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Assessment of Needs for Dementia Care Partners Related to Wellness/Fitness Respite Programs

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Abstract

When an individual becomes ill or disabled, it is common for family members to fill the role of caregiver. The same is true in cases where an individual is diagnosed with dementia. Care partners, or care givers, of individuals with dementia are under a great deal of both mental and physical strain due to the debilitating nature of the disease as well as the demands of providing care. As a result, the mental and physical health of care partners often suffers. There are programs, such as respite, that aim to alleviate some of the strain, however there are few existing programs that provide an opportunity for the care recipients to exercise. **Purpose:** The purpose of this study is to identify needs of the care partners related to fitness/wellness centered respite programs. **Methods:** Six care partners of individuals with early stage dementia were interviewed. The interview questions assess the mental/physical strain of care partners as well as their perception of such respite programs. The responses to the interview questions were analyzed through coding. **Results:** Care partners reported spending large amounts of time in their care-giving role, limiting the opportunity to participate in physical activity and contributing to stress. All care partners expressed the need for wellness/fitness based respite programs. **Discussion:** In response to this need, wellness/fitness centered respite programs should be implemented in YMCA facilities and fitness centers/gyms. This would provide care partners with respite as well as an opportunity to positively impact their mental/physical health through participation in physical activity. **Conclusion:** The implementation and development of wellness/fitness based respite programs is necessary to meet the need expressed by care partners.

Keywords: care partner, dementia, strain, physical activity, respite

Introduction

Voluntary caregiving is not an uncommon practice when an individual's spouse or parent becomes ill or disabled. In fact, most often it is family members who provide care for their loved ones (Cordon & Waun, 2015). However, care giving is not an easy process and can place a lot of strain on the individual in the caregiving role. Caregiving can be considered a chronic stressor because it can last for a long time, potentially years, and it requires a high degree of vigilance. This and many other factors, such as financial and relationship troubles, put caregivers at an increased risk of mental and physical strain (Schulz & Sherwood, 2008). Those who care for individuals with dementia, who will be referred to as care partners for this report, face similar circumstances that result from care giving as well as others which stem from the disease itself. For this reason, caring for an individual with dementia is considered to be an even more difficult task (Ory, Haffman, Yee, Tennstedt & Schulz, 1999).

Dementia is an incurable disease in which the cells of the brain die, leading to both cognitive and physical impairments (Swartout-Corbeil & Frey, 2013). The trademark symptom of dementia is memory loss, however, those who have the disease are also at a heightened risk of falling (Langa et al., 2001). In addition, individuals who have dementia are likely to suffer from comorbidities, or the presence of more then one chronic condition (Hurd, Martorell, Delavande, Mullen & Langa, 2013). The diagnoses of dementia have been increasing in recent years and it is estimated that the numbers will continue to increase to 12-16 million by 2050 (Swartout-Corbeil & Frey, 2013). The growing aging population of the United States will also play a role in these increases and, thus, the resulting increase in the number of care partners (Ory et al., 1999).

Compared to care partners of individuals with other diseases or injuries, care partners of those with dementia spend more hours providing care (Ory et al., 1999). As a result, care partners often struggle to meet the demands of their occupation and may need to significantly reduce their hours at work or leave all together. This can create financial struggles for the care partner and place an additional strain on them. Care partners also have less time to spend in social situations (Ory et al., 1999). Care partners are also at an increased risk for physical disease/injury as well as depression and anxiety (Langa et al., 2001). Fortunately there are existing programs to assist care partners or to provide them with a break, otherwise known as respite.

There are various programs that provide education or a break for care partners. However, there are not many programs that utilize exercise. Respite programs that give the individual with dementia a chance to participate in physical activity could be beneficial as they can be mentally and physically stimulated (Mechling, 2008). Implementing such respite programs in health/fitness centers would also give care partners the opportunity to exercise and improve their own health.

