“There is life after diagnosis”: Dementia, leisure, and meaning-focused coping

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ABSTRACT

While dementia research has tended to focus on the area of caregiving for the person with dementia, less is known about how individuals living with memory loss access and use leisure to cope and adjust upon receiving a diagnosis. Limited research demonstrates that despite negative discourse surrounding dementia, persons living with it find creative ways to cope with change. Indeed, several positive outcomes associated with a diagnosis of dementia have been identified. However, the role of leisure in meaning-focused coping among persons with dementia has not been considered. Interviews, participant observation, and photovoice with four persons with early stage dementia revealed that leisure contributed to five aspects of meaning-focused coping, including benefit finding, benefit reminding, adaptive goal processes, reordering priorities, and infusing ordinary activities with meaning (Folkman, 2008). The findings highlight the importance of leisure participation for coping in positive ways after diagnosis, and as such, are relevant to leisure service providers in understanding the abilities of persons with dementia and how leisure is used to cope with the changes accompanying diagnosis.

Keywords: Dementia, leisure, meaning-focused coping, positive emotions
Introduction

We reside in a global village, with an aging population (MacNeil & Gould, 2012). By 2050, 16% of the world’s population will be over 65 (United Nations, 2005). As individuals age, they are confronted with conditions that may impact their involvement in leisure opportunities (McGuire, Boyd, & Tedrick, 2009). Along with population aging, the incidence of dementia is also increasing. According to the World Health Organization (2012), 7.7 million people are diagnosed with dementia each year, with 35.6 million people affected by dementia. While researchers have extensively considered caregiving for persons living with dementia and implications for leisure (e.g. Carboneau, Caron, & Desrosiers, 2011; Stevens et al., 2004), less is known about persons living with memory loss and how they use leisure to cope and adjust to the diagnosis and accompanying changes.

The growing body of research exploring the subjective experience of memory loss provides insight into what it is like to live and cope with an illness causing dementia. Indeed, persons with memory loss report many creative ways to cope with dementia (Beattie, Daker-White, & Gilliard, 2004; Clare, 2002; Gillies, 2000; Phinney, Chaudhury, & O’Connor, 2007; Preston, Marshall, & Bucks, 2007; Van Dijkhuizen, Clare, & Pearce, 2006). Furthermore, leisure researchers have begun to consider the role of leisure in developing positive emotions to aid in coping with stress (Hutchinson, Yarnal, Stafford-Son, & Kerstetter, 2008). The role of leisure in coping with memory loss, however, is currently less clear, although leisure continues to be valued among persons living with memory loss (Genoe & Dupuis, 2012; Phinney et al., 2007). Persons with chronic illnesses and disabilities often use leisure to cope with negative life situations (Hutchinson, Loy, Kleiber, & Datillo, 2003; Kleiber, Hutchinson, & Williams, 2002; Kleiber, Reel, & Hutchinson, 2008), but how this plays out in the dementia context is unclear.

In this article, I consider the role of leisure in meaning-focused coping. This theory suggests that both positive and negative emotions can occur when coping with a particularly stressful situation (Folkman, 2001). Tugade (2011) notes that capacity to experience positive emotions is vital for successful coping. Indeed, evidence is growing regarding the benefits of positive emotions in dealing with stress, such as bereavement (Tugade, 2011). Furthermore, leisure itself is associated with positive emotions and pleasure (Carruthers & Hood, 2004; Kleiber, 1999; Hutchinson et al., 2008; Liechty, Ribeiro, & Yarnal, 2009), particularly since it is freely chosen and meaningful, and involves active engagement with the environment (Carruthers & Hood, 2004; Hutchinson et al., 2008; Watson, 2002). Leisure researchers have highlighted the ways in which older adults with chronic illness reconstruct leisure, noting positive feelings were associated with adapting to leisure constraints and developing support networks with other older adults. Ongoing adjustment to leisure constraints can lead to positive change (Kleiber, Nimrod, & Hutchinson, 2011).

Similarly to Kleiber et al.’s exploration of chronic illness, there is evidence that living with dementia can also have positive outcomes. Persons with dementia report meeting new people, spending more time with loved ones, greater sensitivity towards others, new interests and sources of meaning, being more open, no longer worrying about less significant things, greater determination, more focus on what brings one enjoyment, and appreciation of what one still has (Beard & Fox, 2008; Genoe, 2009; Genoe & Dupuis, 2012; Preston et al., 2007). As such, this research will explore how leisure can contribute to positive emotions while coping with memory loss.
Coping with memory loss

Persons living with memory loss experience many changes. They may experience changes in memory, body, temporality, spatiality, and relationships (Beard, Knauss, & Moyer, 2009; de Witt, Ploeg, & Black, 2009; Phinney & Chesla, 2003; Truscott, 2003). Mitchell, Jonas-Simpson, and Dupuis (2006) note that persons living with dementia experience bewilderling absences, such as forgetting important events, familiar information, or how to take a familiar route home. Persons with memory loss feel uncertain about themselves and their behaviour as symptoms fluctuate (Phinney, 1998). The world can seem overwhelming as rhythms slow down (Mitchell et al., 2006). Conversation slows down and persons with dementia feel scared when they cannot remember things (Phinney & Chesla, 2003). Doing simple tasks can be tiring, and when fatigue sets in, thinking and speech slow down even further (Truscott, 2003). These changes can impact not only enjoyment of activities, but also self-esteem and self-concept, which are further eroded by communication difficulties, functional losses, and shifts in independence and autonomy (Gillies, 2000; Snyder, 2001).

