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Family Caregiving in Singapore

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Strengths of the Carer and the Contribution
of the Person with a Disability

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1. Introduction and overview

1.1 Rationale for the study

This research study sought to investigate the experience of caring for a family member with acquired brain injury (ABI) in Singapore. Living with and caring for a person with severe disability is demanding and exacts a toll on family members. There is much research literature on the issues, demands on caregivers and their needs, and the notion of the burden of care. For family caregivers providing care for a relative with ABI, cognitive impairment increases this load. However, less research has been conducted on how these caregivers manage to provide care every day after the injury has been acquired. How do they manage to do this? Are there any rewards or satisfactions for them in being a caregiver? Does their family member give anything back in return? Much of the literature about caregiving, including in the field of ABI, is also quantitative in nature, measuring burden and methods of coping. There is less research using qualitative methods and privileging the caregiver's view, or that of the person with a disability or other family members.

The positive outcomes of caregiving are less frequently reported in exploratory, descriptive or explanatory research – what carers gain from their experience and role, and the resilience of families that care for members with a disability. Studies published in Singapore are also scarce. Because of the medical context in which much of the literature is published, the paradigm used is one of pathology and deficit – identifying, assessing and treating problems – rather than a strengths perspective which frames understanding in a positive context, that of attributes and skills. Therefore this study was designed to investigate how families manage and utilise their strengths and assets to provide ongoing care.

The study examined the caregiving process and experience of Singaporeans who care for an adult family member with acquired brain injury (ABI), from the perspective of the strengths and resilience of the caregiver. Positive aspects and rewards of caregiving were

explored as well as the skills caregivers develop. The focus of this study charted a relatively unexplored area of caregiving to date.

Understanding the experience of caregiving in a more holistic fashion and learning about caregivers' strengths and skills will inform health care workers and social services policy makers and providers in their interventions with caregiving families. Better trained and targetted workers and volunteers will be able to more accurately meet the needs of these families and improve the quality of life for carers and people with acquired brain injury. The acknowledgement of the abilities and contributions of people with acquired brain injury will also provide a more accurate representation to the broader society and promote a more inclusive response to people with disabilities and disabuse the public as to their needs.

1.2 Support for the study

The study forms part of a broader study on family caregiving in Singapore funded by the National University of Singapore (NUS). This study comprises three main parts, examining also spousal carers of the aged in Singapore and Japan, and the experiences of children and children-in-law as caregivers. A survey of community-based agencies was carried out also to provide descriptive data on family caregiving between December 2005 and March 2006. The study results provided data on the profile of caregivers, profile of care recipients, caregiving activities, and caring for a second person (Ng, 2006).

1.3 Acquired Brain Injury (ABI)

Acquired brain injury leads to sudden changes, with significant personal and social implications. This injury interrupts personal development and life plans, and interferes with career goals, relationships and identity. The person who sustains this injury often comes to depend on care and supervision from family for an indefinite period after discharge from hospital.

While strategies can be learned and equipment used to accommodate a range of physical, sensory and cognitive impairments, genuine community participation, and the enjoyment of a web of caring, reciprocal relationships, often elude people struggling with the effects of brain injury. Advances in neurosurgical care and patient, intensive rehabilitation deliver impressive results, but these interventions are not able to address many quality of life issues such as how to make friends again.

An Australian study examined the social networks and friendships of adults with acquired brain injury. The finding that prevailed above all others was the loneliness experienced by men and women as a result of this injury. Friendships that predated the accident were not able to sustain the radical changes wrought by the combination of impairments sustained. New friendships were difficult to form and maintain and most participants socialised with fellow peers from the local community access service. These friendships were valued, as they shared common difficulties and understanding, yet they were also somehow insufficient (Rowlands, 1999).

Acquired brain injury of traumatic causation, for example from a blow to the head, can produce diminished or altered states of consciousness, and often results in impaired cognitive abilities and/or physical functioning (Ponsford, Sloan and Snow, 1995). For some people, the level of disability leads to permanent institutional care. Internationally over 70 per cent of those who experience a brain injury are aged between 16 and 25 years, with males at three times greater risk than females. The 'modern era' of brain injury rehabilitation, commencing approximately 20 years ago (Rosenthal, 1996: 88) has meant that increasingly people are surviving brain injuries due to improvements in emergency medical services and acute care.

There are significant personal and social costs accruing from ABI: in individual self respect and dignity, autonomy, and participation in the community (Elsass, 1991). The majority of people with a severe injury are not able to return to work (Ponsford et al., 1995) and many remain financially and socially dependent (Tate, Lulham, Broe, Strettles and Pfaff, 1989). "Many persons with brain injuries are

friendless, dependent on their families, uninvolved in productive community activities and lack a sense of social identity” (Kosciulek, 1997: 821).

Cognitive and behavioural impairments most compromise quality of life (Olver, 1995). Central to the difficulties experienced by people with ABI in resuming interpersonal relationships is personality change, which occurs in all but a minority of cases and increases over time (Bond, 1984). Whereas physical recovery can be good, the changes to personality are not as amenable to treatment and are considered to be permanent (Thomsen, 1984). With time elapsing since injury social networks decrease and density increases, leading to the complaint of loneliness as the greatest subjective burden (Kozloff, 1987; Rowlands 1995; Willer, Allen, Durnan and Ferry, 1990). New relationships are often transient, lacking many of the features of durable, supportive relationships.

Opportunities to develop new relationships are limited. Social skills, already compromised by the injury, are further reduced and self-esteem suffers, thus compounding the sense of isolation, as well as depression. The interaction of unemployment, motor/sensory impairment and behaviour change all contribute to the poverty of social relationships. The effects of traumatic brain injury also influence intimate relationships and sexuality, with losses experienced in the area of intimate relationships and sexual dysfunction, including breakdown of relationships/marriages (Lezak, 1978; Ponsford et al., 1995; Prigitano, 1988; Zeigler, 1989).

Most people with acquired brain injury live with their families. Caring for a family member with acquired brain injury is stressful, is perceived as an increasing burden with time, affects all relationships in the family, and causes most disruption and distress through the cognitive and behavioural impairments (Lezak, 1988; Perlesz, Furlong and McLachlan, 1992; Resnick, 1993; Serio, Kreutzer and Witol, 1997).

1.4 Effects of acquired brain injury on caregivers and families

The stresses of caring for a relative with acquired brain injury have been well documented in the research literature. Relatives' stress in the first year post injury was not significantly associated with severity of injury, as measured by length of post-traumatic amnesia and length of hospital stay (Oddy, Humphrey and Uttley, 1978). These researchers also found that 25% of the relatives in the study reported illnesses in that first year which they had not suffered previously. The majority of these were psychosomatic or emotional illnesses. McKinlay, Brooks, Bond, Martinage and Marshall (1981) found that the higher the perceived stress in relatives in their sample (n = 55), assessed during the first year post injury, the more changes in the injured person's behaviour, emotions, memory, physical or other dependence, were reported. Emotional difficulties, in particular, were reported more frequently at later assessments.

In reviewing the literature on the effects on the carer, Marsh, Kersel, Havill and Sleight (1998) concluded that carers experienced "increased levels of stress, depression and anxiety; a high incidence of psychosomatic disorders; increased consumption of psychotropic medication and alcohol; financial burden and abnormal role changes; and diminished social adjustment and increasing social isolation" (p. 227). Additionally, a high degree of distress for the caregivers was found to be caused by the social isolation of their injured relatives. As social isolation has been found to increase for the injured person over time, increased distress for the caregiver is to be anticipated. Caregivers reported disruption in their relationships with family and friends, with the impact of caring for the person with brain injury affecting the whole family unit. Caregivers' experience of subjective burden was most influenced by the number of behaviour problems in the injured person. Knight, Devereux and Godfrey (1998) reported a similar finding. The study by Leathem, Heath and Woolley (1996) found that both parents and partners as carers experienced moderate levels of stress and role change, with slightly higher stress and role change for partners. In developing an explanation for relatives' stress, Elsass (1991) concluded from the literature that relatives could find it increasingly difficult to cope with these changes and behaviours in their family member; could become more aware over time that there was no improvement, and all family members were being affected; or had not learned coping strategies themselves.

Kosciulek (1997) believed that the way in which a family adapts to brain injury was heavily influenced by its view of the manageability of the brain injury situation. Where

the caregiver appraised the stressor as being beyond his/her resources to cope, burden was experienced. Social support has been identified as possibly mediating the burden response (Brooks, Campsie, Symington, Beattie and McKinlay, 1987; Knight et al, 1998). Research has indicated that families themselves become isolated from social support networks, as do their injured members (Thomsen, 1984). An adequate social support network for the caregiver is therefore expected to be of benefit (Williams, 1991a; 1991b). Kosciulek and Pichette (1996) found that the most important item in family adaptation, as ranked by the 82 families in the study, was friends providing encouragement and support. Of the five most important items ranked by families, three related to social support, from friends, relatives outside the family, and support groups.

Williams (1991b) argued that families need social support after brain injury due to the diminution of the extended family in western societies, difficulties posed at transition points throughout the family life cycle after brain injury occurs, time limited professional support services, and the gaps between services. A range of approaches have been found to prove useful, including self help groups and Circles of Support (Knight et al, 1998; Williams, 1991b). Williams (1991b) argued that social support should be mobilised with professional support immediately after a head injury through a range of interventions, maintaining that as families acquire the skills to mobilise resources they will begin to create their own social support. Shortage of community services means that natural community supports need to be harnessed in an informed, planned way. She also raised implications for professionals who are working to promote friendships (blurring of role boundaries for example).

Leach, Frank, Bouman and Farmer (1994) also found that post injury changes often occurred in the family's functioning, impacting on the family's ability to provide the required social support. Social support has been hypothesised to work as a buffer between a significant life event and levels of depressive symptoms. Thus poor social support after brain injury, due to changes in family functioning, could result in depressive episodes for the individual with a brain injury. Results of this study showed that "effective use of problem-solving and behavioural coping strategies by the family in response to traumatic brain injury was significantly related to lower levels of depression in the person who sustained the traumatic brain injury" (Leach et al 1994: 599). However perceived social support did not predict depression.

In a later study, Wallace, Bogner, Corrigan, Clinchot, Mysiw and Fugate (1998) concluded that a complex relationship exists between family adjustment and the caregiver's perceptions of the injured member's abilities and the amount of support received from family and friends. In exploring indicators of family functioning after brain injury over the longer term, Douglas and Spellacy (1996) found that caregivers' perception of adequacy of social support was a significant predictor of family functioning. The social support factors measured in the study included problems with excessive responsibilities and demands; problems with strong-tie relational support; lack of money; and lack of involvement. "They (families) need hands-on assistance... the adequacy of the social support received by primary caregivers was shown to be the most important predictor of family functioning. In particular, instrumental or practical support appeared to be essential" (1996: 834). This finding lends support to the view that service provision and social support may be more crucial in predicting eventual outcome, than coping skills (Frank, 1994). The findings from Douglas and Spellacy's study pose a dilemma: inadequate social support can be construed as a risk factor for families caring for a member with brain injury, and upon the injured person's return home, families learn of the inadequacy of services to support them in the community. Douglas and Spellacy argued that adequate and ongoing practical and emotional support is essential for these caregiving families if successful community reintegration is to be achieved for the injured member.

It has been found that families turn to professionals only when assistance is not available from present social networks (Dunst, Trivetts, Gordon and Pletcher, 1989). Additionally, personal social networks are more available to families than professional support over the long term (Jacobs and Goodman, 1989). It is important therefore that professional support acknowledges family competence, reinforces family strengths, and assists families to gain access to social support networks (Williams, 1991b).

1.5 Strengths and resilience of caregivers

A different perspective on caregivers has been articulated in qualitative studies more recently. This leads to the question: is it narrowness of methodological approach or theoretical orientation that has obscured this until more recently? Berg-weger, Rubio and Tebb (2001) found that 90% of caregivers of chronically ill family members reported positive feelings associated with caregiving. They applied a strengths-based approach in their research, drawing on the tenets of Saleebey (2006) and others. Informing their study

were ideas such as the capacity of caregivers to grow and change; their assets, strengths and resources; and adoption of a possibilities, rather than problems, orientation.

Positive caring outcomes were found to be linked to behavioural (objective) or emotional (subjective) coping. Behavioural coping included strategies such as learning new skills, closer family relationships, using spiritual/religious support and using social support. Emotional coping referred to strategies such as reframing, adopting a sense of competence and satisfaction, discovery of inner strength, sense of purpose or meaning, ability to cope with challenge, and personal growth.

These authors found that caregiver well-being was influenced by perceptions of their situation, the family's adaptability and their own abilities as caregiver. The relationship with the care receiver was also crucial (Berg-weger, Rubio and Tebb, 2001; Berg-weger and Tebb, 1998). Their participants used strategies such as creativity in identifying the resources that are mobilised; thinking of the future; recognising the importance of spirituality; and obtaining an extensive medical knowledge. Caregivers also articulated their needs, including inadequate resources and knowledge, lack of emotional support, lack of energy for social and recreational activities and insufficient patience and understanding.

Some common characteristics of resilient caregivers have been identified: distancing, physical exercise, hobbies, support, religious or philosophical beliefs, and humour (Ross, Holliman and Dixon, 2003). Many gratifications of caregiving have also been observed, such as sense of satisfaction in fulfilling a duty, awareness, and a deeper meaning to life (Schwartz and Gidron, 2002). Schwartz and Gidron concluded from interviewing parents of mentally ill adult children living at home, that parents generally do not consider the positive potentials of caregiving until asked. When they are asked, they can identify how they have learned about their strengths and inner resources and also how their children provide emotional support to them, the parents. Schwartz and Gidron highlight the importance of how parents create meaning for the role and the range of ways in which adult children receiving care give back or contribute to the family, in such ways as companionship, news about family/friends, instrumental tasks e.g. meal preparation, and financial help.

Nolan, Grant and Keady (1998) recognised these capacities of caregivers and the satisfactions they derive from the role, leading them to develop instruments to assess how

caregivers manage and levels of satisfaction. Two of these instruments were used in this study (see Section 2). Nolan and colleagues also explored a temporal process in the caregiving role or career which comprises: building on the past; recognising the need; taking it on; working through it; reaching the end; and a new beginning. In the present study, the caregivers had been providing care for between 1 and 4 years so were still in the earlier phases of this continuum. The stage in the process that caregivers have reached will influence their experience of caregiving, how they manage, and how they perceive rewards and satisfactions.

1.6 Cultural context of the study

Singapore has a multicultural population of 4 million who are 77% Chinese, 14% Malay and 8% Indian, as a broad description. The Chinese tend to be religious (80%), inclusive of Buddhism, Taoism, Christianity, animism and ancestor worship, and continue to hold many traditional values, patrilineal family structure, and seek support from kin first (Ow, Tan and Goh, 2004). They value industry, harmony, academic and economic success. In this community there is a high level of stigma towards disability and especially cognitive, intellectual or psychiatric impairment. A child with disability may result in lack of face. The Malay population in Singapore is almost entirely Muslim, with a close-knit and supportive community, and clear roles in marriage. The Malay community values families, care and compassion, the sanctity and dignity of life, with commensurate high levels of responsibility and taking care. Each child is a gift from Allah. It is in this cultural context that the present study was conducted. As literature about caregiving in this specific Asian context is sparse, especially with regard to acquired brain injury, the cultural backdrop to the issues being explored is therefore pertinent to bear in mind.

