Canadian Journal on Aging / La Revue canadienne du vieillissement

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Addressing Caregivers' Needs beyond Respite: Enhancing Social Connections and Letting Them Know They Matter

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Article

Cite this article: Fortune, D., & Gauthier-Gilbert, A. (2025). Addressing Caregivers' Needs beyond Respite: Enhancing Social Connections and Letting Them Know They Matter. *Canadian Journal on Aging / La Revue canadienne du vieillissement* **44**(3), 403–412. https://doi.org/10.1017/S0714980825100160

Received: 21 June 2024
Accepted: 20 May 2025

Keywords:
caregiving; dementia; leisure; aging; respite; social needs

Mots-clés:
proche aidance; démence; loisirs; personnes âgées; services de relève; besoins sociaux

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Abstract

Respite for individuals caring for family living with dementia is a common way to take personal time away from caregiving. Other than respite, there is little indication that caregivers receive adequate support from community and healthcare services. As a result, caregivers tend to experience a decline in well-being, due, in part, to a reduction in meaningful leisure experiences. The purpose of this article is to share findings from research aimed at discovering ways to enhance caregiver participation in meaningful leisure. Findings highlight how participants sacrificed their leisure time in favour of caregiving responsibilities and experienced a diminished sense of social connection. Findings also highlight how participants can have their own care needs met through leisure programming that lets them know they matter. We draw from these findings to suggest ways to direct more attention and resources to meeting caregiver needs.

Résumé

Les services de relève sont un moyen courant pour les proches aidants de membres de la famille vivant avec la démence de prendre un moment de répit. En dehors de ces services, il y a peu de signes indiquant que les proches aidants reçoivent un soutien suffisant de la communauté et des services de santé. En conséquence, les proches aidants ont tendance à vivre une baisse de bien-être, notamment en raison d'un nombre réduit d'expériences de loisirs satisfaisantes. Cet article présente les résultats d'une étude visant à découvrir des moyens d'accroître la participation des proches aidants à des activités de loisirs porteuses de sens pour eux. Ces résultats montrent comment les participants ont sacrifié leurs temps de loisirs pour prioriser leurs responsabilités de proches aidants et ont vécu en conséquence une diminution de leur sentiment d'appartenance sociale. Ils soulignent également comment les participants peuvent veiller à leur propre bien-être en participant à des activités de loisirs valorisantes pour eux. À la lumière de ces résultats, nous suggérons des moyens d'accorder davantage d'attention et de ressources à la prise en charge des besoins des proches aidants.

Introduction

Family caregivers[1] of individuals living with dementia commonly experience challenges that affect their life satisfaction and well-being (Steinsheim et al., 2023). While providing care can be an important source of gratification, meaning, and personal growth (Cohen et al., 2002), the demands of caregiving have also been linked to poor health outcomes related to experiences of stress, social isolation, and depression (Cross et al., 2018).

One aspect of life particularly impacted by caregiving responsibilities is leisure time. Caregivers often experience substantial barriers to pursuing valued leisure activities due in part to a diminution of free time and loss of autonomy (Carbonneau et al., 2011; Dunn & Strain, 2001; Xu et al., 2022). Caregiving typically results in individuals participating in fewer leisure activities and experiencing an overall decline in leisure enjoyment (Innes et al., 2016). Studies have also emphasised how familial commitment may prompt caregivers to ignore their own leisure needs to prioritize the needs of the person for whom they are providing care (e.g., Xu et al., 2022).

Spousal caregivers are apt to experience a diminution of leisure experiences as they struggle to preserve their individual identities and often experience feelings of guilt when taking time for themselves (Hammar et al., 2021). The time caregivers spend engaging in leisure with their spouses living with dementia is also often impacted. For example, spousal caregivers who

[1]There are different terms used to describe individuals who care for a family member living with dementia (e.g., carers, partners in care). In this article, we use the term caregiver. We do not use this term to disregard the mutuality present in care relationships; we use it to be consistent with the term used by study participants who describe themselves as caregivers.

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participated in Di Lauro et al.'s (2017) study reported a reduction in shared leisure pursuits requiring cognitive engagement or social interaction. They also spoke about giving up leisure activities that were once mutually enjoyable, such as travel, because these activities became too cognitively demanding for their spouse living with dementia. Roland and Chapell (2015) discovered that spousal caregivers tend to assign negative meanings to leisure experiences involving their spouse because these experiences often produce feelings of anxiety and embarrassment related to what their spouse might do or say.

A reduction in leisure time has been linked to mental health challenges and lower life satisfaction among caregivers (Losada et al., 2010). Yet, studies have confirmed the importance of leisure for relieving caregiving-related stress, reducing depression, and contributing to improved psychological well-being (e.g., Bedini et al., 2018; Lee et al., 2020; Losada et al., 2010; Xu et al., 2022). Upon determining that more frequent access to, and greater satisfaction from, leisure engagement is helpful for reducing caregivers' depressive symptoms, Lee et al. (2020) recommended the provision of respite care to increase engagement in leisure.

A common way to provide respite to individuals who care for family members living with dementia is through day programs (Jarrott & Ogletree, 2019; Liu et al., 2015). When a person living with dementia attends a day program, there is an assumption that their caregiver receives respite from caregiving and has more free time for themselves (Williams et al., 2016). There is no guarantee, however, that caregivers will spend this time engaging in meaningful leisure experiences. Indeed, as Hammar et al. (2021) found, caregivers often use their respite to complete necessary tasks such as grocery shopping. Hammar et al. also found that respite provided from day program usage could be a source of stress for caregivers, particularly when day program staff call to ask questions or seek assistance if family members are upset or anxious.

