

DEVELOPMENT AND PILOT TESTING OF THE CAREGIVER
LEISURE ATTITUDE SCALE (CLAS) AND THE “ME TIME
FOR MUMS” CREATIVE ARTS AND LEISURE PROGRAM

Debbie Zaks

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Abstract

This thesis comprised separate but integrated components. Part 1 describes the development and pilot testing of a new Caregiver Leisure Attitude Scale (CLAS). This scale was used as one of the outcome measures in Part 2, which documents the development, implementation, and evaluation of “Me Time for Mums”, a creative-arts oriented leisure program for mothers caring for a child with a disability.

The CLAS was tested with 118 women ranging in age from 22 to 64 ($M = 40.15$ years, $SD = 8.55$), comprising 64 caregivers of people with a disability and 54 mothers of typically developing children. Results indicated preliminary evidence for the validity and reliability of a 23-item version of the CLAS. While this version of the CLAS was psychometrically sound for use as an outcome measure in Part 2, further research is warranted to refine the CLAS items and confirm its factor structure.

The “Me Time for Mums” leisure program consisted of five weekly two-hour sessions: (a) yoga/relaxation, (b) belly dancing, (c) “Theatresports” improvisation, (d) group drumming, and (e) art making/sensory play. The program was implemented with two groups; one group acted as a waiting-list control group while the other group completed the program. There were 8 participants in each group. Participants were between 30 and 58 years of age ($M = 42.75$, $SD = 7$), provided direct caregiving to their child with a disability for a minimum of 40 hours per week, and reported below average personal wellbeing.

The two intervention groups differed on the basis of participating in a pre-program self-investigation intervention. One intervention group, the “P⁺ group”, received the program plus a pre-program narrative-based intervention, adapted from the self-confrontation method formulated by Hermans and Hermans-Jansen (1995, 2001). The other group, referred to as the “P group” participated in the program only, after first serving as the wait-list control group. In order to evaluate the program, the groups completed a battery of questionnaires before and after the program, provided written feedback after each session, and participated in post-program interviews three months after completing the program.

Results of ANOVAs and planned contrasts demonstrated that the following program outcomes were replicated across the two intervention groups. Compared to the wait-list control group, both intervention groups reported significantly greater pre- to post-program changes on the following variables: Increased perception of the benefits of leisure, greater motivation to increase leisure, increased use of leisure companionship as a coping strategy, decreased stress, increased positive energy, and increased satisfaction with basic needs and activities of living. In addition, compared to both the wait-list control group and the P group, the P⁺ group reported a significantly greater reduction in perceived intrapersonal constraints to leisure. Lastly, the P group reported a greater reduction in tiredness during the program, compared to waiting for it.

Qualitative results of post-program interviews elucidated further salutary effects of the program in terms of attitudinal outcomes (reduced intrapersonal constraints to leisure and increased acknowledgement of personal needs), affective outcomes (uplifted mood and increased affective self-regulation) and behavioural outcomes (increased leisure behavior and “seizing moments” for doing leisure). Participants described these positive outcomes as resulting from experiencing a number of psychological processes: (a) self-expansion; (b) a state of energised focus which approximated Csíkszentmihályi’s concept of “flow”; (c) restorative respite; and (d) social support.

Both the quantitative and qualitative results demonstrated that doing the pre-program self-investigation intervention augmented positive program effects, indicating that the effects of an experiential leisure program may be enhanced when coupled with a priming intervention which makes the multifaceted and dynamic nature of personal identity salient.

Results of this study suggest that experiential leisure programs are a beneficial and feasible positive psychology intervention. Limitations of the present program design and evaluation are noted with a view to future improvements, and implications are discussed with a view to facilitating the sustainable delivery of the “Me Time for Mums” program model in Australia.

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Declaration

This thesis contains no material which has been accepted for the award to the candidate of any other degree or diploma, except where due reference is made in the text of the thesis.

To the best of the candidate's knowledge the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Candidate:

Candidate's signature:

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PART 1. CHAPTER 1: DEVELOPMENT AND PILOT TESTING OF THE CAREGIVER LEISURE ATTITUDES SCALE (CLAS)

1.1 Background and Rationale for Developing a Caregiver Leisure Attitudes Scale

Caregiving research has increasingly moved away from examining deleterious corollaries and effects of caregiving within a stress/illness framework towards the study of stress management or coping (Scorgie, Wilgosh, & McDonald, 1996). It is now well established that stress does not necessarily lead to illness, and that caregiving does not necessarily result in unmitigated stress (Singer, 2006). Researchers who have reviewed carer-specific scales (e.g., Schene, Tessler, & Gamache, 1994; Singer, 2006) have commented on the emphasis on carer-burden and have called for the development of instruments measuring resources and activities that promote coping and wellbeing. Leisure is one such resource.

The definition of leisure has shifted from a focus on leisurely activities to a broader, psychological definition that recognises the power of the individual as a key determinant of leisure experiences. To date there is no consensual and operationalised definition of leisure. The construct of leisure has been conceptualised as both discretionary or “free” time from duties and responsibilities and as a state of mind (Mannell & Kleiber, 1997), which may encompass facets of experience including: enjoyment, a sense of involvement, intrinsic motivation, a desire to separate or escape from every day routine, and experiencing pleasure, self-fulfillment, social connection, and relaxation (Knock & Kitch, 1994).

The positive effects of leisure as a coping strategy are well documented in the literature (see Hutchinson, Bland, & Kleiber, 2008 for a review). Leisure can reduce the negative effects of stress on people’s mental or physical health (e.g., Iso-Ahola & Park, 1996; Iwasaki & Mannell, 2000). Leisure can contribute to life satisfaction and psychological wellbeing (Evans & Haworth, 1991; McTeer & Curtis, 1990; Smale &

Dupuis, 1993; Wankel & Berger, 1990), and to increasing good mood (Mannell, 1980), happiness and enjoyment (Csikszentmihalyi & LeFever, 1989), and the development and maintenance of social support networks (Coleman & Iso-Ahola, 1993). Leisure can help to foster a sense of self-determination, including a sense of personal control and competence (Coleman & Iso-Ahola, 1993; Kelly, 1993). Leisure activities can provide opportunities to experience a sense of mastery, achievement, or “normalcy” and can afford some connection with previous sources of meaning and identity (Hutchinson & Kleiber, 2005; Kleiber, Hutchinson, & Williams, 2002). Iso-Ahola (1994) emphasised how leisure has a positive effect on mood, self-actualisation, life satisfaction, self-esteem, and sense of connectedness and belonging. Leisure has been demonstrated as an effective means of coping and adapting to change, such that having time-out for positive leisure experiences enhances an individual’s ability to take perspective on concerns and improves their subjective well-being (Diener, 2000; Folkman, 1997). Leisure has also been shown to improve physical health (Nieman, 1998; Paffenbarger, Hyde, & Dow, 1991). Hemingway (1996) proposed that the degree to which individuals are able to withdraw from external influences determines the degree of freedom they experience in leisure. Ample research demonstrates the typically engulfing nature of the carer role, which often makes it hard to withdraw from responsibilities and pressures and seek leisure (e.g., Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995).

Carers report multiple constraints to leisure. Therefore it may be erroneous to assume that a carer would have an experiential framework from which to reflect on leisure, or that they would consider leisure to be inherently positive, instead of selfish, for example. Weinblatt and Navon (1995) critically examined the notion that reduced leisure participation among carers results from passive reactions to external constraints. They found that carers still had opportunities for participation in leisure activities, but often did not take advantage of them. In their study, carers variously considered leisure

as being inactivity, a waste of time, and a breeding ground for feelings of anxiety, depression, loss of control, and a strong sense they had betrayed or abandoned their care recipient. They argued that carers might actively choose to avoid and devalue leisure given the problems that leisure may evoke for them.

Carers report that caregiving is often unpredictable, frustrating, draining, and preoccupying, leaving little energy and perceived availability of time left over for leisure (Gahagan, Loppie, Rehman, Maclellan, & Side, 2007). Carers may struggle to feel entitled and give themselves permission to engage in leisure as they may experience time for self as being selfish and guilt-provoking (Aronson, 1992), or may fear that others would not provide the same quality of care as they can (Lewis & Meredith, 1988). Carers frequently report changes to their social network after taking on the role of caregiver. Feelings of social isolation and marginalisation may further constrict opportunities and social facilitation of leisure participation (Cant, 1993; Murray, 2007; White-Means & Chang, 1994). Research amply demonstrates the structural barriers that constrain leisure among carers, including financial restrictions, physical inaccessibility to public spaces, limited respite options, and lack of accessible and supported community leisure programs. In short, carers' whole approach to leisure including its value, benefits, risks of not doing it, priority of it and access to it tends to alter according to how leisure fits in with their role as caregiver (Bedini & Guinan, 1996; Weinblatt & Navon, 1995). This list of constraints to leisure highlights the reality that carers are a specific population that should be assisted to access leisure and self-care, given the numerous constraints many carers cite as resulting from their demanding caregiver role (e.g., Bedini & Guinan, 1996; Cant, 1993; Chenoweth & Spencer, 1986; Dunn & Strain, 2001).

Research indicates that some carers experience a reduction or cessation of leisure activities while others do not. The likelihood of carers reducing the frequency of

leisure participation depends on numerous variables, including: personal attitudes towards leisure, the intensity of the caring relationship, the co-resident status of the care-recipient, the availability of social support, the type of disability of the care recipient, the carer's mental health, and demographic variables such as the carer's gender, their employment, financial, and relationship status, educational level, and cultural background (Bedini & Guinan, 1996; Dunn & Strain, 2001; Miller & Montgomery, 1990; White-Means & Chang, 1994). All these factors combine in a unique fashion for each carer to make them more or less likely to engage in leisure and experience its positive effects.

Despite the wealth of evidence showing the salutary effects of leisure for carers, brief psychometrically validated questionnaires measuring carers' leisure attitudes are non-existent. In their research exploring "Caregivers at Risk?: Changes in Leisure Participation", Dunn and Strain (2001) argued that there are ample global measures of caregiver burden and quality of life, and that what is necessary is increased attention to measuring carers' subjective attitudes and beliefs about caregiving and how this impacts on their leisure perceptions and engagement. To this end, there were several aims associated with the development of the Caregiver Leisure Attitudes Scale (CLAS).

The CLAS represents one attempt to focus on caregiver leisure and self-care attitudes. A questionnaire dedicated to carers' attitudes to resiliency-promoting resources, such as leisure, will hopefully elevate the perceived importance of "having a life outside caregiving" among carers and the people, professionals and communities with whom they interact. The development of the CLAS seems timely as there appears to be increasing efforts to evaluate carer-specific leisure programs. To date, leisure interventions for carers have either not been empirically evaluated or not been evaluated using validated leisure instruments (e.g., Bedini & Phoenix, 1999; Murrant,

2000; Walsh, Martin, & Schmidt, 2004). Without a standardised leisure instrument, comparing program effects across studies is impossible. Given increasing emphasis on delivering evidence-based programs, there is a need to be able to quantitatively evaluate leisure programs in a consistent fashion so as to build an empirical rationale for their continued delivery beyond the pilot phase. In the absence of carer-specific leisure instruments, several programs have been evaluated using general mental health indices, which may not provide a sensitive measurement of program effects. Measuring changes in leisure attitudes will, most likely, provide a more proximal indication of leisure program outcomes. Some evaluations of leisure programs have included a cursory measurement of leisure participation such as the amount of time spent doing leisure per week (e.g., as used in the program evaluation conducted by Won, Fitts, Favaro, Olsen, & Phelan, 2007). This approach may miss important subjective attitudinal changes regarding leisure that may not yet be apparent through objective behavioural measures of time spent or type of activities done in leisure. As well as being a tool for program evaluation, it is also hoped that health and recreation professionals will employ the CLAS to identify carers' leisure values and constraints, and use this information to tailor interventions on an individual and group basis.

1.2 Review of Existing Leisure Scales

In order to develop a leisure attitudes scale suitable for tracking changes in carers' attitudes to engaging in leisure, a review of existing scales was undertaken. Its purpose was to identify appropriate dimensions and specific items that might be incorporated into a leisure attitudes scale for carers. The aim was to develop a scale that might assist in understanding the multitude of reasons that might prevent or facilitate carers engaging in leisure. Scales reviewed covered a broad range and included those that focused on leisure functioning (e.g., Ellis & Niles, 1985; Witt & Ellis, 1989, as cited in Peebles, McWilliams, Norris, & Park, 1999), leisure motivation (e.g.,

Weissinger & Bandalos, 1995), satisfaction with leisure (e.g., Beard & Ragheb, 1980), and leisure attitudes and use of leisure as a coping strategy (e.g., Iwasaki & Mannell, 2000). Through reviewing existing leisure instruments, it became clear that there were no measures of leisure attitudes that have been designed with caregivers in mind.

Existing leisure attitude scales measure individuals' beliefs about the positive, coping-promoting functions of leisure. For example, the Leisure Coping Beliefs Scale (Iwasaki & Mannell, 2000) measures the benefits of leisure across a number of domains such as "Emotional Support", "Self-Determination", "Empowerment", and "Leisure mood enhancement", among others. Items in these scales are worded in positive terms and seem to assume that respondents regularly engage in leisure activities and are therefore in a position to reflect on the ensuing benefits. Similarly, the Assessment of Leisure and Recreation Involvement (LRI; Ragheb, 2002) consists of the six subscales: "Pleasure", "Meaning", "Centrality", "Interest", "Importance", and "Intensity" of leisure and recreation involvement, with items such as "My favorite leisure activities give me pleasure" and "After completing my leisure activities, I usually feel satisfied and full". Once again, these items may not account for the reality of the lack of an experiential leisure framework typically reported by carers (e.g., Dunn & Strain, 2001; Gahagan et al., 2007; Hughes & Keller, 1992; Willyard, Miller, Shoemaker, & Addison, 2008).

The only quantitative, carer-specific measure of leisure attitudes that could be found was formulated (but not psychometrically tested) by Dunn and Strain (2001) to investigate leisure participation among 517 informal caregivers of Adult Day Care clients in Canada. Carers were asked whether they had ceased and/or reduced any leisure activities over the last two years. Caregivers who indicated reducing and/or ceasing their leisure participation were asked "To what extent have you reduced or given up your leisure activities because of [reason]?" The reasons to choose from

included lack of equipment and/or supplies, lack of information, lack of financial resources, lack of others with whom to participate, weather restrictions, physical health, being too tired, lack of time due to caregiving, lack of time due to work outside the home, family commitments, too much stress, lack of interest, and lack of freedom. Some of the reasons were used to inform the development of the CLAS. However, while Dunn and Strain's scale addresses changes to leisure time and constraints to leisure among carers, it does not address carers' attitudes concerning the value of leisure (i.e., perceived benefits of leisure and perceived risks of not doing leisure). As Weinblatt and Navon (1995) argued, it cannot be assumed that leisure is of intrinsic value to caregivers, and furthermore health promotion models advocate assessing values and beliefs concerning the benefits of the doing the behaviour as an important dimension of behavioural motivation (e.g., the Health Belief Model outlined by Rosenstock, Strecher, & Becker, 1994).

Leisure activity participation and leisure satisfaction scales measure satisfaction with amount of time for leisure or extent of participation in a predefined set of leisure activities. The Leisure Time Satisfaction (LTS) questionnaire (Stevens et al., 2004) is a seven-item scale designed to assess satisfaction with the amount of time spent in leisure activities thought to be relevant to the dementia caregiving experience (e.g., "take part in hobbies", "do fun things with people", "visit family and friends"). This scale is similar to the Activities of Living subscale of the Caregiver Wellbeing Scale (Berg-Weger, Rubio, & Tebb, 2000) which measures the extent to which carers feel that certain activity-specific needs have been met (including "relaxing", "exercise", "enjoying a hobby", and "attending social events", among others). These and other general population leisure satisfaction scales (e.g., Leisure Satisfaction Scale (LSS; Beard & Ragheb, 1980); Pleasant Events Scale-Elderly (PES-E; Teri & Lewinsohn, 1982), the social activities scale of the Multilevel Assessment Instrument

(MAI; Lawton, Moss, Fulcomer, & Kleban, 1982), and the Activity Card Sort (ACS - Australia; Packer, Boshoff, & DeJonge, 2008) measure satisfaction with level of engagement in a range of leisure activities. While there is clearly a place for activity-based measures, they cannot illuminate the cognitive processes working to foster or restrict participation in leisure in the first place. Furthermore, leisure researchers have recently critiqued operationalising leisure as a set of activities as people differ in their activity preferences and widely divergent activities based on personal preference may be considered as leisure (Iso-Ahola, 1980).

Existing leisure motivation scales (such as the Leisure Motivation Scale; Pelletier, Vallerand, Blais, & Briere, 1991; and the Intrinsic Leisure Motivation Scale; Weissinger & Bandalos, 1995) typically assess the reasons that motivate individuals to participate in leisure, such as “to know”, “to accomplish”, “to experience stimulation”, and for “competence”, “commitment” or “challenge”. These scales assume that people are motivated to do leisure for a variety of reasons; however, as has been previously stated, it would be erroneous to assume that carers are intrinsically motivated to participate in leisure.

Leisure functioning scales (e.g., Witt & Ellis, 1989; Ellis & Niles, 1985) assess leisure across a number of domains. For example, the Leisure Profile Packet (Olson, 2006, p. 277) consists of nine separate scales (altogether comprising 194 items) originally designed for use by students undertaking a leisure education course at Sacramento State College of Health and Human Services. These scales are designed to measure factors generally viewed by leisure educators as important to effective leisure functioning. However, to date they have not been psychometrically tested, and continue to be modified. The first two “cognitive scales” measure leisure awareness and leisure knowledge. The next three “affective scales” measure leisure values, attitudes, and beliefs. The third set of “behavioral scales” measure one’s actual as well as desired

leisure behaviors. The final “temporal scale” is a measure of one’s perceptions of obstacles to leisure. While large, multidimensional leisure functioning questionnaires are undoubtedly useful for leisure functioning assessment and intervention planning, they are arguably too time consuming and unwieldy for use in evaluating carer-specific leisure interventions. Notwithstanding this point, several items from the LPP pertaining to leisure attitudes and constraints were adapted for use in the CLAS.

Deeken, Taylor, Mangan, Yabroff, and Ingham (2003) reviewed 28 caregiver instruments covering caregiver burden, needs, and quality of life. This review provided an efficient means of exploring whether carer-specific scales already measured leisure attitudes. Items measuring the leisure/respite/self-care domain are included in several caregiver instruments; however, in these scales leisure is typically assessed using one or two questions, which are insufficient to measure carers’ self-reported complicated relationship to leisure and self-care. Furthermore, one-item measures tend to have less reliability than multi-item scales. Some instruments incorporated more leisure items, such as the Caregiver Wellbeing Scale (CWBS, Tebb, 1995), which measures the extent to which certain leisure needs have been met, such as “leisure activities”, “time for self”, “enjoying a hobby”, and “having time for recreation”. Other caregiver scales reviewed either similarly assess the extent to which leisure and respite needs are being met or assess the extent to which leisure time has been lost or disrupted as a result of caregiving. However, as revealed by Deeken et al. in their large review of carer-specific instruments, there is no existing carer-leisure instrument that comprehensively assesses the attitudinal factors underpinning leisure involvement, such as carers’ attitudes about the value of and their entitlement to leisure, the constraints they face to seeking leisure, and their motivation to negotiate these constraints. The development of the CLAS attempts to assess these areas and provide a useful program evaluation and leisure diagnostic tool that is relevant to caregivers.

1.3 Formulating CLAS Dimensions and Generating Items

The goal in item formulation was to capture aspects of health behaviour change theories with specific application to carers' leisure behaviour. This was achieved by using theory to conceptually group items, along with qualitative studies to ensure item content represented carers' self-reports concerning attitudes to leisure (Bedini & Guinan, 1996; Bedini & Phoenix, 2004; Cant, 1993; Dunn & Strain, 2001; Gahagan, et al., 2007; Henderson & Allen, 1991; Hughes & Keller, 1992; Miller & Montgomery, 1990).

In formulating items for the CLAS, the researchers were guided by the following theories: The Health Belief Model of behaviour change (Rosenstock et al., 1994), Crawford, Jackson, and Godbey's (1991) Leisure Constraints Model, and Prochaska and DiClemente's (1983) Transtheoretical Model of behaviour change.

Iwasaki and his colleagues (Iwasaki, 2001; Iwasaki & Mannell, 2000) developed a leisure-coping model that distinguishes leisure coping beliefs from leisure coping strategies. They found that people's beliefs about their leisure, rather than what they actually do in their leisure, contribute most significantly to buffering the effects of stress on psychological wellbeing. Given the paramount importance of beliefs to psychological coping, the Health Belief Model (HBM) was employed to group items into conceptual subscales. The HBM is a psychological model that attempts to explain and predict health behaviors through focusing on the attitudes and beliefs of individuals. Health Belief models generally group the factors influencing performance of health behaviours into three domains: (a) individual characteristics and experiences/sociodemographic factors; (b) behavior specific perceptions, cognitions, and affects; and (c) interpersonal/situational cues to action (for detailed outline of health belief models, see Glanz, Lewis, & Rimer, 2002).

In the development of the CLAS the variables included in the domain of behaviour-specific perceptions were used to group items. According to Rosenstock et al. (1994), these key variables are: Perceived susceptibility (to an illness/condition), perceived severity (of illness/condition and its sequelae), perceived benefits (of doing health behaviour), perceived barriers (to doing health behaviour), and self-efficacy, that is, the belief in being able to successfully execute the behaviour required to produce the desired outcomes. These variables informed the conceptual CLAS dimensions of benefits of doing leisure, risks of not doing leisure, leisure constraints, motivation to increase leisure behaviour, and self-efficacy to negotiate leisure constraints.

Items from the Leisure Coping Beliefs Scale (Iwasaki & Mannell, 2000), the Leisure Profile Packet (Olsen, 2006) as well as qualitative self-reports were referred to for guidance in the formulation of items in the CLAS measuring perceived benefits of leisure and risks of not doing leisure. In a literature review of all HBM studies published from 1974-1984, Janz and Becker (1984) identified perceived barriers as the most influential variable for predicting and explaining health-related behaviors. Given the importance of barriers to behavior change, theoretical formulations regarding leisure constraints and constraint negotiation were consulted.

Constraints are viewed as "...a subset of reasons for not engaging in a particular behaviour" (Jackson, 1988, p. 211). Crawford et al. (1991) identified three categories of leisure constraints: Intrapersonal, interpersonal and structural. Intrapersonal constraints are within the individual such as shyness, stress, depression, and subjective evaluations of the appropriateness, worth, and entitlement to do leisure. Interpersonal constraints result from interpersonal interactions, availability of leisure companions, conflicting schedules or family obligations, and perceived support from others to do leisure. Structural constraints are features of the external environment such as availability of financial resources, respite care, transportation, inconvenient facilities,

and time limitations, among others. These categories were used to group the CLAS items measuring constraints to leisure. Items measuring intrapersonal, interpersonal, and structural constraints to leisure were formulated.

Leisure constraints do not necessarily reduce or preclude leisure participation. Jackson, Crawford, and Godbey (1993) introduced the concept of “negotiation-*efficacy*”, suggesting that “...both the negotiation and the outcome of the negotiation process is dependent on the relative strength of, and interaction between, constraints on participating and motivations for such participation” (p. 9). Current research studies are underway to examine and compare different models of the influence between leisure constraints, leisure negotiation strategies and, and motivation to do leisure (e.g., Son, Mowen, & Kerstetter, 2008), but all models confirm the importance of including self-*efficacy* (i.e., belief in one’s ability to negotiate through leisure constraints) and motivation to increase leisure behaviour as key variables in negotiating leisure constraints. In light of this, two items measuring negotiation self-*efficacy* and seven items measuring motivation to increase leisure behaviour were included in the CLAS.

Motivation items followed the time frames associated with Prochaska and DiClemente’s (1983) five basic stages of readiness to change outlined in their Transtheoretical Model (TTM) of health behaviour change. These are: Pre-contemplation (no intent to change behavior in the near future, usually measured as the next 6 months), contemplation (intent to change within the next 6 months), preparation (intend to take steps to change, usually within the next month), action (perceptible change has been made for less than 6 months), and maintenance (changes have been sustained for more than six months, with aim of preventing relapse and consolidating gains). This approach differs from other leisure motivation instruments (e.g., the Intrinsic Leisure Motivation Scale; Weissinger & Bandalos, 1995, and the Leisure Motivation Scale; Beard & Ragheb, 1983), as it does not presuppose that caregivers are

already engaging in leisure behaviour. Indeed, in light of ample qualitative research demonstrating caregivers' loss or lack of leisure (e.g., Gahagan et al., 2007), the stages of change model provides a way of assessing their leisure motivation in the absence of regular leisure behaviour. For example, movement from pre-contemplation to contemplation is an important step in the behavior change process that does not involve overt behavior change.

The theories undergirding formulation of the CLAS conceptual subscales are summarised below in Table 1.

Table 1

Theories undergirding formulation of the CLAS conceptual subscales

Health belief model of behaviour change (Rosenstock et al., 1994)	Jackson, Crawford, and Godbey's (1991) Leisure Constraints Model	Prochaska and DiClemente's (1983) Transtheoretical model of behaviour change	CLAS conceptual subscales
Perceived benefits			1. Benefits of doing leisure
Perceived susceptibility			2. Risks of not doing leisure
Perceived severity			
Perceived barriers	Constraints to leisure: a) intrapersonal constraints b) interpersonal constraints c) structural constraints		3. intrapersonal constraints to leisure 4. interpersonal constraints to leisure 5. structural constraints to leisure
Self-efficacy	Concept of leisure constraints "negotiation-efficacy" which includes self-efficacy and motivation to increase leisure.		6. Motivation and self-efficacy to engage in leisure
		Motivation stages of change: a) Pre-contemplation b) contemplation c) preparation d) action 3) maintenance	

Following review of these leisure scales, an initial set of 43 items was formulated (reported in Table 2, p. 20). These 43 items were designed to form six conceptual subscales: a) benefits of doing leisure; b) risks of not doing leisure; c) intrapersonal constraints to leisure; d) interpersonal constraints to leisure; e) structural constraints to leisure; f) motivation and self-efficacy to engage in leisure. A panel of researchers and practitioners with expertise in a variety of areas (caregiving and leisure research, disability studies, social psychology, program evaluation research, and survey construction) confirmed the face validity of the initial 43 items.

1.4 Procedure for Recruiting Respondents and Scale Administration

A number of methods were used to recruit respondents. The CLAS pilot study was advertised using flyers (Appendix A) distributed to case workers, and was posted on notice boards in a large number of organisations that mothers and maternal caregivers attend (see Appendix B for list of organisations). Alongside the fliers, hard copies of the questionnaire packs were available with reply paid envelopes in which to send back anonymously completed questionnaires. Three mail-outs were arranged with Carers Victoria, the Association for Children with a Disability, and the Inner East Parent to Parent Support network. The mail-out consisted of 50 packages, comprising an information sheet describing the CLAS pilot study, a hard copy of the CLAS, and a reply paid envelope. In addition, Autism Victoria agreed to publish an advertisement of the study in eSpectrum, their online journal (Appendix C), and the Association of Children with a Disability and the Parent Support Network published an advertisement in their print magazines. The student researcher attended parent support group meetings (Parent Support Network - Inner East and Eastern regions) attempting to raise awareness of both the CLAS pilot study and the “Me Time for Mums”, which was subsequently implemented. These efforts to recruit respondents were largely

unsuccessful. Altogether, 600 hard copies of the scale were disseminated and only 23 carers responded (response rate of 3.8%).

As an alternative to disseminating hard copies of the questionnaires, and in order to recruit more participants to perform an exploratory factor analysis, an online form of the 43-item CLAS was created using the Opinio software program, an application that enables production and publication of surveys using a regular web browser. The CLAS was initially posted to the Internet to be completed by itself in order to encourage respondents to participate by presenting the minimum number of items. Additionally, the student researcher disseminated the CLAS web address to her network of contacts in order to recruit a sample of non-carer respondents. Non-carers were recruited in order to amass participants to perform a factor analysis, as well as to compare carers to non-carers on the CLAS to explore criterion validity. Non-carer respondents needed to fulfil the criteria of being people who care for typically developing children, excluding non-carers with children under the age of two given that caring for infants and toddlers often entails high caregiving demands and could confound comparisons between carers and non-carers. Performing a caring role was necessary given the nature of the CLAS questions, however a comparison group with generally less caregiving responsibilities was needed to assess the criterion validity of the CLAS. The survey was posted on a variety of sites that carers access, including the online newsletters produced by Autism Victoria, Commonwealth Carer Respite Centre Southern Metropolitan Region, and a flyer was posted on the Internet by the Eastern respite centre.

1.5 Participants for the Development of the CLAS

Respondents were 118 women ranging in age from 22 to 64 ($M = 40.15$ years, $SD = 8.55$), comprising 64 (54.24%) carers of people with a disability or illness (41 recruited over the internet) and 54 (45.76 %) non-carers (who were all mothers of

typically developing children over the age of two, all doing the survey online).

Although the scale was open to men, none participated. Location of participants included those in metropolitan (70.5%), regional (20.5%) and rural (9.1%) areas in Victoria. Most of the 118 respondents reported being in relationship, either married (68.6%), defacto (10.2%), or in a relationship but not living with their partner (2.5%), with a minority either separated or divorced (9.3%) or single (9.3%). Highest educational attainment consisted of primary school (1.7%), secondary school (14.4%), TAFE (19.5%), trade qualification (5.1%), university undergraduate (16.9%), university postgraduate (42.4%). Employment status was collapsed into employed (casual, part-time or full-time) (59.7%) and unemployed (28.4%). Respondents were mainly from an Anglo/Celtic background (65.6%), but other cultural backgrounds were represented including Italian (3%), Greek (2.2%), German (1.5%), and Eastern European (3.7%) respondents. The majority of care-recipients were children (i.e., majority of caregivers were mothers caring for children with a disability). The age of care-recipients ranged from 1 to 91 (Mean = 15.06 years, $SD = 16.85$), with only a minority of respondents caring for care-recipients over 18 years of age (4.24%). The majority of care-recipients (93.2%) lived with the respondent, with only a small proportion living in residential care (1.7%), with another relative/friend (1.5%) or alone (1.7%). For carer respondents the number of years in a caregiving role ranged from 1 to 37 (Mean = 8.85 years, $SD = 6.58$). The mean number of hours of leisure per day for carers was 1.51 hours ($SD = 1.33$) and for non-carers it was 3.58 hours ($SD = 3.90$).

1.6 Results of CLAS Factor Analyses

1.6.1 Factor Analysis of the Initial Item Pool

The initial 43 item scale was designed with items reflecting three domains (value of leisure, constraints to leisure, motivation to change leisure behaviour) reflected by six subscales: (a) Risks of not doing leisure; (b) Benefits of leisure

(comprising the values domain); (c) Intrapersonal constraints to leisure; (d) Interpersonal constraints; (e) Structural constraints (comprising the constraints domain); and (f) Motivation and self-efficacy to change leisure behaviour (comprising the motivation domain), (See Table 2, p. 20, for items).

Principal Axis Factoring, a technique that examines common variance and removes unique and error variance to simplify underlying structure (Tabachnik & Fidell, 2000), followed by varimax rotation was used to examine the validity of the intended factor structure. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy, which provides an indication of the homogeneity of variables being subjected to the factor analysis, and hence their suitability for factor analysis, was excellent (0.80). Bartlett's Test of Sphericity was significant ($p < .001$), indicating the factorability of the correlation matrices (Tabachnick & Fidell, 2000).

The initial exploratory analysis yielded 11 factors with Eigenvalues greater than one; that is, factors that explained more variance than a single item alone. Four interpretable factors could be identified, with the Scree test also supporting a four factor solution. These initial four factors explained 51% of the total variance (see Table 2 for factors and loadings; final scale items are indicated in bold typeface).

The first factor comprised items measuring leisure values; specifically perceived risks of not doing leisure and benefits of leisure. Even though risks and benefits both loaded on the same factor, they were later separated to form two separate subscales for conceptual integrity and parity of item numbers across subscales. The second factor reflected the concept of intrapersonal constraints to leisure; the third factor reflected interpersonal constraints to leisure; and the fourth factor consisted of items measuring motivation to increase leisure behaviour.

To refine the scale and create conceptually coherent, parsimonious subscales, items that did not load above .45 on any factor were discarded as well as those items

that loaded onto a factor but lacked conceptual coherence with other items, leaving a reduced set of 30 items. Items measuring structural constraints to leisure and self-efficacy to negotiate leisure constraints either failed to load or did not load in a consistent manner, and therefore these items were not included in the CLAS. For the motivation subscale, only three items loaded appropriately, reflecting the contemplation and preparation stages of change. Next, to achieve parity of number of items in each subscale, the five highest loading items were chosen within risks, benefits, intrapersonal constraints, and interpersonal constraints, as well as the three motivation items, resulting in a 23 item scale, which was then re-factored in the final scale analysis.

1.6.2 Factor Analysis of the Final Version of the CLAS

In order to examine the factor structure of the final 23 item CLAS, Principal Axis Factoring with varimax rotation was again used. In this analysis KMO was again excellent (0.82), and Bartlett's Test of Sphericity was significant ($p < .001$). The final exploratory factor analysis yielded four factors with Eigen values greater than one, that is, factors that explained more variance than a single item alone, with the Scree test also supporting a four factor solution (See Table 3, p. 21, for final factor loadings). The factors extracted, their initial Eigenvalues and corresponding percent of variance accounted for after rotation were: a) benefits of doing leisure and risks of not doing leisure (6.79; 29.54%); b) intrapersonal constraints to leisure (4.13; 17.97%); c) interpersonal constraints to leisure (1.91; 8.29%); and d) motivation to increase leisure (1.73; 7.53%). These four factors explained 63.33% of the total variance. For conceptual integrity, although risks of not doing leisure and benefits of leisure loaded onto the same factor, which may represent perception of the value of doing leisure, risks and benefits were separated to form two independent subscales, for conceptual integrity and parity of item numbers across sub-scales.

The internal consistencies of the five subscales, as well as their intercorrelations based on the data from the 118 respondents are presented in Table 4 (p.21). All subscales show adequate internal consistencies, as demonstrated by Cronbach alphas ranging from .78 to .89. Not surprisingly, the moderate to high subscale inter-correlations suggest that the subscales are tapping into facets that are related to attitudes towards leisure.

1.7 Exploring the Convergent Validity of the CLAS

The convergent validity of the 23-item CLAS was assessed by recruiting caregiver respondents to complete the online version of the 23-item CLAS along with the Depression Anxiety and Stress Scales –short form (DASS-21; Lovibond & Lovibond, 1995) and Personal Wellbeing Index (PWI; International Wellbeing Group, 2006). The main aim was to explore correlations between CLAS subscales and general measures of wellbeing to provide a preliminary test of convergent validity. It was expected there would be a negative relationship between leisure constraints and personal wellbeing and a positive relationship between leisure constraints and the DASS-21 subscales. No other relationships were predicted.

Table 2

Initial CLAS Items and Factor Loadings

Conceptual domains and constituent items	Factor			
	1	2	3	4
RISKS OF NOT DOING LEISURE				
1. If I don't give myself time for leisure, I will become very stressed	.74	-.05	-.08	.00
2. My psychological wellbeing is sacrificed if I do not take any time out for self-care	.83	-.03	-.02	-.06
3. If I don't do activities just for my own enjoyment I will feel resentful	.61	.01	-.12	.07
4. If I don't take time to do self-care activities, my physical health will suffer	.77	-.04	.01	-.06
5. If I don't do leisure activities I will get burnt out and be less able to keep going	.79	-.06	-.05	-.04
BENEFITS OF DOING LEISURE				
6. Doing leisure activities can provide opportunities to regain a sense of freedom	.45	.02	-.12	.23
7. I believe that it is vital for my own mental health to give myself permission to engage in leisure	.75	-.06	-.04	.05
8. Participating in leisure activities makes me feel competent within myself	.65	-.10	-.03	.13
9. Doing leisure activities can increase my enjoyment of life	.76	-.24	-.03	.11
10. Doing leisure activities is important way of feeling connected to others	.59	.03	-.13	.10
11. I believe that doing leisure activities can lift my mood	.67	-.16	.07	.14
12. It is necessary to do leisure activities to maintain good balance in life	.83	-.19	.04	.06
13. I believe that doing leisure activities can allow me to gain a fresh perspective on my problems	.68	-.11	.05	.07
14. I believe that doing self-care activities is essential for me to recharge my batteries	.80	-.15	.09	-.02
INTRAPERSONAL CONSTRAINTS				
15. I have chosen to make my own leisure participation a low priority because of my caring responsibilities	-.08	.11	.68	.14
16. I feel it is wrong for me to do things just to please myself	-.17	.35	.44	-.12
17. I would feel guilty if I engaged in leisure	-.14	.40	.54	-.10
18. I feel too preoccupied with daily responsibilities to engage in leisure	-.00	.21	.67	.27
19. My caregiving responsibilities make me too stressed to have the state of mind to do leisure activities	-.12	.35	.49	.08
20. I have a hard time deciding what to do in my free time, and usually end up not doing anything	-.00	.52	.33	.16
21. I am embarrassed to ask for help so that I can participate in leisure	-.01	.60	.28	-.09
22. I do not think I am entitled to take care of myself through pursuing my personal interests	-.18	.64	.25	.06
INTERPERSONAL CONSTRAINTS				
23. I don't like to go to community meetings/events as I am not comfortable socialising in groups.	-.15	.50	.08	.17
24. I would do more leisure but I don't have companions to do things with	.05	.65	.15	.31
25. I feel pressure from others to sacrifice my leisure pursuits to fulfill my role as caregiver	.07	.69	.18	-.09
26. I would worry about what others might think of me if I did more activities that were just for me	.04	.62	.12	-.09
27. I would do more leisure activities, but my spouse/partner often does not share my leisure interests which limits my leisure participation	-.12	.68	-.09	.15
28. The most important people in my life do not support me in taking time for myself	-.13	.58	.05	-.02
STRUCTURAL CONSTRAINTS				
29. I simply can't find the time to care for myself through leisure activities	.10	.29	.69	.31
30. I can't justify spending money for my own leisure activities	-.14	.51	.36	.13
31. Getting to and from leisure activities is hard and often stops me from participating in leisure	-.07	.34	.12	.17
32. I would do more leisure but I don't have access to caregiving help	.08	.39	.45	-.10
33. I would do more leisure but I don't have the money	-.03	.43	.18	.09
34. I would do more leisure activities, but I don't feel comfortable with someone else looking after my care-recipient	-.23	.41	.30	-.03
MOTIVATION AND SELF-EFFICACY				
35. I do not do many leisure activities and I don't have any plans to do more in the next 6 months	-.22	.49	.37	.02
36. As far as I'm concerned, I don't have any reason to incorporate more leisure in my lifestyle	-.28	.41	.07	-.10
37. I do not do many leisure activities and I'm considering doing more in the next 6 months	.11	.04	.15	.64
38. I am aware that I do not take enough time out for myself and I am considering changing this pattern	.17	.22	.27	.65
39. I don't take much "me time" at the moment, but intend to take more in the next month	.18	.06	.13	.63
40. I do lots of leisure activities and I have been active in doing leisure for less than 6 months	-.09	-.06	-.42	-.02
41. I do lots of leisure activities and I have been active in doing leisure for more than 6 months	.09	-.21	-.34	-.20
42. I feel confident that if I really wanted to take more "me time", I could negotiate any obstacles in the way	.04	-.41	-.44	.24
43. I believe that I can change some of my attitudes that have prevented me from allowing leisure time for myself	.35	-.37	-.19	.34

Table 3

Rotated Factor Matrix Showing Factor Loadings for the 23-item CLAS

CLAS items	Factor			
	Risks/Benefits	Intrapersonal constraints	Interpersonal constraints	Motivation
2	.88			
5	.84			
14	.82			
4	.82			
12	.81			
1	.76			
7	.70			
9	.70			
13	.69			
3	.60			
17		.80		
18		.67		
15		.62		
19		.62		
16		.59		
25			.68	
24			.66	
27			.66	
26			.60	
23			.50	
38				.73
37				.72
39				.68

Note: Extraction Method: Principal Axis Factoring. Rotation Method: Varimax with Kaiser Normalisation; rotation converged in 6 iterations.

Table 4

Cronbach Alpha Coefficients and Inter-correlations of the Five CLAS Subscales

	Risks	Benefits	Intrapersonal constraints	Interpersonal constraints	Motivation
Risks	.89	.74**	-.20*	-.11	.13
Benefits		.88	-.15	-.22*	.18*
Intrapersonal constraints			.82	.38**	.27**
Interpersonal constraints				.78	.21*
Motivation					.78

Note: Cronbach α -coefficients are on the diagonal. Significance level: * $p < .05$; ** $p < .01$.

1.7.1 Participants for Testing the Convergent Validity of the CLAS

A further 58 carers were recruited to test the convergent validity of the CLAS. Ages ranged from 25 to 63 (Mean = 40.43 years; $SD = 7.31$). Most carers were in a relationship, either married (72.7%) or defacto (13.6%), with a minority separated or divorced (11.3%) or single (2.3%). Excepting one carer who did not complete secondary school, all carers had completed at least secondary school, and most reported further education (72.2%). Just over half the carers were employed in some capacity (56.8%), while the remainder were full-time carers. All carers reported living with their care-recipients, and the age of care recipients ranged from 1 to 37 (Mean = 9.07; $SD = 6.88$). Carers reported an average of 1.47 hours of leisure per day ($SD = 1.5$), an average of 11.85 hours caring per day ($SD = 5.98$), and an average of 9.05 years as a caregiver ($SD = 6.86$). Most carers in this sub-sample were caring for a child with a disability or illness (95.45%), and most carers also cared for at least one other child (89.6%).

1.7.2 Measures to Test the Convergent Validity of the CLAS

1.7.2.1 Depression Anxiety Stress Scale – Short Form (DASS-21)

The DASS-21 is a short form of Lovibond and Lovibond's (1995) 42-item DASS. Respondents use a four-point Likert-type scale ranging from 0 ("did not apply to me at all") to 3 ("applied to me very much or most of the time") to rate the extent to which they have experienced symptoms of depression, anxiety and stress over the past week. Each subscale comprises seven items, such as "I felt I wasn't worth much as a person" (Depression), "I was aware of dryness of my mouth" (Anxiety), and "I found it difficult to relax" (Stress). Subscale scores range from 0 to 21, with higher scores indicating increased psychological distress. Reliability, assessed using Cronbach's alpha, has been shown to be acceptable for all three scales in both clinical and non-clinical samples (Antony, Bieling, Cox, Enns, & Swinson, 1998; Brown, Chorpita,

Korotitsch, & Barlow, 1997; Henry & Crawford, 2005; Lovibond & Lovibond, 1995). For the present sample of participants, internal consistency was adequate: Depression (Cronbach's $\alpha = .78$), Anxiety (Cronbach's $\alpha = .78$), and Stress (Cronbach's $\alpha = .77$).

1.7.2.2 Personal Wellbeing Index-Adult (PWI-A, 4th edition)

The PWI (International Wellbeing Group, 2006) is a life domain measure of subjective wellbeing. Respondents use an 11 point Likert-type scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied) to rate satisfaction right now across eight life domains: Standard of living, personal health, achievement in life, personal relationships, personal safety, community-connectedness, future security, and spirituality and religion. Satisfaction scores from all domains are summed to produce a personal wellbeing index score ranging from 0-80, which is then typically standardised on a 0-100 point scale, with higher scores indicative of higher subjective wellbeing. Extensive psychometric analyses have shown the PWI to be a valid and reliable instrument with adequate internal consistency (Cronbach's alpha varies between 0.70 and 0.80 across diverse population sub-groups; Cummins et al., 2004). Good internal consistency was found for the present sample (Cronbach's $\alpha = .81$).

1.7.3 Results for the Convergent Validity of the CLAS

Pearson correlation coefficients presented in Table 5 suggested small-to-moderate correlations. Significant positive correlations were found between intrapersonal constraints and anxiety and stress, and between interpersonal constraints and depression and anxiety. A significant negative correlation was found between perceived benefits of doing leisure and depression.

1.8 Exploring the Criterion Validity of the CLAS

To examine criterion validity, differences in CLAS subscale scores for carers and non-carers were examined (see Table 6). In this preliminary study of the validity of the final 23-item CLAS, it was predicted that carers and non-carers would

significantly differ on their perceptions of leisure constraints, with carers perceiving more intrapersonal and interpersonal constraints. Differences between carers and non-carers on their beliefs about the benefits of leisure, risks of not doing leisure, and their motivation to increase leisure were explored, and no specific predictions made.

1.8.1 Participants for Testing the Criterion Validity of the CLAS

Participants comprised the initial 64 carer respondents who participated in the initial CLAS development study and the further 58 carer respondents who completed the CLAS, DASS-21, and PWI to examine the convergent validity of the CLAS. A total of 122 carer respondents provided data and mean CLAS scores on each subscale were compared to mean scores provided by the 54 non-carer respondents (as described in section 1.5).

1.8.2 Results for the Criterion Validity of the CLAS

The two significant differences between carers and non-carers in mean CLAS subscale scores were found on the “Intrapersonal constraints to leisure” and “Interpersonal constraints to leisure” subscales. The mean ‘Intrapersonal constraints’ score for caregivers was significantly higher than the mean score for non-caregivers, $t(132) = 3.22, p = .002$. Similarly the mean “Interpersonal constraints” score for caregivers was significantly higher than the mean score for non-caregivers, $t(131) = 3.101, p = .002$. No differences were found between carers and non-carers on the remaining CLAS subscales.

Table 5

Pearson Correlation Coefficients for Relationship between CLAS Subscales and DASS Subscales and PWI

	Depression	Anxiety	Stress	Personal wellbeing
Risks	-.10	-.05	.15	.13
Benefits	-.27*	-.06	.12	.21
Intrapersonal constraints	.25	.30*	.35**	-.20
Interpersonal constraints	.41*	.27*	.26	-.12
Motivation	-.12	-.09	-.08	.12

Note: ** $p < 0.01$ level (2-tailed); * $p < 0.05$ (2-tailed); $N = 58$.

Table 6

Descriptive Statistics for CLAS Subscales for Carers and Non-carers

<i>CLAS subscales</i>	Carers ($n = 122$)		Non-carers ($n = 54$)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Risks	29.03	5.79	29.79	4.80
Benefits	30.16	4.79	31.55	3.75
Intrapersonal constraints	21.63	7.69	17.62	5.93
Interpersonal constraints	18.15	6.33	14.72	6.13
Motivation	12.56	3.99	12.66	4.94

1.9 Discussion and Concluding Comments

Understanding the relationship between caregiving and leisure requires a reliable and valid assessment instrument that captures carers' leisure attitudes. Research shows that carers possess unique leisure attitudes, encompassing leisure values, perceived leisure constraints, and motivation to pursue leisure (e.g., Weinblatt & Navon, 1995; Bedini & Guinan, 1996; Gahagan et al., 2007). These perceptions represent a dimension of carers' experience not captured in existing, mainstream population measures of leisure. Results of this pilot study suggest that the CLAS is a valid and reliable measure, which may be used to evaluate leisure programs, and also for the purposes of assessing the leisure-related support needs of individual carers.

A significant difference was found between carers and non-carers in terms of carers reporting significantly higher Intrapersonal and Interpersonal constraints on leisure. This result is understandable given evidence that carers often experience a perceived loss of time to do leisure after assuming the role of informal family carer (e.g., Miller & Montgomery, 1990; White-Means & Chang, 1994). No differences were found between carers and non-carers in terms of risks of not doing leisure, benefits of doing leisure, and motivation to do leisure. These results indicate that carers and non-carers are aligned in their beliefs concerning the value of leisure, suggesting that carers may want to do leisure but struggle to do so given attitudinal constraints. This finding is consistent with Bedini and Phoenix's (2004) finding that, even though the majority of participants valued leisure, only 4% of those caring for children with disabilities stated that they protected their leisure.

This finding that structural constraints to leisure failed to load in a coherent manner may be due to the heterogeneity of the sample of carers recruited in this pilot study. Some carers were married while others were single or separated/divorced, and gross income varied considerably between carers. Variability between carers in terms

of personal circumstances and resources may explain why structural constraints failed to show up in the factor analysis. This finding may be further interpreted in light of research demonstrating the hierarchical nature of negotiating leisure constraints (Raymore, Godbey, Crawford, & von Eye, 1993). Put briefly, an individual must first be able to overcome intrapersonal constraints to tackle interpersonal constraints, which in turn must be overcome to reach the task of negotiating structural constraints. The present findings may indicate that for this sample of respondents (more than half of whom identified as carers), the intrapersonal and interpersonal constraints to leisure may be more salient leisure inhibitors than structural constraints. This notion finds resonance in research on the perceptions of leisure by family carers (Bedini & Phoenix, 2004). This large scale study of 492 carers found carers fell into four distinct groups in their leisure characteristics (“resenter”, “repressor”, “consolidator”, “recharger”). The researchers noted that, while none of these types were significantly wealthier or poorer than the others, for those who denied the value of leisure and their need for it (“repressors”), financial hardship was a concern. On the other hand, for those who functioned as “rechargers”, who maintained leisure, believing that it is essential to recharge and have energy to keep on caregiving, financial hardship was not reported as a constraint. The researchers suggested that perceptions regarding the value of leisure and entitlement to leisure may be more influential in the performance of leisure behaviour than structural barriers. In future examination of the CLAS, it would be worthwhile to include the structural constraints items in the scale (Items 29-34 in Table 2) and perform a factor analysis with more respondents to make a final decision about their inclusion.

The finding that the two constraint negotiation efficacy items failed to load on any factor may be tentatively understood in terms of both these items being worded in positive terms (e.g., “I feel confident that if I really wanted to take more “me time”, I

could negotiate any obstacles in the way”), expressing a sentiment that may have been overly positive and not consistent with carers’ attitudes or experiential framework concerning leisure. To extend measurement of constraint negotiation self-efficacy, negatively worded items should be included (e.g., “I doubt I could overcome all the constraints, even if I really wanted to engage in more leisure”). The final 23-item version of the CLAS does not fully reflect the health belief model as items measuring self efficacy to change leisure behaviour were not included. As with the items measuring Structural constraints to leisure, the self-efficacy items (Items 42 and 43 in Table 2) should be included in future pilot testing of the CLAS, along with additional negatively worded items.

The current pilot study of the CLAS provides preliminary evidence of adequate internal reliability of each subscale. The subscale intercorrelations indicate considerable overlap between the subscales, particularly between the “Risks of not doing leisure” and “Benefits of doing leisure” subscales. This is not surprising given that these two subscales loaded on the same factor and were only separated into subscales for conceptual and methodological reasons (i.e., to better reflect the components within the health belief model and for item parity across subscales). Obviously, further pilot testing is needed with diverse samples of carer subgroups to further establish criterion validity and confirm the four-factor solution, such as with male carers, carers from differing socio-economic and cultural backgrounds, and carer groups on the basis of number of hours caring, duration of time spent caregiving, extent of child behaviour problems, and the relationship of carer to care-recipient. Additionally, the CLAS should be administered to a large sample of carers at several time points to explore test-retest reliability.

The convergent validity of the CLAS was tested using the DASS-21 and Personal Wellbeing Index. No significant correlations were demonstrated between

Personal Wellbeing and any CLAS subscales, probably because the PWI is a composite measure of life satisfaction, and too global in its scope to relate significantly to the specific domain of attitudes to leisure participation. While only some correlations were significant, these results are promising as all correlations reported were in the predicted direction, indicating preliminary evidence for convergent validity. The CLAS should be completed by a larger sample of respondents along with other leisure and wellbeing measures, to better establish convergent and discriminant validity.

Bedini and Phoenix (1999), who are prolific researchers of leisure among informal carers, completed an integrative review of 22 journal articles between 1990 and 1998 to identify common factors in recreation programs for caregivers of older adults. They also reviewed the outcome measures used to evaluate programs and found that none included a questionnaire specifically measuring leisure. Instead, generalist mental health indices were commonly used that lack sensitivity to detect specific program effects, and therefore these studies may have underestimated the benefits of program involvement for carers. It is hoped that the CLAS may go some way in addressing the need for carer-specific leisure scales, to be used in evaluating future leisure interventions and identifying carers who may be at risk of experiencing the deleterious consequences of loss of leisure and caregiver-role engulfment.

The CLAS concentrates on carers' leisure attitudes, and may be expanded in future to assess their actual leisure behaviours, with the possibility of also formulating an index of the congruence between their leisure attitudes and behaviours. The idea of leisure-related cognitive dissonance could provide another interesting measure of carers' leisure satisfaction, and provide insight into an important factor that may distinguish carers in terms of their ability to care for themselves, cope with stress, and maintain wellbeing.

The CLAS was constructed to be face valid by carers, academic researchers, and experts in the caregiving services arena. In summary, the CLAS measure is a valid measure of leisure attitudes among carers with satisfactory internal consistency of each of the five subscales. Further research is warranted to refine scale items and confirm the factor structure. The final version of the CLAS was used as an outcome measure in the evaluation of the “Me Time for Mums” leisure program, which is presented next in Part two of this thesis.

**PART 2: EVALUATION OF THE “ME TIME FOR MUMS”
LEISURE PROGRAM**

**CHAPTER 2: SETTING THE SCENE: UNDERSTANDING THE CAREGIVER
ROLE AND ITS IMPACT ON WELLBEING**

2.1 Who Are Carers and What Do They Do?

The Australian Bureau of Statistics (ABS) defines a “carer” as “...a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older persons (i.e., aged 60 years and over). This assistance has to be ongoing, or likely to be ongoing, for at least six months” (ABS, 2004, p. 71).

The role of carer encompasses numerous responsibilities and commitments, from occasional assistance with transport or shopping through to 24-hour-a-day care. The Victorian Caregivers Program (Schofield et al., 1998), a large scale study into Victorian Carers, found that 27% of caregivers were spending over 100 hours per week in caregiving and a further 15% spent between 31 and 100 hours. While the lived experience of caring cannot be reduced to a list of instrumental tasks, the following activities provide a glimpse into the numerous responsibilities and duties encompassed in the role of carer: Help with self-care, including dressing, bathing, toileting, washing; help with mobility, such as walking and getting in or out of bed; undertaking nursing tasks, including administering medication; taking the care-recipient to appointments; supervising and monitoring the care-recipient; providing emotional support; being a companion; doing practical household tasks, including cooking, shopping, housework; and managing financial matters and paper work (Arksey, Kemp, Glendinning, Kotchetkova, & Tozer, 2005).

In addition, parental carers of children with a disability reported engaging in the following tasks: Managing child(ren)’s behaviour, providing social stimulation, ensuring personal hygiene, providing constant supervision, arranging entertainment and

daily timetables, supervising interactions with others, handling money for the child, keeping the child safe, dealing with socially unacceptable or aggressive behaviour, ensuring medication is taken on time, ensuring the environment is appropriate, liaising with health and other professionals, taking children to appointments, educating family and friends, planning respite/alternative care, accommodation and advocacy, and being able to be flexible about the level of care provided with no advance notice of change (Ballard, 1994; Tucker, 2004).

2.2 The Australian Caregiving Context

2.2.1 The Australian Carer Policy Context

Family carers perform multiple roles on a daily basis. Access Economics (2005) determined that carers in Australia contributed an estimated 1.2 billion hours of care in 2005, which is the annual equivalent of \$30.5 billion of formal aged and disability care services work in Australia. The enormous cost-saving brought to Australia's healthcare system through the work of family carers is paralleled in the huge personal financial and emotional costs they incur.

The Victorian State Disability Plan has as one of its goals the reorientation of supports so that they are more responsive to both the needs of people with disabilities and their families and carers (Department of Human Services; DHS, 2002). The Disability Services Carer Action Plan explicitly recognises that "... carers are both providers of care and individuals with their own needs" (DHS, 2006, p. 5), and documents the importance of "...recognition and respect of the carer as well as the person needing care" (p. 7) and the need for "...participation by both carers and people needing care" (p. 3).

Carers Australia is the national peak body representing carers. Their recent submission to the "House of Representatives' Inquiry into Better Support for Carers" (Edwards, Higgins, & Gray, 2008) concludes by stating: "Through evidence presented

in this submission, we show that carers are not adequately supported in their caring role and have *limited opportunity to have a life outside of caring* [italics added]. Choices are minimal and despite the many benefits that flow from their caring, carers often face deteriorating physical and mental health, social exclusion and isolation, and financial difficulties as a result of caring” (p. 1). It is further argued that priority elements of a national framework for Australian carers should include the “Expansion of the level and range of carer specific support services” (p. 2) towards providing “Support for carers in their capacity to care and to maintain their health, emotional and social wellbeing” (p. 2).

In 2004 the Department of Human Services (DHS) Victoria Aged Care Branch commissioned a report called “What Carers Value” (Dow, Haralambous, Giummarra, & Vrantisidis, 2004), undertaken by the National Ageing Research Institute. This report presents a review of the published and “grey literature” (i.e., unpublished practice wisdom) about current issues and practices for family carers. Among other things, carers reported that they valued the need for “Innovative supports and opportunities to get together” (p.9).

In Australia there appears to be an increasing recognition that legislation is needed to protect carers’ rights, entitlements, and to promote their wellbeing. It appears that the language used in legislation, action plans, and submissions increasingly recognises that carers have their own unique health concerns and support needs and should be considered a population health group in their own right. To identify and understand the health and support needs of carers, a number of large scale Australian studies have focused on the psychosocial effects of caregiving. These studies are reviewed in the following section.

2.2.2 Large-Scale Studies on Australian Carers

In the last fifteen years, there have been five major large-scale community-based studies of the emotional impact of caring for a relative with a disability: the Victorian Carers study; the National Survey of Carer Health and Wellbeing, the ABS Survey of Disability, Ageing and Carers; the Australian Unity Wellbeing Index Project Carer Health and Wellbeing Survey; and the Families Caring for a Person with a Disability Study. Results of these studies will be presented as the first step in building a rationale for choosing carers as a target group for the piloting of a novel creative arts and leisure intervention.

2.2.2.1 Victorian Carers Program (1993 onwards)

The Victorian Carers Program and its surveys of carers and organisations (Bloch & Nankervis, 2001; Schofield, Murphy, Herrman, Bloch, & Singh, 1997; Schofield et al., 1998) was a large scale epidemiological research program to assess the mental health of a representative sample of carers. In stage one of the research, a random telephone survey of 26,000 households in Victoria was conducted in 1993 (see Schofield et al., 1998, for a full description of results). Carers and non-carers who were interviewed in stage one and who were willing to be contacted were re-interviewed at two further time points, 15 and 30 months after the initial interview.

In stage one of the program, female carers ($n = 857$) reported significantly lower levels of life satisfaction and positive affect, as well as higher levels of negative mood, and less perceived social support compared to female non-carers ($n = 257$). Over the course of the next 15 months, the life satisfaction of both female carers who continued to care and non-carers decreased, but at the same rate for carers and non-carers alike. At both measurement periods, however, female carers had lower levels of life satisfaction than their non-caring counterparts. A third of all carers reported major health problems in the previous year, almost half were on medication, and over a quarter rated their

health as only “fair” or “poor”. Almost half felt they had more things to do than they could handle, 58% noted that they were exhausted when they went to bed at night, and 48% reported that they had no time for themselves. The researchers further noted that only 18% of carers in the sample had received any counselling and only 8% belonged to a support organisation. Female carers had significantly higher levels of negative affect and a greater sense of role overload than male carers (Schofield et al., 1997).

2.2.2.2 National Survey of Carer Health and Wellbeing (1999)

A boldly titled report “Warning – caring is a health hazard” (Briggs & Fisher, 2000) documents the results of the 1999 National Survey of Carer Health and Wellbeing conducted by the Carers Association of Australia, involving 1,449 questionnaires returned by carers drawn from state and territory carer associations. Carers were asked whether they felt that caregiving had directly affected their overall mental and emotional wellbeing. Two thirds of all carers (67%) reported that they had been so affected; male carers reported that they had been affected less often (58%) compared to female carers (70%), and carers of children more often than other carer groups (75%). Of those affected, 85% reported that caring had made their mental and emotional wellbeing “worse” or “much worse”. The major negative changes were being sad or depressed (28%), worried/anxious (27%), and being easily upset, frustrated/bored, mentally exhausted, and stressed (varying from 12% to 17% of all carers). Results demonstrated that parent carers deliver the most number of years of caring compared to other carers (i.e., of spouses, parents, other family members), and so it is not surprising that they more commonly reported being both resigned about, yet fearful of, the future than did other groups of carers.

Carers reported a very wide range of reasons for the negative changes in their mental and emotional wellbeing, including: the stress of caring (51%), social isolation and loneliness (34%), changes in relationships (25%), and a sense of grief or loss

(25%). Worsening of the care recipient's health and loss of paid work were also reported by 17% and 14% of carers respectively. Other emotionally stressful aspects of caring included: having no time to one's self (8%), worrying about the medical aspects of care (7%), not having enough money (6%), being housebound/isolated (5%), and having little or no family support or a total lack of support (4%). Once again, gender differences were apparent in that, among other things, female carers reported being affected by changes in family or other relationships more commonly than male carers (28% compared to 19%).

2.2.2.3 Survey of Disability, Ageing and Carers (2003)

The third major Australian carer study was the Survey of Disability, Ageing and Carers (SDAC; Australian Bureau of Statistics, 2004). Data were gathered from both households and supported accommodation. In 2003 there were 2.6 million informal caregivers who provided support to people because of disability or age. About one fifth of these (19% or 500,000) were primary carers. The vast majority of the primary care of children with a disability was provided by the mother (92%). The majority (62%) of these mothers were not in the labour force, compared with 36% of mothers of non-disabled children of the same age. One quarter of maternal carers reported that they had lost, or were losing, touch with friends and 39% said that they had less time to spend with other family members.

Despite the finding that one in four carers reported a sense of satisfaction from their caring role, results demonstrated that around half (51%) of all primary carers of children aged less than 15 years felt they needed more support, and half (50%) felt weary or lacking in energy. Some carers reported feeling worried or depressed (34%) and angry or frustrated (18%) due to their caring role; and almost one-fifth (18%) had been diagnosed with a stress-related illness.

2.2.2.4 Australian Unity Wellbeing Index Project (2007)

In 2000, Australian Unity and Deakin University embarked on a collaborative project to monitor the subjective wellbeing of the Australian population. To date a total of 17 Australian Unity Wellbeing Index surveys have been conducted.

In 2007, Carers Australia contracted with Deakin University's Australian Unity Wellbeing Index Project and surveyed 4107 carers, contacted through the databases of state and territory carers associations. The survey assessed factors related to carers' personal wellbeing, using the Personal Wellbeing Index (International Wellbeing Group, 2006), which measures average level of satisfaction across seven aspects of personal life: health, personal relationships, safety, standard of living, achieving in life, community connectedness, and future security), and their levels of depression and stress (measured using the Depression, Anxiety and Stress Scale - DASS; Lovibond & Lovibond, 1995) and additional questions related to their specific carer situation. The resulting report "The Wellbeing of Australians – Carer Health and Wellbeing" (Cummins et al., 2007) documents the following findings regarding carers' wellbeing.

Most alarmingly, carers have the lowest collective personal wellbeing of any group yet researched in the survey. That is, carers reported lower wellbeing than the six lowest wellbeing groupings identified in Australia, based on a sample of approximately 30,000 (see Figure 1). The extremely low wellbeing of carers is particularly startling given that, with such a large sample of carers, it might be expected that survey scores would approach normality, however this was not the case. In a media release, Professor Cummins reported: "This is truly sad stuff... We have been doing research in this area for more than six years now and after seventeen surveys of the Australian population, I am not aware of any group that has ever been found to have a wellbeing score as low as carers" (Warmington, 2007). Listed as one of the key points of the summary report is

the alarming statement that “...caring could be one of the leading causes of depression in Australia” (Cummins et al., 2007, p. 1).

The sample of carers as a whole had a mean depression score of 38.2, indicating that the average respondent to the survey was moderately depressed¹. More than one third of carers were found to be severely or extremely severely depressed and more than one third of carers reported experiencing severe or extreme stress. The researchers noted that this is an “extraordinary result” given that a far lower proportion (6.0%) of the Australian population are estimated to be depressed (Cummins et al., 2007, p. 5). Female carers reported significantly lower wellbeing than male carers, with results also indicating that personal wellbeing decreased linearly as the number of hours spent caring increased.