Despite changes, persons living with memory loss find many ways to cope. Lazarus and Folkman’s (1984) Cognitive Theory of Stress and Coping provide researchers with one way to consider coping with memory loss. The model presents an appraisal-based method of coping. When a stressor, such as being diagnosed with a chronic illness, is experienced, the individual appraises the stressor to determine its significance. If the stressor is thought to be significant, the individual then considers his or her options for coping (Folkman, 2008). The individual may engage in problem and/or emotion-focused coping in response to the demands of the situation or event. In problem-focused coping (or active coping), individuals define the problem, generate possible solutions, weigh and choose from alternatives, and act upon their decision. In emotion-focused coping, individuals use strategies such as avoidance, minimization, distancing and positive comparisons to cope with stress. Emotion-focused coping can also include reappraising a situation.

A number of practical strategies have been identified that reflect problem-focused coping among persons living with memory loss. These include using calendars, lists, word associations, reminders from others, formal and informal support, navigational devices, and staying busy (Beard et al., 2009; MacQuarrie, 2005; Parsons-Suhl, Johnson, McCann, & Solbert, 2008 MAREP, 2007a, 2007b, 2008; Preston et al., 2007; Van Dijkhuizen, Clare, & Pearce, 2006). Following a routine can contribute to feelings of normalcy (Clare, 2002; MAREP, 2008). Relying on a care partner for reminders is also common, although some are concerned about becoming too dependent on their partner (Clare, 2002; Gillies, 2000; Preston et al., 2007; Van Dijkhuizen et al., 2006). Feeling familiar with the environment is a useful coping mechanism, since practiced skills and routines can help overcome difficulties (Van Dijkhuizen et al., 2006). Although such strategies can fail, they are valued for their ability to maintain or improve self confidence (Clare, 2002).

In addition to these problem-focused strategies, persons with dementia draw on emotion-focused coping. For example, persons with memory loss report maintaining a sense of humour, making the best of things, sharing with others, creating and/or sustaining relationships, relinquishing difficult activities, attending support groups, minimizing or avoiding challenges, normalizing, adopting a positive attitude, and reminiscing to cope (Beard & Fox, 2008; Beard et al., 2009;
Clare, Rowlands, Bruce, Surr, & Downs, 2008; Genoe & Dupuis, 2012; Harris & Durkin, 2002; MacQuarrie, 2005; Parsons-Suhl et al., 2008; Preston et al., 2007; Snyder, 2001; Van Dijkhuizen et al., 2006). Removing pressure from oneself by being aware of limits, focusing on strengths, protecting oneself from and taking time away from stressful situations are other useful coping strategies (Preston et al., 2007). Furthermore, persons with dementia reframe their situations to cope. Some people reframe by hoping that memory loss will improve. Others choose not to worry about the changes (Clare, 2002). Being aware of limits, focusing on strengths, and taking time away from stressful situations are other ways persons with memory loss can reframe their situations (Genoe, 2009; Preston et al., 2007).

Maintaining normalcy is another valued means of coping with memory loss (Beattie et al., 2004; Genoe, 2009; Menne, Kinney, and Morhardt, 2002; Phinney, 1998). For example, people attending a day program wanted to engage in activities that were age appropriate and that they enjoyed prior to diagnosis, such as going out for lunch or attending museums (Beattie et al., 2004). Similarly, Phinney (1998) found that people living with Alzheimer’s disease were concerned about how they could continue to live as they had before being diagnosed in order to diminish the impact of the changes they are experiencing. They did so by monitoring their failing memory and by keeping an active mind to stay on top of the disease. They continued to stay engaged in the world in order to feel as though life is normal and meaningful. Downplaying the disease and interpreting the experience in the context of growing older helps some persons with dementia to feel “normal” (Clare, 2002; Gillies, 2000; Phinney, 1998). Engaging in everyday activities, like completing household chores, continues to be valued, even when assistance is needed from family members (Genoe et al., 2010, Phinney et al., 2007). Rather than give up such tasks, persons with dementia “…emphasized how much it mattered to them to be able to continue in these kinds of activities, even if it meant they had to use different strategies than before” (Phinney et al., 2007, p. 387).