Extant literature highlights the importance of leisure for caregiver well-being as well as the challenges caregivers face in accessing and enjoying leisure due to caregiving responsibilities and obligations. While opportunities for respite may address some of these challenges, there is little evidence suggesting the leisure lives and subsequent well-being of caregivers are improving. Moreover, while some research has highlighted the leisure needs of caregivers (e.g., Bedini et al., 2018; Carbonneau et al., 2011; Hutchinson et al., 2011), caregivers generally receive insufficient attention in research and practice, and their needs are often overlooked (Henwood & Turnpenny, 2024). This research study aimed to address this oversight by focusing on the leisure needs of caregivers. Specifically, the purpose of this study was to discover ways to enhance caregiver participation in meaningful leisure. To give context to the insights shared with us by participants, we first discuss literature relating to experiences of caregiving, including some of the main risks to caregiver well-being and the relationship between caregiving and leisure.

Caregiving experiences and impacts on well-being

There has been increasing attention directed toward the ways caregiving is positively experienced. For example, Yu et al. (2018) conducted a systematic review of research on the favourable aspects of caregiving and found that caregiving can provide a sense of personal accomplishment and gratification, feelings of mutuality, increased family cohesion, and a sense of personal growth and purpose in life. Marino et al. (2017) also highlighted optimistic aspects of caregiving related to personal growth and positive affect and argued for a reframing of caregiver well-being that provides a more balanced view of the caregiving experience. Despite these positive associations, the bulk of the literature related to caregiving is not as encouraging. Indeed, much of the research related to caregiving suggests caregivers experience a great deal of stress and guilt while providing care, which commonly results in a deterioration of their mental health and well-being (Kepic et al., 2019; Schüz et al., 2015; Steenfeldt et al., 2021).

Caregiver stress and guilt

Bressan et al. (2020) conducted a systematic review of the literature focused on the needs of individuals providing care to a family member living with dementia. This review highlighted how substantial care responsibilities often take an emotional and physical toll on family caregivers. Penteado et al. (2021) also noted that the uptake of family caregiving responsibilities renders individuals more susceptible to depression and anxiety-related disorders, due, in part, to an interruption to personal and professional routines.

Kepic et al. (2019) pointed to literature highlighting the various forms of stress associated with caregiving, including the stress of performing multiple roles and the stress of balancing schedules. The stress of trying to find a balance between care responsibilities and fulfilling one's own personal needs can be one of the main challenges for family caregivers, and according to Bressan et al. (2020), this challenge is exacerbated when caring for a family member within the same household. Further, caregivers who experience a lack of support and resources are more prone to experience stress (Schüz et al., 2015).

In addition to stress, feelings of guilt are also a common characteristic of the caregiver experience (Losada-Baltar et al., 2024). Caregivers tend to experience guilt when trying to meet what they believe to be societal standards of good care (Gallego-Alberto et al., 2022). Gallego-Alberto et al. (2022) explored the subjective experience of guilt in the family care of individuals living with dementia and found that guilt often surfaces when caregivers perceive that their behaviour does not match their beliefs about how good caregivers should behave. Gallego-Alberto et al. (2022) also found that taking a break from caregiving to attend to personal needs commonly intensifies feelings of guilt. Losada-Baltar et al. (2024) reported that persistent feelings of guilt and ambivalence are significantly associated with increased depressive symptoms among caregivers and concluded that interventions targeting feelings of guilt and ambivalence could help to address caregiver distress.

It is becoming increasingly apparent in the literature that stress and guilt correlate to experiences of loneliness and social isolation for caregivers. Specifically, stress and guilt experienced during caregiving result in caregivers reducing their social contacts and spending less time engaged in social activities (Hajek et al., 2021; Steenfeldt et al., 2021). The likelihood of caregivers experiencing loneliness, social isolation, and depression points to a need for caregivers to balance their personal needs with their caregiving responsibilities (Waligora et al., 2019).

According to Waligora et al (2019), caregivers have two main types of needs: caregiving needs and personal needs. Caregiving needs encompass needs for support with caregiving responsibilities. Personal needs incorporate self-care, which emphasises the need for caregivers to find a balance between their own time and their caregiving time. One way caregivers could achieve balance and ameliorate some of the stress associated with caregiving is through satisfying leisure experiences (Schüz et al., 2015). As we discuss in the next section, the literature related to leisure for caregivers suggests that while leisure experiences could be quite beneficial, these experiences are largely absent from caregivers' lives.

https://doi.org/10.1017/S0714980825100160 Published online by Cambridge University Press

Caregiving and the loss of leisure

Leisure has received attention for its potential to be an effective coping strategy when experiencing stress related to caring for a family member with dementia (Lee et al., 2020). Leisure-based support and education programs can be effective for reducing stress experienced by family caregivers (Bedini et al., 2018; Carbonneau et al., 2011; Hutchinson et al., 2011). Additionally, leisure can be an important means for maintaining a valued identity separate from caregiving. For example, research by Carbonneau et al. (2011) highlighted how structured leisure activities helped caregivers to reconstruct their identities in a positive light even when experiencing caregiving demands. Similarly, Pienaar and Reynolds (2015) found that engaging in creative arts and social leisure activities provided caregivers with opportunities for self-expression, achievement, and personal fulfillment that helped reinforce a positive identity beyond that of a caregiver. Indeed, caregivers' well-being and sense of self are dependent upon experiencing personal leisure time away from caregiving duties (Waligora et al., 2019). Yet, leisure appears to be a primary aspect of life that is reduced or abandoned after taking on a caregiving role (Carbonneau et al., 2011; Dunn & Strain, 2001; Hammar et al., 2021; Innes et al., 2016; Xu et al., 2022).

Some of the reasons caregivers may reduce or give up their leisure pursuits include fatigue, lack of time (often due to combining caregiving with paid work outside the home), and caregiving-related stressors (e.g., financial strain and limited support from family and friends) (Dunn & Strain, 2001). Literature also points to the tendency for caregivers to prioritise caregiving over their own leisure experiences (Hutchinson et al., 2011; Kepic et al., 2019; Schüz et al., 2015). Relatedly, feelings of guilt often prevent caregivers from engaging in leisure and self-care behaviours because they believe that their own well-being is not as important as the well-being of the person for whom they are caring (Kepic et al., 2019). Caregivers may also experience guilt when engaging in personal leisure activities because they believe that the person for whom they are caring is experiencing loneliness and sadness in their absence (Gallego-Alberto et al., 2022).

