

Caregiver Burnout: The Impact Of Adult Day Programs On Caregivers

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Abstract

The fastest growing segment of the population is those 65 years and older⁴. According to the Toronto Alzheimer's Society, 747,000 Canadians were living with a cognitive impairment including dementia in 2012, and this number is expected to grow to 1.4 million by the year 2031¹². In 2011, family caregivers spent 444 million hours of unpaid work to care for a person with dementia¹². The purpose of this research study was to determine the impact on caregivers when a family member attends an Adult Day Program. The research study included five participants ranging in age from 48-72. Each of the participants was the primary live-in caregiver providing twenty-four hour care for a family member living with a dementia. The study also included two interviews with professionals working at an Adult Day Program. A qualitative research approach was used to synthesize the data from seven semi-structured one to one interviews with caregivers (n=5) and professionals (n=2). The findings revealed five themes related to the caregiver experience: (a) daily challenges of reduced sleep, (b) compromised personal health and wellbeing, (c) lack of time, (d) fears when their family member attends an Adult Day Program and (e) benefits in an Adult Day Program. These findings demonstrate that time away from family members has a positive effect on caregivers because it provides caregivers with a needed break from the day to day challenges and responsibilities of caregiving. Continued research is needed to determine how much time away will make meaningful differences in a caregiver's life and result in decreased caregiver burden and improved health and wellbeing.

Keywords: Caregivers, Adult Day Program, Dementia, Older Adults, Burnout

1. Introduction

The purpose of this research study was to understand the impact of Adult Day Programs on caregivers. With the growing number of people living well into late adulthood, the possibility of developing dementia rises. Caregivers, who are usually family members, provide the bulk of care for older adults residing at home. Caregiving responsibilities can be laden with challenges that impact their physical, emotional, and psychological well-being. Adult Day Programs provide daily respite for caregivers; allowing them time to rejuvenate and complete needed tasks. In this research study we examine the need for and impact of Adult Day Programs on caregivers to determine if attendance at a Day Program improves the health and well-being of caregivers.

2. Literature Review

Burnout has three dimensions: emotional exhaustion, depersonalization and reduced personal accomplishment¹³. Emotional exhaustion refers to a lack of energy and enthusiasm and the draining of one's emotional resources. Depersonalization refers to the development of an indifferent attitude between oneself and the recipient. Lastly, reduced personal accomplishment is the tendency to perceive one's work negatively.

The fastest growing segment of the population is those 65 years of age and over. In Canada, the number of older adults over the age of 65 is expected to rise to 10.4 million in the next twenty five years⁴. According to the Toronto Alzheimer's Society in 2012 747,000 Canadians were living with a cognitive impairment including dementia, and this number is expected to grow to 1.4 million by the year 2031¹². In 2011, family caregivers spent 444 million hours of unpaid work to care for a person with dementia¹². According to Black and others, caregivers providing care and support for people living with dementia are usually family members¹². The role of caregiver can be laden with emotional, physical, psychological and financial challenges¹².

With the strategy of aging in place at the forefront of Canada's health policy, the issue of supporting caregivers comes into question⁷. Aging in place provides people with the option to stay at home rather than moving into a Residential Care Facility¹⁴. It becomes the responsibility of caregivers to provide the necessary supports for people to stay at home as long as possible. This movement assumes that family members will care for and support the aging members as well as themselves. The problem is that the Age in Place movement has placed unintentional burden and cost onto family caregivers⁷.

According to Bekhet, family caregivers provide up to 80% of the care needed by persons with dementia¹. With this large portion of time taken up for caregiving, there may be a higher risk of caregiver burnout. Caregiver burnout is the negative effects the role of caregiving has on an individual's health, including depression, stress and fatigue². Furthermore, it can cause higher physical morbidity and mortality¹³. According to Cangelosi, family caregivers experience feelings of guilt and inadequacy when they are not given sufficient resources for refueling themselves from their caregiving responsibilities³. Without proper channels to rejuvenate themselves they too risk needing supported care.