The current research exploring coping and living with memory loss suggests that people with early stage memory loss appraise their situations and draw on both problem- and emotion-focused coping to meet the demands of the situations. However, meaning-focused coping, which is triggered if the stressful situation is not resolved (Folkman, 2008), has not been considered.

**Meaning-focused coping**

Defined as “…appraisal-based coping in which the person draws on his or her beliefs, values, and existential goals to motivate and sustain coping and well-being during a difficult time” (Folkman, 2008, p. 7), meaning-focused coping provides insight into how positive emotions can occur alongside negative emotions during extremely stressful experiences. Even mild and fleeting positive emotions can have a long term impact on individuals (Tugade, 2011). Folkman discovered that care partners of men with AIDS unexpectedly reported high levels of positive psychological states through caring and bereavement. Based on this finding, Folkman adapted the stress coping model to address meaning-focused coping. Folkman (2008) presents five aspects of meaning-focused coping. The first, benefit finding, refers to the discovery of benefits to coping with stress, such as growth in wisdom, greater appreciation for life, and improvements in the quality of relationships. Longitudinal research indicates that benefit finding contributes to long term health benefits. Persons who have experienced a stressful event or threat to health report benefits such as wisdom, greater feelings of empathy and forgiveness, and strengthened
relationships (Tennen & Affleck, 2002). The second aspect, benefit reminding, is not dissimilar to benefit finding (Folkman, 2008). Benefit reminding refers to the ways in which one reminds oneself of the possible benefits that may result from a stressful situation. Reminding oneself of the benefits can lead to a better mood (Tennen & Affleck, 2002). Adaptive goal processes are a third strategy for meaning-focused coping. This occurs when people recognize that former goals are no longer appropriate and replace them with new, meaningful goals. This may reduce stress that results from the inability to attain an old goal. Fourth, reordering priorities occurs when people recognize that priorities change; some priorities become more significant while others are deemed to be less significant. Finally, Folkman (2008) suggests that meaning-focused coping can occur by infusing ordinary events with positive meaning. A positive event, such as watching a movie or receiving praise, can be particularly meaningful when dealing with stressful events.

As Folkman’s research focused on caring within the context of AIDS, how meaning-focused coping plays out within dementia is unclear, yet such knowledge could expand our understanding of contradictory emotions in dementia and provide a deeper understanding of how coping occurs in the dementia context. Limited research highlights the potential of meaning focused coping for persons living with dementia and begins to explore how positive feelings are created in dementia. Coping with dementia involves balancing abilities and losses (Keady, Williams, & Hughes-Roberts, 2007; Pearce, Clare, & Pistrang, 2002; Steeman, Godderis, Grypdonck, De Bal, & De Casterle, 2007). Focusing on the positive aspects of life and minimizing losses helps to balance feelings of being devalued, lonely, uncertain, shameful, and useless (Steeman et al., 2007). Furthermore, research exploring positive emotions and coping among women belonging to the Red Hat Society (Red Hat Society emerged about 20 years ago for women over fifty to celebrate being over 50 to have fun) suggests that leisure may provide an ideal space for meaning-focused coping, particularly in terms of re-appraising goals and creating positive psychological well-being (Hutchinson et al., 2008).

Purpose

The research set out to explore the meaning and role of leisure in the lives of persons living with memory loss (see Genoe & Dupuis, 2011; Genoe & Dupuis, 2012). Through data collection and analysis, it became apparent that leisure was important for coping with memory loss in positive ways. Meaning-focused coping was clearly reflected in the findings. Therefore, in this article, I discuss how leisure contributed to meaning-focused coping for persons living with early stage memory loss.

Methods

Four participants were recruited from local chapters of the Alzheimer Society and the Murray Alzheimer Research and Education Program (MAREP) in Southwestern Ontario. Two men and two women living with early stage memory loss agreed to participate in this study. Alice, Charles, Jack, and Rita ranged in age from 59 to 82 and were all living in the community. Alice lived alone, and the remaining three lived with their spouses. They had been diagnosed between 1 and 4 years prior to the first interview. Alice was diagnosed with multi-infarct dementia and Alzheimer’s disease, while Charles, Jack and Rita were diagnosed with Alzheimer’s disease.
Data were collected in three ways, including the long interview, participant observation and photovoice. The long interview is a series of interviews that explore lived experience (McCracken, 1988). This method of data collection was particularly useful as participants occasionally experienced fatigue. Scheduling multiple interviews allowed for follow up and for taking a break between discussions. Participants engaged in four interviews. The first interview was designed to build rapport and get to know the participants and their experiences with memory loss. The second interview explored their leisure experiences more specifically, and the third interview allowed for follow-up and further discussion around the participants’ experiences with memory loss and leisure. Finally, consistently with phenomenology, in the fourth interview, I shared a draft of the findings with the participants to confirm whether or not the findings reflected the participants’ experiences. All participants felt that the findings were reflective of their experiences.