1.7 Research questions

This study undertook to answer these questions:

- How do family caregivers experience care giving?
- What are the positive aspects of family caregiving?
- What are the strengths and skills used by caregivers?
- Is there reciprocity in the caregiving relationship and how is this experienced?
- What services or supports are helpful to caregivers in carrying out their role?

- What are the views of caregivers regarding resources or services that would make their role easier?

The assumptions underlying the study that guided its development and execution were:

- families who care for people with severe cognitive and physical impairments draw on previously unrecognised or untapped strengths and abilities;
- values, knowledge, skills and attributes from other life experience or roles are drawn on in caring for a person with a severe disability;
- family members who care for relatives with disabilities experience rewards from caring;
- family members with disabilities who receive care also give something back;
- families prefer to care for family members with disabilities if they have the resources to do so.

2. Methodology

2.1 Research Team

The study was conducted by a research team comprising Dr Allison Rowlands from the Department of Social Work, NUS (Coordinator); Mr Steven Chua, Principal Medical Social Worker, and Ms Alisa Tan, Medical Social Worker, both of Tan Tock Seng Hospital Rehabilitation Centre (TTSHRC), Singapore, and Ms Yao Zhurong, Research Assistant in the Department of Social Work, NUS. Further assistance was provided by NUS social work students, who transcribed some of the audiotaped interviews, and translated the two instruments used in the study into Mandarin.

2.2 Research Design

A qualitative design was used, seeking to answer the questions from the perspective of the caregiver respondents. Grounded theory, based in the interpretivist social science theoretical framework, was the approach used. As such, there were no formal hypotheses. Data were collected through semi-structured interviews and from measurement scales of caregiving experience and satisfaction, treated qualitatively.

The family caregivers were interviewed at a convenient location, generally their own home. The interview themes, Carers' Assessment of Managing Index (CAMI) and Carers' Assessment of Satisfaction Index (CASI) (Nolan, Grant and Keady, 1998) are attached (Appendix 1 and 2). The study received ethics approval from the Institutional Review Board of the National Healthcare Group, Singapore and the Ethics Committee of the Department of Social Work, NUS.

2.2.1 Sample

A purposive sample of 15 family caregivers of adults with ABI, was recruited through TTSHRC. Participants had been caring for a family member for at least 6 months post injury, and who had completed active rehabilitation. The sample was structured to obtain maximum diversity across caregiver characteristics such as age, gender, relationship to family member, ethnicity and religion; and patient characteristics such as type of injury and time elapsed since injury. All participants were adults, providing constant care and attention for a family member with ABI, and not suffering from a mental illness or substance dependent. Most participants were English speaking though a number were interviewed in Mandarin by the TTSHRC social workers. The sampling frame was the full set of caregivers of patients admitted to TTSHRC over the period 2002-2005.

Potential participants were recruited by the medical social workers at TTSHRC and consent obtained. Participants were then interviewed by one of the research team. At the interview the consent form was reviewed with each participant by the interviewer and any questions clarified. Taping of the interview was discussed and consent obtained if the participant was willing.

The TTSHRC social workers only contacted those family caregivers who, from their knowledge of them, were unlikely to find participation in the study a burden or an undue intrusion. It was left to the actual caregiver to decide whether or not they wished to participate. Potential participants were identified from the social workers' previous work with the family members. Recruitment commenced in February 2006 and data collection continued until July 2006. Participants were offered a token of appreciation for their time.

2.2.2 Measurement Scale data

Two instruments, Carers' Assessment of Managing Index (CAMI) and Carers' Assessment of Satisfaction Index (CASI) developed by Nolan, Grant and Keady (1998), were administered (see Appendix 1). These instruments were selected after a review of

the literature on the positive aspects of caregiving and reciprocity in the caregiving relationship.

These instruments¹ were developed to capture the caregivers' perception of caregiving and to account for the complexity of caregiving. They were designed to assess the rewards and satisfactions of caregiving, relationship to the person cared for, motivation for providing care, coping behaviour, access to support and need for information. The instruments were not designed primarily for quantitative analysis and the items were generated from caregivers themselves to capture their subjective appraisal.

Both scales comprise a series of statements which respondents are asked to rate on a 4 point likert scale. The CAMI comprises 38 statements about dealing with the demands of caring; the CASI comprises 30 statements about the satisfactions of caring. As these are assessment tools rather than measurement tools, a numerical sum of the items is not meaningful and descriptive statistical analysis only is considered appropriate by the authors (Nolan et al 1998). Descriptive statistics are presented in Section 3 to provide the overview of the views and experiences of this group of caregivers. The items can also be used as probes in qualitative interviewing and they were used in this sense in the in-depth interview stage of the study.

Coping strategies form the core of the CAMI and the authors developed three sub-scales from the instrument: strategies involving direct action; cognitive strategies, and managing stress. The data presented in Section 3 is organised into these sub-scales. The CASI is designed to explore the rewards of caring which are frequently not considered in the research literature. Therefore the CASI provides a framework for understanding how various rewards might be experienced and related to each other. Caregivers identify satisfactions arising from a range of sources, such as maintaining their family member's dignity, or keeping him/her out of an institution. The CASI structures the data collection on satisfactions around who mainly benefits ("beneficiary"), and whether the source of satisfaction is within the person ("intrapersonal"), relational between two individuals

¹ A third instrument, Carers' Assessment of Difficulties Index (CADI) was not used in this study.

(“interpersonal”), or as a result of some action (“outcome”). Therefore the CASI data is presented in this format in Section 3. The quantitative data from the CAMI and CASI instruments were analysed using SPSS to generate descriptive statistics.

2.2.3 In-depth interview data

In-depth, semi-structured interviews were conducted with the caregivers to gain an understanding of the coping strategies and rewards of caregiving. This data collection drew on the experiences of participants directly (phenomenological approach). The majority of interviews were audio-taped with the respondents’ consent. The interview guide provides the general interview themes which were addressed and probing was used to explore areas in greater depth (see Appendix 2). Eight interviews and measurement scales were conducted in English and seven in Mandarin. The interview notes from these interviews were translated by the interviewer. The scales had been translated in Singapore into Mandarin for an earlier study (Rowlands, Crawshaw and Wong, 2006).

The transcribed interviews or detailed notes were imported into the Nvivo software program (www.qsrinternational.com) for coding and analysis of themes and exploration of relationships between themes and categories.

2.2.3 Integration

The two parts of the study were designed to complement and inform each other – the instruments were chosen because they tapped into the research questions of the study. Many of the items linked to questions in the semi-structured interview and themes could be pursued from the responses to the CAMI or CASI items or vice versa. The qualitative data also enriched and further explained the quantitative findings.

Section 3 presents the quantitative findings from the CAMI and CASI instruments and examines this also in the context of the demographic characteristics of the sample.

Section 4 presents the qualitative findings from the semi-structured interviews. Section 5

concludes the research report with the integration of the key findings from both sets of data and recommendations arising from the analysis of these caregivers' experiences.

3. Quantitative Findings

3.1 Sample

The sample comprised 15 family caregivers of adults with ABI, recruited from discharged patients of TTSHRC (Table 3.1). Caregivers were aged from 26 to 61 years with a mean age of 48.47 years. The majority were Chinese (73.3%) with much smaller proportions of Malay and Indian participants, roughly reflecting Singapore’s ethnic diversity (Figure 3.1)². The caregivers were predominantly women (6 wives; 5 mothers; 1 each sister, husband, father, and son – Figure 3.2). The majority (73.3%) of participants were married (Figure 3.3). The ages of relatives cared for ranged from 19 (son) to 59 years (husband). The majority of relatives cared for sustained their brain injuries through motor vehicle accidents.

Table 3.1 Sample of Caregivers

Participant No./ gender	Carer’s Age cohort	Ethnicity	Religion	Marital Status	Carer’s Relationship	Family member’s age/gender
1 F	40s	Malay	Muslim	Divorced	Sister	50/M
2 F	50s	Indian	Christian	Divorced	Mother	24/M
3 F	40s	Malay	Muslim	Married	Wife	40/M
4 F	40s	Chinese	Christian	Married	Mother	19/M
5 M	50s	Chinese	Buddhist	Married	Husband	54/F
6 F	40s	Chinese	Christian	Married	Wife	41/M
7 F	60s	Chinese	Buddhist	Married	Wife	57/M
8 M	50s	Chinese	Buddhist	Widowed	Father	23/F
9 F	40s	Indian	Hindu	Married	Mother	22/M
10 F	60s	Chinese	Taoist	Married	Mother	33/M
11 M	30s	Chinese	Taoist	Single	Son	56/F
12 F	60s	Chinese	Christian	Married	Mother	35/M
13 F	60s	Chinese	Christian	Married	Wife	56/M
14 F	60s	Chinese	Taoist	Married	Wife	58/M
15 F	60s	Chinese	Buddhist	Married	Wife	58/M

² 76.5% Chinese, 13.8% Malay, 8.1% Indians and 1.6% others (Ow et al, 2004)

Figure 3.1 Ethnicity of caregivers

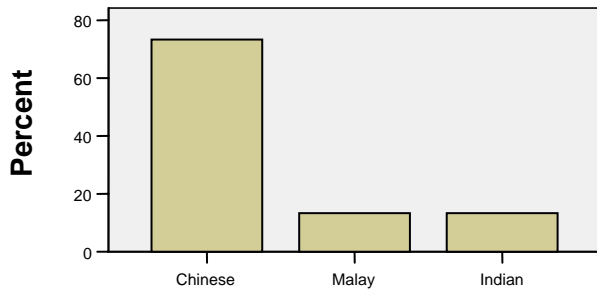


Figure 3.2 Caregiver Relationship

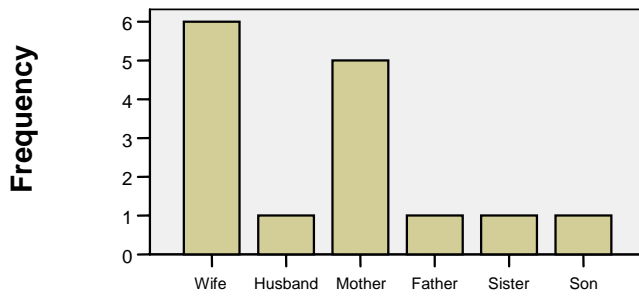
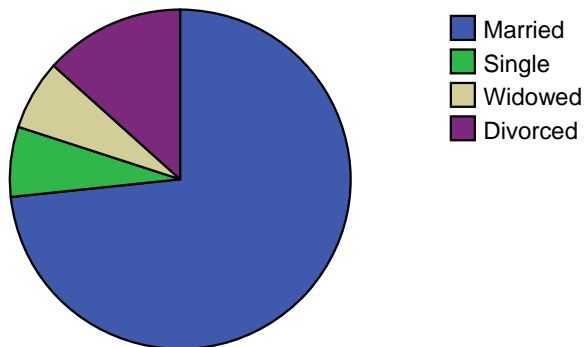


Figure 3.3 Marital Status



3.2 Findings on key variables

3.2.1 CAMI – Managing the caregiving responsibility

Nolan et al (1998:7) have discussed four main types of coping which are reflected in this scale. They assert that the first of these, preventive action to ensure that stressful events do not occur, is rarely used by caregivers, perhaps mainly because it can be difficult to predict stressful events. This was found to be the case in this study, where caregivers did not find these strategies particularly helpful. The remaining three types of coping comprise the three sub-scales described in this section:

- direct action to deal with the stressful event itself
- reframing the meaning of events, and
- managing stress.

a) Direct action

According to Nolan et al (1998) the six most common strategies in this cluster that they have found caregivers use, are the items relating to getting information, getting help from professionals, talking over problems, relying on experience, planning in advance and routine. These data are presented in Table 3.2. Apart from “routine”, 66-86% of participants found these strategies quite helpful or very helpful. The strategy most highly favoured by caregivers was “rely on experience” (see Figure 3.4). This highlights the value of their own experience in managing the responsibilities of caring for their family member. This was also found to be the case for a Singapore sample of caregivers caring for adult children with cerebral palsy (Rowlands et al, 2006). Nolan et al argue that while caregivers have a strong sense of their own expertise, this is often ignored or overlooked by service providers (1998:9). This therefore suggests that more credence ought to be given by service providers to caregivers’ own experience and sense of appropriate management strategies. Also highly rated was “getting help from professionals” (Figure 3.5). This reflects possibly the critical importance of the input that members of the

multidisciplinary rehabilitation team can provide, including for example, the regular sessions provided by social workers and psychologists at TTSHRC for family members on managing difficult behaviours. This is also commented on in the qualitative analysis, with some caregivers requesting more counselling input than the unit generally provided, arguing that this was essential for family caregivers to adjust to their new role. The finding for this sample relating to “routine” is interesting, suggesting that the level of unpredictability in their family members’ behaviour, or the general variability in their daily lives, meant that this is not a particularly helpful strategy, at least in comparison with others.

Table 3.2 Direct action (% of participants)

	<i>Get info</i>	<i>Getting help from professionals</i>	<i>Talk over</i>	<i>Rely on experience</i>	<i>Plan in advance</i>	<i>Routine</i>
I do not do this	33.3	13.3	13.3	13.3	26.7	13.3
Not really helpful	0.0	6.7	6.7	0.0	0.0	20.0
Quite helpful	20.0	13.3	20.0	33.3	13.3	40.0
Very helpful	46.7	66.7	60.0	53.3	60.0	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0
Missing	0.0	0.0	0.0	0.0	0.0	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0

(numbers are rounded)

Figure 3.4 Rely on own experience

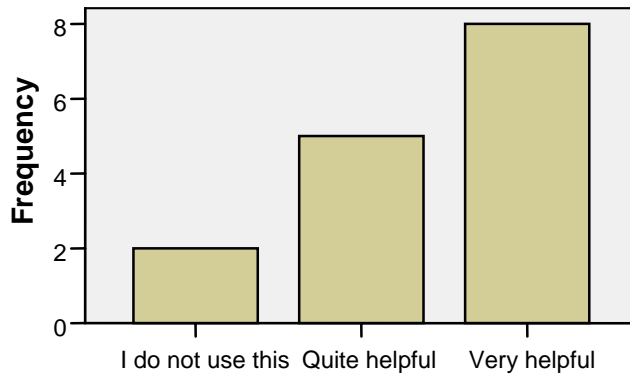
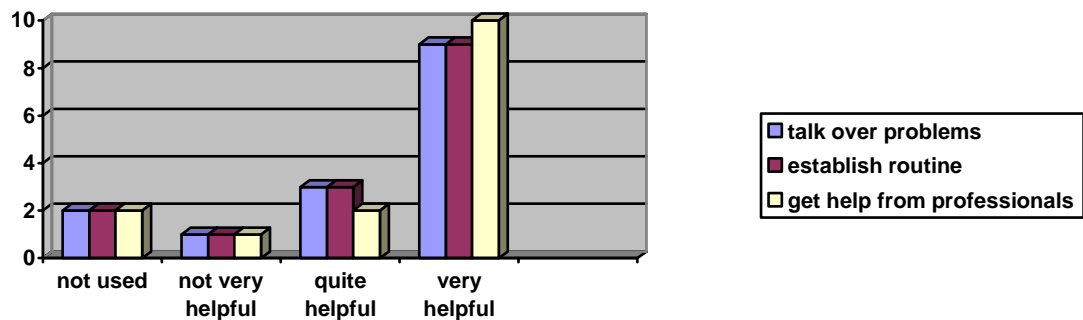


Figure 3.5 Direct action sub scale items



b) Reframing

A further 6 items contribute to the cluster of reframing strategies – cognitive approaches that are often used in generic counselling interventions and specific therapies such as cognitive behavioural therapy (Hepworth, Rooney, Rooney, Strom-Gottfried and Larsen, 2006). These items are: they are not to blame, one day at a time, others are worse off, realise no-one is to blame, see funny side, and get on with it. Between 60% and 93% of the sample found these strategies either quite helpful or very helpful, with the highest proportion valuing “they are not to blame” and “taking one day at a time” most highly (see Table 3.3 and Figures 3.6 and 3.7). This indicates again the importance of the temporal dimension in the experience of caregiving for these participants.