Adult Day Programs offer health monitoring and recreation and social activities to older adults with chronic health problems which enable them to stay in their homes for as long as possible³. According to Stirling and others, caregivers often underutilize Adult Day Programs because they are not confident of the quality of services being provided¹⁰. The element of trust comes into play. Adult Day Programs might be more successful if caregivers had easier access to information explaining the services provided to family members and the benefits themselves. According to Zarit and others, participation in an Adult Day Program may have positive effects for both care recipient and caregiver¹². In this study, daily stressors including anger and depressive symptoms were compared on the day the care recipient attended an Adult Day Program versus the day they did not. This study demonstrated that temporary relief is beneficial, and suggests that respite could play a critical role in comprehensive efforts to assist caregivers and prevent a downward spiral of emotional and physical health¹².

There has been research conducted on caregiver burnout, reasons for lack of attendance at an Adult Day Program and the long range societal concerns. However, there has been less research on the impact on caregivers when a family member attends an Adult Day Program. With the limited studies, there are conflicting reports of caregiver burnout in relation to Adult Day Program usage. The purpose of this research study is to investigate the impact on caregivers utilizing an Adult Day Program. The health and well-being of caregivers is crucial if they are to continue to provide care for their family member at home. Improving quality of life for both the caregiver and care recipient is an important step in supporting caregivers.

3. Methodology

3.1. Research Participants

Stringent inclusion criteria were used in this study. Research participants that had a family member attending an Adult Day Program for a minimum two months were included in the study. All care recipients had to be living with an irreversible chronic condition. In this research study the irreversible chronic condition was dementia. Participants were recruited from two Adult Day Programs in the Metro Vancouver area. The initial strategy used for recruitment was a flyer that was distributed by the Adult Day Program staff at the initial location. This strategy did not achieve the desired result as no caregivers made contact. The Adult Day Program's staff was approached and agreed to liaise directly with caregivers requesting their participation in the research study. This strategy generated some interest and the lead researcher received five phone calls in total. One participant cancelled, and the lead researcher declined another because of the limited amount of discretionary time the potential participant had available each week. Additional participants were recruited via a second Adult Day Program, again with the assistance of the Adult Day Program Manager. The second recruitment generated two participants. Recruitment was challenging because of the

caregiving responsibilities; all participants were the sole caregiver and needed to be with their family member at all times.

There were five caregiver and two professional participants in this research study. The caregiver participants ranged in age from 48-72, with an average age of 65. There were three females and two males. The caregivers were fully responsible for their care recipient's care, as well as day to day running of the household. The participants were the primary live-in caregivers providing twenty-four hour care for a family member living with dementia and had been in a caregiver role for an average of 6 years. Three of the five participants were a spouse; one a child and one a sibling. The care recipients had been diagnosed within four to ten years. All care recipients attended the Adult Day Program two days per week. The first site offers respite services six hours per day while the second site offers five and half hours per day. Four of the five care recipients attended a full day. One caregiver experiences challenges with attendance due to the care recipient's dementia, only attending two and half hours per day. The professional participants had a managerial role in Adult Day Program Services; one a Therapeutic Recreation Practitioner and the other holding a Bachelors of Therapeutic Recreation. We acknowledge that that recruitment was difficult because of the lack of free time caregivers possess while providing twenty-four hour care for a family member living with dementia.

3.2. Data Collection

Qualitative research methods were used including seven semi-structured one to one interviews: five interviews with caregivers and two with professionals. Seven primary documents in the form of verbatim transcripts and five secondary documents in the form of field notes were collected. Semi-structured interviews were used because they allowed the participant to share their experiences freely with the opportunity for the interviewer to probe when necessary to gain specific knowledge about a topic⁶. The purpose of the caregiver interviews was to understand the caregiver's experiences and how these experiences impacted their life. The purpose of the professional interviews was to gain an insight into and perspective of their experiences working with caregivers at an Adult Day Program.

The interviews took approximately thirty minutes to an hour and a half to complete. The participants were open and honest about their caregiving responsibilities, sharing detailed accounts of their experiences. The challenge encountered was keeping the focus on the caregiver rather than the care recipient. One observation was that these caregivers had few opportunities to share their experiences and given this opportunity they talked at length about the family member. The question "Can you describe your caregiving duties?" became ineffective as it kept them talking repeatedly about their family member. Conversely, the questions: "Has the role of caregiver affected your health? If so, explain how," helped participants maintain a focus on themselves. The researchers were struck by the need of these participants to talk about their family member.