As McCracken (1988) suggests that the long interview by itself is not adequate for data collection, I also used participant observation to collect data. I participated in leisure activities along with the participants on one or two occasions for one to three hours each. Sensitizing concepts (Patton, 2002) were used to record notes immediately following each session. These concepts included the physical environment, social environment, physical appearance, affect, body language, social interactions, and involvement in the planned activity. The participants and I engaged in a variety of activities together, including games, crafts, walking, and golf.

Finally, data were collected using photovoice (Wang, 1999). I gave participants cameras and asked them to take photos of objects and subjects important for their leisure. These photos were then developed and used to guide discussion in our second interview (for further discussion of the photovoice process, please see Genoe & Dupuis, 2011; Genoe & Dupuis, 2012).

All data were analyzed following van Manen’s (1997) detailed line by line analysis. Data were read multiple times to get a sense of the lived experience as a whole. Then, each sentence was read while considering what it revealed about the phenomenon being described and key statements were underlined. As they emerged, themes were noted in the margins of transcripts and field notes. Next, themes were compared across transcripts and field notes for commonalities and differences and overall themes that best described the lived experience were identified (Hallldórsdóttir & Hamrin, 1997; van Manen, 1997). Descriptions of the themes and their relationships continued until the experiences of the participants were accurately captured (Parsons, 1997).

**Findings**

Data analysis revealed that participants encountered many challenges, yet they felt a great deal of hope about their present and future lives. In the following paragraphs, a brief outline is given of the negative emotions that participants felt as a result of the challenges and losses they faced, after which the authors will explore how leisure contributed to each of Folkman’s (2008) five characteristics of meaning focused coping for the participants.
As a result of both cognitive changes associated with dementia and negative attitudes towards the disease, participants experienced muddled thinking, fluctuating abilities, and disquieting emotions (Genoe & Dupuis, 2012). Valued skills and a sense of independence were threatened. Once routine tasks became difficult:

…like when I go to write some ah, thank you cards to some people who have done something for me I have to write it in a piece of paper, write it twice. Get out the usually get out the umm, um, ah um, dictionary to see if I’m spelling it right. I know the word I want, but I can’t really write it all the time. So I write it out three or four times, and then I put it in the card, and the card sometimes I’m writing along and I’m dropping letters so I have to do two cards. And that little thing makes me feel really upset because I used to be able to just scribble it off and put my name on it and get it done. I can’t do that anymore. (Jack)

Others viewed participants differently when they learned of the diagnosis and occasionally treated them as though they had very few remaining abilities:

I would say “Let me do the dishes” you know or “Let me set the table”, and she’d say “No no you just go sit down.” And I find that an irritation because I’m thinking you’re saying I’m not able anymore and those are things that you can do, you know. (Rita)

As a result of these changes, participants experienced feelings of embarrassment, frustration, and grief. Charles spoke of feeling embarrassed: “I’m embarrassed because I don’t know what to talk about. I can’t remember things that are happening to talk about, and so, one because I don’t read the paper I feel ignorant”. Rita talked about being nervous about having a conversation:

Um…I don’t know, I think um, I have a hesitation if I, if I feel that I can’t carry on a conversation with somebody because of forgetting names and that. And um but that’s the only thing I worry about is maybe being in a group and feeling kind of stupid because I can’t remember their names or something, you know. (Rita)

All participants were worried about feeling depressed: “Um the mood swings are incredible, and because I’ve had past depressions, it’s so easy to slip into a depression again. I have to be cognitive of that. And there’s many days I feel lost and want to give up” (Alice); Rita stated: “…I don’t want to ever get, I’ve had a fear when I’ve seen people who get down, and get depressed, I’ve had a few that I don’t ever want to get like that…”. Charles similarly stated: “I don’t ever want to get into depression. A deep depression.”

In keeping with meaning-focused coping, participants experienced many positive emotions alongside these negative emotions. Participants reported feeling a great deal of hope for their lives, for the present and the future. They continued to engage in meaningful activities, they started new activities, and spent time in leisure with family and friends. Participants used leisure
to replace lost roles and continue to be themselves despite the changes. They focused on the positive aspects of their lives, their remaining abilities, and celebrated their accomplishments instead of focusing on their losses and changes (Genoe & Dupuis, 2011; Genoe & Dupuis, 2012), for more information related to these findings), while acknowledging the day to day challenges of living with memory loss and their fears of the future:

Like each, each few months it seems to be steadily losing a little bit. And that is very sad. I can still do certain things, but it’s becoming more and more difficult. So that’s…that’s frustrating and sad. But….what keeps me going….are all the other things in my life. And I look at that when I have the sadness of not being able to complete a project, or to do something, I now turn that sadness into reaching out for assistance. Or lowering my expectations of what I can accomplish. I can decrease the sadness…into a more positive emotion… (Alice)

In the above quote, Alice explained both the positive and negative emotions she experienced as she coped with dementia. Further consideration of the findings revealed that leisure played a role in sustaining positive emotions alongside the negative ones. Through participation in meaningful leisure, persons with dementia experienced the five aspects of meaning-focused coping: benefit finding, benefit reminding, adaptive goal processes, reordering priorities, and infusing ordinary events with meaning (Folkman, 2008).