Table 3.3 Reframing (% of participants)

Percent	<i>They are not to blame</i>	<i>One day at a time</i>	<i>Others worse off</i>	<i>Realise no-one is to blame</i>	<i>See funny side</i>	<i>Get on with it</i>
I do not do this	6.7	0.0	0.0	13.3	20.0	20.0
Not really helpful	0.0	6.7	13.3	0.0	6.7	20.0
Quite helpful	13.3	26.7	60.0	20.0	33.3	20.0
Very helpful	80.0	66.7	26.7	66.7	40.0	40.0
Total	100.0	100.0	100.0	100.0	100.0	100.0
Missing	0.0	0.0	0.0	0.0	0.0	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0

(numbers are rounded)

Figure 3.6 They are not to blame

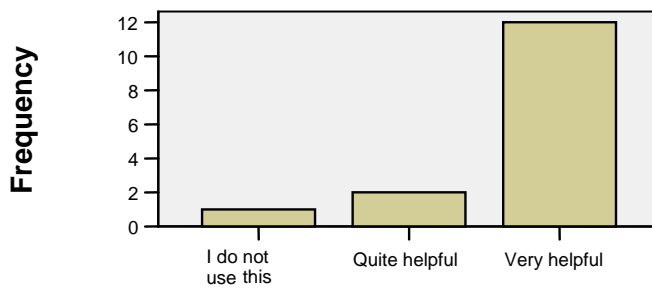
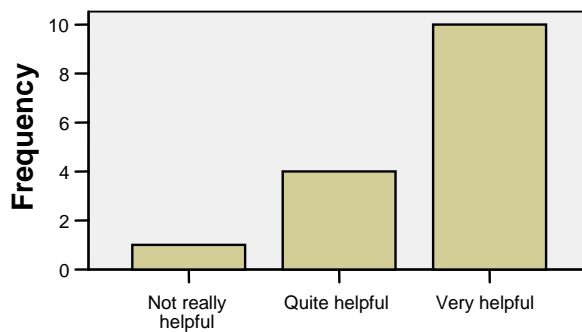


Figure 3.7 One day at a time



c) Managing stress

Key items frequently used by caregivers included here are free time, distractions such as television, and outside interests (Nolan et al, 1998). In this study, between 73% and 100% of caregivers rated these strategies as quite, or very helpful, with distraction rating the highest scores (see Table 3.4 and Figure 3.8). This was also found in the earlier cerebral palsy study (Rowlands et al., 2006). While the take-up of these strategies in this study appears to be consistent with Nolan et al's findings, other findings to note relate to the caregivers' ratings for other stress management techniques such as exercise, self help groups and relaxation/meditation, which are commonly adopted in western countries (Nolan et al, 1996). Here, these were noticeably *not* utilised. For example, only 13.3% found self help groups helpful; 40% did not use either exercise or relaxation, and 66.7% did not use self help groups (Figures 3.9 and 3.10).

Table 3.4 Managing stress (% of participants)

Percent	Free time	Distraction e.g. tv	Outside interests
I do not do this	13.3	0.0	13.3
Not really helpful	13.3	0.0	13.3
Quite helpful	33.3	26.7	20.0
Very helpful	40.0	73.3	53.3
Total	100.0	100.0	100.0
Missing	0.0	0.0	0.0
Total	100.0	100.0	100.0

(numbers are rounded)

Figure 3.8 Distraction e.g. tv

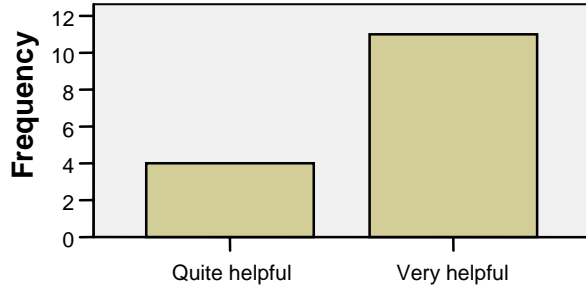


Figure 3.9 Relaxation, meditation

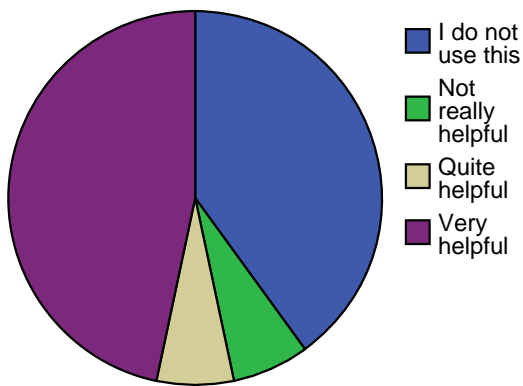
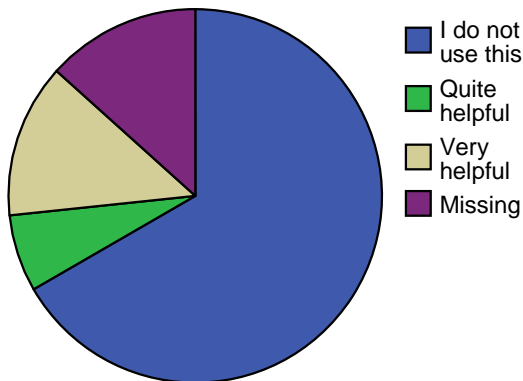


Figure 3.10 Self help group



3.2.2 CASI – The satisfactions of caregiving

Nolan, Grant and Keady (1996) conceptualise the satisfactions of caregiving in two ways: the main perceived beneficiary (cared-for-person, caregiver or both), and the source of satisfactions. These can be derived from the relationship between the two parties, from within the caregiver, or from wanting to provide a positive, or avoid a negative, outcome, for the cared-for-person. They conclude that good caring relationships are inherently reciprocal: a caregiver who is satisfied is a good caregiver and provides better care, resulting in gains for the cared-for-person. Key items from the CASI scale that will be examined therefore are organised along these dimensions – main beneficiary and derivation of satisfaction (Table 3.5).

Table 3.5 Beneficiaries and sources of satisfaction

		<i>Derivation of satisfaction</i>		
		Interpersonal dynamic	Intrapersonal dynamic	Outcome dynamic
Main beneficiary	Cared-for-person	Maintain his/her dignity; Seeing him/her happy	Ensure his/her needs are met; Keeping him/her clean	Keeping him/her out of institution; Seeing improvements
	Shared	Expresses my love for him/her; Stronger close family ties	I have done my best; I enjoy helping people	
	Caregiver	S/he appreciates what I do; Being appreciated by family	Provides purpose in life; I can develop as a person	Widens my interests; New skills and abilities

Note: Adapted from Nolan, Grant and Keady, 1996: 96.

a) Cared-for-person as main perceived beneficiary

In considering the person receiving care as the main beneficiary, these satisfactions stemmed from items such as doing something for him/her to ensure comfort or pleasure, and results or outcomes such as improvements in condition (positive) or avoiding

institutional care (negative). The findings for these variables from the matrix are presented in Table 3.6 below.

Table 3.6 Sources of satisfaction regarding cared-for-person (% of participants)

	<i>Maintain his/her dignity</i>	<i>Seeing him/her happy</i>	<i>Ensure his/her needs are met</i>	<i>Keeping him/her clean</i>	<i>Keeping him/her out of institution</i>
Does not apply	13.3	0.0	0.0	0.0	20.0
No real satisfaction	0.0	0.0	0.0	6.7	0.0
Quite a lot of satis'n	20.0	13.3	26.7	13.3	14.3
Great deal of satis'n	66.7	86.7	73.3	80.0	64.3
Total	100.0	100.0	100.0	100.0	100.0
Missing	0.0	0.0	0.0	0.0	0.0
Total	100.0	100.0	100.0	100.0	100.0

From the above data, it can be seen that caregivers gained high levels of satisfaction on each of these items, ranging from 78.6% to 100% of the sample³. Seeing him/her happy and ensuring his/her needs are met gave all of the caregivers quite a lot or a great deal of satisfaction, implying that satisfaction was strongly linked to providing benefits to the cared-for-person him/herself, in accordance with the literature.

b) Benefits shared between beneficiaries

Table 3.7 Sources of satisfaction – shared between beneficiaries (% of participants)

	<i>Expresses my love for him/her</i>	<i>Stronger close family ties</i>	<i>I have done my best</i>	<i>I enjoy helping people</i>
Does not apply	13.3	6.7	6.7	6.7
No real satisfaction	0.0	0.0	0.0	0.0
Quite a lot of satis'n	6.7	6.7	13.3	33.3
Great deal of satis'n	80.0	86.7	80.0	60.0
Total	100.0	100.0	100.0	100.0
Missing	0.0	0.0	0.0	0.0
Total	100.0	100.0	100.0	100.0

³ Sum of “quite a lot of satisfaction” and “great deal of satisfaction”.

As Table 3.7 demonstrates, these items were rated very highly by caregivers as sources of satisfaction, with scores ranging from 86% to 93% of caregivers deriving quite a lot, or a great deal of satisfaction from these sources. This demonstrates that the caregivers perceived their caregiving and other relationships as reciprocal in nature and saw themselves as giving something back to other people in their networks, not solely their family member for whom they cared. One participant did not consider that these items applied in his/her case (two with respect to “expresses my love for him/her”). As a group, the caregivers also considered that the stronger family relationships gave them satisfaction and, presumably, a source of instrumental and emotional support. This is also supported by Nolan et al’s findings (1996).

c) Caregiver as main perceived beneficiary

Table 3.8 Sources of satisfaction regarding caregiver (% of participants)

	<i>S/he appreciates what I do</i>	<i>Being appreciated by family</i>	<i>Provides purpose in life</i>	<i>I can develop as a person</i>	<i>Widens my interests</i>	<i>New skills and abilities</i>
Does not apply	13.3	6.7	26.7	13.3	33.3	6.7
No real satisfaction	0.0	13.3	13.3	0.0	6.7	6.7
Quite a lot of satis'n	13.3	33.3	13.3	13.3	26.7	40.0
Great deal of satis'n	66.7	46.7	46.7	73.3	33.3	46.7
Total	93.3	100.0	100.0	100.0	100.0	100.0
Missing	6.7	0.0	0.0	0.0	0.0	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0

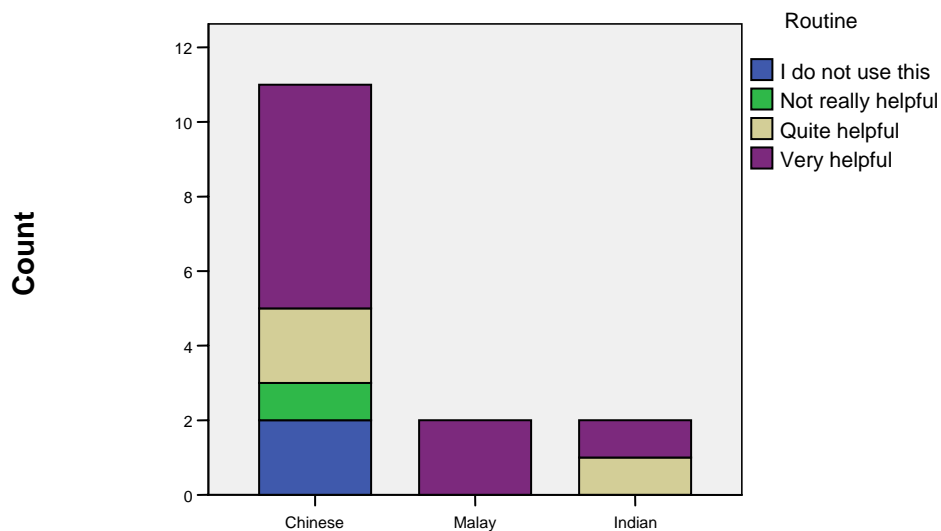
Table 3.8 illustrates that the majority of caregivers obtained some level of satisfaction from these items, ranging from 60% to 96% gaining quite a lot or a great deal of satisfaction. However, the data are more widely spread across the small sample with one or two participants not deriving any satisfaction from caregiving providing a purpose in life, new skills or abilities, new interests, or self development. Interestingly also, between one and five participants did not consider that these items applied to them. With respect to the items caregiving “providing purpose in life” and “widening my interest”, 40% of the participants either thought this did not apply to them, or gained no real satisfaction in

this regard. This finding is consistent also with the cerebral palsy study (Rowlands et al., 2006).

3.3 The role of ethnicity in caregiving

As the sample comprised Chinese, Malay and Indian caregivers, descriptive bivariate analyses were undertaken to explore any impact of ethnicity on the experience of managing the caregiving function or satisfactions derived from caregiving (the CAMI and CASI variables). For the strategies involving direct action, Chinese participants tended to be the only ones who did not adopt the various strategies, with the Malay and Indian participants tending to appraise the strategies more positively (for example establishing a routine – Figure 3.11). These findings need to be interpreted cautiously given the small sample size. (Some research has found that non-Caucasian caregivers experience greater gain from caregiving roles than do Caucasian caregivers – Rapp and Chao, 2000).

Figure 3.11 Ethnicity and establishing a routine



A similar observation can be made from the reframing or cognitive strategies, with Chinese participants tending to be the only ones who did not adopt these strategies. The strategies, “seeing the funny side” and “getting on with it” were considered not helpful by one Indian and one Malay participant respectively (Figures 3.12 and 3.13).