Based on the previous information, it is clear to see that care partners face challenges on a variety of fronts. They are under the pressure of providing care as well as the secondary impacts resulting from that very action. There are impacts on their health as well as their overall experience. Although there are existing programs, it seems that wellness/fitness centered respite programs would be a relevant and positive addition.

Prevalence and Impact of Caregiving

Often times, when loved ones become sick or disabled, family members become primary care givers, otherwise known as care partners. In fact roughly 80% of caregiving is voluntary and conducted by family members of an afflicted individual (Cordon & Waun, 2015). The role of caregiving can be highly stressful and often leads to poor health outcomes for care partners. In many cases they neglect their own health and become sick themselves. In fact care partners are at risk for poor physical, mental and financial outcomes including depression, anxiety and exhaustion. There can also be impacts on relationships, employment and leisure activities (Cordon & Waun, 2015).

Previous studies have found that the mean age of care partners, excluding those who provide for individuals with dementia, to be 42.99 while the mean recipient age was 75.65. In addition 72.5% of care partners are women. Also, 7.2% of care partners have a spousal relationship with the care recipient while 48.9% are their adult children. 68.3% are employed while 10.8% are retired (Ory et al., 1999). This data shows that, on average, care partners are women around the age of 42 while they are caring for their parent who is around the age of 72. The average care partner also has multiple responsibilities as they provide care while they are also employed.

Caregiving in general is considered a form of chronic stress as it usually spans a period of years and can be unpredictable. It also requires extensive attentiveness, which often leads to high levels of strain (Schulz & Sherwood, 2008). Again, this strain can lead the care partner to slacken their own personal care physically and mentally, thus leading to an increased risk for illness. Besides the stress of caring, care partners also have stress resulting from their role’s impact on work and relationships, a point which will be further explained in a following section of this report (Schulz & Sherwood, 2008). Care partners of individuals with dementia experience all of the previously mentioned stress inducing situations as well as dealing with issues specifically associated with dementia. For instance, memory is severely impaired depending on the stage in which the individual is. There are also declines in language skills as well as executive function, which includes the ability to make decisions as well as to respond to stimuli (Swartout-Corbeil & Frey, 2013). Those with dementia can also experience changes in their behavior and personality, making them seem like a different person (Mechling, 2008). Therefore, caring for someone with dementia is likely to be even more difficult (Ory et al., 2001).

Dementia Prevalence and Impact

Dementia is a progressive, incurable disease that results from the death of brain cells within the cerebral cortex in a process known as degeneration, leading to loss of attention, learning capacity, social cognition, language and memory. These declines are observed because the cerebral cortex controls one’s actions, thought process, personality and memory. Dementia may also result from brain injury, the HIV infection, frontotemporal degeneration or cerebrovascular disease (Swartout-Corbeil & Frey, 2013). Those living with dementia gradually lose the ability to perform everyday tasks and can experience personality changes at any point.

Individuals who have dementia also have an increased risk of falling (Langa et al., 2001). Fall risk is a substantial concern in the elderly but it is heightened in those with dementia. These individuals are also more likely to experience comorbidities such as diabetes, hypertension or heart disease and cancer (Hurd et al., 2013). Every year there are between four and six million new cases or one diagnosis every seven seconds (Mechling, 2008). In the United States in 2012, there were six million diagnosed cases of dementia. It is estimated that this number will grow to 7.9 million by 2030 and 12-16 million by 2050 (Swartout-Corbeil & Frey, 2013). As the aging population continues to grow, there will be more cases of dementia, which will result in an increased number of dementia care partners (Ory et al., 1999). The increasing prevalence of dementia may be due to the broadening of its definition, which has taken place over recent years. It is now accepted that dementia is not merely the loss of memory but also includes declines in cognitive function, muscular control, and skills relating to language, planning and decision-making. It has also been found that memory loss is not always the first indicator of the disease depending on the form of dementia or the cause. There has also been more research into different types of dementia besides Alzheimer’s, such as Lewy body disease. In addition, dementia is no longer considered strictly a disease of the elderly as 2-7% of Alzheimer’s cases occur before the age of sixty and are therefore considered to be early onset (Swartout-Corbeil & Frey, 2013).