“It has opened up a whole brand new field of excitement”: Benefit finding

Benefit finding is the most frequently reported aspect of meaning-focused coping and is evident in personal growth, greater appreciation for life, and improved relationships (Folkman, 2008). Participants identified several benefits to living with memory loss while acknowledging the challenges. They found their relationships were improved, they had a greater appreciation for life, they focused on their remaining abilities and opportunities, and were proud of their ability to adapt. For example, Alice talked about having the opportunity to learn how to use a computer after diagnosis: “It has opened a whole brand new field of excitement. And a big accomplishment for me personally.” Alice noted that she may not have learned to use a computer had she stayed in the workforce. She valued her ability to use her computer for engaging in mentally stimulating games, as well as being able to connect with family and friends and to communicate with others about her advocacy work.

Some participants found that coping with dementia gave them the opportunity to share their experiences with others to help them in ways they could not have done without a diagnosis. They found benefit in being able to provide advice or guidance for care partners and other persons living with dementia:

“I feel that it probably helps you and I know it helps me feel useful for other people who are having the trouble of it and how they react…it sort of makes me feel good because some of them want…to know about it you know…” (Jack)
“There’s a lot you can do”: Benefit reminding

In addition to benefit finding, participants engaged in benefit reminding. Benefit reminding differs from benefit finding as participants made the effort to remind oneself of the benefits during a stressful situation (Tennen & Affleck, 2002). Despite feelings of grief, frustration, and fear that the participants felt as they frequently faced new challenges, participants reminded themselves of possible benefits that might result from a stressful situation, such as personal growth and the chance to plan for future change, instead of focusing on the negative aspects of living with memory loss. For example, Jack felt that a diagnosis of dementia was preferable to other illnesses as it gave himself and his family time to prepare and make decisions about the future:

The most important thing is to find out as much as you can as soon as you can when you find out you have dementia. Because that gives you the opportunity to for at least for your caregiver and everybody else that you are with to know that it isn’t something that is going to happen tomorrow.

Jack spoke about being able to plan ahead for moving into long term care. “I want to be in the long term [care facility], before, before I really need it. I’d rather be there ahead of time instead of after until it was too late to be a half decent guy.”

Participants reminded themselves as well that they experienced personal growth by having to figure out how to cope with the changes. For example, Alice talked about learning to ask for help, something she was unwilling to do before. While asking for help threatened her values, she reminded herself that doing so was a sign of personal growth as she acknowledged her own experience with dementia: “I am now asking for assistance. And a proud person like me admitting that, yeah, it’s time, is a big acknowledgement on my own self, of my, of knowing myself.”

Alice explained how engaging in leisure in particular helped her to remind herself of the benefits of having to cope with memory loss. Alice enjoyed working on jigsaw puzzles to challenge herself, but completing a puzzle meant so much more:

That I have patience, persistence, drive…ability to adjust to what the journey’s doing to me at that particular moment. Um, adapting…seeing beauty in it. And it also indicates, even though you’re living alone, there’s a lot you can do. With self motivation. I think that’s one thing it shows, persistence, self motivation. (Alice)

Reminding herself of her ability to complete a puzzle led to reminders about her strengths in coping with dementia.
“Instead of what I can’t do, it’s what can I do”: Adaptive goal processes

As memory, orientation, and communication abilities changed, participants found it more difficult to complete tasks once thought of as routine. They gave up driving and found it difficult to handle money. Using technology, such as programming the DVD player, became more challenging. Adaptive goal processes were used to replace inappropriate goals with new, meaningful goals, thereby reducing stress resulting from inability to attain an old goal (Folkman, 2008). Participants adjusted their goals as their abilities changed, making them achievable, and participation in meaningful leisure activities, although altered, continued:

I have to pick out the things that I’d really like to do that are within my capabilities. Because if I do that, then I achieve the maximum of happiness and pleasure. But if I try to pick out something that’s beyond my ability to understand or to enjoy, it will not give me that fulfillment….So I think that’s really a key element too, is realizing what you can get the… most for the buck. (Alice)

Focusing on abilities and strengths allowed participants to adapt their goals with relative ease. Instead of giving activities up, they altered them to prolong participation as abilities changed: “Instead of what can’t I do, it’s what can I do. How can I change what I’m doing, adapt it, so that I can go further in this activity?” Goals shifted from a focus on competition to a focus on practice or cooperation. Jack stopped participating in competitive darts, and practiced on his own instead, focusing on his hand eye coordination rather than winning the game: “I don’t play in…the league anymore, I just go and practice, practice, practice throwing darts at the dart board…”. Choosing a less challenging activity also led to success. For example, Rita chose an easier card game instead of bridge:

Uh, no it’s a very easy game we play and she plays bridge a lot, and I keep asking her to show me how to play it and she says it’s very complicated, you know. And I don’t think I’d really want to play it, you know. I like the easy ones.