Figure 3.12 Ethnicity and seeing the funny side

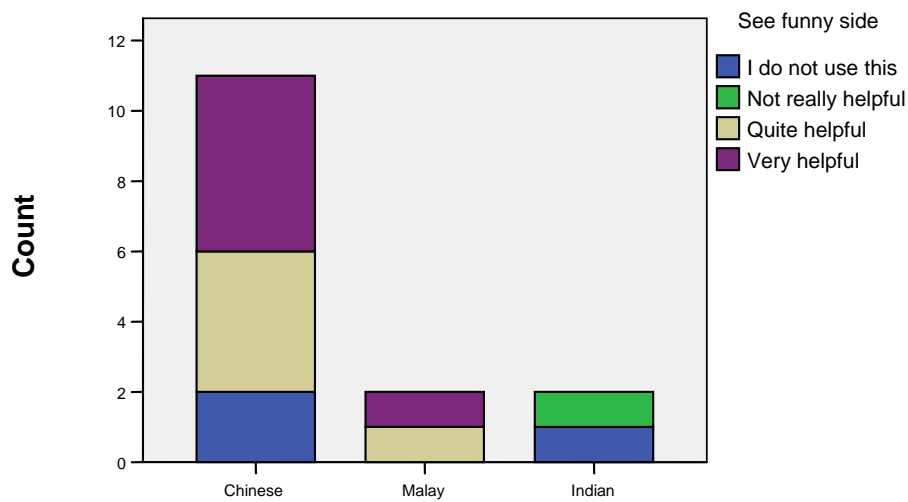
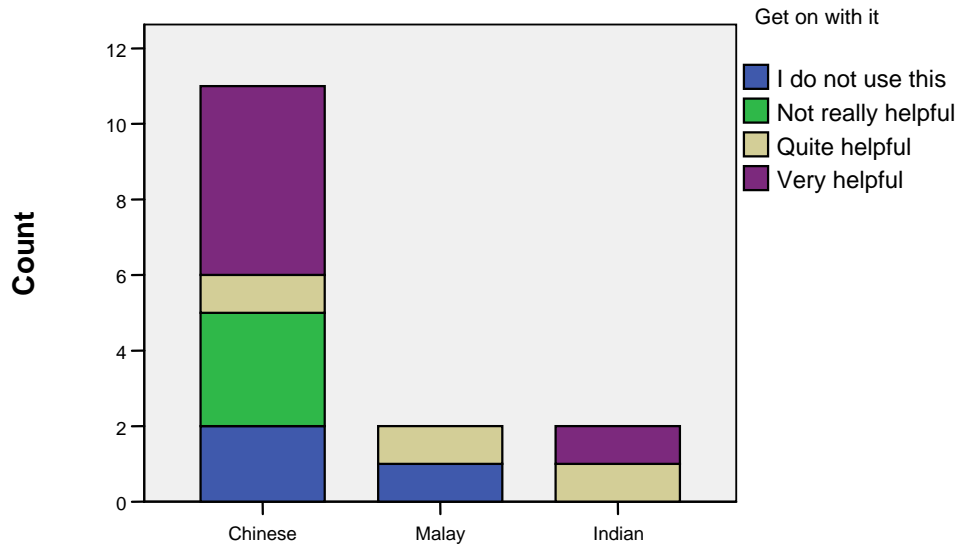


Figure 3.13 Ethnicity and getting on with it



The same pattern was found with respect to managing stress, with Chinese participants finding the strategies somewhat less helpful than Indian or Malay participants. As noted above, these conclusions are only tentatively drawn because of the small sample size and small proportions of Indian and Malay participants.

Bivariate analyses examined the relationship between ethnicity and the satisfactions accruing from caregiving. The Malay and Indian participants tended to be more positive in their appraisal of the satisfactions they gained from caregiving, or they tended to rate the items slightly less critically, with only Chinese participants rating some variables as not applying to them (see Figures 3.14 and 3.15).

Figure 3.14 Ethnicity and I have done my best

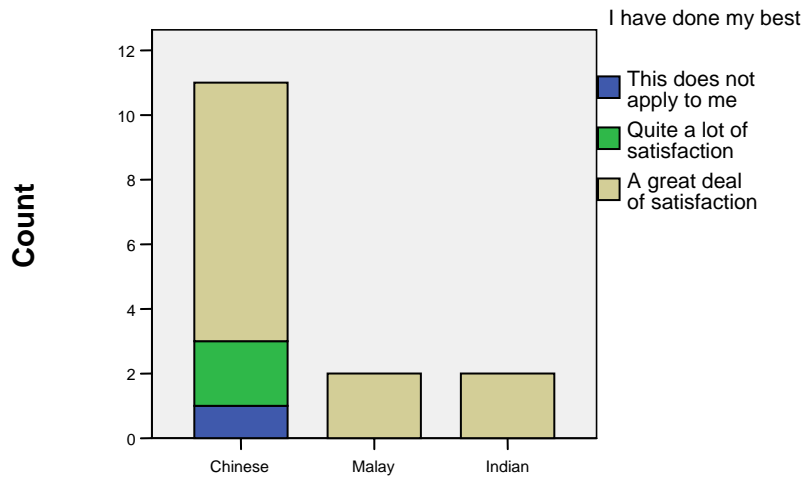
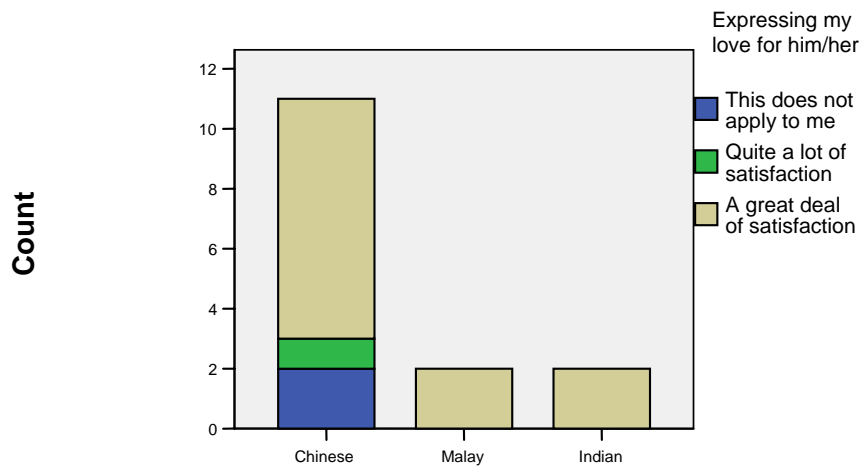


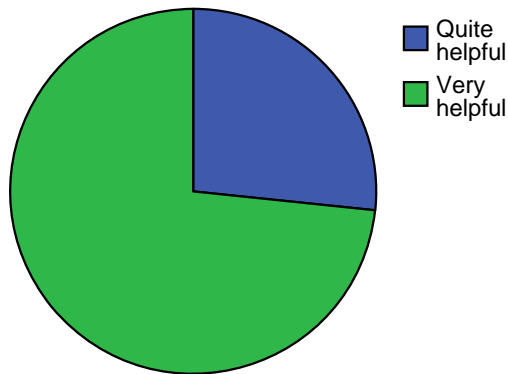
Figure 3.15 Ethnicity and expressing my love for him/her



3.4 Resilience of caregivers – the strengths perspective

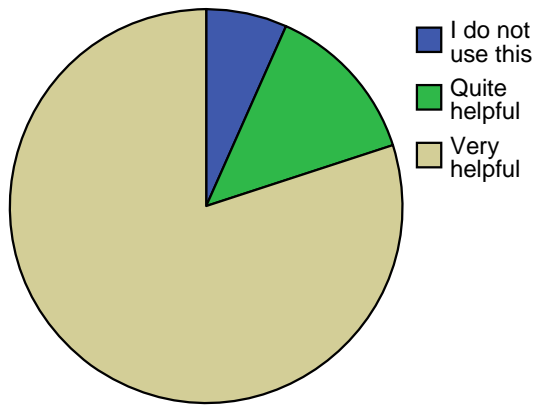
In understanding the caregivers' experience, the study sought to explore the positive aspects of caregiving and the strengths of the caregivers. The CAMI taps into these elements and the findings from this small sample support those of Nolan et al (1996). "Drawing on strong religious or personal beliefs" was a strategy considered helpful by all participants (Figure 3.16). This may also reflect the cultural context of Singapore.

Figure 3.16 Draw on strong personal or religious beliefs



Believing in myself and my abilities was also highly rated by the participants (see Figure 3.17). This variable encapsulates a strengths perspective in social work and other helping professions. Only one participant did not find this a helpful strategy with two finding it quite helpful and twelve finding it very helpful.

Figure 3.17 Believing in myself and my ability



“Looking for the positive things” and “remembering good times” are two more variables that adhere to a strengths-based perspective and are strategies therapists use in cognitive restructuring and strengths-based modalities, commonly seen as “reframing” techniques. In this sample, participants rated these variables highly also (Figures 3.18 and 3.19). All but two participants rated “looking for positive things” as very helpful, whereas with “remembering good times”, four participants did not use or did not find the approach helpful but the remaining eleven did.

Figure 3.18 Look for positive things

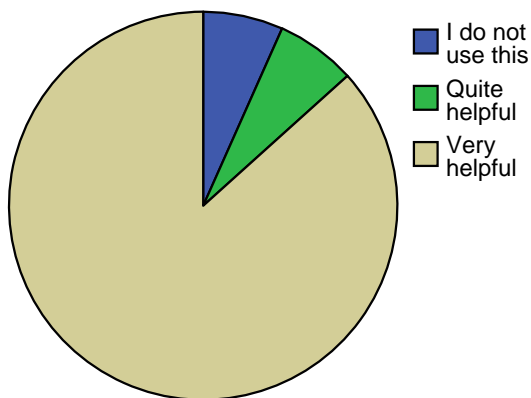
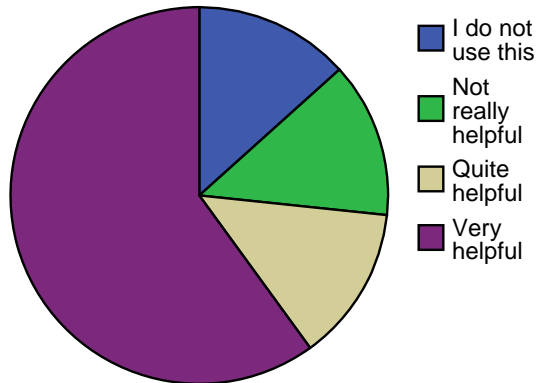


Figure 3.19 Remembering the good times



3.5 Reciprocity in the caregiving relationship

A further question in the study was whether there is reciprocity in the caregiving relationship and how is this experienced. The CASI sub-scale data “sources of satisfaction – shared between beneficiaries” includes variables that probe for this aspect of the caregiving experience for the individual caregiver her/himself, as well as this quality in the relationship between caregiver and receiver. Nolan et al discuss reciprocity briefly in the context of relationships and meaning in caregiving, and found in their research that the largest single source of satisfaction identified by carers was the act of giving to the cared-for person (1996:86). Comparing the results of this study with those published by Nolan et al (1996), the Singaporean caregivers rated their satisfaction higher overall (see Table 3.7 above).

3.6 Conclusion

The quantitative data from the scales measuring how caregivers manage caregiving and what satisfactions they derive from it demonstrate that this small sample of Singaporean caregivers are effective and empowered caregivers. While other family members and maids provided additional support to some extent for some of them (data obtained from in-depth interviews – see Section 4), they used all four main clusters of coping

behaviours: preventive action, direct action, reframing and stress management. They seemed to use help from professionals effectively although many of the family members for whom they cared had been discharged from the rehabilitation unit.

The caregivers also relied heavily on their own experience and skills, many of which were apparently self taught, according to the interview data. A clear majority of the caregivers used cognitive reframing strategies and found these useful. They have learned to pace themselves, “take one day at a time”, and pictured themselves in a broader context of families with members with disabilities and health problems. Maintaining perspective was a coping strategy and this set of findings is consistent with the literature reviewed by Nolan et al as well as their own research (1996, 1998).

The caregivers in this sample appeared to be less active in the realm of stress management approaches or perhaps did not as openly acknowledge stresses and ways they find to deal with them. Thus there was very little take-up of strategies such as self help groups or relaxation, which may not be culturally congruent for them and also may not be easily available or affordable. Participants clearly though were managing stress by such tactics as carving out some free time and the use of distractions. The qualitative data will shed further light on these aspects.

Overall, the sample of caregivers derived a great deal of satisfaction from different aspects of their caregiving role and given the structured opportunity to think about it, responded positively on these items. This again was reinforced in the interviews with clear statements about the relationship they share with their family member with brain injury, their commitment to their continued care, enjoyment and rewards from caring and for some, the ways in which their family member reciprocates the love and attention. Considering all three types of beneficiary, caregivers gave very strong positive responses to the items.

The following section will present the qualitative findings from the interviews of the 15 caregivers.

4. Qualitative Findings

4.1 Overview of the findings

Some descriptive information about the sample was obtained through the in-depth interviews. For those women caring for adult children, their husbands tended to provide income for the family. Additional financial support came from other family members. Female participants caring for their husbands were more reliant on the extended family and/or adult children for financial support. Divorced or widowed caregivers were also reliant on family for financial support, although one of these caregivers was self employed. Additional discussion follows regarding the financial pressures for caregivers in this study.

The caregiving families were nuclear in structure, with the person receiving care residing with the caregiver. Two exceptions to this entailed short term hospital or respite care admissions. Six participants had maids in the household who were a major source of assistance with the caregiving responsibilities. Generally, participants' other family members assisted in caregiving activities also. Thus the family patterns resembled more western patterns than a filial Asian society with three generations living together. Despite this though, financial support from other family members was common, so this instrumental support crossed the boundaries of physical living arrangements. Both the divorced parent caregivers worked at least part-time, necessitating reliance on other family members to assist with the caregiving responsibilities.

Where income from employment of the main breadwinner was limited, due to the nature of the job or less than full-time hours or intermittent work, the family was very reliant on extended family members for financial assistance, and sometimes ad hoc assistance from voluntary welfare organisations (VWOs), as there is no unemployment benefit or ongoing social security payment for low waged earners in Singapore.

The research questions were seeking to understand the relationship between caregiver and recipient of care with reference to how the caregiver *managed* the caregiving role (skills, knowledge, personal qualities, sources of support and so on), the *satisfactions* that accrued to the caregiver, and the *reciprocity* in the caregiving relationship. The coding of the interview data was structured around a number of key categories: “caregiver”, “caring relationship”, “family member” (the person receiving care), “resources”, and “society”. When participants talked explicitly of feelings, or expressed these non-verbally in their responses, these were coded also under the category “feelings”. These included feelings such as sadness/depression, guilt, frustration and fear, and also positive feelings such as happiness and pride. These will not be separately presented but commented upon as the key findings are presented.

The qualitative findings presented in the following sub sections are structured according to the research questions, focusing on the caregivers’ experience of the role, positive aspects, caregiver strengths and skills, reciprocity, helpful services or supports, and caregivers’ recommendations regarding these (see Appendix 3 for list of codes).

4.2 Caregivers’ experience of the role

With respect to the caregiver, the respondent in this study, a wide range of sub categories were established from the data related to the experience of caregiving. This section will report on the major elements of this caregiving experience. While the study sought to illuminate the rewards of caregiving and caregiver strengths, the demands of caring were articulated by all participants and provide the context in which their coping, solution-finding and sense-making of the experience is understood.

4.2.1 Demands of caring

For some caregivers this initially entailed significant assistance in personal care routines and activities of daily living (ADLs). Early discharge from acute care without a period of inpatient rehabilitation meant the following demands for one spouse:

“But I was terrified after the first day because I had to turn him, I had to tube feed, and monitor all the medication and I just left two kids sitting at the dining table, told them ‘Sit quietly’. That was dreadful. Ya, and he kept urinating on the bed – I had to change the bed sheets about six times a day. Very tiring... Yes because I was praying, I prayed to God I said ‘Was it a wrong decision?’ (to take him home). I couldn’t take it.”

“No, no. This is my first (experience of caring). Because, because it is a big blow to me. It is (laughs). Initially I was ‘Oh boy, can I do this? Will I be able to cope? Can I manage?’ ... Broke down once in a while.”

More common were the demands related to cognitive impairments, memory, judgment and mood states. Self absorption, sadness, depression and anger were difficult for the caregivers to manage and they developed strategies over time. Some education sessions were provided for caregivers and some were also aware that early on, not all the information could be absorbed.

“Yeah, I do get guidance from the hospital... they teach me on how to manage him, diaper him, shower him, or feeding him, stuff like that. I think we learn through, through you know seeing what they are doing, you know.”

“I think the hospital people has been very helpful especially P. She has been telling me many times, to be prepared for certain signs, but I think it took time to sink in. I mean, the information was there but it was sort of superficial. It didn’t really sink in until I saw what happened. But she was saying my husband was maybe worse than what she expected. Ya. It took some time to sink in.”