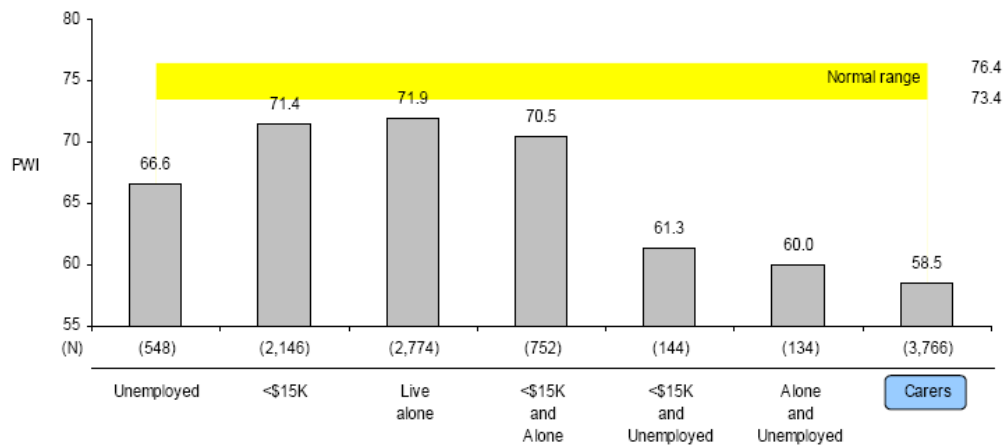


Figure 1. Carer Personal Wellbeing Index versus other Australian low wellbeing groups (Cummins et al., 2007)

2.2.2.5 *The Families Caring for a Person with a Disability Study (FCPDS; 2006)*

The FCPDS was a collaborative study undertaken by the Australian Institute of Family Studies (AIFS) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) in 2006 (Edwards, Higgins, Gray, Zmijewski, &

¹ The DASS depression scale has the following cut-off points: Normal 0-21; Mild depression 22-31; Moderate depression 32-48; severe depression 49-64; extremely severe depression 65+.

Kingston, 2008). A random sample of carers over 18 years of age receiving a carers' payment were selected using the Centrelink database (1,002 carers completed interviews; 77.5% women and 22.5% men). The interview utilised the Medical Outcomes Study Short Form 36 (SF-36; Ware, Kosinski, & Gandek, 2002), among other demographic questions.

The report documents evidence that many carers stopped work, reduced hours or changed jobs because of their caring responsibilities. Financial hardship was more common among caring families than in the general population. A significant minority (one in five carers) had no close support, and relationship difficulties in caring families was common. Many carers reported limited social engagement because of the time associated with caring (60% of carers in the sample cared for more than 100 hours per week).

Rates of clinical levels of depression (using a well-validated cut-off) in the last four weeks were 19% for female carers and 13% for male carers, while for females and males in the general population, they were 11% and 8% respectively. Fifty-one per cent of female carers and 30.7% of males also reported that they had been depressed for six months or more since they started caring.

In contrast, Cummins et al. (2007) in the Australian Unity health and wellbeing project reported that 56% of carers had clinical levels of depression (19% extremely severe, 18% severe, 19% moderate). The discrepant findings regarding depression levels among carers may be due to the different depression measures used and different sampling frames (The FCPDS had a 73% response rate from a representative sample of carers receiving government payments, while in the Carer Health and Wellbeing study, members of the state carers associations were invited to participate (37% took part). Nonetheless, in both studies, the rates of depression present a clear public health concern. Several factors were associated with carers having more mental health

problems, worse vitality and higher rates of depression than people from the general population. These included caring for a child (rather than an adult) with a disability, caring for a person with a disability with high care needs, caring for more than one person with a disability, carers having another care role of looking after children who did not have a disabling condition, carers having one or more problems in family functioning, and carers indicating that they needed a little or a lot more support.

There is ample research evidence that Australian carers experience distress as a result of their demanding role. Some of the common problems faced by parent carers of children with disabilities, particularly mothers, will be outlined in the next chapter to further develop a sound rationale for targeting maternal carers for innovative interventions designed to improve their wellbeing.

2.3 Caregiving is a “health hazard”

2.3.1 Wellbeing of parents of children with a disability

In Australia, since the 1980s, the shift away from institutionalisation and the trend toward shorter hospital stays has resulted in children with disabilities being cared for at home predominantly by parent carers (Australian Institute of Health and Welfare [AIHW], 2003). As previously noted, Cummins et al. (2007) found that the wellbeing of carers who live with the person requiring care was 58.4 points and this was the lowest value ever recorded by a group on the personal wellbeing index. In 1998, 99% of children with a disability aged 0–14 years lived in households. This chapter explores the wellbeing of parents of children with a disability.

Parents of children with disabilities come in all psychological “shapes and sizes”. It is acknowledged that parents of children with disabilities report feelings of love, happiness and hope, in spite of their challenges (Kearney & Griffin 2001; Marsh 2003). There is emerging literature on the perceived benefits, including feelings of happiness and optimism and positive relationships with children, associated with

parents loving and raising their children with disabilities (e.g., Hastings & Taunt, 2002; Leyser, Heinze, & Kapperman, 1996). It is not the intention of this review to minimise the resilience of parent carers. However, the weight of empirical evidence does indicate that parents of children with disabilities typically report a plethora of psychosocial problems more so than parents of typically developing children.

These problems include more parenting stress, higher fear, anger, sadness, depression, anxiety, more psychosomatic symptoms, greater restrictions of roles and activities, strain in marital relationships, higher rates of separation and divorce, diminished physical health, lower cheerfulness, reduced energy and wellbeing, reduced quality of life, greater social isolation, lower employment rates, lower income and greater poverty than parents of children without disabilities (Beckman, 1991; Dumas, Wolf, Fisman, & Culligan, 1991; Dyson, 1991; Emerson, 2003; Friedrich & Friedrich, 1981; Gardner & Harmon, 2002; Lam & Mackenzie, 2002; Mandlco, Olsen, Dyches, & Marshall, 2003; Nachshen & Minnes, 2005; Risdal & Singer, 2004; Scott, Atkinson, Minton, Bowman, 1997; Singer & Irvin 1991). High levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children (Sloper & Turner, 1992), and this stress tends to be chronic (Cummins, 2001; Dyson, 1993; Glidden & Schoolcraft, 2003).

There are numerous reasons why the mental health and quality of life of parents of children with a disability would be at risk. Parenting a child with a disability increases the risk of experiencing loss in many forms (e.g., of the perfect or dreamed of child and of personal freedom), helplessness (e.g., experiencing high stress, not being able to change the situation, and not being able to get the help one needs), and failure (e.g., having a child with difficult behaviour that cannot be controlled and not being able to pursue one's personal goals in life). The lack of acknowledgement from health professionals is often a source of hurt and frustration for parents (Case, 2000). Carers

often report immense guilt that they are not doing enough, which has been shown to significantly predict increased anxiety and depression (Gallagher, Phillips, Oliver, & Carroll, 2008). Holidays are rare due to the lack of energy to arrange them, the lack of discretionary spending, the lack of safe environments for the high-needs child, and the lack of, or difficulties arranging, respite care. The nature of caring for a child with a disability puts parents at risk for role overload and caregiver burden that is cumulative and may lead to, not surprisingly, burnout and depression (Tsai, 2003).

The abovementioned studies report outcomes for *parent* carers but the reality is that predominantly women respond to questionnaires and participate in carer research projects. Indeed, maternal reports of depression have usually been generalised to parental depression, and the very few studies that have included fathers have usually found normal depression scores or reduced symptoms of depression in fathers of children with disabilities compared to mothers (Bristol, Gallagher, & Schopler, 1988; Dumas et al., 1991; Gray & Holden 1989; Olsson & Hwang, 2008; Veisson, 1999; Wolf, Noh, Fisman, & Speechley, 1989).

Several well-designed meta-analyses have reported fairly consistent rates of depression, ranging from 22% to 30% in maternal carers (Bailey, Golden, Roberts, & Ford, 2007; Feldman et al., 2006; Lounds, Seltzer, Greenberg, & Shattuck, 2007; Singer, 2006). Across these meta-analyses, risk factors for maternal depression included child-related factors (including autism diagnosis, greater behavioural and social problems) and maternal and family related factors (including high stress, reliance on escape-avoidance coping strategies, poorer health, low family and social support/cohesion), and the presence of more than one child with a disability in the family.

These meta-analyses only included studies using self-report measures of depression, which may not accurately identify cases of clinical depression. However,

the consistently higher than normative prevalence of elevated distress among maternal carers is cause for concern. Indeed, people with elevated depressive symptoms who do not have clinically diagnosed major depression have nonetheless shown considerable limitations and distress in social, work, and physical functioning (Singer, 2006). For example, sub-clinical levels of depressive symptoms have been associated with lowered wellbeing, impaired role function, impaired social function, and poor general health (Hays, Wells, Sherbourne, Rogers, & Spritzer, 1995, as cited in Singer). It is not only mothers' psychosocial functioning that is affected. Maternal depressive symptoms have been associated with disrupted parenting interactions between mothers and their children (e.g., Downey & Coyne, 1990; Gross, 1989).

The consistent finding of mothers experiencing more distress than fathers probably reflects the fact that women are more likely to be primary carers, defined by the ABS as:

A person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care). (ABS, 2004, p. 77)

In 2003, women accounted for 71 percent of primary carers of older people and people with disabilities. This gender imbalance was even more pronounced for mothers of children with a disability; the majority (92%) of primary carers of children aged 0-14 years with a disability in Australia were mothers (ABS, 2004). In general, providing higher levels of care tends to be associated with experiencing higher levels of psychological distress. As Cummins et al. (2007) reported, the lowest personal wellbeing value yet recorded for a large group of people in Australia was for carers

living with their care recipient (58.4 points), which includes almost all of primary caregiving mothers.

After demonstrating the higher levels of depression among caregiving mothers compared to fathers, Olson and Hwang (2008) suggested that the consistent finding of mothers experiencing more distress than fathers is caused by the fact that mothers take on the more intense role of primary carer, they more often give up their job and other social roles, and lack time and opportunities to pursue their own interests. It has been further suggested that the mother's self-competence may also be more related to the care-giving and parenting role than father's, in accordance with women's socialisation into the ethic of care. However, it is also possible that fathers express their distress in different ways than depression. The researchers concluded that high stress caused by the child's behavioural problems combined with restrictions to personal life are two main factors that contribute to a higher risk of depression in mothers of children with a disability.

In the general population, women report higher levels of mental health problems than do men, which raises the question of whether the more widespread reports of burden and depression in women carers is reflective of apriori gender differences in depression, or a more specific caregiving related outcome. Results of Pinquart and Sorenson's (2006) meta-analysis help to tease this apart. Their study demonstrated that there was a greater difference between female and male caregivers with respect to depression than there were between males and females who did not care for a person with a disability. Furthermore, while women are more likely to assume the primary carer role, this meta-analysis showed that once men do take on the primary carer role, they experience the task in a similar way to women, pointing to the stressful nature of the caregiver role as opposed to the notion that women are more susceptible to experiencing or reporting depression. The gendered nature of caregiving is more fully

examined in the next chapter so as to understand the impact of care-giving on the wellbeing of female carers.

2.3.2 Caregiving is a Gendered Role

Throughout the world, it is an irrefutable, empirical fact that women carry out most of the caring work, whether unpaid or paid and whether for the sick, disabled or healthy (Arber & Khlat, 2002; Doyal, 1990, Luxton, 1997; Meleis & Lindgren, 2002; Miller & Cafasso, 1992; Wuest, 2000). For example, surveys from the UK (Wenger, 1994), Japan (Tokyo Metropolitan Government, 1995, as cited in Lee & Porteous, 2002), US (Hooyman & Gonyea, 1995; Miller & Cafasso, 1992), and Australia (ABS, 2004; Schofield et al., 1997) show that over three-quarters of primary carers are women.

Results of empirical research indicate that outcomes of caring differ according to gender. Caring women suffer more from anxiety and depression, experience greater role overload, and achieve less life satisfaction than caring men (Lee & Porteous, 2002; Morris et al., 1991; Navaie-Waliser et al., 2002; Schofield et al., 1997; Yee & Schulz, 2000). Several studies conclude that women carers provide more time-consuming and complex care than men (Kramer & Kipnis, 1995; Miller & Cafasso, 1992; Navaie-Waliser et al., 2002; Yee & Schulz, 2000) and have more problems balancing caregiving with other family and employment activities (Kramer & Kipnis, 1995; Navaie-Waliser et al., 2002). Further, women are more likely than men to neglect health-promoting activities (Lee & Porteous, 2002; Navaie-Waliser et al., 2002; Sisk, 2000). Women are more likely than their male counterparts to limit leisure time due to caregiving (White-Means & Chang, 1994). Women also receive less formal (Gustafsson & Szebehely, 2001; Morris et al., 1991; Navaie-Waliser et al., 2002) and informal assistance (Yee & Schulz, 2000), and carry on caring longer (Collins & Jones, 1997; Navaie-Waliser et al., 2002; Yee & Schulz, 2000). Pinguart and Sörenson (2006)

conducted a meta-analysis of 229 studies published between 1983 and 2005, and investigated the significance of gender differences in carer stressors, social resources, psychological health, and physical health. They concluded that “Caregiving increases gender differences in depression and physical health, primarily because women experience more caregiving stressors” (p.39).

Altogether, it has been well documented that women tend to carry higher caregiving burdens than men (Yee & Schulz, 2000). Of course, as society changes, and the participation of women in the workforce grows, the roles of men and women are changing. Still, women spend more hours performing domestic and caregiving tasks than do men, regardless of their own or their husband’s employment status (e.g., Baxter, 2002), therefore a gendered approach to understanding caregiving is called for.

There is a large volume of work reflecting feminist concern regarding the ideologically based assumption that it is “natural” for women to want to care (e.g., Baines, Evans, & Neysmith, 1991; Dalley, 1988; Henderson & Allen, 1991; Hooyman & Goonyea, 1995; Larrabee, 1993). Psychologist Carol Gilligan (1982) introduced the concept of the “ethic of care” which posits that, compared to men, women’s personal and moral development proceeds with a stronger focus on relationships with others, and with a natural ethic of care, encompassing nurturance, compassion, and relatedness.

Feminist theorists have argued that the “ethic of care” has become a normative ideal for women, who are expected to do caring jobs otherwise they are not “good women” (Davies, 2001; Hirdman, 1998; Wuest, 2001; Yee & Schulz, 2000). Over and above performing practical caregiving tasks, women tend to do more “emotion work” (i.e., looking after other people’s emotional needs, particularly other family members) than men (Hochschild, 1989). “Emotional labour” is a term used by many feminists to emphasise that care-giving requires time, planning, and effort (Angus, 1994; James, 1989). Oakley (1981), Smith (1987), and Waerness (1987) point out that the everyday

physical and emotional labour that women expend in family care-giving is particularly undervalued and not recognised as work. Aronson (1991) argued that women's identities, while historically, culturally, and geographically varied, typically have been constructed around ideals of nurturance, compassion, and self-sacrifice, such that "a caring self" has been constructed as the normative feminine ideal (Davies, 2001; Giullari & Lewis, 2005; Katbamma, Ahmad, Bhakta, & Baker, 2004; Wuest, 2001).

Feminist theorists have argued that the problem with the ethic of care is not the value placed on caring for others, but rather the sense that it has become a normative social expectation for women, and that caring for the self can be interpreted as being selfish and guilt provoking. It has been further argued that family care-giving epitomises the process whereby socially necessary work is absorbed without pay by women and is implicitly assumed to be "women's work" (Hooyman & Gonyea, 1995). Women are expected to "mother" just because they are women, which influences their sense of self and possibilities, and furthermore, that women judge themselves, and are judged, by their performance in carrying out caring responsibilities.

The concept that women have a natural ethic of care and willingness to subsume their own personal lives to the care of others has been challenged. Implied in the ethic of care is the assumption that women are more emotional than men, and that the emotional contribution is something that women give naturally and without effort. This attitude has been critiqued as another way of obscuring the work that women do as part of their caring (Bowlby, Gregory, & McKie, 1997; Fishman, 1978; Luxton, 1997; Shaw, 1994). One respondent in the Women's Health Australia Project narrated the consequences of the ethic of care:

After spending more than three quarters of your life raising kids...One morning you wake up completely exhausted - everything is gone. And you wonder, "Who the hell are you?" And where am I supposed to go from here? And why

do women – mostly - give so much time of themselves looking after others...never taking some time to themselves or even giving some thought to - one day it might all disappear... everyone else gets on with their lives, and you're left wondering where to start again or... if you've even got or care to have the strength to do so. (Lee & Porteous, 2002, p. 91)

The “force” of the ethic of care can lead to thorough self-denial, and the silent injunction to live up to caregiver role standards means that for female carers, “... ‘unobligated time’ does not exist” (Henderson & Allen, 1991, p. 102). This was apparent in Rogers’ (1997) study, in which female spousal carers’ “obligation” to husband and family “... made leisure, in effect, meaningless and their social lives and leisure dissolved” (p. 45). The following chapter reviews research demonstrating that caregivers experience reduced leisure and discretionary time and explores some of the main constraints to carers’ leisure participation. Finally, empirically demonstrated benefits of leisure for carers will be briefly reviewed, towards building a rationale for the implementation of leisure programs for carers.

CHAPTER 3: CARERS, CAREGIVING, AND LEISURE

3.1 Caregiving, Reduced Discretionary Time, and Limited Leisure Participation

Research consistently demonstrates that care-giving substantially reduces participation in recreation and leisure activities (Miller & Montgomery, 1990; White-Means & Chang, 1994) and significantly diminishes discretionary time. In the U.S, the National Family Carers Association/Fortis study (1998, as cited in Riess-Sherwood, Given, & Given, 2002) found that carers identified loss of leisure as the second most difficult aspect to care-giving out of ten aspects reported. Similarly, Scharlach (1994) found that carers ranked “lack of personal free time” as the second most problematic (out of seven) personal aspects of caregiving. In one study, 91% of female carers wanted to have a break away from caring responsibilities and, of these, 61% said it was difficult for them to get such a break when they wanted (Lamb & Layzell, 1995), showing a widespread lack of self-determination regarding time-use among carers. Constriction to personal freedom is exacerbated by the uncertainty of how long care is going to continue, which often prevents carers from planning future discretionary activities. This is especially so for parents of children with a disability who may be dependent on them across their lifespan.

Having children under the age of 18 in the home has been identified as affecting carers' leisure. In Australia 99.7% of children with disabilities live at home, and 92% of their primary carers are mothers (ABS, 2004). Several studies indicated that the presence of children in the home can prevent family carers from pursuing personal leisure experiences as well as decrease satisfaction with any leisure activities accessed (Loomis & Booth, 1995; Miller & Montgomery, 1990; White-Means & Chang, 1994).

Mothers of children with disabilities are a particularly high-risk group for loss of leisure given that predictors of carer stress and lifestyle restriction include: gender (with women more likely to experience stress than men), the care relationship (with

caring for a partner or child being most stressful), amount of hours spent caring (with mothers more likely to spend longer hours caring) and live-in care relationships (Hirst, 2004).

3.2 Reasons for Reduced Leisure Among Carers

Leisure constraints may be defined as any factors that limit or inhibit participation in leisure. This review uses Raymore, Godbey, Crawford, and von Eye's (1993) categorisation of leisure constraints into "intrapersonal" constraints (person's psychological states, traits, attitudes, beliefs), "interpersonal" constraints (extent of social support and leisure companionship); and "structural" constraints (practical resources including financial and material resources, transport, alternative care available, and existence of leisure programs in the community). As this section demonstrates, carers report multiple constraints to leisure on all categories of leisure constraints.

3.2.1 Structural Leisure Constraints

Research amply demonstrates the structural barriers that constrain leisure among carers, including financial restrictions, physical inaccessibility to public spaces, limited respite options and support services, and lack of accessible and supported community leisure programs.

Higher than normative levels of financial hardship are experienced by households in which there is a person with a disability (Dobson & Middleton, 1998; Saunders, 2006). Primary carers have a much lower employment rate (39%) than people who are not carers (68%) (de Vaus, 2004). While many mothers would like to work outside the home they are often prevented from doing so by the lack of services to cater for the child's needs during working hours, and the inflexibility of service systems such as hospital appointments and school transport (Kagan, Lewis & Heaton 1998).

Studies document how financial assistance and material support are important requirements for pursuing leisure (e.g., Dattilo, Dattilo, Samdahl, & Kleiber, 1994).

In Murray's (1997) Victorian based qualitative study of eight parents of children with severe disabilities (seven out of eight were mothers), carers spoke about the impact of high care demands, limited alternative care support, and lack of financial resources as factors constraining leisure participation. These structural constraints accumulated for Elizabeth, a full-time single mother of three children with disabilities, who receives one 24-hour respite period per month and one weekday evening per week of in-home respite. She reported that she appreciated the respite provided, but struggled to afford to do activities on her time-off. Even paying for her alternative accommodation for the one night each month was a financial strain. A number of the participants had been involved in advocacy work to improve the support system. Participants reported the difficulties in accessing and managing assistance, the need for improved coordination and integration of services, and the often poor communication between support agencies, professionals, and carers. Murray concluded that "The experiences of these parents tell us that formal support services have not enabled families to participate in the wider community to the extent that others take for granted" (p. 228).

Australian carers who experience financial hardship also reported below average face-to-face social contact (Edwards et al., 2008). These results raise the possibility that experience of financial hardship may limit the ability of carers to see friends or relatives outside of the household as socialising may require carers being able to meet the costs of either catering for visitors or the costs of going out (transport, a meal or another social activity and the potential costs of providing alternative care in their absence).

In addition to these structural reasons identified for carers not pursuing leisure there are numerous intrapersonal and interpersonal reasons cited in the literature explaining why carers limit their leisure engagement. Indeed, researchers have suggested that, to some degree, the perceived lack of autonomy and discretionary time results from carer's own attitudes and values (Hughes & Keller, 1992), and their perception of social support and social opportunities for leisure, more so than from structural constraints.

3.2.2 Interpersonal Leisure Constraints

Social isolation is a major interpersonal barrier to leisure among carers, who frequently report limitations to their social life and changes to their social network after assuming the carer role. As part of the Families Caring for a Person with a Disability Study (FCPDS) findings, Edwards et al. (2008) compared levels of face-to-face social contact between 1002 carers (in the FCPDS study) with a representative sample of non-carers drawn from the 2004 Household, Income and Labour Dynamics in Australia (HILDA) survey. Logistic regression models were applied to the variable of wanting more face to face social contact. Financial hardship, poor physical health, and higher care requirements were significant predictors of wanting more social contact among carers. Limited social opportunities affected the nature and degree of carers' leisure engagement. Results suggested that carers from the FCPDS were 1.46 times more likely than the general population to have low face-to-face social contact with friends or relatives outside of the household, after controlling for many demographic variables. Large sample sizes strengthen the robustness of these findings.

Cant's (1993) study, which was based on semi-structured interviews with a random sample of 73 mothers of children with cerebral palsy or spina bifida, found that time spent socialising was low for all mothers, when compared to normative data using a similar time-use methodology among mothers of typically developing children (i.e.,

Sydney Time Use Study; ABS, 1988). Cant emphasised that the leisure pursuits that carers spoke about with the most enthusiasm were those with a high sociability factor, such as chatting with others and going shopping. More than two thirds of mothers reported changes in their friendships. The majority spoke of losing friends and some mentioned their withdrawal from previous friendships. This withdrawal partly occurred due to carers' concerns of not being able to reciprocate friendship gestures. Carers most frequently reported engaging in passive leisure activities, such as watching television, reading or listening to the radio, which lacked a social component. The more active forms of leisure reported, such as gardening, driving, walking and sewing also appeared to offer few options for socialising outside the family circle. This study highlighted that, where friendship networks change because of the assumption of the caring role, identity shifts also.

Friendship ties are important both in terms of sociability and personal identity. Old social ties may dissolve for numerous reasons, and new ones get formed predicated on the commonality of having a child with a disability, as exemplified by the following account:

My social life's gone, largely because of the amount of time required to give care, and it's evolved largely in the 17 years she's been on the planet. Social times we do have are largely with families in similar situations. We are a disability community, I guess, in terms of a social support network in many ways, so we get together and talk about similar issues related to our children. So the circle of friends has been diminished from variety to singularity in terms of types of people we still see. (Gahagan et al., 2007, p. 57)

Some carers may experience social marginalisation which fuels social isolation and limited leisure options. Not only do people with disabilities experience disadvantage but "...it is the family as a whole that is disabled by the unjust society"

(Fazil, Bywaters, Ali, Wallace, & Singh, 2002, p. 238). In a meta-analytic synthesis of qualitative studies on mothers of “other than normal children” (Nelson, 2002), the majority of mothers described an awareness of societal judgment related to their children and themselves. In more than half the studies in this synthesis, mothers described feeling guilt or blame related to their children’s disability. The majority also experienced a realisation that their children were not fully accepted by society. For example, isolation and a feeling that people “don’t understand” was expressed by mothers of children who were dependent on equipment and technological devices and of adult children with schizophrenia (Boydell, 1996; McKeever, 1991). Additionally, for parents of children with behavioural problems, parents may experience strain in social encounters during outings in that they must “invigilate [the child’s] performance and make proper restitution when it gives offence” (Voysey, 1975, p. 132). Carers may consequently avoid outings and become ever more isolated.

3.2.3 Intrapersonal Leisure Constraints

There are many intrapersonal reasons why carers experience limited discretionary leisure time, including guilt and fear about leaving their care-recipient, a low sense of entitlement to engage in leisure, a low value placed on leisure engagement, feelings of stress and exhaustion from caregiving, an overwhelming sense of responsibility to the care recipient, and losing a sense of self and personal interests due to engulfment by the dominant caregiver role. This section details results from qualitative research documenting these constraints.

3.2.3.1 Guilt and Fear

Carers may limit or cease their leisure participation out of fear that something might happen to their care recipient when they are gone (Aronson, 1992; Bedini & Guinan, 1996; Rogers, 1997; Weinblatt & Navon, 1995). Female carers have reported not feeling free to go out even when time was available because of the fear that

something might happen to the care recipient while they were gone (Lewis & Meredith, 1988). Research suggests a high degree of fear and scepticism of the quality of outside help (Bedini & Guinan, 1996; Dunn & Strain, 1998). Carers often report fears about alternative carers handling things correctly, managing the care-recipient's unpredictable behaviour, and particularly being able to cope with emergency situations. These fears can often make carers' lifestyle restrictions and social isolation seem unavoidable.

Not only do carers report fear regarding alternative care, they may also hold a strong belief that concerns with their own needs are selfish so that pursuing leisure activities may be guilt-provoking and thus avoided (Aronson, 1992; Brody, 1985; Pratt, Schmall, & Wright, 1987). Brody identified that 60% of the carers in her study reported feeling guilty about not doing enough for their care-recipients. She suggested that family carers often experience and must suppress feelings of resentment and anger, which also contribute to the guilt. Guilty feelings stemming from the "could and should do more" and the "no matter what I do, it's never enough" syndromes can lead carers to deprive themselves of permission to pursue leisure. In a study of spousal female carers, Rogers (1997) found that carers who were "consumed" by their caregiving role, experienced guilt as a "prominent theme" (p. 237) in their lives. Rogers noted that, "...participants regularly made personal sacrifices to avoid feeling guilty for not providing the best care possible" (p. 237). She noted that for these individuals, guilt prevented them from feeling entitled to leisure. In another qualitative study involving elderly caregivers, the concept of "compulsive sensitivity" was introduced to denote the "...compulsion to see and respond to other people's needs, whatever one's own situation" (Forssen, Carlstedt, & Mortberg, 2005, p. 652). According to the authors, compulsive sensitivity offers a way to understand carers who are unable to stop "sacrificing" themselves, who feel compelled to respond to others' needs at the expense of their own, and who avoid relaxation and leisure to avoid the guilt that might ensue.

3.2.3.2 *Entitlement to Participate in Leisure*

The degree to which a carer feels entitled to make time for leisure plays an important role in performance of leisure behaviour. Bedini and Guinan (1996) conducted a qualitative study of 16 female caregivers and formulated a typology of carers based on data regarding their entitlement to leisure: “Repressors” expressed either no need for leisure in their lives or indicated that they survived by suppressing their desire for leisure. “Resenters” felt pressure to sacrifice their leisure pursuits in order to fulfil their caregiving responsibilities, but this resulted in great frustration, bitterness, and resentment at their inability to access desired leisure time.

“Consolidators” identified both the desire for leisure as well as the constraints of carer burden. The Consolidator negotiated this situation by including their care-recipient in leisure activities (bringing her social activities to the home or her care-recipient to the activity). Consolidators were content with this method of coping but expressed their desire for other, independent leisure options. Finally, “Rechargers” viewed leisure as a means of energising or recharging their batteries for their care-giving responsibilities and they found ways to negotiate through constraints.

Bedini and Phoenix’s (2004) study, based on 492 surveys of caregivers drawn from a random sample of 1000 female caregivers from the National Family Caregivers Association database, found that participants identified themselves as follows:

“Resenters” (54%), “Rechargers” (27%), “Consolidators” (12%) and “Repressors” (3%), with a further 4% of carers creating their own definitions. This research showed that more than half the sample reported sacrificing leisure pursuits to fulfill the caregiver role. Research varies as to whether sacrificing leisure is associated with its devaluation among carers or whether carers highly value leisure but find it hard to pursue it, leading to resentment and other negative states associated with cognitive dissonance (i.e., arising from behaving contrary to one’s important values).

3.2.3.3 *Value Placed on Leisure by Carers*

It has been suggested that ignorance or disregard of the benefits of leisure can lead caregivers not to protect leisure time (Hooyman, 1990; Pratt, Schmall, & Wright, 1987). Disregarding the benefits of leisure could be related to the social perception that leisure is frivolous. Henderson, Bialeschki, Shaw, and Freysinger (1996) stated that "...society tends to devalue leisure and think of it as a "frill", a reward for hard work, or even a waste of time" (p. 116). Though a detailed discussion of the history of leisure is beyond the scope of this review, it is worth noting that the perception of leisure as healthy has been relatively recent. Phrases such as "idleness is devil's worship" and "sloth is the enemy of the soul", the notion that hedonism is a sacrilege, and the protestant work ethic have previously cast leisure in a shameful light. It may be surmised that individuals may still need to shake off the remnants of these negative connotations to avail themselves of leisure today.

Weinblatt and Navon (1995) argued that carers might actively choose to devalue and avoid leisure given the problems that leisure may evoke for them. They argued that reduced leisure participation was not only the result of passive reactions to externally imposed constraints. They found that carers still had opportunities for participation in leisure activities, but often did not take advantage of them. In their qualitative study of spousal carers, they found that leisure was variously considered as being inactivity, a waste of time, and a breeding ground for feelings of anxiety, depression, loss of control, and betrayal of the care recipient. Due to these negative meanings ascribed to leisure, the authors suggested that carers made a personal choice to abstain from leisure in order to maintain an illusion of control over their situation.

Other research further illuminates why carers may forego leisure. Previous social and leisure activities may make caregiving-related losses salient. Public settings, such as shopping centres, restaurants or bars, or social leisure activities may exacerbate

feelings of stigma and self-consciousness. Carers may feel they are being a burden if they ask for help from family and friends to pursue leisure (Caltabiano, 1995; Hutchinson, Loy, Kleiber, & Dattilo, 2003). In the extreme, the stress or sense of loss associated with a relentless caregiving situation can be so great that carers may perceive the suggestion that leisure can help them cope with their problems as trivialising the magnitude of their situation (Kleiber et al., 2002).

It seems, however, that this active devaluing of leisure is not the norm for carers. Indeed, research indicates carers' overwhelming desire for and valuing of leisure and their lament over its loss (Bedini & Guinan, 1996; Cant, 1993; Chakrabali, Kulhara, & Venna, 1993; Dupuis & Smale, 2000; Dunn & Strain, 2001; Farkas & Himes, 1997; Mannell et al., 2002; Rogers, 1997; Scharlach, 1994). This was clearly apparent in Bedini and Phoenix's (2004) study in which only 3% of a diverse group of female carers reported that they had little to no interest in pursuing leisure. These researchers found that for their sample of 492 carers, most carers valued leisure but lacked self-determination in pursuing it: 71.2% of carers stated that they valued leisure, however 60.5% of the respondents reported that they do not protect their leisure. Additionally, 82.9% of the overall sample disagreed that they could do leisure whenever they wanted. There was a statistically significant difference between the caregivers of adults and those of children on this question, with the latter showing 93.8% disagreement. Only 4% of those caring for children with disabilities stated that they protected their leisure. For the last question, "I can do leisure/recreation whenever I want", carers of children with disabilities were significantly less likely to feel free to engage in leisure at their own will compared to all other carer groups. The researchers suggested that: "Further examination of the caregivers of children with disabilities might yield insight to additional barriers and constraints experienced by this unique group of caregivers" (p. 379).

3.2.3.4 *Caring is Often Stressful and Exhausting*

The intense nature of the care-giving role often leaves carers feeling physically and emotionally drained, often without the energy or motivation to pursue active leisure in their free time. Lewis and Meredith (1988) described a common situation whereby “...the carer increasingly needs to take a break but has no energy to break out of the routine” (p. 86). In a study of almost 3,000 women 40 years and older, King et al. (2000) found that care-giving duties and lack of energy ranked as two of the top four barriers to women being physically active. Thus, feeling too tired and stressed are common internal barriers to leisure involvement expressed by carers (Bedini & Guinan, 1996; Dunn & Strain, 2001). Although research has not directly addressed the relationship between depression and loss of leisure among caregivers, given the relatively high incidence of depressed mood among carers (Cummins et al., 2007), fatigue and amotivation, and possibly anhedonia, may further constrain leisure participation among some carers.

3.2.3.5 *Responsibility to Care-Recipient and the “Ethic of Care”*

Responsibility for the care and well-being of care-recipients may result in a greatly diminished sense of self-determination (i.e., choice and control) over decisions to engage in leisure (Bedini & Guinan, 1996; Hawranik & Strain, 2002; Pratt, Schmall, & Wright, 1987; Rogers, 1997; Shaw, 1992; Weinblatt & Navon, 1995). In Bedini and Guinan’s (1996) qualitative study, the 16 female caregivers all strongly concurred that their sense of responsibility to their care-recipients was the primary reason for not doing leisure.

Given that the vast majority of carers are women, socialisation into the ethic of care can be considered a potential contributor to the relinquishing of leisure among most carers. Indeed, leisure may be conceived as concern with self-fulfilment (Howe & Rancourt, 1990) and relinquishing commitments and care for others (Kimmel, 1971),

which may be felt as ego-dystonic to caregivers in light of the caring feminine ideal.

The force of socialisation into the ethic of care can be so strong that women will deny their own needs or feel guilty for enjoying time apart from their care-recipient (Henderson & Allen, 1991). The intense other-focus of caring may even lead to carers losing an awareness of a separate sense of self beyond the caregiver role and becoming out of touch with their own leisure interests and needs (Bedini & Bilbro, 1991; Keller & Hughes, 1991).

Living a restricted lifestyle can cause social isolation, and social isolation perpetuates living a restricted existence, both of which limit possibilities for positive validation, expansion, and expression of aspects of self. Weinblatt and Navon (1995) applied the concept of “Totality” to some carers. Totality is characterised by the eradication of boundaries demarcating the various sectors of life, such as work and leisure, that had previously been allocated separate times, resources and commitment. By channelling all existing resources into one role Hazan (1981) noted that it can enable the individual to perform the role with success and lend a sense of control over a problematic situation, therefore it may be difficult for carers to step outside of the carer role. Totality has been conceptualised as taking up roles that demand exclusive and undivided loyalty. Other similar concepts frequently applied to carers, with more obvious detrimental connotations, are “role engulfment”, “role captivity”, and “role-overload” (e.g., Murphy, Schofield, Nankervis, Bloch, Herrman, & Singh, 1997). These terms seem to apply to primary carers who spend so much time caregiving that there is less time for involvement in other meaningful, socially-affirming, and identity-enhancing roles (e.g., Gahagan et al., 2007).

Furthermore, if the broader society does not recognise caregiving as “real” work, it may become difficult, even for the women themselves, to realise how much labour, effort, and knowledge, is part of caring. This raises the need for carers to

strengthen their sense of personal identity outside the caring role and claim a sense of entitlement to engage in leisure and self-care. For many carers, being able to get out of the house is crucial to maintaining a sense of personal identity, as discussed in the next section.

3.2.3.6 Restricted Capacity to Leave the Home

The pervasive loss of personal freedom reported by carers can include limitations in their ability to leave home at their discretion, which in turn contributes to isolation from friends and community life (Chenoweth & Spencer, 1986; Clark & Rakowski, 1983; Miller & Montgomery, 1990; Montgomery, Gonyea, & Hooyman, 1985; Rabins, Mace, & Lucas, 1982; Stephens & Christianson, 1986; White-Means & Chang, 1994). Research suggests that when primary caregiving mothers engage in leisure activities, it is typically at home. As Henderson (1990) highlights: “If opportunities for leisure are not available in the community, and efforts are not provided to assist women with such services as child care facilities or flexible scheduling of activities, then women have few options for their leisure expression except at home” (p. 238).

Difficulty leaving home is a significant constraint because often this environment is tied to responsibilities and obligations. For example, there is always work around the house that is never complete. Further, the leisure experience itself often changes after an individual assumes caregiving responsibilities, as Weinblatt and Navon (1995) noted: “The few leisure activities that they managed to maintain failed to provide the carers with the feeling of joy, the escape from routine, and the sense of self-actualisation that had characterised these activities in the past. Most of them reported that even when crocheting or watching television, for instance, they constantly felt like prisoners...” (p. 314). Cant (1993) found that for some carers, use of the home as a place of care had disrupted sociability and circumscribed or eliminated the space they

had at home for entertaining. When carers are no longer able to participate in out-of-home activities such as work, community organisations, or social leisure pursuits, visitors often must come to them, and such visits require extra time and effort on the part of the visitor. Furthermore, carers' ability to engage fully with visitors may be compromised if they are simultaneously caregiving.

In Cant's (1993) study, carers raised the need for private space, or space outside the home, to promote sociability and leisure activity. One carer in Gahagan et al.'s (2007), qualitative study, poignantly articulated her homebound situation:

Even a short walk would make a big difference to change your physical location. Far as I get is the clothesline. That's my social life—the clothesline. I stay on the balcony, put clothes on the line, wheel her out, and back in the house I come. (p. 55)

In addition to finding it hard to leave the home, carers further report that leisure travel is impeded by care-giving, which can cause consequences for carers such as resentment (Bedini & Guinan, 1996), strain (Robinson, 1983) and sorrow (Lindgren, 1996).

2.3 Benefits of Leisure for Carers

There are clearly multitudes of constraints that can inhibit carers' access to leisure. There also exists substantial research demonstrating that leisure is an important coping resource for carers, and when they do manage to access this resource, it brings many salutary effects. Leisure activities such as physical fitness and hobbies have been related to decreased physical and emotional stress and improved wellbeing among various family carer groups (e.g., Caltabiano, 1994; King, Baumann, O'Sullivan, WiIcox, & Castro, 2002; Mannell, Salmoni, & Martin, 2002). Results of the Australian Unity Carer health and wellbeing survey showed that high satisfaction with leisure time and leisure quality is strongly associated with higher personal wellbeing, even more so than carers' reported satisfaction with the number of hours they spend caregiving per

week. Carers reported that leisure provided them with rewarding relationships, contributed to their self-confidence and their sense of accomplishment, helped them stay healthy, and helped restore them physically (Cummins et al., 2007). Other studies similarly demonstrated that carers associated their wellbeing with the capacity to engage in hobbies, crafts, social groups and time with friends (e.g., Smale & Dupuis, 1993). Studies on coping strategies used by carers reveals the essential role played by simple leisure activities such as letter writing, listening to songs, going for walks, and being with friends, in terms of their ability to cope effectively with daily stressors (e.g., Barusch, 1988).

In addition to deriving benefits from doing pleasurable leisure activities, caregivers report the inestimable value of companionship and social support, and leisure can be a potent means of generating and sustaining friendships. Leisure contexts provide a chance to experience a sense of unity in the face of similar life experiences and enable people to be in the company of supportive others without having to talk directly about their problems (Hutchinson, 2007). The delivery of group-based leisure programs for carers would respond to findings that informal companionship support supersedes formal instrumental support from professional individuals and groups in terms of stress reduction among parents (particularly mothers) of children with disabilities (Boyd, 2002; Bristol, 1987; Frey, Greenberg, & Fewell, 1989; McKinney & Peterson, 1987; Piquart & Sorensen, 2007; Trute, 2003). Given the plethora of leisure constraints reported by carers, and the demonstrated benefits of leisure, helping professionals "...need to be mindful and diligent in locating family carers as well as making recreation opportunities known to them" (Bedini, 2002, p. 30). The "Me Time for Mums" program was a response to this call, and used the platform of leisure and creative arts to bring mothers of children with a disability together in a light-hearted and playful context where social connections could be easily fostered through mutual

participation in shared pleasurable activities. The present “Me Time for Mums” evaluation study adds to the body of literature on caregiver-specific leisure programs, as reviewed in the next chapter.

3.4 Review of Published Leisure Interventions for Carers

Many researchers have explored carers’ perceived constraints to leisure and self-care. These studies typically conclude that (particularly female) carers need help “...to access services which will provide them with opportunities for leisure” and interventions that “...focus on helping carers recognise their own separate needs and interests and to envision some life of their own” (Brody, 1989, p. 55). Bedini and Phoenix (2004) reflected on the dearth of experiential leisure programs that have been systematically evaluated for carers: “Although social and educational programs can provide the knowledge or opportunities for caregivers to pursue their leisure, the lack of proven leisure interventions is notable” (p. 31). Indeed, a thorough search of EBSCOhost and PsychInfo databases (1985 to present²) revealed very few empirical evaluations of programs involving experiential leisure participation for carers. These studies will be reviewed in this chapter in order to better understand the effects of doing leisure for carers and in order to inform the design and delivery of the “Me Time for Mums” program and the evaluation methodology employed. For the purposes of reviewing the literature, experiential leisure interventions were broadly defined as interventions designed to foster and/or facilitate carers’ engagement in activities that are self-care oriented and may include pleasant events, creative arts, relaxation, exercise, and hobbies, among others. Intervention studies are grouped according to the type of leisure activities in the program.

² Search terms included: “carers/caregivers and leisure”, “carers/caregivers and recreation”, “carers/caregivers and program(mes)/interventions”, carers/caregivers and creative arts”, “carers/caregivers and self-care”, carers/caregivers and support group, “carers/caregivers and exercise”, “carers/caregivers and yoga”, “carers/caregivers and relaxation”.

3.4.1 Physical Activity Interventions

The first systematic investigation of the effectiveness of a physical activity program tailored to the needs of family caregivers was completed by King, Baumann, O'Sullivan, Wilcox, and Castro (2002). They conducted a randomised controlled trial of the effects of moderate-intensity exercise on physiological, behavioral, and emotional responses to family care-giving among 100 female caregivers. Exercise participants ($n = 51$) engaged in at least four 30- to 40- minute exercise sessions per week. The program was provided in a home-based format over a 12 month period. Exercise participants were compared to other women who were randomised to a telephone-based nutrition education program ($n = 49$), matched with the exercise condition on level of staff contact received. All participants received a face-to-face initial counselling session, followed by periodic telephone contact.

Results demonstrated that exercise participants showed significant increases in amount of physical activity relative to nutrition participants. At 12 months, the exercise condition demonstrated increased knowledge of the benefits of exercise and increased motivation for exercise compared with the nutrition education condition. There were no significant differences between the conditions in terms of the psychological outcome variables. At 12 months, participants in both conditions reported improved depression ratings (i.e., reduced their Beck Depression Inventory score to below the cut off point used for mild depression). Likewise, all participants demonstrated reductions from baseline to 12 months in perceived stress and subjective burden. The researchers surmised that involvement in some type of health promotion program that incorporates consistent contact with health professionals may have provided sufficient stress reduction and social support to produce the improvements noted in depression and stress across interventions. This study raises the possibility that the active mechanisms of health promotion interventions for carers may have more to do with the receipt of

attention, recognition, and social legitimisation for the promotion of an ethic of self-care than the nature of the activity undertaken.

The benefits of yoga for carers was demonstrated by Waelde, Thompson, and Gallagher-Thompson (2004) in their evaluation of the “Inner Resources program”. This manualised yoga/meditation program consisted of six sessions involving meditation, gentle stretching, breathing techniques, guided imagery, and mantra repetition. Participants consisted of 12 older female dementia patient family carers. Pre- to post-intervention comparisons revealed statistically significant reductions in depression (Center for Epidemiological Studies–Depression Scale, Radloff, 1977) and anxiety (State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, & Lushene, 1970), and increased self-efficacy (Revised Scale for Caregiving Self-Efficacy; Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). Although there was a small sample and no control group, the positive findings suggest the potential benefits of building yoga and meditation into psychosocial programs for carers.

3.4.2 Relaxation Programs

A program that specifically focused on the effects of relaxation was evaluated by Fisher and Laschinger (2001). They investigated the effects of doing relaxation exercises (e.g., deep breathing, progressive muscle relaxation etc.) on self-efficacy for anxiety-control among 36 carers of relatives with Alzheimer’s disease. The six-week relaxation training program was offered over a six-month period to six separate groups of caregivers. A manual describing the relaxation exercises along with a tape featuring classical music was provided for use at home.

Two self-report instruments were used: Part A of the Memory and Behavior Problem Checklist (MBPC) was used by carers to rate how often each of 25 common memory and behaviour problems, such as restlessness or wandering, had occurred in the last week. Part B of the MBPC was modified to create a self-efficacy scale, which

participants used to rate their level of confidence for controlling the anxiety that each reported problem would likely have caused. Carers' overall self-efficacy for controlling anxiety was significantly higher following the relaxation intervention, however it is unclear how this may have affected carers, as anxiety levels were not measured in this study. A qualitative component may have helped to elucidate what elements of the program were most beneficial in improving self-efficacy. The researchers reported that: "Interventions such as the relaxation program used in this study encourage a healing of mind, body, and spirit by increasing the caregiver's sense of well-being." (p.58) However, carers' wellbeing was not measured. Instead, as is often the case in carer intervention research, positive psychological outcome indices were not included in this evaluation, which raises the point that absence of distress does not necessarily imply wellbeing. Finally, the ability to generalise the study findings is limited as participants were recruited from only one community centre. Addition of a control group would have further strengthened the design. Despite these limitations, the findings were promising in terms of assisting carers to directly participate in relaxation activities, rather than simply discussing the importance of self-care.

3.4.3 Programs Designed to Increase Pleasant Events

Interventions which emphasise engagement in pleasurable activities despite stress appear useful for improving mastery and depressive symptoms in carers. Gallagher-Thompson et al. (2000) compared the effectiveness of two active interventions, a life satisfaction class and problem solving class, to a wait-list control condition in 161 family caregivers of older adults. Outcome variables were depression, caregiver burden, and use of adaptive coping strategies. The Life Satisfaction (LS) class was based on the theoretical premise that decreased engagement in pleasant events and lack of adequate positive reinforcement in daily life often leads to depressed mood and related symptoms. This can lead to reduced engagement in personally satisfying

activities, resulting in more social withdrawal and spiralling depression. The following skills were taught in the LS class: (a) How to monitor daily mood and rate of engagement in pleasant activities or events, (b) how to identify potentially powerful pleasant events by graphing the relationship between events and mood, (c) how to develop a self-change plan targeting at least one specific pleasant event to increase, (d) identification of potential obstacles to doing this, (e) setting reasonable weekly goals, and (f) learning to reward oneself to promote maintaining the new activity schedule. Activities frequently targeted for change included exercising, socialising, and getting away from the house. The LS class was compared to a problem solving (PS) class, which involved discussion and cognitive strategies around managing caregiving problems.

Chi-square analysis of change in depression status from pre- to-post intervention showed a higher percentage of improvement among participants in the LS class compared to the improvement rate in either the PS class or the wait-list condition. While the PS group increased their use of cognitive coping strategies, they also reported additional symptoms of depression present at post-compared to pre-intervention. The PS class may have increased carers' sense of lack of control regarding the many practical problems of caregiving that cannot be "solved", and the potential "over-exposure" to the problems described by carers in the group may have been overwhelming. This heightened awareness of problems may have caused a temporary increase in depression among carers assigned to the PS condition.

The researchers surmised that "Empowerment may be a very important concept here: perhaps caregivers in that [LS] class were more able to accept the legitimacy of pursuing at least some of their own needs, and separating those from the ongoing concerns of caring for their loved one" (Gallagher-Thompson et al., 2000, p. 106). This finding underscores the need for carers to engage in programs that go beyond problem

solving about care-giving and engage in self-development and self-nurturance. The researchers acknowledged that, in order to engage in self-nurturing, carers may need the social validation that accompanies community-based programs.

In the light of this research Gallagher-Thompson et al. (2000) advocated that life satisfaction and pleasant events should be the focus of future interventions for family carers. They suggested that programs for carers should be designed to facilitate engagement in pleasant leisure activities and argued that “These less traditional forms of coping have not yet been studied to any great extent” (p. 106). This study suggests the value of designing interventions that aim to boost pleasure and life satisfaction and promote wellbeing as opposed to traditional interventions for carers that are arguably more concerned with problem solving, problem management, and ameliorating distress.

3.4.4 Leisure Education Programs

Several leisure education intervention models have been outlined, typically including the following components: Discussion of the need to establish a balance between self and caregiving responsibilities, discussion of the benefits of leisure, assessment of leisure interests and barriers, identification of strategies to overcome barriers, identification of community leisure resources, identification of respite or other support programs necessary for leisure, and discussion of guilt related to taking time for leisure (Hughes & Keller, 1992; Rogers, 1999).

Only one published evaluation study of a leisure education program for caregivers could be found. Charters (2006) evaluated a leisure education program called “Learn to take care of yourself too!” that she implemented with four caregivers of institutionalised elderly care recipients. The six weekly leisure education sessions comprised discussions and homework activities designed to explore leisure awareness and knowledge, leisure benefits, leisure values, leisure barriers, leisure resources, and leisure planning. There was one experiential leisure activity in the program which

involved creating a leisure collage in the first session. Evaluation data resulting from ongoing journal writing and post-program interviews indicated that carers reported an increased knowledge of leisure. They reported changes to their thinking, increased self-awareness about leisure, increasing confidence, greater valuing of taking time for self-care, and reduced guilt. They did not, however, report continued leisure participation after completing the program. Participants suggested that future programs should incorporate more experiential group activities that promote doing leisure, rather than just talking about it. A further two leisure education evaluation studies have been undertaken, however only dissertation abstracts were available (Lynch, 1994; McMahan, 2007).

Leisure education programs appear to be just that – educational. The inference from such approaches is arguably a demand for caregivers to learn more, do more, change their attitudes, and plan even more in a world that is already overflowing with responsibilities. An alternative approach that should be tested is leisure activation in which carers are encouraged to be playful, spontaneous and experimental in their engagement with leisure activities, with a view to examining the impact of this leisure behaviour on their attitudes to leisure. It remains to be seen whether behavioural engagement and experimentation with social leisure activities actually alters carers' attitudes.

3.4.5 Creative Arts Programs

Several experiential programs have been evaluated with carers that incorporate creative arts modalities, including music and art making. Walsh, Martin, & Schmidt (2004) evaluated a creative arts intervention (CAI) involving 40 family carers of patients with cancer over a six month period. Carers participated in the program by the bedside of their care-recipient in hospital, where together they chose to make something from a menu of arts activities, including making a Mandala, silk wall hanging,

monoprint, healthy image poster, and silk rubbing. A paired-samples *t*-test revealed significant pre-to-post program reductions in carers' stress (Mini Profile of Mood States (McNair, Lorr, & Droppleman, 1992) and anxiety (Beck Anxiety Inventory; Beck & Steer, 1993, as cited in Walsh et al.). Additionally carers' mean score on the Derogatis Affects Balance Scale (Derogatis, 1975, as cited in Walsh et al.) significantly increased, indicating more positive emotions.

The researchers provided several interpretations of these results, including that the CAI provided carers with choices at a time when few opportunities for either choice or control were open to them. They suggest that the creation of a tangible product provided a positive memory for carers at a time when few positive experiences were present. Nurses reported the arts intervention promoted excitement and positive communication between carer and care-recipient and with the health care team. In their summary, the researchers state that family carers and patients with cancer noticeably changed their demeanour and attitude as soon as they engaged in creative arts activities. They became animated, debated about colours and designs, and laughed and joked about one another's efforts. The researchers note that "Multiple interpretations of the highly significant results are possible" (p. 217), and recognised the need for future studies to include a qualitative component to explore factors contributing to the test results. The addition of a control group would further improve the quality of the evaluation.

A further exploration of the effects of participating in hands-on creative arts activities was provided by Murrant (2000), who reported the implementation of a one-day self-care workshop for paid and voluntary palliative carers at a hospice in Canada. The "Creativity and Self Care for Carers" workshop was designed to counteract the stress from care-giving by encouraging carers to shift their focus to self-care and rediscover their own resources through creativity and play. The workshop began at 9am

and ended at 6pm. Participants met in a large group at the beginning of the day for introductions and were divided into three groups to rotate between writing, art, and music sessions (each of two hours duration). At the end of the day, all participants met again in the large group for debriefing, completion of evaluations, and participation in a closing exercise.

Murrant's (2000) article provides a detailed outline of the rationale and nature of the activities in each creative modality, however the evaluation protocol lacked rigour. Participants completed an evaluation form for each of the three creative arts modalities answering the following questions: What was the most helpful part of this workshop? What would you do differently if you organised this workshop? Any other comments? Seventy-five evaluations were completed and Murrant reports:

All were positive and indicated that participants had learned about and experienced valuable aspects of themselves. They appreciated the opportunity to experience all three modalities. No one modality stood out from the others as being more useful. The evaluations overwhelmingly indicated that participants appreciated the nurturing, supportive, non-judgmental climate of the workshop and the skill level of the facilitators. (p. 48)

Reported benefits included social support (e.g., "It was very helpful being in a group with others who are involved in caregiving and sharing fun activities", p. 48) and identity expansion beyond the caring role (e.g., "It provided a facility for me to get close to who I am, with my many facets, highlight what is important to me, how to let go, relax, experience others", p. 48). Murrant (2000) stated that some participants felt that the day was too long, with suggestions for longer breaks and spreading the sessions over different days/evenings.

A follow-up telephone survey was conducted within two years after the workshop, which seems to be a long follow-up period for a one-day intervention. Of the

75 participants, 34 responded with “absolutely” or “more so than before” to the question: “Are you more aware of the need to take care of yourself as a carer since taking the workshop?” These findings suggest the power of even a one-day creative arts intervention for carers, though the researcher recognised that more research is warranted to quantify these findings.

Group-drumming is another creative arts activity that is proving to be a popular, successful and a cost-effective intervention with therapeutic and clinical applications across healthcare (e.g., Bittman, 2001; Bittman, Bruhn, Stevens, Westengard, & Umbach, 2003; Bittman et al., 2001). Bittman et al. (2003) conducted a randomised, controlled study of the clinical impact of the “HealthRHYTHMS Group empowerment drumming protocol”, which involves exercises using hand drums, percussion instruments and keyboard. The protocol was delivered to 112 long term care workers in a retirement village for one hour per week over six weeks. A subset of participants ($n = 41$) were also tested at set intervals (6 weeks) before starting the intervention to establish a pre-test baseline against which to assess program-related improvements. A further subset of participants ($n = 43$) were tested 6 weeks following completion of the program to examine maintenance of program effects. For participants in the drumming intervention, there were significant pre- to post-program changes on the following burnout and mood dimensions: Emotional Exhaustion, Personal Accomplishment, Tension/Anxiety, Depression/Dejection, Anger/Hostility, Vigor/Activity, Fatigue/Inertia and Total Mood Disturbance, as measured by the Maslach Burnout Inventory (Maslach & Jackson, 1996) and Profile of Mood States (McNair, Lorr, & Droppleman, 1992). There was a 46% reduction in mean Total Mood Disturbance scores. All significant changes were in a eustress direction. Conversely, over the 6-week pre-test baseline period, a (non-significant) distress trend was found (i.e., increases in scores on burnout and negative mood dimensions). The positive effects of

the drumming intervention persisted over time (6 weeks post-program), with all dimensions (excepting Personal Accomplishment and Confusion/Bewilderment) demonstrating significant changes in a eustress direction. In addition, there was a 62.3% reduction in Total Mood Disturbance compared to pre-program scores, indicating the persistence and augmentation of positive program effects. The researchers also conducted a post-hoc economic impact analysis, demonstrating the valuable cost savings associated with implementing the music making protocol as an employee wellness program, in terms of reduced attrition and absenteeism, among other benefits. The results of this well designed evaluation study indicate that group drumming and music making can reduce burnout and improve mood among employed carers.

The relative lack of experiential leisure interventions for carers was revealed in Bedini and Phoenix's (1999) integrative review of 22 journal articles between 1990 and 1998. They attempted to identify factors underpinning the success of recreation programs for caregivers of older adults. Only two articles reported on experiential leisure interventions, and only one of these was empirically evaluated; other "recreation" programs were actually respite services, support groups, education/training, and the combination of support group and education/training. They also reviewed the outcome measures used to evaluate programs and found that none included a questionnaire specifically measuring leisure attitudes among carers.

One recreation program was Smith and McCallion's (1997) horticulture therapy program, which was apparently beneficial due to being located conveniently in the home, being low-cost, and building on existing skills of the caregivers, however, these assertions were not based on any evidence as the program was not evaluated. Secondly, Bedini and Phoenix (1999) reported on Dupuis and Pedlar's (1995) inductive study in which four family caregivers participated in a structured family music program which

took place during visits with their care-recipients twice a week over a six-week period in an aged care home. Data collection strategies consisted of participant observation, open-ended questionnaires, and in-depth interviews. The researchers identified four outcomes for carers, namely: enhanced quality of visits with care-recipients, increased perception of social support, increased coping through leisure participation, and enriched family relationships. Due to the small sample size of four carers, results have limited generalisability. Furthermore, both the horticulture and music making interventions reported by Bedini and Pheonix (1999) involved both carers and care-recipients working together in the program, with the focus on improving the quality of their interactions. This may be partly due to the often cited notion that “Caregivers may feel less guilty about seeking leisure for themselves, if they believe the care recipient also has opportunities for leisure” (Rogers, 1999, p. 7).

So far creative-arts interventions have either been implemented with informal carers together with their care-recipients or with paid or voluntary carers who are employed in care settings. To date, the outcomes of creative arts programs specifically for informal family carers have not been systematically evaluated. As previously described, the notion of helping informal carers to realise and validate their own independent needs is increasingly being recognised in the Australian policy context. It is clear that carers face a plethora of constraints to participating in leisure, and greatly lament the absence of leisure time and opportunities in their demanding daily lives. This behoves the implementation and systematic evaluation of community leisure programs to improve the wellbeing and life-balance for family carers.

3.4.6 Summary of Previous Studies on Leisure Programs for Carers and Future Directions

Although the results of leisure programs for carers must be interpreted cautiously due to the small sample sizes, the common lack of a control group, lack of longer-term follow up evaluations, lack of program replication, and lack of proximal,

psychometrically valid, and consistent outcome measures specific to leisure involvement and wellbeing, they cannot be completely dismissed. The above literature review suggests the therapeutic value of experiential leisure programs for carers. For example, yoga can result in increased self esteem and reduced depression and anxiety. Relaxation strategies can improve carers' self-efficacy for controlling anxiety about caregiving. Participation in exercise can reduce depression, stress, and subjective burden, while engagement in pleasant events can reduce depression. Art and music making can reduce anxiety, decrease burnout and negative mood states, and increase positive emotions. Engagement in creative arts activities allows carers to share fun activities, experience increased social support, realise their own personal interests and strengths beyond the care-giving role, and emerge feeling more relaxed with an expanded sense of personal identity. In light of these salutary findings for carers, there is a growing evidence-based rationale for the inclusion of leisure and creative arts programs for carers in community support services.

The increasing emphasis on measuring the practical value of the effects of an intervention, or the extent to which an intervention makes a "real" difference in carers' lives, calls for ascertaining what carers think and feel regarding the process and outcomes of doing the intervention. At this exploratory, and largely pilot-test phase of evaluation research on carer-specific leisure interventions, a combined qualitative and quantitative approach is necessary. Outcomes of innovative programs cannot be realistically anticipated and properly captured by questionnaires. Qualitative data can also provide important information about overcoming barriers and fostering carers' access and ongoing participation in health promoting interventions, which is crucial to improve program implementation and extend delivery of the intervention beyond the pilot phase. Furthermore, the effects of leisure interventions may be underestimated by

using generic mental health instruments that may be too insensitive to detect the specific effects of a time-limited intervention.

Evaluation measures need to be as specific as possible to the hypothesised treatment effects. At this stage, as researchers have highlighted, there is no carer-specific questionnaire measuring leisure attitudes. Given the numerous intrapersonal constraints to leisure reported by carers, a proximal goal of leisure interventions is to assist carers to negotiate and overcome their own attitudinal constraints to leisure and self-care. The development of a carer-specific leisure attitude measure would provide a more proximal measure of leisure intervention outcomes, compared to more distal mental health indices, and allow different types of leisure interventions with carers to be compared. The previously described study on the development and pilot testing of the Caregiver Leisure Attitudes Scale (CLAS) provides a useful proximal outcome measure for carer-specific leisure interventions.

Lastly, leisure intervention evaluation studies have commonly employed mental health and burden outcomes instruments (e.g., measuring depression, anxiety, and subjective caregiver burden). It is presently argued that evaluation studies need to incorporate positive psychological measures (e.g., positive affect, personal wellbeing, caregiver wellbeing etc.) into the battery of outcome measures in order to shift the focus from ameliorating negatives to enhancing positive outcomes and promoting resilience. A detailed rationale for the implementation of “Me Time for Mums” shall be presented in the next chapter.

CHAPTER 4: RATIONALE FOR THE “ME TIME FOR MUMS” PROGRAM AND ITS CONCEPTUAL FOUNDATIONS

4.1 From Stress Reduction to Wellbeing Promotion: Expanding Existing Carer Support Services to Include Leisure Programs

Many psychosocial programs designed for carers are referred to as “stress management” interventions, primarily designed to reduce anxiety and caregiver burden, so that carers can be better carers. Reflecting this emphasis on ameliorative outcomes, Hastings and Beck (2004) concluded, from their review of interventions for parents of children with disabilities, that “...typical appropriate supports provided by services for children with intellectual disabilities and their families...probably make some contribution to reductions in parental stress” (p. 1345). As Singer et al. (2007) argued in their meta-analysis of 17 psychosocial interventions for parents of children with disabilities, “...efforts to support and assist families should be designed to foster attitudes, skills, and resources that not only reduce distress but also buffer it as well, augment resilience, and promote positive outcomes” (p.357). Leisure interventions, such as the presently evaluated “Me Time for Mums”, offer an alternative approach designed to promote a positive attitude to self-care and leisure among carers towards both reducing stress and increasing wellbeing.

The “Me Time for Mums” program responds to the Australian House of Representatives’ Inquiry into Better Support for Carers (Edwards et al., 2008), which acknowledged that carers are not adequately supported in their caring role and have limited opportunity to have a life outside of caring (p. 1). This report recommended an “Expansion of the level and range of carer specific support services towards providing support for carers in their capacity to care *and to maintain their health, emotional and social wellbeing*” (italics added; p. 2). The “Me Time for Mums” program expands the caregiver support sector by encouraging carers to think about their daily lifestyle and purposefully allocate time for social leisure outside the home. The program offers

implicit social validation for doing leisure via the demonstration that leisure is so important that community organisations have assumed responsibility for delivering leisure programs. In doing so, “Me Time for Mums” provides a space that actively promotes experiencing self and life outside of the typically dominant caregiver role, in ways that do not feel like therapy. It differs from more conventional didactic psycho-educational and CBT programs for carers in its emphasis on generating social contacts via shared engagement in creative activities and shared experiences characterised by feelings of wellbeing, such as interest, enjoyment, and fun. Pinquart and Sorensen (2004), concluded from their review of psychosocial interventions for carers that “...developing and maintaining sources of *positive affect* may counteract some negative effects of caregiving and thus protect carers’ well-being and mental health” (p. 447; italics added).

Through doing creative, playful, and relaxing leisure activities, the “Me Time for Mums” program aims to provide participants with a direct experience of enjoyment, which could stimulate and inspire their intrinsic motivation to practice an ethic of self-care and keep engaging in leisure activities after the program. As Hubbard and Mannell (2001) demonstrated, individuals were more willing to negotiate leisure constraints if they perceived the activity to be enjoyable. Hutchinson, LeBlanc, & Booth (2006) argued that “In reality, enjoyment is not often reflected in treatment goals or processes associated with...functional intervention” (p. 223). Through the dedicated facilitation of playfulness and enjoyment, the “Me Time for Mums” program sought to complement existing carer support services.

In Australia, carer resource centres are in each state capital under the National Respite for Carers Program. Main support services for carers are respite care services, carer payments, and parent support groups. While these services are all essential to cope with caregiving, none of them specifically focus on increasing carers’ leisure

participation and wellbeing, despite ample research demonstrating the pervasive loss of leisure and extremely low wellbeing reported by carers in Australia (Cummins et al., 2007). As outlined in section 3.3, there is clear evidence for the benefits of doing leisure for carers. Researchers who have conducted many studies into caregiving and leisure argued that it is "...imperative that more is done to provide accessible and meaningful leisure to female family carers of older adults and children with disabilities" (Bedini & Pheonix, 2004, p. 378). The requirement now is to put this body of knowledge into practice, to influence service development, to evaluate these developments, and to highlight and disseminate good practice.