Charles and his wife once spent a great deal of time walking. As that became more difficult for Charles, they made use of walking poles to assist with his balance. This made walking pleasurable for Charles and negated the need for a cane. By adapting their fitness goals to include pole walking, whether indoors or outdoors, Charles was able to continue in the activity:

“And pole walking is easier…than walking in some senses because you’re using all four limbs. And um, going up and down a hill it’s easier with poles than it is without”.

Doing one’s best, rather than achieving a particular level, winning a game, or demonstrating a particular skill the right way, became more important, and helped participants to cope with their changing abilities: “And I would think it would be more right to make sure you are doing the best you can. Like I tell everybody ‘I’ll do it the best I can and I know it will be
rough enough’, you know. I use that all the time.” (Jack). Being flexible in goal setting was also important for coping with the changes:

Alice mentioned that she would like to try to crochet a dishrag for each bag for the conference. I asked how many that would be and she told me it would be 200. I said that’s a lot of crocheting and she said she just wouldn’t tell anybody until she got closer to that number so if they didn’t get done, that would be okay. (Alice, participant observation field notes)

Participants adapted their goals in a variety of ways. Being flexible and open to new, meaningful goals allowed them to focus on their abilities and strengths instead of dwelling on their losses.

“Let’s do it while we still can”: Reordering priorities

Reordering priorities is a value-based process that may or may not be deliberate (Folkman, 2008). As abilities and roles changed within the participants’ journeys of memory loss, they began to re-order priorities, focusing on particularly meaningful activities and dropping less significant activities or those that had become too difficult. Jack explained the importance of prioritizing the things he loved to do:

So I’m going to live it to the best I can. And if somebody asks me a question, “What should I be doing to make my life better in, in because of Alzheimer’s?” I would say “Enjoy it, do it, do the best you can and, and enjoy every moment of it and don’t procrastinate, don’t think you should be doing it tomorrow, do it today…”

Participants prioritized activities that they might not be able to engage in for much longer, such as travelling, or fulfilling particular dreams like attending a concert of a favorite singer. Charles noted that since he may have to give up travelling soon, he wanted to do it while he still could: “I think my traveling days are coming closer to an end, and we’re sort of saying let’s, let’s do it while we can”. Similarly, Rita talked about how much she enjoyed attending a concert by her favorite singer:

I love to go out, I love to, to, like I said this thing with Anne Murray was a real highlight for me it was great, and ah my daughter said to me the other day…she says dad was in to the office to talk to them, they’re just down the road and she says your mother was just like a little kid going in there (laughs). She was bouncing around there, she keep hitting me on the arm (laughs). And ah, I was really excited that night, and those kind of things are great, so…

Particular leisure activities were prioritized over others because of the meaning and enjoyment derived from them. Charles loved to read and made sure to devote a significant amount of time each day to that activity. Jack loved to golf, which motivated him to start his day: “Every
morning I get up and think ‘What can I do today?’ …and then I go out and play golf and that makes it get up and go.”

Mentally stimulating and physical active leisure were prioritized over other activities because participants believed strongly that these types of activities would help maintain their abilities and independence:

And I’m doing everything that I know to do, like playing electronic games and reading I feel is very good for me mentally. And walking and um…and exercise is very important for my Parkinson’s. So I’m doing all I know to do in terms of being able to keep going. (Charles)

For example, Alice played computer games when she woke up in the morning to kick-start her brain: “But that’s one of the things in the morning that’s key to me, um…getting my mind active because when I first wake up I’m really lost.” Mentally stimulating activities, including puzzles, dice games, card games, and word games were prioritized even as they became more and more difficult:

The reason I do that [keep trying a computer game that is becoming more difficult] is it still gives me hope. That one day I might conquer. A different level, a different way. It may trigger a recall of something or it may trigger something more positive. And it’s the sense of the stubbornness not wanting to give up. (Alice)

Physically active activities, including walking, golfing, and stretch and balance classes, also took precedence.

If it wasn’t for being active…I probably wouldn’t be as well. With the health, that I am. And I think that everybody has, has to try and, try and …get better and better and better. And, because sometimes, you’re not going to be able to get out of bed, or something, and that’s what we’re trying to do. (Jack)

Although these activities could be frustrating as abilities changed, participants continued to prioritize them in order to sustain what they highly valued – their remaining abilities and independence.

Some activities and tasks were dropped in favour of those that were prioritized, particularly if they were becoming more challenging. Jack gave up sailing and focused on golfing. Alice shifted her priority from working for a living to working in leisure to maintain her independence. Charles changed his priorities from speaking out in prayer group to listening to prayer group: “Well they used to ask me to lead in prayer or do something say something in public maybe. Um it wasn’t a big problem, it is, it is now, and I just say I can’t do it”. Although participants were able to reorder priorities, Folkman (2008) notes that doing so can be stressful
when meaningful goals and activities must be given up. Acknowledging that one must adjust one’s priorities requires acceptance that things have changed. However, being able to recognize changes in one’s priorities is necessary for finding ways to move forward (Folkman, 2008).