One caregiver described her family member as being more easily irritated than before, sometimes losing control and becoming violent, although he apologises afterwards. The caregiver tries to calm him and minimise irritation, hugs him and tries verbal explanation, such as “We don’t like it when you do...” or “it hurts our feelings...”

There were major impacts on some marriages, dealing with the changes and behaviours associated with injury, as well as losses. Children were described as managing well, for example learning to speak slowly and other strategies, although some were frightened of the anger and violence that their injured parent now displayed.

“Yeah, I guess that’s the major part of caring for a caregiver. Because I believe that

without tender loving care, ... you know not, uh, passionately, you know he is my husband. Much as I could I want him to get back to his, you know, self... Taking care of his, you know, daily things... In my religion there're some things that only the wife can do that other strangers can't, strange maids can't do..."

"And all the emotional, I felt that it's been emotional roller coaster. Sometimes I feel that I've been giving him a lot, and he still tells me he wants a divorce. Yes, he does that very often. When I don't let him go out, he would call lawyers, he finds the names on yellow pages and asks them whether they can manage his divorce case (laughed). It's very hurtful. Very hurtful."

How did they manage? Religious faith was very important for ten participants. Self care and relaxation strategies, such as going for walks, quiet times reading or watching television, and the support of family and friends were called upon, as commonly found in other studies (although this was not identified as strongly in the quantitative data). Some spoke explicitly about the need for counselling, from a specialist who was experienced with these patients and families, and others spoke of the need for support groups.

"And also I believe counselling should be provided to be the caregivers. Because I mean, I am very blessed because I have pastors who counsel me, ya, and I have people who take care of the kids, they take turns to bring them out, if there's a meeting, and they talk to me, but I don't know, I don't dare to think about those people who have no support. I think they will probably end up being depressed... I think something could be done in this area where counselling is provided... I mean, at least the caregivers could be given a choice whether they wanted to be counselled."

Despite supports, many of these caregivers lived extremely busy lives and had other caregiving responsibilities as well. Five of the female caregivers spoke explicitly about these other responsibilities – children as well as parents or parents-in-law. One participant, in addition to caring for her son, also visited her mother-in-law daily to provide personal care assistance after her stroke.

A considerable demand of caring was negotiating the physical barriers in the environment for a family member with mobility difficulties. Due to the fact that many HDB flats do not have lift landings on every floor, some families had to struggle to get their family member up or down stairs to a lift landing and also to manage public transport. This was not an option at all for some families as the barriers were insurmountable. Accessible transport options could not always be sourced meaning that the person was effectively

home-bound or able to access only their own immediate neighbourhood within walking distance of their caregiver and their wheelchair.

“Yes, there’s no lift. But I request, but still, I don’t know the answer yet... you know the wheelchair cost me so heavy. And my son, I bring down and I have to carry up... I have to bring all the way, wheelchair up down, and I have to carry my son again. I have more than enough of my life. I suffer. Ya, really I suffer.”

“...and sometimes he want to go down, I say ‘I really cannot. I’m very tired.’ But he will be angry with me, say ‘Why you don’t want to bring me down?’ Not say I don’t want to bring him down, I say ‘I’m very tired.’ When the friends is here, okay, they will carry him down. Then I ask somebody to call and come down, I say ‘Please, can you help me to come down.’ But actually it’s like, the other six, eight months at least, very difficulty I have it! I have some Malay friends, they help me also, they came and help me.”

For some, in describing the demands of caring, the real sense of burden was portrayed, despite the management strategies deployed, support received from others, and rewards and satisfactions of caregiving that also accrued. In other words, although a strengths-based approach might be adopted, and careful questioning reveals the wealth of satisfactions caregivers can receive, this must not concurrently obscure the real demands of the caregiving role and responsibility that must also be tolerated. One participant related her feelings of despair, and also referred to the cathartic value of crying:

“I used to break down. I used to break down because I can’t confide in..., I just confide in her and she just cry along with me. Sometimes she just comes to my house or we go out because my house is near a shopping centre and we had coffee. And I cried my heart off... (Does crying help?) It does (laughed). Funny thing is that I thought it wouldn’t but it does. It kind of lift up the spirit. It’s like too many things in the body, too many things on the shoulder. It’s not a burden, it’s a responsibility I should say, especially the kids, like my eldest son who’s in the express stream which is like a good thing but he flunked and went to normal academic.”

4.2.2 Accepting and adjusting to the role of caregiver

Acceptance was an important process for the caregivers to undergo in order to sustain the caring responsibility over the longer term and given the relatively short period of time that the caregivers in this sample had been providing care, it is anticipated that this process would continue for some time yet. Religious beliefs played a part in the process

of accepting that their family member had significant disabilities and would require some level of care indefinitely. Culture, family support and informal support from friends or neighbours, played a part in the acceptance process, as did obtaining information and advice from doctors and other rehabilitation and health care staff.

Adherence to a particular faith did not seem to influence the role of religious belief in the acceptance process, as illustrated by these quotes by participants of different religions:

“Ya. Actually I go to the temple more or less also, I’m relaxed because I have so many friends... They will advise me ‘Don’t worry, be very cool, you will be fine.’ And all my friends help me to pray for my son.”

(Indian Hindu)

“It’s like a giving time for me, you know, I’ve been receiving a lot from my husband it’s a give back time and from the Quran it states that when you’re strong, you’re sick, our god’s strength, strength from him, you want him to bless in any way so god’s great and with that I become strong from religion... We believe that once you believe in god we do our best and god do the rest. That’s where I’ll do my best as a wife, I know that god has something good for us in return... He won’t let you down.”

(Malay Muslim)

“Like a miracle. ‘Miracle J (son’s name)’. So I accepted Jesus. My Indian god didn’t help him. I had prayed to her gods. I am a hindu lady. J also accepted God and my other son as well... So we thank God for his amazing recovery to date and the doctor said he would be a vegetable.”

(Indian Christian)

“I think the only reason I was able to cope is because of my faith. Ya, definitely. That is the most apparent reason I can think of.”

(Chinese Christian)

Buddhist and Taoist participants were least expansive in referring to their religion, though some referred to their meditation practice and how this helps their coping, and some also referred to participating in temple activities as part of their regular routine and a possible source of social support.

4.2.3 Managing the caregiving responsibility and caregiver qualities

Participants demonstrated their commitment in a range of ways. Explicitly they referred to perseverance, patience and tolerance in the caregiving role. Some of the wives

preferred to have their husband discharged home as early as possible and assumed significant hands-on caring tasks. Other participants described the active exercise regimen that they structured for their family member and made major adjustments to their daily activities so that the exercise and therapy could be attended to. Skills and knowledge were obtained through practice as well as some formal input and guidance from rehabilitation staff. There were also some criticisms regarding hospital care and treatment, and some participants did not feel adequately equipped to manage the responsibilities. For some, the difficult behaviour of their family member has necessitated respite care or longer-term placement in other facilities as they could not be managed at home.

“Yes, yes, so that gives you a short respite and often it’s really nice to get out of the house by yourself... Once in a while maybe, twice a month.”

“Although that time was very panicky, because he couldn’t breathe and I didn’t know what to do... So on hind sight it was dreadful, but at that time, I don’t know, I just had the notion to carry on, carry on, ya.”

“Ya. I’ll give him some time to settle but if he really cannot settle, I’ll take a look at the one set up by (VWO). I haven’t visited them yet, but they sound... I don’t know... they sound pretty positive. I’ve got to go and take a look. See whether that’s a good alternative.”

Caregivers were also very proactive in seeking out resources and information to support them, from formal and informal networks:

“Ya. It’s just whenever anything’s necessary, just surf the net, look at the yellow pages or ask friends. But I don’t know, it’s very amazing, maybe thank God, the help just comes.”

“And I read somewhere from the notes that this mother, that I told you, she gave me, it says to record down every improvement. I recorded and it helped the therapist tremendously. Ya. It really helped. So all these bits of info just came in. I’m very thankful (laughed).”

Neighbours were often helpful, for example minding children while the spouse caregiver was attending medical appointments, hospital visits or training. Neighbours also helped with children during episodes of violence and one participant called police to assist in that situation.

“... The police came a number of times, yes, because that time he tried to hit me with a metal rod, and I called the police because I didn't know what to do. And the policeman asked me whether I wanted to send him to (name of psychiatric hospital). That time, I don't know, I was a bit soft hearted I said no. I should have actually. Ya. I didn't know it was that bad. I thought he was just moody, in a bad mood.”

For another participant, instrumental support from a neighbour through providing tutoring was valued:

“Ya, the budget. The budget is important. And my son is tuition now, at least my neighbour aunty never collect from me money. She said ‘Never mind, I will teach him free.’ My Chinese neighbour aunty.”

Some participants described as helpful the training they received at the major hospitals or the rehabilitation centre: this assisted in personal care as well as managing memory problems and difficult behaviour. A couple of participants acknowledged that more group programs or support groups would be helpful.

“Saturday classes are projected by the social worker and psychologist. Yes they take turns. It's more like anger management, carers... how caregivers should take care of themselves, something like that. I think all these are very important.”

“Yeah, I do get guidance from the hospital. You know, they teach me on how to manage him, diaper him, shower him, or feeding him, stuff like that. I think we learn through, through you know seeing what they are doing and err you know?”

Some caregivers when asked explicitly about skills and knowledge and how they managed to assume these caregiving responsibilities, interpreted the question very concretely and referred to what they were taught by health care professionals. With further probing some were able to identify innate skills and capacities that were as important in managing the caregiving role. And some described it as more innate: “I should say it's more instinct”.

A further phenomenon with this sample was the way in which eastern or traditional caring methods and skills were valued and integrated into their caring regimes. Many articulated their search for traditional methods that might be more effective than western clinical treatments; some were frustrated by hospitals refusing to allow massage or

acupuncture within their institutions and followed up “alternate” remedies once discharged. Some were very active in exhaustively searching for options for their spouse or child: yoga, pilates, tai chi, massage, and meditation were all used. One spouse considered that eastern philosophies complemented western medicine.

“The acupuncturist told me he could have done a lot more had he see my husband earlier. But I feel the western doctors don’t seem to have a very good opinion of traditional Chinese medicine. In fact I believe more in Chinese medicine than I do western medicine.”

Strategies that caregivers used in shouldering the responsibilities included adequate rest, relaxation, exercise and meeting friends. A couple of participants referred to instances when doctors or friends had urged them to rest more or take a break.

“Trying to get enough rest, and mainly this way, keeping myself happier, taking breaks. But the rest is very important. I find that I can get better rest when he’s not around.”

“Mainly reading. Sometimes I will just go for long long walks, on my own. But I’ve been attending a bible class regularly. It has helped me a lot. And sometimes I will just go out, I will just chat with church friends over the phone, ya, that helps a lot also.”

“He said ‘You have a migraine attack. Now you take your medicine and you rest, and you go for counselling. You need to relax your mind’.”

“For me it’s the time out... we go for window shopping (laughed)... Yeh, when I have the maid then we could do that. Oh, when he’s in the hospital sometimes the doctor just shoo us, ‘you go, you go, I don’t want to see you here, just take a break. Go some where else’.”

Many participants spoke directly of perseverance, tolerance and patience as being critical in their acceptance of the injury and the changes it had wrought, and the responsibilities of caring. While some described various people in their support network urging them “stay strong and be positive”, others were less clear about how it is that they do manage:

“I try to manage. What I can manage, all I’ll try to manage.”

“I don’t know how I get this from okay.”

Hope also played an important part in their accommodation to the new reality. Hope was

referred to the context of hoping for a full recovery immediately after the injury occurred. Other participants spoke of hope for increasing improvement in the years ahead and how this sustained them.

“It kind of lift up the spirit. It’s like too many things in the body, too many things on the shoulder. It’s not a burden, it’s a responsibility.”

“We believe that once you believe in god we do our best and god do the rest. That’s where I’ll do my best as a wife, I know that god has something good for us in return.”

Co-existing with the hope and optimism and strategies for managing the caregiving tasks, was the pervasive sense of loss. Even though caregivers were positive in outlook, strong and resilient, this did not obscure the sense of loss that persisted. They referred to their loss as well as the loss for the family member and other members of the family, such as children and siblings of the injured person.

“The children are very afraid of him. I think they miss their dad. They are very confused... My daughter is torn between wanting her dad to come back and being terrified of him yelling at her or maybe hitting her even.”

“... but he’s most concerned with those that he held dearest to him. That means, very self-centered. He’s most concerned about his job (as an engineer), his ability to feel self-worth. That’s most important. And he’s not so much concerned about the relationships. So that’s why he kept asking ‘Why can’t I come home?’ He didn’t think beyond himself and how his coming home is going to impact on the kids and I.”

“He lost... actually he has lost his life...”

“Ya, ya. Still I’ll pray. I hope so he will... one day be mobile. Still I’ll hope, always. .. And the doctors said in the hospital, said he would be a vegetable always. That’s why I want to one day, I want to bring and show him to the doctor. Ya, I want to show it to him, ‘You know who is this boy or not?’ I’m going to show them... Really I want to scold them... But they send me a letter to apologise, okay. I won’t accept. I won’t accept the apologies. Because you break... as a mother, you know you really break my heart... Don’t tell me, he told me ‘Don’t think so your son will be good like last time you know. He will be vegetable, he’s not very good 100%’ ... Aiyo... I very heart pain because of the doctor is telling me like that.

“But he’s just being..., you know boys, the pride is too high I guess. He doesn’t want to tell me that he misses his father, he doesn’t want to cry, he has to be strong but he does write a letter to me once, saying that he, he lied to me that he said that he passed his

examination when I got to know from his teacher that he flunked. That's where I was crying so badly and he said that he doesn't want to see me sad. His way of thinking you know... And he said that he always saw me crying myself to sleep and that kind of upset him..."

4.3 The Caregiving relationship

The relationship between the caregiver and family member is the focus of this study. Understanding the nature of this relationship illuminates the experience of caregivers in terms of reciprocity, rewards and positive aspects of their role, as well as their experience of burden. The previous section on the Caregiver incorporated discussion of the demands of caring and the daily experience of the responsibilities the participants carried. This section examines their responses regarding the relationship between them and their family member. Aspects of the relationship that caregivers described were coded at a node titled "tie of caring". The notion of the "tie of caring" arose from the statements from caregivers that they were so closely involved with the caregiving functions that they were practically tied together. This coding encapsulated the dynamics of the unique relationship between caregiver and family member that developed post injury, as described in the participants' terms. It reflected the closeness borne of providing personal care in some situations; the complex communication required as a result of impairments; and the reliance and reciprocity between the two members of the relationship. There was also a sense of a unique relationship between caregiver and family member that was more intense than with other family relationships. No doubt the needs of the family member demanded this heightened surveillance and physical care but it also generated a feeling response that was strong and a bond between the caregiver and care-receiver that was intuitive. This reached the point where many participants stated that no-one else could in fact care for their family member – either as skillfully as they, or at all, because no-one else could understand the nuances of communication between the pair.

Distinguishing between other codes such as "demands of caring" and "commitment" was not always clear, however the difference is in the level of intensity in this caregiving relationship, its exclusiveness, and its specialness, with its own rewards, that separates the concepts. And it is apparently as a result of this powerful relationship that these

caregivers gained much of their strength to carry on, and from which so many rewards of the caregiving process stemmed. While in the interviews they did not generally articulate the rewards in the phrases about satisfactions as in the CASI scale, some participants did articulate the returns they felt and the demonstrations of love or gratitude from their family member, in cases where there were no behavioural management issues – in other words, a level of reciprocity in this relationship.