The tendency for caregivers to reduce or give up their leisure pursuits is particularly problematic when considering that a diminution of leisure opportunities partly explains the detrimental toll caregiving can have on one's mental health (Schüz et al., 2015). As such, Dunn and Strain (2001) argued that the trend of caregivers reducing or completely giving up their leisure activities is deserving of more attention.

Despite the leisure needs of caregivers receiving some attention in the literature (e.g., Bedini et al., 2018; Carbonneau et al., 2011; Hutchinson et al., 2011), these needs, as well as other caregiver needs, typically go unrecognized by healthcare professionals (Bressan et al., 2020). Henwood and Turnpenny (2024) observed that the needs of the person receiving care tend to take precedence, which results in the neglect of family caregivers' needs. Further, support available for caregivers usually consists of receiving information or advice (Henwood & Turnpenny, 2024). Respite services are another common measure of support for caregivers (Jarrott & Ogletree, 2019; Liu et al., 2015).

While it is possible that caregivers will use their respite time to engage in leisure, relying solely on respite to meet the leisure needs of caregivers is likely to be ineffective. In some cases, respite may offer caregivers opportunities for social leisure experiences; however, caregivers' ability to relax and enjoy their time away from caregiving is contingent upon their perception of the quality of respite services and the feeling that their family member is receiving good care (Steenfeldt et al., 2021). Some caregivers may even refuse respite services altogether due to high feelings of loyalty and a sense of obligation to their family members (Bressan et al., 2020).

The leisure needs of caregivers may be addressed through leisure programming, and such programming can be designed to help caregivers develop meaningful leisure-based activities aimed at reducing stress (Bedini et al., 2018). Nevertheless, providing a leisure program for caregivers is not without its challenges. Hutchinson et al. (2011), for example, found that caregivers are unlikely to attend multi-session leisure programs that take time away from their caregiving responsibilities.

Summary and statement of purpose

Literature reviewed in this section suggests that while caregiving can be associated with personal growth and accomplishment, it is also very common for caregivers to experience stress and guilt in relation to their caregiving roles in ways that contribute to loneliness and isolation and negatively affect their well-being. Balancing personal time with caregiving by way of leisure engagement may help to enhance caregiver well-being. Yet, leisure pursuits are often largely absent during caregiving. These findings highlight the importance of addressing caregivers' needs for leisure. There are limited studies that have focused specifically on the leisure needs of caregivers. There is also a gap in the literature related to what might help caregivers sustain valued leisure pursuits. To help address this gap, this study aimed to discover ways to enhance caregiver participation in meaningful leisure. The following objectives guided our study:

(1) To examine how family caregivers of individuals living with dementia describe their current state of leisure
(2) To provide leisure sessions for caregivers to uncover personal meanings and attitudes related to leisure and understand ways leisure experiences change when caring for someone with dementia
(3) To explore what supports are required to sustain meaningful leisure experiences for caregivers

Research context and methodology

Setting

Data collection for this study took place at a day program located in Montreal, Quebec, that operates out of a local community centre specifically chosen for its normative environment and ease of access. The program aims to meet the needs of older adults living with dementia while supporting their caregivers. The day program offers leisure programming comprised of stimulating activities to promote members' physical, cognitive, and social well-being while simultaneously providing respite for their caregivers. Approximately 45 older adults participate in the program each week, and due to funding provided through a public health grant, the day program was offered free of charge for the duration of this study.

Recruitment

After obtaining university ethics approval, we sent an invitation to caregivers of members of the day program, inviting them to take part in a research study aimed at discovering ways to enhance their participation in meaningful leisure. This invitation was emailed to

https://doi.org/10.1017/S0714980825100160 Published online by Cambridge University Press

caregivers on our behalf by staff who worked at the day program, and interested caregivers were asked to contact Darla if they were interested in participating in the study. We informed caregivers that the first phase of the study would involve participating in a focus group to discuss their leisure experiences. We also informed them that a second phase of the study would involve participating in a leisure program intended to help address leisure-related challenges and identify ways they could derive greater satisfaction from their leisure.

Focus group and interview procedures and development of leisure sessions

After receiving responses from interested caregivers, Darla conducted three focus groups (n = 10) as well as five individual interviews (for 15 participants in total). The individual interviews were arranged with caregivers who wished to participate but were unable to attend a focus group. Social distancing protocols related to the pandemic were still in place during this phase of data collection, so focus groups occurred via Zoom, and individual interviews occurred via Zoom and by telephone. Focus groups and interviews were conversational in nature. Sample interview questions included:

- What types of things do you enjoy doing on a regular basis?
- What do you most enjoy about these activities?
- What types of social experiences do you most enjoy?
- What stops you from doing the things you most enjoy?
- What do you think would be most helpful to have included in a leisure program for caregivers?

Each focus group lasted approximately 1 h in length, and interviews ranged in length between 30 min to 1 h. With consent from participants, focus groups and interviews were audio-recorded for the purpose of analysis. When conducted via Zoom, the automatic transcription feature was used. When conducted by telephone, Darla transcribed the audio recording.