Caregiving and Dementia

Caring for an individual with dementia is complicated and can stretch over a time span of years in which care partners are responsible for all physical and emotional needs of the care recipient (Swartout-Corbeil &Frey, 2013). It has also been found that the degree of severity and hours of care have a significant positive relationship. Compared to care recipients who have a disease or impairment other then dementia, those who have mild dementia require 8.5 more hours of care each week. Moderate level cases require 17.4 more hours and severe cases require 41.5 more hours each week (Langa et al., 2001). Overall, dementia care partners also spend significantly more time providing constant care, roughly 40 hours or more per week (Ory et al., 1999). As a result of these demands on care partner’s time, they often experience problems related to their occupation. Due to the inability to give the required time to their occupation, many care partners resign in order to get a less stringent job, turn down promotions or retire early (Ory et al., 1999). The impacts of occupational strain are troublesome considering that the financial effects further contribute to care partner outcomes.

Income is a predictor of both physical and emotional strain for care partners (Ory et al., 1999). Thus, having a lowered income as a result of occupational changes or early retirement can have huge impacts on the care providing experience. Generally the costs associated with dementia care are institutionalization and home based care conducted over the duration of the disease (Hurd et al., 2013). For the purpose of this report, institutionalization is not further explored. Home based care consists of all aspects of care for which a care partner is responsible. This includes medical costs as well as household costs and assisting the care recipient in daily activities. Balancing all costs on one income, which may be lowered as previously stated, is certainly a source of stress. In 2010, the estimated cost of dementia in the United States ranged from 157-215 billion dollars. Of this cost, Medicare covered about one billion dollars according to the Health and Retirement study (Hurd et al., 2013). For each care partner, it is estimated that the cost of care per year, depending on the case, it about 1,500-35,000 dollars (Langa et al., 2001). These costs are a huge financial strain, especially for those who don’t have supplemental health insurance to pay for what Medicare doesn’t cover. For those without such insurance these costs must be paid out-of-pocket.

The role of a dementia care partner also has negative social effects. Caring for someone with dementia can be an engulfing experience that takes up the vast majority of one’s time. In many cases this leaves little room for socialization. Dementia care partners are more likely to report negative outcomes compared to non-dementia care partners, especially regarding their social lives. 55% of dementia care partners report giving up their leisure time activities compared to 40.9% of non-dementia care partners. They are also more likely to report spending less time with family members (52%) compared to non-dementia care partners (38.1%) as well as to report that their family members do not contribute enough to care (Ory et al., 1999). The high reporting by dementia care partners of social isolation is a considerable problem especially since social support is predictive of care partner stress levels. In fact, care partners who report more close relationships outside of the care relationship also reported being more satisfied with their lives overall (Haley, Levine, Brown & Bartolucci, 1987).

Caring for an individual with dementia is a stressor in itself due to the effects of the disease. Dementia is cognitively debilitating, creates behavioral problems and limits one’s ability to care for themself or perform everyday tasks over time (Haley et al., 1987). As the disease progresses, the care recipient requires increasingly attentive care and also becomes less likely to show gratitude for the help they receive. In some cases this may make caring seem more tedious or make the care partner feel alone. A care partner’s perception of the amount of suffering the recipient is enduring also plays a role on stress levels (Schulz & Sherwood, 2008). This is an understandable component to a care partner’s overall experience and stress levels. Care partners are generally caring for someone who they love and are close to. Watching a loved one suffer over time, or perceiving that they are enduring a great deal of suffering, is likely to cause the care partner to feel stressed as there is only so much they can do to help them. All of these factors can contribute to a care partner’s stress in their role. The increasing demands may also cause care partners to overlook their own health. All of these factors as well as the previously discussed financial difficulties, lead dementia care partners to a higher likelihood of physical and mental strain compared to non-dementia care partners. In fact care partners are 22.3% more likely to experience mental strain, such as depression, and have a 12.6% higher likelihood of mortality (Ory et al., 1999) (Langa et al., 2001). In an attempt to limit the negative health impacts of caring for individuals with dementia, many intervention programs have been implemented.