At the same time, there were many instances when the “tie of caring” also seemed burdensome, in that caregivers had no time for a life of their own. This gives rise to notions such as “enmeshment” in family dynamics terms, where relationships between family members become so close that they appear to be suffocating the individuals or not leaving sufficient space for individuation and growth (Hepworth et al, 2006; Minuchin, 1974). In the families in this study this kind of enmeshment serves a function and has come about through circumstances. Whether it also connotes a less functional relationship pattern is not a question that the study sought to answer, as it was consciously adopting a strengths perspective, but this possibly could develop. It is also possible that the primary caregiver, frequently the mother, may not experience this level of commitment as a burden although other family members, friends or professionals may suggest to her that she needs to step back or that perhaps other children are not receiving enough attention from her. The common response from these participants was to deny that the caring role, or the family member, was a burden to them. The role of guilt in these caregiving relationships is also relevant here though again not a focus of this present study because of its theoretical orientation and parameters.

In some families, explicit discussion of the notion of “rewards” from caregiving did not seem to make sense to them. They preferred to express this in the form of familial responsibility, because they are a parent or spouse, for example. This was closely related to the notion that these participants did not see themselves, or were not comfortable being portrayed as, caregivers – “it’s just my responsibility to care for him/her”. This comment often occurred within a cultural or religious discussion, for example, it was a tenet of Islam to care for someone like this. This suggests that the “tie of caring” has a cultural

and possibly religious overlay for these caregivers and suggests that the Asian value of filial piety is also caught up in it.

For spousal carers, the marriage relationship underwent a transformation due to the reliance of the injured spouse on his/her partner for personal care, exercise, transport, and various aspects of living. For some participants, loss was experienced as the earlier relationship was forced to change:

“TLC. Tenderness.... Because nursing, nursing, nursing care I should say they are just concentrating more on feeding him, you know, all those daily routines. As for us you know I could give him a hug, you know, kiss him, peck, give him a peck and all that... I mean tender loving care with a kiss and stuff like that.... (laughed) Uh, I should say being, still being deeply in love with my husband. (laughed)... Except we don't have any more that sort of relationship.. (mumbled). It does make me feel good, you know. At least he feels (mumbling) ... he appreciates.”

“Small gestures, small small tap or when I was beside him he'd lean his head on my shoulder and when I lean to him to wipe his face and he just give me a peck on my cheek...(laughed) I guess that's just a small....just, just... it does boost my morale though and motivated me in a way to even be of help to him.”

Another spouse became totally focused on his wife's recovery and invested significant amounts of time in her daily exercise routine. Her schedule at home was described as:

“1 hour walking exercise in the morning at the stadium. Then rest. Then on the 'gallop' machine to improve balance, like an automatic horse. I read about it so I bought one. Have seen immediate improvement. Aqua exercise. Also a stepper machine to strengthen arms. She used to use a stair crawler but now no need. All day long she is doing some exercise or resting. I monitor it all. Treadmill. And I fit my work in around her schedule.”

Friends and social support networks, including religious ones, were also important in supporting spousal caregivers. One participant described the influence of a friend in adjusting to the changes in their marital relationship post injury:

“She's the one who has been very very supportive and was telling me from day one that, you know, look here, this is just beyond your control... you just have to take this in your stride. Take it as a strong positive aspect of being a wife, this is your responsibility, this is your giving period, you know.”

One spouse also described her husband's changed relationship with his children:

"I should say that in my point of view maybe he felt helpless (pause), hopeless (laughs). You know, was going to say that he has been a very protective and a very caring and doting father. So not being able to you know share that responsibility now, I guess that contributes to him being sad."

There were five mothers and one father in the sample, caring for adult children aged between 19 and 35 years (all but one of whom were sons). Two of these mothers' lives revolved around their sons who were more recently injured, sustaining relatively severe injuries, including orthopaedic ones. For the remainder of the parents, the level of day-to-day care and involvement in personal care, rehabilitation and exercise was much less extensive. All of the adult children however needed a level of daily care and supervision with regard to cognitive impairments. Concerns for these parents included maximising recovery, social and community integration, and employment and a financially secure future. In describing the care and commitment these parents had for their adult children, it was clear that their relationships were close, and required a high level of intimacy due to the personal care involved. Possibly the relationships were further strengthened by the tie between parent and adult child because of the dependence on the parent to maintain quality of life. One mother described her son as her "best friend". None of the parents used a professional or volunteer personal carer although two had maids who provided assistance.

Personal care started even in the hospital ward, with one mother commenting that she believed it was necessary to provide this:

"So I don't want the nurse to look after him, cos they look after him... you know, he will get the bed sore. I know it. Not say I blame the nurses there. There are so many patients there, okay. I say okay, for my things, I will look after my son no problem, I after go back home, you all take care of my son. That's why... I cleaning, everything I will do for him. Ya, I will sit down there and do for him everything. I will sit the whole day."

Later, caring for him at home accentuated for her the losses he had sustained:

"I don't mind to change for him, everything (i.e. diapers). But when I change when he's this age, as a mother, I change for him, everyday will cry. Can't take it (crying). But I

think, this kind of thing, I know my son will come back to me. I know that.”

A common observation from the mothers was that they were better carers than anyone else could be.

“What I’m doing is the best – parents are the best to provide the care cos you understand them the best.”

For one of the intensely involved parents, a daily and weekly schedule were maintained for her son:

“Breakfast, then exercise for a couple hours or we go to the park. Then lunch, then computer work – type sentences, relearning how to use MSN, learning how to download songs again. He’s very motivated now.

Monday: education therapy (provided by a VWO; hospital occupational therapy
Tuesday: occupational therapist comes to the house; doctor visits and reads with him (family friend). He’s up to primary 3 maths. His English vocab is good – P3/P4 and P6 for comprehension. He draws and paints in an art lesson
Wednesday: physiotherapy and swim
Thursday: speech therapist (at VWO). Other family friends visit for reading
Friday: educational therapy; gym
Saturday: go to park
Sunday: church”

Literally, her life revolved around him. This mother was convinced that the exercise in his program had led to his good recovery. As well as the maid, family members and friends were also involved. They worked in a concerted fashion on balance, standing, stretching and cycling, learned from the physiotherapist, and used massage to work on his weaker side.

Regarding future prospects for their adult children, parents expressed concern about employment opportunities. Commonly expressed was a desire for the government to do more to help their children obtain jobs.

“... there are so many of my son’s age, there’s so many boys, that is for my son also, try to get the government help them, try to get them a simple job, at least make them satisfied. You know what they feel now or not? ‘I’m a waste. I’m a waste. I cannot work,

I cannot support my parents. No point I am living a life.' He's telling me, every time is the same answer to me. He said 'Mother I'm going to die. Mother I commit suicide.' At least they can help us, try to get him a simple job... As a request, as a mother. Try to help them... In future, try to help them. Don't say this type of accident, the brain injured, the leg is not good. Don't chuck him one side. Let them come out in the life. Support them... Try to give them a simple job, and give them at least a simple pay. At least, they will know that the pay ah, they feel 'Oh, in my life, I'm working, I'm getting amount of pay. I can run my future.' Ya, that is the one I want."

4.4 Rewards and reciprocity – the satisfactions of caregiving

Exploring the rewards that participants considered they received from caring for their family member was not straightforward. Several caregivers clearly did not understand what was being asked – being rewarded was not a concept they appeared to have thought about, or it ran contrary to their beliefs, culture and values. Some participants were able to articulate their ideas after some thought, and others were immediately able to express rewards they recognised. These were clearly related to the notions of communication and reciprocity within the caregiving relationship. Therefore much of the text was coded at several of these categories as they are so interlinked. As some participants elaborated on their responses to these questions, they clarified further their thinking about the rewards of caregiving. Some quotes will be presented, from the least sure participants to the most forceful about their rewards.

Eight of the participants, when directly asked, claimed not to receive any reward from their caregiving experience. At the same time, all but one of these referred to the personal satisfaction that they gained from providing care. The other participants spoke at some length about rewards. While gender may be a distinguishing characteristic, it is not possible to conclude this absolutely – of the three men in the sample, one of these spoke clearly about the rewards for him in caring for his wife. He considered that he grew as a person through the crisis and that this experience would help him cope in the future. He also thought that his interests had grown as a result of encouraging her in her recovery. Nonetheless the women were more articulate in describing the rewards for them. These related to their faith, in feeling closer to God; relationships with family, friends or church members being strengthened as a result of the accident; support from friends also for

other family members; greater closeness to their injured family member's networks; and learning new skills and more about themselves. These forms of reward link directly to the items in the CASI instrument, with all caregivers' responses in the interviews relating directly to one or more items. These reward types therefore relate to the matrix presented in Table 3.5 – Beneficiaries and sources of satisfaction. Some rewards clearly accrue to a particular beneficiary in the caregiving relationship or is shared between them, and the satisfaction derives from inter- or intra-personal dynamics or an outcome dynamic. Thus without prompting, participants identified this wide range of rewards or positive elements for them. And it is partly from these rewards, and the reciprocity and responsiveness in the relationship, that the caregiver derived strength and resilience to continue with the caregiving responsibility. Some quotes are provided below to illustrate the range of rewards.

“Oh tremendously. I find that there have been a lot of good things that happened. First of all, I feel a lot closer to God, the kids also felt that they, especially my daughter, she's learnt to be lots more sensible, especially in looking after the needs of others, and I've been closer to a lot more people in the church and I meet a lot of new friends. Suddenly the help just comes and then there are people whom I don't know, they just come forth. They show concern, I have lots and lots and lots of new friends and financially I am being helped by a person who is able to help me. And, what else, the kids also grown a lot closer, not only each other, but also to the church members. They feel absolutely at home with their aunts and uncles... Ya, there are lots and lots of things. I grew closer to my husband's colleagues. Yes, they are still in touch, they come here and celebrate his birthday...”

“Learned a lot how to care for him. Give advice to others. Lots came to visit after reading the papers. Get help from them. Now we can give advice to others.”

The effects of the brain injury on communication and insight impacted on the extent of reciprocity in the injured person's family relationships, as reported by caregivers. There were few accounts of reciprocity described in the interviews. References included attempts by the injured family member to relate to other family members, for example their children, and attempts to assist in the household tasks that now fell largely to the caregiver to perform. Compromised communication skills and physical disabilities reduced their capacity to reciprocate.

“He shows mainly for the kids, like if the kids fall down he'll say “Oh dear, oh dear.” But

that's all he shows... (laughs)"

"Superficial!! Ya... But he's very concerned about his own family. Like his father was down with cancer recently and he's so worried. I find that he's more, he seems to be closer to his own family than now, our family."

"He does say thank you to people. Until you disagree with him."

"Ya, actually sometimes when I'm busy... he help me pick up the clothes... And he try to sweep the floor but his sweeping you know, when he sweeps the dust will fly, because his hand is very weak. And I tell him if you cannot make it then no need to make it."

"He's not able to help with chores... Even though he'd like to."

Caregivers also gave things back, or reciprocated in other relationships by supporting other members in the community, apart from their family member. Some spoke of wanting to offer help to others who became caregivers for someone with acquired brain injury, partly motivated by the support they had themselves received. Others concurrently provided care for other family or community members that may have pre-dated the acquired brain injury.

"I'll give them all the notes, whatever support. In fact there was a baby in my church who was badly shaken by the maid, resulting in brain injury. So we all rallied around there also."

"I am keen to help anybody that I can afford to or not necessarily with money. I don't like to see people/children suffer. I like to give support, encouragement."

"Ya. I heard one of his friend, accident, at NUH. I bring my son on the wheelchair, I went to see the parents. Yes, I went to advise and talk to them, I said the same problems occurred."

4.5 Resources and sources of support

There were many resources referred to by participants as they described their caregiving experiences (as denoted in the list of nodes in Appendix 3). Most references to services related to the health system, as anticipated with this sample of caregivers caring for family members within one to four years of injury. In addition to health care professionals, and specific references to nurses, doctors and psychiatrists, there were

frequent references to the hospital rehabilitation unit (the source of the sample). Some caregivers had dealt with either nursing homes or the major psychiatric hospital as their husbands had had admissions.

As hospital-based services were most frequently accessed by the participants they were also often criticised by these caregivers. Some participants acknowledged the demands on nurses for example, yet considered that their family members received inadequate attention. More criticism was leveled however at the medical staff. Participants expected more information, empathy, access to alternative treatments and personal consideration, from the medical staff. There were also more generalised criticisms of the hospitals and protocols and procedures. One mother referred to “barriers” that the system seems to erect in front of families. Some described doctors as sarcastic and more than one participant had her family member described to her by the treating doctor as a “vegetable” and found this extremely distressing.

“I’m pretty disappointed with (name of hospital). I think they could probably give the caregiver a choice. Because they assume that these patients will end up in nursing homes or end up at home doing nothing. Because from the notes that I was given, there were many many ways to turn the coma patient around, various stimulations that we could do. Of course we don’t expect the hospital staff to do it because the nurses are very busy. At least if the caregivers were told, we would arrange something to be done, that’s one way. At that stage, at that critical stage.”

Another parent was clearly very assertive in demanding the care she expected for her son, despite the fact that she was not a professional woman, was a single mother and was not Chinese.

“And I told them, ‘No, I don’t want the re-operation by you. I don’t want.’ And I said ‘I’m not happy to stay here.’ And I never go back. I stayed with my son whole day. I never go back. Because I’m not happy. And I told them ‘No, I want a transfer’... I am no more trusting them already. I said ‘I don’t want. I have to bring back my son to (different hospital)’. We still had two days argument. Two days argument. At last, they signed la, and I bring back my son alone, the team never help me to, give me ambulance to send my son to (other hospital). Ya, they just never help me anything at all.”

“I guess, it’s a mindset, change of mindset to the whole, I’m going to speak rather harshly, but I think (name of hospital) need to change their mindset.”

There were also many accounts of very helpful treatment and support provided through the hospitals and the range of health care staff, including doctors, nurses and allied health staff. Participants appreciated input with exercise programs, behaviour management and personal care assistance. Participants also praised staff at other facilities such as non government rehabilitation centres. One service of particular value were the information groups run by TTSHRC.

“Saturday classes are run by the social worker and psychologist. Yes they take turns. It’s more like anger management, carers... how caregivers should take care of themselves, something like that. I think all these are very important.”

“I think the Tan Tock Seng people has been very helpful especially the psychologist. She has been telling me many times, to be prepared for certain signs, but I think it took time to sink in. I mean, the information was there but it was sort of superficial. It didn’t really sink in until I saw what happened. But she was saying my husband was maybe worse than what she expected. Ya. It took some time to sink in.”

Other than health services, caregivers derived great support from churches and religious organisations, voluntary welfare organisations such as day centres; philanthropic foundations; schools; police and counsellors. One participant made reference to a day care centre and one family had strong support from a VWO and the allied health professionals there. Another participant had approached a VWO that provided services for that specific ethnic group, seeking financial assistance. There were also a couple of examples where caregivers sought assistance with aids (for example a wheelchair) through VWOs or financial assistance through their Community Development Centre.

Churches were likened to extended family:

“In fact I find that they are closer to me than... (hesitates) my husband’s family (crying).”

For a parent caring for a teenage son, the school was a major source of support, providing access to school facilities such as the gym and art rooms, and ongoing support from teachers.