Data collected during the focus groups and interviews informed the development of several initial leisure sessions for caregivers. Specifically, answers to questions related to the things participants enjoy and what they would like to have included in a leisure program were analysed for common responses and then considered in relation to available opportunities and resources. For example, participants most expressed enjoying active, creative, and social leisure, so leisure sessions were planned to incorporate physical activity, creative expression, and social experiences. For the physical activity session, we hired a Pilates instructor. For the session tailored to creative expression, we sought the services of an art facilitator, and to facilitate a social experience, we reached out to individuals who were hosting virtual trivia sessions to help keep people socially engaged during the pandemic. By necessity, these sessions were scheduled to occur virtually. We eventually discovered that the virtual nature of these sessions posed challenges for participants who were caring for a family member within their home and who were unable to participate in leisure sessions while simultaneously providing care. Thus, in the end, only one of these three initial sessions (Pilates) occurred, and the other two were cancelled due to a lack of participant availability. After discovering that virtual leisure sessions would not be conducive for meeting participants' leisure needs, we consulted with staff from the day program and decided to put the second phase of the project on hold until we could hold leisure sessions in person.

Given the gap of several months between when the focus groups and interviews occurred and when in-person programming could resume, some participants from the first phase of the project were either no longer involved in the day program or no longer had the time or interest to participate in the leisure sessions. We then recruited additional caregivers. We also worked with day program staff to coordinate the leisure sessions to coincide with the timing of the day program so interested participants could attend the leisure program while the person for whom they were caring attended the day program.

In-person leisure sessions

In keeping with the objectives for this study, the overarching goal of the leisure program was to uncover meanings and attitudes related to leisure and understand ways leisure experiences change when caring for someone with dementia. Another key component of the program was for participants to engage in leisure experiences, so we could determine what supports are required to sustain such experiences. With this in mind, we planned to offer six leisure sessions in total. We planned for the first three sessions to focus on topics such as leisure interests and awareness, general information on the benefits of various types of leisure, strategies to address leisure-related challenges, and the identification of leisure opportunities of interest to participants. We planned for the subsequent three sessions to be decided in collaboration with participants and consist of leisure experiences based on the commonly expressed leisure needs and interests of the group. In the end, we added a seventh session due to participants' expressed interest in a community outing involving an arts-based activity.

Fourteen participants attended one or more of the seven in-person leisure sessions. Five of these participants took part in the first phase of the study, and nine participants were new to the study (bringing the total number of individuals who participated in some aspect of the study to 24, which represented approximately half of the caregivers involved with the day program). Attendance at leisure sessions varied, with as many as 10 participants to as few as four participants attending.

The first six leisure sessions occurred in a room at the same community centre where the day program took place. The seventh session involved a visit to an art museum. The seven sessions occurred over approximately 6 months. The first three sessions occurred approximately every 2 weeks, and the remaining four sessions occurred approximately once per month.

Darla collected feedback from participants during and after each session and recorded observational notes at the end of each session. Observational notes focused on general impressions of how each session went, the disposition of participants, and the nature of the relationships that were forming among participants. Participant feedback generally focused on what participants liked best about the session, what they would change about the session, the types of things they would like to include in future sessions, and what supports they believe they would need to sustain leisure engagement. Participants could choose to provide this feedback verbally or in writing. Most often, participants provided feedback verbally, which was recorded in note form. Some participants also followed up and expanded on their ideas via email. Time at the end of the first three sessions was also devoted to brainstorming and identifying leisure experiences participants were interested in having as a group. These brainstorm sessions led to the incorporation of an art workshop, therapeutic yoga, music appreciation, and a visit to an art museum into the final four sessions.

https://doi.org/10.1017/S0714980825100160 Published online by Cambridge University Press

Data analysis

Data for this study consisted of focus group and interview transcripts, written and verbal feedback from participants during leisure sessions, observational notes recorded after each leisure session, and demographic questionnaires provided to participants when they signed a consent form that asked them to indicate their age range, gender, race, to whom they were providing care (e.g., spouse, parent, and friend) and how long they have been accessing the services of the day program.

Analysis was conducted in stages throughout the project by Darla. The first stage involved analyzing data from focus groups and interviews following Braun and Clarke's (2022) six phases of analysis, including: (1) becoming familiar with the dataset; (2) coding the data; (3) generating themes; (4) developing and reviewing themes to determine whether they answer the research question; (5) refining and naming themes; and (6) writing the narrative. In keeping with Braun and Clark's phases of analysis, Darla began by reading and re-reading focus group and interview transcripts to become familiar with the data. This also involved identifying aspects of data most relevant to developing a better understanding of participants' perceptions and experiences of leisure and the types of things that undermine or enhance their leisure experiences. Drawing from Braun and Clark's second phase, coding the data, Darla looked across the transcripts to identify data that was most salient to the research questions and used an inductive approach to assign codes to excerpts of data that helped to answer the research questions. The third phase, generating themes, involved reviewing and refining the initial codes and grouping them into broader categories or themes. The fourth phase involved reviewing these themes to determine the extent to which they answered the research questions and returning to the focus group and interview data to search for additional data in support of the identified themes.

A similar process was followed in the second stage of the project with the written and verbal feedback from participants during leisure sessions and the observational notes recorded after each leisure session. When reviewing this data, the focus was on identifying further supporting data for the previously identified themes and searching for data that revealed new or different understandings related to the research questions. While no new understandings came from data collected during the leisure sessions, this additional data was helpful for shaping and deepening the themes previously identified in the first stage. The final steps of analysis involved reviewing the themes, developing thematic descriptions, and finalizing each theme by considering them in relation to the research questions and selecting participant quotes and research notes most illustrative of the data in order to write the narrative in a way that captures the essence of each theme.

Participant descriptions

The demographic questionnaires were not part of the thematic analysis but served to provide basic descriptive information about the research participants to help understand their realities. Five participants identified as male and 19 as female, which generally reflected the gender composition of caregivers involved with the day program. Fifteen participants were providing care to a spouse living with dementia, and nine participants were providing care to a parent living with dementia. Participants ranged in age from mid-50s to mid-80s and were accessing the services of the day program between 6 months and 4 years.

All participants were white. We did not ask participants to identify their ethnoreligious affiliation; however, most participants indicated they were Jewish. The day program was in an area of the city with a high concentration of white, English-speaking, Jewish older adults, and approximately 85 per cent of members of the day program were Jewish. We also did not ask about socioeconomic status, but a relatively high socioeconomic status was evident, and approximately half of the participants discussed being able to afford private caregivers to provide additional support for their family members.