Existing Programs

To begin, there are various programs that are generally used to aid care partners and the care recipient. Some are geared towards education and information while others strive to create a sense of community. Some examples of existing programs are as follows:

- Case management programs focus mainly on advising and providing care partners with information pertaining to their situation.
- Psycho-education follows an orderly format that gives information pertaining to stress coping strategies and methods of behavior management.
- Pharmacotherapy uses medications to control behavior, decrease depression and stabilize the progression of the disease in the care recipient.
- Support groups provide care partners, as well as the care recipient in some cases, with a sense of community and support within the group.
- Combination programs include components of multiple programs.
- Respite programs provide care for the care recipient so the care partner is able to take a break.

(sörensen, Duberstein, Gill & Pinquart, 1987).

Looking at those in the early stages of dementia and their care partners, there are few programs aimed specifically at their needs. One program that addresses this need is the Memory Club, which was created in California. This program provides a time for care partners, and the care recipients, to be around people in the same situation. They are also given resources, educated on ways to address other relationships and taught strategies for problem solving. However, one of the most impactful components is the aspect of socialization (Zarit, Femia, Watson, Rice-Oeschger &Kakos, 2004). This is similar to a local program called the Memory Café. Memory Cafes provide a monthly meeting time for care partners and the individual with dementia to socialize in a safe, non-judgmental space. They participate in activities and discussions, while enjoying a feeling of community. The programs previously listed are not one size fits all. The best program for a given care relationship depends on the situation in which that relationship exists. Even with such programs, care partners may still feel overwhelmed and in need of a break. Another family of programs has been developed for this very reason.

Respite programs are used so that the care recipient can be under sufficient supervision for a given amount of time while the care partner takes some time to step out of their role, essentially taking a break (Cordon & Waun, 2015). Respite is essential in that it gives care partners time to step away from their strain so they can reduce their stress. Besides using the time to relax, care partners can also visit with other family or friends, take care of errands or work. Respite enables care partners to socialize, exercise or take time for their mental health because they know their loved one is safe. Care partners participating in respite also have higher quality of life and lower levels of stress and depression (Cordon & Waun, 2015). However not many respite or alternate programs are incorporating fitness into their programming. This is important to note as fitness may have a positive impact on the caregiving experience as well as care partner health.

Fitness Centered Respite Programs

Individuals who have dementia are at an increased risk of muscle atrophy due to the fact that they are likely to be less physically active. Regular exercise can help to limit this process. It is recommended that individuals with dementia adhere to a walking program of 15-20 minutes per day or, in mild cases, to elongate this to two 60 minute sessions a week (Mechling, 2008). However, a fitness based program that incorporates exercises other then walking may be even more beneficial as they can reduce anxiety, increase balance, reduce the number of falls and help to keep biological systems healthy (Mechling, 2008). Physical activity may also slow cognitive declines in those with dementia. Fitness classes for individuals with dementia also enable them to socialize while being mentally stimulated. Often times, these individuals are not given the opportunity to participate in mentally or physically stimulating activities (Mechling, 2008). Creating these fitness programs as respite is ideal, especially in health/fitness clubs because it would also give the care partners a chance to focus on their own health if they so choose. Care partners may also find their care giving role less stressful as the care recipients would make physical gains as a result of such programs, making it easier for them to perform functional tasks in daily life while also reducing injury risk.

