family'. The overall impact on the families was very positive. 'It to some degree unified us as a family'. Although one participant made the salient point: 'I am under no illusions that just because I have certain views that they will have them later in life'. Another commented: 'It is not really our childrens' responsibility to care for them you know'. The value of caring passed on through parental influence is supported by this study. The study is too small to indicate if this is a strongly internalized cultural norm. Community interconnectedness and the fostering of a social conscience with family members were strong family values supported by the study.

Discussion

Specific questions asked about values and motivations did not result in as much information as the analysis of the carer's experience of respite. The anticipated themes of 'caring', 'sharing', 'community' and 'social conscience' were found in the participants' responses. The experience evolved from uncertainty 'initially we thought we had to prove ourselves to her' to 'we can make her feel comfortable just doing the very basics that we do'. It was often an opportunity to re-parent. 'What about a rule that X goes to bed a certain time it works amazingly well for us. Look its eight o'clock, its bed time and off she goes' which produced a 'Wow!' There was a benefit experienced in improved parenting skills; being calmer and more patient. Frustration was expressed as one saw things that the children needed. 'It would almost be better to have them during the week and have (them) go to their mum's on the weekend'. 'Just a bit more structure would be good for them. I wonder what good am I actually doing, am I just a glorified babysitter?'

One of the unexpected areas the data uncovered was the issue of boundaries. This came up in a few specific ways. One couple felt strongly about 'stepping over a line' into a more educative role, however decided the experience ought to be 'purely respite for the child; not too stressful'. Another couple found the opposite wanting 'to get involved more', despite being 'constrained' as they saw the child in need of medical care. In every case the perceived benefits for the children, the respite carers and their families was considerable. Everyone interviewed said 'they would do it again'. Initially the children were often very challenging and there was a considerable settling in period for all involved. The reported improvements in the childrens' behaviour are an endorsement of the dedication, persistence and the commitment of all of the respite carers and their families.

Motivation is intimated in the language from the semi-structured interviews conducted in this project. Altruism and empathy in some form are suggested as strong motivators for those who offer respite care. This is evidenced by the overall enthusiasm expressed by the participants for the experience of respite; the predominantly positive impact on their families; the benefits and marked improvement in the behaviour of the children over the period of contact and the extension of the childrens' world into the wider community were all major findings of the study. This study has been a snapshot of how very successful this program is for the children involved.

'The foster family potentially provides a healthy context for a child to learn new skills, modify the maladaptive aspects of his/her behavioural repertoire, and enhances the factors that promote resilience' (Wyman, 2001, cited in Nilsen, 2007, p45).

Limitations of this study

While this study provided important insight into perceptions and experiences of respite care, it is best thought of as an exploratory, pilot study with several limitations. The first and most significant limitation in the research involves the small sample size. Only eight participants were interviewed. This sample size is small, even for a qualitative analysis and, as a result, each interview continued to add unique themes to the analysis. Saturation in all domains was not reached, suggesting that there is more to the experience of respite care than is revealed by these interviews and analyses, especially when considering wider community application. It is likely that interviewing other participants would introduce more variability in the sample, and possibly influence the overall results. There is the possibility that participants left out parts of their narratives that they did not feel comfortable sharing with the interviewer.

Conclusion

There is a distinct lack of knowledge in the literature about what motivates the offer of respite care, especially in the area of general respite care. It has also been shown that there are many different respite care programs around the world. Respite care has been found to reduce stress, strain and burnout in families thus providing a valuable means of enhancing the families' coping resources. The available literature is often only on foster care or in the areas of disability, mental health or aged care. Almost no research was found evaluating or determining what type of person most appropriately provides respite care. This study found in agreement with Martin and Dowson, (2009), that individuals develop beliefs and values that are consistent and relate to their internal and relational environment (p328). Whether empathy is 'innate' as Rushton (1991) maintains is beyond the scope of this study however there is evidence of the influence of intergenerational caring values. The participants did favour their own group or community in altruistic acts of respite care. According to Eisenberg (1991) Batson and Shaw define altruism as 'a motivational state with the ultimate goal of increasing another's welfare' (p128). However these results would indicate that motivation is a consequence of unintentionally acting altruistically. There is a rebound effect with the helping person benefiting enormously from the experience. Future research is needed to determine the nature of these possible differences. Research into caring applied to respite care givers could offer further insight into values and motivation. In agreement with Keigher (2000), this study found that values represent basic convictions of what is right, appropriate or desirable, and motivate social behaviour.

Family-based respite provides a quality and cost effective service which needs to be elevated from its existing status as an appendix to main stream respite services. In order for this type of respite service to be offered as a meaningful

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choice to families it needs to be given recognition as an equally important respite alternative. A more 'respite carer-centred' approach is required in both the provision and evaluation of respite care. The provision of such services to the wider community needs to be further investigated in a future study.

Host carers are the lifeblood of family-based respite care programs. The programs are only as good as the carers that they attract. I would like to pay tribute to all those involved in the provision of services and to acknowledge the exceptional commitment that these carers have evidenced in this project.

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