Findings

Sacrificing meaningful leisure

Participant descriptions of their current state of leisure are depicted through the theme of *sacrificing meaningful leisure*. This theme illustrates the ways participants prioritized caregiving over leisure experiences and put their leisure needs aside to assume their caregiving responsibilities. Factors contributing to and explaining leisure sacrifices are captured through the subthemes of *narrowing leisure pursuits*, *putting care partners first*, *being dependent on others*, and *preferring downtime to leisure pursuits*.

Narrowing leisure pursuits

A narrowing of leisure pursuits initially became evident during focus groups and interviews when participants could only discuss their leisure activities in the past tense. Almost every time a participant identified a valued leisure activity, they described the activity as something they used to do. For example, David explained, 'I used to go swimming, but it is not possible anymore.' Abigail stated, 'We used to take trips, but that's all gone.'

A lack of time for personal leisure was often the main reason given for no longer pursuing some of the pastimes participants once enjoyed. As Ben mentioned, 'I love to read, but it's a matter of time, and I don't get a lot of time to read. Basically, these things have been curtailed.' Deborah noted the discrepancy between her desired leisure pursuits and her reality when she said, 'I don't have very much leisure, I have to tell you that much. What I like to do and what I do are two different things.' Ava similarly spoke about a diminution of free time that resulted from her caregiving responsibilities: 'I have no time. I take care of everything in the house, and I don't leave him.'

Putting care partners first

Participants regularly spoke of putting their care partners' needs before their own, and they recognized that to have more time for leisure would entail receiving more support for caregiving to ensure their care partner's needs were met. For example, Sophia explained, 'For me to have more leisure time would mean giving him more activities with other people.' David agreed that when it comes to enjoying personal leisure time, 'It's important to ensure we have the help for our partners.' When she discussed her participation in the leisure program, Miriam similarly shared, 'I can come and enjoy myself as long as I know my loved one is cared for.' Anna described how her own enjoyment was contingent upon knowing her husband was being well cared for: 'I am able to enjoy the moment as long as I know he is looked after.' The consensus among participants was that their need for personal leisure time could not come at the expense of the happiness of the person for whom they were caring. Leah captured this sentiment when she said, 'I want him to

https://doi.org/10.1017/S0714980825100160 Published online by Cambridge University Press

be happy, but I also want to have time to be alone. I just really miss having me-time.'

Being dependent on others

When it came to taking any time for themselves, participants described how they were dependent on other people and were therefore not in control of their own time. This dependence impacted their ability to participate in the leisure program with regularity as well as their leisure experiences more broadly. As Tovah explained, 'My mother cannot be handled for an extended period of time by the [paid] caregiver, so I cannot take time for myself.' The stress of being dependent on other people was evident when participants attended various leisure sessions. During these sessions, caregivers often arrived late and in a frazzled state, and discussed being upset with other family members or paid caregivers for not following their instructions. Participants were also often distracted during these sessions either by waiting for someone to call or by calling to check on their family members.

Preferring downtime to leisure pursuits

While participants easily identified a range of leisure pursuits they considered to be personally meaningful, they did not usually refer to these pursuits when describing their leisure-related needs. Instead, they commonly identified that what they needed most was simply having downtime. As Ava described, 'Sometimes it's just really being able to have a break. I would like a real break when there aren't any interruptions.' Some participants also described routine, task-focused activities as enjoyable, not because these activities were necessarily meaningful or fun, but because they provided an escape from caregiving responsibilities and enabled participants to take time for themselves. For example, when Deborah mentioned, 'Even going grocery shopping makes me happy if you can believe that [laughs],' Carol responded in agreement, saying, 'I used to hate grocery shopping, but now it's like the highlight of my week.' David also shared this sentiment when he explained, 'I was out for an hour this morning buying groceries. It isn't fun, but I enjoy it because I get out and I like to be by myself.'

As this theme highlights, participants had many demands on their time that impeded them from having meaningful leisure experiences. The leisure pastimes that they most enjoyed consisted of activities they were no longer doing due to time deficiency. When support was in place to take a break from caregiving, participants described the need to simply have time alone, even if that meant doing routine tasks outside of the home, such as grocery shopping. Despite an expressed need to spend time alone, participants also regularly highlighted needs for social connection, as we describe in the next theme.

Desiring social connection

The theme, *desiring social connection*, highlights the value participants placed on social connection when discussing their leisure-related needs. The ways they described the loss of such a connection and their desire for it are captured through the subthemes. *Struggling to maintain social relationships*, *seeking connection based on shared understanding*, *connecting beyond caregiving*, and *experiencing a sense of belonging within the group*.

Struggling to maintain social relationships

While some participants described that they had social relationships in place, they also explained that it was a challenge to maintain these relationships. For example, Carol highlighted the joy she experienced when her mother attended the day program as she stated, 'I would get excited because that meant I got to go out for coffee with my girlfriends. I seldom get to do that, so that was my leisure time.' Other participants admitted that one of the biggest losses associated with having reduced leisure time was the loss of social relationships. When Ben described how he worked hard to maintain an exercise routine at home, he also highlighted how maintaining social relationships was much more challenging: 'The socialization part is not there now.' Miriam also shared, 'What's missing for me is any form of social connection.'

Seeking connection based on shared understanding

When it came to social connection, most participants admitted they had a particular need for establishing such a connection with people who had a shared understanding of caregiving. During one of the focus groups, Hannah stressed the need for connecting with individuals in a similar situation and lamented, 'I feel like I don't have anybody that I could really chat with about these issues. I need to know that other people are in the same situation because I feel very much alone.' Sarah also expressed a need to connect with other caregivers when she described the pleasure that she derived from attending the leisure sessions: 'I enjoy meeting with the caregivers because we can socialize and have each other as support.' Similarly, Ruth described the leisure sessions as 'a time to connect and have fun with other people who are in the same boat.'