The Andover/North Andover YMCA is implementing a pilot program entitled Revive and Thrive. The pilot consists of six one hour weekly sessions in which care partners receive respite. The Andover Memory Café coordinator and Merrimack College graduate interns lead the care recipients through a series if relaxation, mental and physical activities. These include stretching and yoga as well as Brain Gym, strength and balance exercises. Stretching and yoga are implemented at the start and finish of each session in order to have a sense of routine as well as to relax the members and prepare them for the following activities or to rejoin their care partners. Brain Gym exercises are used every session as well, typically utilizing one or two exercises. These exercises are designed to activate both sides of the brain through movement. One example is the seated cross-crawl. This exercise requires the individual to touch their elbow/hand to the opposite knee, crossing the midline of the body. The strength component of the exercise varies as well. Participants may participate in body weight exercises, such as hamstring curls, or they may stretch resistance bands to work their arms and shoulders. Balance exercises utilize activities such as heel to toe walking. Through these exercises, the participants are socializing, being cognitively stimulated and improving their strength and balance.

Revive and Thrive also allows care partners a time of respite. Care partners who are members can participate in any exercise class offered by the YMCA or exercise in the open fitness areas. Care partners can also attend seminars held at the YMCA, whether they are members or not. Even if they do not feel like exercising every time, care partners can use the time to socialize with one another either sitting in the café or leaving the YMCA facility. The most important thing is that they are able to use the time to step out of their care giving role and decompress in a manner that they see fit.

The presence of the Revive and Thrive program as well as the general lack of respite programs using the component of fitness set the stage for the present needs assessment, the aim of which is to determine if care partners of individuals with dementia express the need for such programs.

Summary

In summation, the role of care partner can have various health impacts both mentally and physically. The constant providing of care and demands on their time often lead care partners to neglect their own health. Respite programs can be very useful as they can help to lower the levels of stress and strain under which care partners often find themselves.

The Andover/North Andover YMCA has begun to implement a new kind of respite program entitled Revive and Thrive. This program allows the individuals with dementia to exercise and socialize in a safe, positive environment so that their care partners are able to step out of their role temporarily. It also gives them the chance to exercise on their own if they so choose because the facility in which Revive and Thrive is held offers a variety of formats for physical activity.

Exercise has the potential to improve the mood of individuals with dementia as well as to help strengthen them physically, which could help make daily activities easier and reduce the risk of falling. This could in turn make providing care easier. This poses the question of whether care partners would be interested in participating in wellness/fitness cantered respite programs. The purpose of the present needs assessment is to answer this question by addressing it with care partners. When completed, the data gathered will be vital to providing appropriate facilities with necessary information to ensure that future programs will be as impactful as possible while meeting the perceived needs of care partners.

Methodology

Participants

The participants for the needs assessment were care partners of individuals with early stage dementia. Ideally, 15-20 participants would have selected using the convenience sampling method, however, only six care partners agreed to participate. The care partners selected care for an individual with early stage dementia who is either their parent or spouse. Those caring for individuals with advanced dementia were not selected for the needs assessment. The aim was to sample care partners with varying backgrounds who are in the age range of 40-70.

The participants were recruited from dementia service programs within the community including: care partners whose care recipients are members of the pilot Revive and Thrive program at the Andover/North Andover YMCA and those who attend Memory Café meetings offered in Andover. Additionally, as needed, members of the community who care for an individual with dementia were asked to participate in the needs assessment. Care partners from Revive and Thrive were asked, in person, to participate in the study while those from the Memory cafés and community were asked via email.

Measures

This needs assessment measured the strain under which care partners find themselves and their perception of the benefits of fitness on the care recipients as well as their overall need for wellness/fitness centered respite programs. To attain these measurements qualitative methods were used. An interview was conducted in person with the care partners who are part of the Revive and Thrive program, Andover Memory Café and general community. The researcher designed the interview.

