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Occupational Transitions of Family Caregivers of Loved Ones with Dementia

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Abstract

Purpose: The primary purpose of this study was to explore how family caregivers of people with dementia experience transitions in occupations as they assume the caregiver role. Because unpaid family caregivers play a vital part in the scheme of health care, it is important to understand their supports, their perceptions of themselves as caregivers, and the impact of caregiving on relationships, identity, and physical and mental health. Many researchers have studied the effects of caregiver burden, yet minimal attention has been given to the lived experiences of caregiving on their daily roles and routines. **Methods:** A qualitative descriptive design was used to obtain data from eight caregivers through semi-structured interviews. Content analysis was then applied to all data. **Results:** The following categories were identified: 1) *Benefits,* which consisted of the positive experiences gained as a result of caregiving; 2) *Consequences,* which included the physical, mental, and emotional burdens attached to being a caregiver; and 3) *Supports,* which were positive resources utilized by caregivers to be both better prepared to care for their loved ones and more capable within their caregiving role. **Conclusion:** Findings confirm that unpaid caregivers of loved ones with dementia experience dramatic changes in many aspects of their lives. Caregivers felt a strong responsibility as a family member to provide care for their loved ones. It has been found that caregivers spend most of their time engaged in caregiver related tasks, consequently impacting their occupational balance and ability to engage in what they would like to do. Health care providers must be mindful of the changes that caregivers experience, by assisting them to increase supports, anticipate the consequences, and recognize and value the benefits.

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Occupational Transitions of Family Caregivers of Loved Ones with Dementia

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Purpose: The primary purpose of this study was to explore how family caregivers of people with dementia experience transitions in occupations as they assume the caregiver role. Because unpaid family caregivers play a vital part in the scheme of health care, it is important to understand their supports, their perceptions of themselves as caregivers, and the impact of caregiving on relationships, identity, and physical and mental health. Many researchers have studied the effects of caregiver burden, yet minimal attention has been given to the lived experiences of caregiving on their daily roles and routines. **Methods:** A qualitative descriptive design was used to obtain data from eight caregivers through semi-structured interviews. Content analysis was then applied to all data. **Results:** The following categories were identified: 1) *Benefits,* which consisted of the positive experiences gained as a result of caregiving; 2) *Consequences,* which included the physical, mental, and emotional burdens attached to being a caregiver; and 3) *Supports,* which were positive resources utilized by caregivers to be both better prepared to care for their loved ones and more capable within their caregiving role. **Conclusion:** Findings confirm that unpaid caregivers of loved ones with dementia experience dramatic changes in many aspects of their lives. Caregivers felt a strong responsibility as a family member to provide care for their loved ones. It has been found that caregivers spend most of their time engaged in caregiver related tasks, consequently impacting their occupational balance and ability to engage in what they would like to do. Health care providers must be mindful of the changes that caregivers experience, by assisting them to increase supports, anticipate the consequences, and recognize and value the benefits.

Keywords: Transition, caregivers, occupations, dementia

INTRODUCTION

Millions of unpaid family caregivers are responsible for innumerable hours of unpaid care.[1] Those numbers are expected to rise with the predicted increase in dementia diagnoses. Because unpaid family caregivers play a vital part in the scheme of health care, it is important to determine what they lack in terms of supports, how they see themselves as caregivers, and how caring for someone with dementia can affect relationships, identity, and physical and mental health. The research identified that the caregiver experience is often overlooked.[1] From that data, healthcare providers can glean information that has the potential to help alleviate caregiver burden, help establish clear roles and responsibilities within the caregiver/receiver relationship, and work to widen the support network for this vital population. The aim of the study was to understand how family caregivers of people with dementia experience transitions in their occupations and daily routines. Occupation can be defined as participation in activities individuals need and want to do including but not limited to self-care tasks, social participation, work, and home management.[2] Transitions may be described as changes in experience, which may include a change in each role or context.[3]

General health concerns associated with dementia include agitation, confusion, apathy, memory loss, depression, and limited social and motor skills.[4] These common signs of dementia may worsen and lead to personality changes, paranoia, and inability to complete daily activities.[4] The literature shows that individuals experiencing dementia begin to disengage from their daily routines because of how other people view them.[5]