Some participants explicitly mentioned counselling, arguing for greater access to counselling services, while appearing unaware of the counselling services that could have been accessed through medical social work departments in the hospitals. Some caregivers also differentiated between their understanding of unqualified counselling and professional counselling.

“And also I believe counselling should be provided to be the caregivers. Because I mean, I am very blessed because I have pastors who counsel me, ya, and I have people who take care of the kids... but I don’t know, I don’t dare to think about those people who have no support. I think they will probably end up being depressed... I think something could be done in this area where counselling is provided. I actually mentioned to (staff member). Perhaps counselling could be provided. I mean, at least the caregivers could be given a choice whether they wanted to be counselled.”

“I think... I don’t know how receptive he would be to counselling, but I think that would be a good help. Counselling would be a good help. From somebody who’s trained, to deal with brain injured patients, not the lay counselling, because they may not be able to handle him, if he perseverates, which he does a lot. That would really help a lot. But as the (hospital) doctor told me, he himself wasn’t very sure how much counselling would help because the brain is damaged. I guess it’s just trial and error.”

While self help groups were not rated as of value in the CAMI scale (Figure 3.10), participants considered that support groups would be helpful in the interviews. The extent to which the information groups at TTSHRC also functioned as a form of support group was also alluded to by this participant:

“Support group would be great. But I don’t know how committed the members are, because like I said it’s not easy, because some require all round-the-clock care. Support group should meet regularly, if it’s going to be of any help, I believe. Whether that could be carried out is another thing. And somebody has to come in and lead and serve. It’s not easy. If it’s voluntary, I would think it’s very difficult. But if there’s a pool of professionals there, it would help. That’s why I actually recommended, or suggested counsellors, professional counsellors. But I think TTSH Rehab Centre is doing something, they have Saturday training classes, which is good. I attend some of the training classes.”

4.6 Caregiver needs and recommendations

In describing their lives as caregivers, participants highlighted a range of unmet needs. For those caring for a family member with physical impairments, mobility was a key concern. Access to a wheelchair was difficult and HDB blocks without lift landings on each floor created a significant barrier to travelling around the community. The range of charges for health services was an impediment for some families and insurance was not always adequate. Prohibitive ambulance charges were mentioned by a few participants, as was lack of accessible vehicles or taxis.

“I will carry the wheelchair down, and I put it in the staircase, and I come up again, I will hold him and I come down again, to the staircase, to the ground floor. I really cannot carry him because he’s very big. Actually I use my shoulder to hold here and hold staircase... and sometimes he want to go down, I say ‘I really cannot. I’m very tired.’ But he will be angry with me, say ‘Why you don’t want to bring me down?’ Not say I don’t want to bring him down, I say ‘I’m very tired.’ When the friends is here, okay, they will carry him down.”

“The help, sometimes you know, the wheelchairs, the person cannot buy... Actually in Tan Tock Seng, they help me to give me for my son, I think more than eight months they borrow me. If you ask me in future, you ask me to buy, really I got not enough cash. And that way, maybe the government can help all the poor people. The wheelchair is very difficult to buy. If you ask me to buy at that time, I know I can’t... Really I can’t. Not everybody is rich. Maybe the wheelchair they can give a monthly payment, I may think about it. Not say only for my son, maybe in future there’s other young boys also, or that family is in difficulty.”

Paying by instalments was also recommended for ambulance charges.

“It costs us \$40, one trip. If it’s two trips it cost me \$80. And how you need to pay an ambulance for you. And the government one, they charge us \$80... The patient is serious or not serious, they charge you \$80. It’s very high. Okay, sometimes the parents don’t have enough money, they can’t manage, and sometimes they say they will try to pay you later, they send the \$80. (Interviewee sounds quite irritated and angry from this point onwards.) They will send us a reminder. They will send us a letter. They will send me a lawyer-addressed letter. How much you are going to spend for that? Why you are doing the stupid thing? Come please! Give them instalments! Try to pay monthly \$10... you are sending all the reminder, lawyer letters, all this is rubbish, you spend your own time. You

should give us a time, send a letter, say ‘Can you try to pay me? Monthly \$10.’ That’s all only.”

For one caregiver, hospital fees were largely offset by the injured family member’s employer, but without that support the high fees would have been a severe impost.

“(Employer) is paying 80%. I’m happy for that. Means I don’t need to pay full amount. Yes, it costs me so much! Yup, (name of hospital) costs me sixty over thousand for one month. And (second hospital), also I think got thirty-seven thousand. (Third hospital), I think got forty-two... I’m not sure is forty-two or is it... I have so much of these. Then how you want me to pay all these? That’s why... of course, you have CPF, I know. But this don’t have CPF, for myself, I don’t have. Only my husband... Even he only have fourteen thousand there, how he settle all these payment? It won’t be enough.”

For some injured family members, the loss of employment and income was painful and several participants described their family members’ depression and argued for greater psychological support, as well as retraining and employment assistance, as described in Section 4.3

“He feel ‘I don’t have respect in my family. My sister working, and I’m not working, what I have in my life? Nothing already. I cannot work. Why must I be living?’ His life is like that. And I say ‘No, it’s okay. You are going soon to work, but I let you rest first.’ This is what I’m telling him. ‘You rest first. Later maybe you can get a job, no problem.’ If the government can’t help us, there’s no other way to bring my son to work.”

“Only gap is psychologist – he needs someone to talk to him. Dr T at (name of hospital) does testing not counselling. We think he’d benefit from someone to talk to – he has a lot inside he can’t express.”

“She was depressed, according to the psychologist who saw her. What she’d lost, she felt she couldn’t measure up, causing me a lot of trouble etc. So I don’t force her and don’t want physiotherapy to make her feel worse if she can’t do what’s asked of her, or confronted all the time by what she can’t do.”

4.8 Conclusion

Through these interviews, the coping strategies of the caregivers were further explained. Despite the demands of caregiving, these caregivers used creative solutions, humour, skills and knowledge to bear on the task. They found ways to accept the impairments and

disabilities imposed by acquired brain injury and displayed many personal qualities that underscored their capacity to care. They also drew on the support of family and friendship networks and used community services as appropriate when these were available. Religion played a significant role in the approaches caregivers used and helped them make sense of their role and responsibilities. These aspects also were sources of support and comfort.

Parents in the sample were concerned about their adult child's future prospects especially employment. Financial concerns and stereotyping and discrimination were further causes of concern and solutions to these issues were difficult or non-existent for some participants.

Despite these factors however, participants also articulated the rewards experienced in caring for a family member with acquired brain injury, and these were rich and varied. A key source of satisfaction was the relationship between caregiver and family member and the appreciation the injured family member was able to show. Important also were the bonds of friendship and support from family, colleagues, church and community members.

While it seems that these caregivers, especially the women who in this study assumed the major load in caring, are heavily committed or even burdened with the demands of caring, complaints were rare. Criticisms of the range of services and supports provided were offered, but complaints and regrets were very rarely articulated.

The final section of the report will summarise the key findings related to the research questions and articulate recommendations from the participants and their concerns.

“Having to, you know, because sometimes when you're feeling down you tend to get this sort of you know, negative thinking? You just have to stay focused and stay positive... I just have to read the Quran you know (laughed). I believe even in christianity they teach you to do this”

5. Conclusion and Recommendations

This study sought to address a set of research questions related to family caregivers' experiences of caring for a relative with acquired brain injury with specific reference to the coping strategies, rewards and reciprocity. As discussed in Section 2, the findings from the CAMI and CASI instruments cannot be generalised beyond this sample because of sample size and recruitment approach but they suggest general indications for such family caregivers in Singapore. The interview data based on qualitative methodology also is not generalisable beyond this sample but provides an in-depth understanding of the caregivers' experiences.

5.1 Research questions

5.1.1 Caregivers' experience care giving, strengths and skills, positive aspects

Caregivers experience many demands from their caregiving. They described the demands in terms of personal caregiving, time and emotional energy, as well as financial and other costs. They also described the skills, knowledge, personal attributes and beliefs that sustained them as well as the resources and support from family, friends, neighbours, agencies and health care professionals. The adjustment process for caregivers in assuming this role after an unexpected injury was described and phases in the adjustment process articulated. Participants drew on personal qualities and the support of their networks in making this adjustment and creating meaning for them in this new role. Nonetheless, the cognitive impairments of the family members were experienced by caregivers as generally the most stressful to deal with, in keeping with the literature.

Family caregivers in this study also use the wide range of coping strategies that caregivers have found helpful in international studies. The caregivers employed a broad and effective range of strategies, including direct action, reframing and stress management, to assist them in maintaining the ongoing caregiving activities and remaining largely healthy and positive.

They also derived similar satisfactions and rewards from the experience. Satisfactions accruing from caregiving related very strongly to the relationship between caregiver and family member receiving care, but also were derived from a sense of pride in the caring activities undertaken for him/her, enhanced family relationships, and for the caregiver personally, such things as being appreciated and developing as a person.

5.1.2 Reciprocity in the caregiving relationship

There was less emphasis given by participants to this aspect of their caregiving experience, in contrast to some of the literature. At the same time, the available literature on reciprocity in caregiving relationships draws on other caregiving contexts, particularly carers of adults with mental illness. The nature of the impairments of people with acquired brain injury, and the relatively short period of time as caregivers in this sample, are possible explanations for this difference. A few participants could provide specific examples of their relative giving something back in the relationship, for example helping with household chores. However, some of the wives in this sample were dealing with their husbands' irritability, personality change, lack of awareness and threats or actual incidents of violence, and any examples of their husbands giving something back to them were infrequent and overshadowed by these concerns at the current time.

5.1.3 Services and resources used and recommended by caregivers in carrying out the role

The caregivers in this study were using a range of health services even though their family member had been discharged from active rehabilitation. Follow up consultations were regularly occurring. For a minority of participants, assessment and treatment from mental health services had occurred or was currently underway to address depression, violence, and difficult behaviour. Other placement options had been utilised also, such as nursing homes and respite facilities. Services other than health services were less commonly utilised. The common themes from caregivers related to insufficient financial

support for their relatives' treatment, physical access issues such as lack of accessible transport or lift access, and lack of retraining and employment support.

It can be concluded that strategies such as self-help groups could be explored to see if they were efficacious in mediating some of the stresses that do arise from the demands of caring – the participants were not reluctant to discuss demands of caring but were not active in seeking this particular form of support. It may be that the notion of self-help groups is alien to these caregivers and modification of standard groupwork approaches is needed. Introducing the value of meditation and relaxation exercises is also indicated, allowing caregivers to take up the offer if interested. Some caregivers may be less inclined to seek out this particular form of support or may not wish to appear to be asking for help but may avail themselves of it if it is offered in a non-stigmatising way.

5.2 Recommendations

The recommendations suggested by the participants in this study are summarised below

5.3.1 Information

The flow of information between professionals and caregivers is critical therefore avenues need to be kept open for a two-way flow of information. Easy access to professionals is important for caregivers to maintain their role and remain effective.

Information and education for caregivers should be provided on a one-to-one basis but can also be augmented through group meetings for caregivers. Such psycho-education groups can in addition to disseminating information provide opportunities for caregivers to meet each other and develop mutual support. Some participants in this study received such access to information but not uniformly and some stated that they did not understand the significance of the information on first hearing. Therapeutic support groups could also be offered. In these ways caregivers can provide support to each other which in some instances may be more acceptable than professional support.

5.3.2 Family involvement

Support of family members cannot be assumed – they are not always in a position to help or family dynamics may be such that support is not feasible or acceptable. Caregivers with little family support may need more active outreach from professionals.

There are also instances where inadequate family support leaves the individual with acquired brain injury at some risk of inadequate care or possibly abuse when caregivers are overwhelmed by their responsibilities and therefore trusting relationships with professionals are important to facilitate support for them. No participants in this study appeared to be so overwhelmed by the caregiving task but the availability of family support cannot be always assumed.

5.3.3. Ageing caregivers/self care

Ageing of caregivers was not an issue addressed in this study nor was it raised by participants, possibly because they were in the early years post injury and recovery was still occurring. Nonetheless, parental caregivers of adult children with acquired brain injury, and often spousal caregivers, are in middle age and have finite years of caring available to them. Two implications are future care arrangements and maintaining the health of caregivers. Opportunities should be provided for these caregivers to talk through their concerns, fears and plans with a professional as they see fit, and at a time that is appropriate for them. Information on community resources should be easily available. A needs assessment might be indicated to substantiate what resources are available for this and other groups of people with severe disabilities, and gaps identified so that policy and service development can be well informed of the unmet needs.

Consideration should be given to a range of supports for these full-time caregivers to protect their health. Respite services, in culturally acceptable forms, should be explored to provide short breaks for parents and other family caregivers so that their energy can be maintained. Other services and information should be easily accessible to caregivers so

that physical and mental health is protected. For caregivers engaged in heavy lifting and personal care, adequate training should be provided for back care.

It is further recommended that home help services and befriender services offered by some community organizations be explored for the caregivers to enable them to have time to attend support group activities or engage in social activities that they may enjoy.

5.3.4 Community involvement

It was apparent from these interviews that some of the family members with acquired brain injury were at risk of becoming isolated from their communities and interacting only with some family members. Options for a greater level of social participation should be explored through community centres or other outreach projects. Immediately at issue is the problem of transport as without free or heavily subsidised transport many of these adults would not be able to take up any such services. Some parental caregivers expressed an interest in their adult child being able to participate in structured activities which would be rehabilitative and offer social relationships as well, as well as re-training and employment assistance.

5.3.5 Disability Policy

From the comments of some of these family caregivers there is need to raise the profile of the needs of people with disabilities in the broader social policy arena so that more resources can be channelled into this field. Awareness-raising at both government and non-government levels is necessary and also within the community as a whole. Significant access barriers are faced by people with acquired brain injury and those who care for them. Entitlement to public and private support and services is difficult and not clearly disseminated so that families can easily access the services that they require and can be confident of eligibility. The heavy costs of long-term caregiving are in no way compensated through public policy channels and with insufficient personal resources or family support, caregiving families can experience significant financial strain. Their

family members can be at risk of not receiving some essential health, rehabilitation or pharmaceutical services.

Lack of provision of a range of needed services such as community-based and in-home respite, transport, day activity, workshop, therapy and community integration services, compromises the quality of life of these citizens. The needs assessment referred to in Section 5.3.3 above could be expanded to assess these other needs of this population group.

5.3.6 Access issues and stigma

This issue is linked to the need for broad public education and awareness-raising mentioned above. While improvements are noted in some areas of physical access, such as lifts at all MRT stations and accessible buses, there remain many access barriers in the community including barriers due to ignorance and stigma. Advertising campaigns such as those at bus shelters on the abilities of people with disabilities are commendable. However more sustained intervention is needed and avenues should be explored to move towards a more genuinely inclusive society in Singapore for people with disabilities. Key players in the social service field could develop plans for awareness-raising options such as school programs, co-curricular activities, mainstream advertisements and disability awareness weeks. Comparison with other countries' programs and legislative developments should be pursued with a view to gradually developing comprehensive policies and minimum standards to ensure that the rights of people with disabilities are asserted and protected.

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Appendix 1: CAMI and CASI scales (English and Mandarin versions)

Carers' Assessment of Managing Index (CAMI)

CAMI is a 38-item index and contains a series of statements which carers have made about the coping strategies they use. Carefully read each statement and show if it applies by placing a tick in the space available. Together, responses can be used as the basis for discussing an agreed programme of support with the carer.