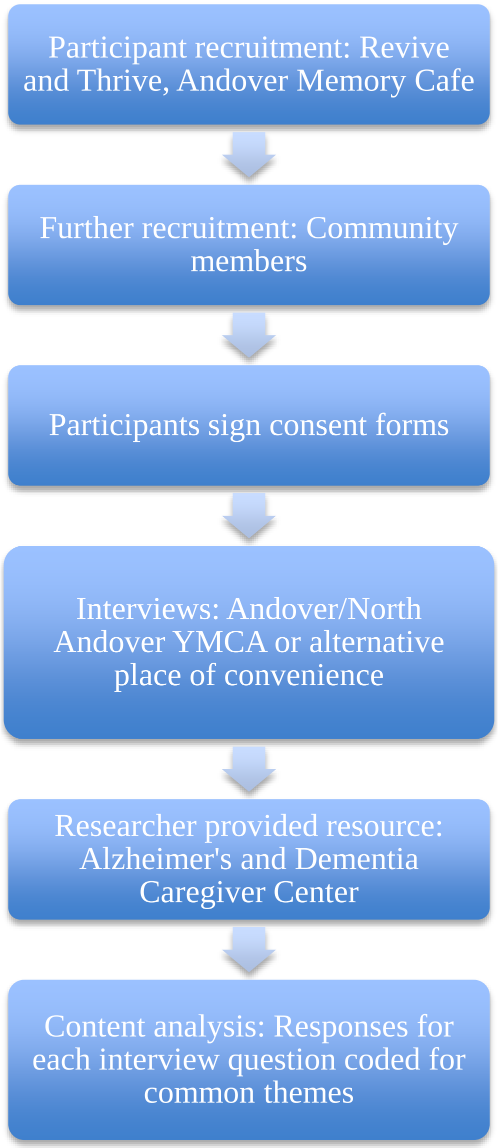
The interview was conducted using open-ended questions to assess the physical and emotional strain/health as well as their life satisfaction. The interview also helped to obtain the number of hours of care per day that the care partners provide and how much time they spend out of their care-giving role per week. For example, “How many hours per day are you NOT providing care?” There were also questions to get a sense of their perception of how physical activity for the care recipient may positively impact their care giving role such as “Are you aware of the possible positive impacts of physical activity on your care recipient or the caregiving relationship?” Finally the care partners were asked if they feel that respite programs that incorporate physical activity are a relevant service that should be more widely utilized.

Procedures

After agreeing to participate the participants were assured of confidentiality and signed a document of informed consent. The graduate student researcher met with all but one of the care partners from Revive and Thrive, Memory Café and community in person to conduct the interviews. The sixth participant participated in a phone interview. Care partners were asked if the researcher could record them for later referral. The researcher also took handwritten notes of the care partner’s answers to the questions. The interview process took 20 to 30 minutes, however, the researcher did not rush the care partners or cut the process short in order to meet this time constraint. Resources were provided for the participants in case they felt the need to reach out to a professional to discuss any emotional responses resulting from the process. This included the Alzheimer’s and

Dementia Caregiver Center web address (www.alz.org/care/) as well as their 24/7 helpline number (1-800-272-3900). After the interviews had been conducted the researcher analyzed the data. Figure 1 below is a flow chart depicting the procedures of the needs assessment.