Much of the literature focuses on being a family caregiver, occupational transitions in relation to becoming a caregiver, the cost that comes with this new role, and social supports as well as unmet needs of the unpaid family caregiver.[6,7] Occupational transitions include the changes experienced in participation of meaningful and everyday activities.[2,3] While findings identify factors that make up caregiver burden, there are no clear answers on how to mitigate its impact on health and quality of life. Unexpected occupational transitions have to do with the identity of people who find themselves in unforeseen circumstances fulfilling roles in which they are not prepared; additionally, the relationship between the caregiver and person with dementia becomes more complex as these transitions evolve.[6]

As human beings confront changes in their connection to the world and personal relationships, including major life events, changes to those occupations can occur. Occupational transitions regarding caregivers vary greatly, but the literature shows that transitioning into the role of caregiver proves to be challenging and complex due its demands.[7] Within the role of caregiver, new habits, roles, and routines emerge, all of which revolve around the person receiving care. Even within set familial roles, there are transitions that occur when responsibilities and power dynamics shift.[7] Family caregivers report that they assume roles of authority within a family dynamic where formerly, they were in dependent roles.[7,8]

Research demonstrates that people who assume the role of a caregiver experience this occupational transition differently from one another; some frame it as an interruption and a sense of duty while others see it as the natural progression of the younger generation caring for the older generation.[9] These new roles become contextualized within the framework of the caregiver's sense of their previous self; some take it with a degree of poise – that this is their new role and their new life - while others see their former lives diminish in the wake of this new demanding role.

Yet there are shared experiences between unpaid family caregivers regarding occupational transitions, they undergo a wide range of personal changes as well as challenges as they confront these transitions.[7] Many caregivers relate occupational changes to their psychological state as well as their stress levels.[10] In many cases, family caregivers lose a sense of identity because they become so engrossed with becoming a caregiver.[7]

The research has thus primarily considered caregiving from the perspective of burden, while there is some limited research to suggest that caregivers do experience growth and other gains. These gains include greater opportunities to spend time together, increased sense of personal capacity, self-efficacy, and enablement through family support.[6]

The literature indicates that unpaid family caregivers are responsible for numerous hours of care and that many of those hours reduce institutionalization rates.[7] Caregivers providing these hours experience high levels of stress as they transition from their paying jobs to unpaid work that takes a significantly higher psychological toll.[7] Many of these caregivers trade job satisfaction, monetary compensation, and a set of habits and routines for no monetary compensation, high stress levels, and little time for their friends and families.[7,8] Because identity is highly linked to engagement in occupation, caregivers are at risk for the loss of a sense of self as they transition to their new role. That sense of self is often seen within the context of occupational engagement.[7] As once valued occupations are neglected as roles shift, it usually yields a negative impact on the caregiver in the form of loss of control over one's life.[7] However, some caregivers have been able to find meaning in these new roles and have been able to sustain a positive outlook.[8]

According to the literature, caregiver burden has many negative effects on health including feeling distressed, and lacking social support, healthy diets, and personal time.[4,6,11] These negative effects lead to chronic stress that impacts overall health, also known as the caregiver burden phenomenon defined as the strain or distress caused during the activity of caregiving.[12] Taking care of a family member with dementia is demanding work that entails daily care for their loved one, communication with health care providers, handling behavioral problems and money/home management.[10,12] With each added responsibility, the unpaid family caregiver becomes more challenged. The impact of this added stress, when left untreated, may become detrimental.[10] The literature shows that caregivers experience social, emotional, and physical challenges that commonly lead to depression.[13,14] Although research considers the relationship between caregiver burden and caring for someone with dementia, there is limited literature on approaches to resolving the issue. Transitioning into the family caregiver role may result in the loss of personal activities of daily living (ADLs), but it may also result in the gain of new instrumental activities of daily living (IADLs) such as handling medications or finances for their loved one. According to Tatangelo et al[8], caregivers may lack necessary social and emotional supports, become less attentive to their own diet and exercise needs, feel isolated, and lack personal time. These unmet mental and physical health needs lead to a feeling of being overwhelmed.[8] Each caregiver may have to take on unfamiliar, challenging roles in which they lack the professional training, compensation, and comprehension of what is to come. The literature is inconclusive on prevention techniques for caregiver burnout, but there have been studies which found a correlation between mindfulness and better mental health.[15]