It is arguably not enough for case workers and health professionals to recommend that carers take breaks and engage in leisure and mood-lifting activities. As discussed in section 3.2.3, there are abundant intrapersonal constraints that preclude carers giving themselves permission to nurture the self. Community services therefore need to be proactive in designing leisure programs, locating carers, and informing them of leisure opportunities. Carers may view support for themselves as an admission of failure as a parent (Beresford 1994). They might find it difficult to ask for support from others for various reasons including fear of not being able to reciprocate or of being a burden (Kazak & Marvin 1984; Todd & Shearn 1996). Bedini (2002), a prominent leisure theorist and researcher, emphasised the need for external validation and support to encourage carers' leisure participation:

Family caregivers typically do not self-identify, nor do they initiate contact with community recreation programs seeking opportunities. Instead, because of the various barriers ... family caregivers try to quietly do what they can. Therefore, recreation professionals need to be mindful and diligent in locating family caregivers as well as making recreation opportunities known to them. (p. 30)

For some parents, participation in a structured community support program may be equated with needing therapy. The stigma against seeking psychological treatment and the implication that they are incapable of managing alone may further prevent help-seeking. Alternative formats for psychosocial support need to be considered in order to widen access, particularly formats that feel less like therapy. It has been widely advocated that innovative approaches are needed for the hard-to-reach caregiver population (Walsh, Martin, & Schmidt, 2004). Furthermore, structural support, such as financial, childcare, and transportation assistance is also necessary to enable some carers to leave the home and attend community programs.

Available sources of support for carers will be briefly reviewed in the next section in order to understand how the “Me Time for Mums” program provides a new and important complement to existing support services for carers in Australia.

4.2 Leisure Programs Complement Existing Carer Support Services

Respite care, support groups, case management, and counselling are among the most prevalent support options available to carers in Australia. It is beyond the scope of this review to detail the empirical support for each intervention. Instead, the following overview of existing services seeks to demonstrate how the “Me Time for Mums” program fills an important gap in the Australian carer community support sector.

4.2.1 Support Groups and Counselling

Support groups are the most popular and prevalent intervention available to carers. According to research on support groups for parents of children with disabilities, “...parents discuss the problems they are experiencing and discover that others are often confronted with similar events and reactions” (Seligman, 1993, p. 117). Major themes presented during carer support groups include: information about carers’ situations, information about the child’s disability, development of a mutual support system, discussion around the emotional impacts of care-giving and the importance of

self-care, management of children's behaviour problems, discussions around problematic interpersonal relationships, information regarding support systems outside the group, and home-care skills (Toseland & Rossiter, 1989). There may be sporadic attention to relaxation and other coping skills, however, the focus is on talking about issues rather than doing shared activities.

Some evidence points to the function of support groups as providing a space for carers to "unload" their problems and concerns. This may bring relief and a sense of mutual understanding and support. However, problem-focused interventions may not provide a distinct and rejuvenating break if carers are still focused on care-giving concerns. Furthermore, without an experiential self-care component, insights gained from discussions around personal wellbeing may not be internalised and translated into practice. Studies have shown that participants in support groups evaluate these groups as useful and beneficial (e.g., Gonyea, 1989; Toseland, Rossiter, & Labrecque, 1989), and there is some evidence that they enhance informal support networks (Bourgeois, Schulz, & Burgio, 1996).

However, there is much less evidence demonstrating their effectiveness in improving carers' mental health or that carers in these groups are able to learn specific coping skills to manage their situations more effectively and promote their personal wellbeing (Dura, Stukenberg, & Kiecolt-Glaser, 1991; Gage and Kinney, 1995; Gonyea, 1989; Monahan, Green, & Coleman, 1992; Russo, Vitaliano, Brewé, Katon, & Becker, 1995; Shu & Lung, 2004; Toseland et al., 1989). The "Me Time for Mums" program aims to encourage social connections through wellbeing-promoting leisure activities, where bonds could be formed around shared interests and uplifting experiences, as opposed to shared difficulties and problems.

Individual counselling, similarly to support groups, aims to help caregivers improve their ability to cope with the stresses of caring. In a literature review of carer

support interventions in California, the authors outlined the functions of counselling as typically striving to "...relieve caregiver depression and/or anxiety, resolve pre-existing personal problems which complicate caregiving, mollify conflicts between the caregiver and recipient, and/or improve family functioning" (Whittier, Coon, & Aaker, 2001, p. 53). Bourgeois et al. (1996) did a comprehensive review of over 100 Alzheimer's disease caregiver intervention studies and found that individual counselling interventions have shown positive outcomes for narrowly defined problems. Once again, the emphasis in counselling interventions appears to be problem-focused talking. In contrast, the "Me Time for Mums" program sought to facilitate *lived experiences* that lift mood and offer freedom and respite, with a focus on getting in touch with aspects of self on the "lighter side of life".

4.2.2 Respite Care Services

Carers often report needing respite to engage in the lifestyle interventions recommended by health professionals, but even when they get respite, due to the fatigue and disavowal or neglect of their own health needs, many struggle to take care of themselves (Stacey, 2002). A recent Australian study found that 88.6% of informal carers had never used respite services and that women carers were less likely to use respite services than men (Vecchio, 2008). Furthermore, it is apparent that the provision of a respite *service* does not necessarily result in a respite *experience* for carers. A review of the literature reveals that many carers, while desperately in need of a break, often use the time their care-recipient is in respite care to do caregiving and other necessary tasks (Gill, Hinrichsen, & DiGiuseppe, 1998; Gottlieb & Johnson, 2000; Lawton, Brody, & Saperstein, 1989). Deimling (1992) tested a program of respite for carers and found that, when given modest amounts of respite, carers did not pursue social and recreational activities. In most cases, carers used the respite time to "...catch up on other responsibilities, to work...or simply rest" (p. 129). Thus respite services,

while essential, do not automatically lead to carers experiencing a mental break or freedom from worry, which is arguably the essence of respite (Strang & Haughey, 1999). Factors contributing to carers' non-use of services include lack of understanding of respite care, passivity towards organising respite care, negativity towards mental health services, lack of flexibility and inadequate availability or accessibility of respite care, guilt for separating from their care-recipient, and lack of financial resources.

A strong distinction underpinned the "Me time for Mums" program in terms of not just facilitating time apart from care-recipients, but actively reorienting carers away from preoccupation with their care-giving concerns via engaging activities, in order to facilitate an authentic respite experience.

4.2.3 Multi-Component Psychosocial Programs

A range of psychosocial interventions for parents of children with disabilities have been tested, the preponderance of which focus on psycho-education, stress-management, and skills for behavioural management of children. From their systematic review of parent interventions, Hastings & Beck (2004) concluded that implementing any form of more structured intervention appears to have a greater positive impact over no support or the receipt of standard services (e.g., respite care, case management). They identified the key features in designing effective interventions as "...the matching of parents with similar needs/experiences, and the facilitation of contact between parents" (p. 1346). They noted the predominance of cognitive behaviour therapy (CBT) group interventions, and argued that multimodal CBT interventions raise difficult questions regarding identification of the active components of the intervention. In being multi-focused and time-limited, the effects of any one component are typically difficult to evaluate. This raises the need to test more focused interventions, where there is enough practice time for carers to internalise the coping skills being presented, and the active ingredients promoting change can be more easily delineated. Additionally, most

evaluation research has compared CBT programs to no-treatment controls, therefore there is very little evidence indicating that resource intensive CBT programs are more efficacious than more easily implemented behavioural interventions. In the absence of evidence suggesting that one model of psychosocial intervention is better than others, there is scope to explore innovative approaches, such as the “Me Time for Mums” program, to fostering carers’ wellbeing.

In summary, the “Me Time for Mums” program was designed to focus on participation in leisure activities, with a clear emphasis on shared doing, rather than talking, and a clear focus on carers having “me time”, rather than using the forum to discuss children and caregiving issues. There have been no systematically evaluated leisure programs for carers in Victoria, therefore the present evaluation study seeks to contribute to knowledge regarding the viability and benefits of leisure programs for carers. Hastings & Beck (2004) concluded that it is “... important that more research evaluations are conducted to enhance the evidence base for alternative models” (p. 1346). The present evaluation of the “Me Time for Mums” program responds to this call.

4.3 Rationale for Activities Presented in the “Me Time for Mums” Program

A distinction needs to be made between creative arts therapy, a professional psychological discipline with various sub-disciplines (e.g., art therapy, dance therapy, music therapy) and participation in creative activities outside of a structured psychological context. The former implies a therapist-facilitated, purposeful therapeutic endeavour usually involving some psychotherapeutic processing of the creative process and/or product, whereas the latter involves participating in creative activities for their own sake. The use of creative activities to promote health and wellbeing, where engagement in the creative process *per se* is seen to have therapeutic value, has increased dramatically in the last 20 years. This is reflected in the increasing number of

arts activities, including painting, sculpture, photography, music, poetry, drama, and dance, among other modalities, that are offered in hospitals, healthcare, and community organisations (e.g., Scher & Senior, 2000; White, 2003).

There is a growing body of literature about the impact of the arts on health. Doing creative activities has been associated with growth in self-confidence and empowerment, development of self-expression and self-esteem, enhanced motivation, enhancement of perceived control, and increased sense of purpose and meaning (e.g., Callard & Friedli, 2005; Landry & Matarasso, 1996; White, 2003). Engagement in creative arts programs has been related to reduced anxiety and depression, reduced sense of fear and isolation (Matarasso, 1997), and increased absorption and relief from worrying thoughts (Reynolds, 2000). Creative programs have been associated with the development of skills (both physical and cognitive), restoring the balance between work and leisure, opportunities for social connections and links to community groups, and inspiring engagement in a wide range of further projects (e.g., Griffiths, 2008; Heenan, 2006). These outcomes contribute to the development and reinforcement of a positive self-concept and personal identity: “Each creative mark reaffirms the self. It says ‘I am here’, ‘I have something to express’” (Warren, 1993, p. 4).

The “Me Time for Mums” program consists of the following five wellbeing/creative arts modalities: (a) Yoga and Relaxation, (b) “Theatresports” Improvisation, (c) Belly Dancing, (d) Group drumming, and (e) Art and Sensory Play. Each of these modalities has been found to have salutary health effects, albeit reinforced more through clinical reflections and qualitative findings than on quantitative grounds. Researchers and funding bodies are increasingly calling for more robust evaluations of arts and health programs (e.g., Hughes, 2005; Jermyn, 2004; Ruiz, 2004). To demonstrate an evidence-based rationale for the inclusion of the above

modalities in the “Me Time for Mums” program, a brief outline of pertinent research is given.

Yoga and breathing relaxation strategies have been incorporated into many multi-component psychosocial programs due to their impact in decreasing depression and anxiety (Pilkington, Kirkwood, Rampes, & Richardson, 2004; Waelde & Thompson 2004; Woolery, Myers, Sternlieb, & Zeltzer, 2004), decreasing stress (Anand, 1999), and reducing negative affect (West, Otte, Geher, Johnson, & Mohr, 2004). Yoga techniques have also been shown to improve perceived self-efficacy (Waelde & Thompson, 2004), sleep (Cohen, Warneke, Fouladi, Rodriguez, & Chaoul-Reich, 2004), and perceptions of mental and physical energy and positive mood (Wood, 1993).

Theatre sports improvisation was the second modality included in the program. Improvisational games have proven to be useful in psychotherapy for enhancing and developing skills that promote good relationship functioning (Weiner, 1998) and in stimulating management personnel to think in new ways, outside of their typical perceptual and response frameworks (Corsun, Young, McManus, & Erdem, 2006). Preliminary evidence suggests that participation in a theater improvisation program increased cohesion in a group of prisoners in the San Francisco County Jail and, according to the researchers, increased prisoners’ positive emotional risk taking in the group (Tucci, 2002). A detailed qualitative study was conducted by Lemons (2008), who conducted interviews with seven individuals from diverse fields who all use improvisational techniques in their work. Respondents reported positive effects of doing improvisation, including improved communication, enhanced sense of community and teamwork, a greater sense of risk and challenge within a safe context, honest emotional expression, self-actualisation, and joy. Further themes were that drama improvisation provided opportunities to explore different roles and aspects of

self, with common “by-products” of fun and laughter which promote trust and group cohesion. Doing improvisation activities was also found to encourage being open and alert in the moment, rather than carried away with thoughts.

The third modality, dance activities, has been associated with improved quality of life and body image (e.g., Dosamantes, 1990; Dosamantes-Alperson & Merrill, 1980; Kuettel, 1982; Leste & Rust, 1990; Sandel, Judge, Landry, & Faria, 2005). Belly dancing has been qualitatively studied and found to be associated with the following beneficial outcomes: acceptance of self and others, improved body image, enjoyment with costumes, enhanced creativity, support through group connection, expanded relationships, improved self-confidence, stress reduction, fun, comfort with femininity, enhanced fitness, a sense of personal growth, enhanced valuing of culture/history, and enhanced spirituality (Paul, 2007).

Group-drumming was incorporated into the “Me Time for Mums” program given evidence that it is a flourishing tool for improving wellbeing (Blackett, 2003). Drumming enhances communication (Bittman et al., 2003; Friedman, 1997; Longhhofer & Floersch, 1993; Stevens & Burt, 1997), reduces stress and tension (Bittman et al., 2003; Quinn, 2002; Strong, 2000), and can be experienced as spiritual or as altering perception and consciousness (Atwater, 1999; Neher, 1962; Woodside, Kumar, & Pekala, 1997). Drumming is creative (Camilleri, 2002; Longhhofer & Floersch, 1993; Stevens & Burt, 1997) and absorbing, with implications for focusing the mind in the present and aiding concentration and other mental processes (Clair, Alicia, Berstein, & Johnson, 1995; Clair, Berstein, Johnson, & Hoover 1993; Quinn, 2002; Stevens & Burt, 1999; Strong, 2000). Group drumming is social, and has been shown to enhance group cohesion (Camilleri, 2002; Longhhofer & Floersch, 1993; Stevens & Burt, 1997).

Finally, the benefits of participating in arts activities, including painting and sculpting, have been supported by a number of studies. As reviewed earlier (see Section 3.4, p. 63), carers reported positive outcomes of making various craft objects such as a Mandala and wall hanging, including lowered stress, reduced anxiety, and increased positive emotions (Walsh et al., 2004). Huxley (1997, as cited in Eades & Ager, 2008) reviewed the effects of an “arts on prescription” scheme, whereby GPs in the UK prescribed involvement in community arts programs to clients with mild to moderate depression and anxiety. After doing the arts programs, there was a significant reduction in the numbers of participants with recognisable mental health problems. As demonstrated in research performed at the Behavioural Medicine Clinic, Harvard University, the beneficial impact of artistic activity may be explained at the physiological level as it releases neurochemicals, including endorphins, into the brain. These neurochemicals assist deep concentration, slow down pulse and breathing, reduce blood pressure and boost the immune system through what is termed “The Relaxation Response” (Benson & Klipper, 2000). Research has shown that arts projects promote optimal “flow” experiences, involving absorption, control, skill use and development, clear goals, variety, and security, which combine to improve self-esteem (Reynolds & Prior, 2006).

The creative arts modalities included in the present leisure program were chosen based on the research previously described as well as on their anticipated novelty value. The following chapter details the conceptual frameworks which underpinned the development and implementation of the “Me Time for Mums” program, followed by the specific aims and hypotheses of the present evaluation study.

4.4 Conceptual Frameworks Underpinning the “MeTime for Mums” Program

The development of the “Me Time for Mums” program was based upon several conceptual frameworks, drawing on carers’ own self-reported concepts of leisure as well as theoretical models regarding the salutary functions of leisure.

4.4.1 Carers’ Conceptualisation of Respite and Leisure

The development of the “Me Time for Mums” intervention model was informed by subjective meanings of respite and leisure reported by carers in qualitative research. As opposed to providing a respite service, the program sought to evoke a respite *experience* free of “caring”.

In Bedini and Phoenix’s (2004) survey of 524 carers, leisure was most commonly defined as “unobligated time” (58%), “freedom from responsibility” (19%), “activity that was fun” (15%), and “state of mind” (8%). These descriptors were elaborated in Watts and Teitelman’s (2005) phenomenological study with 15 family carers of people with Alzheimer’s disease, which explored ways in which they achieved a “mental break” (defined as distinct periods of freedom from care-giving behaviour and concerns). They found that traditional respite services, temporary stress coping strategies, and social support were associated with, but not primarily responsible for, achieving a mental break. Similarly, personal attributes (e.g., having a positive attitude and humorous and playful disposition) and situation conditions (e.g., trust that the care-recipient is safe), while associated with being able to experience a period of time out, did not directly lead to a mental break. Instead, for carers in Watts and Teitelman’s study, the most proximal, causal ingredient of having a mental break was absorption in an activity. Small and simple pleasures and faith-based activities emerged as two distinct forms of absorbing activity. Small and simple pleasures were activities lasting up to 20 minutes, often characterised by enhanced sensory awareness (e.g., walking outside, watching birds, and playing with pet). Carers described how mental breaks

feel: “Freedom: you just forget about everything”; “you’re ready to go again”; “you can face the next challenge”; “what a lot of fun...a lot of laughs”; “I get rejuvenation and exhilaration”; “It’s a relief” (p. 287). Watts and Teitelman proposed that “...absorbing activities function as triggers that sever past emotional patterns (e.g., caregiving worries), permit respite from a stifling mental state or set patterns, and produce relaxation and a more serviceable, effective mental state...absorbing activities permit access to one’s natural healing, energising capacities” (p. 289).

The experience of “quality respite” was described by Strang and Haughey (1999) as a three phase cognitive journey towards a sense of “being free” based on their study of 10 carers of family members with dementia. The first stage is recognising the need to get out of the carer world, the second involves giving oneself permission to get away from caregiving responsibilities for a while, and the third is realising the availability and adequacy of social supports that would allow them to get away. The researchers developed an image of two “spheres of existence” (p. 5): The “caregiving world” was the dominant sphere, often threatening the existence of a smaller, but no less important sphere, where carers experienced “quality respite”. The predominant meaning of respite expressed by carers was “to be free”, encompassing being free to be themselves, to pursue their own interests, to not worry about their family member, and to not be in the role of carer.

The description of respite as a period of reprieve and freedom from the role of caregiver was again confirmed in Gahagan et al.’s (2007) qualitative study involving 17 focus group discussions with a diverse sample of 98 carers. This freedom was considered integral to maintaining a sense of personal identity for many participants, as exemplified by the following comment: “It’s really important that you don’t give up your own self...*Because it’s very easy to lose yourself in caregiving* (italics added).

You wonder who you are. But the more things you do that you enjoy for your own, helps” (Gahagan et al., p. 56).

These qualitative studies highlight the importance of several key aspects of respite for carers, all of which informed the development and delivery of the “Me Time for Mums program”. The quality of respite was more important than the duration. Achieving a restorative mental break through absorbing activities is within one’s control and can be practiced. Giving oneself permission to step outside the carer role, getting in touch with personal interests, and engaging in absorbing activities that are fun and sensorally stimulating, can provide a springboard to carers experiencing freedom and a sense of self beyond the carer role. However, as empirical research shows, carers face many constraints to leisure and may need external support to legitimise and cultivate an ethic of self-care in order to “exit” the caregiving sphere and immerse freely in leisure activities. The need to help carers break through patterns of activity restriction and access restorative leisure experiences, with the social legitimacy afforded through community programming, underpinned the development of the “Me Time for Mums” program.

4.4.2 Activity Restriction among Carers

As has been previously documented, carers are at risk of elevated depression symptoms and loss of personal leisure. The Activity Restriction Model (Williamson & Shaffer, 2000) poses that life stressors that result in restriction of normal or pleasurable activities will result in increased depressive symptoms.

Several studies have identified activity restriction as a key mediator of caregiver depression (e.g., Williamson, Shaffer & Schulz, 1998). One study of a sample of dementia caregivers found that reduced engagement in pleasurable activities was directly associated with greater depressive symptoms (Thompson et al., 2003). Reduced opportunities for socialising, personal self-care, and leisure activities were associated

with lower self-reported health (Keller & Tu, 1994, as cited in Dunn & Strain, 2001) and greater levels of global stress (Miller & Montgomery, 1990) among carers. Silliman (1993) found that carers reporting that caregiving had not restricted the amount of time they had for leisure activities were more likely to have good self-rated health. Similarly, Staight and Harvey (1990) found a significant negative relationship between depression scores and satisfaction with the amount of relaxation time for a primary carer group. In an often cited study on carers and leisure, White-Means and Chang (1994) tested a stress-process model using logistic regression, finding that the probability of high stress levels was 62% when the caregiver reduced personal free time. They concluded that denying oneself leisure time is likely to increase social isolation and stress, and reduce physical and mental well-being. Activity restriction and its detrimental impact can be easily identified among carers and this behooves making engagement in pleasurable activities a prioritised target for carer interventions. In focusing on fostering carers' engagement in fun and absorbing activities in a socially supportive setting, the "Me Time for Mums" program was considered a positive psychology initiative designed to promote the resilience and wellbeing of participants.

4.4.3 Positive Functions of Leisure Participation

Research about parents who have children with disabilities has shifted from being risk and deficit-oriented to investigating factors that promote coping, adaptation, wellbeing, and resilience (e.g., Dunst, Trivette, & Deal, 1994; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). The "Me Time for Mums" program was premised on "Salutogenesis" referring to a perspective where healthy aspects of functioning are emphasised instead of what causes sickness (pathogenesis). As Antonovsky (1987) noted, it is important to focus on possibilities in existence, rather than concentrate only on risks. Participating in creative arts and leisure activities offer many possibilities for carers to expand their frame of reference beyond the caregiving sphere. Numerous

important therapeutic functions are served through engagement in pleasurable activities and leisure.

In research with general population groups, leisure has been linked to coping, adapting to change, stress-reduction, and a variety of positive emotions, including optimism and subjective well-being (e.g., Diener, 2000; Folkman, 1997; Lykken, 2000; McCraty, Atkinson, Tiller, Rein, & Watkins, 1995). Furthermore, leisure and physical health are closely associated (e.g., Hartig, Evans, Jamner, Davis, & Garling, 2003; Ostir, Markides, Black, & Goodwill, 2000; Salovey, Rothman, Detweiler, & Steward, 2000). It is clear that leisure experience may serve as an important coping resource, though the precise mechanisms responsible for this remain unclear.

Early research concentrated on testing the stress-buffering hypothesis that leisure buffers the individual from negative effects of stress via the mechanisms of increased social support and perceived self-determination (see Iwasaki & Smale, 1998, for a review of this literature). While empirical research supports the buffering role of these two mechanisms (e.g., Iso-Ahola & Park, 1996), the literature remains ambiguous as to the reasons why this is the case, and some studies demonstrated equivocal findings in terms of the role of leisure-related factors in moderating the deleterious effects of stress. Furthermore, the stress-buffering hypothesis asserts that leisure buffers an individual experiencing high stress levels (Coleman & Iso-Ahola, 1993), while more recent research demonstrated that leisure mediated the impact of stress at all levels in terms of the effects of both the beliefs one has that leisure will promote coping and the leisure behaviours one performs (e.g., Iwasaki & Mannell, 2000a, 2000b). After reviewing the limitations of the leisure-as-stress buffer literature, Kleiber, Hutchinson, and Williams (2002) sought to formulate a more personalised and dynamic account of leisure-related coping and adjustment. They theorised that negative life events may

disrupt an individual's life narrative, and leisure may provide a mechanism through which that personal narrative is resolved.

Kleiber et al. (2002) distilled four main propositions explaining the functions of leisure and pleasant events in transcending negative life events, two related primarily to coping and two that identify the role of leisure in promoting adjustment through more profound processes of self-restoration and personal transformation. These four propositions neatly collate and extend previous theories and research regarding the benefits of leisure.

Proposition 1: "Leisure activities buffer the impact of negative life events by being distracting" (Kleiber et al., p. 225). Doing leisure diverts one's attention from difficult situations or negative feelings and supplants them with neutral or positive feelings, which may, in time, stimulate reappraisal of the situation in question. Distraction, "palliative escape", and gaining temporary distance from problems and concerns are all associated with doing leisure, as indicated by other leisure researchers, allowing "...people to feel refreshed and regroup to better handle problems" (Iwasaki, 2001, p. 131). Diverting attention to leisure activities can stimulate mood enhancement or the reduction of negative mood, enabling greater emotional regulation by individuals under stress.

Proposition 2: "Leisure activities buffer the impact of negative life events by generating optimism about the future" (Kleiber et al., p. 226). Through experiencing enjoyable states, a brighter future with new opportunities is more readily imagined. Leisure can open up the realm of possibilities, provide an emotional uplift, and facilitate perspective-taking and cognitive reappraisal of problems. According to the early work of Lazarus, Kanner, and Folkman (1980), leisure can engender "positively-toned emotions", such as enjoyment, excitement, hope, and challenge, which serve three main coping functions. They may provide a "breather" from stress as a result of

diverting attention away from the stress and focusing on pleasurable diversionary activities; they may function as “sustainers” and foster commitment to ongoing coping efforts in the face of extremely trying circumstances; and they may result in restoring self-esteem and hope for the future, and may promote the replenishing of depleted resources and/or the developing of new ones to aid in future coping. Folkman and Moskowitz (2000) speculated that experiencing positive affect in the context of chronic stress may serve to prevent clinical depression, and they cited evidence indicating that chronic stress and concomitant prolonged negative affect, without relieving experiences of positive affect, may overwhelm the regulatory function of emotion and result in clinical depression (Gross & Munoz, 1995, as cited in Folkman & Moskowitz, 2000).

In order to explain the reasons why positive emotions not only feel good, but aid coping, Fredrickson’s (2004) “broaden-and-build” theory suggests that positive emotions (including enjoyment, happiness, anticipation, and interest) broaden one’s awareness and habitual ways of responding, and encourage novel, varied, and exploratory thoughts and actions. Over time, this broadened cognitive and behavioral repertoire builds resources to cope in life. Positive emotions foster cognitive reappraisal and problem solving in times of stress, while negatively-toned emotions (e.g., anxiety) prompt narrow, immediate survival-oriented behaviors (e.g., “flight or flight” response). Fredrickson’s empirical research demonstrated the reciprocal relationship between positive affect and broad minded coping among undergraduates. In accordance with her theory, Fredrickson advocated psychosocial interventions designed to facilitate involvement in positive events that engender positively toned emotions. The potential of leisure to generate positive affect and therein promote coping underpinned the design and delivery of the “Me Time for Mums” program.

As Kleiber et al. (2002) suggested, beyond the function of coping in times of stress, leisure experiences may be self-protective in terms of both restoring an

individual's connection to valued aspects of their self-concept, and prompting consideration of "possible selves" (Markus & Nurius, 1986) towards self-expansion and transformation, as described in the next two propositions.

Proposition 3: "Leisure activities buffer the impact of negative life events by aiding in the reconstruction of a life story that is continuous with the past" (Kleiber et al., p. 228). Engaging in leisure can promote a sense of biographical continuity and coherence of self-concept and help individuals to reconcile and accept changes (e.g., role-related losses). Participation in leisure activities can remind people who are immersed in difficult situations that "all is not lost" and that they still have familiar avenues of generating meaning, interest, achievement, and enjoyment that allow them to "get back to normal". Leisure may provide a social space that keeps an individual connected to familiar others, thus maintaining social identity continuity and social reinforcement for valued aspects of one's self-concept.

Engaging in a repertoire of leisure activities would also contribute to self-complexity by providing varied contexts that arouse different aspects of self. Linville (1987) demonstrated that people who maintained more complex representations of self were less depressed in stressful circumstances than those who maintained less complex self-representations. Indeed, even relatively casual leisure activities have been found to be symbolically important to people when these activities enabled them to enact personal values and preserve or restore a sense of self beyond role-imposed limitations (Hutchinson & Kleiber, 2005).

Proposition 4: "Leisure activities are used in the wake of negative life events as vehicles for personal transformation" (Kleiber et al., p. 229). As well as promoting coping and identity-continuity, participation in leisure can promote adaptation to changed life circumstances. The development of new activity interests can encourage people to bring their attention to the present more fully, focusing on what the

environment affords, developing the skills necessary, and making full use of personal resources for positive adaptation. Realising that leisure and pleasant events are still possible despite restrictive life circumstances can be a source of enjoyment and pride. Notions of personal transformation through leisure raise questions about how to conceptualise the self that is being “transformed”. The development of the “Me Time for Mums” program was based upon a particular theory of selfhood in which the caregiver role, while often dominant in maternal primary carers, is one of many possible ways of positioning the self vis-à-vis others and the world.

4.4.4 Theory of Selfhood: The “Dialogical Self”

The raison d’être of the “Me Time for Mums” program was the invigoration of a lighter, playful, imaginative, and pleasantly engaged experience of self among mothers of children with a disability. This central aim was premised on a particular theory of selfhood formulated by Hubert Hermans and his associates in the Netherlands (e.g., Hermans, 1999, 2003; Hermans, Kempen, & Van Loon, 1992). Inspired by the writings of William James and Mikhail Bakhtin, they have written extensively on the concept of the “dialogical self”, in which notions of identity and self are decentralised and diversified. There is no one true, authentic self, but rather many self-aspects, referred to by Hermans as “I-positions”. The term “I-position” and its connotations of active “positioning” are used to express the theoretical idea that the I can move from one I-position to another I-position in accordance with changes in situational context and time. Indeed, the “I” can fluctuate “...among different and even opposed positions” (Hermans, 1999, p. 72). In dialogical self theory, the mark of a healthy self-system is the ability to move flexibly from one I-position to another in tune with the heterogeneous contexts one operates in, while at the same time, maintaining a sense of an “I” that has agency and continuity through space and time. The dialogical self straddles the dialectic between unity and diversity, discontinuity and continuity.

The “dialogical self” has been defined as “... a dynamic multiplicity of relatively autonomous I-positions” or as aspects of self that each have their own autonomous voice and own narrative in the “society of mind” (Hermans et al., 1992, p. 28). Different internal self-aspects, other external individuals, external groups, and larger structures, can all be incorporated as I-positions in the mini-society of the self. The self is embedded “...in a dialogic process that continually shapes and reshapes the self and other” (Barge & Little, 2002, p. 383), rather than a fixed or determined entity.

The dialogic character of self and group identity means that we typically discover “...who we are by addressing ourselves to others or the voices of others within us” (Murchison, 1998, p. 465). The “interlocutors” of the “dialogical self” are infinite, including voices within the self and voices of other people, whether actual, imaginary, or implied. The self is formed continuously through intrapersonal and interpersonal dialogue. Intrapersonal dialogue has also been referred to as self-talk and inner speech. The dialogue may serve multiple functions, including self-consolation, self-reassurance, self-denigration, self-aggrandising, self-healing, and self-rationalising, among many others.

At times the interlocutors may pull the self in different directions, and at the same time forces of integration pull the self into unity. Disorder and dysfunction can result from the restriction of I-positions and narratives, such that dialogue is constrained or repetitive. Relevant and salutary voices may not get an opportunity to be heard if the voices of dominant I-positions are too loud, as appears to be the case for many women whose main role is primary caregiver.

Through a variety of case studies, Hermans appears to advocate creatively “playing” with different I-positions, and experimenting with neglected and new positions and their associated thoughts, sensations, behaviours, and emotions (e.g., Hermans, 2003; Hermans & Hermans-Jansen, 1995). Through cycles of positioning,

counter-positioning, and repositioning, the dialogical self moves and grows. When previously conflicting I-positions have a dialogue with each other to form a new positive collaboration, when background positions move into the foreground, when new positions gain a voice and engage in dialogue, and when old dominant positions are challenged, the self-system can improve in its overall functioning.

Of particular interest to the present study is the case study of Richard who, at the time of the research, was 38 years of age and suffering due to indecision, unsatisfying work, and an overall sense of shame, guilt, and doubt about his own qualities and about his life as a whole (Hermans, 2003). Through the process of exploring Richard's self system in psychotherapy, Richard recognised that the "I-as-perfectionist" position was the most dominant position in his self-system. To destabilise the dominance of the perfectionist and the crippling impact of his unattainable standards, the therapist set out to introduce a new position into Richard's repertoire of I-positions. This was done through proposing that Richard engage in "innocent" pleasurable activities (including running, cycling, and watching birds) "...which were, in the eyes of the perfectionist, scarcely noteworthy... somewhere beyond the reach of the dictatorial perfectionist" (Hermans, 2003, p.118).

Two weeks later, Richard reported mood improvement and reported that participation in these activities stimulated moments in which he could accept the possibilities he had: "In these activities, not much progress is needed, there is less self-blaming and there are far fewer obstacles, and less energy is spoiled". He continued: "By this acceptance, I experience somewhat more lightness in my existence. I often continue to ruminate, yet I have created some islands of well-being" (p. 119). These pleasurable leisure activities created a new context ("islands of well-being") which liberated Richard from permanent feelings of obligation and never feeling good enough. Doing these pleasurable activities facilitated the innovation of a new I-position,

which Richard called “I-as-accepting”. This I-as-accepting position interrupted the self-blaming dialogue that was being fuelled by the dominance of the I-as-perfectionist position. The introduction of the I-as-accepting position changed Richard’s dialogical activity and as a result he reported a changing view of himself, as he provided the following feedback to his therapists: “You accept me, and that’s okay; I pick up ordinary activities and you agree with that; there is not the pressure to take it very seriously. And these activities work. They provide an antidote to my self-image. *I make space* for doing these things and also my friends give me that space. This also liberates me from isolation” (p. 119).

These outcomes of Richard’s therapeutic experience paralleled the aims of the “Me Time for Mums” program, which was designed to provide a novel “island of wellbeing” for the repositioning of the self from the dominant “I-as-caregiver” position to experiment with the “I-as-leisure seeker” and “I-as-self-carer” positions in a socially supportive setting. In Hermans’ theory of I-positions, the focus on developmental end states (such as integration or competence) give way to a more process-oriented notion of giving space, time and voice to varied parts of self. Over-identification with roles such as caregiver limits a person’s range of social contexts and relationships, therefore limiting potential dialogues and, consequently, restricting the emergence of varied I-positions. The “Me Time for Mums” program aimed to provide a creative and social context, and a supportive structure for participants to temporarily let go of ordinary identifications and roles and engage in playful re-positioning, experiencing themselves through an expanded repertoire of I-positions.

An important caveat to the rather ambitious aim of encouraging participants to invigorate I-positions on the “lighter side of life” is the power-laden nature of processes taking place between I-positions at the intrapersonal level. In particular, I-positions that are heavily infused with normative social expectations, which are frequently reinforced

by others, are especially power-laden and harder to shift out of. Through socialisation into the normative feminine “good mother” and “good woman” nurturing roles, women may be more prone to judging themselves on the basis of their relations with others and the degree of nurturance and support they provide. As Markus and Nurius (1986) attested, “Possible selves thus have the potential to reveal the inventive and constructive nature of the self but they also reflect the extent to which the self is socially determined and constrained” (p. 954).

Given that carers are typically pressured and preoccupied, it was deemed important to provide activities that were novel and interesting to immediately “grab” participants’ attention. It was hoped that the slightly “off-beat” and playfully challenging activities would require all of participants’ attention and skills, so that no attention would be left to process concerns. In the words of Csikszentmihalyi (2002), the selection of activities and delivery of sessions was geared towards encouraging optimal “flow” experiences, as described in the next section.

4.4.5 Leisure and “Flow” Experiences

Many leisure researchers have adopted Csikszentmihalyi’s (2002) theorising about “flow” to explain the relationship between enjoyment and leisure. Csikszentmihalyi proposed that when people engage in activities that are intensely absorbing, and where there is a match between the demands of the activity or environment and someone’s skills, then an optimal experience of flow is most likely to manifest. Flow describes a state “...in which people are so involved in an activity that nothing else seems to matter: the experience itself is so enjoyable that people will do it for the sheer sake of doing it” (Csikszentmihalyi, p. 4). In the flow state, challenge and skill are balanced, concentration is focused, there is deep involvement or absorption, with a sense of being able to exercise control over one’s actions, a lack of concern about failure, and a sense that the activity resonates with one’s “true self” (Csikszentmihalyi, 2002).

This intense absorption can result in a disappearance or suspension of concern for oneself: “One acts with a deep but effortless involvement that removes from awareness the worries and frustration of everyday life” (Csikszentmihalyi, 2002, p. 49). The temporary loss of self-consciousness can result in the loss of the sense of a self separate from the world around it, accompanied by “...feeling of union with the environment...” (Csikszentmihalyi, p. 63). According to Csikszentmihalyi, the sense of self emerges stronger after the flow experience is over as it has taken in and engaged directly with more of life. The state of absorption characteristic of flow resonates with carers’ own definitions of “quality respite”, particularly Watts and Teitelman’s (2005) finding that absorbing activities provided a direct springboard to achieving a mental break from caregiving concerns. Lastly, while in flow, the sense of the passage of time is altered; hours pass by in minutes and minutes can seem like hours. The combination of all these elements is tantamount to the “optimal experience” of flow in which activity participation is autotelic, or rewarding in and of itself, and deeply enjoyable.

In designing the “Me Time for Mums” program, the researchers were conscious to include activities, such as belly dancing, group drumming, and improvisational Theatresports games that would likely be novel and slightly risky or challenging to participants. These activities were hypothesised to be likely to captivate participants’ attention, diverting it from worries and concerns. The activities in each creative arts session were structured (i.e., were clearly explained, with clear goals and clear time frames, and challenges matched to skill), leaving little opportunity for participants to feel threatened. Structuring the activities aimed to promote a present-focused and ordered state of mind that is highly enjoyable (Csikszentmihalyi, 2002). Furthermore, the challenges that the creative arts activities presented were distinct from those presented by their caregiving role, and were chosen with the aim of engendering

stimulation and bringing interest into daily life but also because, unlike the unpredictable nature of caregiving, they could be mastered in just a single session.

In providing a creative context, fostering a spirit of playfulness and experimentation was considered paramount. The main way in which this was attempted was to offer the chance for participants to *play* with a smorgasbord of new activities without any evaluation of creative products. Carl Jung once asked, “The small boy is still around, and possesses a creative life which I lack. But how can I make my way to it?” (Jung, 1965, p. 174). He subsequently learned that a key to unlocking his creative potential was to engage in the constructive play he had particularly enjoyed as a child. Furthermore, through offering opportunities for creative play, fun and social connections, the program aimed to broaden participants’ sense of self, as captured by Winnicott’s connection between play, creativity and identity:

It is in playing and only in playing that the individual child or adult is able to be creative and to use the whole personality, and it is only in being creative the individual discovers the self. (Winnicott, 2005, p. 73)

The program was constructed to promote flow through attempting to fulfill the flow-promoting conditions specified by Csikszentmihalyi (2002). The “umbrella” goal of the program, as conveyed to participants in the introduction to the program (see “Setting the scene” in Appendix J), was to suspend, as much as possible, ordinary life concerns and create a space for creativity and enjoyment. Each facilitator provided a clear introduction, specifying activity goals for the session, and providing clear, consistent, and encouraging feedback.

4.4.6 Leisure as Contributing to Identity Development

Eudaimonistic identity theory provides a useful framework for understanding self-discovery and identity development through activity participation. This theoretical framework proposes that individuals recognise elements of their best potentials or

“daimon”, through participation in identity-affirming activities (see Waterman, 2004 and Schwartz, 2001, for more detailed reviews of eudaimonistic identity theory).

Personally salient identity-related activities help an individual to clarify their beliefs, values and goals, and select activities that give direction and meaning to life.

Eudaimonism is an ethical theory which calls upon individuals to recognise and strive to realise their true potentials, thus furthering one’s purposes in living. Eudaimonic happiness connotes human flourishing and self-actualisation, as differentiated from hedonic enjoyment, which connotes a short term state of pleasure and feeling good (Waterman, Schwartz, & Conti, 2008).

In the eudaimonistic identity framework, identity work occurs through experimentation with different activities to discover the ones that provide an individual with three key subjective, identity-promoting experiences (Waterman, 1992, 2004). The first experience is “personal expressiveness”, which involves the perception of a good fit between elements of the activity and an individual’s interests, talents, and potentials (Waterman, 1992), such that the individual experiences feelings of intense interest and involvement, with a sense of “being where one wants to be, doing what one wants to do” (Norton, 1976, as cited in Waterman et al., 2003, p. 1449). The second key experience is the flow experience, as previously described. Flow experiences are thought to be autotelic or self-reinforcing and are thought to contribute to identity development via increasing intrinsic motivation (Waterman, 2004) and motivation to seek out and create leisure opportunities that match growing level of skill with the appropriate level of challenge (Csikszentmihalyi, 2002). The third identity-related experience is goal-directed behaviour in activities. Setting goals and striving to reach them are important elements of initiative (Larson, 2000). The presence of goal-directed behaviours indicates that an individual is developing commitments to personally salient identity-related activities. Conceptually, these three experiences (personal

expressiveness, flow experiences, and goal-direction) can occur in a variety of activities. However, some activities have been found to be more generative of identity-affirming experiences than others, such as activities that are creative, pro-social, active, and structured (Csikszentmihalyi, 2002; Waterman, 1990).

Research on activity participation as a context for identity work mainly involves adolescents and emerging adults (e.g., Eccles & Barber, 1999; Fredricks et al., 2002; Hansen, Larson, & Dworkin, 2003; Waterman, 1990). Leisure activities have been described as a prime context for adolescents to discover interests and nurture their personal identity (Waterman, 1990). The present “Me Time for Mums” program started from the premise that identity development is a life-long process, and that leisure activities should be considered crucial in this ongoing development.

Given that carers commonly report role-engulfment and reduced opportunities to pursue identity-affirming leisure activities, the eudaimonistic identity theory conceptually underpinned the development of the program. Specifically, through creative, pro-social, and structured activities, the program sought to maximise opportunities for participants to experience personal expressiveness, flow, and an increased motivation and willingness to set leisure goals. The specific aims and hypotheses of the present “Me Time for Mums” evaluation study are outlined in the next chapter.

4.5 Aims and Hypotheses of the “Me Time for Mums” Program Evaluation Study

In light of the generally positive outcomes of leisure programs for carers and the abovementioned theories regarding the salutary functions of leisure, the following aims and related hypotheses were formulated regarding outcomes of participating in the “Me Time for Mums” program.

The “Me Time for Mums” program aimed to positively affect participants’ mood, wellbeing, and sense of lifestyle balance. Compared to a waiting-list control

group, it was hypothesised that the two intervention groups (P⁺ and P group)³ would report greater positive changes ensuing from the program across a number of domains, including mood and wellbeing, attitudes towards engaging in personal leisure, leisure motivation and behaviour, social support, and life satisfaction.

It was hypothesised that participating in the program would result in significantly greater positive changes to self-reported personal wellbeing, positive affect, depression, anxiety, stress, and tiredness levels compared to waiting for the program.

The program sought to provide an opportunity for participants to develop social connections and broaden their social support network through engagement in shared creative leisure activities. It was hypothesised that participation in the program would lead to significantly greater positive changes in self-reported use of leisure-companionship as a coping strategy compared to waiting for the program.

In providing a structured time and space for personal leisure away from children and caregiving-related issues, the program aimed to improve participants' sense of balance and perceived satisfaction with their lifestyle. Accordingly, it was hypothesised that participation in the program would result in significantly greater positive change in participants' self-reported satisfaction with basic needs in general and greater perceived fulfillment with activities of daily living compared to waiting for the program.

In providing a socially validated space dedicated to leisure and self-care, and facilitating enjoyable engagement in leisure activities, the program sought to effect a positive change in participants' attitudes to doing leisure and creative activities. Specifically, it was hypothesised that participation in the program would result in significantly greater positive changes in self-reported awareness of the benefits of doing

³ The P⁺ group completed the "Me Time for Mums" leisure program *and* the pre-program narrative-based self-investigation. The P group completed the leisure program only.

leisure and risks of not doing leisure, intrapersonal constraints to pursuing leisure, and motivation to participate in leisure compared to waiting for the program.

Lastly, this program evaluation study sought to explore whether participating in a short leisure program would lead to increased participation in leisure and increased awareness of types of leisure activities that participants would be interested in pursuing in their daily lives.

“Me Time for Mums” aimed to provide participants with the opportunity to broaden their sense of identity beyond the caregiver role and regain a sense of freedom from role obligations and concerns. It aimed to encourage participants to give themselves permission to engage in leisure and self-care, and connect to personal strengths and interests that strengthens their sense of personal identity and future possibilities.

Given the function of the pre-program self-confrontation intervention in terms of encouraging participants to consciously invigorate aspects of self other than the caregiver position, an exploratory research question was posed as to whether the P⁺ group would report greater benefits from the program compared to the P group and if so, what these differences would be. The two intervention groups were compared on both quantitative outcome variables and reporting of perceived program outcomes and processes in the post-program follow-up interviews. These comparisons aimed to provide insight into whether adding a cognitive/affective intervention to the delivery of an experiential leisure program would augment positive program outcomes, and therein add value to the implementation of future carer-specific leisure programs.

CHAPTER 5: METHODOLOGY USED TO DEVELOP AND EVALUATE THE “ME TIME FOR MUMS” PROGRAM

5.1 Inclusion Criteria for Participants

The following entry criteria were required for inclusion in the “Me Time for Mums” program: a) Mother and primary carer of a child with a physical, mental, intellectual disability, illness or condition; b) Spends 40+ hours caregiving per week; c) Has been a primary carer for at least six months; and d) Reports below-average wellbeing, operationalised as a standardised score of between 50-70 on the Personal Wellbeing Index (PWI; International Wellbeing Group, 2006).

5.1.1 Why Mothers?

The preponderance (92%) of primary carers of children with a disability in Australia are women (ABS, 2004). As reviewed in the introduction, ample research shows that mothers of children with a disability are an “at risk group” on a variety of psychosocial indicators, including stress, depression, social isolation, fear, anger, sadness, anxiety, psychosomatic symptoms, restrictions of roles and activities, strain in marital relationships, and diminished physical health (e.g., Emerson, 2003; Nachshen & Minnes, 2005). Furthermore, maternal primary carers have been singled out as being a high risk group for loss of leisure (Bedini & Phoenix, 2004). Groups were also limited to mothers in order to enhance the potential for social identification and group bonding, and reduce subject variability in outcome analyses.

5.1.2 Why a Minimum of 40 Hours Caring per Week?

In his review of the subjective wellbeing of carers of people with severe disabilities, Cummins (2001) stated: “...there is a ceiling effect such that once the level of care required is substantial, the difference between the forms of disability become relatively trivial in terms of their impact on family functioning” (p. 91). Thus, in the present research, eligibility criteria were not based on the nature of the child’s disability, but rather on the basis of being the primary carer, and contributing a

minimum number of 40 hours per week caregiving. This number was drawn from results of the Survey of Disability, Ageing and Caring which revealed that over half of primary carers of children with a disability in Australia were spending more than 40 hours a week providing care for their child (ABS, 2004).

5.1.3 Why Caregiving for More Than Six Months?

The commonly used definition of a “primary carer” in Australia includes performing the role for at least six months (ABS, 2004), therefore this criterion was employed. Mothers of children with disabilities in the role of primary carer for less than six months (i.e., immediate post-diagnostic period) are also likely to be experiencing emotional reactions that are different to carers who have been in the role for a longer period of time. To minimise this potential source of subject variability, only carers performing the role for more than six months were included.

5.1.4 Why Focus on Participants who have Personal Wellbeing Index

Scores of 50-70?

The normative wellbeing level in Australia, using mean Personal Wellbeing Index (PWI; International Wellbeing Group, 2006) scores as data (standardised to a 0-100 scale) is 75.03, with a normative range of 73.6 to 76.5 (Cummins et al., 2008). Participants were considered eligible for this pilot program if their PWI score was below the normal range, thus indicating a need for increased wellbeing (i.e., between PWI = 50-70), but not so low as to suggest depression (i.e., PWI < 50; R. Cummins, personal communication, September 6, 2006). Prior caregiver intervention research cautions against including participants demonstrating high levels of depression due to risk of attrition, difficulty connecting to other group members, and difficulty experiencing pleasure in a leisure intervention (e.g., Buckwalter et al., 1999; Hutchinson, Bland, & Kleiber, 2008). In addition, selecting participants below the normative wellbeing range provided more scope for the measurement of change,

compared to participants in the normal range (i.e., who arguably have less room for improvement). The decision to include participants with a PWI score between 50 and 70 was reached through discussions with the researchers and Professor Cummins at Deakin University, who has been involved in every stage of developing and using the PWI.

5.2 Participants for the “Me Time for Mums” program

The program was advertised via direct referral, mail-outs, newsletter advertisements, flyers (Appendix D), and awareness raising at several parent-to-parent support groups in Melbourne. The student researcher provided program information to case-workers from various disability and carer specific organisations (including Carers Victoria, Autism Victoria, Autism Action, Association for Children with a Disability, Downs Syndrome Association, and Scope, among others) so that they may inform and refer maternal carers to the program. Flyers were distributed to caregivers attending parent support network meetings around Melbourne, and via mail-outs to members of Carers Victoria, the Inner East parent support network, the Eastern Region Parent Support Network, and Extended Families Australia. Flyers for the program were pinned on notice boards at various early intervention centres, caregiver conferences, libraries, disability organisations, and at the program venue (Hawthorn Community House). An advertisement for the program was published in the newsletters of several disability and carer support organisations. Additionally, several individuals who participated in the Caregiver Leisure Attitudes Scale pilot study provided their details so that the researcher could contact them for later inclusion in the program. One participant in the first group wrote an article about the program which was published in “The Bugle”, a magazine produced by Uniting Care Community Options, in order to raise awareness and encourage other women to participate (Appendix E). Most participants (15/20) were referred to the program by a personal contact (case-worker, support group

facilitator, or another program participant), indicating that, for new pilot interventions, word of mouth tends to be the most effective method of recruitment.

Initially 20 mothers caring for a child with a disability enrolled in the program. One participant was not considered eligible to participate due to scoring below 50 on the PWI. In the P⁺ group group, one participant attended the first session and could not continue participation due to her child's condition deteriorating, which necessitated a higher level of care. Another participant attended three of the five sessions, missing two sessions due to unexpected complications with her child, and on the other occasion, due to her own illness (flu). In the P group, two participants attended four out of the five sessions, missing one session each due to unexpected issues with their children (illness unrelated to the nature of the disability and last-minute problems with respite care arrangements). Only participants attending all sessions were included in the evaluation, leaving 16 participants (two groups of eight participants) who could provide valid data for the purposes of program evaluation.

Participants ranged in age from 30 to 58 years ($M = 42.75$; $SD = 7$). Age of the child (care recipient) ranged from 1 to 23 years ($M = 10.23$; $SD = 7.01$) with 9 children ≤ 10 years old and 7 children between 11 and 23 years of age. Participants reported caring for a child with a disability for between 1 year and 23 years ($M = 11.22$ years; $SD = 6.40$). The majority of participants (11; 68.75%) were married, and a minority were divorced (3; 18.75%), defacto (1; 6.25%) or in a relationship but not living with their partner (1; 6.25%). Most participants had completed high school and some form of tertiary study, including TAFE (6; 37.5%), university undergraduate (4; 25%); AND university postgraduate (5; 31.25%). Only one (6.25%) participant reported educational attainment below year 10 level. Most participants were full-time parents/caregivers (10; 62.5%), while others were employed on a casual or part time basis (4; 25%), involved in voluntary work (1; 6.25%), and studying (1; 6.25%). Participants were from diverse

cultural backgrounds, including Anglo/Celtic (9; 50%), Chinese (1; 6.3%), Indian (1; 6.3%), Italian (1; 6.3%), Eastern European (1; 6.3%), Cambodian (1; 6.3%) and Other non-specified (2; 12.5%) backgrounds, reflecting the cultural diversity of Melbourne, a cosmopolitan city of more than three million people. Gross annual income ranged from under \$10,000 (2; 12.5%), between \$20,000-40,000 (6; 37.5%), between \$40,000-60,000 (2; 12.5%), between \$80,000 – 110,000 (3; 18.8%) to \$120,000+ (3; 18.8%). Participants reported between 40 hours and 160 hours of care-giving per week ($M = 92.8$ hours; $SD = 41.12$) and between 0 to 1.5 hours of leisure per day ($M = .76$ hrs (45 minutes); $SD = 0.86$).

5.3 Design of the “Me Time for Mums” Evaluation Study

Program evaluation employed a matched-groups, controlled quasi-experimental design and encompassed quantitative and qualitative data collection procedures. All participants completed the following evaluation tools: (a) Pre- and post-program questionnaire pack, completed within one month before and one month after program completion (Appendix H); (b) Post-session feedback questionnaire, completed immediately after each weekly session (Appendix K); and (c) Post-program telephone follow-up interview, delivered three months after completion of the program (Appendix L).

Participants were randomly assigned into two groups after matching them on depression scores using the Depression, Anxiety, and Stress scale short-form (DASS-21; Lovibond & Lovibond, 1995). One group completed the program (from 18th July to 15th August 2007), while the other group acted as a waiting-list control group, and then later completed the program (from 22nd August to the 19th September 2007). The three resulting groups are as follows: (a) “Control”: Subjects in the waiting list control group were asked to maintain their routine activities and not initiate any new recreational activities for the duration of the length of the program. Control subjects were tested at

time-matched points (baseline and five weeks) to correspond with the data provided by those in the intervention groups; (b) “P⁺” completed the “Me Time for Mums” program *plus* a pre-program intervention (see Chapter 6 for a description of this intervention); (c) “P” completed the “Me Time for Mums” program only (previously wait-list control group). Sessions took place over five consecutive Wednesdays from 10am to 12 noon, followed by a light lunch which provided an opportunity for participants to talk and form informal support networks.

5.4 Quantitative Evaluation Measures

5.4.1 Demographic Variables

A demographic information form was developed for this study. Background demographic data included age, ethnic/cultural background, relationship status, education, employment status, gross income, years as caregiver, hours caregiving per week, and hours of leisure per day.

5.4.2 Depression Anxiety Stress Scale – Short Form (DASS-21)

The DASS-21 is a short form of Lovibond and Lovibond’s (1995) 42-item DASS. Respondents use a four-point Likert-type scale ranging from 0 (“did not apply to me at all”) to 3 (“applied to me very much or most of the time”) to rate the extent to which they have experienced symptoms of depression, anxiety and stress over the past week. Each subscale comprises seven items, such as “I felt I wasn’t worth much as a person” (Depression), “I was aware of dryness of my mouth” (Anxiety), and “I found it difficult to relax” (Stress). Subscale scores range from 0 to 21, with higher scores indicating increased psychological distress. Reliability, assessed using Cronbach’s alpha, has been shown to be acceptable for all three scales in both clinical and non-clinical samples (Antony, Bieling, Cox, Enns, & Swinson, 1998; Brown, Chorpita, Korotitsch, & Barlow, 1997; Henry & Crawford, 2005; Lovibond & Lovibond, 1995).

For the present sample of participants, internal consistency was adequate: Depression (Cronbach's $\alpha = .78$), Anxiety (Cronbach's $\alpha = .78$), and Stress (Cronbach's $\alpha = .77$).

5.4.3 Personal Wellbeing Index - Adult (PWI-A, 4th edition)

The PWI (International Wellbeing Group, 2006) is a life domain measure of subjective wellbeing. Respondents use an 11 point Likert-type scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied) to rate satisfaction right now across eight life domains: Standard of living, personal health, achievement in life, personal relationships, personal safety, community-connectedness, future security, and spirituality and religion. Satisfaction scores from all domains are summed to produce a personal wellbeing index score ranging from 0-70, which is then typically standardised on a 0-100 point scale, with higher scores indicative of higher subjective wellbeing. Extensive psychometric analyses have shown the PWI to be a valid and reliable instrument with adequate internal consistency (Cronbach's alpha varies between 0.70 and 0.80 across diverse population sub-groups; Cummins et al., 2004). Good internal consistency was found for the present sample (Cronbach's $\alpha = .81$).

5.4.4 Four Dimensional Mood Scale

Recent research indicates that affect is best measured using four mono-polar dimensions of affect: high positive affect (or "positive energy"), low positive affect (or "Tiredness"), high negative affect (or "Negative activation"), and low negative affect (or "Relaxation") rather than a bipolar scale (positive and negative affect, as used in the PANAS; Watson, Clark, & Tellegen, 1988). The present research used a selection of 20 adjectives from the list of 60 adjectives covering the four dimensions of affect provided in the appendix of Huelsman, Nemanick, & Munz's (1998) study. Participants were asked to rate to what extent the adjective reflected the way they have been feeling on a 5-point Likert-type scale from 1 (very slightly or not at all) to 5 (extremely) over the last week. Five adjectives were chosen to measure each of following dimensions of

affect: Positive energy (active, interested, alert, inspired, strong); Tiredness (drained, worn out, bored, numb, dull); Negative activation (nervous, irritable, distressed, upset, guilty); and Relaxation (calm, pleased, restful, peaceful, and contented). Subscale scores range from 5 to 25, with higher scores indicating greater experiencing of that mood dimension. Internal consistencies were reasonably low for the present sample across the four mood dimensions: Positive energy (Cronbach's $\alpha = .55$), Tiredness (Cronbach's $\alpha = .70$), Negative activation (Cronbach's $\alpha = .30$), and Relaxation (Cronbach's $\alpha = .64$). Reliability analysis revealed that by eliminating the adjective "inspired" from the Positive energy subscale, the internal consistency increased (Cronbach's $\alpha = .67$). Eliminating the adjective "drained" increased the internal consistency of the Tiredness subscale (Cronbach's $\alpha = .72$). The internal consistency of the Negative activation subscale could not be improved substantially by altering items therefore this subscale was not included in the present study. Lastly, the internal consistency of the Relaxation subscale could not be further improved by altering the items in the subscale, however it was retained given that Cronbach's alpha was adequate ($\alpha = .64$).

5.4.5 Leisure Coping Strategy Scale (LCSS)

The LCSS (Iwasaki & Mannell, 2000) measures the extent to which leisure pursuits specifically help people cope with stress. It incorporates three subscales: Leisure companionship, leisure palliative coping and leisure mood enhancement. The leisure companionship subscale was used in the present research to measure the degree to which participants were accessing social support in their leisure pursuits. The subscale consists of six items (e.g., "My leisure allowed me to be in the company of supportive friends") and is measured using a 7-point Likert-type scale from 1 (very strongly disagree) to 7 (very strongly agree). Items are summed to form a scale ranging from 6-42, with higher scores indicating a greater sense of leisure-generated social

support. The scale has previously demonstrated adequate internal consistency ($\alpha = .87$) and validity (Iwasaki & Mannell). Internal consistency was lower, though still adequate, for the present sample (Cronbach's $\alpha = .72$).

5.4.6 Caregiver Wellbeing Scale – Shortened Version

The full version of the Caregiver Well-Being Scale (Tebb, 1995) is a 45-item scale which measures caregiver wellbeing from a strengths-based perspective and has demonstrated good reliability and validity (Berg-Weger, Rubio, & Tebb, 2000). A shortened 22-item version of the scale was used in the present study. Items were selected on the basis of high factor loadings as reported by Tebb (1995) and face validity for the purposes of the present “Me Time for Mums” program evaluation. Items are measured on a 5-point Likert-type scale measuring level of satisfaction from 1 (rarely) to 5 (usually) and summed to form two subscales (which were also in the original scale): Basic Needs comprises 10 items (e.g., “Feeling loved”, “Having time for recreation”) and Activities of Living comprises 12 items (e.g., “Relaxing”, “Exercise”). Subscale scores range from 10-50 for Basic needs and from 12-60 for Activities of living, with higher scores indicating greater satisfaction. In the present study the subscales demonstrated good internal reliabilities: Basic needs (Cronbach's $\alpha = .81$) and Activities of living (Cronbach's $\alpha = .84$).

5.4.7 Caregivers' Leisure Attitudes Scale (CLAS)

The CLAS is a 23 item scale measuring respondents' perceptions of the following factors: Risks of not doing leisure (e.g., “My psychological wellbeing is sacrificed if I do not take any time out for self-care”), Benefits of doing leisure (e.g., “I believe that doing leisure activities can allow me to gain a fresh perspective on my problems”), Intrapersonal constraints to leisure (e.g., “I would feel guilty if engaged in leisure”), Interpersonal constraints to leisure (e.g., “I would do more leisure but I don't have companions to do things with”) and Motivation to increase leisure (e.g., “I don't

take much ‘me time’ at the moment, but intend to take more in the next month”). The researchers constructed this scale given the lack of caregiver-specific leisure attitude scales. Items are rated on a 7-point likert-type scale from 1 (strongly disagree) to 7 (strongly agree). Scores on each subscale range from 7-35, except for the Motivation subscale which ranges from 3-21. The subscales have good internal consistency in the present study: Risks (Cronbach’s $\alpha = .89$), Benefits (Cronbach’s $\alpha = .88$), Intrapersonal constraints (Cronbach’s $\alpha = .82$), Interpersonal constraints (Cronbach’s $\alpha = .78$), and Motivation (Cronbach’s $\alpha = .78$). The pilot study, which forms the first part of the present research, also indicates preliminary evidence of convergent and criterion validity (see Chapter 1, sections 1.7 and 1.8, pp. 18-24).

5.5 Qualitative Evaluation Measures

5.5.1 Post-Session Feedback Questionnaire (Appendix K)

A short questionnaire was designed to record participants’ feedback immediately after the session by asking them to rate the following: The degree to which they “got into” (i.e., felt absorbed in) the activities during the session, degree of enjoyment in the session, and the likelihood that they will incorporate something from the session into life outside the program. Participants were asked to identify the most enjoyable parts of the session and identify what they would do differently if they organised this session, with space provided for any further comments.

5.5.2 Follow-up Telephone Interview (Appendix L)

Three months post-program, follow-up interviews were conducted to investigate (a) perceptions of the effects of the program (attitudinal, affective, and behavioural), (b) perceptions of the program processes contributing to these effects, (c) perceived leisure constraints, and (d) suggestions for improvements to the program.

5.6 Procedure for “Me Time for Mums” Implementation and Evaluation

The project was approved by the Swinburne Human Research Ethics Committee. The student researcher attended meetings with the manager of Hawthorn Community House (HCH), a non-profit organisation, and organised a collaboration which provided a venue for the program (large room at the back of HCH) and the opportunity to apply to philanthropic trusts for funding. Two of the six funding submissions were successful; The Hawthorn Community Chest donated \$1695 and the Helen Macpherson Smith Trust donated \$2695, which fully covered the costs stipulated in the program budget (Appendix I). As the auspicing organisation, the Manager of HCH was responsible for dispensing the funds received.

Participants registered their interest in participating by contacting the student researcher by phone or email. A registration form (to gather contact details and ensure that participants would be available to start the program at either one of two possible time points) was completed and sent by prospective participants via email, post, or phone. The student researcher phoned each prospective participant to answer any questions about the program and offer them the chance to receive funding to cover respite care, other childcare costs, and transportation to the venue where needed. Participants were informed that a pre-program questionnaire package would need to be completed two weeks prior to the start of the program to assess their eligibility to participate. This package contained a detailed information sheet (Appendix F), consent form (Appendix G), pre-program questionnaire pack (Appendix H), and reply paid envelope with the request to send the questionnaires back to the researchers at least two weeks prior to commencing the program. Without informing participants, the researchers matched participants according to their depression scores prior to random assignment into two groups.

For those participants assigned to the program plus pre-program intervention group (P⁺), the student researcher arranged to meet with participants individually for one to one and a half hours at their home at a convenient time (see Chapter 6 and Appendix M for detailed information about the nature of the pre-program intervention). After the interview session, the student researcher arranged a second meeting time for the following week to provide feedback and have a brief discussion about the results of the interview. These two meetings constituted the pre-program intervention and occurred in the two weeks prior to the start of the program. Those assigned to the program-only group (P) waited for five weeks (Control group) and then completed the program. For a schematic overview of the procedure and groups, see Figure 2. For a detailed description of the “Me Time for Mums” program, including facilitating and promoting attendance, weekly session activities, and the way that participants were oriented to the program, see Appendix J.

One month after program completion participants completed the quantitative questionnaire pack, which was identical to the pre-program questionnaire pack, with the only difference being that participants only responded to demographic questions that had changed since completing the pre-program questionnaire. A research assistant was employed using the remaining funds for the purpose of conducting the follow-up telephone interviews with participants three months post-program completion. It was deemed necessary to have a non-familiar researcher, external to the program, to conduct the follow-up interviews in order for participants to feel comfortable to provide honest feedback about their experiences during and appraisal of the program. The research assistant transcribed the taped telephone interviews and co-analysed the data with the student researcher to ensure consensual validation at every stage of the qualitative analytic process.