Connecting beyond caregiving

While participants deemed connections with other caregivers to be important because they were surrounded by understanding and supportive others, some participants stressed that they wanted these connections to extend beyond a sole focus on caregiving. As David mentioned, 'I would like to get together with people and discuss extraneous things, not just focusing on the caregiving, you know.' While topics of conversation during leisure sessions usually extended beyond caregiving, participants generally conveyed their preference for engaging in these sessions alongside other caregivers because of the added comfort derived from their shared experiences. As Ruth described, 'It is easier to interact with people who are going through similar things. We don't have to talk about it, but I also don't have to explain my situation, so it's just easy.' Similarly, when providing feedback about the leisure sessions, Naomi explained, 'It's such a comfortable environment and I can relax and be myself because other people know exactly how I feel.'

Experiencing a sense of belonging within the group

When participants spoke about what they most enjoyed about participating in the leisure sessions, they regularly highlighted the value of social connection and deriving a sense of belonging from being part of the group. For example, when Leah was providing feedback about the art activity, she said, 'I loved this activity because it provided an opportunity to connect socially with other caregivers.' Also, in relation to the art activity, Adam explained, 'I appreciated the opportunity to select a work of art from several alternatives and to discuss my choice with other members of the group. This provided me with a strong sense of belonging within the group.' Following the leisure session on music appreciation, Naomi explained, 'I liked building positive connections and exchanging my ideas with others in the group' and Sam similarly conveyed, 'I really enjoyed learning about the experiences and perspectives of others. It's a nice form of connection.'

Participants spoke appreciatively about being part of a group and suggested that an affiliation with the group helped to alleviate

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the loneliness they experienced due to their loss of social connections. Miriam, for example, shared, 'I enjoy coming to these sessions because I know I'm not going to be alone. I really like being part of a group.' The centrality of social connections was evident when we took time to brainstorm and discuss ideas for future leisure sessions with the group. Adam's comment showed that connecting with other participants was much more important than the leisure activity itself: 'My preference would be cultural activities rather than athletic ones, but I'm willing to try anything if it means I can connect with other caregivers.' Sarah also captured the importance of social connection when she said, 'A program for caregivers is very useful because it addresses our social needs.'

This theme highlights how social connections may diminish during caregiving, in part due to the lack of time to sustain such connections and in part due to the lack of opportunities to connect with people who understand the caregiving experience. Participants' desire for social connection became very apparent throughout the study and was often the most frequently described benefit associated with participating in the leisure program. With the next theme, we highlight the value of leisure provision for caregivers.

Wanting to be cared for

This theme describes how, in the face of caregiver-related stress and time scarcity, participants benefited from having leisure activities planned and provided for them, even if they were not able to participate as often as they would have liked. It was evident that the provision of such programming enabled participants to feel cared for. The specific ways in which leisure programming helped participants to feel cared for are captured through the subthemes. *Having activities planned* and *letting them know they matter*.

Having activities planned

When brainstorming ideas for experiences to include in the leisure program, participants offered suggestions for a range of leisure experiences that would stimulate them both mentally and physically (e.g., art exploration and physical activities). They also expressed a desire for day trips outside of the city or visits to museums or cultural sites where no planning on their part is required. As Miriam explained, 'As much as I enjoy art and cultural activities, it is a lot of work to organize those types of experiences for myself.' Other suggestions involved the types of things they would like to be doing, but do not have time or energy to schedule. For example, Ava suggested, 'An exercise class would be good because I never seem to be able to schedule that on my own.' Deborah also revealed that as much as she would like to have more opportunities for doing the things she most enjoys, she admitted, 'I don't feel I have the capacity to add this to my already busy schedule.' Ruth similarly mentioned, 'It's hard to organize things on my own because I'm usually too tired, so I love that this is organized for me.' Participants also recognized that having activities planned for them enabled them to have new experiences. As Naomi explained, 'I appreciate the exposure to activities I am not familiar with or that I might not think of doing on my own.'

During one of the leisure sessions, we discussed what participants might do if they had a free day, and their responses reflected a need to be taken care of and have a stress-free day. For example, Zelda mentioned, 'I would like to be able to go out for a day without a worry on my mind.' Similarly, Sarah expressed a desire to 'go on a guided day trip where they look after me.'

Indeed, participants acknowledged that having leisure activities planned for them minimized the stress and pressure of trying to add another thing to their already full plates by organizing their own leisure activities. As Sarah shared, 'I really enjoy having these things planned for us. This morning, I was extremely stressed over a situation, yet I was able to just show up, shed the heaviness, and feel much more relaxed.' Similarly, Ruth conveyed, 'When there is a structured activity planned for us and I don't have to do the planning or thinking, I am able to lose myself in the activity and just enjoy it.' Sam captured one of the commonly stated benefits when he said after one of the leisure programs, 'I benefited from coming here and getting out of my mind for a while.'

Letting them know they matter

In addition to minimizing stress by removing the need for participants to plan and organize their own leisure activities, offering a leisure program that was dedicated to trying to meet the needs of caregivers let them know that they matter and were deserving of a program designed just for them. Naomi mentioned, 'These activities make us feel special and provide a feeling of belonging because we feel like we are being taken care of.' Being unaccustomed to having programs designed for them, some participants expressed gratitude for having something for themselves. As Ruth explained, 'It was so nice having something to look forward to that was just for me.' Similarly, Sarah shared, 'I really felt it was something for just me. I'm always arranging things for him [her husband] to do, but I also need to have things that are just for me.' Referring specifically to the outing to the art museum, Naomi shared, 'We really enjoyed the outing and felt like we were being spoiled.'

This theme captured the value of leisure programming designed specifically for caregivers. This type of programming helped meet needs that participants were not always able to meet on their own, minimized the stress involved with planning and organizing things for themselves, and enabled participants to feel cared for by having their personal leisure needs addressed.