3.3. Data Analysis

Qualitative data were collected through interviews and then transcribed verbatim. The next step was to code the data descriptively. This was done by completing a codebook. The codebook helped with the formulation of themes by making connections between and grouping the codes. Further analysis challenged emergent understandings and relationships⁶. The authors worked together to identify major themes in the data. In the final stage we examined critically and challenged the themes that were developed.

Overall the analysis is trustworthy due to the measures taken. Credibility of the data analysis was addressed by searching for negative instances throughout the data. Furthermore, judgment-free note taking was consistently done to maintain credibility. Due to the similarity between data sites and stringent inclusion criteria we believe these findings are transferable to a similar research population and context. We worked rigorously together and with peers to critique and question where needed. Lastly, the peers were also used for alternative explanations and the audit of data when sharing our own findings.

4. Ethics

This research study received ethical approval from the Research Ethics Board at Douglas College through the course instructor. Informed consent was given voluntarily and participants were notified that they could withdraw at any

time. Confidentiality was respected at all stages in the research study and pseudonyms were used to protect identities. There were no unexpected ethical issues.

5. Research Findings

The findings this research study demonstrated five themes related to the caregiver experience: (a) daily challenges of reduced sleep, (b) compromised personal health and well-being, (c) lack of time, (d) fears when their family member attends an Adult Day Program and (e) benefits in an Adult Day Program.

5.1. Daily Challenges of Reduced Sleep

Four of the five participants spoke about their lack of sleep and it had impacted their role as a caregiver. Three participants average four to five hours of sleep per night. Lack of sleep affected their concentration, emotions and energy levels. Sheryl, Adult Day Program manager said that “I think for caregivers the sleep is a very big issue, if you don’t get enough sleep you can get angry during the day, things that would not usually bother you, you snap²⁰”.

One participant made a direct correlation of the daily challenges of poor sleep and decreased self-control. This decrease in self-control led to moments of anger and frustration towards her family member. Four participants reported times when they unintentionally caused harm to their family member. “I find myself grabbing her and sort of being rough¹⁸”. “But sometimes I have to be mean to him and then he listens¹⁹”. Caregivers’ lack of sleep causes them to lose control when interacting with their family member and, at times this lack of control leads to unintentional abuse. Sheryl, the Adult Day Program manager reiterated the importance of extra time for the caregivers and stated that rest is crucial for caregivers because they are going to become fatigued very quickly if they are not well rested¹⁶.

5.2. Caregiver’s Personal Health

Four participants experienced negative health outcomes that they attributed to be directly related to their caregiving experience. Sleep deprivation contributed to the decreased health of these caregivers. Periods of depression and anxiety were identified by three of the participants. This creased anxiety is due to the increased stress and burden placed on caregivers. Three participants reported specific health related problems such as depression, anxiety and increased stress levels, while one referred to the lack of sleep as an ongoing health concern. One participant indicated minimal health problems related to their caregivers responsibilities. Those who had been in a caregiver role the longest reported an increased number of health concerns. Sally (caregiver) reported depression and elevated blood pressure¹⁹, while Sam (caregiver) reported depression and anxiety- a general anxiety all the time; just wondering how things are going to go. The health issues reported by participants were not present prior to their role as caregiver, which could mean that their health concerns are a resulted from their caregiving responsibilities. All participants reported increased stress levels. “I think the stress is there all the time...I would say that the stress is a big problem²⁰”, and Sally (caregiver) said “I have to take high blood pressure pills and before I don’t have to¹⁹”.

Caregivers interviewed in this research study indicated that caregiving is very stressful and can increase anxiety levels. The professionals confirmed statements made by the caregivers. Sheryl (professional) commented regarding the caregivers “they are not handcuffed by another person so they are free.¹⁶” These insights from the caregivers and professionals strongly illustrate how complexed caregiving is.

The professionals emphasized the importance of educating caregivers. This may ease the transition of having a family member attend an Adult Day Program. Also, many caregivers are not aware of the negative health risks involved. Caregivers are extremely vulnerable to stress, and the ongoing stressors may lead to the development of diseases⁹. With their family members enrolled in an Adult Day Program, the caregivers will have time for self which can reduce stress and anxiety. Reduced stress and anxiety can lead to healthier caregivers which can lead to an overall improved quality of life.