As the number of people who have dementia is increasing, so is their need for care.[16] Most support that people with dementia receive comes from their informal or family caregivers, but these caregivers often lack support for themselves.[1] "However, some educational and emotional support tools have proven effective in empowering caregivers in their role, and delayed need for placement of loved ones in a facility".[17]

The research reveals that most unpaid caregivers feel like they do not have an option to become their loved one's caregiver, but they do it because their family needs them.[11] With this transition comes the new responsibilities that a caregiver assumes.[6] Many of these people do not know how to care for someone with dementia and need assistance learning how to take on this role.[11] Because of this, a Family Caregiver Training Program was developed to teach caregivers how to help their loved ones perform their activities of daily living safely and effectively.[18] Many other interventions have been identified in the literature that aim to reduce caregiver burden and anxiety including direct occupational therapy interventions with caregivers (education on dementia and coping), interventions in the home, and technology mediated interventions.[16]

In summary, the research reveals that becoming a family caregiver leads to a transition in daily activities, unwanted burden[7], and diminished support physically, emotionally, and socially. Unpaid caregivers lack the choice of adopting this new caregiving role and often lack the formal education to care for a person with dementia.[7] In addition, relationships between caregivers and their loved ones are often complex and can have a bearing on the quality of care and stress level of the caregiver. The focus of this research relates to the detrimental effect of dementia on people and their families. Support for caregivers can be found through groups and programs, however, these resources are few and far between.[7] Research also offers limited perspective on the effectiveness of those supports and how accessibility of support varies among caregivers. The lack of research on positive aspects from caregiving and how identity is affected through occupational transitions warrants further investigation. While some of the data shows that as people transition to the role of caregiver, they can experience positive aspects in their daily lives, there is much more to be explored about this facet of the caregiver experience.

METHODS

Research Design

A qualitative descriptive design was chosen to resolve the research question: How do family caregivers of people with dementia experience transitions in their occupations and daily routines? Qualitative research aims to interpret the problems that affect specific populations by understanding their subjective experiences.[19]

Participants

Convenience sampling was used to recruit eight individuals who are or were unpaid family caregivers for people with dementia. The caregivers ranged in age from 48-69 years old. The mean age of caregivers is 62.125 years, and the standard deviation is 6.6. All caregivers were white and located in the Midwestern United States. All participants had at least one year of caregiving experience, received no formal caregiver education, and were not paid for their services. Participants were given compensation in the form of a $20 Target gift card for participating in this study. The University Internal Review Board approved all procedures and participants provided informed consent.

Data Collection

An interview guide was created using concepts derived from the Model of Human Occupation (MOHO).[20] Interviews were chosen as the main source of data collection because they provide deep exploration of the caregiver's thoughts and experiences. Researchers individually conducted semi-structured interviews via video chat using Zoom with the caregivers (N=8) ranging from 45-90 minutes. Interviews were transcribed and stored on a secure hard drive. A narrative slope depicting the caregiver's life history from The Occupational Performance History Interview - Second Version (OPHI-II)[21] was created by each caregiver. A narrative slope is a metric used to describe life events on a continuum using plot points to visually convey the context of the caregiver's experience with other life events[21]. This was intended to serve as a cue and reflective tool for the interview process to aid participants in recalling life events and their importance.

Data Analysis

Audio files were transcribed verbatim and content analysis was applied to that data. Content analysis refers to a systematic approach used to understand and infer communicated data which is then coded to identify certain categories or concepts.[22] Researchers used codes and categories to report commonalities and patterns.[22] The caregiver's narrative slopes were used to provide a visual representation of the qualitative findings.

To enhance rigor, researchers initially coded independently, then collaborated to discuss and recode. Additionally, data collection tools and initial findings were reviewed by an expert reviewer and member checks were conducted with 6 out of 8 participants. During this process, participants were provided with initial researcher interpretations and data, then asked to confirm, dispute, clarify, and/or add to the findings.[23] According to Birt et al,[23] member checking provides researchers with a way to validate results. Thus, assuring correct interpretations and providing the opportunity for adding new information contributed to accuracy, transferability, and credibility. Lastly, researchers identified that saturation was reached because no new codes were identified during data analysis and no additional relevant information was found.