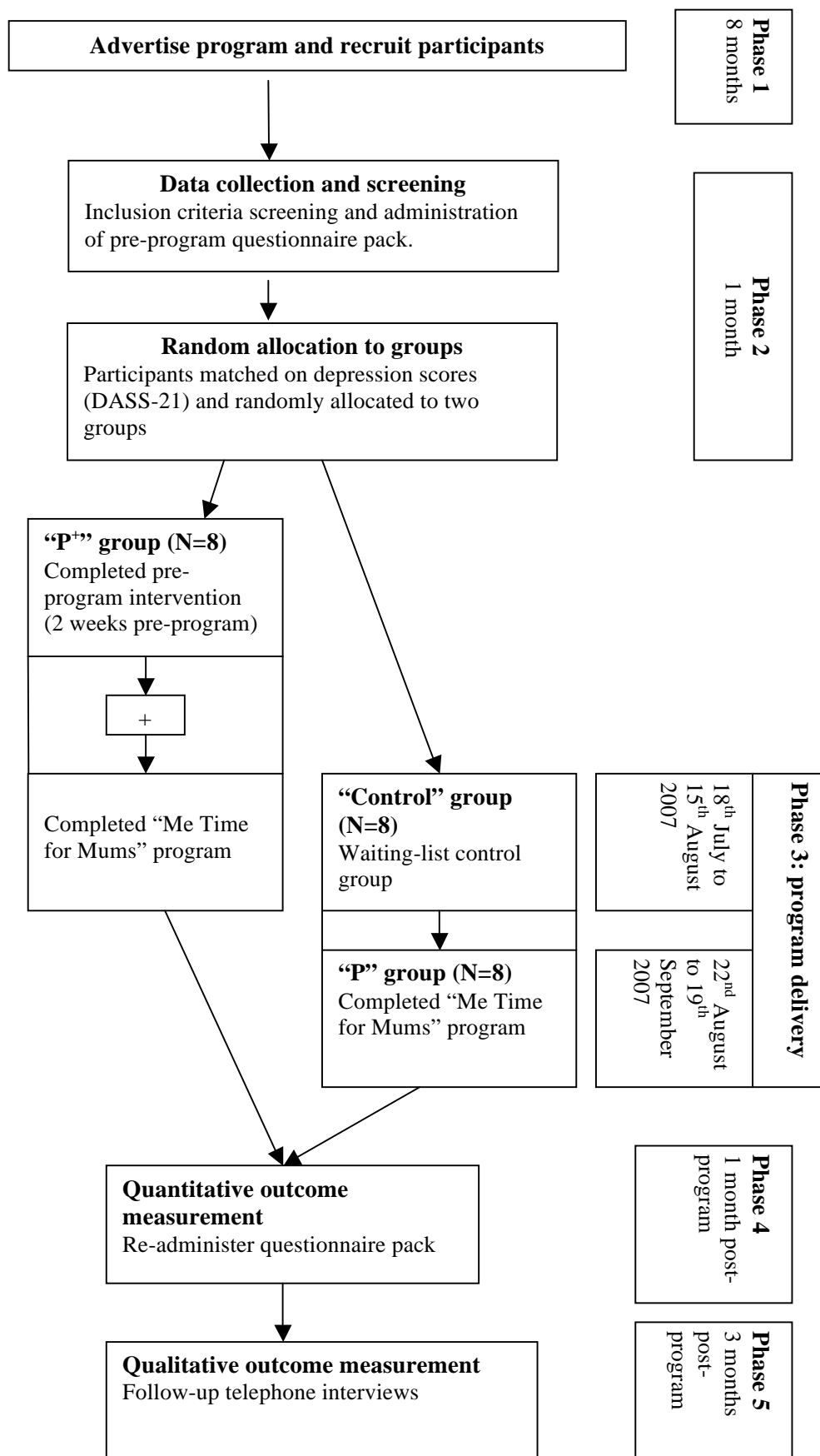


Figure 2. Outline of procedural phases and groups involved in the “Me Time for Mums” program.

CHAPTER 6: PRE-PROGRAM SELF CONFRONTATION METHOD INTERVENTION

Participants assigned to the Program plus pre-program intervention (P⁺) group ($N = 8$) participated in a brief intervention adapted from Hermans and Hermans-Jansen's (1995) Self Confrontation Method (SCM).

6.1 Description of the Self Confrontation Method (SCM) and its Conceptual Underpinnings

The SCM is premised on a constructivist, narrative approach to personality assessment. It functions both as an assessment tool and as a cognitive-affective, change-generating intervention in itself (Hermans & Hermans-Jansen, 1995) and was developed in reaction to the perceived impersonal and static character of traditional questionnaire-based personality assessment procedures.

The SCM interview method is an idiographic instrument that facilitates collection of a person's narrative which is contracted into sentences or "valuations" that carry strong meaning and affective connotations. The SCM combines qualitative and quantitative analyses. The qualitative component is captured by the richness of clients' stories as told in very personally meaningful ways and the quantitative component codes the affective and motivational character of their statements and identifies salient narrative themes. Quantitative coding of participants' utterances permits comparison of individuals along quantitative (or nomothetic) lines.

The SCM is based on "valuations theory" (Hermans & Hermans-Jansen, 1995) which is grounded in a narrative approach to the experience of selfhood, viewing people as "motivated story tellers" who "...formulate their experiences in terms of valuations which take the form of sentences or short texts" (Hermans, Hermans-Jansen, & van Gilst, 1987). Here, "motivated storytelling" means that when people narrate experiences they relay those parts in which they are affectively involved. They do not tell their stories like an objective observer who dispassionately relates events from a

detached point of view. In valuations theory, the primary unit of data is a sentence or utterance. For example, a person might state that: “Being a caregiver is so draining that I don’t have time or energy to do pleasurable things for myself”. The same person might also state: “Being a caregiver is rewarding as I feel so close to the people I love in my life”. These utterances may carry two quite different motivational and affective patterns. Hermans and Hermans-Jansen (1995) state that a valuation is “...any unit of meaning that has a positive (pleasant), negative (unpleasant), or ambivalent (both pleasant and unpleasant) value in the eyes of the individual” (p. 248). The construction of a valuation is both a cognitive and emotional process of systematic self-reflection. For example, valuations can originate from a dear memory, a personal problem, a forbidden love, a significant intimate relationship, an unattained goal, significant loss, and so forth.

A person may tell ever-changing stories, with valuations that change as a function of the passage of time, context, and nature of interactions with significant others (thus the term “valuation” as opposed to the more static term “value”). According to valuations theory, underlying motivations for valuations are fairly stable. According to Hermans and Hermans-Jansen (1995), particular events receive emotional value when the two central motives of self-enhancement (“S-motive”) and motivation for communion with others (“O-motive”) are either fulfilled or frustrated in the individual’s encounters with the world. These two core motivations correspond to the constructs of “agency” (focus on the self, autonomy, separation, self-protection, self-assertion, and self-enhancement) and “communion” (focus on relationships with others, connection, union, solidarity and intimacy) first introduced by Bakan (1966) to reflect the two “fundamental modalities” of human existence. These constructs now pervade the psychological literature (conveyed using varied terminology), and have become widely used to cluster themes in narrative oriented research and therapy.

The SCM is a technique premised on a narrative and constructivist approach to the nature of self-hood, which radically departs from notions of self as decontextualised, immutable, and singular. As Nietzsche (1887/1968) wrote:

The self is the fiction that many similar states in us are the effect of one substratum...the assumption of one single subject is perhaps unnecessary; perhaps it is just as permissible to assume a multiplicity of subjects, whose interaction and struggle is the basis on our consciousness in general? (pp. 269-270)

Hermans (2003) theorised that each individual is made up of a system of ever-changing perspectival positions (I-positions). The term “I-position” refers to an aspect of self with its own frame of reference, stories about itself and the world, its own beliefs, affective patterns, expectations, and behavioural tendencies (Hermans, 2003). The voices (or life narratives) of these I-positions function like interacting characters in a story; each of them has a story to tell about their own experiences. At times there may be a kind of a dialogue between these I- positions, and at other times positions may compete to become the dominant frame of reference, thereby limiting dialogue and expression. Different I-positions emerge through interaction with different people, environments, and events through time and space. The dominance of one or other I-position can have critical ramifications for the lived experience and emotional wellbeing of the individual concerned. Hermans’ thesis is that a healthy self comprises “unity in diversity” of I-positions and disagrees that flexibly moving between I-positions connotes self-fragmentation.

People have a variety of internal I-positions, including role based positions such as I-as-wife, secretary, grandmother, gardener, caregiver, friend, as well as attribute or personality based I-positions, such as I-as-perfectionist, grateful, jealous, accepting and so on. These positions emerge in relation to differing contexts and through interacting with real or imaginal others. These others are referred to as “external positions” (e.g.,

my husband, my children, my colleagues, my guardian angel, my God). Particular valuations will be more or less salient depending on which I-positions are dominant in the self-system. In turn, the salience of valuations affects a person's wellbeing and fulfilment of basic drives.

Seeing this in a clear and simplified fashion through doing the SCM can allow a person to step outside of being subsumed and over-identified with certain I-positions in order to see a birds-eye view of their self-system. The SCM assumes that there is an "...I that actively investigates the Me in different manifestations" (Hermans & Hermans-Jansen, 1995, p. 62). This process can promote recognition that the self is not fixed and immutable, but rather multi-faceted, with the capacity for self-aspects that have been oppressed, neglected, or disavowed to once again find expression.

In recent years an important variation of the SCM involves clients performing self-investigations from a strategic selection of I-positions that might engage in a struggle for power or other conflicted interchanges (e.g., Gregg, 1991). According to several published self-investigations, using the SCM to juxtapose two opposed, contradictory, or otherwise "split" positions can result in better integration of the positions and self-innovation (Hermans, 1993; 1995; 1999). For example, as described by Hermans and Hermans-Jansen (1995), Mary, who was suffering from a dissociative disorder, was asked to perform a self-investigation from the perspective of two positions she identified, one from her ordinary position as "Mary", and the other from the position of "the witch", which Mary experienced as an "alien power" that felt stronger than herself. The rationale behind this idea was that, given the split between the two positions, an improvement of her fragmented self could be expected by (a) clearly distinguishing the two positions with regard to their specific wishes, aims, and feelings, and (b) establishing a process of dialogue between the two positions, so that

the witch could get the opportunity to express her specific wishes and concerns and come to be understood, less feared and more integrated into Mary's experience of self.

The self-confrontation process makes the consequences of living in certain I-positions explicit. Taken-for-granted valuations are externalised (i.e., the I is confronted with its Me in different positions). This can result in an individual's ability to make more informed choices about the positions that they need to actively foreground in order to achieve greater fulfilment of basic needs (i.e., wellbeing, self-enhancement, and connection with others). Awareness of what kind of valuations are under- or overrepresented and their accompanying affective and motivational patterns may function as a precursor to change (Lyddon, 1990). Over the past two decades the SCM has gained support for its utility as a research and counselling tool (see Lyddon et al., 2006 for a review of its applications).

6.2 Aim of the SCM in the Context of the Present Pre-Program Intervention

The SCM used in this pre-program intervention was a modified and shortened version of previously documented SCM protocols in the literature (for a description of the full SCM interview protocol, see Hermans, Fiddelaers, de Groot, & Nauta, 1990; Lyddon, Yowell, & Hermans, 2006). Such adaptations have been encouraged by Hermans and Hermans-Jansen (1995) in order to fit the SCM to specific research aims and contexts. The adapted version of the SCM protocol was designed and implemented by the student researcher (Appendix M). Participants were first oriented to the SCM:

Today we are going to explore some of the different parts of yourself that make up who you are. Some people talk about these parts as being aspects of the self. Another way of referring to these self aspects is using the word I-position, to describe how the experience of ourselves changes according to the context we are in, role we play and way we position ourselves. People position themselves in many ways, such as "I as mother", "I as leisure seeker", "I as friend", "I as daughter" and so on. Today we are going to

focus on two I-positions within your “self-society”. The positions I want to explore are “I as caregiver” and “I as leisure seeker”.

The SCM procedure was implemented with the aim of increasing participants’ awareness of and reflection on the different ways they experience life and themselves when they are in the position I-as-caregiver in comparison to I-as-leisure seeker. It was designed to act as a “primer” to consciously approach the program as a chance to invigorate a part of their identity (I-as-leisure seeker) that is typically denied or disavowed in day-to-day life. Through participating in this intervention it was expected that participants would become more aware of the negative effects of over-identifying with or otherwise prioritising their caregiver I-position, and more aware of the importance of engaging in self-care and leisure activities to achieve greater fulfilment of wellbeing and motives for self-enhancement and connection with others. For these Program Plus (P⁺) participants it was expected that the addition of a cognitive/affective identity “priming” element would result in more positive outcomes compared to participating in the behavioural (i.e., experiential) program alone.

There was some hesitation about inviting mothers to concentrate exclusively on the I-as-caregiver and I-as-leisure seeker positions. The researchers did not want to set these positions up as necessarily opposed to each other or mutually exclusive. However, given abundant research on the typical dominance of the I-as-caregiver position and difficulty that mothers of children with a disability have reported in living and giving voice to the position I as leisure seeker, the researchers felt there was a sound rationale for strategically limiting the self investigation to these two positions. The present focus on only two positions within each participant’s “personal position repertoire” was made transparent by orienting participants to the notion of taking a distilled sample of the infinite number of I-positions that individuals may assume. Further, it was made clear to participants that within the over-arching positions of I-as-caregiver and I-as-leisure seeker are a plethora of other internal positions (e.g., I-as-fun

loving, I-as-burdened, I-as-liberated etc.), but that to fulfil the present aims of the intervention, the focus was on these two positions. Each participant was invited to change the terms “caregiver” and “leisure seeker” if she thought she could reformulate them to better fit her own experiences and language, however all participants felt that the terms captured their experience. Only present-time valuations were elicited (not past or future) as the focus of the intervention was priming participants to become aware of these two I-positions in the present time, as they begin the “Me Time for Mums” program. Deciding on the number of valuations to elicit in this intervention involved a trade-off in terms of data manageability. It was assumed that the primary narrative themes constituting the I-as-caregiver and I-as-leisure seeker positions should be decipherable from 1-3 sentences distilled from the many utterances shared during the brainstorming activity. It was also considered important to contain the self-investigation in these ways to ensure that participants were not opening up about more than what could be appropriately addressed in a brief intervention.

6.3 SCM Procedure

Implementing the SCM involved three parts: (1) Elicitation of valuations, (2) Rating each valuation in terms of four indices: positive and negative affect and the core motivations of self-enhancement and connection with others, (3) Analysis of indices and integration of themes, and (4) Discussion of findings with the person.

6.3.1 Valuation Elicitation

In accordance with documented SCM procedures, a series of open ended questions were used to elicit valuations (statements that carry strong affective connotations). In the present process, participants firstly drew pictures of each “I-position”, with words and images that conveyed their experiences (see Figures 4-11, pp.134-148). From this visual “brainstorming” activity, participants were asked open ended questions specifically about the way they experience life as a caregiver and a

leisure seeker. They responded to questions that had the most eliciting quality.

Participants were encouraged to frame and reframe valuations in their own terms until they felt that the sentence captured their unique cognitive and affective experience.

They formulated up to three valuations for each position.

6.3.2 Affective Rating of Valuations

After valuations were formulated they were written down to form the rows of a matrix, and the columns of the matrix contained affect terms (see Table 7 for the list of 24 affect terms). Participants then worked alone to assign a rating of the degree to which each affect term related to each specific valuation; a 6 point rating scale was used (0= not at all, 1 = a little bit, 2 = to some extent, 3 = rather much, 4 = much, and 5 = very much).

In SCM research affect lists have varied from 16 to 30 affect terms depending on the nature of the research. Van Geel and De Mey (2002) analysed the factor structure and unidimensionality of a list of 30 affects. They proposed a list of 24 affect terms, six terms in each of the Self-enhancement (S), connection with others (O), positive affect (P), and negative affect (N) indices. The researchers then performed a principal components analysis on two samples (127 clients and 67 students; collectively analysing 6941 affective profiles). They found a three factor solution for both samples; a first bi-polar Positive/Negative affect factor, a second self-enhancement factor, and a third connection with others factor. They concluded that this list of affects is parsimonious, "...psychometrically sound and optimally suited for use in research and practice" (Van Geel & De Mey, p.1833). Given this rigorous psychometric validation, the present research employed this list of 24 affect terms.

Table 7

*Psychometrically Validated List of Affect Terms for Use in the Self-Confrontation**Method, constructed by Van Geel and De Mey (2003)*

Self-enhancement	Other connectedness	Positive affect	Negative affect
Self-esteem	Caring	Joy	Disappointment
Strength	Love	Happiness	Anxiety
Self-confidence	Tenderness	Enjoyment	Stress
Pride	Intimacy	Inner calm	Loneliness
energy	Solidarity	Trust	Inferiority
Freedom	Warmth	Security	Anger

6.3.3 Analysis of Indices

For each valuation, affect ratings were averaged to form four basic motivational and affective indices: Self-enhancement (S), connection with others (O), positive affect (P) and negative affect (N). In addition to these indices, participants were asked to rate their general experience (GE) and Ideal experience (I) in response to the questions: “How do you generally feel these days?” (GE) and “How would you like to feel?” (I). These two additional questions and associated affect ratings formed two extra rows in the valuations x affect matrix. These indices were computed in accordance with the set of computations formulated by Hermans, Fiddelaers, de Groot, and Nauta (1990), with the modification of using the mean affect rating for each index as opposed to the sum of the affect ratings, as outlined in Table 8.

The extent of generalisation of each particular valuation was found by computing the product moment correlation between the affect ratings for each valuation and the affect rating for general experience. The more positive the correlation, the more that particular valuation is believed to have generalised within the system, and the more it may therefore reflect a dominant I-position or theme in the person’s subjective experience. Similarly, to measure the extent to which a valuation is idealised in the person’s experience, the affect ratings for each valuation was correlated with the pattern of affect for their ideal experience.

By using a set of heuristic guidelines Hermans, Hermans-Jansen, and Van Gilst (1987) formulated a typology of valuation themes derived from combining relative levels of the S, O, P, and N indices, as outlined in Table 9. This typology may be represented via a circular organisation, as depicted in Figure 3, in which the horizontal axis depicts the “self vs. other” dimension and the vertical axis depicts the “positive affect vs. negative affect” dimension.

Table 8

List of Indices and Formulae for their Computation

Indices	Description	computation
S	Self-enhancement index	Average rating across the six affect terms used to measure self-enhancement: Self-esteem, Self-confidence, Pride, Strength, Energy, Freedom
O	Connection with others index	Average rating across the six affect terms used to measure connection or communion with others: Tenderness, Intimacy, Caring, Love, Solidarity, Warmth
P	Positive affect index	Average rating across the six affect terms used to measure positive affect: Inner calm, Joy, Happiness, Enjoyment, Excitement, Security
N	Negative affect index	Average rating across the six affect terms used to measure negative affect: Disappointment, Anxiety, Stress, Anger, Loneliness, Inferiority
G	Extent to which a valuation has generalised	Product moment correlation between the affective profile of a valuation and the affective profile of general experience
I	Extent to which a valuation is idealised	Product moment correlation between the affective profile of a valuation and the affective profile of ideal experience

Table 9

*Typology of Valuations and Corresponding Themes Associated with Relative Index**Levels*

TYPE	S	O	P	N	THEME
+S	HIGH	LOW	HIGH	LOW	Success, autonomy, perseverance
-S	HIGH	LOW	LOW	HIGH	Aggression, anger, opposition
+O	LOW	HIGH	HIGH	LOW	Love and unity
-O	LOW	HIGH	LOW	HIGH	Unfulfilled longing, loss
-LL	LOW	LOW	LOW	HIGH	Powerlessness and isolation
+HH	HIGH	HIGH	HIGH	LOW	Strength and unity

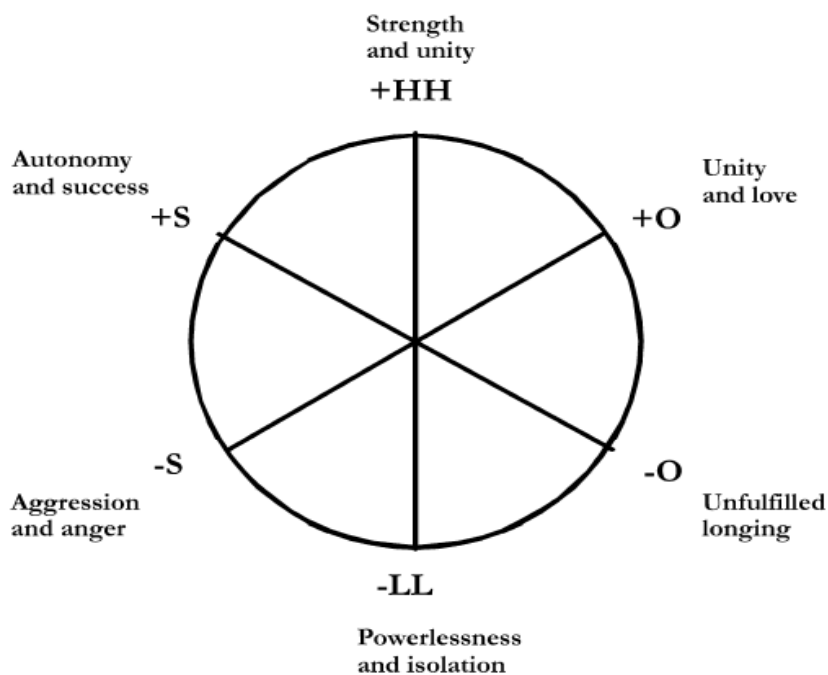


Figure 3. Types of valuations according to relative index levels (van Geel & De May, 2003).

The present SCM employed a list of 24 affect terms and used an alternative model to the one used by Hermans et al. (1987) for classifying valuation types, referred to as Finn Tschudi's "compensatory model" (F. Tschudi, personal communication, December 2, 2008). This model has the advantage of forcing more affect profiles into the typology (i.e., removing ambivalent types). In model the following computations are used to generate types. Firstly, each type is computed: $S+ = (S-O+P-N)/2$; $S- = (S-O-P+N)/2$; $O+ = (O-S+P-N)/2$; $O- = (O-S-P+N)/2$. Next, the maximum and minimum of the S, O, and P indices are computed. Then, $HH+ = (S+O+P-\text{maximum})/2 - N$ and $LL- = (S+O+P+\text{minimum})/2 + N$. The maximum value (referred to here as "Max-type") of all the above types is identified. Lastly, types are classified according to the criteria listed above in Table 9. These criteria are arguably more straightforward compared to Hermans' et al. typology guidelines as one single criterion can be used to select types (i.e., the type must have the highest mean affect rating out of the six types and the mean rating must exceed 1).

6.4 Discussion and feedback based on SCM results

A discussion of the results of the interview with all participants followed one week after implementing the modified SCM protocol. Results of the index and typology analysis and brief qualitative content analysis of valuations was presented in the feedback session. Hermans and Hermans-Jansen's (1995) model of the valuation x index matrix was used for the efficient presentation of results. Participants then "positioned" their valuations on the circular diagram (Figure 3) to further clarify motivational and affective valuation themes.

In the present SCM intervention, after discussing feedback, the student researcher presented the "Me Time for Mums" program as a context to actively position the self in the I-as-leisure seeker position, and to give this position regular time for expression in day to day life. It was assumed that the dominance of the I-as-caregiver

position would result in motivational and affective imbalances that would be improved by increasing the salience of a self-caring I-position such as I-as-leisure seeker. This intention is consistent with the proposition that the “healthy personality” develops their motivations towards self-enhancement and connection with others in a complementary fashion (Hermans et al., 1987).

As described in the pre-program protocol (Appendix O), before formulating valuations, each participant got “in touch” with the two positions I-as-caregiver and I-as-leisure seeker through drawing pictures and brainstorming their experiences, thoughts, and feelings accompanying each position around the picture. These brainstorming drawings and related valuation x affect matrices, along with the quantitative results of the SCM procedure are presented in the next section.

6.4.1 Brainstorming Drawings and Results of the SCM

I-as-caregiver

I-as-leisure seeker

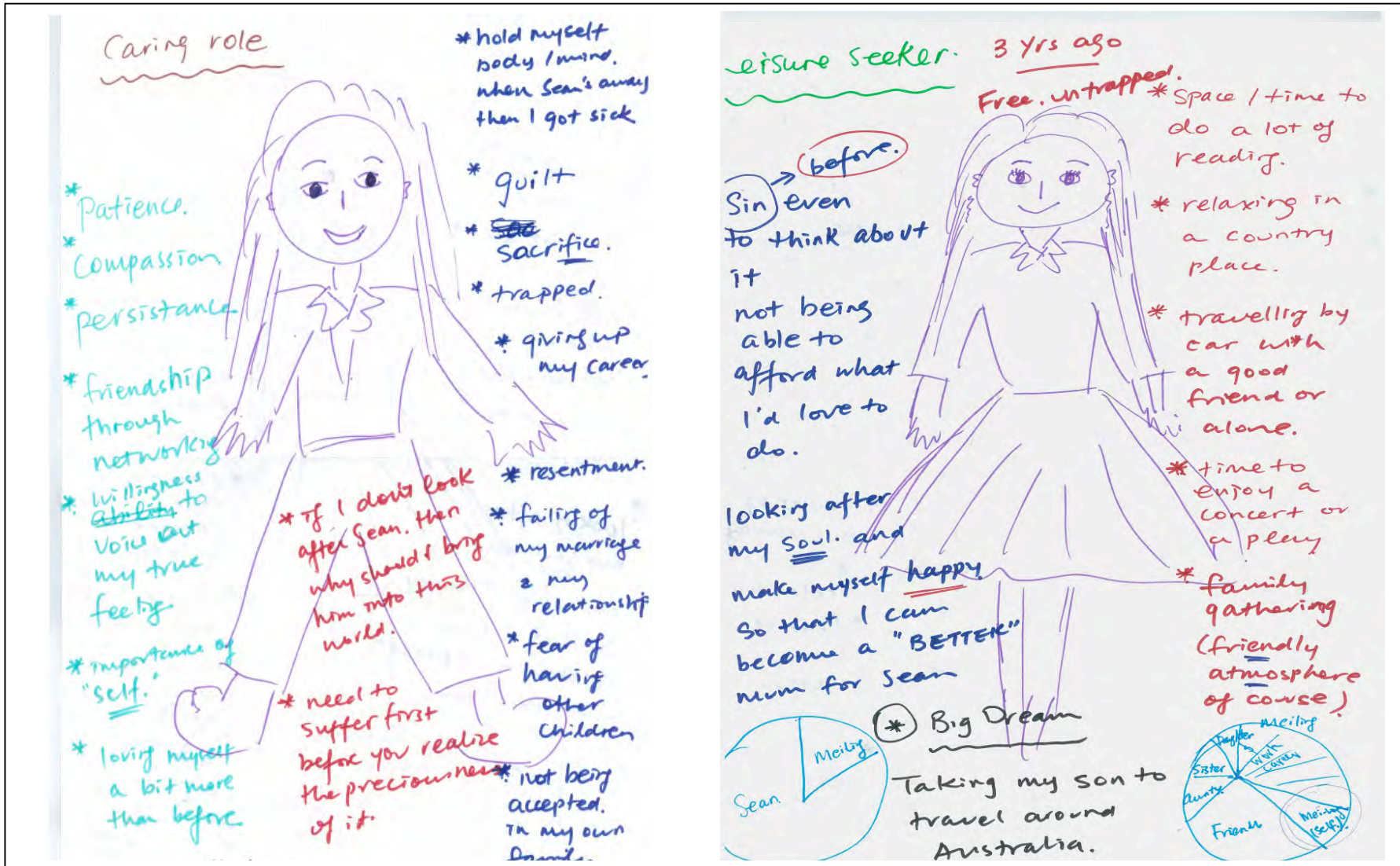


Figure 4. Participant 1 (P⁺1): Brainstorming activity to explore experience of self as caregiver and leisure seeker.

Table 10

Matrix of Valuations x Indices and Valuation Types for P⁺ I

Valuation	S	O	P	N	GE	I	Type
I-as-caregiver							
1. I think this role has made me a better person. I love who I am. I like that my son has turned me into a compassionate person	3.17	3.83	3.17	3.17	.36	.18	
2. There are times that I want to escape from this role. Strong moments of wanting to f**k it and go.	2.83	1.83	1.17	4.17	.32	-.68**	
I-as-leisure-seeker							
1. I want to feel free and relaxed	3.33	3.00	4.17	1.17	-.31	.79**	+HH
2. I miss my old self	2.83	2.00	1.17	2.50	.79**	-.21	
General feeling	2.17	3.5	2.00	3.50			-O
Ideal feeling	4.17	4.67	4.67	0.67			+HH

Note: S =affect referring to self enhancement; O = affect referring to contact with the other; P = positive affect; N = negative affect; GE = affect referring to general experience; I = affect referring to ideal experience.

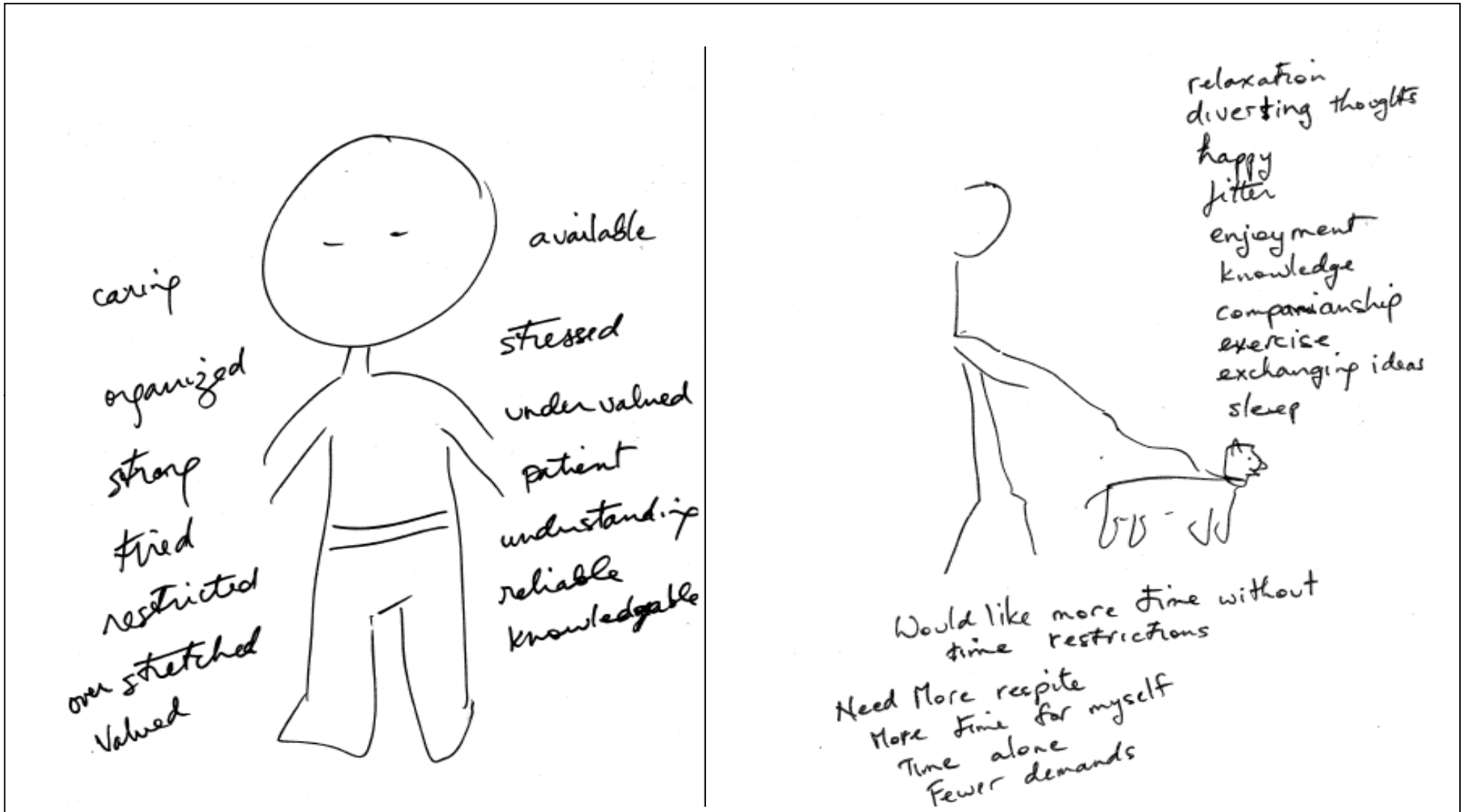


Figure 5. Participant 2 (P²): Brainstorming activity to explore experience of self as caregiver and leisure seeker.

Table 11

Matrix of Valuations x Indices and Valuation Types for P⁺2

Valuation	S	O	P	N	GE	I	Type
I-as-caregiver							
1. It's a full-time 24 hour a day job	2.67	2.33	2.67	2.50	-.03	0.54	
2. I enjoy caring for [name of child]. It has given my life a direction and made me stronger	3.50	3.33	3.33	2.17	.08	.73**	+HH
3. At times it is extremely stressful and you never know what's around the next corner	1.50	0.33	2.50	3.00	-.07	-.49	-LL
I-as-leisure-seeker							
1. I don't have or make as much time for myself as I should	1.50	2.00	2.33	2.17	.33	-.10	
2. I use reading as a means of escape as well as enjoyment	0.50	0.67	1.17	0.67	.29	.05	
3. I am scared that I will be losing my caregiving role by taking more time for leisure	1.00	1.00	2.00	1.83	-.30	-.07	
General feeling	1.17	2.83	2.83	2.00			+O
Ideal feeling	4.33	4.17	3.17	1.33			+HH

Note: S =affect referring to self enhancement; O = affect referring to contact with the other; P = positive affect; N = negative affect; GE = affect referring to general experience; I = affect referring to ideal experience.

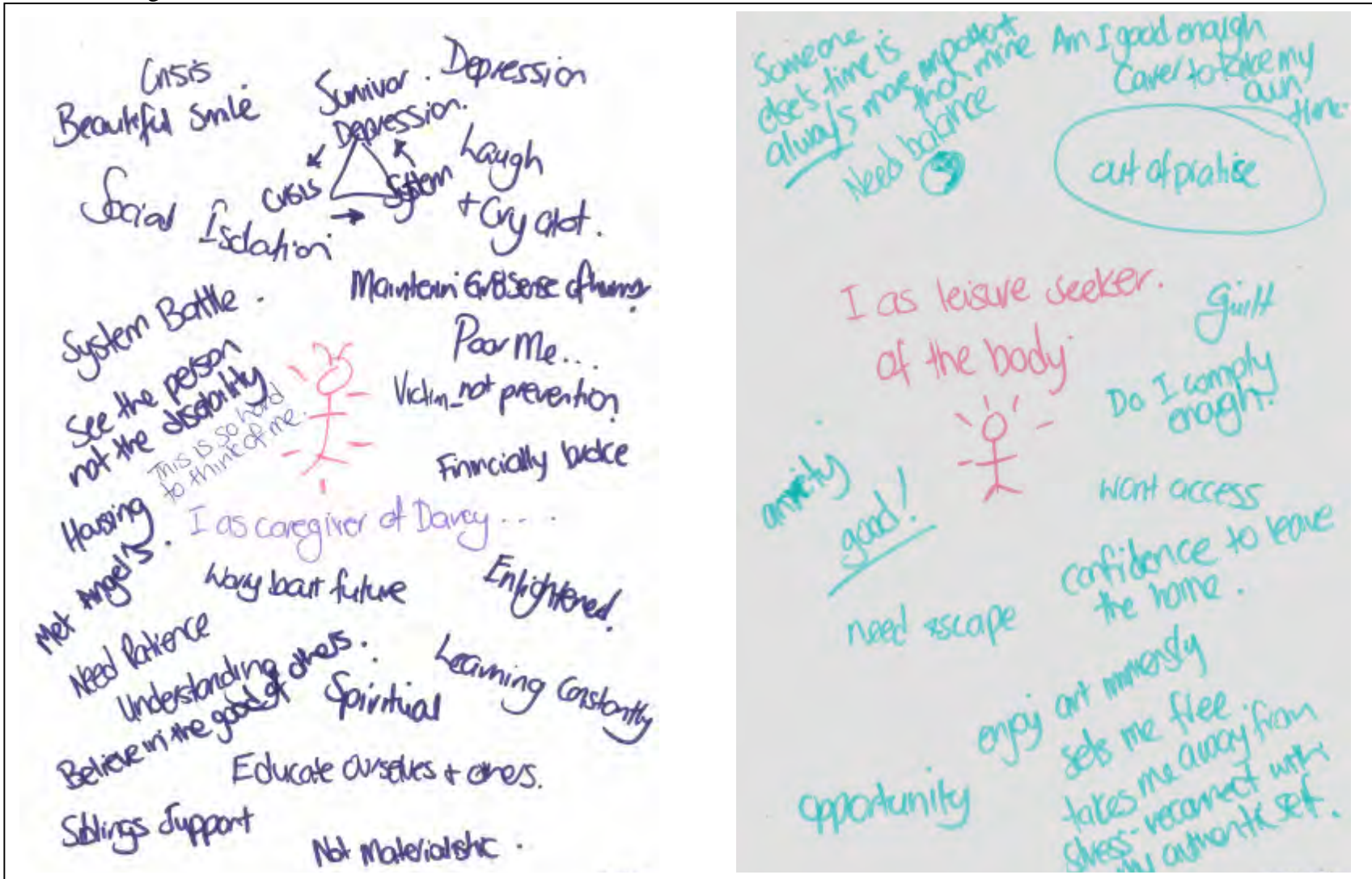


Figure 6. Participant 3 (P+3): Brainstorming activity to explore experience of self as caregiver and leisure seeker.

Table 12

Matrix of Valuations x Indices and Valuation Types for P⁺3

Valuation	S	O	P	N	GE	I	Type
I-as-caregiver							
1. I am stronger than I ever thought I would be	4.00	4.33	4.00	0.17	.54**	.75**	+HH
2. I know what heartache is	2.83	3.83	0.50	2.67	.14	-.04	-O
3. I know what it is like not to conform to society	2.50	3.00	1.50	3.83	.02	-.33	-O
I-as-leisure-seeker							
1. Reconnect with my authentic self	3.67	3.50	3.17	1.50	.21	.58**	+HH
2. I need to practice taking care of myself because it doesn't come naturally	2.50	2.50	4.50	0.83	.11	.30	+O
3. I am looking forward to trying something new in a supportive environment	3.50	2.00	4.83	0.17	.26	.73**	+S
General feeling	1.67	4.33	2.83	1.33			+O
Ideal feeling	5.00	5.00	4.50	0.00			+HH

Note: S =affect referring to self enhancement; O = affect referring to contact with the other; P = positive affect; N = negative affect; GE = affect referring to general experience; I = affect referring to ideal experience.



Figure 7. Participant 4 (P+4): Brainstorming activity to explore experience of self as caregiver and leisure seeker.

Table 13

Matrix of Valuations x Indices and Valuation Types for P⁺4

Valuation	S	O	P	N	GE	I	Type
I-as-caregiver							
1. A never ending responsibility that feels like you're on three roller coasters at once	2.67	4.00	2.67	2.50	.54**	.30	
2. Moments of pure joy and moments of utter despair	3.50	4.00	3.33	1.83	.78**	.55**	+HH
I-as-leisure-seeker							
1. I need me time	4.00	2.33	1.83	2.33	.60**	.12	
2. I need to know everything is okay to have me time	2.83	2.67	1.67	3.33	.18	-.362	
3. She's a much nicer person	4.00	3.67	3.50	2.00	.59**	.87**	+HH
General feeling	4.00	3.17	3.00	1.83			+HH
Ideal feeling	5.00	4.83	4.67	0.50			+HH

Note: S = affect referring to self enhancement; O = affect referring to contact with the other; P = positive affect; N = negative affect; GE = affect referring to general experience; I = affect referring to ideal experience.

I-as-caregiver

I-as-leisure seeker

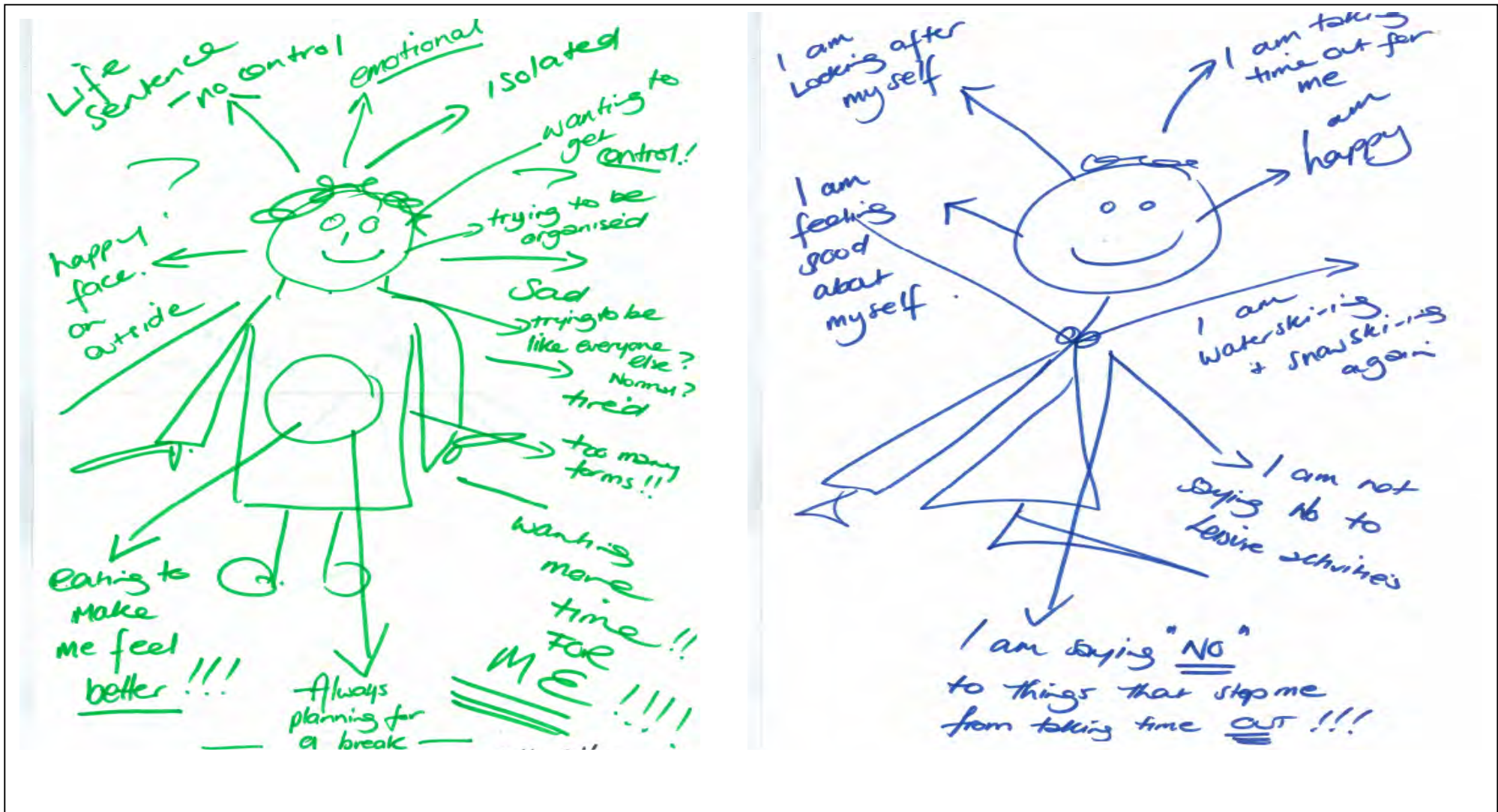


Figure 8. Participant 5 (P⁺5): Brainstorming activity to explore experience of self as caregiver and leisure seeker.

Table 14

Matrix of Valuations x Indices and Valuation Types for P⁺5

Valuation	S	O	P	N	GE	I	Type
I-as-caregiver							
1. As a caregiver I feel emotionally, physically and financially drained. But I am trying to survive and have a life	1.00	3.67	0.00	2.00	.60**	-.13	-O
2. She needs a break	5.00	3.33	2.50	2.33	.42**	.66*	
I-as-leisure-seeker							
1. I'm going to learn to not feel guilty about me time – Let go!	5.00	4.00	3.67	0.67	.13	.90**	+HH
2. I feel excited about the program because it means I'm finally taking time out for me	5.00	4.00	4.33	0.83	.26	.92	+HH
General feeling	3.17	4.67	3.00	3.17			
Ideal feeling	5.00	5.00	5.00	0.00			+HH

Note: S = affect referring to self enhancement; O = affect referring to contact with the other; P = positive affect; N = negative affect; GE = affect referring to general experience; I = affect referring to ideal experience.

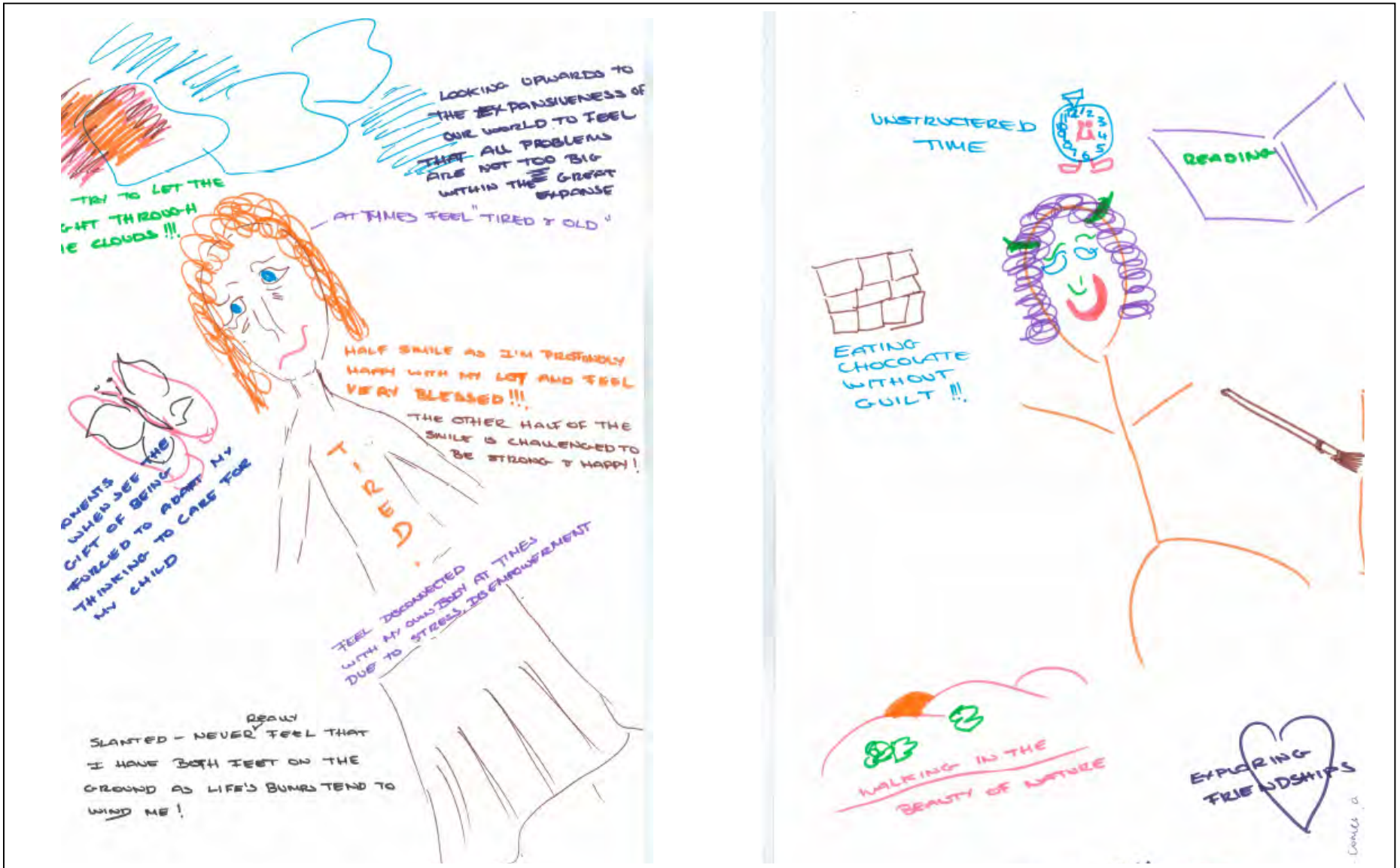


Figure 9. Participant 6 (P+6): Brainstroming activity to explore experience of self as caregiver and leisure seeker.

Table 15

Matrix of Valuations x Indices and Valuation Types for P⁺6

Valuation	S	O	P	N	GE	I	Type
I-as-caregiver							
1. I feel humbled, on a learning curve and tired	2.33	3.67	1.5	2.17	.78**	.17	
I-as-leisure-seeker							
1. I feel unrestrained, light and loving to embrace with strength and vigour	5	5	3.67	1.17	.15	.80**	+HH
General feeling	2.17	2.67	1.83	2.67			
Ideal feeling	4.83	5	4.17	1.17			+HH

Note: S =affect referring to self enhancement; O = affect referring to contact with the other; P = positive affect; N = negative affect; GE = affect referring to general experience; I = affect referring to ideal experience.

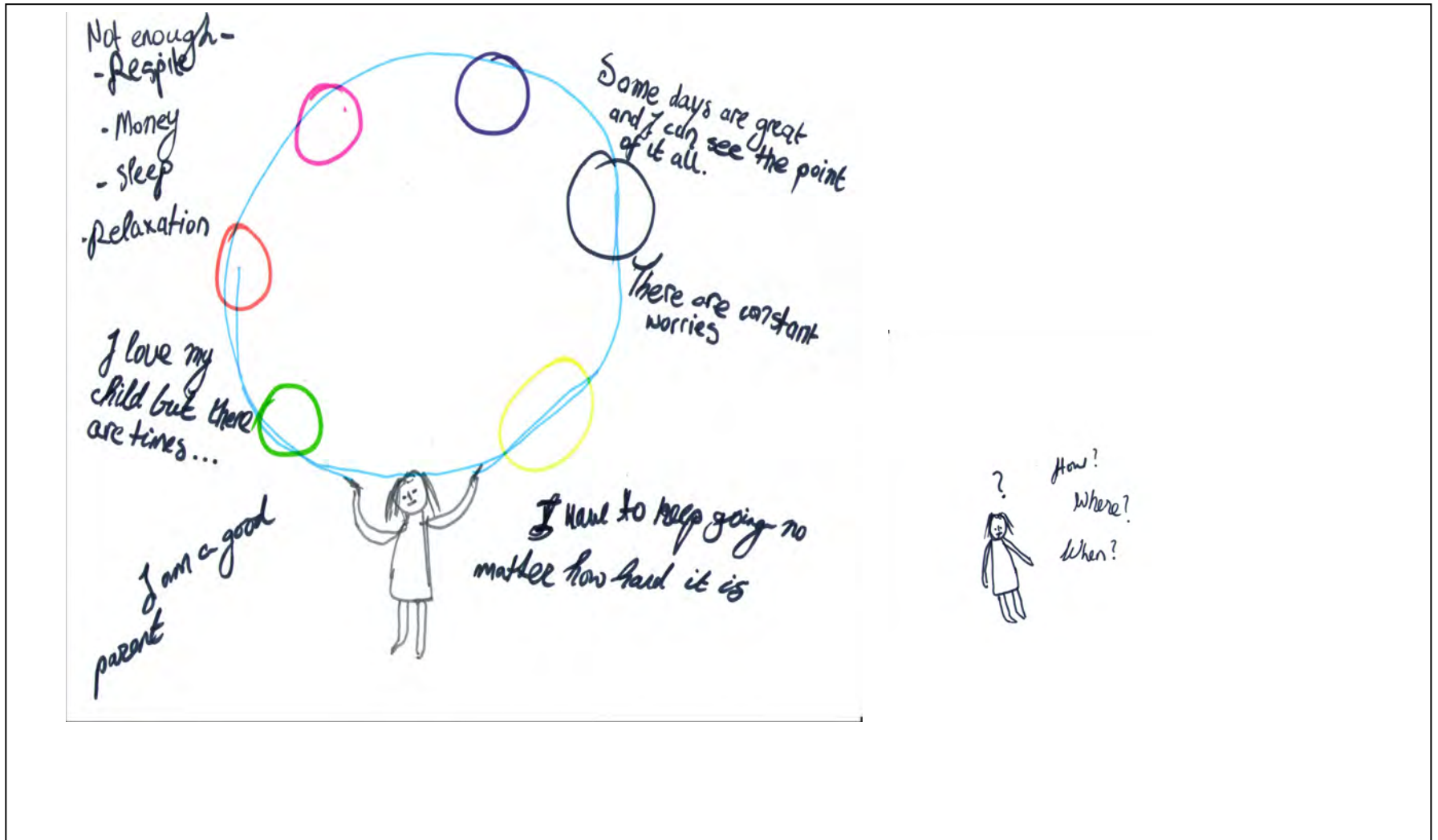


Figure 10. Participant 7 (P⁷): Brainstorming activity to explore experience of self as caregiver and leisure seeker

Table 16

Matrix of Valuations x Indices and Valuation Types for P⁺7

Valuation	S	O	P	N	GE	I	Type
I-as-caregiver							
1. I want to break free. I never expected my life would be like this.	8.00	18.00	10.00	19.00	.95**	-.21	-O
2. I feel alone and depleted most of the time, with not a lot to look forward to.	6.00	15.00	6.00	22.00	.78**	-.30	
I-as-leisure-seeker							
1. I feel cut off from the fun part of myself	8.00	10.00	7.00	20.00	.57**	-.49**	-LL
2. I don't have a lot of time, energy or interests that I know of for my own leisure	7.00	9.00	6.00	22.00	.48**	-.60**	-LL
General feeling	14.00	14.00	6.00	20.00			-O
Ideal feeling	26.00	7.00	26.00	0.67			+S

Note: S =affect referring to self enhancement; O = affect referring to contact with the other; P = positive affect; N = negative affect; G = generalisation; I = idealisation

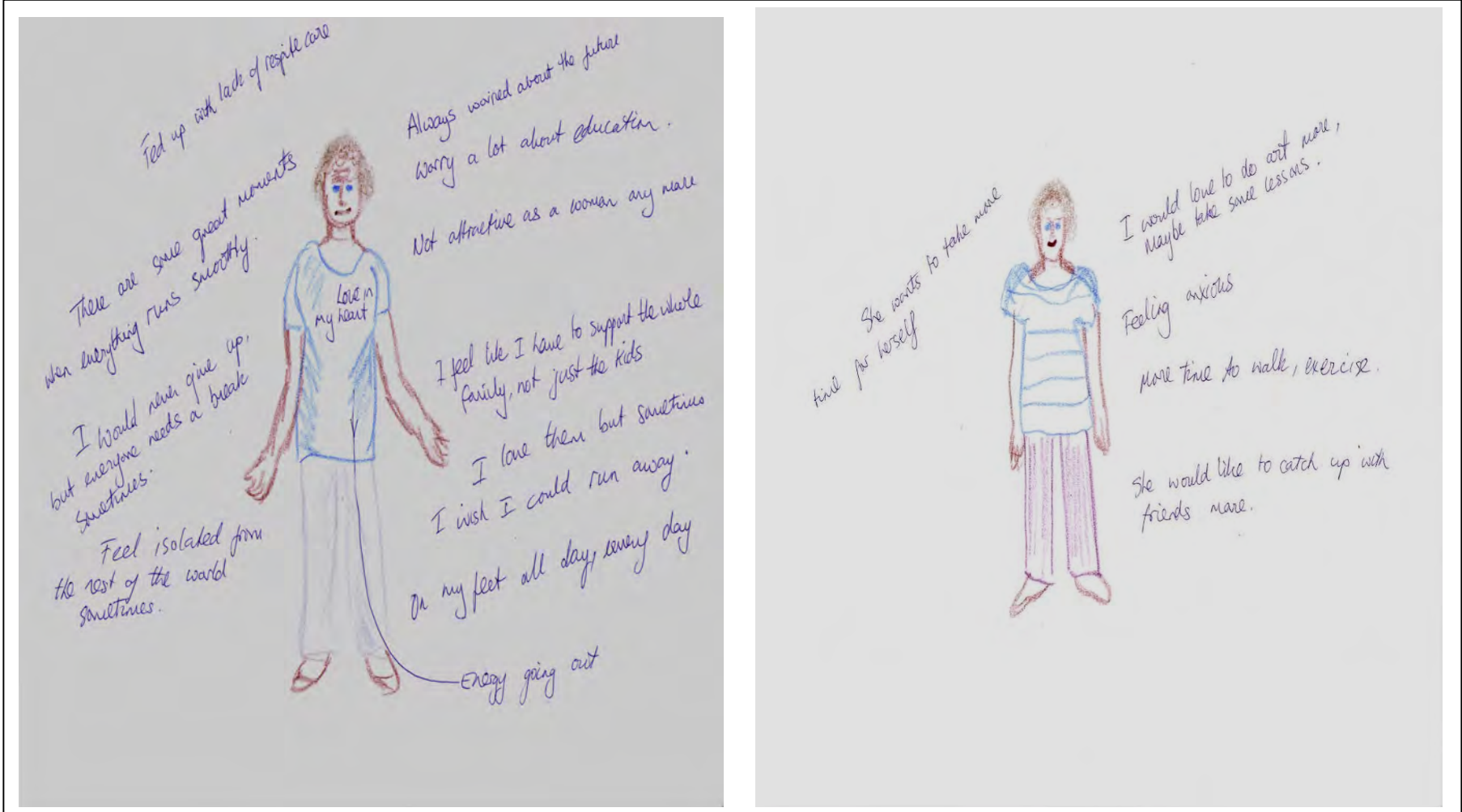


Figure 11. Participant 8 (P+8): Brainstorming activity to explore experience of self as caregiver and leisure seeker.

Table 17

Matrix of Valuations x Indices and Valuation Types for P⁺8

Valuation	S	O	P	N	GE	I	Type	
I-as-caregiver								
1. I love my son and would do anything for him. This is wholeheartedly true, but so is my secret wish to have a completely different life to the one I am living		2.00	3.33	2.33	2.67	.87**	.01	
2. Chores, obligations, concerns, patience, love		2.33	4.33	2.50	3.33	.64**	.38	-O
I-as-leisure-seeker								
1. She would like to laugh more and spend more time with friends and chat		4.17	2.83	3.17	2.00	.18	.73**	+S
2. She wants to paint		4.67	2.33	3.33	1.50	.10	.82**	+S
General feeling		2.17	4.50	2.33	3.67			-O
Ideal feeling		5.00	5.00	5.00	0.00			+HH

Note: S =affect referring to self enhancement; O = affect referring to contact with the other; P = positive affect; N = negative affect; G = generalisation; I = idealisation

CHAPTER 7: QUANTITATIVE RESULTS OF THE “ME TIME FOR MUMS” PROGRAM EVALUATION

7.1 Description of Quantitative Analyses

Outcome variables were grouped into three conceptual domains as follows (with constituent dependent variables listed in parentheses): a) Leisure attitudes and behaviours (risks of not doing leisure, benefits of leisure, intrapersonal constraints to leisure, motivation to increase leisure, and leisure companionship); b) Mental health (depression, anxiety, stress, positive energy, tiredness, and relaxation); and c) Life satisfaction (personal wellbeing, basic needs, and activities of living). Within each conceptual domain, three sets of analyses were conducted:

a. P⁺ compared to Control

First, the P⁺ group was compared to the Control group on all dependent variables using a mixed between-within subjects analysis of variance model. There were two independent variables: a between-subjects variable (Group: Control/ P⁺) and a within-subjects variable (Time: Time 1/ Time 2). The interaction effect (Group x Time) demonstrated whether there were significant differences between the Control group and the P⁺ group on change in scores from Time 1 to Time 2 on each dependent variable (i.e., measured the treatment effect). Post hoc independent-measures *t*-tests were conducted to compare the P⁺ and Control groups pre and post test scores for each dependent variable when a significant interaction effect was obtained.

b. P compared to Control

The second analysis compared the P group to the Control group on all dependent variables. However, the groups were not independent in this case as the P group was formed from the wait-list Control group. In the five weeks separating Time 1 and Time 2, participants acted as the Control group and waited to do the program, and then later

participated in the program as the P group from Time 2 to Time 3. To compare these two groups of the same people a one-way repeated measures analysis of variance was conducted with all dependent variables, in which the independent variable was time (T1, T2, and T3). Planned contrasts were performed to examine whether scores significantly changed from T1 to T2 (Control period) and from T2 to T3 (Program period).

c. P compared to P⁺

Lastly, the P group was compared to the P⁺ group using a mixed between-within subjects analysis of variance model. The interaction effect assessed the difference in change in scores from pre- to post-program between the two intervention groups. This analysis was conducted to investigate whether doing the pre-program intervention influenced program outcomes. Independent measures *t*-tests were again used to test for differences between the groups on pre and post tests when a significant interaction effect was found.

In the subsequent analyses, the alpha significance level was set at .01 to assess main and interaction effects in order to guard against testwise error when using multiple ANOVAs.

7.2 Quantitative Results

7.2.1 Quantitative Results for Leisure Attitudes and Behaviour Variables

Table 18 presents the descriptive statistics (pre-test, post-test and change score means and standard deviations) for each dependent variable assessing leisure attitudes and behaviours for the three groups (Control, P⁺, and P). Table 18 also presents univariate *F* test statistics comparing the P⁺ group to the Control group (mixed between-within subjects ANOVA) and comparing the P group to the Control group (repeated measures ANOVA with planned contrasts).

Table 18

Descriptive Statistics and ANOVA Results for Leisure Attitudes and Behaviour Variables

Outcome variable		<i>F</i> tests								<i>F</i> tests			
		Control (<i>n</i> = 8)				P ⁺ group (<i>n</i> = 8)				P ⁺ compared to Control		P compared to Control	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	Main effect (time)	Main effect (group)	Interaction group x time (Partial Eta Squared)	Main effect (time)	Control (T1/T2)	P (T2/T3)
Risks of not doing leisure	Pre	29.00	4.84	28.88	4.36	30.00	5.71	.35	.06	.21	2.83	4.00	1.22
	Post	30.00	5.71	29.00	5.50	31.25	5.18						
	Change	1.00	1.41	0.12	5.22	1.25	3.20						
Benefits of leisure	Pre	29.88	4.94	30.13	4.42	30.38	5.07	30.33**	.374	14.54**	7.89**	3.50	6.50*
	Post	30.38	5.07	32.88	3.56	32.50	2.88			(.02)			
	Change	0.50	0.76	2.75	1.49	2.12	2.36						
Intrapersonal constraints to leisure	Pre	22.88	5.25	20.25	7.74	23.00	5.04	25.58**	2.30	28.99**	1.78	.30	2.03
	Post	23.00	5.04	16.25	6.52	23.38	5.21			(.65)			
	Change	0.12	0.64	-4.00	2.07	0.38	0.74						
Interpersonal constraints to leisure	Pre	13.50	5.90	16.25	5.12	14.12	6.36	.10	.44	1.95	2.48	3.72	1.78
	Post	14.12	6.36	15.25	6.36	16.50	3.55						
	Change	0.62	0.92	-1.00	3.16	2.38	0.46						
Motivation to increase leisure	Pre	14.13	2.85	12.63	3.02	14.75	3.20	20.46**	.10	11.70**	12.58**	5.65*	9.91*
	Post	14.75	3.20	17.13	2.64	18.63	2.26			(.59)	(.64)		
	Change	0.62	0.74	4.50	3.12	3.88	2.62						
Leisure companionship	Pre	29.13	4.55	25.25	7.49	30.00	5.09	16.03**	.30	8.04*	11.04**	4.83	6.81*
	Post	30.00	5.09	30.38	8.42	33.00	4.69			(.53)	(.61)		
	Change	0.87	1.13	5.13	4.09	3.00	3.25						

Note: ** $p < .01$; * $p < .05$

7.2.1.1 P^+ Compared to Control

As shown in Table 18, there was a significant main effect for time, which was further qualified by a significant interaction effect (group x time) for the following variables: Benefits of leisure, intrapersonal constraints to leisure, motivation to increase leisure, and leisure companionship. The effect sizes, calculated using partial eta-squared, for these significant interactions were very high (according to Cohen's criteria; Cohen, 1988), ranging from .53 to .65. Firstly, as demonstrated by the significant interaction effect and the pattern shown in Figure 12a, the P^+ group showed a significantly greater increase in perceived benefits of leisure compared to the Control group, although the post-program difference between the groups failed to reach significance. Perception of intrapersonal constraints to leisure, as demonstrated by the significant interaction effect shown in Figure 12b, decreased markedly for the P^+ group after doing the program such that while there was no significant pre-test difference, at post-program the P^+ group scored significantly lower on intrapersonal constraints to leisure than the Control group ($t(14) = 2.32, p < .05$). The P^+ group also showed a significantly greater increase in motivation to increase leisure after doing the program compared to the Control group (Figure 12c), although the groups did not significantly differ at pre and post test. Finally, the P^+ group, while tending to start from a lower base, showed a somewhat larger increase in leisure companionship than the Control group (Figure 12d), although the groups did not significantly differ at pre or post tests. In this final instance, the result is somewhat more tentative given it was significant only at the .05 level.