Discussion

This study explored how to enhance participation in meaningful leisure for caregivers who use the services of a day program located in Montreal, Quebec. Taken together, the findings highlight some of the main leisure-related challenges experienced by caregivers and shed light on some ways that caregivers can receive support to have their needs met within the realm of leisure.

Although participants in this study received respite when their family member attended the day program, they described how they had a lack of leisure time and were dependent on other people when it came to taking any personal time away from their caregiving responsibilities. This finding is consistent with the literature suggesting that respite alone in insufficient for reversing the trend of reducing or abandoning leisure after assuming caregiving responsibilities (e.g., Carbonneau et al., 2011; Dunn & Strain, 2001; Hammar et al., 2021; Innes et al., 2016; Xu et al., 2022).

Another consistency with the literature was participants' admission that their ability to enjoy their leisure time was contingent upon knowing their family member was receiving good care. Steenfeldt et al. (2021) described how caregivers would be more inclined to take personal time away from caregiving if they believed quality respite services were available. It was evident in this study that participants would not allow their own leisure time to come at the expense of the care and attention provided to their family member, which was in keeping with the common practice of

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prioritizing caregiving over leisure time (Kepic et al., 2019; Schüz et al., 2015).

Considering our study's findings alongside extant literature is helpful for understanding that caregivers have substantial unaddressed leisure needs, and perhaps chief among these is their need for social connection. Previous research has suggested that caregivers have trouble maintaining social relationships and often feel isolated and alone (Waligora et al., 2019). When highlighting the leisure gap that exists for both individuals with dementia and their spouses, Fortune and McKeown (2016) emphasised challenges related to meeting social needs. Participants in their study spoke of their disappointment with community dementia programming because they believed programs were too structured and education-based rather than social. Participants in our study also expressed a common desire for social connection because social leisure experiences were largely missing from their lives, and often the most difficult forms of leisure to plan for themselves. Essentially, since participants devoted so much of their time to caregiving, they had less time to dedicate to existing relationships and new social experiences.

While social connections are beneficial for everyone, they can be particularly beneficial for caregivers because they also serve as sources of knowledge and support (Di Lauro et al., 2017). Participants in this study spoke appreciatively about having opportunities to socialize and derive support from one another. Waligora et al. (2019) argued that caregivers need social support to compensate for the lack of support they typically receive from community and healthcare services. Bressan et al. (2020) similarly acknowledged that healthcare professionals often fail to recognize family caregiver needs and argued that promoting caregivers' well-being and quality of life should be considered a public health priority.

An area where this study extends our knowledge is the realization that through the provision of social leisure programs, there is support for caregivers' well-being and quality of life. While it would be ingenious to think that all social leisure programs will automatically address caregivers' needs and enhance their well-being, we argue that paying more attention to caregiver needs and offering more caregiver-specific programming is an important first step.

While the benefits of leisure experiences are commonly known, our study highlighted a key benefit related to caregiver leisure that has received limited attention. Specifically, our study showed that leisure provision can let caregivers know that they matter and that their needs are important. Caregivers are undoubtedly used to having their family members' needs placed above their own. Indeed, they often play an active role in prioritizing their family members' needs to the detriment of their own (Xu et al., 2022). Acknowledging this juxtaposition means we must ask ourselves, with caregivers doing much of the care work in relation to individuals living with dementia, who is caring for them and attending to their needs?

Certainly, caregivers have needs beyond those specifically related to caregiving. For example, caregivers who participated in Hammar et al.'s (2021) study described wanting to receive recognition as a person and not just a caregiver. A study by Pienaar and Reynolds (2015) also highlighted identity issues related to caregiving and suggested there are benefits to cultivating a positive identity outside of caring. So, while individuals may receive caregiving-specific support in the form of education or respite, it is important for them to receive support for their personal needs and expressions of identity as well. This study showed that meaningful leisure experiences can provide this support and help caregivers reconnect with themselves and their interests in ways that may preserve their sense of self and stave off potentially detrimental effects of caregiving.

Calls to care for caregivers are not new; however, evidence suggests they are going unheeded, and caregivers' well-being is suffering as a result (Beach et al., 2022; Henwood & Turnpenny, 2024; Kepic et al., 2019; Sullivan & Miller, 2015). Beach et al. (2022) implored for a policy shift that would see more done to address the holistic needs of caregivers in ways that enable them to flourish. Several researchers (e.g., Bressan et al., 2020; Henwood & Turnpenny, 2024; Sullivan & Miller, 2015) have expressed the need to pay greater attention to the needs of caregivers within the healthcare system. We believe this study supports caregiver-specific leisure programming as one way to address caregiver needs, and we highlight some implications for practice that stem from our findings.

Implications for practice

This study highlights specific benefits of one type of social leisure program, and the findings are not generalizable to all caregivers. As Waligora et al. (2019) pointed out, a 'one size fits all approach' does not work for addressing diverse caregiver needs. Thus, the structure and format of a leisure program will change depending on participants' specific needs and interests. Researchers have emphasized the need for individualized approaches to addressing caregiver needs (e.g., Carbonneau et al., 2011; Ducharme et al., 2010). Ducharme et al. (2010) stressed the importance of evaluating the needs of individual caregivers to determine what support they require to dedicate more of their time to leisure pursuits in ways that would enhance their quality of life. Henwood and Turnpenny (2024) also recommended assessing caregivers' needs and offering them services beyond simply general information or advice. The findings of this study lend support to the need for increasing support and resources for caregivers and suggest that community and healthcare agencies that provide programming and services to individuals living with dementia should expand their services and also include caregivers in their program offerings.