5.3. Living with Little Time for One’s Self

The most surprising finding was the caregivers’ experience of a complete lack of privacy. All participants stated they had no freedom at all. The entire day and night was focused on the care and well-being of their family member. Even

the smallest of tasks like taking out the garbage is done with their family member by their side. This leaves caregivers struggling to complete daily tasks, which leads to caregiver burnout.

All participants reported how little time they had for themselves. Their caregiving responsibilities took over their life. "I can't go anywhere without him²¹". There was little privacy; they were connected to their family member both day and night. The little spare time they had while their family member attended the Adult Day Program was used to conduct basic every day needs like banking and grocery shopping. Comparing her situation to that of her mother-in-law's who lived in a care facility, Susan (professional) stated, "you know when you are in a care facility....its three shifts, three people caring for groups of people. It's different when you are at home²¹". All the caregiver participants experienced feelings of isolation, being left alone to care for their family member both day and night. Scott (caregiver) said: "it is affecting my health in the sense that it is really lonely¹⁸".

Both professionals shared how caregivers have more time to themselves when the care recipient attends an Adult Day Program. The caregivers are able to relax and re-energize until their family member returns. "I think the more time the caregiver have time to rest and rejuvenate themselves... they will be able to carry out their caregiver duties better⁷". Lack of time for self was connected to how well the caregiver was able to carry out their caregiving duties. Caregiving entails providing twenty-four hour care, therefore it is pertinent that caregivers have some down time just to rest and relax. With extra time away from caregiving duties, caregivers can have a reduced stress and anxiety level.

5.4. Caregivers' Fears When Their Family Member Attends the Adult Day Program

All the caregivers commented on their concerns regarding their family members' behavior while at the Adult Day Program. They had reservations and fears. The fears stemmed from the potential their family member had for being aggressive. "I feel sorry you know....I know how difficult she can be, and I feel sorry for them²⁰". Susan (caregiver) said: "If something went wrong I don't know how he would react...might not be a good reaction²¹". Concern about their family member's behaviors caused the caregivers to be hesitant about placing them into an Adult Day Program. However, Brook (professional) believed that the attachment was so strong between the caregiver and care receiver that they are hesitant about letting go of that bond¹⁷.

5.5. Benefits of Participation in the Adult Day Program

Attending an Adult Day Program was an avenue for reducing stress and anxiety in caregivers. "Their stress and anxiety levels can go down¹⁶" when their family member is attending the Adult Day Program. During time away, caregivers are not burdened by constantly paying attention to their family member. Caregivers can relax during this period of time while their loved ones are attending the Adult Day Program.

Participants shared the positive effects of having their family member attend the Adult Day Program. Caregivers were able to complete tasks, relax and prepare for their family member's return. One participant described how his anxiety level was reduced, and another stated that her mind was so much clearer and this clarity helped her refocus. For one participant, it was time to relax and for another it was time to do the most basic task of having a shower. There was a sense of freedom and time to complete needed tasks, refuel and prepare for the home coming. "Your shoulders just drop...²¹". Time alone for Susan (professional) meant a reprieve from answering questions. "It's just because...you don't have to answer questions all day²¹". This time alone allowed an opportunity for personal freedom and self-care. "Generally the anxiety level wretches down, wretches down a little, so I am not at 5 I am at a 3.5, things calm down a little²⁰".

All participants felt that one day a week was not sufficient to improve their health. One day a week is 5.5 hours of a 24 hour day. Sam (caregiver) said "I think in general that caregivers would get the best benefit from visiting two times a week or more²⁰". All participants felt a minimum of two days week would have a positive effect on their caregiving duties, but more would be better. Three participants shared that involvement in the Adult Day Program had slowed the decision to move their family members into Residential Care.

When asked about other resources offered at the Adult Day Program, one of the participants stated he used all available resources: Community Bath, Foot Care, Hairdressing and Annual Flu Shot. When referring to the Bathing Program one participant stated, "...sounds like a small thing but that was a huge help²⁰". Brook (professional) furthered the idea that the resources available at an Adult Day Program could greatly benefit the care receiver¹⁷. Although all participants stated that participation in the Adult Day Program had a positive impact on them, increasing the number of days a family member attends would have a greater effect on their quality of life.