RESULTS

Three categories were identified, including the following: 1. Benefits: Positive experiences of caregiving, including finding new leisure activities to perform with their loved one, having the opportunity to give back to their loved one, and building stronger relationships with their loved one. 2. Consequences: The physical, mental, and emotional burdens of being a caregiver. 3. Supports: Resources that prepared the caregiver to care for their loved one, including caregiver education, family/community assistance, and personal coping strategies. Pseudonyms for each caregiver will be used.

Benefits

Caregivers described many benefits or positive experiences they gained due to caring for their loved one. These included having the opportunity to give back to their loved one, acquiring new leisure activities, positive experiences with their loved one such as conversations revealing fond shared memories, and building new/stronger relationships with their family. Most caregivers described that they were blessed to be able to take care of their loved one. Gabby mentioned that "I just wanted to kind of give back to her toward the end of her life. You know, all the wonderful years she brought me up." This sentiment was described as one of the main reasons caregivers assumed the caregiver role for their loved one. Another common experience of caregivers was that they found new leisure activities that they participated in with their loved one. Whether it was doing the loved one's prescribed exercises together, taking walks around the park, or participating in group activities at an assisted living home; the caregivers felt satisfied that their loved one was able to enjoy this time in their life. Michelle articulated that she enjoyed watching their loved one participate in activities at their assisted living facility stating, "She had fun, so that made me happy, and I felt like that was worth the struggle." Some caregivers also explained that this time in their life also facilitated positive experiences in general. Jennifer described it as such, "It got me being better at time management and … being more empathetic and understanding [of] older people."

Finally, most caregivers expressed the opportunity they had to gain connections with their family-whether it be their loved one they were caring for, or other family members supporting them. The caregiving experience brought them closer to someone and they described this as a benefit to becoming a caregiver. Gabby stated that "It was kind of nice to reconnect with my sister again too and I have friends that would come over and visit so it ... was good." These caregivers cherished the time they were able to spend caring for their loved one. They all described that the times where their loved one thanked them or reminded them how much they loved them was something they could not forget and appreciated. Michael noted that "She still loved me, and she always said she loved me. And that was the main thing. And the most important thing to me." While many benefits were identified because of becoming a caregiver, consequences were also prevalent.

Consequences

Caregivers identified several physical, mental, and emotional stress factors that impacted them during their experiences as a caregiver. These consequences came as a result of caring for a loved one with dementia, and included loss of social network, occupational imbalance and deprivation, sense of unpreparedness, and emotional stress related to their roles as a caregiver.

Each caregiver had unique experiences with their loved one regarding being taxed emotionally. Each caregiver also experienced a change in relationship to their loved one due to assuming the role of caregiver. Beth expressed, "This is not the woman I grew up with." and another, Frank, similarly expressed, "You have to realize that it's not the same relationship." The emotional tax that comes with having to adapt to a loved one who has profoundly changed took an immense emotional toll on caregivers.

Another emergent consequence was the impact of occupational imbalance being compounded by the subsequent guilt that unfolds because caregivers felt that they were not meeting the responsibilities of other roles to which they assigned great importance. For example, Michelle remarked, "I felt guilty all the time...I didn't have time for anybody...I felt like a bad daughter, I felt like a bad wife...I had a lot of guilt...I felt like I wasn't doing a good job at anything." As a result, caregivers expressed a lack of opportunity to participate in a range of meaningful and diverse occupations.

Finally, caregivers described a sense of unpreparedness. The sense of being overwhelmed entered the fray as the caregivers became aware of how much care was required as the diagnoses evolved. Not only did the caregivers express unpreparedness in the sense that they lacked professional caregiver skills, but they also expressed that as their loved one's condition worsened, the responsibility and the emotional tax increased. Michael expressed, "It (caregiving) wore me down and it got harder." Gabby commented, "I was not prepared at all." However, despite all the hardships related to being a caregiver to a loved one with dementia, none of the caregivers ever complained about the work, rather, they lamented the loss of their loved one and identified a network of support.