In keeping with the idea that individualized support and resources are necessary, it is unlikely that other leisure programs would be similar to the one we describe here. There are surely to be common challenges experienced by caregivers, but individual leisure needs and interests are apt to be quite different. Participants in our program, for example, commonly expressed an interest in art, but this would not necessarily be an interest shared by all caregivers. Moreover, the leisure-related needs of caregivers will not be consistent, causing practitioners and researchers to arrive at different conclusions when seeking to address caregiver needs. For example, Hutchinson et al. (2011) argued that caregivers require education designed specifically to address their self-care and leisure needs. While caregiver education was a core component of Hutchison et al.'s study, our study showed that education might not be as critical as leisure provision that addresses caregiver needs in ways that minimize their stress and time pressures.

One way we aimed to minimize stress and time pressure during our leisure program was ensuring participants had access to respite care with which they were familiar and trusted. Participants' family members normally attended the day program on different days of the week, but day program staff offered to welcome them all on the day the leisure program was scheduled, even if it was not their regular day for attendance. Not all participants took advantage of this offer, but those who did received peace of mind from knowing their family member was simultaneously engaged in enjoyable

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leisure programming and they did not have to worry about their care. Relatedly, holding the program in a familiar location that was accessible helped to ensure participants experienced no additional stress or pressure from attending. Given that caregivers tend to sacrifice their own leisure needs to prioritize the needs of their family members (e.g., Xu et al., 2022), caregivers are likely to benefit more from leisure programs if they do not perceive that their participation is jeopardizing their family members' care.

We discovered during this study that even with efforts to minimize stress and time pressure, it can be challenging to account for every circumstance that may impede caregivers' ability to participate in leisure programming. Despite providing positive feedback about the program, participants in this study did not attend the leisure program with regularity. Reasons for their intermittent attendance varied and were personal to each participant. While there are bound to be circumstances that impede one's ability to participate, findings from this study suggest that continuously trying to understand the multitude of barriers that exist for caregivers is a worthwhile endeavour, and in the meantime, fluctuating attendance should not be used as a reason for not offering the program.

While we did not anticipate this at the beginning of the program, a main way we minimized stress and time pressure was by planning and organizing everything for participants so that all they had to do was show up and enjoy themselves at the program. It became abundantly clear throughout the study that this component of the program was necessary because participants did not have the inclination to organize leisure pursuits on top of their already busy schedules.

The busyness related to caregiving can bring about symptoms of burnout, including exhaustion, social withdrawal, and feelings of isolation (Krishnan et al., 2017). To alleviate such symptoms, Krishnan et al. (2017) suggested that caregivers participate in leisure activities to take a break from their caregiving duties. As we have seen in this study, however, participating in leisure activities is likely to contribute to further exhaustion if caregivers do not receive support addressing their leisure needs. Thus, for leisure activities to hold promise for alleviating symptoms of burnout, it may be necessary to rethink how to make such activities available and to actively work to ensure the mental load of planning caregiver leisure does not fall squarely on the shoulders of caregivers.

Implications for future research

This study illuminated the perspectives and experiences of caregivers who used the services of a day program and participated in a focus group, individual interview, and/or a leisure program. Our study is limited by the fact that we spoke only to caregivers who received support in the form of respite care. As such, experiences of caregivers who may not have access to, or opt not to use, respite services are missing from the study. Future research would benefit from hearing from caregivers who do not use respite services to understand how the absence of such services shapes their leisure experiences and social needs. Future research would also benefit from hearing from caregivers who are enjoying satisfying social leisure experiences to understand the conditions that best support these experiences and how they affect caregivers' overall well-being.

There is likely to be a socioeconomic component to receiving respite care because of the associated cost. Most participants in this study not only used the respite services offered by the day program, but it was also evident that they could also afford additional respite provided by private caregivers. Future research could focus on differential experiences and needs related to the socioeconomic status of caregivers, particularly given that access to, and opportunities for, leisure are also bound to be impacted by financial considerations.

The discrepancy related to the sex and gender identity of caregivers evident in this study should also receive further attention in subsequent studies. Family caregivers are often adult children or spouses and are much more likely to be female than male (Kepic et al., 2019), and this study reflected this trend. Future research could incorporate an analysis related to caregiver leisure needs to better understand the role that sex and gender identity play in how caregivers balance their caregiving responsibilities with personal time.

Previous research has highlighted situations where caregivers who are dissatisfied with their social experiences have taken matters into their own hands. For example, participants in Fortune and McKeown's (2016) study had initiated a peer-led social leisure program with other caregivers and their spouses. Conversely, participants in our study indicated that without having leisure experiences planned for them, they would be unlikely to engage in leisure. An interesting future study could examine the conditions that prompt caregivers to either proactively address or forsake their leisure needs.

Conclusion

Caregiving can be both positively experienced and contribute to the deterioration of caregivers' mental health and well-being (Kepic et al., 2019; Schüz et al., 2015; Steenfeldt et al., 2021). While meaningful leisure experiences help to relieve caregiving-related stress and improve psychological well-being (Bedini et al., 2018; Lee et al., 2020; Losada et al., 2010; Xu et al., 2022), leisure time and enjoyment tend to be negatively impacted by caregiving responsibilities (Carbonneau et al., 2011; Dunn & Strain, 2001; Xu et al., 2022). As this article makes clear, respite is not enough, and caregivers require greater support and resources aimed at addressing their leisure-related needs. Specifically, caregivers can benefit from leisure programming that helps them to connect socially with other caregivers in ways that alleviate their loneliness and contribute to feelings of belonging. Not only can the provision of such programming help to ease the stress and pressure on caregivers, but it also lets caregivers know they matter, and their personal needs are as important as their caregivers' needs. The number of caregivers and the demands of caregiving will undoubtedly increase in the coming years (Beach et al., 2022), and caregiver health and well-being will surely continue to deteriorate if left unchecked. Thus, it is incumbent on community and healthcare services to direct more attention and resources to assessing caregiver needs and providing services aimed at enhancing their lives.

Acknowledgements. We gratefully acknowledge caregivers who took time out of their busy schedules to participate in this project. We also gratefully acknowledge the day program manager and staff who supported this research and helped with various components of the leisure program.

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