“Even the weeds look pretty”: Infusing ordinary events with meaning

Folkman’s (2008) final aspect of meaning-focused coping, infusing ordinary events with meaning, was particularly poignant as participants faced challenges and losses daily. Finding meaning in every day events and activities allowed participants to focus on the positive aspects of their lives, rather than dwelling on their losses. Participants noted the importance of acknowledging bad days and grieving losses, which inspired them to work hard to avoid feeling depressed. Furthermore, bad days emphasized the joy and meaning that came with good days, spending time with loved ones, achieving new goals, and having fun:

But it’s not all a bed of roses. There are those down days too. And those down days are very intricate part of the disease process, but they have to be, you have to allow yourself to have them, for me personally, I allow myself to have them because then I appreciate the good times more. (Alice)

Alice went on to explain her new appreciation for everyday pleasures: “The little things mean more and are much more significant. Because when you’re, when you don’t have a problem with your memory you take things for granted and now every little thing, like even the weeds look pretty…”

Spending time with loved ones became more meaningful, as did accomplishing previously taken-for-granted tasks, like completing a puzzle. Having an invitation to go out with friends was valued highly:

Um, I know if a friend calls and says would you like to go to the show…I just jump to anything that’s outside of here you know (laughs)…I do enjoy a sunset, I do enjoy things like that very much, or a good movie…(Rita)

Charles spoke about how engaging in his favorite leisure activity, reading, meant more to him after diagnosis:

I allow myself to do the things that I enjoy doing without feeling guilty about it in any way. Um, the reading is a good illustration of that, spending as much time as I do and also having the mechanism to make it comfortable, and yeah, in those days I can continue to enjoy what I was doing before, and sometimes some new ways, leisure.

Accomplishing goals that were once simple became much more meaningful. Jack spoke about feeling good when he completed a jigsaw puzzle: “And, and, and then finally when you put that
last piece in, jeez it feels good”. Similarly, Rita spoke of feeling accomplishment when finishing a crossword puzzle: “And you get a great sense of uh, strength when you realize you’ve done right” (Rita, Interview 2). Alice talked about how important acknowledging accomplishments became when they were more challenging:

When it happens, it’s like a party time. Like we’re going to have a big debutante ball tonight because I got this done. After this number of weeks, I finally accomplished this. Yeah. So, it’s celebrating the, umm…accomplishments is ah, is actually a celebration. Because, I don’t know if two weeks from now I could do it again, so why not enjoy the moment?

Through leisure, participants experienced all five aspects of meaning-focused coping, helping them to manage and live with the changes that memory loss brought into their lives.

**Discussion**

Jack, Alice, Charles, and Rita engaged in meaning-focused coping and, in doing so, experienced positive feelings along with the frustration, embarrassment, and grief that resulted from the stress and loss of living with memory loss. Focusing on positive aspects of their illness led to a cycle of increased ability to cope with change and loss. This cycle included five components (see figure 1): The first component, engagement in meaningful leisure, resulted in positive emotions and served as a reminder to participants that they were able to cope with the many stressors that they faced. This flowed into the second component of the cycle, in which participants found meaning in life with memory loss, particularly when leisure engagement led to feelings of independence, contribution to others, and time spent on priorities and meaningful goals. Third, participants recognized their ability to cope and thus feel hope for the future, which led to increased motivation to engage further in meaningful leisure. This, in turn, resulted in increased confidence in their ability to cope with memory loss and sustained feelings of hope for their futures, despite their acknowledgement that the future could be very difficult.
Jack, Alice, Charles, and Rita identified benefits of having to cope with memory loss, particularly in terms of a greater appreciation for life and positive relationship changes. They gained feelings of competence as they learned how to cope with the changes they were experiencing, which they also deemed to be beneficial. This is in keeping with Folkman’s (2008) suggestion that when a stressful situation is ongoing rather than resolved, as is the case with dementia, there is “…a co-occurrence of positive emotions generated by benefit finding and the negative emotions associated with the unwanted outcome” (p. 8). These positive states can assist with problem focused coping by affording people with the opportunity to consider negative information and choose which problems to solve. For example, Alice considered her diagnosis to be a blessing in some ways because it allowed more time for leisure. As well, having bad days resulted in greater appreciation of better days. Furthermore, reminding themselves of these benefits helped participants feel more positive about their situations, particularly on difficult days. In acknowledging both gains and losses, participants were able to adapt their goals and reorder their priorities, dropping more challenging activities and goals, and replacing them with achievable goals. While acknowledging losses, participants focused their thoughts and efforts on remaining abilities and achievable goals to avoid experiencing greater negative emotions, as they worried that too much grief would lead to depression, and would, in turn, exacerbate memory loss.