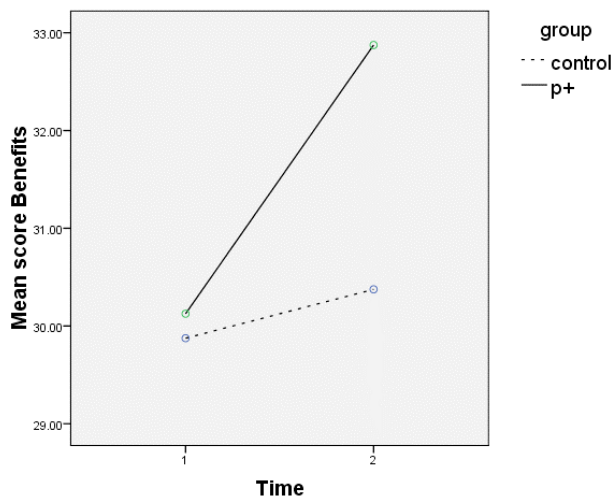


Figure 12a. Change in benefits of leisure.

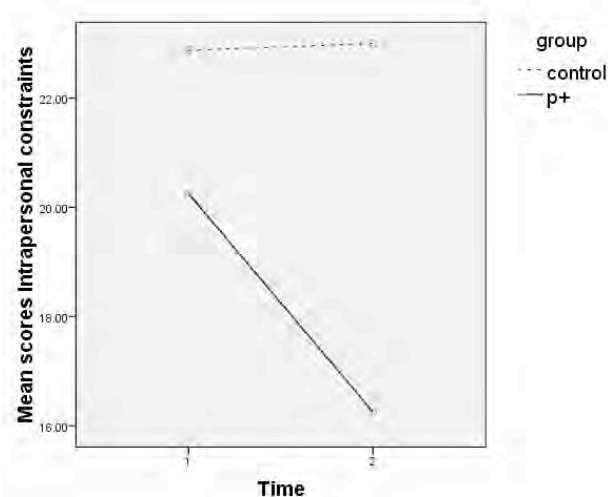


Figure 12b. Change in intrapersonal constraints.

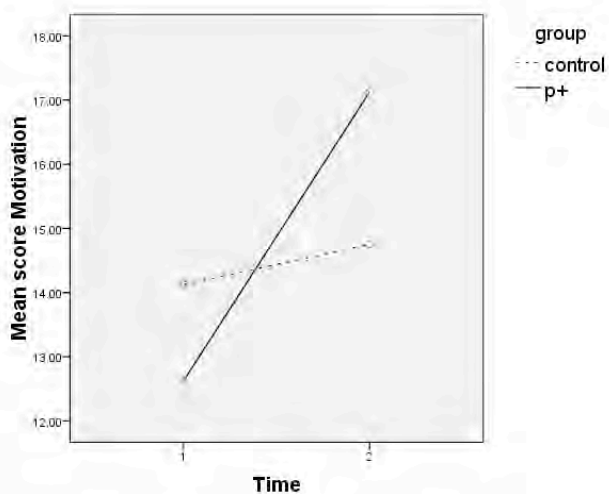


Figure 12c. Change in motivation to increase leisure

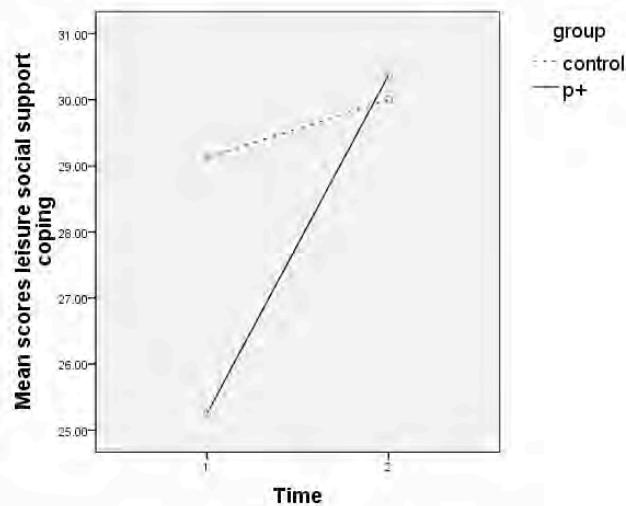


Figure 12d. Change in leisure companionship

Figure 12. Plots showing the significant interaction effects for leisure attitude and behaviour variables from pre- to post- program for the P⁺ versus the Control group.

7.2.1.2 P Compared to Control

A one way repeated measures ANOVA was conducted to assess change in scores across time. There was a significant main effect for time on the following

variables: Benefits of leisure, motivation to increase leisure, and leisure companionship. Planned contrasts were performed to examine the difference between the Control and P groups' change in scores across time. As shown in Table 18, there was a significant increase in participants' perception of the benefits of leisure, in their motivation to increase leisure, and in their use of leisure companionship from pre to post program (T2 to T3). Conversely, there were no significant differences on these variables while waiting to do the program (T1 to T2). To substantiate whether the P group changed more during the program compared to when they were waiting for it (as seen in Figures 13a and 13c), repeated measures *t*-tests were performed to examine difference in change scores across time. While there was a clear trend showing that the P group changed more during the program period than during the waiting-list control period, there was no significant difference between the change scores for benefits of leisure and leisure companionship. As illustrated in Figure 13c, there was a significantly greater magnitude of change reported in motivation to increase leisure during the program period compared to the control period ($t(7) = -2.35, p < .05$).

7.2.1.3 P Compared to P⁺

When differences between the two intervention groups were assessed using a mixed analysis of variance model, the only significant interaction effect for leisure attitudes and behaviour was found for intrapersonal constraints to leisure ($F = 31.64, p < .01$; see Appendix N for complete results comparing the P⁺ group to the P group). Figure 14 represents this significant interaction effect, illustrating that the P⁺ group showed significantly greater reduction in intrapersonal constraints to leisure than the P group. While post hoc independent measures *t*-tests showed that the two groups did not differ at pre-test, at post-test the P⁺ group scored significantly lower on intrapersonal constraints to leisure ($t(14) = -2.42, p < .05$).

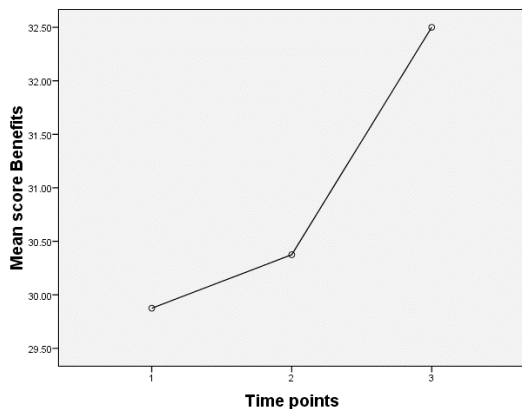


Figure 13a. Change in benefits of leisure.

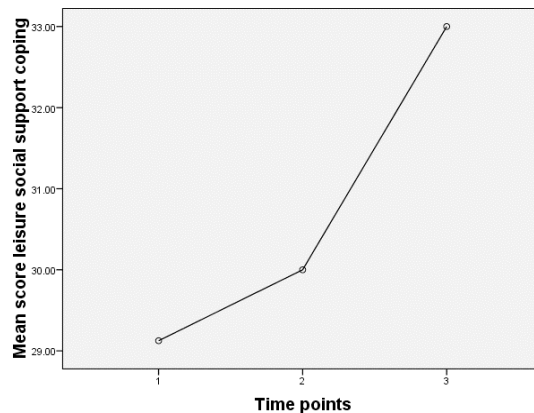


Figure 13b. Change in leisure companionship.

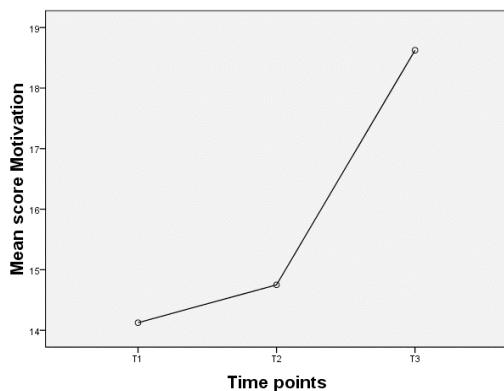


Figure 13c. Change in motivation to increase leisure.

Figure 13. Plots showing change in mean scores for the leisure attitude and behaviour variables for the Control group (T1 to T2) and the P group (T2 to T3).

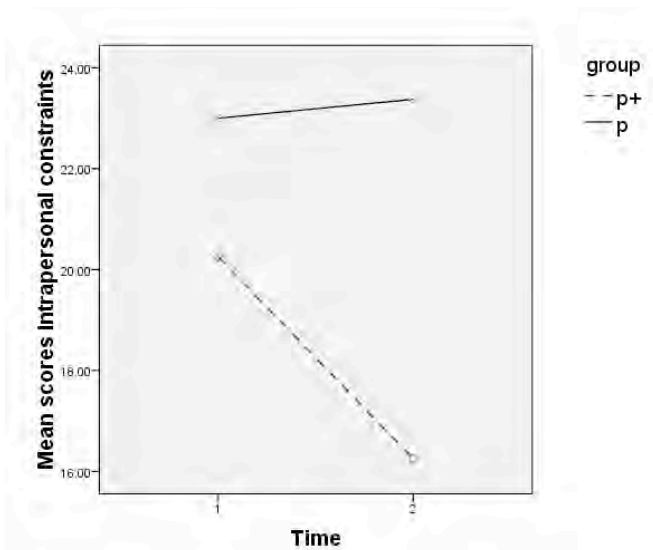


Figure 14. Plot showing the significant interaction effect for intrapersonal constraints to leisure comparing P⁺ to P.

7.2.2 Quantitative Results for Mental Health Variables

7.2.2.1 P⁺ Compared to Control

Table 19 presents descriptive statistics and ANOVA results comparing the three groups on mental health variables. There was a significant main effect for time, which was further qualified by a significant interaction effect (time x group), for stress and positive energy, with high reported effect sizes of .48 and .50 respectively, as calculated using partial eta squared. Firstly, as shown in Table 19 and the pattern of change illustrated in Figure 15a, the P⁺ group showed a significantly greater decrease in stress compared to the Control group, although the groups did not significantly differ at pre or post test. As shown in Figure 15b, the P⁺ group reported a significantly greater increase in positive energy than the Control group, although the groups did not significantly differ at pre or post test.

7.2.2.2 P Compared to Control

A one way repeated measures ANOVA was conducted to assess change in scores across time. As shown in Table 19, there was a significant main effect for Time for the following variables: Stress, positive energy, tiredness, and relaxation. In the case of relaxation, the result was somewhat more tentative as it was only significant at the .05 level. Planned contrasts were performed to examine the difference between the Control and P groups' change in scores across time. As reported in Table 19 and illustrated in Figure 16a, there was a significantly greater decrease in stress during the program period compared to the control period. Repeated measures *t*-tests that compared change scores for the two groups showed a greater reduction in stress ($t(7) = 3.06, p < .05$) after doing the program compared to waiting for it. As reported in Table 19 and illustrated in Figure 16b, there was a significantly greater increase in positive energy after doing the program compared to waiting for it. Repeated measures *t*-tests further demonstrated a significantly greater increase in positive energy after doing the program rather than waiting to do

the program ($t(7) = -3.06, p < .05$). Planned contrasts, as reported in Table 19 and depicted in Figure 16c, further showed a greater decrease in tiredness after the program period compared to the control period, however there was no significant difference of change scores between the two groups.

7.2.2.3 P Compared to P⁺

The results of a mixed between-within subjects ANOVA showed no significant interaction effects, indicating no differences between P and P⁺ regarding effects of the program on mental health variables (Appendix N).

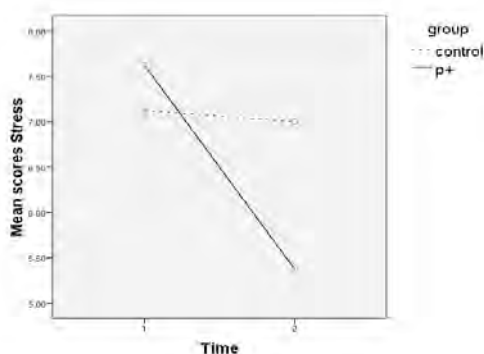


Figure 15a. Change in stress.

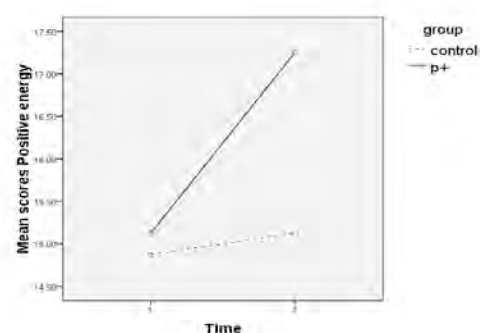


Figure 15b. Change in positive energy.

Figure 15. Plots showing significant interaction effects from pre- to post-program for mental health variables comparing the P⁺ group to the Control group.

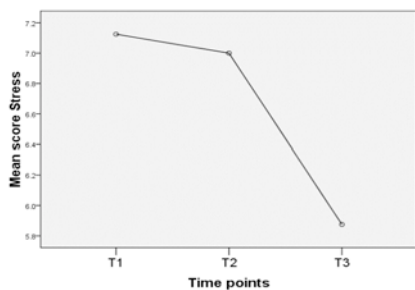


Figure 16a. Change in stress.

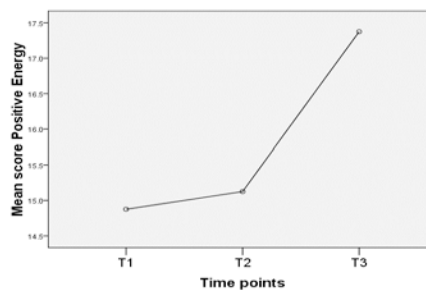


Figure 16b. Change in positive energy.

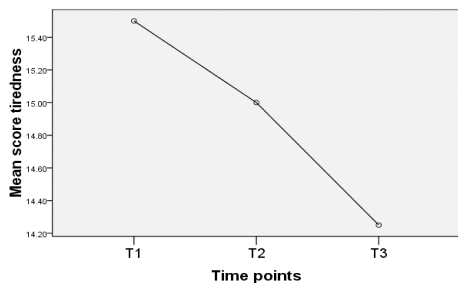


Figure 16c. Change in tiredness.

Figure 16. Plots showing change in mean scores for mental health variables for the Control group (T1 to T2) and the P group (T2 to T3).

Table 19
Descriptive Statistics and ANOVA Results for Mental Health Variables

Outcome variable		Group						F tests			F tests		
		Control (n = 8)		P ⁺ (n = 8)		P (n = 8)		P ⁺ compared to Control			P compared to Control		
		M	SD	M	SD	M	SD	Main effect (time)	Main effect (group)	Interaction time x group (Partial Eta Squared)	Main effect (time)	Planned contrasts	
										Control (T1/T2)	P (T2/T3)		
Depression	Pre	4.75	2.71	2.88	1.96	4.75	2.71	.00	2.54	.00	3.5	.00	3.5
	Post	4.75	2.71	2.88	1.96	4.25	2.31						
	Change	0.00	0.00	0.00	0.76	-0.50	0.76						
Anxiety	Pre	3.63	2.83	3.38	3.38	3.50	2.83	.93	.03	.00	3.42	1	3.5
	Post	3.50	2.83	3.25	3.01	3.00	2.45						
	Change	-0.13	0.35	-0.13	0.64	-0.50	0.76						
Stress	Pre	7.13	3.56	7.63	3.74	7.00	3.38	12.96**	.11	10.37**	14.16**	1	14.54**
	Post	7.00	3.38	5.38	2.88	5.88	2.99			(.48)			
	Change	-0.13	0.35	-2.25	1.83	-1.12	0.83						
Positive energy	Pre	14.88	2.17	15.13	3.60	15.13	2.42	14.12**	.56	8.80**	23.59**	2.33	18.29**
	Post	15.13	2.42	17.25	4.27	17.38	2.39			(.50)			
	Change	0.25	0.46	2.12	1.73	2.25	1.49						
Tiredness	Pre	15.50	4.07	12.50	4.50	15.00	3.63	3.43	2.54	.26	7.82**	3.5	9.00*
	Post	15.00	3.63	11.63	4.03	14.25	3.45						
	Change	-0.50	0.76	-0.87	1.96	-0.75	0.71						
Relaxation	Pre	10.75	1.83	12.00	2.27	10.50	1.41	2.33	1.95	2.33	4.59*	2.33	4.2
	Post	10.50	1.41	12.14	2.23	10.13	1.46						
	Change	-0.25	0.46	0.14	0.00	-0.37	0.52						

Note: ** $p < .01$; * $p < .05$

7.2.3 Quantitative Results for Life Satisfaction Variables

7.2.3.1 P⁺ Compared to Control

Table 20 presents descriptive statistics and ANOVA results comparing the three groups on life satisfaction variables. There was a significant main effect for time for the dependent measures of satisfaction with basic needs and activities of living, although the result for basic needs is somewhat more tentative as alpha only reached .05. Significant interactions were found for satisfaction with basic needs and activities of living. As shown in Table 20 and the pattern of change illustrated in Figures 17a and 17b, the P⁺ group showed a significantly greater increase in satisfaction with basic needs and activities of living compared to the Control group, although the groups did not significantly differ at pre or post test on these variables.

7.2.3.2 P Compared to Control

As shown in Table 20, the results of repeated measures ANOVA tests showed a significant main effect for time on basic needs and activities of living. Planned contrasts revealed that there were no significant main effects for time between T1 and T2 (wait-list time period), however from pre- to post-program (T2 to T3) there was a significant main effect for time for basic needs (Figure 18a), and activities of living (Figure 18b). Repeated measures *t*-tests further demonstrated the beneficial effects of doing the program over waiting for it as significantly greater mean change scores were found for the P group compared to the Control group for satisfaction with basic needs ($t(7) = -3.97, p < .01$) and activities of living ($t(7) = -5.29, p < .01$).

7.2.3.3 P Compared to P⁺

The results of a mixed between-within subjects ANOVA showed no significant interaction effects, indicating no differences between P and P⁺ regarding effects of the program on life satisfaction variables (see Appendix N).

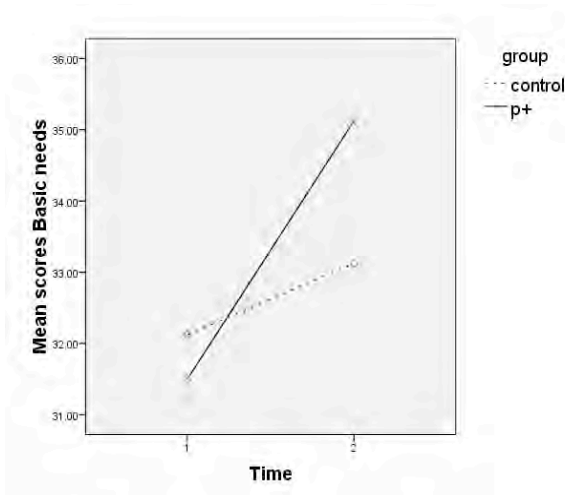


Figure 17a. Change in basic needs.

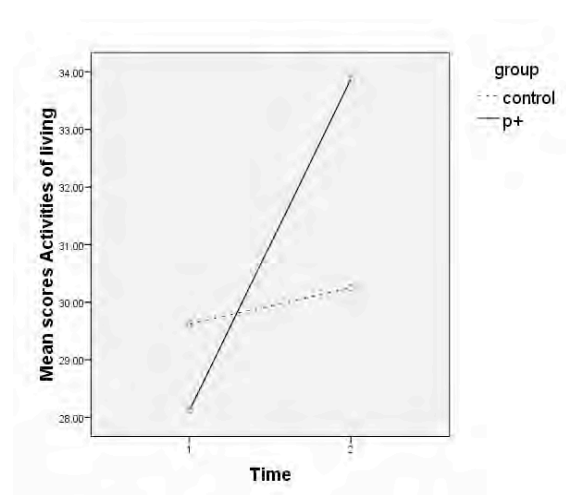


Figure 17b. Change in activities of living.

pre- to post-program comparing the P⁺ group to the Control group.

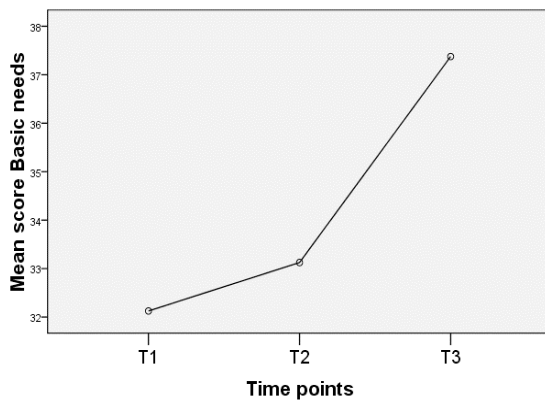


Figure 18a. Change in basic needs.

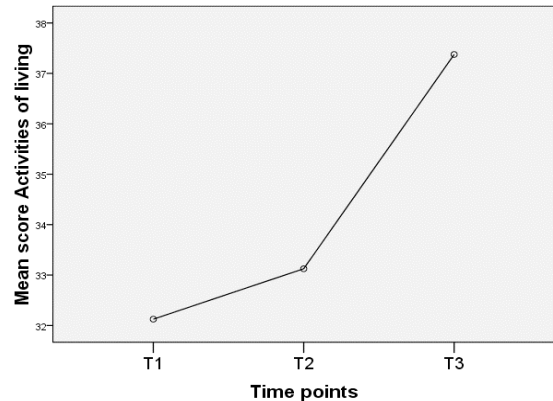


Figure 18b. Change in activities of living.

Figure 18. Plots showing change in mean scores for life satisfaction variables for the Control group (T1 to T2) and the P group (T2 to T3).

Table 20

Descriptive Statistics and ANOVA Results for Life Satisfaction Variables

Outcome variable		Group						F tests			F tests		
		Control (n = 8)		P ⁺ (n = 8)		P (n = 8)		P ⁺ compared to Control			P compared to Control		
		M	SD	M	SD	M	SD	Main effect (time)	Main effect (group)	Interaction group x time (Partial Eta Squared)	Main effect (time)	Planned contrasts	
												Control (T1/T2)	P (T2/T3)
Personal Wellbeing	Pre	65.92	7.83	61.09	14.72	66.17	7.81	.89	.64	.27	1.24	.26	1.50
	Post	66.17	7.81	61.97	13.78	66.70	7.74						
	Change	0.25	1.39	0.88	3.09	0.53	0.99						
Basic Needs	Pre	32.13	4.39	31.50	8.12	33.13	4.09	15.00**	.04	4.83*	17.07**	4.67	19.64**
	Post	33.13	4.09	35.13	9.17	37.38	3.81			(.52)			
	Change	1.00	1.31	3.63	3.11	4.25	2.71						
Activities of living	Pre	29.63	7.56	28.13	8.11	30.25	7.49	26.66**	.08	17.23**	30.83**	3.72	31.12**
	Post	30.25	7.50	33.88	8.17	38.88	5.28			(.66)			
	Change	0.62	0.92	5.75	3.37	8.63	4.37						

Note: ** $p < .01$; * $p < .05$

7.2.4 Summary of Quantitative Results

Results of ANOVAs and planned contrasts demonstrated that the following program outcomes were replicated across the two intervention groups. Compared to the waiting-list control group, both intervention groups reported significantly greater pre- to post-program changes on the following variables: Increased perception of the benefits of leisure, greater motivation to increase leisure, increased use of leisure companionship as a coping strategy, decreased stress, increased positive energy, and increased satisfaction with basic needs and activities of living. In addition, compared to both the wait-list control group and the P group, the P⁺ group reported a significantly greater reduction in perceived intrapersonal constraints to leisure. Lastly, the P group reported a greater reduction in tiredness during the program, compared to waiting for it.

CHAPTER 8: SUMMARY OF QUALITATIVE FINDINGS

8.1 Qualitative Results of Post-Session Feedback

8.1.1 Comparing Sessions and Groups on the Basis of Engagement, Enjoyment, and Likelihood of Incorporating Activities into Life

Immediately after each creative-arts session, participants filled in a post-session feedback form with three self-rating questions and room for qualitative comments (Appendix K). Sessions were conducted in the following order: 1) yoga and relaxation, 2) theatre sports improvisation, 3) belly dancing, 4) group drumming, 5) art making and sensory play (see Appendix J for a detailed description of session components).

Participants rated the degree of engagement, enjoyment, and likelihood of incorporating activities into life outside the program at the end of each session. Two-way between-groups analyses of variance were conducted to explore differences between the groups on mean level of each of these variables as a function of session type. Firstly, participants rated the degree to which they “got into” (i.e., felt absorbed in and engaged by) the activities during the session, from 1 (did not get into the activities at all) to 11 (thoroughly got into the activities). Figure 19 presents the mean engagement ratings for each session reported by the P group and the P⁺ group.

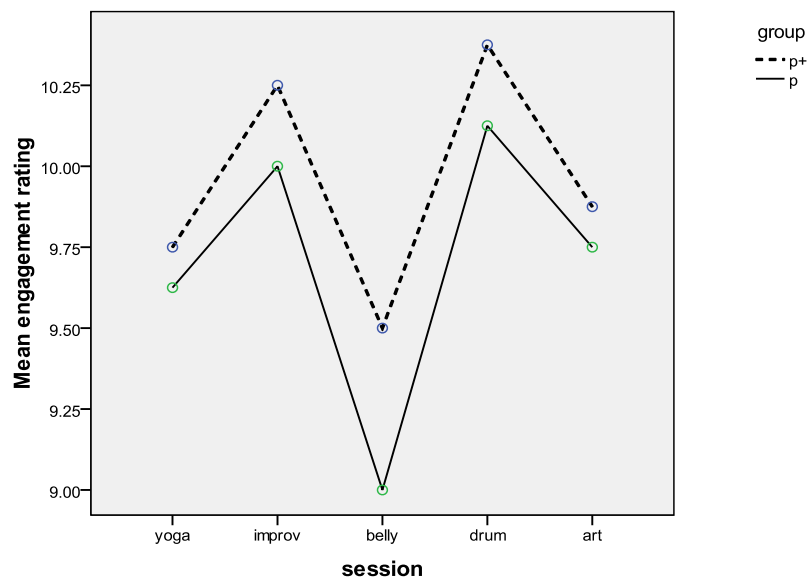


Figure 19. Mean level of absorption and engagement in each session for the two groups.

As shown in Figure 19, all participants reported a very high level of engagement in the activities across all the sessions (ratings were consistently above 9/11 or $\geq 81\%$). The highest level of engagement reported by both groups was during the drumming session, closely followed by the Theatresports improvisation session, while the lowest level of engagement was reported for the belly dancing session. A two-way between-groups analysis of variance was conducted to explore the differences between the groups on mean level of engagement as a function of session type. There were no significant interaction or main effects found, indicating that the engagement was fairly consistent across sessions and the two groups reported consistently similar levels of engagement in each session, as illustrated in Figure 19.

Secondly, participants rated their degree of enjoyment in each of the sessions. Both groups reported the highest mean level of enjoyment in the theatre sports improvisation session, however mean enjoyment ratings were consistently high across all sessions ($\geq 81\%$). The groups followed a similar trend in their enjoyment levels in each session, however the P⁺ group reported a relatively higher mean enjoyment rating for the art and sensory play session compared to the P group, as shown in Figure 20.

As shown in Figure 20, both groups reported high mean enjoyment ratings across all sessions ($>9/11$ or 81%). There was a significant main effect for session type ($F(4, 11) = 3.09, p = .01$), however the effect size was small (partial eta squared = .20). Post hoc comparisons using the Tukey's HSD test indicated that the mean enjoyment rating for the theatre sports improvisation session was significantly greater than enjoyment ratings for belly dancing.

Lastly, participants in each group rated the degree to which they anticipated incorporating activities from the session into their lives after the program finishes,

from 1 (No chance of incorporating activities into my life) to 11 (Definitely will incorporate activities into my life), as shown in Figure 21.

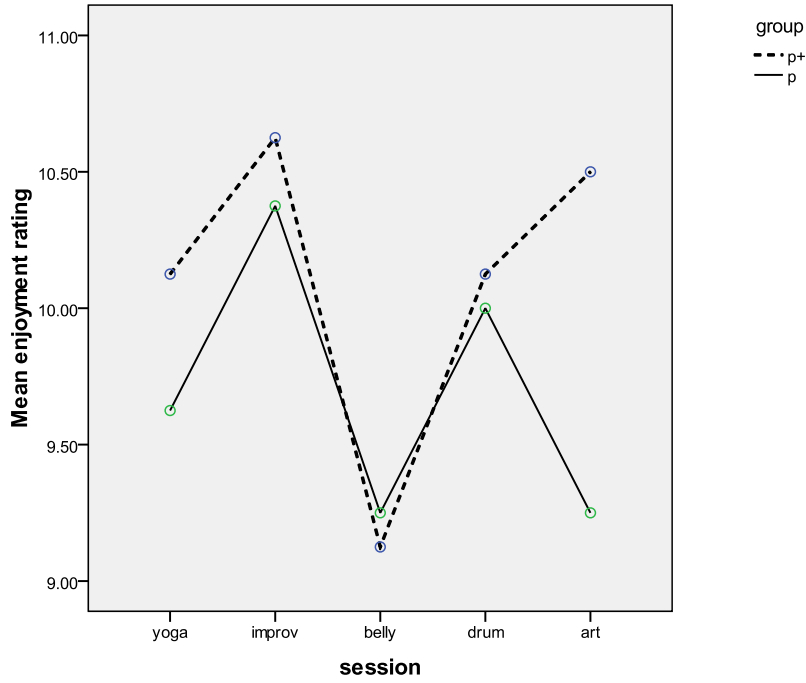


Figure 20. Mean self-reported rating of enjoyment in activities across sessions for the two groups.

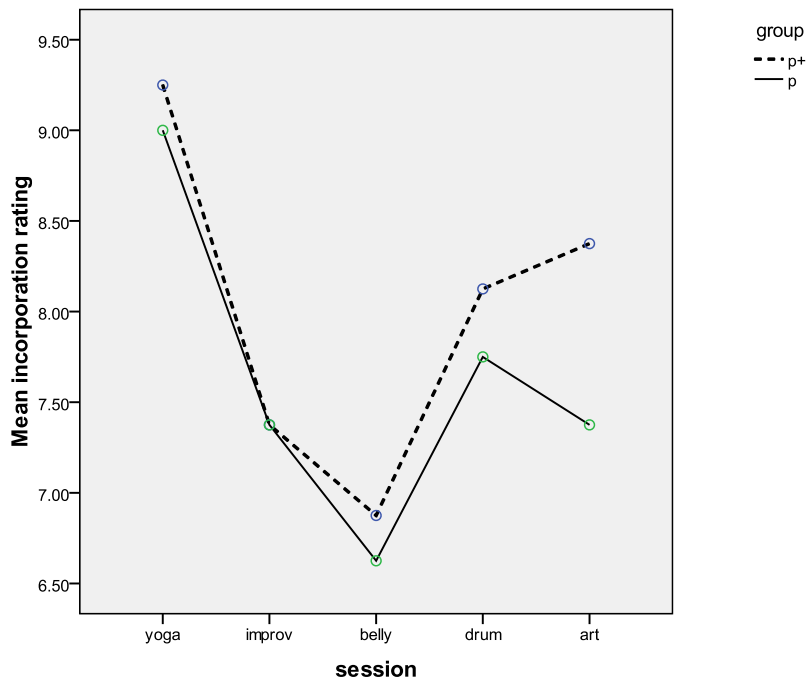


Figure 21. Mean self-reported rating of the likelihood of incorporating activities from the program into life outside the program for the two groups.

As shown in Figure 21, all participants reported a moderate or greater chance of incorporating activities from each of the sessions into their lives. The relative likelihood for incorporating session activities into life followed a similar trend across groups, such that yoga and relaxation, art and drumming showed a relatively higher likelihood of incorporation compared to Theatresports improvisation and belly dancing. Participants in both groups reported the greatest likelihood of incorporating relaxation and yoga activities into their life outside the program. There was a significant main effect for session ($F(4, 11) = 3.52, p = .011$), however the effect size was small (partial eta squared = .17). Post hoc comparisons using the Tukey's HSD test indicated that the mean likelihood of incorporating yoga and relaxation activities into life outside the program was significantly greater than incorporating belly dancing.

8.1.2 Summary of Qualitative Post-Session Feedback Data

8.1.2.1 Session 1: Yoga and Relaxation

Participants reported that the yoga and relaxation session was beneficial in terms of raising their awareness of ways to breathe and yoga postures that promote a relaxed state. Participants reported the following comments: "What an amazing sense of calm"; "I have gained an awareness of my breathing that I've never had before"; "Relaxing, stretching, just not doing anything. Great!"; "It was great – I just wish I could do this weekly. Thank you"; "Fantastic session – the teacher was excellent". Suggested improvements included: "Provide illustrations of the postures to take home"; "Provide padded mats and improve heating in the room"; "Give out copies of the relaxing music played during the session"; and "Include a shoulder massage".

8.1.2.2 Session 2: "Theatresports" Improvisation

Participants universally commented on the laughter, joy and sense of triumph theatre sports improvisation provided. The joyous effects were captured in statements such as: "It's the best high I've had in ages"; "Being able to let go and

have fun and watch the great acting of everyone –I didn't think I would be able to do it at first- a total blast!"; and "Having a good laugh, talking gibberish and having someone's hands acting as your own – what fun. Thank you!"; "This was heaps of fun, more so than I thought it would be. Laughing feels so good. I really laughed today!".

Overcoming fear and operating in the unknown led participants to a sense of mastery or triumph. As one participant wrote:

I was unsure at first as the idea of acting is terrifying for me, especially without a script. But then I discovered its just playing games, making stuff up, having a laugh and saying the first thing that comes to you. I stopped thinking and let go. I am thrilled that I was so out there today.

The importance of a safe place and orientation to the session was highlighted: "It was run fantastically – great facilitator who got us laughing at first to put everyone at ease". In addition to the laughter, joy and sense of triumph reported, several participants reported additional effects of the session. For example, one participant reported that "These sessions are making me realise how important it is to stop and have time out and a different focus". Another commented on the absorbing nature of the session, stating: "It took me a little while to get into it but once I did I got lost in it in a wonderful way". These improvisation games and activities promoted empowerment from a sense of community: "It just flowed out and I knew what to say. I ran with whatever anyone suggested. I made stuff up with the others that I don't think I would have come up with alone". Another reflected on what happens when you "accept the unexpected", stating: "I was laughing my head off at some of the crazy things we came up with. When reality is not in the way you can play with the usual order of things and even the maddest make believe things have their own logic". There were no improvements suggested for this session.

8.1.2.3 Session 3: Belly Dancing

Many participants were initially hesitant about the belly dancing session, however as the following comments demonstrate, they “warmed up” into engagement: “Learning this new form of dance was great exercise and fun”; “It was a very comfortable environment and I moved my body in ways I didn’t think I could”; “To be able to let the belly out!! Fun day and great teaching”; “I enjoyed doing something out of the ordinary. Though I felt uncomfortable at the start I warmed up and was happy to participate”. One participant suggested that it would be good to get a copy of the music to play and dance at home. No other improvements to the session were suggested.

8.1.2.4 Session 4: Group Drumming

Participants reported that the music therapy session was new and energising, with post-session comments including: “I loved combining the rhythms and then going “freestyle”. Loved it!”; “I enjoyed drumming in the group, listening to others and playing as well. When I came today I was feeling quite flat and this activity was uplifting”; “Sharing the laughter and the beats is really fun and took my mind off things”. There were no suggested improvements for this session.

8.1.2.5 Session 5: Art and Sensory Play

Participants commented on their enjoyment of the art making, premised on the lack of any critical or evaluative component: “The art was really relaxed with no expectations which made it really fun”. Some participants were inspired to pursue the art activities at home: “Now I know that adults can love finger painting just as much as kids. I might even get some clay after this and do it at home”. Others commented on the way their mood shifted after expressing themselves through clay sculpture: “The journey from being inside my swirling head to making something I could see and feel that expressed my feelings really lifted me out of being stuck in feeling flat”. The session was infused with communion and connection with others: “Chatting while

getting my fingers into the clay at the same time was really relaxing”. Relief from thoughts and immersion in the body’s senses and intuition was mentioned by several participants: “To be able to create and not to think too much and use my hands. I love to use my hands. Thanks for the activities” and “Great to get back to basics in the sensory world”. There were no suggested improvements for this session.

8.2 Results of Qualitative Analysis of Post-Program Interview Data

8.2.1 Qualitative Analytic Procedure for Analysis of Post-Program Interview Data

Narrative and constructivist theorists view a person’s sense of self as an ongoing construction of identity, rather than locating the self as a static experiencing entity. Dan McAdams, for example, formulated the term “selfing” to describe a process in which, through narrating our lives to others, we adopt experiences as part of ourselves:

To self - or to maintain the ‘stance’ of an ‘I’ in the world - is to apprehend and appropriate experience as a subject, to grasp phenomenal experience as one’s own, as belonging ‘to me.’ To self, furthermore, is to locate the source of subjective experience as oneself. (McAdams, 1997, p. 56)

From this perspective, the follow-up interviews provided a forum for participants to author and re-author their leisure narratives, providing them with a “selfing” avenue to consolidate and integrate realisations and developments experienced during the program. From a narrative psychological perspective the follow-up interviews functioned as an identity-affirming intervention and an assessment tool.

The qualitative analytic methodology encompassed conducting interviews and transcribing data, reducing data into quotations, coding quotations into thematic categories and sub-categories, and verifying the coded data.

8.2.1.1 Interviews and Transcription

Interview questions were reviewed by three senior researchers to ensure that they had the potential to elicit truly open-ended responses consistent with the evaluation aims. The interview was conducted by a hired research assistant who was not involved in the delivery of the “Me Time for Mums” program, therefore maximising participants’ capacity to provide honest responses. Interview transcriptions were read by the student researcher and an independent research assistant to scrutinise the data for evidence of interviewer bias and leading questions, as well as to ensure that the interview elicited truly open-ended responses. In accordance with Patton’s (1980) recommendations for a recursive model of interviewing, specific clarification and elaboration probes (e.g., “Can you tell me what you mean by...?”; “Can you tell me more about...?”; “What was it about the program [process] that led to[outcome mentioned]?”) followed the open-ended responses to gain more in-depth individualised information. The basic unit of analysis involved quotes from the transcriptions that represented “...a statement made by the subject which was self-definable and self-delimiting in the expression of a single, recognizable aspect of the subject’s experience” (Cloonan, 1971, p. 117, as cited in Scanlan, Stein, & Ravizza, 1989). All audiotaped telephone interviews were transcribed verbatim. A total of 154 quotes, which varied in length from a few words to a paragraph, comprised the data content for analysis.

8.2.1.2 Coding Data into Thematic Categories

Analysis of data content into interpretable and meaningful themes and categories employed a combined deductive and inductive approach. The deductive approach involves using a predetermined set of themes and categories to organise the quotes, while the inductive approach allows the themes and categories to emerge from the quotes (Patton, 1980).

The first line of analysis was deductive in that quotes were isolated according to the following umbrella program-evaluation domains: Program outcomes (attitudinal, psychological, behavioural, social), program processes (active ingredients promoting program outcomes), constraints to leisure (intrapersonal and structural constraints), and suggested changes to the program. The student researcher and research assistant independently read all transcripts and coded quotations according to these domains. They then reconciled and argued their differences of opinion until a consensus was reached. Within these program-evaluation domains, a “start-list” of thematic categories was formulated, based on the salient conceptual frameworks underpinning the development of the program and prior leisure and carer research. Additional emergent categories and sub-categories were inductively formed that did not relate to pre-conceived theoretical constructs.

The constant comparative method of content analysis was used which involved comparing and contrasting each quote with all the other quotes and emergent themes to unite quotes with similar meaning and to separate quotes with different meanings (Glaser & Strauss, 1967; Patton, 1980). The analysis continued until it was not possible to locate further underlying uniformities to create either categories or sub-categories. Table 21 presents the constituents of each thematic category that emerged from the interviews. It is worth acknowledging that the discrete thematic categories created in the qualitative coding process was by no means attempting to provide a veridical representation of reality. Lived experience is of course more fluid, inchoate, overlapping, and interdependent than a set of themes can convey. The post-program interviews were intended to allow participants to narrate their experiences in their own voices, while the reduction of narratives into themes provided for an efficient way of conveying these narratives.

In accordance with Miles and Huberman's (1994) template coding approach, matrices were created for each participant. The rows contained the categories and sub-categories within the four over-arching program-evaluation domains. The columns contained quotations. At this stage, each quote was reassessed to ensure that it reflected a singular aspect of the participants' experience. Some quotes were broken down further and re-assigned to more appropriate sub-categories. Consensus validation between the student researcher and research assistant was achieved in terms of the final form for each quote and the categorisation of themes. Quotations from all participants were then grouped under the finalised set of categories and sub-categories (Appendix O).

8.2.1.3 Verification of Coded Data

Participants had the opportunity to validate, confirm and reinterpret the findings, thereby ensuring an authentic reflection of their experience. Each participant was sent a synopsis of the findings, accompanied by quotations from her interview that would be used in reporting the study, and was asked for her comments and amendments.

Nine out of sixteen participants responded with gratitude for the provision of results, concurring with the way their data had been represented. One participant called the student researcher to qualify her findings by stating: "I had just got back from holidays so this assessment has to be seen in that context. I was away for 5 days by myself with some girlfriends and so I was relatively relaxed. But I am not usually like this. It's about context of assessment". Another participant objected to the use of verbatim quotations and asked for words such as "um" and "you know" to be removed, arguing that these words are not usually seen in print and therefore give the impression that the speaker is less articulate than she probably is. All such words that could be removed without affecting the meaning of what was said, as well as some repeated

words, were removed from all quotations to ensure consistency of data presentation.

8.2.1.4 Presentation of Qualitative Findings

In line with previous recommendations for reporting qualitative research (Krane, Andersen, & Streat, 1997), as much primary data (i.e., quotations) as possible are presented. The next section provides a synopsis of each category and the frequency with which categories were represented across all participants ($N=16$), as well as by group (P compared to P⁺), allowing for comparison of qualitative outcomes. Because qualitative data analysis tends to be intertwined with interpretation (Stake, 1995), this frequency analysis of qualitative data is presented first.

The next section presents illustrative quotations to explicate each thematic category and sub-category within the four domains of program outcomes, program processes, constraints to leisure, and suggested changes and extensions to the program. The delineation of program processes and program outcomes was made on the basis of participants' own discourse in combination with theory and research. Table 22 provides an overview of the proportion of participants in the whole sample ($n = 16$) and the proportion of participants within each group reporting each thematic category.

Table 21

List of Thematic Categories and Their Constituents

Thematic categories	Constituent themes
Program Outcomes	Hypothesised effects of doing the program
Attitudinal outcomes	<p>Reduced intrapersonal constraints</p> <ol style="list-style-type: none"> 1. Increased permission to engage in leisure and self-care 2. Increased sense of entitlement to engage in leisure and self-care 3. Increase value of leisure and awareness of the importance of leisure to wellbeing <p>Acknowledgement of personal needs</p> <ol style="list-style-type: none"> 1. Increased self-acceptance of having personal needs 2. Increased self-determination in leisure
Affective outcomes	<p>Uplifted mood</p> <ol style="list-style-type: none"> 1. Experience of increased wellbeing 2. Decreased stress and emotional “catharsis” 3. Experiencing the “lighter side of life” through being playful, spontaneous, and imaginative <p>Affect regulation</p> <ol style="list-style-type: none"> 1. Increased ability to get perspective on distressing situations and problems 2. Realisation of how mood positively reacts to leisure behaviour 3. Sense of empowerment in having the ability to shift mood state
Behavioural outcomes	<ol style="list-style-type: none"> 1. Perceived increase in leisure options 2. Increased participation in specified leisure activities <p>“Seizing moments”</p> <p>Shift in approach to using time from only doing leisure when there is a large enough block of time towards “seizing moments” for leisure and self-care activities</p>
Program Processes	Hypothesised mechanisms causing program outcomes
Flow	<ol style="list-style-type: none"> 1. Deep absorption, vital engagement and concentration in activities Distraction from self and worries through immersion in activities 2. Movement in and out of self-awareness 3. Taking risks and experiencing a sense of accomplishment 4. Altered sense of time
Self expansion	<ol style="list-style-type: none"> 1. Reviving and strengthening aspects of self beyond caregiver role 2. Sense of increased opportunities for self-expression 3. An attitude of self-exploration and self-discovery 4. Sense of “self-in-the-making”, and experiencing self in a process of “becoming”

Restorative respite	<ol style="list-style-type: none"> 1. The program as a restorative mental break 2. The program as facilitating “getting out of the caregiving world” 3. Engaging in creative arts activities as engendering “real respite”
Social support	<p>Social connection</p> <ol style="list-style-type: none"> 1. Increased connectedness 2. delighting in each other’s company 3. social modelling <p>Social legitimacy</p> <ol style="list-style-type: none"> 1. Provision of social legitimacy to engage in leisure 2. External support through provision of community-based leisure program 3. Social and structural support for leisure serving to override personal constraints
Leisure constraints	<p>Constraints to increasing leisure and self-care</p> <p>Intrapersonal constraints</p> <ol style="list-style-type: none"> 1. Increased permission, entitlement, value of leisure 2. Increased trust that child will be okay 3. Increased ability to relax despite caregiving duties 4. Increased ability to shift focus to self 5. Decreased guilt and negative connotations of leisure <p>Structural constraints</p> <ol style="list-style-type: none"> 1. Lack/changes of respite 2. Untrained carers 3. Nature of care needs (complications, increase severity symptoms) 4. Lack of case management 5. Financial and transportation barriers
Program Changes	<p>Suggested changes and extensions to the program</p> <ol style="list-style-type: none"> 1. More support to access programs 2. Program content and structure 3. Location, timing and continuity

Table 22

Proportion of Participants in the Whole Sample (N=16) and the Proportion of Participants Within Each Group Reporting Each Thematic Category

<u>CATEGORIES</u>	All participants	P⁺ (n = 8)	P (n = 8)
<u>PROGRAM OUTCOMES</u>			
Change of attitudes towards leisure and self-care			
Reduced intrapersonal constraints	7 (43.75%)	5 (62.5%)	2 (25%)
Acknowledgement of personal needs	9 (56.25%)	6 (75%)	3 (37.5%)
Affective outcomes of program			
Uplifted mood	11 (68.75%)	6 (75%)	5 (62.5%)
Affect regulation	13 (81.25%)	6 (75%)	7 (87.5%)
Leisure and self-care behavioural change			
Increased leisure	12 (75%)	8 (100%)	4 (50%)
Seizing moments	7 (43.75%)	5 (62.5%)	2 (25%)
<u>PROGRAM PROCESSES</u>			
Flow	10 (62.5%)	7 (87.5%)	3 (37.5%)
Self expansion	11 (68.75%)	8 (100%)	3 (37.5%)
Restorative respite	8 (50%)	7 (87.5%)	1 (12.5%)
Social support			
Social connection	9 (56.25%)	6 (75%)	3 (37.5%)
Social legitimacy	8 (50%)	5 (62.5%)	3 (37.5%)
<u>LEISURE CONSTRAINTS</u>			
Intrapersonal constraints	7 (43.75%)	2 (25%)	5 (62.5%)
Structural constraints	9 (56.25%)	4 (50%)	5 (62.5%)
<u>PROGRAM CHANGES</u>			
Suggested changes and extensions to the program			
More support to access programs	8 (50%)	2 (25%)	6 (75%)
Program content and structure	6 (37.5%)	2 (25%)	4 (50%)
Location, timing and continuity	13 (81.25%)	7 (87.5%)	6 (75%)

8.2.2 Attitudinal Program Outcomes

Attitudinal outcomes of the program comprised two main themes: Reduced intrapersonal constraints to leisure and increased acknowledgement of personal needs.

8.2.2.1 Reduced Intrapersonal Constraints

Nearly half (43.75%) of the participants reported that the program resulted in reduced intrapersonal constraints to doing leisure and self care. In the P⁺ group, 62.5% of participants reported this outcome, compared to 25% of the P group. Reporting reduced intrapersonal leisure constraints appeared synonymous with a reduction in the “emotional traps” associated with the ethic of care. These included an increased sense of entitlement to leisure, reframing leisure as being necessary for self-care rather than selfish, and decreased guilt for taking time for self. Several participants reflected on how the program strengthened their value of doing leisure.

P⁺2 I am more aware of the importance of making time for myself, especially general exercise.

Other participants reported that the content of their values did not change, but the program augmented the salience of these values to the point of motivating congruent behaviour.

P4 My beliefs have not changed but they have been strengthened to the point of doing something about it.

Increased entitlement appeared to be associated with consciously giving oneself permission for leisure.

P⁺5 The program made me think of me time as my right as a human being. I do feel more entitled to take my own time. I keep having to give myself permission...

Furthermore, increased entitlement to leisure brought with it a reduction in guilt for some participants.

P6 During the program I had to train myself not to feel guilty in taking time for my own leisure. That's not my natural self. So, I kind of faked and said: "Hey I'm going out and I'm going to enjoy it I hope you guys do okay"; Not sorry at all, but I had to train myself to be that way. I feel very empowered – liberated - when I do it. It's funny. When I demand it, then they [her family] give it to me, and they act like I am entitled. When I act apologetic, then they kind of treat me like I am guilty. You are treated like you treat yourself.

This data suggests that claiming guilt-free entitlement to leisure may be “symbiotically” related to receiving support from significant others to pursue leisure. In addition to letting go of the guilt tied to leisure, participants also reported letting go of the need to continually “get things done”. Indeed, entitlement to leisure appeared to be associated with exercising choice to leave things undone and take a break.

P+6 The trick is to know that there is always stuff to do or finish or prepare. It's never-ending. You just have to force yourself to step out of the rat wheel in spite of everything to have a break and somehow trust that things won't fall apart.

8.2.2.2 Acknowledgement of Personal Needs

More than half of all participants (56.25%) reported increased acknowledgment of personal needs. There was a pronounced between-group difference in that 75% of the P⁺ group reported this theme compared to 37.5% of the P group. In the path towards acknowledging personal needs, participants reported a growing awareness of the extent to which their life was premised on self-denial and disavowal of being a person with needs.

P+8 At least for the past 5 or 6 years, I have struggled with boredom or monotony. Just being trapped in a routine. I haven't really done activities that inspire me or grab me.

P⁺7 For a long time I've probably just sort of denied that I have any needs of my own...treated myself like a robot.

Realisation of self-denial was accompanied by increased awareness of the risks of not taking time for self-care for several participants.

P⁺6 Now I think twice before I fill up the whole day running around with caregiving and other housework because I know that I will deplete myself and probably end up going back into bad habits...I used to over-eat in my down time and I put on heaps of weight and felt embarrassed and trapped.

P⁺2 If not now, when? And if not me, then who? I know I can't keep putting myself off, because I'll fall in a heap.

As a result of doing the “Me Time for Mums” program, participants reported greater self-acceptance of having personal needs and greater willingness to attend to these needs to promote coping and wellbeing.

P⁺7 I'm more conscious of myself and the impact of caring and how I need to do pleasurable things to cope with the load.

P⁺4 From the first interview I felt affirmed as an individual with needs of my own. Now I tell myself that 'I am a woman with my own needs' every day.

The choice to attend the program appeared to generate an (albeit tentative) sense of self-determination regarding leisure and time use.

P⁺6 This program has been the first time in ages that I have felt that I owned some of my time, which I hope I can continue.

P⁺6 When my daughter is in care I allow myself the opportunity to do what I feel like for at least an hour a day. It's my private time, which I try to protect instead of filling it with things I have to do.

This outcome seemed to result from “de-catastrophising” the impact of being temporarily absent from caregiving, as expressed by P3: Life goes on even if I put myself first sometimes. This realisation was particularly apparent for participants who discovered that they could leave the house, which was an important manifestation of increased acknowledgment of personal needs and self-determination. For several participants, this discovery was only achieved through attending the program and amassing direct evidence that things were okay without them.

P2 The most crucial thing I got from the program is realising that I can get out of the house and life doesn't end.

Given that home generally houses people that need care, getting away offered participants the chance to stop caregiving and focus on themselves and the world “out there”.

P7 I have realised that getting out of the house keeps me sane. I need to get away from anyone who needs me so that I can refuel. It keeps me in touch with the fact that there is a whole world going on out there, which I can easily feel out of touch with.

8.2.3 Affective Program Outcomes

Affective outcomes of the program comprised two thematic categories: Uplifted mood and increased affective self-regulation.

8.2.3.1 Uplifted Mood

The program engendered an uplifted mood for the majority (68.75%) of participants. A similar proportion of participants in the P⁺ group (75%) compared to the P group (62.5%) reported this outcome. Getting in touch with the “lighter side of life” through being playful, silly, uninhibited, and spontaneous was joyfully recalled by many

participants. In particular, the tension relieving and energising functions of laughter were emphasised, and for some participants, laughter was a “gift that keeps on giving”.

P⁺3 God, did I realise how much I needed a good time!

P⁺8 The group got me back in touch with my silliness and laughter. It's been a long time since I had a good laugh like that in the theatre sports. Each one of us had our own blocks to doing the program but together we could override them.

P⁺4 Sculpting clay and doing finger painting and when we threw paint onto this big sheet on the wall it made me laugh...and still does!

P2 It's so good to go somewhere and have fun!...Have a big laugh, relax, and be with others in similar situations as you.

P3 This program, especially the drumming and belly dancing, gave me intense pleasure and intense emotional satisfaction, so it definitely contributed to my wellbeing. The group freed me, lightened the heaviness.

P5 I couldn't stop laughing when P7 was narrating in gibberish and I was translating for her with P7's arms as my own! Whenever I remember it I grin. It just goes to show how much fun you can have when you get a bunch of women in a room with a lot of pent up energy!

P7 But the best part was being able to shed all my inhibitions and being able to be myself...

With its focus on fun, creativity, and frivolity, the program provided participants with relief from operating in permanent “survival mode”.

P⁺4 The program helped me to lighten up and get out of always planning and worrying.

P3 For a long time my whole aim was to just get through the day until the time when I could go to bed, read and sleep. I looked forward to the program

each week as it was new and made me feel more energised and interested in things again.

P7 ...not having to talk to therapists or professionals, not being on guard the whole time was wonderful.

Enjoyable experiences during the program appeared to provide a “circuit breaker” to depressive states and remind participants of other, more pleasant ways of experiencing and appraising themselves in the world.

P⁺1 I was in a funk at the time of the first interview and going to these sessions took me out of it...interrupted the downward spiral....It got me out which was very important. It got me into...back into my imagination...it got me around strong people, it got me away from home...it gave me a space to just relax.

P⁺5 Well of course my mood feels better, you know. I've been a bit depressed since my son had an extra diagnosis and the activities in the group lifted my spirits. I got a real joy from it.

8.2.3.2 Affect Regulation

The majority of all participants (81.25%) reported that doing the program increased their awareness of the mood-regulating power of doing leisure and creative activities. The proportion of participants reporting this outcome in the P⁺ group (75%) was similar to the proportion of participants in the P group (87.5%). Participants described the way that focusing on creative arts activities helped to reduce stress, restore perspective, and improve overall wellbeing.

P⁺4 When so much that I have to deal with is frightening and worrying, the process of focusing on a creative project brings things back into perspective.

P⁺6 I am more relaxed if I have time out for myself and this makes me more able to look after my kids in good spirits- which is better for them.

P7 It's amazing to have a piece of paper and paints, and life can be temporarily reduced to putting colours and shapes on the paper. Nothing else you have to do, no where else you have to be... When so much that I have to deal with is frightening and worrying, the process of focusing on something creative gives me back perspective.

P8 I was reminded of the power of music to ground me. If I have some difficult tasks to do and I hear, say on the radio, the right music, I do better, I'm more efficient. I work better. I think more clearly, I feel healthy. If I'm down or feeling tired, or my muscles are aching and I play some music and dance around I feel better. I feel fitter...

Several participants narrated their experiences of tension reduction and resulting feelings of calm and relaxation from participation in various sessions.

P⁺5 The yoga and relaxation session taught me how to breathe from the diaphragm, which I had never ever been shown before. We did this yoga pose which involves lying down flat with your palms open and breathing from our tummy to the top of the chest. The instructor suggested that we do it everyday for five minutes when we need to recharge and I have been doing it. It's really relaxing and the pose itself feels like you're letting go you know, just accepting things as they are and having a rest. It gave me a new relaxing way of being in my body.

P2 ...I usually went in feeling stressed and left having blown off a lot of pressure- more ready to get on with the day to day jobs not feeling so weighed down.

Through doing the program, participants gained first hand evidence of their ability to shift into more positive moods in a short space of time.

P4 I found this time, although it was a very short space of time, a special time to "tune-in" and relax. . . just calm down and relax and I guess to have some light-hearted fun. As the program went on it was easier to relax more quickly and leave home stuff at home.

P⁺6 There was this culture in the program that we could, in two hours, have the possibility of having enjoyment. They believed in the possibility of suspending your worries and immersing yourself in the activities. It was initially hard to come in the space and get out of my head but over the time of the program I could do it faster...

With this increased appreciation of the way they can reposition themselves from caregiver to leisure seeker, participants reported greater empowerment in being able to lift their mood state.

P7 It is very satisfying to have something I can do to lift myself when I'm down.

P⁺5 I have realised that my meaning and satisfaction in life comes from what I actually do each day; maybe it's no more complex than that.

P⁺1 I think if you didn't have pleasure and your own interests and things you find interesting and meaningful, you get depressed. There'd be an emptiness there. This is what was happening to me. The program and now the short course has enhanced my life and helped me to fill that emptiness.

P3 ...and I use it [music at home] to feel better. I think it gets me awake, thinking well, and having more energy to function better. It's uplifting.

The power of doing creative arts activities in terms of emotional “catharsis” or, in other words, increasing the “motion” in emotion, was articulated.

P⁺7 When I made my clay sculpture it really meant something to me, because it's expressing things that I keep inside and don't often discuss with others. I mean it is important because it validates you and, especially when you don't have much time to think about yourself or how you feel or what you need, it tells you what's going on inside. And it tells others who you are sharing with in the group. So instead of being all caged up, it releases your mood and you make something you can see and touch. It helps move you through the mood.

It seems that creative activities functioned to help participants express and externalise their emotions and thereby reduce the extent to which they were “fused” with difficult emotional states. For several participants, the experiential program led directly to reframing unhelpful beliefs and attitudes, which in turn improved their affect regulation. For example, one participant commented that she had begun to think of socialising as being arduous, and she reported having a “low people tolerance”. This participant altered her attitude as a result of doing the program.

P5 When I do have some time, going out and being with people feels like such an effort, or I don't feel presentable or can't be bothered. I have had a low people tolerance. I am trying to shift my thinking now because I found that going to the program didn't drain my energy; it gave me energy. So now I am more willing to go out even when I don't feel like it, and you do come home uplifted.

It seemed that daily life outside the program continued to exert its tiring effects, however participants commented on how they felt uplifted during the program.

P⁺3 I ended up feeling like I'd got rid of a lot of pent up frustration and tension. I just really hit that drum [laughter]. I came to that session so stressed from the morning and I left different and...just more relaxed and clearer. I probably play atrociously without rhythm but feel so much better for it.

Through doing the program each week, several participants learnt to espouse the “do it anyway” approach to combat resistance to socialising and leisure, and to use consequential thinking as a motivator (i.e., I will feel better after I do leisure).

P1 The first couple of weeks there was so much going on at home that even though I wanted to go to the sessions, it felt really hard. And I questioned whether I should go if I'm feeling exhausted and stressed. But I said I'd go and all the care was paid for and arranged already by the program. I decided

that I had made a commitment to myself and I went no matter how I felt. I was always stunned at how I felt buoyed up by the group and more able to get on with the day. So by the third session, there were no voices holding me back. I looked forward to it and went more easily even if I was tired.

8.2.4 Behavioural Program Outcomes

Leisure behavior change comprised two thematic categories: Increased leisure behaviour and seizing moments for leisure.

8.2.4.1 Increased Leisure Behaviour

The majority (75%) of participants reported increased leisure behaviour since completing the program. There was a pronounced between group difference in that 100% of participants in the P⁺ group reported this outcome, compared to 50% of participants in the P group. The category of increased leisure encompassed actual leisure behavioural change as well as increased awareness of leisure opportunities. In some cases, participants expressed changing their leisure time use from engaging in passive activities, such as watching television, to active and creative pursuits. Participants in the P⁺ group reported specific leisure behaviour changes, covering a wide variety of creative modalities.

P⁺1 ...I hadn't even held clay before and after the program finished I enrolled in a five week long CAE ceramics course...

P⁺1 We have a small shed at the bottom of our garden which my husband says he'll turn into a studio for me - it will be my place for clay where I can go and be me and keep all my stuff.

P⁺2 This course has given me the space to think about myself and it has given me a greater knowledge of what's out there to do. I got a lot of good feedback in the belly dancing session and felt that it came naturally for me. [The belly dance facilitator] put me in touch with a place and I have recently enrolled in a dance course.

P⁺2 I try to do a walk each day now which I didn't do as regularly before because I was always telling myself that I don't have time.

P⁺3 I am doing a course in drumming at this place that [the group drumming facilitator] told me about. And I went and bought my own drum.

P⁺4 After the art session I went and bought clay...I find it's a good way to hit the pause button when I can during the day or in the evening instead of just switching on the TV.

P⁺5 [The relaxation/yoga facilitator] got me linked into a yoga school and I have been going weekly or fortnightly since the program which helps me to reset myself.

P⁺6 I do some of the activities. We did finger painting and clay in the program and now I've set up a space at home to do it. Also I have looked into music therapy for my daughter. This was inspired by the group as I loved the drumming. Through the music facilitator I found out about the Access drumming circle for people with disabilities which is on every month. It's great. It's an evening off for me and I know she's having fun.

P⁺7 I found out about things I never heard about before. [The student researcher] introduced us to laughing yoga and I'd never heard of such a thing before. There is actually one every Saturday morning in the park near me which I go to when I can. There is a concept of fake it till you make it and it has become my mantra. I have taken to laughing in the car!

P⁺8 I loved it [theatre sports] so much and I was really inspired so I took myself off to the theatre sports competition, on Sunday evenings at "Theatreworks" in St Kilda for several weeks after the Me Time program finished. It was hard at first to allow myself the outing as I didn't think my husband would be able to manage without me, but it worked out fine. I keep my phone on silent and tell him to call only in an emergency. I introduced some friends to it and we have a girls' night and love it!

In contrast to the specific leisure behaviour changes reported by participants in the P⁺ group, only two participants in the P group reported specific behavioural change.

P3 I went and bought an Ipod and Middle Eastern CDs and I dance to it in the car and at home...

P7 "I've started making greeting cards with finger painting and drawing. Or if I have no energy for making things, I put music on that calms me or lifts me up. I may even start selling my cards through the respite centre down the track".

The other two participants reported their intention to expand their leisure practices, rather than actual behavioural change.

P1 In the lunches afterwards we shared some respite ideas and I learnt a new place for my son to go, which will free up an afternoon a week to do things for myself.

P2 Yes, it's opened my eyes to things you wouldn't normally look at doing yourself.

8.2.4.2 Seizing Moments

Of the 16 participants, 43.7% reported becoming more opportunistic and vigilant to "seize moments" of time for leisure more regularly throughout the day. The proportion of participants reporting this theme in the P⁺ group (62.5%) was greater than the P group (25%). Attending the program showed several participants that taking time for leisure is under their conscious control.

P⁺1 Yes, I've always known there is a benefit of having time out and time to explore your own interests, but I've always just thought that I have no time for those sort of things. But I could come to 'Me Time' so I have learnt that it is possible to make time.

P3 I have been reminded of my interests and ability to access them if I choose a little bit every day.

Seizing moments emerged from several background processes, including relaxing expectations, giving oneself permission to leave things undone, setting up the environment to promote creative activities, re-evaluating the nature of time to privilege quality over quantity, and making active choices.

P⁺3 If I relax the expectations I put on myself, then there is more space in the day where I can do things just for my enjoyment.

P⁺6 I guess this has made me more opportunistic about taking time for myself and knowing that I can shift gear and leave things undone. And it will be okay.

P⁺4 ...now it's [the clay] always out and on the ready in case there is a spare 20 minutes.

P⁺8 In the yoga session we learnt that if you lie down on the ground and breathe deeply following a certain method for fifteen minutes, it's as good as an hour's sleep, so I have been doing that when I can remember and it does refresh me.

This shift regarding leisure time indicated that participants had changed their thinking from an absolute “all or nothing” stance towards being “opportunistic” about doing leisure. This was poignantly represented in P7’s experience. She disclosed that before finding out about the program “I had had it up to my throat - I wanted to escape”. She disclosed that she used to imagine staging a car accident, admitting herself into hospital and running away, so that “I would be freed from all my responsibilities”. The program seem to provide a springboard to adopting an opportunistic stance towards making time for regular leisure and, in so doing, it functioned to reduce P7’s “drastic” fantasies of escaping her life.