Figure 1. Flow chart depicting the methodology of the needs assessment



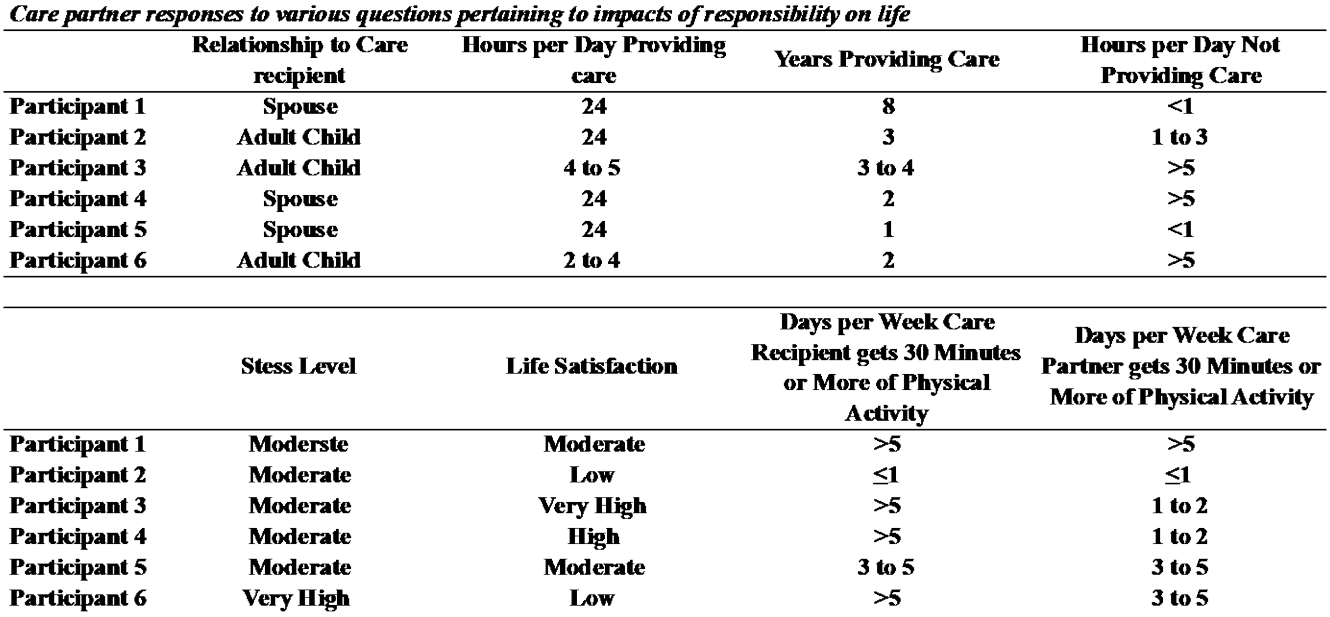
Data Analysis

The data obtained from the interviews was compared together. The statements for each question were looked over and reoccurring themes and categories were identified. Next these themes were coded through content analysis. These code categories will be described in the results section with specific examples provided. Comparisons between the spousal and adult child care partner responses to questions pertaining to occupation, desire for physical activity and time use for exercise were compared directly. From this, the researcher drew conclusions based on the responses and the perception of need for dementia respite programs that incorporate physical activity.

Results

21 care partners were asked to participate, however only 6 volunteered to participate contributing to the low participation rate of 28%. Out of the care partners selected, three have a spousal relationship to their care recipient while three are the adult child of their care recipient. This and other descriptive information about each care partner pertaining to the impacts of their caregiving role on their lives is depicted in table 1.

Table 1.



Care partner responses to various questions pertaining to impacts of responsibility on life

	Relationship to Care recipient	Hours per Day Providing care	Years Providing Care	Hours per Day Not Providing Care
Participant 1	Spouse	24	8	<1
Participant 2	Adult Child	24	3	1 to 3
Participant 3	Adult Child	4 to 5	3 to 4	>5
Participant 4	Spouse	24	2	>5
Participant 5	Spouse	24	1	<1
Participant 6	Adult Child	2 to 4	2	>5

	Stess Level	Life Satisfaction	Days per Week Care Recipient gets 30 Minutes or More of Physical Activity	Days per Week Care Partner gets 30 Minutes or More of Physical Activity
Participant 1	Moderste	Moderate	>5	>5
Participant 2	Moderate	Low	≤1	≤1
Participant 3	Moderate	Very High	>5	1 to 2
Participant 4	Moderate	High	>5	1 to 2
Participant 5	Moderate	Moderate	3 to 5	3 to 5
Participant 6	Very High	Low	>5	3 to 5

All of the spousal care partners, along with one adult child care partner, reported providing care 24 hours a day, 7 days a week. Two-thirds of adult child care partners reported providing care between 2-5 hours a day. When asked about the amount of time not providing care, most care partners reported that they only spend a short amount of time out of their caregiving role, noting that even during this time they are still close by. Another common response was that the majority of time spent not providing care occurs at night when the care recipient is sleeping.