These findings contribute to our understandings regarding the experience of memory loss and the creative ways that people cope with it as they work to balance their losses with remaining abilities. For example, Beard et al. (2009) found that persons with dementia experienced “rough spots” (p. 229), but got through them by using a variety of coping strategies, including both problem and emotion-focused coping. In fact, keeping busy helped their
participants to cope with the “rough spots”. Removing oneself from a stressful environment allowed for refocusing on positive things. Similar to the participants of the current study, Beard et al. found that persons with memory loss coped by re-evaluating expectations, avoiding or leaving stressful situations, and accepting their situations. Choosing to have a positive attitude and engage in a variety of physical, social and cognitive leisure activities leads to “an enriched life” (Beard et al. 2009, 232) with dementia. Likewise, in this study, active engagement in leisure and the subsequent cycle of positive feelings and increased confidence and hope about the future contributed significantly to living an enriched life with dementia. Leisure participation facilitated engagement with their environment, thereby contributing to positive feelings (Carruthers & Hood, 2004). Focusing outside of oneself led to positive moods and interactions with the environment instead of focusing on challenges and losses.

The current findings also contribute to our understandings of the role of leisure in coping with chronic illness. Kleiber et al. (2011) identified several ways in which older adults with chronic illness reacted to leisure constraints. These included allowing for mourning, appreciating what one still has, and realizing that things could be worse. Changing aspirations in leisure helped those with chronic illness adjust. Similarly, in this study, participants acknowledged their losses in order to move forward, found meaning in remaining abilities, and appreciated what they still had. Reframing and adapting to leisure constraints may be part of meaning-focused coping, particularly when adjusting goals and focusing on remaining capacities.

Although limited, our understanding of leisure’s contributions to positive emotions is growing, and this study contributes to the body of research combining leisure and positive psychology. For example, Hood and Carruther’s (2007) Leisure and Well-being model for therapeutic recreation practice provides an alternative lens for considering these findings. Hood and Carruthers have adopted a strengths-based approach to their model, which calls for facilitation of positive aspects of life. In terms of practice, adoption of the Leisure and Well-being model, with its emphasis on the positive emotions that leisure brings, may be particularly beneficial among persons living with memory loss who experience changes in capacity over time. Using the model in practice may encourage service providers to consider remaining strengths in planning therapeutic recreation programs and allow for enhanced leisure experiences (Hood & Carruthers, 2007). Furthermore, use of the model could promote and support meaning-focused coping long term, particularly as persons living with dementia move into long term care.

Further research is required to better understand the connections and tensions between positive and negative emotions and engagement in leisure. How meaning-focused coping plays out over time could also be explored. Going beyond the individual’s experience with memory loss to include the perspectives of family care partners and other loved ones would also provide deeper insight into positive emotions through the caring relationship.

There are other theories and models that consider positive emotions with stressful situations that may lend further insight into the role of positive emotions when living with memory loss. For example, the broaden-and-build theory posits that positive emotions can broaden thoughts and actions and in turn, help to build personal resources (Fredrickson, 1998; 2001). Researchers could explore how positive emotions enable persons living with memory loss to develop their personal resources and coping skills. The dynamic model of affect (Zautra,
Affleck, Tennen, Riech, & Davis, 2005) could also be considered. This model states that positive emotions can interrupt stress and increase ability to adapt to further stressors. This model has been used to explain positive emotions in dealing with stress (Ong, Bergement, Bisconti, & Wallace, 2006), and again could provide insight into the experience of positive emotions in memory loss.

Leisure service providers have a role to play in helping persons living with memory loss to experience positive emotions despite the diagnosis. Determining what leisure means to individual clients and helping them to identify particularly meaningful leisure pursuits could increase the ability of persons living with dementia to engage in leisure and experience positive emotions. Leisure education for persons living with early stage dementia may be particularly beneficial to identifying opportunities for meaningful leisure in one’s community and home. Furthermore, it may provide opportunities for persons with memory loss to identify novel activities that they might like to try, or substitutions for activities that are becoming more difficult as a result of memory loss. Focusing on remaining strengths abilities rather than dwelling on losses or designing recreation and leisure programs to alter behaviour should also be considered (see also MAREP, 2011). Consider innovative opportunities that reflect lifelong and newly acquired interests. For example, dementia friendly holidays may be a good way to engage in leisure that contributes to meaning-focused coping in a welcoming environment for both persons living with memory loss and their care partners (see Gibbs & Gibbs, n.d.)

Understanding how both positive and negative emotions can occur within the context of memory loss highlights the strengths and abilities of persons living with memory loss, moving away from a tragedy discourse often associated with memory loss. This study highlights the importance of engagement in meaningful leisure for experiencing positive emotions in order to cope with memory loss. Despite the stressful nature of the progressive disease, there can be “life after diagnosis” (Alice).
References


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