P7 It's strange...those drastic fantasies are no longer on my mind ...Instead of wishing I could leave it all I have changed my approach... Now I'm on the ready to take full advantage of moments for myself throughout the day, like I've got back into knitting in my spare moments and listening to music, and I've started making greeting cards, which has made a huge difference in my life.

In summary, the most frequently reported outcomes of the program were increased affect regulation and increased leisure behaviour. There was evidence that doing the pre-program intervention promoted greater reduction in intrapersonal constraints to leisure, greater acknowledgement of personal needs, greater willingness to seize moments for leisure, and more specific leisure behavioural change, compared to doing the program alone.

8.2.5 Program Processes

Analysis of the interview data revealed that certain experiences in the program enabled the abovementioned attitudinal, affective, and behavioural outcomes of the program to occur. These “active ingredients” of change were categorised as “program processes”.

8.2.5.1 “Me Time for Mums” and the Phenomenology of “Flow”

“Flow”, a construct describing a psychological state characterised by intense concentration and full involvement in an activity (Csikszentmihalyi, 1990, 1996, 1997), was reported by 62.5% of participants. A greater proportion of the P⁺ group (87.5%) narrated their experience of flow than in the P group (37.5%). Participants narrated various components of the phenomenology of flow, including: taking risks and embracing challenges, absorption in activities, reduced self-consciousness and rumination, an altered sense of time, and feelings of enjoyment and accomplishment.

8.2.5.1.1 Risks and Experiencing an Optimal Balance Between Challenge and Skills. The challenges and risks involved in doing certain activities during the program and the captivation and sense of accomplishment this brought was expressed by several participants. In particular, participants reported optimal challenge, taking risks, and absorption in connection with the drumming, belly dancing, and, particularly, the theatre sports improvisation session. These activities appeared to have the added quality of novelty.

P⁺5 ...it's new, it's a bit challenging. You have to take a bit of a risk and just give things a go. I was especially nervous to put on the skirts and dress up for the belly dance session as I've put on so much weight but I did it and felt better for not holding myself back afterwards. And we were all a bit shy at first. No one had been to the program before so we were all trying something different and all encouraged each other .

Several participants spoke of the challenge of theatre sports because it is an emotional risk to think and act spontaneously, especially in front of a group.

P⁺1 It [theatre sports] takes a huge amount of risk. You just have to sort of trust in your own capability that you're going to be okay in the process. The saying yes ...what they call the idea of 'accepting all offers' is a key thing. You just pick up and run with ideas. You just somehow get this confidence and, you have no idea what's going on and what you're going to say or do ahead of time and..well.. it all just works!

As this quote illustrates, the shared creative activities were risky in a way that was communal and engaging, as opposed to alienating. In contrast to the risky situations and unpredictability typical in many of the participants' lives, the risks they experienced in the program were fun and stimulating, such that they could happily relinquish control with the knowledge that danger or failure was impossible.

P⁺8 You're really right on the edge with the theatre sports ... it's very stimulating and hilarious.

P⁺8 ...and it all flows out spontaneously without having to control any part of it. And the best thing about it is the belly laughs.

P4 To be able to do that [theatre sports] is very challenging as you are sort of on the spot but it's so satisfying when it all comes together.

8.2.5.1.2 *Intense Concentration and Absorption.* Absorption in enjoyable activities among peers seemed to distract participants from the negative, painful aspects of their lives as carers, as well as promote feelings of intense enjoyment. These creative arts activities enticed caregivers into the here and now, and necessitated such concentrated attention that there was "...no room for the worries" (P⁺6) to intrude.

P⁺4 When I was doing the improvisation it was remarkable that I didn't think of my son once. I was totally in the scenes we were creating. It was truly relaxing and uplifting. Really a whole new space to exist in....

P⁺2 It was bizarre. It's like there is a constant radio frequency in my mind about [daughter] and whether she is okay, and what I need to do, but when I did the improvisation the station was changed or the volume was actually off and I could get into the activities fully. It was very strange, but probably good for me!

8.2.5.1.3 *Reduced Self-Consciousness.* Participants' accounts indicated that the experience of absorption and flow brought with it a concomitant reduction or loss of awareness of self-referential thoughts, including concerns and habitual patterns.

P⁺6: I was distracted from my worries because these different activities needed full attention. There was no room for the worries.

P3 The experiences during the program were really enjoyable and distracting and there was no room to really think that much...I just sort of stopped mulling over things.

P7 ...what was really unusual for me is that I didn't even go for a cigarette or want one during the sessions.

Several participants commented on experiencing a sort of exhilarated oneness with the task, embodying what Csikszentmihalyi (2002) referred to as a state of action and awareness merging.

P⁺8 The drumming... it's transcendental and yet totally grounding at the same time. That's a word I was trying to look for. And it does take you above yourself. It does me... you know, there are few moments when you hear a rhythm that is really, really wonderful and you just play along without effort and you become part of it and it takes you away. And that does, yes. It does have that effect...I really needed to be reminded of ME!

P⁺8 But the drumming and drama sessions were the highlights for me. I wasn't just going through the motions like in my day to day...I was right in it.

8.2.5.1.4 *Contacting the Present Moment with Enhanced Sensory Experiencing.* During the flow state, a lowered level of self-consciousness led to a heightened connection to bodily sensations and sensory experiencing for some participants.

P⁺1 The movement and sensations in my body when I was playing drums, belly dancing and making clay brought me into myself. I know it may sound stupid but – well – it made me feel human again.

P⁺6 I really felt that the drumming session coaxed me out of my self, out of my head, and into my body. It was actually wonderful to be in my body for a change.

8.2.5.1.5 Altered Experience of Time. When one is in a flow-state, there is a complete focus on the “extended present” and perceptions of time become distorted, seemingly passing more slowly or more quickly (Nakamura & Csikszentmihalyi, 2002, p. 90). Several participants commented on their experience of time passing quickly in the sessions, and this resulted in a conscious change in some participants’ attitude towards time.

P⁺3 It [the program] has changed my approach to time and I guess my attitude towards it. When I am at home doing routine house and care activities, not really doing anything creative or meaningful, time goes pretty slowly. But when you’re having fun and being creative it flies!

P3 I completely lost track of time in these sessions. Before I knew it [the student researcher] would be arranging the lunch for us and two hours would have gone past.

P7 I almost disappeared for two hours. It was like time was just not a factor... I didn’t look at the clock...

8.2.5.1.6 Increased Confidence and Sense of Achievement. For Csikszentmihalyi, flow states promote feelings of achievement and thereby strengthen self-worth, as expressed by several participants.

P4 Belly dancing was really awkward at first and I felt at odds with my body but after a while I just felt the rhythms almost pulse through my veins and I got into it and I felt really good, like I had accomplished something.

P⁺3 I have discovered new interests and abilities that I never knew I had.

8.2.5.2 “Me Time for Mums” and the Phenomenology of Self-expansion

The essence of the process of self-expansion was the revival and strengthening of aspects of self beyond the caregiver role. Self-expansion was narrated by the majority (68.75%) of all participants, with more than double the proportion of participants in the

P⁺ group (100%) reporting this theme compared to the proportion of participants in the P group (37.5%). On the journey towards self-expansion, many participants realised that the lifestyle they had been leading was restricted. This became salient only once they had changed their lifestyle through participating in the program.

P⁺1 For the first time it became clear that I had been underestimating the effects that giving up leisure time has had on me, both mentally and physically. It's only when you do it [leisure] that perhaps you realise that you have been living a really constricted life.

The “Me Time for Mums” program offered participants a space to stand outside their regular contexts and structures and exist in the fluid space “in between”, where there were no preconceived standards to live up to. In these “in between” spaces, participants seemed to discover that they are more than their role-identities.

P⁺4 It's interesting that, while we came together because we were all mothers of kids with special needs, this almost gave us support that did not have to be centered around the disability. We could be together as a group of strong, creative women.

P⁺4 I am not just a caregiver, mother, wife, and daughter. I have been blocking out my needs for a long time and I think it created a lot of resentment. The program was a great interruption to this.

For some participants, a clear distinction was articulated between being a caregiver and being themselves.

P⁺8 It's good therapy just to be where we can be ourselves, just ourselves, and not really be a caregiver when we are there . . . I can laugh. I can talk.

A key pathway to this more authentic self-experiencing seemed to be flow-like experiences. For example, P⁺8, emerged from her flow-like drumming experiencing feeling more in touch with herself: “I really needed to be reminded of ME!...”. However,

this was by no means an easy distinction to make outside of the program milieu. Social reinforcement of the female carer role made it extremely hard for some participants to see themselves, and maintain a sense of personal identity, beyond the caregiver role.

P⁺8 I need to reflect more on who I am as a person other than a mother and carer, but it's much harder to do on my own.

The dominance of caregiving responsibilities was typically found to be confining for most participants in terms of expressing and exploring non-caregiving aspects of self, however there was one clear exception to this. P⁺2 confided that when she finished school she did not know what she wanted to do and never enjoyed the various jobs she had. She described feeling attached to the caregiving role as the dominant role in her life in large part due to the direction and meaning it provided. This woman was 58 years of age with three children one of whom was 30 years of age with a severe disability.

P⁺2 I've given my whole life to my family and others and I've sort of, well I guess that I have found my purpose in my life because of it.

Despite her commitment to the carer role and the vital part it played in maintaining a positive self-concept, P⁺2 was able to stand back from her identification with it after doing the program, and find other aspects of self that she wanted to nurture, as she later elaborated in the interview.

P⁺2 I guess I am realising that this role [caregiver] is not all of me. In the past my husband has offered to take time off work and care for my daughter to allow me to take a trip or do a course or something for me, but I always said no. Maybe I didn't want her [daughter] to stop needing me as much, and maybe I didn't really have my own interests. It sounds stupid doesn't it? Well I've been thinking that I am going to take him up on his offers. My daughter will always need me. I guess I can see a way to do both.

Participants' accounts frequently represented creative activity as a potent means of self-exploration and self-expression towards restoring a satisfactory sense of self. Participants reported establishing a greater sense of biographical continuity and hope for the future, through reconnecting with previous interests, and thinking about future creative and leisure pursuits.

P⁺7 It's [the clay sculpture] expressing things that you don't talk about normally I suppose.

P3 So, it was a way, as I say, of expressing how I was feeling in a very safe environment with an opportunity to be creative. And there was ...how can I say... self exploration.

Several participants rediscovered activities and interests that were meaningful before assuming the role of primary carer.

P⁺5 Doing creative things and accessing a different part of my brain is more linked to who I am a person. Before having children I used to design wall paper and after [son] was born I just stopped. I was exhausted and lost the motivation. After the art session I dug out my old designs and think I will print some of them.

P⁺7 I really enjoyed the classes and it was a bonus to realise that I could actually be quite creative. I got so much positive feedback about my sculpture. I did clay in high school and I remember loving it and also getting encouragement to make something of my interest back then, but I never pursued it. And I've never thought about actually doing it as a regular hobby at home until now.

One participant described achieving a sense of biographical continuity through reconnecting with her pre-caregiver practice of exercising.

P⁺6 Since doing the program I have lost around about 8kg. When [student researcher] came over for the first interview I told her that my self-care goal

is to come to the program and commit to going to the gym twice a week as my new religion, like I used to do before [child with disability] was born. Saying my goal out loud and then having the support and company of another woman in the program has kept me on track. I feel almost normal again!

The program provided a context for participants to playfully experiment with embodying different characters and aspects of self. This was particularly evident in participants' reflections on the theatre sports session. This creative modality offered a forum dedicated to playing with different characters and imaginary scenes, without over-identifying with any of them.

P⁺2 [Theatresports]... gives you a moment where you step out of your identity and create multiple, endless identities. It's refreshing to take on different characters!

P⁺2 That's why my favourite session was the improvisation. You can be whoever you want from your imagination...

Through positioning the self as a leisure seeker and "enjoyer of life" during the program, other related self-positions emerged, such I-as-interested, I-as-fun loving, and I-as-surrendering control.

P⁺2 After I had [daughter with disability] 30 years ago ...I think I just gave up on all my hobbies. I remember how inspiring it is to develop new creative pastimes. It's great to be stimulated with new ideas.

Self-expansion was sometimes associated with being in touch with an almost child-like gleeful state of delighting in the imagination, which appeared to be a potent antidote to carrying excessive responsibility.

P⁺8 It's exhausting running such a tight ship. That's why my favourite session was the improvisation. You can be whoever you want from your imagination...

P2 It felt like being a kid again with all the different fun activities each week, in our own space... and I let my imagination free, which has been pushed down for a long time because I always have to be the responsible one.

Participants spoke of being inspired with a renewed sense of self and possibilities projected into the future. The re-emergence of lighter, playful and “role-less” aspects of self generated a sense of possible future trajectories.

P⁺1 Suddenly there is something for me, there are possibilities and I look at the world around me and I see colours, shapes, and designs that I can use in my sculptures.

P4 ...I'm coming to the point now where I want more for me...now I'm looking at me and looking where I am going. I have got this incredible daughter and family, but there is me. Two and a half years is a long time and I haven't really thought about what I want to do...

The program helped several participants realise that their old lifestyle will not fit their becoming “self-in-the-making”, and that finding a balance between caregiver and leisure seeker is essential for wellbeing.

P⁺5 I feel almost simultaneously trapped and freed. The lifestyle I want to live, and really need to start living, will involve a balancing act. I've seen how doing these games and activities wakes me up and refreshes me.

8.2.5.3 Restorative Respite

Participants spoke of the program as being “a block of freedom” (P⁺4), an opportunity to “get out of the caregiving world and into my own world” (P⁺3), and into a “burden-free zone” (P⁺1), all of which culminated in feeling that the program facilitated “real respite” (P⁺5). Of the 50% of participants narrating the theme of restorative respite, a far greater proportion of participants in the P⁺ group (87.5%) reported this theme

compared to the proportion of participants in the P group (12.5%). Participants narrated their experiences of getting “swallowed up” in the dominant caregiving world.

P⁺4 It's so easy to get swallowed up with caregiving ...especially when you're on your own, trying to navigate a maze of services and make sure your children are okay, keeping everything afloat. Doesn't leave much time left over for your own life.

Participating in the “Me Time for Mums” program provided an opportunity to temporarily exit this world and experience a sense of personal freedom. Escaping from preoccupation with responsibilities and concerns and connecting to the present moment was an important feature of restorative respite.

P⁺1 It was a pleasure to escape into a fresh enjoyable task away from responsibilities.

P⁺3 Me time was an opportunity to get out of the caregiving world and into my own world. And that's just ... it's a total break.

P⁺7 Usually I run around from task to activity doing ...constantly doing. Well this felt like a chance to give over to something else and just enjoy the moment – nothing I have to do...just enjoyment.

P⁺6 I felt freed up to try new things. It was stimulating. It broke through the week's obligations and responsibilities. It felt a bit like it was my play time.

Participants described that restorative respite was made possible through a number of mechanisms. Firstly, the nature of the discourse shared during the program contributed to creating an atmosphere of freedom. Several women emphasised how refreshing it was to have non-problem talk with people who understand each other.

P5 You don't talk about your kids . . . you talk about something else or you play. And I find that is very important. It's different to other support groups for parents; it's really important time off.

Secondly, for several carers, leaving the house signified leaving their routine and daily contexts, and having their own space to be themselves.

P⁺4 It's easier to do this outside the house when it has been arranged ahead of time. Leaving the house allows me to tune into something else.

P⁺8 It was so great to have a space for myself, "a room of ones own", otherwise you can lose yourself.

The third mechanism that seemed to foster restorative respite was triggered by flow-like experiences during immersion in creative activities.

P⁺7 When I was laughing, singing, moving about happily, or simply engrossed in making clay or art, I totally felt more relaxed and care free- actually I was care-free wasn't I for those two hours, in all senses of the term!

8.2.5.4 Social Support

8.2.5.4.1 *Social Connection.* More than half of all participants (62.5%) spoke about their greater sense of social connectedness during and, in some cases, after the program. A greater proportion of participants in the P⁺ group (75%), compared to the proportion of participants in the P group (50%), reported this theme.

Several participants reported that attending the "Me Time for Mums" program reduced their sense of social isolation. Participants spoke about the comfort they derived from realising that they are not alone.

P2 It's been a very long time since I have connected to other women. I had become more and more socially isolated. It was a blessing for me to get out and be around these women.

P⁺1... [it] went really well- the first session before the program opened my eyes and provided feedback for me. It was someone taking an interest in me and who I was. The love and support and genuine sense of connectedness with other carers made things less isolating.

P⁺6 It was good to meet others in similar situations and know you're not alone."

P⁺7 What brought me the most comfort was to be amongst other women who had gone through similar journeys. I have felt very alone and well ... sort of trapped being a single mum.

Not only did participants report deriving social support from other participants and facilitators, but some also reported that their husbands had become more supportive of taking time for leisure once they could see the improvement in their mood and wellbeing derived from participating in the program.

P⁺3 I am more conscious about taking care of myself and how this reflects on the family, and my husband will support me to take me time as he can see the benefits of it in my mood.

P2 My husband encouraged me to take more time for myself when he saw that I was much easier to be around!

During the program, connections could be easily forged through mutual participation in shared pleasurable activities, as opposed to focusing on childhood disabilities and other caregiving issues.

P3 I found it easier to make friends in this setting compared to the parent-to-parent support groups. In sessions we talked to each other and had another shared focus instead of our children and problems. Making and doing stuff together is a great conversation starter...

Participants spoke of delighting in each other's company and of gaining strength from the collective willingness to give things a go. In some ways, participants engaged in social modelling with one another, which gave them confidence to try new activities and learn new skills.

P⁺1 At first there is sort of a fear factor going 'you're not going to belly dance! You can't paint!' but then you do it because everyone else is in the same boat and the facilitators warm you into it. You see how enjoyable it is.

P⁺7 All the facilitators totally believed that experiencing enjoyment was a vital part of everyday life. It was so good to be around people who give some importance to their own needs.

P7 "There was so much openness to try things in the other participants that I think it rubbed off on me. I pretty much stick to what I know usually and this program challenged me to have a go..."

Being a part of something larger than the self empowered participants through their identification with the group. Social support and a sense of being part of a collectivity seemed to motivate participants to "stretch" themselves and go beyond what they would ordinarily do.

P⁺5 These whacky activities – I would have never tried them myself - there's force in numbers – it's a great motivator.

P⁺6 ...I mean I felt very much a part of this group of women – all very warm and very strong, and maybe I saw myself in a new way... as strong too cause I was a part of it.

Being part of a group enabled participants to make things up together that each individual would not normally make up alone. This point was succinctly captured by P7, who stated: "In the sessions the whole was more than the sum of its parts".

Several women reported linking in with each other and with community workshops and education courses after the program. These linkages gave participants ongoing contexts for the emergence of aspects of self other than the role of carer. It also gave them something to positively anticipate.

P3 ...we were encouraged to hook up outside the group... which I have already done with a couple of people. And I'm looking forward to the film night and catching up with everyone again.

Attending group-based community programs to pursue creativity and leisure allows for the development of social roles other than caregiver (i.e., “I-as belly dancing student”, and “I-as-yoga participant”, for example). Each act of socialising in leisure seemed to affirm that participants have many aspects of self other than the role of mother and carer.

8.2.5.4.2 Social legitimacy to Pursue Leisure. Another aspect of social support described by half of all participants was the social legitimacy to participate in leisure provided through an community group program. Social legitimacy was reported by a greater proportion of participants in the P+ group (62.%) compared to the P group (37.5%). A community program like “Me Time for Mums” conveys the message that it is okay to do leisure and take time for self-care. With the “sanction” and referral of community case workers and other professionals, it appeared that participants found it easier to give themselves permission to do leisure and to justify this pursuit without feeling guilty.

P⁺5 And it was not until [the student researcher] came over before the program started that somebody outside the family actually asked me how I was. I felt so overwhelmed by the concern shown that I had tears well up...it's so good to have your efforts and your situation recognized. I think it hit me how much stress...and maybe pent up frustration... I was harbouring inside...being able to talk about it to an outside person is so helpful to release some of the pressure we are under. And I realised that maybe I do need to do something to cope better.

P⁺5 They [facilitators] believed that self-care is not a privilege – it's a necessity to keep going, so that helped me give myself permission”.

P⁺3 I don't think I feel as guilty anymore. When you have your case worker and then program facilitators all saying it's okay to do things for yourself, it's reassuring. Looking back I can't believe the pressure I put on myself. Unlocking the guilt has taken the pressure off and I feel I have more energy and- yeah- more like myself.

P2 You kind of feel that if there is a program, with money for alternative care, then it's okay to do it. I didn't have guilt coming to Me Time. Also you're there with a bunch of other women in similar positions and there is this sense of ...yeah...we are going to give ourselves this time because we really deserve it!

The program conveyed a sense of validation and legitimacy to participants in taking care of their own needs and pursuing leisure. Some participants indicated that they were so consumed with caregiving that they needed an external intervention to alter their lifestyle to make room for leisure.

P⁺6 I've been so consumed as a caregiver and mum, with the preparation, planning, housework, dropping off, picking up, shopping, healthcare visits, and so on and on, that to think about taking leisure time was almost impossible. I needed this program...I needed help to get the balance back.

This was not a straightforward process for several participants who reported needing several “doses” of encouragement and validation from others to pursue the program.

P⁺1 When I agreed to do the course I really had little interest in it... well I had little interest in anything... and I didn't think I could fit any more into my day because I was at boiling point which my case worker could see and that's why she kept encouraging me to do join the Me Time group.

P⁺8 It was only after pressure from many sources including my case worker and friend and even my GP that I decided to go ahead and come to the program.

P7 I wasn't in a good way. My husband knew I was not coping and he really encouraged me to do the program to get some time out, which was unusual for him, and I'm glad he did that because I don't think I would have had the energy to try a new thing if he hadn't.

Cognisant of their many constraints to leisure, several participants reported the need for continued structural support for leisure programs. Some participants acknowledged that they need this external support to help themselves look after their own needs.

P⁺8 It's a bit harder to motivate myself alone. So I'm determined to find another community art group to join. It satisfies a need that I must have".

P5 When you have a program like this one paying for a carer for your child, and being organised, with people urging you to participate, it's possible to have leisure. But, for me, I'm not sure how I will go on my own.

In summary, the most frequently reported program processes (reported by more than 60% of participants) were flow and self-expansion. The proportion of participants in the P⁺ group was consistently greater than the proportion of participants in the P group reporting each program process theme (i.e., flow, self-expansion, restorative respite, and social support), suggesting that the pre-program intervention may have “primed” participants to experience these program processes to a greater level or with greater self-awareness than participants who did the program alone.

8.2.6 Constraints to Leisure

Leisure constraints were categorised according to Raymore, Godbey, Crawford, and von Eye's (1993) framework of intrapersonal constraints (person's psychological states, traits, attitudes, beliefs, and health), interpersonal constraints (extent of social support and leisure companionship) and structural constraints (practical resources including financial

and material resources, transport, alternative care available, and existence of leisure programs in the community). There was no evidence of interpersonal constraints in participants' reports.

8.2.6.1 Intrapersonal Leisure Constraints

Of the 16 participants, 43.75% reported intrapersonal constraints that limited their engagement in the program and/or ability to maintain leisure participation after the program. Intrapersonal constraints were mentioned by a lower proportion of participants in the P⁺ group (25%) compared to the proportion of participants in the P group (62.5%). Participants reported a variety of intrapersonal constraints to leisure. Some participants narrated their sense of guilt attached to pursuing personal leisure.

P⁺8 Initially I struggled with my own guilt about doing something just for me. I worried and had trouble sleeping leading up to this program and on the first morning I got up and ... didn't go to the first session.

P7 I still feel guilty taking time for myself. The cards are good, because I am doing them at home, but it is harder for me to get out of the house, as much as I know I need to do it.

The demanding, preoccupying, and tiring role of caregiver often made it too hard to find the energy to pursue leisure. There was some evidence that the range of leisure activities pursued was limited to passive forms of leisure due to feelings of exhaustion.

P1 It gave me awareness of the importance of continuing on in a program like this as I really struggle when I am on my own financially and I guess with my energy...I get tired and then just slump on the couch and I don't see many people and things spiral down. I have to break this pattern. "Me time" was the first step. I think I need help though to do this.

P8 ...often when I have a bit of time to myself I am often too tired to do something active or creative so I have been resting or watching TV.

For some participants, there was evidence that becoming “submerged” in caregiving and other duties lead to self-neglect and perceived lack of time for leisure. The all-consuming focus on caring for their child with high needs made it hard for some participants to perceive their own needs as worthy of attention. Data indicated that the P group was more likely to report perceived lack of time, whereas a greater proportion of P⁺ participants appeared to have made a shift towards “seizing moments” for self and leisure where possible.

P6 I don't have much free time at the moment because of my son's care needs and lack of proper support, and I also have a teenager on school holidays, plus the committees I belong to on disabilities and so on. So making the time and sticking to it is difficult for me.

P5 ...because from the moment you are awake, you are, you know, being a mother and a carer and you start your jobs, and it really never ends ... just to keep things running and you are always thinking about what needs to be done and planning, so it does take some effort to even stop and ask myself “how am I feeling” or “what do I need?”.

P8 I have always been aware that self care should be a high priority as I am aware about how my wellbeing impacts on my parenting, but in practice it's different. It's hard to think of yourself as someone with needs when your children constantly need your support and attention.

8.2.6.2 Structural Leisure Constraints

Structural constraints to leisure were reported by just over half of all participants (56.25%), with a similar proportion of participants in the P⁺ group (50%) and the P group (62.5%) reporting this theme. Structural constraints mainly entailed loss or limitations in availability of care and respite services. Lacking family support compounded these external limitations.

P⁴ I am currently going through a tough time as I am only being offered untrained carers so respite care is limited and I can't go very far or be out for very long in case my son needs injections or has a seizure and they are not trained to deal with it.

P1 I'm having problems with the council for respite care. I feel totally responsible for my son. I'm a single parent without any real family support. So in a way, things are similar to how they are before the program for me. I've been under a lot of pressure.

Comments on structural constraints highlighted the need for improved respite and alternative care services.

P7 And to me, you can take all the tablets you like under the sun, you can go and see all the counsellors, case workers and all the doctors, but it really is so hard to get the support you need. I really need more respite from trained caregivers.

P⁷ [Constraints to leisure include] Time and energy and having someone to fill in the caregiver role, and doing it at the right level, and in the right way, so it can be a benefit for you and your child. At the moment, the help I'm getting is mostly babysitting. It's better respite if you know that your child is engaged in learning activities. Otherwise it's not really caregiving...

Without alternative support at the appropriate level, leisure was not possible for some caregivers, and this appeared to be more pronounced for single mothers and mothers with children whose care needs were at the higher end of the spectrum. There was a sentiment of frustration among many participants when it came to respite services.

P⁶ My absolute frustration at the moment is that there is no equivalent of Very Special Kids for adults and that's what I'm rallying with in terms of the advocacy work I've been doing with the council. Once your child turns 18, they are no longer eligible for their respite care services. At the VSK hospice there are nurses on the premises 24 hours a day and they have doctors on call

all the time. So you can leave your child and not worry... There is a huge need for a similar service for over eighteens who need a higher level of respite care. This is critical for me so that I can get time off for my own interests.

One participant disclosed social marginalisation, which severely limited her family's leisure options.

P7 D has high-functioning autism and a mild intellectual disability. He has poor social skills, is highly active and has no concept of what may be a danger to him so he requires continuous supervision. I have two other boys. D's condition makes it almost impossible for us to go out all together and the younger boys mimic his behaviour. Our family had become increasingly socially isolated. We can't go out and do the everyday things that most families can – even something as simple as grocery shopping together. Some people in the community would get very upset when they would see him acting in a way that was not in line with his age - such as yelling and inappropriately approaching strangers. In the end it just became easier to stay home. With all my family living overseas, there was no one to rely on for a break from D's constant care.

This participant relied on the external support she received in order to pursue personal leisure interests.

P7 In March last year we got involved in Anglicare's Family Respite Solutions program in Melbourne's eastern region. Now once a month another couple take care of D and we get a break. For me I need actual help to get the time off to do my own leisure.

Lastly, several participants mentioned lack of time as a constraint to leisure.

P⁺6 I have recently had a number of problems with the wheelchair, and my daughter is recovering from a procedure so we are having a hard time at the moment. I have less time for leisure this month...

P2 I always think it [leisure] would be beneficial, just finding the time on a regular basis is the problem, when things are generally pretty unpredictable with [child with disability].

P3 The time I spend caregiving has recently increased as a result of my mother's illness and all the logistics that go into moving her into a nursing home, leaving less time for me.

P8 I need to arrange larger blocks of respite time so that I can manage the chores and also do an activity or program for myself.

Despite having less time for self as a result of the extra caregiving duties necessitated by her daughter's recent procedure, P⁺6 reported a commitment to protecting some time for self-care and leisure.

P⁺6 ... but I'm still managing the gym and walking, which I probably would have dropped in the past when things got tough.

This comment suggests that doing the program may have bolstered P⁺6's commitment to securing at least some time for purposeful self-care and leisure, demonstrating that the increase in structural constraints to leisure did not result in a complete loss of leisure time. The perception of a lack of time for leisure was a difficult leisure constraint to categorise, as it seemed to be a product of both intrapersonal and structural constraints. For example, P8 reported her perception of needing a large block of time to do leisure ("I need to arrange larger blocks of respite time so that I can manage the chores and also do an activity or program for myself"). It may be argued that this perception reflects more of an intrapersonal constraint that might be reduced through adopting a "seize the moment" stance towards leisure participation. On the other hand, P3 reported increased caregiving duties due to her mother's recent illness, which appears to be more of a structural or external reason for reduced leisure time.

In summary, a variety of ongoing intrapersonal and structural constraints to leisure were reported by participants. The P⁺ group reported a lower proportion of intrapersonal constraints to leisure compared to the P group, indicating that doing the pre-program self-investigation intervention in addition to the program may have stimulated more profound attitudinal shifts towards embracing leisure and self-care as necessary for wellbeing. This group difference was not apparent in reporting of structural leisure constraints. A similar proportion of participants in each group reported various practical barriers to leisure, which are far greater than what a brief leisure intervention can ameliorate, and which require large-scale systemic change in the provision of supportive infrastructure and resources to assist caregivers to attend to their own needs.

8.2.7 Suggested Changes and Extensions to the Program

8.2.7.1 The Need for More Support to Pursue Leisure

Half of all participants contributed suggestions about their need for more support to facilitate better access to future programs. The need for more support to access programs was expressed by a greater proportion of participants in the P group (75%) compared to the proportion of participants in the P⁺ group (25%). Several participants highlighted their need for better access to information about community-based programs. Participants provided several suggestions regarding ways to increase caregivers' awareness of community initiatives.

P⁺3 People who need it don't know how to access the information or know where this and other programs like this are held... a newsletter or regular mail-out would be helpful.

P⁺4 "Maybe there could be a website for mothers with a list of community arts and leisure services and programs in one place as well as carer organisations and respite options.

P5 I found out about the program through my friend who was in the first group. There needs to be a central liaison set up to find leisure opportunities in different suburbs, and new programs like the Me Time program, so that we could know what's out there. And it would be great if you could call a central place and find out about creative arts activities for ourselves and our kids and for whole families all together.

In addition to formal, structural support, the need for informal support networks was also raised to combat social isolation.

P1 I got a lot of benefit from sharing details and experiences about support organisations with the other women...It goes to show how important it is to be a part of a network. I reckon there should be networks of parents of kids with special needs where you can help one another out with transport and other duties and mainly to combat social isolation.

The need for financial assistance to access leisure programs was raised by a participant who was a single mother and full time carer.

P2 I am struggling a lot financially, so any leisure I do outside the home I really would need support. I was able to do Me Time because it was free and all the extra child care costs were covered by the program, but if I wanted to do a regular short course or something I couldn't pay for it myself.

The need for ongoing support to access leisure was highlighted. One participant suggested that parent support groups incorporate leisure, creative arts and self-care activities, while another recommended that the facilitators of the leisure program should link participants into other community programs.

P3 It's a different type of support to talking about your children and how to cope and when you think about it it's just as necessary to have a place where you can stop being a carer and stop talking about being a carer! And do other things that pick you up.

P6 It would be great if the facilitators could sign you up to other community creative arts and leisure services to follow through with the various activities – because if it's too flexible or a choice, or have to arrange it yourself, at the end too many things get in the way.

8.2.7.2 Program Content and Structure

Out of all participants 31.25% made suggestions or comments regarding changes to the content and structure of the program. The proportion of P group participants who commented on the content and structure of the program (50%) was double the proportion of participants in the P⁺ group (25%). Some participants commented on inclusion of care-recipients in a contemporaneous, though separate, leisure program. Others commented on the types of activities included in the sessions, with one participant raising her desire for consultation and input from prospective participants regarding the activities included, while others expressed their satisfaction with the range of activities included in the “Me Time for Mums” program.

P⁺2 It would be great if there was a program for mums and a similar one for kids running separately but at the same place and same time. Then you know that your child is close and engaged in meaningful activity and you could all come together at the end.

P⁺7 It was a great broad taster of a variety of things...yes I would definitely be keen to do it on a regular basis if it was organised and provided in the same format.

P⁺8 In future I think it's important to ask people about what they may like to do... Like you could do a survey after the initial five-week trial of all different activities and find out what activities people want more of and what other options people may be interested in and incorporate these other chosen activities into the program. I mean if were up to me the whole program would be theatre sports and drumming!

P1 If the program was ongoing I would like there to be a greater emphasis on physical exercise as it would make me do it.

P4 Activities were all a great choice, and the modulators were all very good and considerate.

One participant expressed her experience of not identifying with other participants, and recommended that leisure programs should be delivered to a more homogenous group of caregivers.

P8 In my opinion the composite structure of the group is important, in particular the differences in disabilities, like respite or full-time care, and whether or not you have other commitments like I do ... which meant that I had a little trouble relating to other mothers, so having groups of people that are a little more similar would help.

Conversely, another participant commented on her desire to participate in the program with the same group of people to facilitate the continuity of social bonds that were forming during the program.

P2 ...knowing that you were going to see the same people again next time would be nice, especially since we got to know each other and soon the program was over.

8.2.7.3 Program Location, Timing and Continuity

The majority of participants (81.25%) reported that they would like the “Me Time for Mums” program to be offered on an ongoing basis, with a similar proportion of participants in the P⁺ group (87.5%) and P (75%) group contributing comments and suggestions to that end.

P⁺1 I would like to come to the program more often, with the same people running it, and make it more widespread.

P⁺2 [There is] A huge need to make it ongoing - it's infinitely great!”

P⁺3 It was really enjoyable, well run and I would love to participate again if it was possible.

P1 I would love to do this on a regular basis!

P2 Yeah I'd do it for sure and I also know of a few other mums who would want to be involved.

P6 It was a great experience and I really enjoyed it I would recommend it to all mothers.

Several participants made suggestions regarding location and frequency of the sessions to foster their ability to attend if it was ongoing.

P⁺6 ...maybe if the program was offered at different times in different locations for all the sessions then you may get one which is not too far away.

P⁺4 Having it fortnightly would be better as I wasn't getting other things done, like the shopping and other errands. It may have also been better if it was in a better location to me, or started earlier in the day because as it was it took most of the day for me with travel time, and then waiting after school drop off for it to start.

P⁺5 If it was ongoing, I wouldn't be as likely to do it, not continuously because ongoing would be too hard juggling what I do in a week. I think if you just commit to the course of a given time frame its okay, you know just stints of time is okay. And then if you can come back at some time when it suits you it would be good, but weekly would be too hard...monthly would suit me...yeah that would be easier... I could plan around it more in advance.

In summary, the majority of participants reported that they would like the “Me Time for Mums” program to be offered on an ongoing basis, with additional support to promote their attendance, and with various suggestions regarding location and frequency of program delivery according to each participant’s personal circumstances.

CHAPTER 9: DISCUSSION AND CONCLUSION

The following discussion presents an analysis of both the quantitative and qualitative findings in light of previous research and theoretical models. The discussion is structured according to the framework used in the previous qualitative analysis. Firstly, program outcomes are examined across attitudinal, affective, and behavioural domains, covering pertinent quantitative variables and qualitative themes. Next, program processes evident in the quantitative results and qualitative themes are considered in light of previous research and theory. Finally, the conclusion presents an overview of some of the main outcomes of the study, implications for future leisure program design and delivery, limitations of the present evaluation study, implications for future leisure program evaluation research, and suggestions for the future delivery of leisure programs for caregivers in Australia.

9.1 Program Outcomes

9.1.1 Attitudinal Outcomes of the Program

The program aimed to positively affect participants' attitudes to leisure, as measured by the Caregiver Leisure Attitude Scale (CLAS), and the leisure companionship subscale of the Leisure Coping Strategies Scale, and further explored in qualitative data from the follow-up interviews.

Both intervention groups reported significantly greater increases on motivation to increase leisure compared to the Control group, indicating that a brief experiential leisure program can significantly increase participants' stage of readiness to change their leisure behaviour from the contemplation stage to the preparation stage. Prochaska and DiClemente's (1983) Transtheoretical Model (TTM) of behaviour change has been studied in relation to numerous health risk behaviors such as smoking cessation (Prochaska & DiClemente, 1983), and positive health behaviors such as exercise (Burbank, Reibe, Padula, & Nigg, 2002). The TTM provides a useful

framework for the measurement of leisure motivation among individuals who typically report multiple barriers to leisure. In measuring pre-activity changes in motivation (i.e., in the pre-contemplation, contemplation, and preparation phases), it allows for assessment of motivation in the absence of overt behavioural change. It also allows for research to investigate the processes that are associated with caregivers' backward and forward movement through the stages. As described in more detail below in terms of the limitations of the present study, the CLAS should be extended in future to assess all stages of change included in the TTM model.

Through participating in the "Me Time for Mums" program, participants reportedly increased their perception of the benefits of leisure. For the P⁺ group, this change was significantly greater than the Control group, whereas the P group showed a clear positive trend in this regard, although the extent of change was not significantly different to the Control group. This CLAS subscale contains items regarding the reasons why leisure is beneficial, including its role in protecting mental health, increasing enjoyment of life, maintaining a balanced lifestyle, improving perspective-taking on problems, and "recharging one's batteries". The pre-program intervention provided participants in the P⁺ group with a quantitative comparison of their wellbeing levels in the "I-as-caregiver" position compared to the "I-as-Leisure seeker" position. This information may have made the connection between leisure and wellbeing more salient for those in the P⁺ group, resulting in greater positive change in their beliefs about the benefits of leisure.

Both intervention groups did not significantly differ from the control group on perceived risks of not doing leisure. This CLAS subscale comprises items measuring potential detrimental consequences of denying oneself time for leisure and self-care, including becoming stressed, sacrificing psychological wellbeing and physical health, feeling resentful, sacrificing physical health, and experiencing burnout. Participants'

scores on this variable were already high at pre-program testing, indicating that they generally believed in the protective function of leisure for mood and wellbeing. Therefore, participants may have had limited room to demonstrate increases on this variable. The qualitative data provides evidence that doing the program did in fact lead to an increased awareness of the risks of not doing leisure for some participants. It is possible that participants were already aware of the risks of not doing leisure in a general or theoretical fashion, and that doing the “Me Time for Mums” program served to increase the relevance of these risks on a personal, tangible level.

The quantitative results demonstrated a clear, positive trend in terms of increased leisure companionship. The P⁺ group reported a significantly greater increase compared to the Control group, while the P group showed a positive trend, though the extent of change was not as marked. Positive change on this outcome variable presages the fuller elaboration of program outcomes pertaining to social support presented later in the discussion (see Section 9.2.4, p. 244).

The P⁺ group reported a significantly greater reduction in intrapersonal constraints to leisure compared to the Control group and again to the P group, which showed no significant difference in change scores compared to the Control group. This group difference was also evident in the qualitative post-program interview data. The proportion of participants in the P⁺ group who reported reduced intrapersonal constraints to leisure was higher than the proportion of participants who reported this theme in the P group. Similarly the proportion of participants in the P⁺ group reporting acknowledgement of personal needs was double than the proportion of participants reporting this theme in the P group. These findings indicate that there was something about the pre-program intervention that contributed to positive attitudinal changes towards leisure and self-care over and above doing the program.

The pre-program self-confrontation intervention was a tool that made the multifaceted nature of identity salient. It reinforced to participants that they are women with many aspects of self, such as “I as leisure seeker” in addition to the primary carer position. The intervention encouraged and validated personal needs and self-care, and may therefore have caused a reduction in intrapersonal constraints to leisure even before the program started.

In Linville’s (1987) terminology, the program appeared to promote greater “self-complexity” in terms of participants’ broadening their self-representations beyond the caregiver role. In turn, experiencing the self as a woman and person beyond pressures to meet role-based identity standards, appeared to result in participants’ reporting a greater acknowledgment of their personal needs, and increasing their sense of entitlement and permission for self-care and leisure. These changes signified an expansion of the “ethic of care” to include self-care, signifying a departure from feeling guilty and selfish for attending to personal needs, which are major intrapersonal constraints to leisure reported by (particularly female) carers (e.g., Aronson, 1992; Bedini & Guinan, 1996; Brody, 1985; Pratt, Schmall, & Wright, 1987; Rogers, 1997; Weinblatt & Navon, 1995).

Participants also reported a greater perceived ability and willingness to leave the house to pursue self-care and leisure. These findings are consistent with several qualitative studies on leisure constraints, in which carers emphasised the need for private space, or space outside the home, to promote sociability and leisure activity (e.g., Cant, 1993; Miller & Montgomery, 1990; Sneegas, 1988; Weinblatt & Navon, 1995; White-Means & Chang, 1994). As Wearing (1998) proposed, carers, through interactions outside of the home, “...enable a “becoming” beyond categories assigned at home; the performative acts of this space may allow a “becoming” beyond that possible at home” (p. 139). Some participants created spaces within the home to

pursue creative activities, while others realised that they could leave the home to pursue personal leisure and their family would be able to manage without them.

9.1.2 Affective Outcomes of the Program

Several leisure and positive psychology theorists have questioned whether the importance of “having fun” has been diminished or devalued as an end in itself in clinical and treatment settings (e.g., Hutchinson et al., 2006). Results of the post-program interviews in the current study demonstrated the immense power of having fun, laughing, and being “silly” and playful in terms of lifting mood and empowering participants with the capacity to regulate their mood. Compared to the Control group, both the P⁺ group and the P group reported a significantly greater increase in positive energy and a significantly greater reduction in stress from pre- to post-program. The P group also reported a significantly greater reduction in tiredness compared to the Control group.

Neither intervention group reported significant changes in depression and anxiety levels compared to the Control group. This may be because participants were pre-selected on the basis of having below normative scores on the Personal Wellbeing Index, but not so low as to indicate depression and other pronounced mental health problems. Given that inclusion criteria may have served to “screen out” clinically depressed or anxious individuals, the Depression, Anxiety, and Stress Scale- short form (DASS-21) may have had limited power to detect positive change on these variables.

While participants did not indicate significant changes in depression and anxiety scores from pre- to post-program, the positive quantitative results in terms of stress reduction and increased positive energy across two separate groups provides preliminary evidence that engagement in a brief leisure program can generate greater

facility in stress management and mood regulation. These positive findings were elaborated in more depth in the follow-up interview reports.

The majority of participants reported uplifted mood and improved affective self-regulation, and the proportion of participants reporting these affective themes was similar in the two intervention groups. Thus, it appears that doing the program generated positive affective outcomes irrespective of doing the pre-program intervention. The present study adds to existing evidence that creative and relaxation oriented experiential leisure programs generate improvements in mood and coping and reduction in stress among carers, although different quantitative outcome measures have been employed across studies (e.g., Bittman et al., 2003; Fisher & Laschinger, 2001; Waelde et al., 2004; Walsh et al., 2004). Additionally, these outcomes are broadly consistent with previous findings regarding the benefits of leisure on coping, mood, and wellbeing for carers specifically (e.g., Barusch, 1988; Cummins et al., 2007; Mannell et al., 2002; Smale & Dupuis, 1993), and for general population groups (e.g., Caltabiano, 1995, 1995; Coleman & Iso-Ahola, 1993; Iso-Ahola & Park, 1996; Iwasaki & Mannell, 2000; Iwasaki & Smale, 1998; Iwasaki, 2001).

Participants' interview data indicates that the emotionally uplifting effects of doing the program were associated with experiencing playfulness, encompassing characteristics such as spontaneity, expressiveness, fun, creativity, and silliness. Humour and laughter provided a great foundation for encouraging trust and cohesiveness in the group, and encouraged participants to release their inhibitions and play. As Lemons (2005) poignantly described, "Laughter provides a train wreck of the mind, suspending thought and being in the moment, which opens the channels for innovative, creative thinking" (p. 32). The program signified a different state of being

for many participants, which was different and more energising and “alive” in comparison to being in the typical “survival mode” of daily caregiving.

Perhaps paradoxically, fun and frivolity may ultimately improve coping for carers. As Fredrickson (2004) postulated in her “broaden and build” theory of positive emotions, “Those of our ancestors who succumbed to the urges sparked by positive emotions - to play, explore and so on—would have accrued more personal resources. . .[which would] have translated into greater odds of survival” (p. 1369) and broadened “...individuals' habitual modes of thinking and...their personal resources for coping. The capacity to experience positive emotions remains a largely untapped human strength” (Fredrickson, 2000, p. 1-2). The present results indicate the therapeutic power of a program specifically designed to “tap” positive emotion as a key human strength. In this sense, the “Me Time for Mums” program recapitulates Hutchinson et al.’s (2006) qualitative finding regarding the profound effects that “just having fun” (p. 235) had on the lives of patients in a rehabilitation hospital setting. As these authors concluded,

Clearly, from the patients’ perspectives, “just having fun” was critical to their efforts to cope with and in the hospital environment and was central to their understanding of what therapeutic recreation can do to help them as they rebuild their lives. (p. 235)

Indeed “just having fun” through leisure activities appeared to have profound effects in helping participants to gain perspective and reduce their stress levels, in accordance with Iwasaki’s (2001) notion that leisure allows people to gain distance from their problems and restore perspective. Several participants reported that they came to the program feeling stressed and left feeling more relaxed and uplifted. Although not apparent from the quantitative data, an important finding that emerged from the qualitative data was that participants reported greater self-efficacy and

empowerment as a result of having more options to lift their mood when they are feeling down. As Csikszentmihalyi wrote: “Those who know how to transform a hopeless situation into a new flow activity that can be controlled will be able to enjoy themselves and emerge stronger from the ordeal”. (p. 203)

These qualitative outcomes are consistent with Kleiber et al.’s (2002) first proposition in terms of leisure experiences aiding coping through palliative distraction and generating positive emotions, and Lazarus et al.’s (1980) notion that positively-toned emotions serve as “breathers” from stress. The present results are consistent with Iwasaki and Mannell’s (2000a) findings regarding the coping benefits of leisure among university students, particularly in fostering *leisure palliative coping* (“a temporal break through leisure which allows people to feel refreshed and regroup to better handle problems”; Iwasaki, 2001, p. 131) and *leisure mood enhancement* (“the enhancement of positive mood or the reduction of negative mood through leisure to regulate emotions/moods of individuals under stress”; Iwasaki, 2001, p. 131).

Even further than increased affective regulation and stress reduction, the “Me Time for Mums” leisure program appeared to help some participants to combat depressive states. While not evident in the quantitative data, some participants reflected on the power of the program in terms of interrupting depressive thinking and in expanding their sense of interest and engagement in pleasurable activities. These affective outcomes support the activity restriction model of depression (Williamson & Shaffer, 2000), which posits that life stressors that result in the restriction of normal or pleasurable activities will result in increased depressive symptoms. The present results demonstrate that light-hearted leisure programs can promote positive affect, even in the context of stressful life circumstances, and may even serve to buffer individuals from spiralling into depressive states. As Folkman and Moskowitz

(2000) asserted: “Experiences of positive affect in the midst of stressful circumstances may interrupt and thereby short-circuit this rumination spiral and prevent the decline into clinical depression.” (p. 649)

Participants’ accounts strongly point to the need for more structural community support for carers in scheduling pleasurable events into their daily lives and in accessing experiential programs to stimulate personal leisure interests and behaviours, both to promote positive mood and wellbeing and as a preventative mental health and stress management initiative.

9.1.3 Behavioural Outcomes of the Program

In providing a structured time and space for personal leisure, away from children and caregiving issues, the program aimed to improve the quality of participants’ lifestyle. Accordingly, it was hypothesised that participation would result in greater self-reported satisfaction with basic needs and activities of daily living, compared to waiting for the program.

Both intervention groups reported a significantly greater increase in satisfaction with basic needs and activities of living from pre- to post-program compared to the Control group. The Caregiver Well-being Scale (Tebb, 1995) divides wellbeing into basic needs (i.e., physical needs, security, leisure needs, expression of feelings, feeling loved and supported, and self-esteem) and activities of living (including time for self, household maintenance, leisure activities, functions outside of the home, and family support). The basic needs subscale assesses the extent to which a variety of needs have been met over the last month, whereas the activities of living subscale measures individuals’ ability to perform activities that are needed to meet these basic needs. For example, “having time for recreation” is a basic need, and “relaxing”, “exercising”, “enjoying a hobby”, “starting a new interest or hobby”, and “attending social events” are related activities.

Though differences between the two intervention groups were not apparent in the quantitative data, pronounced differences in leisure behaviour change were illuminated in the follow-up interviews, conducted three months after the program finished. All participants in the P⁺ group reported making specific additions to their leisure repertoire, whereas only two participants in the P group reported such additions. This group difference further suggests that the pre-program self-confrontation intervention augmented program outcomes. This points to the benefits of incorporating a cognitive/affective identity-investigation component into experiential leisure programs in order to boost post-program behavioural change. This finding is broadly consistent with prior research demonstrating that multiple component programs incorporating cognitive and behavioural elements were more effective in reducing parent carers' distress levels compared to either behavioural training or cognitive interventions alone (Singer, Ethridge, & Aldana, 2007).

Participants indicated greater self-determination in pursuing leisure and self-care through their self-reported increases in satisfaction on activities of daily living, as described above. The qualitative data provided insight into the manner in which participants incorporated leisure and self-care into their lives, revealing that they did not renounce their dominant role as primary carers, but instead became more conscious and willing to weave opportunities for mental breaks and leisure into everyday life, whenever and wherever possible. This theme was termed "seizing moments", as reported by nearly half the participants. The proportion of participants reporting this theme differed markedly between the groups, with many more participants in the P⁺ group reporting seizing moments for leisure compared to participants in the P group. The pre-program self-confrontation intervention may have confronted participants with the costs to wellbeing associated with neglecting their self-care and leisure needs. As a result, participants in the P⁺ group may have been

more primed to use the program as a springboard to incorporate more leisure and time for self into their lifestyle before, during, and after the program, as opposed to viewing the program as an end in itself.

Numerous qualitative studies have shown that carers consider lack of time to be a major contributor to loss of leisure (e.g., Lamb & Layzell, 1995; Scharlach, 1994). Several participants indicated that they thought there was no such thing as “free time” before doing the program. It is possible that carers do have some time for regular leisure, but that they do not feel at liberty to use their time in a self-determined fashion. Therefore the sense of having no time may actually be a loss of self-determination about the way they use their time.

For caregivers, this lack of self-determination regarding time use may be fuelled by having been socialised into the “ethic of care”, and the perception that it is wrong to put personal needs and enjoyment above caring responsibilities. As previous studies have shown, carers often use the time their care recipient is in respite to do errands, caregiving tasks, and other household and family-related duties (e.g., Gill et al., 1998; Gottlieb & Johnson, 2000; Lawton et al., 1989). For nearly half the participants, the program appeared to stimulate an opportunistic stance towards perceiving newly gained time as freedom to do leisure and nurture the self. Some researchers have found that the function of leisure as a coping strategy is linked more to forms of interstitial leisure that are incorporated into everyday life as opposed to forms of “serious”, or high investment, leisure activities (Kelly et al., 1987; Mannell, 1993; Stebbins, 1992). As Csikszentmihalyi (2002) argued: “To gain personal control over the quality of experience, however, one needs to learn how to build enjoyment into what happens day in, day out” (p. 48).

The theme of seizing moments for leisure is consistent with past research and theories on leisure and respite among carers. Henderson et al. (1996) noted the

potential for "...fleeting intermittent moments" to serve as meaningful leisure for women (p. 107). Research on the definition of respite demonstrated that one of the six meanings of respite identified by carers was termed "stolen moments", referring to activities that temporarily take them away from caregiving tasks, but do not cause a big interruption to the daily routine of caregiving (Teitelman & Watts, 2004). In their study of carers of people with Alzheimer's disease, Watts and Teitelman (2005) further emphasised the importance of "caregiver carpe diem" (p. 288), or the strategy of watching for opportunities to engage in desired restorative activities.

The "seizing moments" theme also reinforces past research on maintaining wellbeing and positive emotion. For example, Lykken (1999, 2000) coined the term "happy habits" to describe a set of practices designed to incorporate small moments of pleasure in daily life and maintain positive mood. Bedini (2002), in her article titled "Family Caregivers and Leisure: An Oxymoron?" advocated the need to "...design leisure education programs that focus on teaching the caregiver to "enjoy the moment" during leisure blocks in an attempt to mitigate the emotional burden of feeling constantly responsible (even during times when the loved one is in the care of others)" (p. 28). It seems that the "Me Time for Mums" program answered this call.

All participants who mentioned a reorientation to seizing moments for "me time", also mentioned flow-like experiences during the program. The connection between these themes may be explored in relation to the phenomenology of time in the flow state. The experience of time often feels distorted when one is absorbed in the moment to moment unfolding of activity. In this process of "vital engagement", as described by Nakamura and Csikszentmihalyi (2002), minutes can feel like hours and hours like minutes, and consequently, the quality of engagement and degree of absorption is more important than the quantity of time spent doing an activity. As a result of their flow experiences, participants had direct evidence that a balance of

activities in life does not necessarily require equal amounts of clock time, and that seizing some moments for leisure on a regular basis is both possible and life-enhancing. In this sense, some participants reported that the program had the effect of challenging their “all or nothing” thinking about how much time is needed to engage in leisure. A poignant example of this was P7 who disclosed having drastic fantasies of escaping so that she would be “freed from all my responsibilities”. After doing the program, she described changing her approach to being “on the ready to take full advantage of moments for myself throughout the day”.

The theme of being on the look out to seize moments of time for self-care and leisure may be interpreted as signaling a new way that participants’ positioned themselves (i.e., “I-as-seizer of moments for leisure”), which finely straddled the dialectic of possibility and limitation for carers. As with the case study of Richard discussed by Hermans (2003), the position “I-as-seizer of moments for leisure”, may be thought of as a coalition “...between positions that were initially opposed and seem to exclude each other” (p. 111). This position may be conceived of as reconciling the polarised positions of “I-as-burdened carer” with “I-as-motivated leisure seeker”.

In acknowledging the benefits of being able to flexibly re-position the self as ready to seize moments for leisure, it must also be recognised that women in this program, and carers more generally, are not totally free to “re-author” themselves and disrupt the dominance of their caring roles. It would be naïve to think that participation in a short five-week leisure program could disrupt the dominance of the I-as-carer position. Individuals operate in socially conditioned contexts within normative roles. The role of “maternal carer” comes with a host of personal and societal expectations, and women judge themselves and are judged on whether they live up to social norms about how a “good mother” and a “good carer” should be. The

“seizing moments” theme indicated that, rather than renouncing their caregiving role, participants adopted an approach which allowed them to operate skillfully and strategically within socially imposed role restrictions.

Attending the “Me Time for Mums” program was a special unobtrusive round-trip excursion the women made. Whereas the literature on respite services indicates that carers never leave the caring role even when apart from their care-recipient(s), many participants in the present study reported their sense of entering a different space in the creative sessions, with different potentials and opportunities compared to daily life. As revealed in participants’ post-program interviews, the many attitudinal, affective, and behavioural outcomes described above were fuelled by several underlying processes, which will now be explored.

9.2 Program Processes

9.2.1 “Me Time for Mums” and the Phenomenology of Flow

Participants’ accounts of their experiences in the sessions were replete with references to the phenomenology of flow, including the experience of optimal challenge and risk, absorption in the activities, loss of self-consciousness, losing track of time, forgetting personal problems, and a sense of action and awareness merging. Given that 10 out of the 16 participants expressed entering a flow-like state, there is evidence that the activities in the program provided a “just right” challenge. This would not have been the case if activities had been too difficult, as research has demonstrated that excessive task difficulty creates anxiety rather than optimising flow (e.g., Rebeiro & Polgar, 1999).

Post session feedback data revealed that theatre sports was rated as being the most engaging (i.e., absorbing) session by both groups. Not surprisingly, it was also rated as being the most enjoyable. The pattern of engagement and enjoyment ratings showed a similar trend (see Figures 19 and 20 in Section 8.1.1, pp. 164-166),

which is consistent with Csikszentmihalyi's (2002) proposition that "...being able to forget temporarily who we are seems to be very enjoyable. When not preoccupied with ourselves, we actually have a chance to expand the concept of who we are..." (p. 64).

Participants' descriptions of absorption in the creative activities paralleled Watts and Teitelman's (2005) finding that absorption in activities was the most proximal, causal ingredient of having a mental break from caregiving. The present findings reinforce the validity of Watts and Teitelman's conclusion that "...absorbing activities function as triggers that sever past emotional patterns (e.g., caregiving worries), permit respite from a stifling mental state or set patterns, and produce relaxation and a more serviceable, effective mental state" (p. 289).

In summary, participants reported highly enjoyable experiences consistent with the state of flow as conceptualised by Csikszentmihalyi (2002). However, in contrast to the view that flow principally stems from engagement in more "serious", high investment activities that involve commitment and self-discipline (e.g., Csikszentmihalyi, 1988; Iso-Ahola, 1999; Mannell, 1993; Mannell & Kleiber, 1997; Stebbins, 1999), the present results demonstrated that individuals can experience flow-like states during more simple and novel creative arts activities, within a short space of two hours. This finding is consistent with Hutchinson et al.'s (2006) arguments that more simple and casual forms of leisure can provide opportunities for flow-experiences and heightened enjoyment.

9.2.2 "Me Time for Mums" and the Phenomenology of Self-expansion

Leisure "...may be a crucial life space for the expression and development of selfhood, for the working out of identities that are important to the individual" (Kelly, 1983, p. 23). It was hypothesised that engagement in leisure and self-care activities would generate an expanded sense of personal identity. This prediction was

amply represented in participants' interview accounts, with eleven out of the sixteen participants reporting themes of self-expansion beyond the caregiver role.

There was a pronounced between-group difference in reporting themes of self-expansion. Frequency analysis of quotations from the follow-up interviews demonstrated that most of the P⁺ group reported self-expansion and identity-related themes, compared to half of the P group. For P⁺ participants, the program was consciously set up as a “playground” for the emergence and re-emergence of a more multi-faceted sense of self. In the self-confrontation procedure, participants were introduced and oriented to the notion of self-positioning and the importance of expressing I-positions, such as I-as-leisure-seeker, that are often denied or neglected through privileging the caregiver role in daily life. Through this fuller articulation of self-expansion themes, participants in the P⁺ group may have experienced the program more consciously as part of an identity project/process, not just as a string of pleasant creative activities. The first step in self-expansion appeared to be recognition of the constraints imposed by identifying the self with a role.

9.2.2.1 Realising the Confinement of Living in Role-Identified I-Positions

Roles are culturally defined norms, rights, duties, expectations, and standards for behaviour that can enlarge or narrow the range of individuals' capacities. McCall and Simmons (1978) developed “role identity theory”, which addresses the process of forming an identity based on the categorisation of the self as an occupant of a role. The social expectations and meanings associated with the role form a set of standards that guide behaviour (Burke, 1991; Burke & Reitzes, 1981). The multiple reinforcements of being a “good carer” and “good mother” make it difficult for women who perform the caregiver role to acknowledge that they have personal needs. Role-related assumptions and personal theories can become habitual,

taken-for-granted modes of interpreting self and world. This can drastically reduce the flexibility of positioning in the individual's self-system.

According to dialogical self theory, the self should be conceived as being continually shaped and reshaped through dialogue between internal positions and through dialogue with others. Hermans (2003) argued that when one internal position becomes dominant, the "...possibility of the dialogical self is seriously reduced and the dialogue becomes extremely asymmetrical and power-laden or even totally disappears" (p. 104).

This in turn limits the individual's capacity for change, growth, and can affect their sense of optimism and hope for the future. The aim of constructionist theories of selfhood is to foster freedom from taken-for-granted assumptions about self and world, thus freeing individuals from the constraints of their roles, habits, and automatic thoughts (Gergen & Kaye, 1992), and allowing for an expansion of personal identity.

The importance of maintaining a multifaceted self-concept is also advocated by Linville (1985, 1987), who suggested that when a stressful event occurs, it affects the self-aspect most pertinent to the stressor. For a person with numerous self-aspects (high quantity), the affected self-aspect is only one of many aspects, therefore a relatively small proportion of the total self will be affected. By contrast, a stressor will negatively affect a greater proportion of the total self in persons who have fewer aspects in their self-concept. Multiple aspects of self, or self-complexity, serves as a cognitive buffer against extreme affective reactions to life events.

These sentiments echo Eagar et al.'s (2007) conclusions from their synthesis of evidence concerning carer needs and interventions, that parents of older children with disabilities may present "...a challenge for service providers", as

“These people have often had a long career in caring. They may resist interventions that seek to establish the independence of their disabled adult child, because it means relinquishing some control and a loss of role...” (p. 81). Thus, not only do carers need to give themselves permission to nurture aspects of self beyond the caregiver role, some may also need to risk stepping outside of a role that provides them with purpose, structure, and positive reinforcement.

9.2.2.2 “Me Time for Mums” as a Turning Point

The “Me Time for Mums” program appeared to offer participants a turning point, defined as a “...redirection in the path of a person’s life...when a person undergoes a major transformation in view about the self, identity, or the meaning of life” (Wethington, 2003, p. 37). Literature on turning points suggests that people may achieve increased wellbeing and growth through positively valenced life events that generate significant shifts in one’s view of self (Clausen, 1995). Similarly, the importance of “fresh start events” (e.g., new job, relationship, leisure pursuit) has been recognised as bringing hope and perception of a new way forward (Dowrick, 2004). The program was a positive psychology intervention that emphasised the anticipation, experience of, and reflection upon involvement in a positive life event.

9.2.2.3 “Me Time for Mums” Program as a Catalyst for Self-Expansion and Growth

Participants’ accounts of self-expansion can be viewed as corresponding to Hermans’ (1999) notion of the self being a dynamic process of positioning and repositioning according to the time, place, and context one is operating in. Self-expansion involves both addition of new ways of positioning the self and reconnection to old “I” positions that may have been neglected or dormant given the dominance of the “I-as-carer position”. In other words the program fostered both change and biographical continuity. There were four main pathways through which participation in the “Me Time for Mums” program provided a vehicle for self-

expansion: a) Restoration of former I-positions; b) Emergence or increased salience of I-as-leisure-seeker position; c) Flow-generated self-expansion; and d) Introduction of “I as Me Time for Mums group member” as a new internalised I-position.

9.2.2.3.1 Restoration of former I-positions. The program stimulated participants to rediscover meaningful, personally salient activities that were feasible within, and in spite of, the constraints imposed by caregiving obligations. Research on wellbeing has demonstrated that, as we perceive ourselves becoming more like the person we want to be, our life satisfaction increases (Pavot, Fujita, & Diener, 1997). The results indicated that through the ability and inspiration to engage in former pursuits, participants felt they were still the same kind of person they had always been. Simple leisure and creative activities provided ways for participants to restore a connection to previously valued, though dormant or neglected, aspects of their self-concept. As Kleiber et al. (2002) theorised:

...such experiences seem to point the way to using leisure not only to relieve the stress associated with a negative life event, but also to use leisure more instrumentally in reconstructing a life that may recover the best of what was lost or may offer new roads to happiness and well being. (p. 225)

Achieving a sense of biographical continuity helped participants resist over-identification with the caregiver role, and promoted the development of relationships based on mutual interests rather than the disability of children or caregiving issues. In addition to reconnection to previously valued I-positions, the program invited participants to experiment with ways of positioning the self as a self-carer, leisure seeker, and creative and playful individual, which led to a sense of expanded future possibilities.

9.2.2.3.2 Emergence or increased salience of I-as-leisure-seeker position. The “Me Time for Mums” program provided a forum for participants to engage in activities that may have been beyond the reach of the dominant carer position. As documented by Hermans (2003) in his work with “Richard”, doing “‘innocent’ activities, which were, in the eyes of the perfectionist, scarcely noteworthy” (p. 118) stimulated the innovation of a new I-as-accepting position in Richard’s self-system. This case-study provides an analogue to the processes that seemed to occur for many participants through engaging in creative and playful activities in the “Me Time for Mums” program.