Supports

Finally, caregivers identified a variety of resources that prepared them to care for their loved one. The most prominent support identified was emotional support from family, friends, and their community. Through the emotional support from others, caregivers were provided an outlet. Gabby spoke about family support, noting that "my sister probably came over three nights during the week to have dinner and she'd bring food. So that was always nice." While Michael gave an example of community support, "But you meet a lot of different people that are helpful too." Another support the caregivers noted was caregiver education, the type of which varied. Gabby commented, "My sister and I took some courses together on how to deal with dementia patients." Additionally, Lucy expressed that the physician "basically wrote a prescription for me to attend a support group. That was the smartest thing they could have ever done."

Furthermore, caregivers highlighted coping strategies as a support to fulfilling their caregiver role. Lucy mentioned, "I ask for spiritual help all the time," while other caregivers noted naps, leisure participation, and socialization as means for coping with caregiver burden. Lastly, the caregiver's intrinsic motivation supported them throughout their caregiver experience. Michael expressed, "If you love the person enough, you'll do it. It's kind of what it takes." The caregivers not only had external supports, but they also supported themselves through this challenging experience. Throughout the interviews, caregivers alluded to similar patterns of supports. These positive resources helped them be better prepared to care for their loved ones. They also felt more proficient in their role as a caregiver because of these supports. The narrative slopes created during the interview sessions depict a positive course of life experiences succeeding the initial attainment of their caregiver role.

NARRATIVE SLOPES

Researchers collected supplemental information regarding major life events to provide a visual interpretation in the form of a narrative slope to depict how these caregivers perceived their transition into this new role through the use of the OPHI-II (See Appendix A). Overall, these caregivers plotted their initiation to caregiving negatively. However, as shown through these graphs, throughout their participation in caregiving, they eventually rated their time caring for their loved one as a positive experience within the context of other events in their lives.

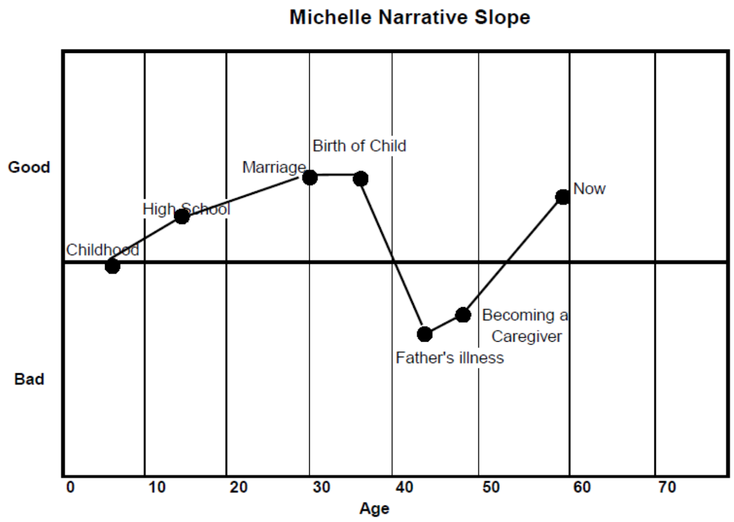

Figure 1. Michelle Narrative Slope

Michelle's narrative slope depicts an increase of positive experiences from mid-childhood until the birth of their first child. A somewhat steep decline in positive experience occurs with the illness of her father. However, there is a slight uptick in positive experience due to her role as a caregiver just prior to turning 50 years of age followed by a continued trend in this positive direction at her current age.

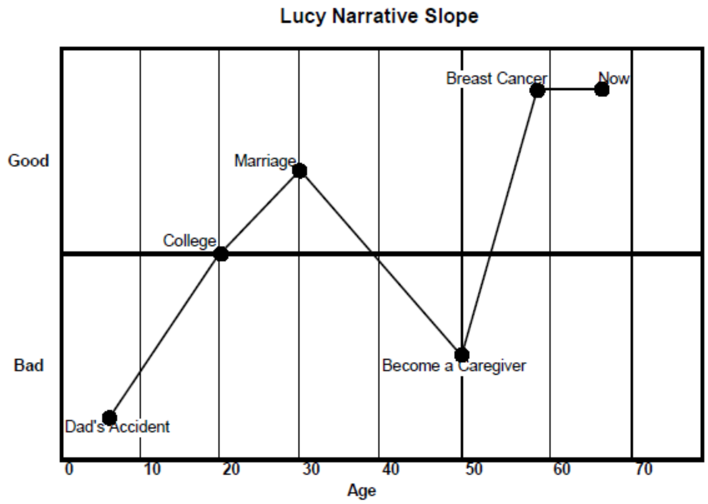

Figure 2. Lucy Narrative Slope

Lucy's narrative slope starts by depicting a gradual increase of positive experiences which she encountered throughout her life. At age 50, she notes taking on the role as caregiver for her loved one with dementia to be her second most negative life event. It is shown that moving forward, she rated the continuum of caregiving on a positive incline. She stated that this caregiving experience gave her a positive outlook on future hardships, such as being diagnosed with breast cancer.