I use this and find it:

ONE WAY OF DEALING WITH DEMANDS OF CARING IS BY:	I do not use this	Not really helpful	Quite helpful	Very helpful
1. Establishing a regular routine and sticking to it				
2. Letting off steam in some way – shouting, yelling or the like				
3. Talking over my problems with someone I trust				
4. Keeping a little free time for myself				
5. Keeping one step ahead of things by planning in advance				
6. Seeing the funny side of the situation				
7. Realising there's always someone worse off than me				
8. Gritting my teeth and just getting on with it				
9. Remembering all the good times I used to have with the person I care for				
10. Finding out as much information as I can about the problem				
11. Realising that the person I care for is not to blame for the way they are				
12. Taking one day at a time				
13. Getting as much practical help as I can from my family				
14. Keeping the person I care for as active as possible				
15. Altering my home environment to make things as easy as possible				
16. Realising that things are better now than they used to be				
17. Getting as much help as I can from professionals and other service providers				
18. Thinking about the problem and finding a way to overcome it				
19. Having a good cry				
20. Accepting the situation as it is				
21. Taking my mind off things in some way, by reading, watching TV or the like				
22. Ignoring the problem and hoping it will go away				

23. Preventing problems before they happen				
24. Drawing on strong personal or religious beliefs				
25. Believing in myself and my ability to handle the situation				
26. Forgetting about my problems for a short while by day-dreaming or the like				
27. Keeping my emotions and feelings tightly under control				
28. Trying to cheer myself up by eating, having a drink, smoking or the like				
29. Relying on my own experience and the expertise I have built up				
30. Trying out a number of solutions until I find one that works				
31. Establishing priorities and concentrating on them				
32. Looking for the positive things in each situation				
33. Being firm and pointing out to the person I care for what I expect of them				
34. Realising that no one is to blame for things				
35. Getting rid of excess energy and feelings by walking, swimming or other exercise				
36. Attending a self-help group				
37. Using relaxation techniques, meditation or the like				
38. Maintaining interests outside caring				

Please add below any other coping methods you use and indicate how helpful you find them:

Carers' Assessment of Satisfaction Index (CASI)

CASI is a 30-item index and contains a series of statements which carers have made about the satisfactions they have experienced. Carefully read each statement and show if it applies by placing a tick in the space available. Together, responses can be used as the basis for discussing an agreed programme of support with the carer.

This statement applies to me
and provides me with:

CARING CAN BE SATISFYING BECAUSE:	This does not apply to me	No real satisfaction	Quite a lot of satisfaction	A great deal of satisfaction
1. Caring has allowed me to develop new skills and abilities				
2. The person I care for is appreciative of what I do				
3. Caring has brought me closer to the person I care for				
4. It's good to see small improvements in their condition				
5. I am able to help the person I care for reach their full potential				
6. I am able to repay their past acts of kindness				
7. Caring provides a challenge				
8. Despite all their problems the person I care for does not grumble or moan				
9. It is nice to see the person I care for clean, comfortable and well turned out				
10. Caring enables me to fulfil my sense of duty				
11. I am the sort of person who enjoys helping people				
12. I get pleasure from seeing the person I care for happy				
13. It's good to help the person I care for overcome difficulties and problems				
14. It's nice when something I do gives the person I care for pleasure				
15. Knowing the person I care for the way I do, means I can give better care than anyone else				
16. Caring has helped me to grow and develop as a person				
17. It's nice to feel appreciated by those family and friends I value				
18. Caring has strengthened close family ties				

and relationships				
19. It helps to stop me from feeling guilty				
20. I am able to keep the person I care for out of an institution				
21. I feel that if the situation were reversed, the person I care for would do the same for me				
22. I am able to ensure that the person I care for has their needs tended to				
23. Caring has given me the chance to widen my interests and contacts				
24. Maintaining the dignity of the person I care for is important to me				
25. I am able to test myself and overcome difficulties				
26. Caring is one way of showing my faith				
27. Caring has provided a purpose in my life that I did not have before				
28. At the end of the day I know I will have done the best I could				
29. Caring is one way of expressing my love for the person I care for				
30. Caring makes me feel needed and wanted				

Please add below any other aspects of caring that you find satisfying and indicate how much satisfaction they give you:

护理人对处理压力的评估指数(CAMI)

CAMI 是个有 38 个项目的指数，所有的项目是护理人，对于他们使用的应付方法，所提出的一系列的看法。请仔细阅读每一个项目，然后在适当的空位中划个勾(√)，来显示这个项目对你是否适用。总的来说，你的答案能够作为护理人援助计划重要的讨论基础。

我使用了这个方法后,认为它:

一种应付护理时所遇到的压力时的方法是:	我没有使用这方法	没有什么帮助	相当有帮助	非常有帮助
1. 建立一个有规律的例行程序, 并且严谨地履行它.				
2. 以某种方式发泄- 大喊, 大叫, 等等.				
3. 与自己信任的人讨论自己的烦恼.				
4. 为自己保留一些放松的时间.				
5. 事先计划好要做的事, 之后才有呼吸空间.				
6. 保持乐观的态度.				
7. 了解到一定会有人的情况比自己糟糕.				
8. 咬紧牙根, 坚持下去.				
9. 回忆自己与护理的人所分享过的美好时光.				
10. 寻找有关于问题的资料, 追根究底地察出问题的根源在哪里.				
11. 了解到自己所护理的人不应该为他(她)的病况承担责任.				
12. 抱着`过一天, 算一天`的态度.				
13. 尽量从自己家人那里得到实际的帮助.				
14. 让自己所护理的人尽量保持活跃的生活.				
15. 改善家里的环境, 尽量让一切从简.				
16. 了解到现在的状况, 比起以前, 已经改善了很多.				
17. 尽量从专业人士和社工那里得到帮助.				
18. 思考所遇到的问题, 然后尽量找出解决的方法.				
19. 好好地哭一场.				
20. 接受现在的情形.				
21. 借着收看电视节目或读书来转移自己的注意力, 不要去想自己的烦恼.				
22. 不理睬问题, 希望问题会自己消失.				
23. 事先预防问题的出现.				
24. 从自己个人的力量或宗教信仰中获得依靠.				
25. 信任自己和自己处事的能力.				
26. 通过做白日梦, 等方法, 来暂时忘掉烦恼.				

27. 很坚定地将自己的情绪和感情控制下来.				
28. 通过吃东西, 喝饮料或者抽烟, 等方法, 来放松心情.				
29. 依靠自己所累积的经验和技能.				
30. 尝试不同的问题的解决方法, 来寻找最好的方法.				
31. 为重要的职责建立优先权, 将精神集中在它们上.				
32. 在不同的情况下往好的方面看.				
33. 坚定地对护理的人说自己对于他(她)的期望是什么.				
34. 了解到没有人应该为任何情况承担责任.				
35. 通过游泳, 散步或其他的运动来消磨多余的精力和情绪.				
36. 参加自助小组.				
37. 运用打坐, 放松的方法, 等.				
38. 除了护理以外, 还有维持其他的兴趣与爱好.				

请在以下的空位内填上其他你使用过的应付方法和它们有帮助的程度.

护理人对所得的满足感的评估指数(CASI)

CASI 是个有 30 个项目的指数. 所有的项目包含了护理人对于自己所经历过的满足感所提出的一系列看法. 请仔细阅读每一个项目, 然后在适当的空位中划个勾(√), 来表示这个项目对你是否贴切. 总的来说, 你的答案能够作为护理人援助计划重要的讨论基础.

这个项目对我适用, 并且给了我:

护理能够带来满足感, 因为:	这对我 不适用	没有什么 满足感	相当有满 足感	很多的满 足感
1. 护理帮我培养我的技能与能力.				
2. 我护理的人对我的付出有所感激.				
3. 护理帮助我与我护理的人培养出良好的关系.				
4. 看到自己护理的人的情况有所改善是好事.				
5. 我能够帮助自己护理的人完全地发挥出潜能.				
6. 我能以好好地照顾自己护理的人的方式, 来报答亲朋好友给予我的支持.				
7. 护理对我是一种自我的挑战.				
8. 虽然自己护理的人面对着许多困难, 但他(她)并没有哀声叹气.				
9. 我很开心看到自己护理的人保持着干净, 舒适, 美好的生活.				
10. 护理让我满足自己的义务感.				
11. 我是那种喜欢帮助别人的人.				
12. 我从自己护理的人的快乐中得到快乐.				
13. 能够帮助自己护理的人征服问题与困难是好事.				
14. 能够为自己护理的人带来快乐是好事.				
15. 由于我对自己护理的人有深厚的了解, 便代表着我能给予他(她)最好的照顾.				
16. 护理让我成长, 并且培养了我的人格.				
17. 我很开心自己的付出能够得到自己所珍惜的家人和朋友的感激与赏识.				
18. 护理增强了家庭之间, 或与其他人之间的关系.				
19. 护理帮助我减少自己的罪恶感.				
20. 我能帮助自己护理的人, 让他(她)不必住在收容所里.				
21. 我认为要是情况是相反的话, 我护理的人				

也会一样地照顾我.				
22. 我能够确保自己护理的人的需求都有妥善的照顾.				
23. 护理给了我扩展兴趣与交际圈子的机会.				
24. 维持自己护理的人的尊严对我来说是很重要的.				
25. 我能够接受考验, 并且征服考验.				
26. 护理是一种信心的表现.				
27. 护理提供了我生命的意义.				
28. 到最后, 我知道我已全力以赴.				
29. 护理让我对自己护理的人表达关怀.				
30. 护理让我觉得自己是有用的, 和不可缺少的.				

请在以下的空位中填入护理还为你带来哪一方面的满足感, 和它所带给你的满足感的程度:

Appendix 2: Interview Guide

Family caregiving in Singapore – Strengths of the carer and the contribution of the person with a disability

Demographics

(Note: some of these details will be observable at interview or obtained during the conversation, without needing to ask explicitly. If not mentioned by respondent, interviewer to ask.)

About respondent

Age

Gender

Marital status

Race/ethnicity

Religion

Accommodation

Employment status

Household (who lives in the household)

About relative with acquired brain injury being cared for)

Age

Gender

Marital status

Race/ethnicity

Religion

Employment status

Household if not living with carer (where living)

About caregiving relationship

How long have you been caring for your son/daughter/other relative?

What limitations are experienced by him/her because of his/her condition?

What services does he/she receive from TTSH?

- how are these are evaluated – helpfulness; timeliness; cost; convenience; communication; relationship of relative with staff etc.

What services are received from other agencies and how these are evaluated?

What services are needed but not presently available?

About the care

What is the nature of assistance required; extent; any particular demands or requirements

Are there any behavioural issues (e.g. mood swings; anger; aggression)?

Are there any mental health issues e.g. depression? Any other health issues?

Carer skills and attributes

What values, knowledge, skills and attributes from other life experience or roles do you draw on in caring for him/her? (explore slowly; probe)

What rewards do you receive from caring?

Does your relative also give something back, to you or the family?

What support do you receive from the health care, social services or education systems? (e.g. professionals, therapists, agencies, volunteers, doctor etc)

What support do you receive from family, friends and neighbours, in your caring responsibility?

Do you prefer to care for family members with disabilities if you have the resources to do so?

Do you have any health concerns yourself?

If not already covered:

How do you manage to care for your relative who has a severe disability?

How do you deal with memory and behaviour problems?

How do you look after yourself?

What do you and other family members gain from caring for your relative who has a disability?

In what ways does your relative with a disability contribute to the family or broader community (what does he/she give back?)

What skills and knowledge do new carers need to take on this role?

What resources, services, training or support are the most helpful to you?

About relatives' needs

What needs does the person have that TTSH or other agencies do not provide some assistance with?

If not already mentioned, what kinds of services are not currently available or used that would be helpful?

Are there any barriers to using either TTSH or other agency services that you know are available?

What improvements would you recommend in TTSH services or other services you know about? Does your relative complain about any services he/she receives?

Other comments

Have you received any training to be a caregiver? Would you be interested in receiving any training?

What social activities are you involved in?

What sport or recreation are you involved in?

What hobbies or interests do you have?

What church activities are you involved in?

Are you involved in any other activities?

Are there any other family concerns?

Finally

Is there anything else you would like to say?

Thank you for all your time and interest!

When and how results will be available

Appendix 3: List of nodes

Nodes in Set: All Tree Nodes

- Number of Nodes:** 73
- 1(1) /carer
- 2 (1 1) /carer/caring ADLs
 - 3 (1 2) /carer/demands of caring
 - 4 (1 3) /carer/faith~beliefs
 - 5 (1 4) /carer/skills & knowledge
 - 6 (1 5) /carer/commitment
 - 7 (1 6) /carer/own health issues
 - 8 (1 7) /carer/other carers
 - 9 (1 7 1) /carer/other carers/maid
 - 10 (1 7 2) /carer/other carers/siblings of pwabi
 - 11 (1 7 3) /carer/other carers/carer's mother
 - 12 (1 8) /carer/rewards
 - 13 (1 9) /carer/self care~relaxation
 - 14 (1 10) /carer/culture
 - 15 (1 11) /carer/qualities
 - 16 (1 12) /carer/acceptance
 - 17 (1 13) /carer/loss
 - 18 (1 14) /carer/hope
 - 19 (1 15) /carer/humour
 - 20 (1 16) /carer/finances
 - 21 (1 17) /carer/family
 - 22 (1 18) /carer/other caring responsibilities
 - 23 (1 19) /carer/carer employment
 - 24 (1 20) /carer/carer giving back
 - 25 (1 21) /carer/gender
 - 26 (1 22) /carer/disempowered
- 27 (2) /caring relationship
- 28 (2 1) /caring relationship/tie of caring
 - 29 (2 2) /caring relationship/communicate
 - 30 (2 3) /caring relationship/protectiveness
- 31 (3) /family member
- 32 (3 1) /family member/ability~capacity
 - 33 (3 2) /family member/activities
 - 34 (3 3) /family member/limitations~losses
 - 35 (3 4) /family member/enjoyment~satisfaction
 - 36 (3 5) /family member/reciprocity
 - 37 (3 6) /family member/hosp and rehab treatment
 - 38 (3 7) /family member/post injury emplt~train
 - 39 (3 8) /family member/boredom; lack com involve
 - 40 (3 9) /family member/friendship network
 - 41 (3 10) /family member/difficult behaviour
 - 42 (3 11) /family member/mood swings; emotions
 - 43 (3 12) /family member/mental health

- 44** (4) /resources
- 45** (4 1) /resources/other carers
- 46** (4 2) /resources/TTSH
- 47** (4 3) /resources/professionals
- 48** (4 4) /resources/day care
- 49** (4 5) /resources/carer support group needed
- 50** (4 6) /resources/church
- 51** (4 7) /resources/school
- 52** (4 8) /resources/AWWA
- 53** (4 9) /resources/needs
- 54** (4 10) /resources/ psychiatrists
- 55** (4 11) /resources/media
- 56** (4 12) /resources/nursing home
- 57** (4 13) /resources/police
- 58** (4 14) /resources/sinda
- 59** (4 15) /resources/CDC
- 60** (4 16) /resources/counselling
- 61** (4 17) /resources/wheelchair

- 62** (5) /society
- 63** (5 1) /society/access barriers
- 64** (5 2) /society/social support
- 65** (5 3) /society/com involvement; interests

- 66** (6) /quote

- 67** (7) /feelings
- 68** (7 1) /feelings/anger
- 69** (7 2) /feelings/sadness, loss
- 70** (7 3) /feelings/bitterness, hurt
- 71** (7 4) /feelings/lost, scared
- 72** (7 5) /feelings/fear

- 73** (8) /researcher