Some participants reflected on how the pressure to live up to the role of “good caregiver”, resulted in living a lifestyle that failed to stimulate interest and intrinsic motivation. Psychologists within the positive psychology tradition have underscored the importance of interest and personal expression in terms of intrinsic motivation and identity development (e.g., Hunter & Csikszentmihalyi, 2003). Without interest it is hard for individuals to enthusiastically proceed toward the future, in a process of “becoming”, with goals and motivation. It has been further proposed that when “becoming” is blocked, people are unable to foresee meaningful futures. These processes were elucidated by Bargdill (2000) in his phenomenological study of chronic “life boredom”. Bargdill’s study found that participants shared the experience of having to compromise their intrinsic motivation as a result of being compelled to commit to projects that were inconsistent with their interests and self-defined strengths. As a consequence of these compromises, participants reported emotional ambivalence to the projects they were involved in, which limited their personal investment in these projects, and consequently reduced their self-esteem. At an extreme level, participants reported feeling empty and apathetic

because of the belief that no matter what they do, they will not be able to sustain intrinsic interest, and thus action was futile.

This process may apply to some caregivers who report a loss of personal leisure interests and above normative levels of depression. Assuming the primary caregiver role is rarely a choice for mothers of children with disabilities. It is possible that experiencing engulfment in this role leads to a limitation in performing intrinsically motivated activities due to the high volume and intensity of extrinsically motivated instrumental caregiving tasks. In turn, the loss of perceived self-determination to engage in identity-affirming activities may result in chronic feelings of emptiness, apathy, and diminished self-esteem. In accordance with the activity restriction model of depression (Williamson et al., 1998) and eudaimonistic identity framework, assisting caregivers to pursue personally salient interests and potentials may provide a useful focus for helping professionals working towards improving carers' wellbeing. In addition to encouraging a repositioning of the self as a playful leisure seeker, the program also offered participants the chance to detach from their typical roles through absorption in the activities, and therein experience a role-less sense of self.

9.2.2.3.3 Flow-generated self-expansion. Interview data strongly suggested that experiencing flow was connected to self-expansion. Several mechanisms may explain how the experience of flow enables an expansion of the boundaries of self.

Constructionist theories posit that over-identification of the self with a role can lead to entrenched automaticity of thoughts, feelings, and behaviours, or taken-for-granted assumptions that “this is who I am” and “this is what I can and can't do”. Luckily, as Csikszentmihalyi (2002) proclaimed, “For each person there are thousands of opportunities, challenges to expand ourselves” (p. 3). For participants in the “Me Time for Mums” program, it may be postulated that absorption in creative activities

brought with it a clearing away of self-evaluative thoughts regarding meeting role-based standards. Through absorption and clearing away self-evaluative thoughts, participants seemed to expand their usual experience of self by connecting with their imagination and creativity. As Rollo May described:

When you are completely absorbed or caught up in something, you become oblivious to things around you, or to the passage of time. It is this absorption in what you are doing that frees your unconscious and releases your creative imagination. (May, 1994, p. 14)

The mechanisms involved in the flow-state may be further elucidated with reference to “escape theory”, as expounded by Baumeister (1989, 1990a, 1990b) and Heatherton and Baumeister (1991). Narrowing one’s focus to the present and immediate stimulus environment can allow one to escape aversive higher-order self-awareness concerning measuring up to self and socially imposed standards. At the lowest levels of self-awareness, “...self is reduced to body, experience is reduced to sensation, and action is reduced to muscle movement.” This “...deconstructive process may be an appealing way to escape from worries, threats, and pressures” (Heatherton & Baumeister, 1991, p. 88). The notion of escaping the self by shifting levels of awareness has been applied to several phenomena, most of which have self-destructive implications, including alcohol use, binge eating, cigarette smoking, and suicidal ideation. As demonstrated by participants’ accounts, immersion in creative activities, such as drumming, belly dancing, improvisational Theatresports, and art making, can provide a more salubrious pathway to bringing awareness into the present moment and diverting attention away from aversive thought patterns.

Through experiencing flow-like states, a new I-position was created for many participants, which may be called the “I-as-beyond-roles-in-flow” position. This position is capable of “being” spontaneously and instinctually, rather than doing

prescribed tasks to meet the demands of others and the environment. In this state of absorption and “oneness with the task” participants reported a shift of awareness out of the thinking, worrying mind. Rather than treating the self like a robot without needs, participants experienced heightened interest and engagement, captured in their post-program discourse which was replete terms such as “awakened”, “alive”, “vital”, and “creative”, among others. Experiencing this authentic self seemed to embody Csikszentmihalyi’s (2002) conception of the link between the experience of flow and self-expansion:

During the flow experience an individual does not have the opportunity to reflect on what this means in terms of the self...But afterward, when the activity is over and self-consciousness has a chance to resume, the self that the person reflects upon is not the same self that existed before the flow experience: It is now enriched by new skills and fresh achievements. (p. 66)

Indeed, through doing the program, participants expanded their behavioural repertoire and surprised themselves that they could do things, like belly dancing, Theatresports, and playing drums, which they may not have thought they could do before. Flow-like experiences provided an action-oriented route towards self-enhancement via transcending roles and living more fully and spontaneously in the unfolding present moment. As participants in the “Me Time for Mums” program demonstrated, throughout the lifespan we need playful and imaginative spaces to reinvent and “refresh” ourselves.

As outlined so far, the “Me Time for Mums” program may be conceived of as leading to the invigoration of previously valued I positions, the emergence of the leisure seeker position, and the experience of the “I-as-beyond-roles-in-flow” position. In addition to these different avenues for self-expansion, participants’

accounts suggested the “birth” of a new I position, which may be described as “I-as-‘Me Time for Mums’-group-member.”

9.2.2.3.4 Introduction of “I-as-‘Me Time for Mums’-group-member” as a new internalised I-position. Michel and Wortham (2002) introduced the notion that people can relate to each other as mutually constitutive parts of a situated system. Situated systems are defined by the task they accomplish (e.g. in this case, group drumming, creating theatre sports scenes etc.). Each week participants in the “Me Time for Mums” program entered the room and became mutually constituting players within a group of belly dancers, drummers, theatre sports players and so on. That is, participants experienced themselves not only through the agentic position of I-as-leisure seeker, but also as part of a collective of women all doing creative leisure activities together as a unified system, which may be termed the “I-as-‘Me Time for Mums’-group-member” position. The women in the group authored a shared story. Over the five weeks, the group itself became a subject position, with its own collective “voice”, which was perhaps stronger and more courageous than each woman alone. This collective position of the group may be conceived of as another I-position that may become internalised in each woman’s repertoire of I-positions.

Interview data indicated that participants experienced themselves in ways that were simultaneously self-enhancing and unified with other group members and facilitators. One participant noticed the self-enhancing effects of being part of a greater whole. In other words, doing “Me Time for Mums” resulted in both agentic and communal rewards that were mutually reinforcing. The group may be said to have provided a forum for the realisation of what Csikszentmihalyi (2002) termed differentiation and integration, and what Hermans et al. (1990) referred to as the “self-enhancement” and “union with others” motives. Differentiation implies a movement towards uniqueness, self-enhancement, and towards separating oneself

from others. Integration refers to a union and contact with other people, with ideas and entities beyond the self. These tendencies or motives are thought to reflect the “...basic duality of human experience” (van Geel & De Mey, 2002, p. 1834).

While most participants indicated that they felt a sense of group belonging and cohesion, there was an exception to this. One participant seemed to impose habitual categories on her self-identification, which made her feel different to other group members. She suggested that future groups should comprise groups of women who were more similar in the nature of their child’s disability and extent of their caregiving role. This participant was not exposed to the pre-program self-confrontation intervention, which might have helped her to see her caregiver role as only one position among numerous ways of positioning the self. Her entrenched role-identification as a particular type of caregiver seemed to get in her way of connecting with the group in a role-less capacity, and letting herself move with and become part of the unfolding situated system.

In their theory of “direct involvement” Michel and Worthan (2002) proposed that individuals can experience themselves in terms of the ongoing activity, instead of in terms of pre-determined categories that define the individual. They argued that “...identification with a particular construction of the self stands in the way of those situated processes that might otherwise let meaning emerge from the unique dynamics of the joint situation” (p. 627). Stepping out of these pre-defined caregiver categories and becoming immersed in creative activities were key ingredients in experiencing restorative respite during the program.

9.2.3 Restorative Respite

Participants conceptualised their respite experience during the “Me Time for Mums” program using very similar language to carers’ subjective definitions of respite reported in previous qualitative research (e.g., Gahagan et al., 2007; Strang &

Haughey, 1999). When the P⁺ group is compared to the P group on this issue, a striking result emerges. Seven of the eight participants who explicitly referred to the program as a respite experience were in the P⁺ group. It appears that exposure to the pre-program intervention may have both sensitised participants to reflect on their own self-positions, and provided them with a conceptual framework and language to articulate the link between freedom from the carer role and restorative respite.

The playful nature of activities in the program invited joy, being in the moment, and a letting go of the tyranny of self-surveillance and punitive internal narratives. Once freed from the emotional traps associated with the ethic of care (e.g., guilt, perfectionism, over-responsibility) participants were free to be themselves, and this seemed to be a defining feature of restorative respite experiences.

The connection between respite and flow experiences reinforces results of previous qualitative research on carers' subjective definitions of real respite. Specifically, the present findings support Watts and Teitelman's (2005) findings that absorbing activities were the most proximal trigger for carers to experience "quality respite". Carers in Chappell et al.'s (2001) qualitative study also talked about respite as "...freedom from concern through disengagement of the mind" (p. 205), which is a commonly cited feature of the flow state. Some participants further suggested that, in addition to the relief from thoughts, immersion in creative activities created a fresh and controllable world, providing a restful contrast to the unpredictability of stressful caregiving situations. Carers may use respite services, but not experience respite outcomes. Results of the present study indicate the utility of leisure and creative activity programs for carers as a service that produces respite outcomes. In addition to facilitating restorative respite, the "Me Time for Mums" program augmented participants' leisure companionship, sense of social connectedness, and perceived legitimacy of pursuing leisure.

9.2.4 Social Support

Social support was quantitatively measured using the “leisure companionship” subscale of the Leisure Coping Strategies Scale (Iwasaki & Mannell, 2000), which measures the degree to which participants accessed social support in their leisure pursuits. Compared to the Control group, the P⁺ group reported greater pre- to post-program increases in leisure companionship. The P group exhibited a similar trend, reporting greater change during the program period compared to the wait-list period, although the change was not as marked. The qualitative data elaborated on the nature and benefits of program-generated social support.

Post-program interview data revealed that more than half of the participants reported increased social connectedness as a result of doing the program. There was a pronounced group difference such that three quarters of participants in the P⁺ group, compared to three eighths of the P group, reported this theme. In more consciously approaching the program as a leisure seeker, P⁺ participants may have been more inclined to approach each other as potential companions for leisure after the program.

Participants’ post-program reports are consistent with numerous studies demonstrating the value of informal social support to coping with the stressors of caregiving in parental caregivers (Boyd, 2002; Frey et al., 1989; Pinqart & Sorensen, 2007; Schofield et al., 1998; White & Hastings, 2004). Participants’ accounts reinforced previous findings that leisure contexts can enable people with similar life experiences to be in the company of supportive others without having to talk directly about their problems (Hutchinson, 2007). Leisure, in its companionate forms, and through social activities, clearly has the potential to provide people with feelings of social support and a decreased sense of loneliness and isolation (Coleman & Iso-Ahola, 1993).

However, equivocal findings have been demonstrated in relation to the buffering role of social support. Caltabiano (1988, 1995) found that minimal levels of social leisure after stressful events buffered deleterious effects while high levels of social leisure actually increased illness symptoms. Coleman and Iso-Ahola (1993) also acknowledged that in times of high stress, high levels of social support may lead to feelings of dependency or perceptions of lack of control and competence, and alienation rather than togetherness. These equivocal findings point to the need to understand the psychosocial processes operating to either make leisure-generated social support beneficial or detrimental. The potential stress-buffering effects of leisure companionship specifically procured through brief leisure programs, such as “Me Time for Mums”, is therefore worthy of future empirical investigation.

In addition to increased social connectedness, half of the participants reported the theme of social legitimacy, or the sense that attending a community-based leisure program provided them with social validation and legitimacy for pursuing leisure. A greater proportion of participants in the P⁺ group compared to the P group reported this theme. The pre-program intervention provided P⁺ participants with two sessions with the student researcher who advocated taking time for leisure and self-care, and this potentially increased participants’ sense of social validation for taking leisure time over and above program-generated social legitimacy outcomes. Hughes and Keller (1992), proponents of leisure education programs for carers, recommended the “...endorsement of health care professionals” (p. 126) as necessary to minimise caregivers’ resistance to engage in leisure activities. Bedini (2002) further emphasised the need for external validation and community support to encourage carers’ leisure participation. Results demonstrated that by attending a community, group-based program, which was endorsed by workers and health professionals, participants enhanced their permission for self-care.

In providing social validation via community programming, the “Me Time for Mums” program provided opportunities for re-socialisation into an ethic of self-care where leisure, play, creativity, and enjoyment were prioritised values. Participants were encouraged to approach each other as “playmates” rather than caregivers, and a concerted effort was made to orient participants to the action-oriented, playful spirit of the program, distinguishing it from other caregiver groups that may provide a space for sharing problems and concerns. In describing role-based identity, Kielhofner (2002) suggests that over-identification with certain roles, or role-identity, is “...generated when others recognise and respond to us as occupying a particular status” (p. 72). In responding to each other as leisure-seeking women, rather than carers, interactions during the program appeared to facilitate a collective and legitimised ethos of self-care, which presumably differed from the “macro system” characterised by the ethic of care and concomitant pressures of being good caregivers and mothers.

9.3 Conclusion

9.3.1 Overview of Findings and Implications for Future Programs

Many interventions have been implemented to ameliorate stress in parent carers (for reviews of interventions, see Hastings & Beck, 2004; Singer et al., 2007). The “Me Time for Mums” program differed from previously documented leisure education and cognitive behavioural multi-component interventions for carers in that it did not contain structured cognitive or educational components. The primary agenda of the five-week program was activity participation, which appeared to indirectly achieve many of the aims stipulated by designers of leisure education models (e.g., Charters & Murray, 2006), including stimulating increases in leisure participation, awareness of leisure interests, capacity to negotiate through leisure constraints, ability to organise environments conducive to leisure, and clarification of

leisure values. Although some leisure programs have been developed for carers, "...the literature is silent on the relative effectiveness of social, recreational, educational, service, and advocacy groups [for carers]" (McCallion & Toseland, 1995, p. 22). It would be interesting to compare an activity-based leisure program, such as "Me Time for Mums", to a cognitive-based leisure education program, to help tease out the relative therapeutic effects of cognitive versus behavioural leisure programs. Results of the present program suggest that experiential programs can generate important cognitive and affective outcomes. This is pleasing given that activity-based programs may be more easily implemented by staff in community organisations who have not been trained in implementing cognitive strategies.

The "Me Time for Mums" program signified a departure from typical avenues of support for carers, and is the first creative leisure program for carers in Australia that has been systematically evaluated. In the program sessions, companionship and support was generated through collectively contributing to leisure and creative activities, where self-definition was mediated through shared activities and new friendships, rather than centred on being a primary carer. This provided a different focus and atmosphere to the educational and problem focused discussions that tend to occur in carer support groups.

The present evaluation study provides preliminary evidence that an experiential leisure program can provide a springboard for the initiation of changes in attitudes, feelings, and behaviours that decrease stress and augment wellbeing in caregivers. Program outcomes indicate that engagement in relaxing and creative leisure activities is not mere escape or fleeting pleasure. Though not traditionally incorporated in therapeutic interventions, the present results indicate that leisure and creative "play" are capable of generating significant psychological change. Regarding quantitative outcomes, within the domain of leisure attitudes, both groups reported

significantly greater motivation to increase leisure compared to the Control group. Within the domain of mental health, both intervention groups reported a significantly greater reduction in stress and a significantly greater increase in positive energy compared to the Control group. In the domain of life satisfaction, both groups reported a significantly greater increase in satisfaction with basic needs and activities of living compared to the Control group. Given the replication of these positive program outcomes over two separate intervention groups, preliminary empirical evidence demonstrated that doing the program generated significantly greater positive changes compared to waiting for it. The only quantitative difference found between the two intervention groups was that the P⁺ group reported a significantly greater reduction in intrapersonal constraints to leisure compared to the P group. Further differences between the intervention groups were elucidated in the qualitative data, which provided evidence that the pre-program intervention improved program outcomes.

The post-program follow-up interviews provided rich information that elaborated on the quantitative outcomes as well as revealing unexpected positive effects of both the program and pre-program self-confrontation intervention. More than twice the number of participants in the P⁺ group compared to the P group reported the attitudinal outcomes of increased acknowledgement of personal needs and reduced intrapersonal leisure constraints, as well as the behavioural outcome of seizing moments for leisure. Moreover, all participants in the P⁺ group reported specific leisure behaviour change, compared to two out of eight participants in the P group. These results suggest that the P⁺ group experienced more positive outcomes of the program compared to the P group. This trend was not apparent regarding affective outcomes, as a similar proportion of participants in both groups reported that doing the program resulted in an uplifted mood and improved affect regulation. These

qualitative results suggest that doing a pre-program constructivist self-investigation in combination with a leisure program engenders more profound attitudinal and behavioural change than doing the experiential leisure program alone. However, it seems that participating in an experiential leisure program, in and of itself, engenders powerful mood lifting and mood regulation outcomes.

Regarding qualitative process themes, at least twice as many participants in the P⁺ group, compared to the P group, reported the process themes of self-expansion, flow, restorative respite, and increased social connection. The finding that P⁺ participants provided more frequent and elaborate articulations of the self-expansion theme is not surprising given that the *raison d'être* of the pre-program intervention was to broaden participants' concept of personal identity beyond the caregiver role. Another possible interpretation is that the P⁺ group may have been assisted in expressing self-expansion themes through the conceptual frameworks and language introduced in the pre-program intervention. The pre-program intervention also provided participants with a comparative analysis of their wellbeing when they are operating in the "I-as-caregiver" position compared to the "I-as-leisure seeker" position. In overtly connecting leisure to personal wellbeing, this analysis may have highlighted the need to expand the self beyond the carer role to maintain wellbeing. The theme of self-expansion included several routes through which participants reportedly expanded their personal identity, including through identifying the self as a "leisure seeker"; through accessing flow-like states; and through identifying the self as a member of a leisure-championing collective. In turn, as previously described, expanding personal identity was associated with experiencing "restorative respite" during the program.

These between-group differences in reported program process themes warrant some interpretation. The pre-program intervention encouraged individuals to stand

back and take an observer's perspective of their typical I-positions, roles, attitudes, motivations, and wellbeing. In standing back from themselves, and outside of their taken-for-granted roles and obligations, participants had the opportunity to develop a consciousness of how their self-experience changes according to the way they position themselves. Each person in the P⁺ group was assisted in doing their own self-awareness study. P⁺ participants did the program with a more conscious concept of where they started from by way of self-positioning, and therefore had a point of comparison from which to articulate attitudinal and identity related changes. Incorporation of the pre-program self-awareness priming intervention served to enhance the depth of program effects beyond mood enhancement and towards more profound attitudinal and behavioural change, which would seem to promote sustained leisure participation. The program outcomes and processes articulated by participants reveal the many positive psychological functions served through leisure participation.

Participants' interview accounts gave voice to each one of Kleiber et al.'s (2002) four propositions regarding the positive restorative and transformative functions of leisure. Participants reported that the leisure activities took their mind off stress by being absorbing and distracting (proposition one). The discourse used by participants to describe their engagement in the program was significant, not simply in terms of enjoying the activities, but in terms of the meanings they attributed to experiencing a different sense of self in ways including light-hearted, fun, imaginative, creative, physically active, and social. Participants spoke of a "becoming self", with a sense of self projected into the future through the medium of anticipated leisure participation (proposition two). Participants were reacquainted with creative, playful, silly, and imaginative aspects of self which had been buried under the weight of responsibilities. Therefore the program provided a bridge from the present to the past, enhancing biographical continuity (proposition 3). Perhaps most profoundly,

evidence from the post-program interviews demonstrated that a short leisure program can provide a vehicle for personal transformation (proposition four), in terms of enhancing individuality as well as union with others, and engendering a sense of self-determination in repositioning the self out of dominant roles via seemingly “simple” and “ordinary” activities.

In addition to these functions, leisure activities arguably provided an avenue for these women to resist the emotional traps of socially constructed and heavily reinforced carer and mother roles, towards embracing an ethic of self-care. Indeed, feminist leisure researchers have suggested that empowerment from feminised roles, such as carer, can result from successfully negotiating constraints to leisure (e.g., Henderson, 1994; Henderson, Bedini, Hecht, & Shuler, 1995; Henderson & Bialeschki, 1993; Shaw, 1994).

The eudaimonistic identity theory (Waterman, 2004; Waterman et al., 2008) was well represented in participants’ accounts of increasing their self-expression, and expanding their sense of self-realisation and personal identity through creative activities. Through the medium of activity participation, the program enabled different desires and feelings about self that were alive, vital, and “becoming”. Experiencing interest, flow, enjoyment, and personal expressiveness during these activities seemed to ignite participants’ intrinsic motivation to keep pursuing leisure after the program, as evidenced by the outcome that 14 out of the 16 participants reported increasing their leisure behaviour, or thinking about doing so, after the program. Additionally, participants reporting the “seizing moments” theme seemed to realise the importance of ensuring that an adequate quota of intrinsically motivated activity is incorporated into their lifestyle on a regular basis. The eudaimonistic identity theory provides a useful theoretical framework to guide the future development and evaluation of caregiver-specific leisure activity programs. Indeed,

this theoretical framework and its core variables of personal expressiveness, self-realisation values, flow, intrinsic motivation, and identity development are relevant to all groups who typically experience activity restriction due to role engulfment, and associated difficulties in connecting with a valued sense of personal identity.

To use occupational therapist, Ann Wilcock's (1999) language, the "Me Time for Mums" group offered many opportunities for "doing, being and becoming". Regarding "doing", participants took the risk to participate in an unknown program, to engage in a novel array of activities with a group of new people, which involved leaving the house and their responsibilities, and doing something just for themselves for the sake of enjoyment and fun. Regarding "being", the group provided a space for participants to get inside their bodies in new ways and to be in the moment through relaxation and heightened sensory awareness. Through entering the state of flow, participants were able to be in the present moment without worries or cognitive processing of their experience. These "doing" and "being" processes seemed to result in a sense of "becoming", similar to the notion of self-realisation, involving the stimulation of leisure interests and community linkages, a shift in approach towards opportunistically seizing moments for leisure, and envisaging a life outside of care-giving.

Carers themselves report that respite means freedom from operating in the care-giving sphere. For most participants, the "Me Time for Mums" program appeared to provide a space for this role freedom. Results of this evaluation study demonstrated that community leisure programs may offer a "repositioning" space for carers to shift out of their dominant role, and invigorate other positions, such as I-as-leisure seeker, I-as-creative, and I-as-fun loving, that are not typically stimulated in daily life. Health professionals might give more attention to the power of enjoyable and creative pursuits for expanding lives limited by caregiving. Indeed, perhaps

Australia should follow the example set by the “arts-on-prescription” schemes operating in the UK, in which arts courses are provided as an alternative, positive psychological mental health initiative to people who are vulnerable due to an experience of mental or emotional distress. The arts course is “prescribed” by doctors and mental health professionals to help individuals regain their confidence, learn about art, experience creativity, and meet others whilst involved in a positive activity (Huxley, 1997, as cited in Eades & Ager, 2008). In being fully funded, facilitated in a community setting, and promoted by case-workers and other support personnel, the “Me Time for Mums” program offered a powerful “lifestyle permission slip” which provided social validation for maternal carers to engage in creative leisure activities.

9.3.2 Limitations of the Present Study and Possible Directions for Future Evaluation Research

It must be acknowledged that the present evaluation study was limited in several ways. These limitations point towards possible refinements and extensions to future leisure program design, delivery, and evaluation research. First, the qualitative methodology and analytic procedure may be scrutinised. As interviews are inevitably a co-production of interviewer and interviewee, it is possible that participants framed their answers in ways that they thought the interviewer wanted. Nevertheless, some confidence is warranted that participants’ views were not simply borne of social desirability. The interviewer was an independent research assistant, with no personal agenda in terms of delivering or evaluating the program, who was employed for the specific purpose of conducting the follow up interviews. Additionally, the themes from the qualitative data were represented in many participants’ accounts suggesting shared aspects of participants’ experiences, and indicating reliability of qualitative results.

The interpretation of qualitative data is inevitably dependent upon the researchers’ own personal and professional sensitivities. The analysis of dominant

themes was clearly influenced by the researchers' a priori conceptual frameworks. A researcher with alternative theoretical perspectives on creative leisure activities may have been sensitised to different issues within participants' post-program accounts. There is inevitable subjectivity about coding complex verbal reflections on personal experience using preconceived conceptual frameworks. However, such conceptual and theoretical frameworks are arguably necessary to guide the development of interventions and to anticipate and reflect upon possible mechanisms of change, thus facilitating program evaluation and research (Peterson & Bredow, 2004).

It is recognised that the demarcation between program "processes" and program "outcomes" was speculative. Of course, in lived reality, processes and outcomes overlap, and arguments can always be made that outcomes are processes and vice versa. In the present study, participants had the opportunity to read through their coded transcripts and all participants concurred with the thematic categories and their delineation into processes and outcomes. This consensual validation process provided an additional safeguard for authentically representing participants' accounts, thus enhancing methodological rigour.

There were several limitations associated with use of the Caregiver Leisure Attitudes Scale (CLAS) as an outcome measure, particularly regarding measurement of leisure motivation. The version of the CLAS used in the present program evaluation study measured leisure motivation according to only two out of the five basic stages of change included in the Transtheoretical model of behaviour change, "contemplation" and "preparation". Items measuring the other stages of change (pre-contemplation, action, and maintenance) failed to load on any factor in the CLAS pilot study (see Chapter 1, Section 1.6.1, p. 16) and were therefore excluded. In order to increase the scope of leisure motivation measurement in future use of the CLAS, items pertaining to all five stages of change should be included and the CLAS should

be pilot tested again with a larger sample of caregivers. Future research should investigate whether the effectiveness of experiential leisure programs, such as “Me Time for Mums” differs as a function of caregivers’ pre-program stage of change. This would assist in appropriate targeting of carers for leisure interventions, and may also introduce the need for pre-program motivational enhancement interventions.

A second limitation associated with the CLAS concerns measurement of the two variables measuring leisure values (perceived benefits of leisure and perceived risks of not doing leisure). Although some significant change was reported by the P⁺ group compared to the Control group on perceived benefits of leisure, participants’ scores on these two variables were generally high before the program and remained high after the program, indicating that these items may be assessing stable attitudes towards leisure. For the purposes of program evaluation, measuring attitudes that are fairly stable over time does not provide for a sensitive measurement of program outcomes. As Bedini and Phoenix (2004) demonstrated, while the majority of carers in their study valued leisure, only a minority protected leisure time, showing that valuing leisure does not necessarily translate into performance of leisure behaviour among caregivers. In future, the CLAS should be revised to measure the congruence between carers’ perceived value of leisure (i.e., perceived benefits of leisure and risks of not doing leisure) and their performance of leisure behaviour. Measuring leisure value/behaviour congruence may provide a more accurate and sensitive indication of how salient and influential leisure values are in caregivers’ daily functioning, providing for a more sensitive program evaluation tool. Additionally, future pilot testing of the CLAS should examine the test-retest reliability of each subscale to further evaluate its suitability as a program evaluation tool.

There were several limitations of this evaluation study due to the extreme difficulty involved in recruiting participants. Small sample sizes appear to plague the

majority of carer intervention studies. Asking carers to add one more duty by participating in a program and research study is quite a challenge. The women who “took the plunge” and committed to attending the program were a self-selected sample. They may have already had a stronger willingness to increase “me time” and pursue leisure and self-care behaviour. They may have been more ready to embrace a wellbeing promoting intervention, and this willingness and motivation may have partially driven the positive evaluation outcomes. This self-selection possibility, however, cannot be held responsible for all of the positive outcomes reported, especially given the pronounced differences between the P⁺ and P groups in reporting qualitative attitudinal and behavioural outcomes and process themes. Further, in relation to participants, maternal carers have been distinguished as a vulnerable group in terms of reduced personal wellbeing and loss of leisure and were therefore prioritised for delivery of this pilot program. Obviously, evaluating the program with other carer sub-groups is of interest, including male carers, those from a wider cross-section of cultural and linguistic backgrounds, and those with diagnosable mental health problems.

Inclusion criteria for the “Me Time for Mums program” served to pre-select participants with below normative personal wellbeing scores, but not so low as to indicate depression and other clinical disorders. Previous meta-analytic research demonstrates that primary maternal carers of children with disabilities are at a higher risk of suffering from depression compared to mothers of typically developing children (Singer, 2006). In future, the “Me Time for Mums” program, and similar caregiver-specific leisure programs, should be implemented with carers who have been diagnosed with mental health problems such as depression. Indeed, an important part of behaviour therapy for depression is activity scheduling in which individuals monitor their mood and daily activities, develop an awareness of the connection

between these, and actively plan to increase the number of pleasant activities in their lifestyle in order to increase positive and reinforcing interactions with their environment (Cuijpers, van Straten, & Warmerdam, 2007). Indeed, the provision of community-based, scheduled leisure activities, such as “Me Time for Mums”, may be viewed as a preventative mental health intervention for caregivers.

The present study may have been limited as a result of activities in the program being pre-selected rather than chosen by individual participants. Many leisure theorists and researchers have emphasised that enjoyment derived from leisure activities is maximised when this participation is freely chosen or voluntary (e.g., Stumbo & Peterson, 1998). Some theorists have even argued that free choice regarding the activity is an essential condition of leisure (e.g., Iso-Ahola, 1980; Neulinger, 1981). The eudaimonistic identity theory literature further emphasises that intrinsic motivation and identity development proceeds from engaging in self-selected, personally salient activities (Waterman et al., 2003).

While participants did not choose the individual activities, they self-selected to participate in a five week creative leisure program, so they had a broad level of choice and could choose the extent to which they engaged in the activities presented in each session. The qualitative data from the post-session feedback forms and follow-up interviews indicated that participants were delighted with the array of activities presented. Additionally, there was an important novelty value to each session which helped to excite participants, enabling them to surprise and empower themselves by trying activities that they might not ordinarily choose to do themselves. Furthermore, post-session feedback data demonstrated unanimous satisfaction with the creative modalities included in “Me Time for Mums”. The present “Me Time for Mums” program involved a trade off in terms of promoting social connectedness at the expense of personal choice regarding activity selection. It is recommended that

individualised leisure programs be compared to group leisure programs on the basis of eudaimonistic identity theory variables to examine the importance of selecting personally salient activities compared to shared participation in researcher-selected activities.

Themes formulated to categorise the qualitative data share common elements with components of eudaimonistic identity theory. To provide a more rigorous test of the relevance and application of this theory in terms of caregiver leisure programs, future evaluation protocols should incorporate the instruments used by Waterman et al. (2003) and Waterman (2004) to measure the core components of interest, flow, personal expressiveness, fulfilment of self-realisation values, intrinsic motivation, and goal-directed behaviour. Examination of these variables would assist in understanding the links between leisure activity participation and identity development, and the mechanisms underpinning the relationship between leisure and wellbeing among caregivers.

In terms of differential outcomes as a function of the type of creative arts activity, qualitative results indicated that participants reported higher engagement in the theatre sports and drumming sessions more so than the other modalities. Not surprisingly, given the connection between absorption and enjoyment germane to the experience of flow, these two modalities also received the highest enjoyment ratings across both groups. However, they were not the activities that participants' reportedly incorporated into their life, presumably because of the specialist facilitation required for participation and the limitation of community programs available, especially regarding theatre sports. Participants reported continuing engagement in yoga and art activities outside the program to a greater extent than activities incorporated in the other sessions. In future, additional research with larger numbers of carers and a wider array of activities is needed to determine whether certain activities are more

identity and wellbeing promoting than others, in terms of experiencing personal expressiveness, interest, and flow. Large scale studies may help to identify activities that should be incorporated into future leisure programs for carers.

It may be argued that the success of the “Me Time for Mums” program was dependent on the specific expertise of the facilitators. This points to the need for performing replication studies of this pilot program. As mentioned, some of the activities, particularly theatre sports and belly dancing, were largely dependent on the knowledge and experience of the facilitator. This makes certain aspects of the program difficult to manualise. In the present evaluation study, factors such as the skill and personality of the facilitator were not controlled for. However, an attempt was made to mitigate the strength of facilitator-effects by involving five different facilitators. It would be useful to conduct comparative research on leisure groups facilitated by other trained creative arts facilitators to explore the reliability of positive program outcomes.

In the present evaluation study, several important factors were not controlled. The effects of being in a supportive group were not controlled. In the present study there was no active control condition that could be used to evaluate non-specific effects of contact with professionals or social support. This limitation plagues carer intervention evaluation studies, most of which included a no treatment, standard service support, or waiting list control group in the design (e.g., Gammon & Rose, 1991; Nixon & Singer, 1993; Singer et al., 1988, 1989). This hinders the drawing of strong conclusions about the active ingredients causing positive change. In the present study, this limitation was partly mitigated through conducting in-depth follow-up interviews to analyse the processes fuelling change. In future, experiential group leisure programs for carers should be compared to an active, group-based

control condition to control for the effects of social support. Parent-to-parent support groups would provide a readily accessible active control group option.

Additionally, the present study may be greatly improved by administering more follow-up tests and interviews, conducted at several points after the program finishes to control for the interaction of time of measurement and treatment effects. Monitoring participants over a longer time would also allow tracking of factors that promote sustaining beneficial program outcomes, as compared to becoming absorbed back into to a leisure-less “daily grind”.

The implementation of the pre-program self-confrontation method was limited in terms of exploring only two I-positions (“I-as-caregiver” and “I-as-leisure seeker”) out of the array of I-positions in each individual’s personal position repertoire. Limiting the self-exploration in this way was deemed necessary in order to implement a brief and contained intervention. The purpose of limiting the self-investigation was made clear to participants, specifically in terms of contemplating the relative dominance of the I-as-carer position and the impact this has on individuals’ wellbeing and fulfilment of basic drives for self-enhancement and connection with others.

In previously documented implementations of the self-confrontation method (e.g., Hermans, 2003; Hermans & Hermans-Jansen, 1995), clients completed the procedure again after treatment. They were “confronted” with the valuations they had constructed in the first session. In terms of the present evaluation study, program outcomes may have been further consolidated by asking participants in the P⁺ group to re-read each of their pre-program valuations and consider whether they still agreed with the content, offering them the chance to reframe, replace, eliminate, or add to their pre-program valuations.

In addition to reviewing and revising their initial self-confrontation investigation, it may also be useful to offer participants the chance to engage in

imaginal dialogues between different I positions. In such an intervention, participants could engage in dialogues between I-positions that are identified with roles (e.g., I-as-carer and I-as-mother) and I positions that are relatively unencumbered by role-identity standards (e.g., I-as-leisure seeker and I-as-in-a flow state). Some participants already indicated new forms of internal dialogue transpiring during the program. For example, one participant heard the internalised collective “voice” of the group well after the program finished, and found this voice to “free her up” to give herself permission and encouragement to pursue leisure. The addition of a new wellbeing-promoting “voice” was apparent for others in terms of altering the nature of participants’ self-talk about honouring personal needs, and treating the self as a human rather than a machine. In some cases, participants’ post-program interview accounts exemplified Hermans’ (1999) three step dialogical strategy for the promotion of self-innovation. In step one the person speaks from a dominant position (e.g., “I-as-carer”). In step two the voice of a real or imaginary other speaks from a counter-position (e.g., “I-as-‘Me Time for Mums’ group member”), and, finally, step three represents a repositioning, in that the original position of step one is reformulated under the influence of the intermediate step two, towards re-positioning the self (e.g., “I-as-worthy-of-leisure-and-self-care”).

The present program evaluation provides evidence that engaging in a light-hearted leisure program can introduce new wellbeing-promoting “voices” into caregivers’ dialogical self system, disrupting the typical hegemony of the I-as-caregiver position and narrative, and therein promoting the emergence of the I-as-self-carer that improves overall functioning. Indeed, for carers and others who report numerous leisure constraints, community leisure programs provide necessary initial experiential “playgrounds” for the (re)emergence of self-caring I-positions.

9.3.3 Future Implementation of Carer-Specific Leisure Programs

For carers, who are typically overrun with responsibilities and tasks everyday, it may be hard to strategically set and pursue personal goals. In future delivery of “Me Time for Mums”, and other leisure programs for carers, individualised assessment at both pre- and post-program would be useful, in order to contextualise the leisure intervention as part of a larger personal identity project. Given that the P⁺ group seemed to become more empowered to negotiate their personal leisure constraints, and also more actively followed through with increased engagement in leisure activities post program, there is evidence that including a brief self-investigation component enhances potential outcomes. Additionally, use of the Personal Expressive Activities Questionnaire (PEAQ; Waterman, 1998), which was adapted in accordance with the eudaimonistic identity theory for the specific measurement of personally expressive activities in the leisure and hobby domain (PEAQ-LH), could be usefully incorporated into pre- and post-program assessments for carers to monitor their continued engagement in identity-related leisure activities after the program. A session dedicated to formulating operationalised leisure and self-care goals and to setting up home environments conducive to leisure might also help to perpetuate positive program outcomes. Additionally, family based interventions could be implemented to maximise the practical and emotional support provided by other family members to the primary carer in order for them to protect their personal leisure time. The implementation of a state-wide website and chat-room dedicated to carers and leisure might foster information sharing, social support, and ongoing leisure companionship.

Given the many constraints to leisure reported by participants, and issues with committing to regular program attendance, there needs to be alternative leisure intervention models. With appropriate funding, leisure programs for carers should be

provided at a range of times, in a range of locations. Of course, due to varying individual situations, it was impossible for one time to meet the needs of all carers in this localised, pilot program. For carers who are largely homebound due to care-giving commitments, it would be useful to have leisure outreach consultants who could visit carers in their homes and help them to identify and pursue leisure interests. Such a consultant could provide support and information regarding leisure activities and be a person for carers to regularly stay in touch with in order to maintain the salience of leisure as an important facet of living a balanced lifestyle.

Previous research indicates that carers may be reluctant to use social support services. Some reasons that have been identified are associating social services with a sense of failure (Heenan, 2000), cultural influences (Fitzpatrick & Freed, 2000), caregiver isolation (Tebb & Jivanjee, 2000), and reluctance to entrust the duties of caregiving to others (Ganzer & England, 1994). Furthermore, as the present qualitative results demonstrated, nearly half the participants reported ongoing intrapersonal constraints to leisure, including a sense of guilt attached to pursuing personal leisure, devaluing personal needs, and feelings of preoccupation and exhaustion which limit active forms of leisure. Given the plethora of intrapersonal and structural constraints in carers' lives, it seems necessary that leisure is facilitated in some way, whether through community programming or outreach workers. It may be beneficial to implement leisure motivation enhancement workshops to assist individuals to negotiate constraints to leisure. Such a workshop might include time management, social support, coping with guilt, resisting patterns and habits that reduce wellbeing, problem solving, goal-setting, and building leisure action plans. Carer support groups might provide an accessible format for leisure and self-care motivation enhancement interventions.

In light of the structural constraints to leisure reported by carers in this program and numerous previous studies, genuine efforts to increase carers' wellbeing need to move beyond a focus on ameliorating the plight of individual carers, towards implementing structural change. Despite the undeniable potential of programs and interventions for carers, these do not address the broader social structure which places intolerable demands on a predominantly female section of the community. In fact, it has been argued that individual carer programs, which help unpaid family carers to accept and adjust to a role in which they have limited personal freedom, are actually teaching them to "...connive at their own exploitation" (Lee, 1999, p. 33). Individual programs have the potential to problematise the carer, rather than seeing external factors, such as limited funding and respite services, as problematic. It is argued that a profound cultural change is necessary in order to become a "caring society", where the need to care for our carers is prioritised so that they can lead a fuller life, not dominated by caregiving.

The alarming finding that carers reported the lowest collective personal wellbeing of any group yet researched in the Australian National Health and Wellbeing survey (Cummins et al., 2007) presents a clear national public health concern. The plight of family carers (especially primary carers) needs to be addressed, for the wellbeing of carers, their children and families, and, from an economic perspective, to save the huge amount of money necessary to ameliorate mental health concerns experienced by distressed carers. Indeed, while support is crucial to help carers perform the role, the role itself must also be questioned. Furthermore, while both men and women in Australia are responsible for caregiving, the majority of primary caregiving is done by women who, in turn, carry most of the negative impacts, such as reduced personal wellbeing, reduced employment possibilities, reduced financial security, and reduced personal leisure participation.

Government policy should reflect this reality. What is ultimately necessary is systemic change addressing gender imbalances in informal caregiving, and consistent funding dedicated to carers having time off to engage in self-renewal via leisure in a facilitated, socially legitimised way.

“Me Time for Mums” participants reported that they need more support to increase their leisure time, including provision of more respite options. Meals on wheels and home-help services, personal care attendants, home health programs, and increased financial benefits, would provide additional relief and assistance to help carers pursue their own leisure activities. The development of health promotion campaigns directed to caregivers might be a useful strategy to enhance the significance of leisure for carers, and promote a sense of entitlement to taking “me time”.

The present “Me Time for Mums” program, if provided in multiple locations in a sustainable fashion, would fill an important gap in the community caregiver support sector. The delivery of ongoing carer leisure groups could potentially take place at neighbourhood houses, which may provide low or no cost venues for leisure groups in a variety of locations. Another potential host for carer leisure programs are the numerous parent-to-parent support groups that operate around Victoria. These support groups are already up and running with a large base of attendance, and sessions could be regularly devoted to shared leisure activity participation. A third potential host for the “Me Time for Mums” program model is the recently initiated, and (coincidentally) similarly named, “My Time” groups (see the Website: www.mytime.net.au). Groups are run out of numerous community organisations across Australia (e.g., early parenting centres, disability specific organisations, playgroup associations etc.). “My Time” groups offer a space for a variety of psycho-education and social activities for carers, including professional guest speakers who

provide information and link carers to services, discussion about relationship and parenting strategies, exercise activities, and child behavioural management strategies. A play helper engages the children separately while the parental carers engage in the session. This new program provides an excellent potential forum for ongoing delivery of structured leisure activities for carers.

It may be argued that existing caregiver support programs, such as support groups, behavioural management training, and early intervention programs for caregivers are not “free from caring” as they are geared to helping carers “care better”. The “Me Time for Mums” program has a somewhat different focus as it aims to broaden and enrich participants’ lives so they expand beyond the caregiver role, so as to improve the overall quality of their lives. The success of the present “Me Time for Mums” pilot program provides preliminary evidence for the effectiveness of delivering creative leisure programs for the wellbeing of maternal carers. The present evaluation study raises important implications in terms of supporting carers in the community. It is hoped that community support groups and organisations will continue to offer avenues for carers to pursue leisure and, as the recent submission from Carers Australia to the Australian House of Representatives put it, to have the “...opportunity to have a life outside of caring” (Edwards et al., 2008, p. 1).

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APPENDIX A

FLYER ADVERTISING THE CLAS PILOT STUDY

Calling all parents and family caregivers

("family caregivers" are family and friends who provide unpaid care to an individual with a disease or disability).



My name is Debbie Zaks, and I am a Doctoral student from Swinburne University. I am examining the wellbeing of parents and family caregivers. Research consistently demonstrates the benefits of leisure and 'me time' time for caregivers' mood and wellbeing. I have designed a questionnaire to measure attitudes and beliefs about taking time for leisure.

It would be wonderful if you would help me to validate this questionnaire by filling in your responses firstly to demographic questions and then filling in the questionnaire. It takes about 10-15 minutes to complete.

The questionnaire can be filled in online, via the Website:

<http://opinio.online.swin.edu.au/s?s=2002>

By completing the questionnaire mothers of children with a disability will have the opportunity to register their interest to take part in a free creative arts/leisure program in July 2007.

If you have any queries, you can contact me via email at dzaks@swin.edu.au

Thanks for your time!!!

<http://opinio.online.swin.edu.au/s?s=2002>

<http://opinio.online.swin.edu.au/s?s=2002>

<http://opinio.online.swin.edu.au/s?s=2002>

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<http://opinio.online.swin.edu.au/s?s=2002>

APPENDIX B

LIST OF ORGANISATIONS/SCHOOLS CONTACTED TO RECRUIT RESPONDENTS FOR THE CLAS PILOT STUDY

Organisations:

- Access for All Abilities—Sport and Recreation Victoria
- Anglicare Victoria; Anglicare Parentzone Eastern region
- Arts Access Society (Arts Access)
- Asperger Syndrome Support Network
- Association for Children with a Disability
- Autism Action
- Autism Victoria
- Autistic Family Support Association
- Carers Victoria
- Cerebral Palsy Support Network
- Cystic Fibrosis Association of Victoria
- Down Syndrome Association of Victoria
- Extended families: Foster Grandparent Scheme
- Irabina Childhood Autism Services
- Jewish care
- Association of Relatives and Friends of the Emotionally and Mentally Ill (ARAFEMI).
- Parent to parent support network: Eastern Region and Inner East
- Prader-Willi Syndrome Association of Victoria
- Regional Carer Respite Centres
- Parent Resource Centre
- Royal Children’s Hospital
- Scope
- SPELD Victoria (Specific Learning Disabilities Association)
- Uniting care community connections
- Very Special Kids
- Victorian Advocacy League for Individuals with Disability (VALID)
- Victorian Network on Recreation and Disability (VICNORD)
- Yooralla Society of Victoria

Schools:

- Kamaruka (RICHMOND)
- Andale School (KEW)
- Carnegie Education Centre (KEW)
- The Currajong School (EAST MALVERN)
- Rossbourne School (HAWTHRON)
- Wesley College (PRAHRAN)
- Mount Scopus College (BURWOOD)

APPENDIX C

ADVERTISEMENT IN THE “ESPECTRUM” ONLINE NEWSLETTER

Research Project – “Me time for Mums”

Debbie Zaks, a PhD candidate from Swinburne University, is examining the wellbeing of mothers of children with a disability. It has been shown that mothers of disabled children limit their leisure, social and relaxation time. Many mothers feel guilty and selfish for taking time for themselves. Yet research consistently demonstrates the benefits of leisure time for caregivers’ wellbeing. This project aims to provide a creative arts leisure program for mothers of disabled children to experience leisure in a validated and supported space. It is predicted that participating in a hands on leisure program will decrease stress and improve wellbeing. The project involves developing a questionnaire to measure attitudes towards self-care and leisure, delivering a pilot creative arts and leisure program and finally evaluating the program and its impact on the wellbeing of participants. Do you want to be involved in this innovative and valuable project? Go to the online questionnaire for full details. You can also contact Debbie via email at dzaks@swin.edu.au .

(Autism Victoria’s online newsletter, eSpectrum, September 2006, no.9, Available at: <http://www.autismvictoria.org.au/newsletter/espectrum/eSpectrumNo.9.htm.php#mums>)

APPENDIX D

FLYER ADVERTISING THE “ME TIME FOR MUMS” PROGRAM

You are invited to join...
ME TIME FOR MUMS

**WHAT IS IT?**

'Me time for Mums' is a cost-free **creative arts and leisure program** for mothers who are caring for a child or children with special needs. It offers a 'sampler' of hands-on fun and relaxing activities with a range of experienced practitioners. After the sessions there will be nourishing refreshments and a chance to get to know each other. This is a play group for mums only. Financial assistance with obtaining childcare may be arranged.

- **Week 1: yoga and relaxation**
- **Week 2: drama and games**
- **Week 3: movement**
- **Week 4: music**
- **Week 5: art**

**WHEN IS IT AND HOW LONG DOES IT GO FOR?**

The program runs for five weeks, for two hours per week on a Wednesday morning, 10am-12pm. The first program will go from July 18th to August 15th and the second from 22nd August to 19th September.

WHERE IS IT?

Hawthorn Community House. 32 Henry St Hawthorn.

HOW CAN I FIND OUT MORE OR REGISTER MY INTEREST?

To find out more and register to take part in "Me time for Mums" simply email Debbie at dzaks@swin.edu.au or call **0401637449**.

An initiative of Swinburne University and Hawthorn
 Community House versity and Hawthorn Community House

APPENDIX E

PARTIPANT'S ARTICLE IN "THE BUGLE"

September 2007

Page 7

UnitingCare Community Options

Me Time

By Catherine Catlow

My name is Cathy Catlow and I am married with two beautiful daughters. I am a stay at home mum for my daughters Elisha, 12, and Amanda, 19. I never thought I'd still be changing nappies and have someone totally dependant on me at the age of 51.

Amanda has a disability known as Tuberous Sclerosis. She was diagnosed with this rare brain disorder at the age of four and half months and as a result she is intellectually and physically disabled.

Amanda is totally dependant and requires assistance for all of her basic needs. I feed, dress, and bathe her every day, and because she has a sleeping disorder, the family sleeps an average of 4 - 6 hours a night. At times Amanda has been wheelchair-bound though she is now able to walk with assistance. She is unable to speak or use any form of communication.

Life with Amanda is very different. Day to day life can be exhausting and I rarely get time for myself. At times it can be difficult to cope.

My case manager suggested I take time out for myself. She suggested I join the free 'Me Time for Mums' program, a sampler program of hands-on fun and relaxing activities for mothers of children with special needs that includes everything from



art to movement to musical improvisation. I even tried yoga for the first time with the support of an experienced practitioner.

At the end of each session the other mothers and I get the chance to get to know one another and share experiences over morning tea.

I have already completed three weeks now and only have two more to go. However I'm already thinking about what else I can do for myself when it finishes. It has been wonderful to take this time out and have a different focus for a few hours each week. As a mum - we do need 'Me Time' occasionally!

Remember to take time out and look after yourself so that you are able to care for those in your life that need you.

To find out more and register to take part in 'Me Time for Mums' simply email Debbie at debbiezaks@hotmail.com or call 0401637449. Financial assistance with obtaining childcare is available.

Preventative Respite

As carers we often forget how important it is to take time out for ourselves. Various options are available for carers seeking some time out for themselves, including the possibility of setting up regular, planned respite.

If you would like to find out more about what respite options are available, contact the Commonwealth Carers Respite Centre on 1800 059 059. Please note that this is a freecall number except from mobiles where normal rates apply.

APPENDIX F

INFORMATION GIVEN TO PARTICIPANTS ABOUT THE “ME TIME FOR MUMS” PROGRAM



“Me time for Mums” Program information sheet



The program

“Me time for Mums” is a cost-free creative arts and leisure program for mothers who are caring for a child or children with a disability, illness or condition. The program runs for five weeks, for two hours per week. It offers a ‘sampler’ of hands-on fun and relaxing leisure activities, including art, music, and relaxation techniques with a range of community-based practitioners. After the sessions there will be nourishing refreshments and a chance to get to know each other. We aim to offer a ‘play group’ especially for mums to be with other mums and join together to celebrate each others strengths, resources and discover pleasurable ways to achieve restorative mental breaks from obligations and concerns.

Week 1: yoga and relaxation

Week 2: drama and games

Week 3: movement

Week 4: music

Week 5: art

Are you eligible for the program?

This program is specifically for mothers who are the primary caregiver for a child or children with a disability, illness or condition that necessitates three or more hours of direct care for that child per day. We are offering the program to women who are aged between 20 and 60 years and who have attained a minimum of year 10 level education.

Please note: Financial subsidy may be provided to participants who need help to obtain childcare.

Evaluating whether the program is effective

As this is the first time we have run this program, we wish to evaluate its effectiveness.

We need a strong commitment from participants to attend all sessions and complete the following:

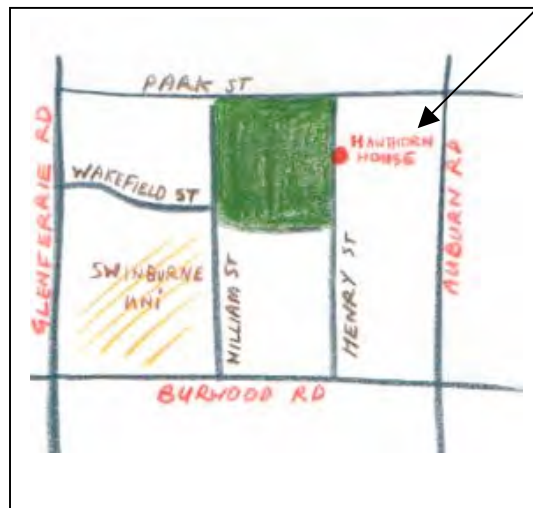
- **Questionnaire package:** before and after program (approx 30-45 minutes each time).
- **Interviews:** before the program (approximately 1 hour).
- **Post-session feedback form:** A form is given out each week to obtain your feedback on the session (approximately 5 minutes).
- **follow-up interview:** Two months after program (1-1.5 hours)

Program dates

The program runs for five weeks, for two hours per week on Wednesday mornings, 10am-12pm, from 22nd August to 19th September.

Venue

Hawthorn Community House:
32 Henry Street Hawthorn
Melways Map 45E9



Confidentiality - protecting privacy and anonymity

Government law requires that privacy and confidentiality be protected. Your responses to all questionnaires and interviews will be kept confidential.

With your consent, I will be audio-taping the follow up interview. This will take approximately 1 hour and will be conducted at a mutually agreed upon place. If at any time you wish to stop the interview or not answer a question, you are free to do so. You may erase the tape at any time. I will remove all identifying features

when your interview is transcribed and in any publications. After interviews are transcribed, tapes will be destroyed.

I will return the transcription to you for any changes or comments. Information obtained from the interview will contribute to the evaluation of the “Me Time for Mums” program and may be disseminated in research, conference papers, and journal articles. No individual participants will be identifiable in the reporting of this project and in any publications. Cover sheets on questionnaires will be coded to protect your anonymity. Questionnaires and interview data will be securely stored in a locked filing cabinet in the student researcher’s office and on password protected computers, which only the researchers have access to, as far as the law allows, and will be destroyed by shredding after five years.

Voluntary participation

Participation in this program and all aspects of its evaluation is entirely voluntary. If you agree to participate you may withdraw participation from the whole program or any of its components at any time by speaking to the organisers.

Given that we aim to perform a sound evaluation of the program, we do ask that you carefully consider whether you are able to commit to attending all sessions and whether you are able to spend the time necessary to fill in questionnaires, as we do need a strong commitment from all participants in order to successfully evaluate the program.

Study results and ethical standards

The results of this research may be published in a scientific journal. Results from the questionnaire will be aggregated and presented as group data. Quotes will be used to reflect themes from the interviews, however NO individual will be identifiable. This program evaluation methodology has been approved by the Swinburne University Ethics Committee and conforms to the Australian National Health & Medical Research Council guidelines on ethical conduct on research involving humans.

Registering for the program

To register for this program, please email **Debbie** debbiezaks@hotmail.com or call **0401637449** to obtain a registration form.



We can only provide this program to limited numbers at this time.

Please let us know if you would like to participate as soon as possible to secure your place.

If you know of a caregiver who is eligible for this program, please ask them to call or email Debbie Zaks for details

For information and support

Please note that this program is about letting your hair down, having fun, being creative, meeting other mums, and relaxing. It is not a counselling program. There are a number of carer-specific and generalist counselling/support services in Victoria should you need to talk through any issues or obtain referrals. Some of these are listed here:

Carer-specific services:

- Carers Victoria Tel : 1800 242 636
- Commonwealth Carer Resource Centres Tel : 1800 242 636
- CareLine (24 hr) Tel: 1800 059 059



Generalist telephone counselling and referral services:

- Women's Information and Referral Exchange Tel : 1300 134 130
- Care Ring (24 hr) Tel : 136 169
- Life line (24 hr) Tel : 131 114

If you have questions or complaints

For questions or complaints please contact the Researchers: Debbie Zaks: Tel. 0401637449, email dzaks@swin.edu.au or Dr Roslyn Galligan: Tel. 03-92145345, email: r.galligan@swin.edu.au. If you have any questions or concerns which the Researchers cannot answer, please contact: The Chair, Human Research Ethics Committee, Swinburne University of Technology, PO Box 218, Hawthorn, Vic, 3122, tel. 03-9214 5223.

APPENDIX G

CONSENT FORM FOR PARTICIPATING IN THE “ME TIME FOR MUMS” PROGRAM

Letter of Agreement to participate in the “Me Time for Mums” program evaluation study

I _____ have read and understood the information above.
Any questions I have asked have been answered to my satisfaction.

I agree that research data collected for the study may be published or provided to other researchers on the condition that anonymity is preserved and that I cannot be identified.

I agree that the follow-up interviews will be audio-taped and transcribed. I realise that the tapes will be destroyed after transcription and no identifying information will be included in presentation of findings.

I agree to participate in this activity, realising that I may withdraw at any time.

NAME OF PARTICIPANT.....

SIGNATURE..... DATE

NAME/S OF PRINCIPAL INVESTIGATOR/S:

.....
Dr Roslyn Galligan
Senior Researcher and
Lecturer

Date

.....
Debbie Zaks
Student researcher
(Doctoral Candidate)

Date



APPENDIX H

“ME TIME FOR MUMS” QUESTIONNAIRE BATTERY

I hope that you will enjoy (/enjoyed) the Me time for Mums program. As you know I would like to evaluate the program to make a good case for the implementation of further leisure programs for mothers caring for children with a disability. To that end, I present to you several questionnaires to be completed before and after participating in the program.

Fill it in at your own pace and contact me if you have any questions:

Debbie Zaks: 0401637449 or debbiezaks@hotmail.com

So that I can match the pre and post questionnaires, please indicate the first three letters of your mum’s maiden name.

<p>FIRST 3 LETTERS OF MY MOTHER’S MAIDEN NAME</p> <p>-----</p>

Once again, thanks for being brave enough to try out a new program without knowing very much about it to begin with. This is a courageous move and I hope that you will give yourselves permission on a daily basis to take ME TIME. It is a basic human right and an essential self-care practice, like brushing teeth or having a shower.

It was a pleasure to meet you all and I wish you all the very best on your journeys....

Best regards,
Debbie Zaks



Background Information

Age: _____ years

Relationship status:

Single Married Defacto
 Separated Divorced
 Widowed
 In a relationship (not living with partner)

Other _____ please specify

Highest level of education attained:

Primary school To year 10
 End high school TAFE/diploma
 University undergraduate degree
 University postgraduate degree

Other _____ please specify

Your employment status (tick as many as apply)

Unemployed Student Full-time parent/caregiver Employed full-time
 Employed part-time Employed casual Volunteer work Retired

Other _____ please specify

Your postcode _____

Your cultural/ethnic background

Anglo/Celtic Aboriginal/Torres straight islander Vietnamese
 Chinese Japanese Indian
 Italian Greek German Eastern European New Zealand Middle eastern

Other _____ please specify

Gross annual household income:

Under 10,000 10,000-19,999
 20,000-29,999 30,000-39,999
 40,000-49,999 50,000-59,999
 60,000-69,999 70,000-79,999
 80,000-89,999 90,000-99,999
 100,000-109,999 110,000-119,999
 120,000 +

Your residential location:City Regional Rural **Your living status:**

Live alone
 Live with housemate(s)/friends
 Live with family of origin
 Live with partner/spouse
 Live with partner/spouse and children
 Live with children

Other _____ please specify

Number of people in your household

Number of children you are the primary caregiver to

Average number of hours you spend in a caregiving role per week
_____hours

Number of children who live with you

Average time PER DAY you spend caring for yourself (e.g., leisure, social, relaxing, health-related behaviours)
_____hours_____m
inutes

My child(ren) with a condition/disability who requires care lives:

With me Alone
Residential care With relative or friend
Other _____ please specify

Community health/support services you currently access to help you cope (tick all that currently apply on a regular basis)

Age of my child with a disability:

Psychologist/counselor/psychiatrist
 Doctor Massage therapist
Physiotherapist Natural therapies
 Carer support organisation
Disability support organization
Support group Respite care
Home help

Diagnosis/diagnoses given to my child (please list):

Other _____ please specify

Number of years you have spent in caregiver role

Average total number of hours PER WEEK that child is cared for by someone else (e.g., relative, paid carer, respite care, school, disability worker)
_____hours

Caregiver Wellbeing Scale

Below are listed a number of basic needs. For each need listed, think about your life **over the past month**. During this period of time, indicate to what extent you think each need has been met. Circle the appropriate number using the scale provided below.

Never or almost never	Seldom, occasionally	Sometimes	Often, frequently	Almost always
1	2	3	4	5

1. Having time for recreation	1	2	3	4	5
2. Feeling loved	1	2	3	4	5
3. Expressing love	1	2	3	4	5
4. Expressing laughter and joy	1	2	3	4	5
5. Learning new skills	1	2	3	4	5
6. Feeling worthwhile	1	2	3	4	5
7. Feeling appreciated by others	1	2	3	4	5
8. Feeling good about yourself	1	2	3	4	5
9. Having close friendships	1	2	3	4	5
10. Having meaning in your life	1	2	3	4	5
11. Relaxing	1	2	3	4	5
12. Exercising	1	2	3	4	5
13. Enjoying a hobby	1	2	3	4	5
14. Starting a new interest or hobby	1	2	3	4	5
15. Attending social events	1	2	3	4	5
16. Taking time for reflective thinking	1	2	3	4	5
17. Having time for inspirational or spiritual interests	1	2	3	4	5
18. Noticing the wonderment of things around you	1	2	3	4	5
19. Getting support from your friends or family	1	2	3	4	5
20. Laughing	1	2	3	4	5
21. Treating or rewarding yourself	1	2	3	4	5
22. Taking time to have fun with family or friends	1	2	3	4	5

Four Dimensional Mood Scale

This scale consists of a number of words that describe different feelings and emotions. Read each item and then circle the appropriate answer next to that word. Indicate to what extent you have felt this way during the **past week**. Please circle one number only for each adjective according to the following scale:

	Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
drained	1	2	3	4	5
active	1	2	3	4	5
dull	1	2	3	4	5
alert	1	2	3	4	5
numb	1	2	3	4	5
interested	1	2	3	4	5
distressed	1	2	3	4	5
strong	1	2	3	4	5
worn out	1	2	3	4	5
irritable	1	2	3	4	5
guilty	1	2	3	4	5
pleased	1	2	3	4	5
bored	1	2	3	4	5
upset	1	2	3	4	5
inspired	1	2	3	4	5
calm	1	2	3	4	5
nervous	1	2	3	4	5
peaceful	1	2	3	4	5
restful	1	2	3	4	5
contented	1	2	3	4	5

Personal Wellbeing Index

The following questions ask how satisfied you feel in your life **right now**, on a scale from 0 to 10. Zero means you feel completely dissatisfied. Ten means you feel completely satisfied. The middle of the scale is 5, which means you feel neutral, neither satisfied nor dissatisfied. Please rate your level of satisfaction on the following domains of life by circling one number using the following scale.

	0	1	2	3	4	5	6	7	8	9	10
Completely dissatisfied	neutral									Completely satisfied	
1. How satisfied are you with your standard of living?	0	1	2	3	4	5	6	7	8	9	10
2. How satisfied are you with your health?	0	1	2	3	4	5	6	7	8	9	10
3. How satisfied are you with what you are achieving in life?	0	1	2	3	4	5	6	7	8	9	10
4. How satisfied are you with your personal relationships?	0	1	2	3	4	5	6	7	8	9	10
5. How satisfied are you with how safe you feel?	0	1	2	3	4	5	6	7	8	9	10
6. How satisfied are you with feeling part of your community?	0	1	2	3	4	5	6	7	8	9	10
7. How satisfied are you with your future security?	0	1	2	3	4	5	6	7	8	9	10
8. How satisfied are you with your spirituality and religion?	0	1	2	3	4	5	6	7	8	9	10

Caregivers' Leisure Attitudes Scale

Listed below are some statements about your current attitudes towards doing leisure and self-care activities. In the following scale, 'leisure' refers to any activity you do *for yourself* that you find interesting, relaxing, enjoyable, and/or fun, whether on your own or with others. 'Self-care' activities are those pursuits that help you relax and look after yourself physically, emotionally, and mentally. Please remember that there are no right or wrong answers. Please choose an option that best describes how much you agree with each statement.