DISCUSSION

Researchers aimed to answer: How do family caregivers of people with dementia experience transitions in their occupations and daily routines? According to Edwards,[7] the increase in caregiving demands may result in added responsibility and mental health concerns. Our findings are consistent with this research and additionally defined responsibilities in the following paragraph. Although there is little research regarding the positive effects of caregiving, our study found through the use of narrative slopes that major life events succeeding the initial attainment of the caregiver role were depicted in a positive trajectory thereafter.

Responsibility

Findings revealed that caregivers had a strong sense of responsibility with respect to becoming a caregiver for their loved one with dementia. They identified a strong sense of obligation to becoming the primary caregiver. This commitment stemmed from the established relationship with their loved one. Caregivers noted that with major responsibility came dissatisfaction with their performance in multiple roles. This is consistent with findings in the literature that explained the caregiver experiences as never feeling satisfactory in any area of life, including caregiving.[8] Caregivers felt inadequate in their caregiver role due to lack of knowledge, sense of unpreparedness, negative emotional responses from their loved one, and trying to meet other responsibilities while caring for their loved one. This coupled with the emotional toll of watching a loved one become progressively more ill was a great source of stress. Caregivers mentioned dissatisfaction in their performance of other roles such as parent, spouse, sibling, friend, and employee. Caregivers felt as if they were overextending themselves and as a result felt as if none of their other responsibilities were being met or if they were being met, it was not to the caregiver's satisfaction. However, each caregiver expressed that they would have done more if they could, such as quitting their job, becoming the full-time caregiver, or making other sacrifices to fulfill their perceived commitment to their loved one.

Occupational Imbalance

Occupational balance can be defined as an equal engagement of physical, mental, and social occupations and how one is able to give meaningful attention to occupations in order for the individual to experience adequate balance.[24] These caregivers' lives are full of occupations but may not include all activities they would like to do. They often found themselves driving their loved one to appointments, completing medication management, laundry, and cooking additional meals. Other meaningful occupations become less of a priority for caregivers as they assume this role. Previous research has found that caregivers become consumed by their new role as caregiver and find themselves choreographing their life around the impact of dementia[6]. Our study found that the caregiver's ability to engage in previous meaningful occupations fades as the role of caregiver begins to take priority over their career, leisure, familial responsibility, and rest.

Application for Allied Health Care Providers

While health care providers may treat the person with dementia, it is also crucial to consider the experiences that their caregiver is confronted with. To address the lack of research, this study defines the relationship between the practitioner and caregiver. Health care providers need to be aware of the change that these caregivers have/are going to experience, increase access to appropriate supports and services, anticipate the range of consequences from caregiving, and encourage the benefits they will experience.

The sense of unpreparedness is demonstrated throughout this entire study. Much of what the caregivers expressed was the feeling of being overwhelmed. Caregivers may have felt less overwhelmed had they been more adequately prepared for the duties of caregiving by providers at the onset. The caregivers in this study all claimed they would have benefited from some measure of education. There were several instances when caregivers expressed this in the form of "if I had known...I would have…" Other caregivers expressed wanting some form of formal training to prepare them for practical elements of care such as assistance with ADLs.

Many of the caregivers described taking on the responsibility in a solitary sense. That is, they were reluctant to recruit other family members for fear of burdening them as well. Although the inclusion of other family members and friends was outside of the scope of this study, they are vital in understanding the breadth of the caregiver experience. Encouraging caregivers to strengthen their social support system for the long term should be a key component of not only occupational therapy interventions, but also the focus of the interdisciplinary care team as a whole.[16] Education regarding what these caregivers and their loved ones will experience, can be used as a powerful tool to involve these family members in an effort to provide an empathetic window to the caregiver's experience. Primary care physicians should continue to educate those undergoing cognitive changes and their caregivers on how these changes may impact their daily routines. Educating the family as a whole could benefit these caregivers by improving their confidence in caring and self-efficacy in this new role. Pharmacists can assist caregivers with understanding medications, their side effects, and the management of medications. Nursing staff can educate caregivers regarding observance and clean-up of mishaps related to toileting, wound management, and vital checks.