Overall, the benefit of having family members attending an Adult Day Program is improvements in the caregivers' quality of life. "[The caregivers] can just have a better quality of life compared to ... ones [who] do not attend the

day program¹⁶”. An Adult Day Program is an available resource for respite to the caregivers who are on the verge of fatigue and burn out. Ultimately, the caregivers’ health is important for continued care for their family members. Sheryl (professional) believed “if these caregivers are not healthy, how can they be caregivers.”

6. Discussion and Implications

Caregiver burnout is the negative effect the role of caregiving has on an individual’s health, including depression, stress and fatigue². In this research study caregiver participants reported decreased health, specifically, depression, elevated blood pressure and anxiety that resulted from their caregiving role. All but one participant experienced a lack of sleep that left them struggling with the day to day challenges of caregiving. Furthermore, caregivers experienced loss of self-control. Additionally, feelings of isolation and loneliness were also consistent with all participants. They had little support throughout the day and little contact with family and friends. These findings are directly related to increased incidences of caregiver burnout.

All participants stated that time away from their family member provided them with some freedom and reprieve from their caregiving responsibilities. They were able to complete needed tasks independently without worrying about their family member. All participants concluded that attending the Adult Day Program one day a week is not enough to make a significant difference in their quality of life. Attendance once a week only equates to five and half hours a week leaving so much to be accomplished within that time period. Two potential participants in the research study declined participation due to the limited time they had without their family member; this time was just too valuable to them to participate in a research study.

The element of caregiver guilt painted a very different picture than anticipated. According to Stirling and others, caregivers often underutilize Adult Day Programs because they are not confident in the quality of services being provided¹⁰. Caregivers are left with feelings of guilt about enrolling their family member in the Adult Day Program. The findings of this study demonstrated that caregivers were happy with the services offered, but felt guilty and apprehensive about their family member’s possible unpredictable behavior when at the Adult Day Program.

According to the professionals, the caregivers’ strong attachment to their family member can interfere with them enrolling care recipients into the Adult Day Program. There is a lack of trust. The lack of trust stems from the caregivers belief they are the only people that can safely care for their family member. Furthermore, there is belief that staff members of an Adult Day Program are not sufficiently capable of caring for their family member. The study confirmed caregiver burnout has the potential to lead to unintentional elder abuse. Over time caregivers became overwhelmed and tired from lack of sleep and the daily responsibilities, leaving open the possibility of unintentional abuse. Two of the participants stated that there are times when their anger was difficult to manage and they can raise their voices towards their family member in an inappropriate manner.

7. Recommendations

7.1. Researchers.

Future researchers: use a quantitative approach to measure how many days a week a family member attendance at an Adult Day Program impacts caregivers.

7.2. Service Providers

Providers and managers: providing on going education for caregivers.

7.3. Caregivers

Caregivers: caregiver support through which caregivers have an opportunity to share their struggles and emotions related to their caregiving responsibilities.

8. Study Limitations

A larger sampling size would allow for more data which would confirm or contradict the findings. Additionally, expanding the number of professionals would also broaden the findings. Enhanced background information including how to access Adult Day Program services and the number of days for each care recipient would be beneficial. A wider demographic of caregivers could be beneficial to explore any possible differences of the findings. Enhanced interview questions would elicit increased depth and understanding of the caregivers experiences.

9. Conclusion

The study concluded that more research is required to determine the impact of Adult Day Programs on caregivers. Caregivers require a great deal of support and understanding if they are to be successful in caring for their family members at home. Interviews with the caregivers demonstrated the negative impact twenty-four hour caregiving has on their health. Professionals interviewed emphasized the need for ongoing caregiver education. Caregivers will be more likely to enroll their family member in an Adult Day Program if they better understand the positive impact participation in an Adult Day Program has on their health and well-being. This includes understanding the importance of taking time for themselves, which enables them to continue their caregiving duties with decreased anxiety and stress levels while improving sleep. With the growing strategy of “aging in place” coupled with the number of older adults living with a cognitive impairment, policy makers must examine the needs of caregivers or they too will become a burden on Canada’s health care system.

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