Strongly disagree	Neither Agree nor disagree		Strongly agree							
1	2	3	4	5	6	7				
1. If I don't give myself time for leisure, I will become very stressed				1	2	3	4	5	6	7
2. My psychological wellbeing is sacrificed if I do not take any time out for self-care				1	2	3	4	5	6	7
3. If I don't do activities just for my own enjoyment I will feel resentful				1	2	3	4	5	6	7
4. If I don't take time to do self-care activities, my physical health will suffer				1	2	3	4	5	6	7
5. If I don't do leisure activities I will get burnt out and be less able to keep going				1	2	3	4	5	6	7
6. I believe that it is vital for my own mental health to give myself permission to engage in leisure				1	2	3	4	5	6	7
7. Doing leisure activities can increase my enjoyment of life				1	2	3	4	5	6	7
8. It is necessary to do leisure activities to maintain good balance in life				1	2	3	4	5	6	7
9. I believe that doing leisure activities can allow me to gain a fresh perspective on my problems				1	2	3	4	5	6	7
10. I believe that doing self-care activities is essential for me to recharge my batteries				1	2	3	4	5	6	7
11. I have chosen to make my own leisure participation a low priority because of my caring responsibilities				1	2	3	4	5	6	7
12. I feel it is wrong for me to do things just to please myself				1	2	3	4	5	6	7

Strongly disagree	Neither Agree nor disagree					Strongly agree					
1	2	3	4	5	6	7					
13. I would feel guilty if I engaged in leisure					1	2	3	4	5	6	7
14. I feel too preoccupied with daily responsibilities to engage in leisure					1	2	3	4	5	6	7
15. My care-giving responsibilities make me too stressed to have the state of mind to do leisure activities					1	2	3	4	5	6	7
16. I don't like to go to community meetings/events as I am not comfortable socialising in groups					1	2	3	4	5	6	7
17. I would do more leisure but I don't have companions to do things with					1	2	3	4	5	6	7
18. I feel pressure from others to sacrifice my leisure pursuits to fulfill my role as caregiver					1	2	3	4	5	6	7
19. I would worry about what others might think of me if I did more activities that were just for me					1	2	3	4	5	6	7
20. I would do more leisure activities, but my spouse/partner often does not share my leisure interests which limits my leisure participation					1	2	3	4	5	6	7
21. I do not do many leisure activities and I'm considering doing more in the next six months					1	2	3	4	5	6	7
22. I am aware that I do not take enough time out for myself and I am considering changing this pattern					1	2	3	4	5	6	7
23. I don't take much 'me time' at the moment, but intend to take more in the next month					1	2	3	4	5	6	7

Depression, Anxiety and Stress Scale

Please read each statement and circle a number 0, 1, 2 or 3 that indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement. Please circle one number only for each statement according to the following scale:

Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
0	1	2	3
1. I found it hard to wind down	0	1	2 3
2. I was aware of dryness of my mouth	0	1	2 3
3. I couldn't seem to experience any positive feeling at all	0	1	2 3
4. I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2 3
5. I found it difficult to work up the initiative to do things	0	1	2 3
6. I tended to over-react to situations	0	1	2 3
7. I experienced trembling (eg, in the hands)	0	1	2 3
8. I felt that I was using a lot of nervous energy	0	1	2 3
9. I was worried about situations in which I might panic and make a fool of myself	0	1	2 3
10. I felt that I had nothing to look forward to	0	1	2 3
11. I found myself getting agitated	0	1	2 3
12. I found it difficult to relax	0	1	2 3
13. I felt down-hearted and blue	0	1	2 3
14. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2 3
15. I felt I was close to panic	0	1	2 3
16. I was unable to become enthusiastic about anything	0	1	2 3
17. I felt I wasn't worth much as a person	0	1	2 3
18. I felt that I was rather touchy	0	1	2 3
19. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2 3
20. I felt scared without any good reason	0	1	2 3
21. I felt that life was meaningless	0	1	2 3

Leisure Coping Strategy Scale

Listed below are some statements about your current use of leisure companionship as a coping strategy. Please choose an option that best describes how much you agree with each statement.

Very strongly disagree 1	2	3	4	5	6	7 Very strongly agree
		Neither Agree nor disagree				
1. My leisure allowed me to be in the company of supportive friends						
1	2	3	4	5	6	7
2. Socializing in leisure was a means of managing stress						
1	2	3	4	5	6	7
3. I dealt with stress through spending leisure time with my friends						
1	2	3	4	5	6	7
4. Engaging in social leisure was a stress-coping strategy for me						
1	2	3	4	5	6	7
5. Lack of companionship in leisure prevented me from coping with stress						
1	2	3	4	5	6	7
6. One of my stress-coping strategies was participation in social leisure						
1	2	3	4	5	6	7

**YOU HAVE REACHED THE END OF THE
QUESTIONNAIRE.**

**THANKS SO MUCH FOR HELPING US WITH THIS
IMPORTANT RESEARCH!**

**APPENDIX I
PROGRAM BUDGET**

Total Program Expenditure	Description (where applicable)	Total Budget
Salary for co-facilitators Art Belly dancing Improvisation/theatre sports Drumming/music Yoga/relaxation	All co-facilitators receive workshop delivery fee - \$100 per hour	\$2000
Venue hire		In kind support from Hawthorn Community House
Hawthorn Community House administration fee	Administration of funds Assistance room prep/clean up Receiving calls	\$300
Food/drinks	Light refreshments in session break	\$250
Transport	MET cards for participants (all day adult fares = \$6 x 20)	\$120
Program materials	Materials for art therapy workshop (paper, paints)	\$150
Postage	Participant selection criteria and group matching questionnaire mail-out and reply paid envelope postage (C5, >5mm thickness = \$1.00 x 40) Pre and post program questionnaire mail-out to all participants (pre and post program) and reply paid envelope postage for their return (C5, >5mm thickness = \$1.00 x 80)	\$40 \$80
Printing	MAIL OUT: Flier, registration brochures, information sheets, consent forms, questionnaires, feedback sheets (5.5 cents per page) BOOKLET: 16 X 40 colour pages	\$250
Stationery	Reply paid C5 envelopes (\$0.25 per item x 120)	\$30
Research assistant - program evaluation	Research assistant to complete follow up interviews and to cross check qualitative data analysis (20 hrs at \$ 35 p/hr)	\$700
Post-program social event	Film and dinner	\$500
TOTAL EXPECTED EXPENSES		\$4420

APPENDIX J

ASPECTS INVOLVED IN DEVELOPING AND IMPLEMENTING THE “ME TIME FOR MUMS” PROGRAM

Promoting attendance

In their qualitative study on family caregivers' perceptions of leisure, Bedini and Guinan (1996) found that the definition of leisure as being “unobligated time” was chosen most often by caregivers of children with disabilities (72%). Attending a program is arguably ‘obligated time’, which necessitated a balancing act between encouraging regular attendance without adding to participants’ sense of obligations. The student researcher informed participants about the positive implications of performing a rigorous evaluation study to encourage their commitment to attend all sessions. However, they were also reassured that if it was too hard for them to make the session, they should listen to that and not pressure themselves.

Financial assistance

The lower socio-economic status of many carers can be a barrier to utilisation of community support programs.. Possible reasons as to why carers on low incomes are unable to access support include not being able to access transport or substitute care (Kendrick & Simon, 2002). To ensure equitable access the “Me Time for Mums” program and promote weekly attendance, childcare and transportation funding was provided to participants where required.

Setting the scene

A letter was sent to participants one week before the program started to request that they provide their ‘key’ people with Hawthorn Community House’s telephone number in case they needed to be contacted in an emergency. Participants were reassured that there would be a receptionist present at all times during the session to receive calls. This arrangement was proposed so that participants could

keep their mobile phones off or on silent during the sessions. All participants concurred with this proposal and several provided feedback that it was a good idea to help them ‘get into’ the session. Participants were asked to come earlier to the first session so that the student researcher could introduce the program and ‘set the scene’.

The program was presented as offering an “Island of playfulness”, a place to experience through hands-on creative arts activities the “lighter side of life” and get in touch with the imagination, laughter, creativity, social enjoyment and pleasure. The program culture was experimental and playful and non-evaluative, in line with Carl Rogers’ “conditions of creativity” (1954, cited in Sternberg, 1988) which recognises the importance of setting up situations of psychological safety and freedom where external evaluations are absent.

The student researcher requested that the participants consider this program as an experiential space and it was explicitly stated that the program is not a support group where problems are discussed, but rather a chance to do creative and relaxing activities together. Participants were asked to try to steer away from talking about their children and caregiving matters during the sessions to facilitate both geographic *and* mental ‘me time’, away from care-giving issues.

The student researcher and facilitators focused on creating an ethos of enjoyment within the Hawthorn Community House room. They did this in several different ways by (a) creating a welcoming physical environment in the room (including adequate heating, having all materials set up, music, drinks available at all times), (b) serving as facilitators (rather than leaders) of the activities enabling participants to assume ownership for the activities, providing a context for the session and ‘warming’ participants up to the activities, especially when they could be seen as confronting (e.g., belly dancing), (c) fostering meaningful social

connections and social interactions (e.g., within the group session and in the lunch provided afterwards), (d) modelling enjoyment and humour; and (e) providing a follow-up film and dinner night for participants from both groups to reconnect six months after the end of the second program.

In terms of the implementation of the program, the abovementioned theories and concepts were not discussed or analysed in the groups. Rather, after the ‘scene was set’ and the participants were oriented to the experiential nature of the program, Jung’s advice was headed: “Learn your theories as best you can, but lay them aside when you touch the miracle of the human soul. *Lay them aside and play!* (italics added)” (Jung, 1956, as cited in Schaefer, 2003).

After each session, interested participants were given information on where to continue to pursue further activities within that session’s activity genre. The lunch after each session allowed the women to complete the post-session feedback form and to get to know each other and form their own informal social-support networks. Many participants exchanged numbers and arranged to contact each other outside the program.

Facilitation and creative arts activities

Each session was facilitated by a different creative arts practitioner, with the student researcher acting as a co-facilitator in all sessions. Through word of mouth and Internet research the student researcher met with several community based creative arts practitioners and ultimately recruited five practitioners to run the sessions. Facilitators were asked to run the session in the same (or as similar as possible) way with each group to ensure valid between group comparisons. Facilitators ran sessions in yoga and relaxation (week 1), belly dancing (week 2), drama and improvisation (week 3), group drumming (week 4) and art and sensory play (week 5). Each practitioner submitted a brief session plan to the student

researcher and proposed activities, which were revised where necessary to fit with the aims of the program

Session outlines

Session 1: Yoga and Relaxation

Aim: Introduce women to breathing techniques and basic yoga poses to promote deep relaxation.

Description of activities

1. Philosophy: Describe the Philosophy (Asthang) behind yoga and deep breathing
2. Breathing exercises (Pranayama): Women are invited to lie on mats provided. Women are shown how to take deep breathes, activating the diaphragm, middle and upper lungs. During the deep breathing, the facilitator explores breath awareness; the relationship between the breath and stress and simple ways of how to move and breathe effectively in order to increase energy intake and nourishment to the body.
3. Yoga postures (Asanas): A selection of gentle movements will be explained in detail with emphasis on the positioning, the breathing, the focus and the benefits. These postures will be specifically tailored to be accessible to all women (i.e., slow, gentle and relaxing postures).
4. Deep relaxation (Nidra): Women are guided through progressive muscle relaxation incorporating imagery and a series of sensory techniques to further alleviate strain and stress in the body and provide women with the chance to practice shifting their attention from their thoughts to their breathing and body sensations. The emphasis is on settling the mind and reaching a state of relaxation which allows one to turn inwards and away from external experiences.

Session 2: “Theatresports” Improvisation

Aim: The aim of the workshop was to provide the women with an opportunity to experience something different, to learn new skills, explore their creative thinking, laugh and enjoy each other’s imagination as well as their own. Improvisation works on literal and lateral thinking, support of each other’s ideas, trusting in the process of ideas flowing spontaneously, rolling with uncertainty, ‘happy failure’, enjoying the unexpected, and inspiring each other. Throughout the session the women keep swapping partners, working with different people, so they get to know each other and mix and socialise at the same time as play theatre sports (improvisational) games.

Description of activities

1. Knife and fork: working in pairs, creating physical shapes to given images from instructor. (For example, a knife and fork, goldfish in a bowl). Then the group becomes larger – working in 4’s. This exercise creates laughter, breaks the ice and also begins the lateral thinking process. Participants are generally very ‘surprised’ by what they can do.
2. “Yes let’s” stories: One person leads the creation of a story for the two people by saying “Let’s ...” And offering an activity to do. For example, “Let’s go into this costume hire shop”. The partner responds with “yes, let’s” and then both do the activity. This exercise works to create a continuing story that both experience with the leader looking to have fun and keep their partner inspired too, as well as experiencing having a positive sidekick. This exercise can be extended by allowing the ‘sidekick’ to say a happy “NOPE” instead of always saying ‘yes’, whenever they feel ‘uninspired’. This keeps the leader on their toes.
3. Being an expert: Working in pairs, one person is the Interviewer the other person is the Expert. The Expert is given an unlikely area of ‘expertise’ (like

creating sculpture out of garbage), which allows them the freedom to explore ‘having the answer’. This then develops into ‘expert double figures’ where we have two people as the Interviewer and Expert and then have two others kneel down behind their chairs and become the ‘arms’ of the characters – so two people make up one character. This is great to watch, always surprises the participants and audience and is often a ‘release moment’ for the participant as they really begin to let go and simply say the first thing that comes into their minds.

4. Gibberish interpreters: Working in pairs one person speaks in gibberish and the other person translates. This is then played as a scene with three people: The Interviewer speaking in English, the Expert speaking Gibberish and then there is an Interpreter who translates into gibberish and also from gibberish to English.

5. Emotional replay: A simple scene is played and then replayed with the women overlaying an emotion – for example, buying the milk with sadness. This creates comedy from a simple scene.

Session 3: Belly Dancing: “Unveiling the Woman Within”

Aim: To invite the women to discover more about themselves and to liberate their bodies through the ancient art of Belly Dance. This workshop aims to introduce the women to ancient rituals and an exciting dance form that still holds the same fascination and fun today as it did centuries ago. Women will be invited to dress-up in belly dancing apparel. Women will discover the intricate use of belly dance and the Chakra system as a form of self-expression and as a tool to learn more about themselves.

Description of activities

1. Introduction & welcome: Discussion and introduction to this ancient dance form including: workshop overview, facilitator’s background, history of the dance,

Benefits of dance, dance & self-awareness, Middle Eastern dance and the Chakra system

2. Frocking-up: Choosing a costume and belt to wear for the session the role of the costume
3. Finding your dance spirit: Warm up and setting the basic alignment of the body; Importance of reflection – what your body can tell you about yourself. Discuss safety issues. stance, breathing, shoulder rolls, windmill arms, foot warm-up
4. Body isolations and basic moves: Walking – side to side hips (chakra 1); Hips (chakra 1 & 2) - Knee flex, Shimmy, Hip lifts, Hip flicks, Hip drop, Os, Pelvic circles; Stomach/diaphragm (chakra 3) - Chest drops, Pokes, Flutters, Belly roll; Shoulders/arms (chakra 4): undulations, water arms, snake arms; Ribs (chakra 4) – slides, circles, half moon; Neck (Chakra 5) - Fwd/back slides.
5. Range of moves: Introduce a range of moving steps in preparation for routine combinations
6. Routine: Complete a couple of simple combinations of moves learnt so far (introduce the Zagareet)
7. Veil techniques (air & water movements): Walking, Turning, Swinging, Emphasising hips, Masking & unveiling.
8. Closure: Cool down, Discussion & reflection, Breathing, Stretching, Spinal rolls, How does your body feel? What is your emotional and physical response to the dance experience?

Session 4: Drumming

Aim: Facilitate engagement in a variety of group drumming activities as a platform for relaxation, stress-release, and a sense of being part of an ‘up-beat’ group.

Description of activities (adapted from the Health Rhythms (HR) drumming protocol, a composite, evidence-based drumming intervention)

1. Introduction: Introduce the women to two different drums (djembe and darbuka) chosen for their different tonal range and user-friendliness. Introduce how to make different sounds depending on how and where you hit the drum.
2. Rhythmic naming: Each participant is invited to play out the syllables of their name. The group listens and then mirrors back, amplifying the sound that a participant has made, providing immediate gratification and feedback.
3. Rhythmic responses: Women respond to the following specific questions using their drums to communicate their answers in a non-verbal way: How do you feel about taking care of yourself? How do you feel about giving yourself time for leisure and self-care?
4. “I feel...”: Women are given a chance to make a statement about who they are and what they are feeling through the abstract medium of the drum, and to have that statement echoed back to them.
5. Mirror game: One person makes a sound on the drum and the group copies it back.
6. Echo game: One person makes a drum sound and then one person at a time around the circle copies the rhythm creating a wave effect, similar to a game called “Telephone” in which a whispered message is sent around a circle, and the group discovers at the end whether the message was conveyed correctly, or whether it changed into something else.
7. Getting ‘in-sinc’: One person starts a rhythm and each consecutive person in the circle adds to the rhythm with their own beat, getting in-sync or in-step with the underlying shared pulse.

8. Body language activity: Women take turns, or can go in two's or threes, to be the leader who goes into the middle of the circle and conducts the drumming with her body language (others drum to match the way she is moving)
9. Freestyle drumming (optional dance) – each participant is given the opportunity to direct the group and signal for changes in tempo and dynamics, with space created for comments and responses, whether verbal or musical.

Session 5: Art and Sensory Play

Aim: The following activities were designed to facilitate a process of playful engagement with a variety of sensory-focused self care activities and then encourage expression of these experiences and reflection on “Me Time for Mums” experiences through two art mediums.

Description of activities

1. Sensory play: The aim of these activities is to create a warm and inviting encounter that provides the women with opportunities to experience their senses through a variety of self-care activities. Music is playing and the women are invited to experiment with activities set up in several sensory self-care “stations” around the room. The women are encouraged to track their moment-to-moment experience and feel and notice as many sensations as possible. A secondary aim is to encourage sensory awareness and the experience of shifting focus and getting absorbed in sensations, flexibly shifting their attention between sensory experiences over a short period of time.

TACTILE STATION	SMELL STATION	TASTE STATION	SOUND STATION	SIGHT STATION
Hands in bowl of jelly	10 different essential oils	Poster outlining steps involved in mindful eating.	Ipod docks set up with earphones to listen to different sounds (classical music, jazz/pop music, sounds of nature, and meditation bells)	Women encouraged to get in touch with their visual sense
Playing with clay	5 different types of flowers	Women focus on a raisin or prune and take themselves through the steps.		Looking at each other while making funny faces
Rubbing olive oil into hands	25 bottles of different herbs, spices and extracts		Women invited to lie down and count the sounds	Looking at each other's faces – observing shapes, textures, contours, colours.
Hot aromatherapy packs	freshly baked cookies			
Finger painting	hot vegetable soup			

2. Celebratory self care sculpture: This activity aims to bring the women together to celebrate their experiences in the program and to look to the future to visualise how they may secure time and space in their lives for leisure, creativity and to ensure they take care of themselves. The celebratory self-care sculpture (“totem”) begins by bringing the women together to play with clay while they talk about their experiences in the sensory self-care stations and in the program generally. Music is playing while the women make their own individual self-care sculpture. Once their sculptures have been completed, the women will be asked to display them and be encouraged to respond to what they see by writing comments or key words of response as they wander around the room. The group unites and joins together each of their individual sculpture to make a great group sculpture.
3. Wall collaborative finger painting: The women will be asked to take up a paint brush or their fingers and do a “splatter” painting (throwing paint on a poster pinned to the wall) to lively music as a joyous “no holds barred” finale to the activity.

APPENDIX K

POST-SESSION FEEDBACK FORM



Please take a moment to reflect on your experience of today's session and then answer the following questions. There are no right or wrong answers.

1. Rate the degree to which you "got into"(i.e., felt absorbed in) the activities during the session today

1	2	3	4	5	6	7	8	9	10	11
Did not get into the activities at all					Moderately got into the activities					Thoroughly got into the activities

2. Rate the degree that you enjoyed the activities in the session today

1	2	3	4	5	6	7	8	9	10	11
Did not enjoy the activities at all					Moderately enjoyed the activities					Thoroughly enjoyed the activities

3. Rate the likelihood that you will incorporate something you did during the session into your life outside the program

1	2	3	4	5	6	7	8	9	10	11
No chance of incorporating activities into my life					Moderate chance of incorporating activities into my life					Definitely will incorporate activities into my life

4. What was the most enjoyable part of the session?

5. Would you do anything differently if you organised this session. If so, what would you do?

APPENDIX L**TELEPHONE FOLLOW-UP INTERVIEW QUESTIONS**

1. I'd like you to think about your experience in the Me Time for Mums program and tell me what it was like?
2. Has your involvement in leisure or self-care activities changed since doing the program?
3. Has doing the program changed your awareness of leisure or self care activities you may like to pursue?
4. As a result of your experiences in Me Time for Mums, has your understanding of leisure changed?
5. Did Me Time for Mums change the way you understand the choices you make during your free time?
6. How did it feel for you to take 'me time'?
7. What did you enjoy about the sessions?
8. What didn't you enjoy about the sessions?
9. Were there sessions you particularly enjoyed – why? What made them enjoyable for you?
10. How would you describe how much you “got into” the activities – did it vary with different activities – why?
11. Were there features of the group that had an impact?
12. What was your experience of being involved in this group of women?
13. Were there features of the environment that had an impact?
14. Were there certain qualities of the facilitators that had an impact?
15. Have you made discoveries about yourself as a result of doing the program?
 - Have you learnt things about yourself?
 - Have you remembered things about yourself?
 - Have you discovered desires, interests, motivation?
 - Do you see any changes in yourself because of the “Me Time for Mums program”?
16. Did your participation in the program have an effect on your:
 - Thoughts, feelings, sensations during/after sessions
 - Mood and wellbeing
 - attitudes and beliefs about doing leisure and self care
 - attitudes and beliefs about caregiving
 - relationship with yourself
 - relationship with others
 - lifestyle expectations and intentions
 - day to day use of time
 - plans for future
 - support and social life
17. Were there any other effects of the Me Time for Mums program that we have not covered?
18. Were there any barriers in your life that has made it hard for you to pursue leisure activities since doing the program?
19. If you could change things about the program, what would you make different?
20. Would you recommend the program to other caregivers?

The interviewer shows the participant a card with the following list of affect terms and tells them that each term corresponds to the number in the columns:

AFFECT TERMS			
1. Self-esteem	7. Caring	13. Joy	19. Disappointment
2. Strength	8. Love	14. Happiness	20. Anxiety
3. Self-confidence	9. Tenderness	15. Enjoyment	21. Stress
4. Pride	10. Intimacy	16. Inner calm	22. Loneliness
5. Energy	11. Solidarity	17. Trust	23. Inferiority
6. Freedom	12. Warmth	18. Security	24. Anger

Interviewer: “Now I want to invite you to work successively through each sentence, indicating on a 0-5 scale to what extent each term applies to each of the sentences you have stated, using the following scale”:

<p>Affect term rating scale</p> <p>0=not at all</p> <p>1=a little bit</p> <p>2=to some extent</p> <p>3=rather much</p>

Next, the interviewer presents the woman with another blank sheet of paper and asks them to draw an outline of their body/self as a leisure seeker, again asking for any images, themes, thoughts, feelings, and behaviours that accompany this aspect of self.

****The participant does the brainstorming activity for “I-as-leisure seeker”****

The interviewer now invites the woman to concentrate on her experience of herself as a leisure seeker and self-carer and follows the same sentence formulation and affect-matrix procedure just completed for ‘I as caregiver’.

++COMPLETE BRAINSTORMING AND VALUATION X AFFECT MATRIX FOR ‘I-AS-LEISURE SEEKER++

Interviewer: “We have just gone into detail looking at two positions or aspects of yourself. Now I am interested to know how you generally feel in your day to day life overall, without focusing on any particular aspect of yourself. Can you give a rating for each term in relation to the way you generally feel in your day to day life right now? Next, can you give a rating for each term in relation to the way you would ideally like to feel in your day to day life right now?”

	<i>Affect terms</i>																			
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
General feeling																				
Ideal feeling																				

Interviewer: “Now we have a ‘map’ of the different moods and feelings that emerge when you are in the position of ‘I as caregiver’ and when you are in the position of ‘I as leisure seeker’ as well as a profile of how you feel overall and how you would like to feel. Through doing this exercise we can see how there are different positions we occupy in our lives and each position has its own ‘voice’ so to speak and ways of experiencing life and relating to others. I am going to go away and have a look at the matrices you have filled in today in more detail. Can we make a time to meet again next week to discuss the overall prominence you give to the positions of caregiver and leisure seeker in your life and how each position affects your overall wellbeing?”

++++++BETWEEN INTERVIEW SESSIONS 1 AND 2 – RESEARCHER ANALYSES INTERVIEW DATA++++++

The researcher now has two matrices – one depicting the participant’s cognitive/affective experience of ‘I as caregiver of child with a disability’ and one depicting ‘I as leisure seeker’. The researcher qualitatively analyses the interview data for dominant themes and differences between the sentences given for the two positions. Next, the researcher quantitatively analyses the matrices using the statistical procedures appropriate for the ‘self-confrontation method’ outlined by Hermans et al. (1990). These statistical procedures provide standardised indices which allow the affective profile of one position to be compared to the affective profile of another position. These indices are positive affect, negative affect, self-enhancement motivation and communion with others motivation. The affective profiles of individual sentences can also be correlated with the general-self and ideal-self affective profiles to assess the extent to which they are generalised and wellbeing enhancing or depleting to the self-system as a whole.

INTERVIEW SESSION 2 (one week after initial interview)

The interviewer explains the nature of the positions ‘I as caregiver’ and ‘I as leisure seeker’ in terms of the degree of positive and negative affect and self-enhancement and communion with others motivation that goes along with their experience of both positions. The interviewer then invites the participant to elaborate on their experience of both positions.

Interviewer: “As you know we have developed a playful creative arts and leisure program that you will be participating in. We have developed this program as a result of research evidence that mothers of children with a disability often feel very busy and pressured in their lives, and often do not spend a great deal of time on themselves to unwind and experience the lighter side of life. This program can be thought of as a playground for your position ‘I as leisure seeker’ to have space to come out and occupy a more prominent position in life”.

APPENDIX N

**P⁺ GROUP COMPARED TO THE P GROUP ON QUANTITATIVE
OUTCOME VARIABLES**

Table N1

*Descriptive Statistics and ANOVA Results Comparing the Two Intervention Groups on
Leisure Attitudes and Behaviour Variables*

Outcome variable		P ⁺		P		F tests P ⁺ compared to P		
		M	SD	M	SD	Main effect (time)	Main effect (group)	Interaction group x time (Partial Eta Squared)
Risks of not doing leisure	Pre	28.88	4.36	30.00	5.71	.40	.51	.27
	Post	29.00	5.50	31.25	5.18			
	Change	0.12	5.22	1.25	3.20			
Benefits of leisure	Pre	30.13	4.42	30.38	5.07	24.48**	.00	.40
	Post	32.88	3.56	32.50	2.88			
	Change	2.75	1.49	2.12	2.36			
Intrapersonal constraints to leisure	Pre	20.25	7.74	23.00	5.04	21.72**	2.56	31.64** (.69)
	Post	16.25	6.52	23.38	5.21			
	Change	-4.00	2.07	0.38	0.74			
Interpersonal constraints to leisure	Pre	16.25	5.12	14.12	6.36	.43	.03	2.57
	Post	15.25	6.36	16.50	3.55			
	Change	-1.00	3.16	2.38	0.46			
Motivation to increase leisure	Pre	12.63	3.02	14.75	3.20	25.69**	2.56	.14
	Post	17.13	2.64	18.63	2.26			
	Change	4.50	3.12	3.88	2.62			
Leisure coping	Pre	25.25	7.49	30.00	5.09	19.37**	1.35	1.33
	Post	30.38	8.42	33.00	4.69			
	Change	5.13	4.09	3.00	3.25			

Table N2

Descriptive Statistics and ANOVA Results Comparing the two Intervention Groups on Mental Health Variables

Outcome variable		P ⁺		P		F tests P ⁺ compared to P		
		M	SD	M	SD	Main effect (time)	Main effect (group)	Interaction (group x time)
Depression	Pre	2.88	1.96	4.75	2.71	1.75	2.13	1.75
	Post	2.88	1.96	4.25	2.31			
	Change	0.00	.76	-0.50	0.76			
Anxiety	Pre	3.38	3.38	3.50	2.83	3.18	.00	1.15
	Post	3.25	3.01	3.00	2.45			
	Change	-0.13	0.64	-0.50	0.76			
Stress	Pre	7.63	3.74	7.00	3.38	22.48**	.00	2.50
	Post	5.38	2.88	5.88	2.99			
	Change	-2.25	1.83	-1.12	0.83			
Positive energy	Pre	15.13	3.60	15.13	2.42	29.47**	.00	.02
	Post	17.25	4.27	17.38	2.39			
	Change	2.12	1.73	2.25	1.49			
Tiredness	Pre	12.50	4.50	15.00	3.63	4.87*	1.77	.03
	Post	11.63	4.03	14.25	3.45			
	Change	-0.87	1.96	-0.75	0.71			
Relaxation	Pre	12.00	2.27	10.50	1.41	4.2	3.19	4.2
	Post	12.00	2.27	10.13	1.46			
	Change	0.00	0.00	-0.37	0.52			

Table N3

Descriptive Statistics and ANOVA Results Comparing the two Intervention Groups on Life Satisfaction Variables

Outcome Variable		P ⁺		P		Main effect (time)	Main effect (group)	Interaction (group x time)
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Personal Wellbeing	Pre	66.88	8.66	59.79	14.49	7.05*	1.56	.18
	Post	71.66	11.30	63.25	15.53			
	Change	4.78	8.23	3.46	3.07			
Basic Needs	Pre	31.50	8.12	33.13	4.09	29.09**	.35	.18
	Post	35.13	9.17	37.38	3.81			
	Change	3.63	3.11	4.25	2.71			
Activities of living	Pre	28.13	8.11	30.25	7.49	54.23**	1.01	2.17
	Post	33.88	8.17	38.88	5.28			
	Change	5.75	3.37	8.63	4.37			

APPENDIX O

QUALITATIVE POST PROGRAM INTERVIEW QUOTATIONS ORGANISED BY THEMATIC CATEGORIES

PROGRAM OUTCOMES

Change of attitudes towards leisure and self-care

Reduced intrapersonal constraints

P⁺2 “I am more aware of the importance of making time for myself, especially general exercise”.

P⁺4 “When I came to the Me Time program I had some freedom structured into my week. I knew that I’m out for three hours and that he’s going to be all right and I just kind of made a pact with myself that I’m not going to think about his needs for three hours”.

P⁺5 “The program made me think of me time as my right as a human being. I do feel more entitled to take my own time. I keep having to give myself permission, and I hear the voices of the facilitators and remember the group and the way we all desperately needed and loved having fun and being silly, and each time I do it frees me up”.

P⁺6 “The trick is to know that there is always stuff to do or finish or prepare. It’s never-ending. You just have to force yourself to step out of the rat wheel in spite of everything, to have a break, and somehow trust that things won’t fall apart”.

P⁺7 “I have always been aware that self care should be a high priority as I am aware about how being under too much stress impacts on the level of patience I have with my kids”.

P4 “My beliefs have not changed but they have been strengthened to the point of doing something about it”.

P6 “During the program I had to train myself not to feel guilty in taking time for my own leisure. That's not my natural self. So, I kind of faked and said: “Hey I'm going out and I'm going to enjoy it I hope you guys do okay.” Not sorry at all, but I had to train myself to be that way. I feel very empowered – liberated - when I do it. It's funny. When I demand it, then they [her family] give it to me, and they act like I am entitled. When I act apologetic, then they kind of treat me like I am guilty. You are treated like you treat yourself”.

Acknowledgement of personal needs

P⁺1 "... and I feel like...like at last it is okay to be me".

P⁺2 "If not now, when and if not me then who? I know I cant keep putting myself off, because I'll fall in a heap".

P⁺4 "From the first interview I felt affirmed as an individual with needs of my own. Now I tell myself that 'I am a woman with my own needs every day'".

P⁺6 "Now I think twice before I fill up the whole day running around with caregiving and other housework because I know that I will deplete myself and probably end up going back into bad habits...I used to over-eat in my down time and I put on heaps of weight and felt embarrassed and trapped".

P⁺6 "When my daughter is in care I allow myself the opportunity to do what I feel like for at least an hour a day. It's my private time, which I try to protect instead of filling it with things I have to do".

P⁺6 "This program has been the first time in ages that I have felt that I owned some of my time".

P⁺7 "I'm more conscious of myself and the impact of caring and how I need to do pleasurable things to cope with the load".

P⁺7 "For a long time I've probably just sort of denied that I have any needs of my own...treated myself like a robot".

P⁺8 "At least for the past 5 or 6 years, I have struggled with boredom or monotony. Just being trapped in a routine. I haven't really done activities that inspire me or grab me".

P2 "The most crucial thing I got from the program is realising that I can get out of the house and life doesn't end".

P3 "Life goes on even if I put myself first sometimes".

P7 "I have realised that getting out of the house keeps me sane. I need to get away from anyone who needs me so that I can refuel. It keeps me in touch with the fact that there is a whole world going on out there, which I can easily feel out of touch with."

Affective outcomes of program

Uplifted mood

P⁺1 "I was in a funk at the time of the first interview [pre-program self-confrontation intervention] and going to these sessions took me out of

it...interrupted the downward spiral....It got me out which was very important. It got me into...back into my imagination...it got me around strong people, it got me away from home...it gave me a space to just relax”.

P⁺³ “God did I realise how much I needed a good time!”

P⁺⁴“Sculpting clay and doing finger painting and when we threw paint onto this big sheet on the wall it made me laugh...and still does!”

P⁺⁴ “The program helped me to lighten up and get out of always planning and worrying”.

P⁺⁵ “Well of course my mood feels better, you know. I’ve been a bit depressed since my son had an extra diagnosis and the activities in the group lifted my spirits. I got a real joy from it.

P⁺⁶ “I am more relaxed if I have time out for myself and this makes me more able to look after my kids in good spirits- which is better for them”.

P⁺⁸ “Doing creative activities enlivens me”.

P⁺⁸ “The group got me back in touch with my silliness and laughter. It’s been a long time since I had a good laugh like that in the theatre sports. Each one of us had our own blocks to doing the program but together we could override them”.

P² “It’s so good to go somewhere and have fun!...Have a big laugh, relax, and be with others in similar situations as you”.

P³ “For a long time my whole aim was to just get through the day until the time when I could go to bed, read and sleep. I looked forward to the program each week as it was new and made me feel more energised and interested in things again”.

P³ “This program, especially the drumming and belly dancing, gave me intense pleasure and intense emotional satisfaction, so it definitely contributed to my wellbeing. The group freed me, lightened the heaviness”.

P⁵ “I couldn’t stop laughing when P⁷ was narrating in gibberish and I was translating for her with P⁷’s arms as my own! Whenever I remember it I grin. It just goes to show how much fun you can have when you get a bunch of women in a room with a lot of pent up energy!”

P⁶ “Doing these creative activities awakened me. I felt more alive”.

P⁷ “But the best part was being able to shed all my inhibitions and being able to be myself, not having to talk to therapists or professionals, not being on guard the whole time was wonderful”.

Affect regulation

P⁺1 “I think if you didn't have pleasure and your own interests and things you find interesting and meaningful, you get depressed. There'd be an emptiness there. This is what was happening to me. The program and now the short course has enhanced my life and helped me to fill that emptiness”.

P⁺3 “I ended up feeling like I'd got rid of a lot of pent up frustration and tension. I just really hit that drum [laughter]. I came to that session so stressed from the morning and I left different and...just more relaxed and clearer. I probably play atrociously without rhythm but feel so much better for it”.

P⁺4 “When so much that I have to deal with is frightening and worrying, the process of focusing on a creative project brings things back into perspective”.

P⁺5 “I have realised that my meaning and satisfaction in life comes from what I actually *do* each day; maybe it's no more complex than that”.

P⁺5 “The yoga and relaxation session taught me how to breathe from the diaphragm, which I had never ever been shown before. We did this yoga pose which involves lying down flat with your palms open and breathing from our tummy to the top of the chest. The instructor suggested that we do it everyday for five minutes when we need to recharge and I have been doing it. It's really relaxing and the pose itself feels like you're letting go you know, just accepting things as they are and having a rest. It gave me a new relaxing way of being in my body”.

P⁺6 “There was this culture in the program that we could, in two hours, have the possibility of having enjoyment. They believed in the possibility of suspending your worries and immersing yourself in the activities. It was initially hard to come in the space and get out of my head but over the time of the program I could do it faster...”.

P⁺7 “When I made my clay sculpture it really meant something to me, because it's expressing things that I keep inside and don't often discuss with others. I mean it is important because it validates you and, especially when you don't have much time to think about yourself or how you feel or what you need, it tells you what's going on inside. And it tells others who you are sharing with in the group. So instead of being all caged up, it releases your mood and you make something you can see and touch. It helps move you through the mood”.

P1 “The first couple of weeks there was so much going on at home that even though I wanted to go to the sessions, it felt really hard. And I questioned whether I should go if I’m feeling exhausted and stressed. But I said I’d go and all the care was paid for and arranged already by the program. I decided that I had made a commitment to myself and I went no matter how I felt. I was always stunned at how I felt buoyed up by the group and more able to get on with the day. So by the third session, there were no voices holding me back. I looked forward to it and went more easily even if I was tired”.

P2 “...I usually went in feeling stressed and left having blown off a lot of pressure-more ready to get on with the day to day jobs not feeling so weighed down”.

P3 “...and I use it [music at home] to feel better. I think it gets me awake, thinking well, and having more energy to function better. It’s uplifting”.

P4 “I found this time, although it was a very short space of time, a special time to “tune-in” and relax. . . just calm down and relax and I guess to have some lighthearted fun. As the program went on it was easier to relax more quickly and leave home stuff at home”.

P5 “When I do have some time, going out and being with people feels like such an effort, or I don’t feel presentable or can’t be bothered. I have had a low people tolerance. I am trying to shift my thinking now because I found that going to the program didn’t drain my energy; it gave me energy. So now I am more willing to go out even when I don’t feel like it, and you do come home uplifted”.

P7 “It is very satisfying to have something I can do to lift myself when I’m down”.

P7 “It’s amazing to have a piece of paper and paints, and life can be temporarily reduced to putting colours and shapes on the paper. Nothing else you have to do, no where else you have to be... When so much that I have to deal with is frightening and worrying, the process of focusing on something creative gives me back perspective”.

P8 “I was reminded of the power of music to ground me. If I have some difficult tasks to do and I hear say on the radio the right music, I do better, I’m more efficient. I work better. I think more clearly, I feel healthy. If I’m down or feeling tired, or my muscles are aching and I play some music and dance around I feel better. I feel fitter...”

Leisure and self-care behavioural change

Increased leisure

P⁺1 “I hadn’t even held clay before and after the program finished I enrolled in a five week long CAE ceramics course...”

P⁺1 “We have a small shed at the bottom of our garden which my husband says he’ll turn into a studio for me - it will be my place for clay where I can go and be me and keep all my stuff.

P⁺2 “This course has given me the space to think about myself and it has given me a greater knowledge of what’s out there to do. I got a lot of good feedback in the belly dancing session and felt that it came naturally for me. [The belly dance facilitator] put me in touch with a place and I have recently enrolled in a dance course”.

P⁺2 “I try to do a walk each day now which I didn’t do as regularly before because I was always telling myself that I don’t have time”.

P⁺3 “I am doing a course in drumming at this place that [the group drumming facilitator] told me about. And I went and bought my own drum”.

P⁺4 “After the art session I went and bought clay...I find it’s a good way to hit the pause button when I can during the day or in the evening instead of just switching on the TV”.

P⁺5 “[The relaxation/yoga facilitator] got me linked into a yoga school and I have been going weekly or fortnightly since the program which helps me to reset myself”.

P⁺6 “I do some of the activities. We did finger painting and clay in the program and now I’ve set up a space at home to do it. Also I have looked into music therapy for my daughter. This was inspired by the group as I loved the drumming. Through the music facilitator I found out about the Access drumming circle for people with disabilities which is on every month. It’s great. It’s an evening off for me and I know she’s having fun”.

P⁺7 “I found out about things I never heard about before. [The student researcher] introduced us to laughing yoga and I’d never heard of such a thing before. There is actually one every Saturday morning in the park near me which I go to when I can.

There is a concept of fake it till you make it and it has become my mantra. I have taken to laughing in the car”!

P⁺⁸ “I loved it [theatre sports] so much and I was really inspired so I took myself off to the theatre sports competition, on Sunday evenings at ‘Theatreworks’ in St Kilda for several weeks after the Me Time program finished. It was hard at first to allow myself the outing as I didn’t think my husband would be able to manage without me, but it worked out fine. I keep my phone on silent and tell him to call only in an emergency. I introduced some friends to it and we have a girls’ night and love it!”

P1 “In the lunches afterwards we shared some respite ideas and I learnt a new place for my son to go, which will free up an afternoon a week to do things for myself”.

P2 “Yes, it’s opened my eyes to things you wouldn’t normally look at doing yourself”.

P3 “I went and bought an Ipod and Middle Eastern CDs and I dance to it in the car and at home...”

P7 “I am considering enrolling in an eight week business course by correspondence”.

P7 “I’ve started making greeting cards with finger painting and drawing. Or if I have no energy for making things, I put music on that calms me or lifts me up. I may even start selling my cards through the respite centre down the track”.

‘Seizing moments’

P⁺¹ “Yes, I’ve always known there is a benefit of having time out and time to explore your own interests, but I’ve always just thought that I have no time for those sort of things. But I could come to ‘Me Time’ so I have learnt that it is possible to make time”.

P⁺³ “If I relax the expectations I put on myself, then there is more space in the day where I can do things just for my enjoyment”

P⁺⁴ “...now it’s [the clay] always out and on the ready in case there is a spare 20 minutes”.

P⁺⁶ “I guess this has made me more opportunistic about taking time for myself and knowing that I can shift gear and leave things undone. And it will be okay”.

P+8 “In the yoga session we learnt that if you lie down on the ground and breathe deeply following a certain method for fifteen minutes, its as good as an hour’s sleep, so I have been doing that when I can remember and it does refresh me”.

P3 “I have been reminded of my interests and ability to access them if I choose a little bit every day”.

P7 “It’s strange...those drastic fantasies are no longer on my mind ...Instead of wishing I could leave it all I have changed my approach... Now I’m on the ready to take full advantage of moments for myself throughout the day, like I’ve got back into knitting in my spare moments and listening to music, and I’ve started making greeting cards, which has made a huge difference in my life”. [“This participant shared that before she found out about the program “I had had it up to my throat - I wanted to escape”. She disclosed that she used to imagine staging a car accident, admitting herself into hospital and running away, so that “I would be freed from all my responsibilities”]

PROGRAM PROCESSES

Flow

P+1 “It [Theatresports] takes a huge amount of risk. You just have to sort of trust in your own capability that you’re going to be okay in the process. The saying yes ...what they call the idea of ‘accepting all offers’ is a key thing. You just pick up and run with ideas. You just somehow get this confidence and, you have no idea what’s going on and what you’re going to say or do ahead of time and..well.. it all just works!”

P+1 “The movement and sensations in my body when I was playing drums, belly dancing and making clay brought me into myself. I know it may sound stupid but – well – it made me feel human again”.

P+2 “It was bizarre. It’s like there is a constant radio frequency in my mind about [daughter] and whether she is okay and what I need to do but when I did the improvisation the station was changed or the volume was actually off and I could get into the activities fully. It was very strange, but probably good for me!”

P+3 “Drumming felt like a type of meditation which I appreciate. It keeps your mind focused”.

P+3 “It [the program] has changed my approach to time and I guess my attitude towards it. When I am at home doing routine house and care activities, not really

doing anything creative or meaningful, time goes pretty slowly. But when you're having fun and being creative it flies!"

P⁺³ "I have discovered new interests and abilities that I never knew I had".

P⁺⁴ "When I was doing the improvisation it was remarkable that I didn't think of my son once. I was totally in the scenes we were creating. It was truly relaxing and uplifting. Really a whole new space to exist in..."

P⁺⁴ "It's a mind set...like my mind is completely on something that I'm doing rather than half occupied with my son".

P⁺⁵ "...it's new, it's a bit challenging. You have to take a bit of a risk and just give things a go. I was especially nervous to put on the skirts and dress up for the belly dance session as I've put on so much weight but I did it and felt better for not holding myself back afterwards. And we were all a bit shy at first. No one had been to the program before so we were all trying something different and all encouraged each other".

P⁺⁶ "I was distracted from my worries because these different activities needed full attention. There was no room for the worries".

P⁺⁶ "I really felt that the drumming session coaxed me out of my self, out of my head, and into my body. It was actually wonderful to be in my body for a change".

P⁺⁸ "But the drumming and drama sessions were the highlights for me. I wasn't just going through the motions like in my day to day...I was right in it".

P⁺⁸ "The drumming... it's transcendental and yet totally grounding at the same time. That's a word I was trying to look for. And it does take you above yourself. It does me... you know, there are few moments when you hear a rhythm that is really, really wonderful and you just play along without effort and you become part of it and it takes you away. And that does, yes. It does have that effect...I really needed to be reminded of me!"

P⁺⁸ "You're really right on the edge with the theatre sports ... it's very stimulating and hilarious".

P⁺⁸ "...and it all flows out spontaneously without having to control any part of it. And the best thing about it is the belly laughs".

P3 "The experiences during the program were really enjoyable and distracting and there was no room to really think that much...I just sort of stopped mulling over things".

P3 “I completely lost track of time in these sessions. Before I knew it [the student researcher] would be arranging the lunch for us and two hours would have gone past”.

P4 “It [belly dancing] was really awkward at first and I felt at odds with my body but after a while I just felt the rhythms almost pulse through my veins and I got into it and I felt really good, like I had accomplished something”.

P4 “To be able to do that [theatre sports] is very challenging as you are sort of on the spot but it’s so satisfying when it all comes together”.

P7 “... I almost disappeared for two hours. It was like time was just not a factor. I didn’t look at the clock, and what was really unusual for me is that I didn’t even go for a cigarette or want one during the sessions”

Self-expansion

P⁺1 “For the first time it became clear that I had been underestimating the effects that giving up leisure time has had on me, both mentally and physically. It’s only when you do it [leisure] that perhaps you realise that you have been living a really constricted life”.

P⁺1 “Suddenly there is something for me, there are possibilities and I look at the world around me and I see colours, shapes, and designs that I can use in my sculptures”.

P⁺2 “After I had [daughter with disability] 30 years ago ...I think I just gave up on all my hobbies. I remember how inspiring it is to develop new creative pastimes. It’s great to be stimulated with new ideas”

P⁺2 “I guess I am realising that this role [caregiver] is not all of me. In the past my husband has offered to take time off work and care for my daughter to allow me to take a trip or do a course or something for me, but I always said no. Maybe I didn’t want her [daughter] to stop needing me as much and maybe I didn’t really have my own interests. It sounds stupid doesn’t it? Well I’ve been thinking that I am going to take him up on his offers. My daughter will always need me. I guess I can see a way to do both”.

P⁺2 “I always thought that art, music and dance and being creative was something for other people but I have discovered that I can do it and I do enjoy it ... I guess I see that you can do it for the fun of it, without taking yourself too seriously”.

P² “It [Theatresports] gives you a moment where you step out of your identity and create multiple, endless identities. It’s refreshing to take on different characters!”

P³ “I felt comfortable, maybe more so than if you were in a program for any mums, to connect with the other women who you know are in a similar boat. And it was great that it was stated at the beginning that it’s not group to discuss and workshop issues about your children’s disability or illness. It was about us as women beyond that part of our lives”.

P⁴ “It’s interesting that, while we came together because we were all mothers of kids with special needs, this almost gave us support that did not have to be centered around the disability. We could be together as a group of strong, creative women”.

P⁴ “I am not just a caregiver, mother, wife, and daughter. I have been blocking out my needs for a long time and I think it created a lot of resentment. The program was a great interruption to this”.

P⁵ “I feel almost simultaneously trapped and freed. The lifestyle I want to live, and really need to start living, will involve a balancing act. I’ve seen how doing these games and activities wakes me up and refreshes me”.

P⁵ “Doing creative things and accessing a different part of my brain is more linked to who I am a person. Before having children I used to design wall paper and after [son] was born I just stopped. I was exhausted and lost the motivation. After the art session I dug out my old designs and think I will print some of them” .

P⁶ “Since doing the program I have lost around about 8kg. When [student researcher] came over for the first interview I told her that my self-care goal is to come to the program and commit to going to the gym twice a week as my new religion, like I used to do before [child with disability] was born. Saying my goal out loud and then having the support and company of another woman in the program has kept me on track. I feel almost normal again!”

P⁷ “It’s [the clay sculpture] expressing things that you don’t talk about normally I suppose.

P⁷ “I really enjoyed the classes and it was a bonus to realise that I could actually be quite creative. I got so much positive feedback about my sculpture. I did clay in high school and I remember loving it and also getting encouragement to make something of my interest back then, but I never pursued it. And I’ve never thought about actually doing it as a regular hobby at home until now”.

P⁸ “I am such a responsible adult because I have to be. I have to always be alert, vigilant and thinking ahead to make sure my son gets through the day with no hick-ups. It’s exhausting running such a tight ship. That’s why my favourite session was the improvisation. You can be whoever you want from your imagination...”

P⁸ "It's good therapy just to be where we can be ourselves, just ourselves, and not really be a caregiver when we are there . . . I can laugh. I can talk. I need to reflect more on who I am as a person other than a mother and carer, but I guess its much harder to do on my own”.

P2 “It felt like being a kid again with all the different fun activities each week, in our own space... and I let my imagination free, which has been pushed down for a long time because I always have to be the responsible one”.

P3 “So, it was a way, as I say, of expressing how I was feeling in a very safe environment with an opportunity to be creative. And there was . . .how can I say . . . self exploration”.

P4 “..I’m coming to the point now where I want more for me. ..now I’m looking at me and looking where I am going. I have got this incredible daughter and family, but there is me. Two and a half years is a long time and I haven’t really thought about what I want to do...”

Restorative respite

P¹ ‘burden-free zone’.

P¹ “It was a pleasure to escape into a fresh enjoyable task away from responsibilities”

P³ “Me time was an opportunity to get out of the caregiving world and into my own world. And that’s just a, it’s a total break”.

P⁴ It’s easier to do this outside the house when it has been arranged ahead of time. Leaving the house allows me to tune into something else”.

P⁴ “It’s so easy to get swallowed up with caregiving ...especially when you’re on your own, trying to navigate a maze of services and make sure your children are okay, keeping everything afloat. Doesn’t leave much time left over for your own life”.

P⁴ ‘Me time was a block of freedom in my week’

P⁵ ‘This is real respite’

P⁶ “I felt freed up to try new things. It was stimulating. It broke through the week’s obligations and responsibilities. It felt a bit like it was my play time.”

P⁷ “When I was laughing, singing, moving about happily, or simply engrossed in making clay or art, I totally felt more relaxed and care free- actually I *was* care-free wasn’t I for those two hours, in all senses of the term!”

P⁷ Usually I run around from task to activity doing ...constantly doing. Well this felt like a chance to give over to something else and just enjoy the moment – nothing I *have* to do...just enjoyment”

P⁸ “It was so great to have a space for myself, ‘a room of ones own’, otherwise you can lose yourself”

P⁵ "You don't talk about your kids . . . you talk about something else or you play. And I find that is very important. It’s different to other support groups for parents; it’s really important time off".

Social connection

P¹ “At first there is sort of a fear factor going ‘you’re not going to belly dance!’ ‘You can’t paint!’ but then you do it because everyone else is in the same boat and the facilitators warm you into it. You see how enjoyable it is”.

P¹ “[The student researcher] and all the facilitators emphasised not taking yourself seriously and being playful and experimenting, so that paved the way”.

P¹ “...went really well-the first session before the program opened my eyes and provided feedback for me. It was someone taking an interest in me and who I was. The love and support and genuine sense of connectedness with the other women made things less isolating”.

P² The leaders [i.e., facilitators] were great, with lots of energy and positive strength we could draw from”.

P³ “I have already seen several women in the group for coffee and walks. During the program I decided to give myself at least a half an hour a day of pure me time. I convinced P² who lives around the corner, to do the same and now we walk together every few days. I realise now that my family will not crumble without me and my sanity is worth upkeeping, so to speak! It’s great to have someone to chat and laugh with, especially who lives so close”.

P³ “I am more conscious about taking care of myself and how this reflects on the family and my husband will support me to take me time as he can see the benefits of it in my mood”.

P⁶ “I loved the drumming session because you were communicating with people in such a different way; we did this call and response activity and I felt a part of something. I mean I felt very much a part of this group of women – all very warm and very strong, and maybe I saw myself in a new way... as strong too because I was a part of it”.

P⁶ “It was good to meet others in similar situations and know you’re not alone”.

P⁷ “...and when you share the meanings [of the artwork] with the others it lets them understand me as well”.

P⁷ “What brought me the most comfort was to be amongst other women who had gone through similar journeys. I have felt very alone and well..... sort of trapped being a single mum”.

P⁷ “All the facilitators totally believed that experiencing enjoyment was a vital part of everyday life. It was so good to be around people who give some importance to their own needs”.

P⁸ “Theatre, cinema, pubs, restaurants, after [son with disability] was born, we just cut down how much we went out until I found that we hardly ever did anymore, so going to the theatre sports competition was a really big deal for me and good to give me something positive to share and do with friends of mine I don’t see that often”.

P⁸ “It was hard at first to allow myself the outing as I didn’t think my husband would be able to manage without me, but it worked out fine. I keep my phone on silent and tell him to call only in an emergency. I introduced some friends to it and we have a girls’ night and love it!”

P² “My husband encouraged me to take more time for myself when he saw that I was much easier to be around!”

P² “It’s been a very long time since I have connected to other women. I had become more and more socially isolated. It was a blessing for me to get out and be around these women”.

P³ “I found it easier to make friends in this setting compared to the parent-to-parent support groups. In sessions we talked to each other and had another shared focus instead of our children and problems. Making and doing stuff together is a great

conversation starter and we were encouraged to hook up outside the group... which I have already done with a couple of people. And I'm looking forward to the film night and catching up with everyone again".

P7 "In the sessions the whole was more than the sum of its parts"

P7 "There was so much openness to try things in the other participants that I think it rubbed off on me. I pretty much stick to what I know usually and this program challenged me to have a go. And I felt so good afterwards".

Social legitimacy

P⁺1 "When I agreed to do the course I really had little interest in it... well I had little interest in anything... and I didn't think I could fit any more into my day because I was at boiling point which my case worker could see and that's why she kept encouraging me to do join the Me Time group".

P⁺3 "I don't think I feel as guilty anymore. When you have your case worker and then program facilitators all saying it's okay to do things for yourself, it's reassuring. Looking back I can't believe the pressure I put on myself. Unlocking the guilt has taken the pressure off and I feel I have more energy and- yeah- more like myself".

P⁺5 "And it was not until [the student researcher] came over before the program started that somebody outside the family actually asked me how I was. I felt so overwhelmed by the concern shown that I had tears well up...its so good to have your efforts and your situation recognized. I think it hit me how much stress...and maybe pent up frustration... I was harbouring inside...being able to talk about it to an outside person is so helpful to release some of the pressure we are under. And I realised that maybe I do need to do something to cope better".

P⁺5 "They [facilitators] believed that self-care is not a privilege – it's a necessity to keep going, so that helped me give myself permission".

P⁺5 "These whacky activities – I would have never tried them myself – the group was so much fun to be with in a way that was different to my general life. There's force in numbers – it's a great motivator"

P⁺6 "I've been so consumed as a caregiver and mum, with the preparation, planning, housework, dropping off, picking up, shopping, healthcare visits, and so on and on, that to think about taking leisure time was almost impossible. I needed this program...I needed help to get the balance back".

P⁸ “It was only after pressure from many sources including my case worker and friend and even my GP that I decided to go ahead and come to the program”.

P⁸ “It’s a bit harder to motivate myself alone. So I’m determined to find another community art group to join. It satisfies a need that I must have”

P2 “You kind of feel that if there is a program, with money for alternative care, then it’s okay to do it. I didn’t have guilt coming to Me Time. Also you’re there with a bunch of other women in similar positions and there is this sense of –yeah –we are going to give ourselves this time because we really deserve it!”

P5 “When you have a program like this one paying for a carer for your child, and being organised, with people urging you to participate, its possible to have leisure. But, for me, I’m not sure how I will go on my own”.

P5 For me I need help to get the time off to do my own leisure”.

P7 “I wasn’t in a good way. My husband knew I was not coping and he really encouraged me to do the program to get some time out, which was unusual for him, and I’m glad he did that because I don’t think I would have had the energy to try a new thing if he hadn’t”.

CONSTRAINTS TO LEISURE

Intrapersonal constraints

P² “I need to know that my daughter is being looked after properly to be able to relax”

P⁸ “Initially I struggled with my own guilt about doing something just for me. I worried and had trouble sleeping leading up to this program and on the first morning I got up and ... didn’t go to the first session”.

P1 “It gave me awareness of the importance of continuing on in a program like this as I really struggle when I am on my own financially and I guess with my energy...I get tired and then just slump on the couch and I don’t see many people and things spiral down. I have to break this pattern. “Me time” was the first step. I think I need help though to do this”.

P5 “...because from the moment you are awake, you are, you know, being a mother and a carer and you start your jobs, and it really never ends just to keep things running and you are always thinking about what needs to be done and planning so it does take some effort to even stop and ask myself ‘how am I feeling’ or ‘what do I need?’

P6 “I don’t have much free time at the moment because of my son’s care needs and lack of proper support and I also have a teenager on school holidays, plus the committees I belong to on disabilities and so on. So making the time and sticking to it is difficult for me”

P6 “After the program, as time went on, I guess I have been absorbed back into the daily grind of working, caregiving and housekeeping and I am in transition at the moment with case workers so I don’t really have the support I need to commit to out-of-home leisure activities right now”

P7 “I still feel guilty taking time for myself. The cards are good, because I am doing them at home, but it is harder for me to get out of the house, as much as I know I need to do it”.

P8 “...often when I have a bit of time to myself I am often too tired to do something active or creative so I have been resting or watching TV”.

P8 “I have always been aware that self care should be a high priority as I am aware about how my well being impacts on my parenting, but in practice it’s different. It’s hard to think of yourself as someone with needs when your children constantly need your support and attention”.

Structural constraints

P⁺1 “Its [constraints to leisure] always environmental, for example I have just lost three services of support throughout Christmas so everything for me is on hold until these return”

P⁺4 I am currently going through a tough time as I am only being offered untrained carers so respite care is limited and I can’t go very far or be out for very long in case my son needs injections or has a seizure and they are not trained to deal with it”

P⁺6 “I have recently had a number of problems with the wheelchair, and my daughter is recovering from a procedure so we are having a hard time at the moment. I have less time for leisure this month, but I’m still managing the gym and walking, which I probably would have dropped in the past when things got tough”.

P⁺6 “My absolute frustration at the moment is that there is no equivalent of Very Special Kids for adults and that’s what I’m rallying with in terms of the advocacy work I’ve been doing with the council. Once your child turns 18, they are no longer eligible for their respite care services. At the VSK hospice there are nurses on the

premises 24 hours a day and they have doctors on call all the time. So you can leave your child and not worry... There is a huge need for a similar service for over eighteens who need a higher level of respite care. This is critical for me so that I can get time off for my own interests”.

P⁷ [constraints to leisure include] “Time and energy and having someone to fill in the caregiver role, and doing it at the right level, and in the right way, so it can be a benefit for you and your child. At the moment, the help I’m getting is mostly babysitting. It’s better respite if you know that your child is engaged in learning activities. Otherwise it’s not really caregiving...”

P1 “I’m having problems with the council for respite care. I feel totally responsible for my son. I’m a single parent without any real family support. So in a way, things are similar to how they are before the program for me. I’ve been under a lot of pressure”.

P2 I always think it [leisure] would be beneficial, just finding the time on a regular basis is the problem, when things are generally pretty unpredictable with [child with disability]”.

P3 “The time I spend caregiving has recently increased as a result of my mother’s illness and all the logistics that go into moving her into a nursing home, leaving less time for me”.

P7 “D has high-functioning autism and a mild intellectual disability. He has poor social skills, is highly energetic and has no concept of what may be a danger to him so he requires constant supervision. I have two other boys. D’s condition makes it almost impossible for us to go out all together and the younger boys mimic his behaviour. Our family had become increasingly socially isolated. We could not go out and do the everyday things that most families can – even something as simple as grocery shopping together. Some people in the community would get very upset when they would see him acting in a way that was not in line with his age - such as yelling and inappropriately approaching strangers. In the end it just became easier to stay home. With all my family living overseas, there was no one to rely on for a break from Darcy's constant care.

P7 “In March last year we got involved in Anglicare's Family Respite Solutions program in Melbourne's eastern region. Now once a month another couple take care

of D and we get a break. For me I need actual help to get the time off to do my own leisure”.

P7 “And to me, you can take all the tablets you like under the sun, you can go and see all the counsellors, case workers and all the doctors, but it really is so hard to get the support you need. I really need more respite from trained caregivers”

P8 [constraints to leisure are the] “Lack of case manager and support. I have recently lost a carer... I need to sort out alternative care so I will have more time for myself”

P8 “I need to arrange larger blocks of respite time so that I can manage the chores and also do an activity or program for myself”

SUGGESTED CHANGES AND EXTENSIONS TO THE PROGRAM

Suggested changes to the program

More support

P⁺3 “People who need it don’t know how to access the information or know where this and other programs like this are held... a newsletter or regular mail-out would be helpful”.

P⁺4 “Maybe there could be a website for mothers with a list of community arts and leisure services and programs in one place as well as carer organisations and respite options”

P1 “I got a lot of benefit from sharing details and experiences about support organisations with the other women.... goes to show how important it is to be a part of a network. I reckon there should be networks of parents of kids with special needs where you can help one another out with transport and other duties and mainly to combat social isolation”.

P2 “I am struggling a lot financially, so any leisure I do outside the home I really would need support. I was able to do Me Time because it was free and all the extra child care costs were covered by the program, but if I wanted to do a regular short course or something I couldn’t pay for it myself”

P3 “I would like to see more leisure and self-care activities incorporated into the parent support group I attend. I’d love to do more art and music and go to a film or out for dinner now and then. It’s a different type of support to talking about your children and how to cope and....when you think about it it’s just as necessary to

have a place where you can stop being a carer and stop talking about being a carer!
And do other things that pick you up”

P5 “I found out about the program through my friend who was in the first group. There needs to be a central liaison set up to find leisure opportunities in different suburbs, and new programs like the Me Time program, so that we could know what’s out there. And it would be great if you could call a central place and find out about creative arts activities for ourselves and our kids and for whole families all together”

P6 “It would be great if the facilitators could offer to sign you up to other community creative arts and leisure services to follow through with the various activities – because if it’s too flexible or a choice, or have to arrange it yourself, at the end too many things get in the way”.

P8 “I worry leaving my son in respite. At the last place where I have just removed him from, the ratio of staff to care-recipient is so poor. So it would be good if there was an ongoing program with an organised respite program attached for your child”

Program content and structure

P⁺2 “It would be great if there was a program for mums and a similar one for kids running separately but at the same place and same time. Then you know that your child is close and engaged in meaningful activity and you could all come together at the end”.

P⁺8 “In future I think it’s important to ask people about what they may like to do... Like you could do a survey after the initial five-week trial of all different activities and find out what activities people want more of and what other options people may be interested in and incorporate these other chosen activities into the program. I mean if were up to me the whole program would be theatre sports and drumming!”

P1 “If the program was ongoing I would like there to be a greater emphasis on physical exercise as it would make me do it”

P2 “Ongoing but in chunks, for example once during the semester with a break in the middle as the time commitment is difficult, but knowing that you were going to see the same people again next time would be nice, especially since we got to know each other and soon the program was over”.

P4 “Activities were all a great choice, and the modulators [facilitators] were all very good and considerate”

P8 “In my opinion the composite structure of the group is important, in particular the differences in disabilities, like respite or full-time care, and whether or not you have other commitments like I do ... which meant that I had a little trouble relating to other mothers, so having groups of people that are a little more similar would help”

Location, timing and continuity of the program

P⁺1 “I would like to come to the program more often, with the same people running it, and make it more widespread”

P⁺2 “Huge need [to make the program ongoing]... it’s infinitely great”

P⁺3 “It was really enjoyable, well run and I would love to participate again if it was possible”

P⁺4 “Having it fortnightly would be better as I wasn’t getting other things done, like the shopping and other errands. It may have also been better if it was in a better location to me, or started earlier in the day because as it was it took most of the day for me with travel time, and then waiting after school drop off for it to start”

P⁺5 “If it was ongoing, I wouldn’t be as likely to do it, not continuously because ongoing would be too hard juggling what I do in a week. I think if you just commit to the course of a given time frame its okay, you know just stints of time is okay. And then if you can come back at some time when it suits you it would be good, but weekly would be too hard...monthly would suit me...yeah that would be easier... I could plan around it more in advance”.

P⁺6 “Distance to get there was difficult, may be if the program was offered at different times in different locations for all the sessions then you may get one which is not too far away. Also, more information and options to commit to ongoing programs so that it all doesn’t get lost when you get back to you own life”.

P⁺7 “It was a great broad taster of a variety of things...yes I would definitely be keen to do it on a regular basis if it was organised and provided in the same format”

P1 “I would love to do this on a regular basis!”

P2 “Yeah I’d do it and I also know of a few other mums who would want to be involved”.

P3 “I would like to be in the loop if it becomes ongoing. I would have to see what’s going on and what the situation is at that time, but yes, I would really want to be involved again... it really was a good idea”

P6 “It was a great experience and I really enjoyed it I would recommend it to all mothers”

P7 “It would have been great to have it closer to home”

P8 “Look...ideally I would like the program to be on at different times, with a choice to have it after hours, when your caring and work commitments don't impact as much”.