Health care providers could use the informal caregiver experience to inform ways to prevent this population from enduring hardships described in this study. The caregivers overall expressed that the limitation of available time was the biggest barrier to seeking resources that would have ultimately helped them cope with the stresses of their experiences. Such concerns lay the foundation for possible program implementation. It may have been beneficial if the caregivers had someone to assist or coach them with strategies while engaging in their day-to-day activities with their loved one. A program where the caregiver could receive some form of on-the-job-like training to develop a skill set that could both train them with practical elements and other relevant coping strategies.

Strengths and Limitations

The study included caregivers who had a wide range of relationships with the loved one but was limited by a lack of variety in partner relationships. The research study consisted of a sample size of eight caregivers. Although this might be considered small, saturation was reached, and findings were confirmed through member checks. Lack of diversity may limit the research; all caregivers were white and located in the Midwestern United States. The study was strengthened by use of narrative slopes to triangulate the data, use of an expert reviewer and enhanced rigor using member checks.

CONCLUSION

Findings confirm that unpaid caregivers of loved ones with dementia experience dramatic changes in many aspects of their lives. Caregivers felt a strong responsibility as a family member to provide care for their loved one. These caregivers' lives are full of occupations, but they are not balanced and may not include what they would like to do. Health care providers should be aware of the change caregivers experience to help increase their supports, prepare them for potential consequences, and facilitate overall positive caregiving experiences. Future research should include larger samples and more diverse participant demographics to better understand lived experiences of all caregivers for individuals with dementia. Potential program implementation of practical experience should be considered.

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APPENDIX A

Semi-Structured Interview Guide

I. Warm Up Questions
    A. Tell me a little bit about yourself.
    B. Tell me a little bit about [the person you care for]. How did that come about (i.e. the decision for you to be the caregiver)?
        1. How would you describe yourself as a caregiver?
        2. How would your loved one describe you as a caregiver?
II. Routine
    A. What do your mornings look like?
    B. What about your days? Your evenings? Nights? Weekends?
    C. How would you say that your daily routine has been impacted by your role as a caregiver? What has changed? What did your routine used to look like?
    D. What is your loved one’s routine? What does their day look like? How much of that are you involved in?
    E. What’s the best part of your daily routine? The most difficult?
III. Occupations
    A. Other than caregiving, what are your major responsibilities? How much does caregiving impact those responsibilities?
    B. What are your favorite things to do for fun? Are you able to do them as often as you used to? What’s different?
    C. What are the things you do on a daily basis to care for your loved ones (i.e. what tasks?)? How do you feel about these things (are they hard? Do they give you a chance to connect?)
        1. How did you learn how to do these caregiving tasks? Did a healthcare provider teach you or did you learn by doing?
    D. What is your favorite thing about caregiving? What is most challenging?
    E. What other daily activities have changed as you have been caring for your loved one?
        1. Are there certain activities you don’t have the opportunity to do but wish you did? Are there new things you do? Do you enjoy those?
    F. How have your roles changed while you have been providing care for your loved one? For example, is it different now to be a parent? Or to be a partner?
    G. What have you gained from caregiving? For example, do you feel a sense of accomplishment while providing care? Have you been able to get closer to your loved one?
IV. Miscellaneous
    A. How prepared did you feel to fulfill the role of a caregiver? What surprised you? What didn’t you expect? What do you wish you had known?
    B. What education and training did you receive? From who? Was it sufficient?
    C. Tell me about the supports you currently have for being a caregiver? What supports do you need?
    D. What would your advice be to anyone at the beginning of the caregiving journey?
    E. What recommendations do you have to healthcare providers to better prepare families for caregiving?

Narrative Slope Interview Guide

Please create your Narrative slope, which is a visual plot of all of your major life events and how you would categorize them on a line plot. Events considered “positive” will be placed above the middle line, events considered “negative” will be placed below the midline.