As a result of the time demands that result from providing care, and the lack of time spent outside of their role, the care partners have had to give up activities they previously found enjoyable such as hobbies or spending time with friends. One care partner stated, “I just feel like sometimes resentful because I don’t feel like I have much of a life.” Every care partner except one is currently utilizing some form of respite.

Examples of respite included adult day programs, support groups and home visits from nursing agencies.

Pertaining to questions regarding the impacts of care giving on mental and physical health, a common response was that the caregiving role is mentally draining. Care partners also reported that they are not in the physical shape they feel they would be if not for their role as a care partner. The adult child care partners gave this response more often. One care partner is the exception to such statements as she feels she is more physically active due to her role. She involves her care recipient in various programs at the Andover/North Andover YMCA and joins in as well. Overall, three care partners stated that they have not experienced any mental or physical ailments since assuming the role of care partner. However, one of the care partners stated that since becoming a care partner, he has been diagnosed with cancer and believes it to be directly linked to his role.

"I got cancer. I think it's a direct result."

In relation to stress the care partners rated their levels as moderate. There was only one outlier who rated their stress as very high. However, this care partner has other circumstances unique to her life that contribute to her overall stress levels. These factors are separate from this individual's role as a care partner and, although they contributed to the stress rating, are not in alignment with the purpose of the assessment of need in this population. There are many factors that the care partners repeatedly named as components of their overall stress. All participants are strained by the fact that they are constantly in their caregiving role and must remain attentive to the care recipient at all

"I feel like I have to be vigilant constantly. I have to know where he is, what he's doing, it's very hard to relax."

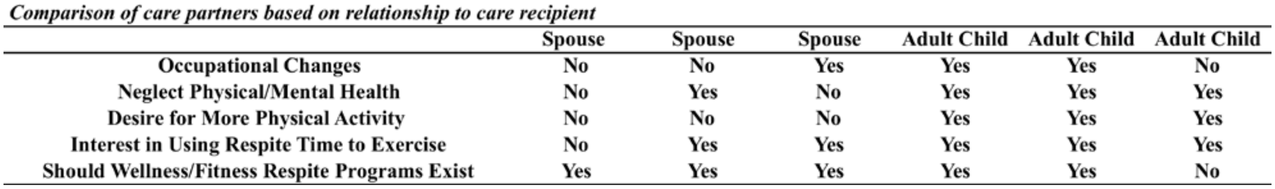
times. Care partners reported feeling unable to live how they would like to. Stress was also attributed to the unpredictability of care recipient behavior. One care partner touched upon her feelings regarding the disease itself, stating, “I think the overwhelming-ness of his condition…the fact that there’s no cure…I get exacerbated.”

Overall, care partners reported that their care recipients generally get more physical activity during the summer. The number of days per week that care recipients get 30 minutes or more of physical activity varied. It was reported that 66% of care recipients get 30 minutes of physical activity 5 or more days a week compared to 15% of care partners. However, physical activity was commonly attained through walks or activities of daily life. Structured physical activity was mentioned far less often. Care partners also commonly stated that the care recipients participated less in physical activity, especially walking, during the winter.

When asked if aware of the possible positive impacts that physical activity may have on care recipients or the caregiving relationship, the vast majority of care partners responded that they were aware. However, when asked if they believed an exercise based respite program would make their caregiving role easier, only three care partners responded yes. One care partner was not sure while the remaining two believed such a program would not make their role easier.

A direct comparison of care partners, based on their relationship to their care recipient, can be seen in table 2, where 50% of the care partners have a spousal relationship to their care recipient and 50% are the care recipient’s adult child. 1/3 of the spousal care partners had to make occupational changes compared to 2/3 of adult child care partners. When asked if they neglected their own mental and/or physical health, 2/3 of spousal care partners stated that they did not while all of the adult child care partners confirmed mental and/or physical neglect.

Table 2



Comparison of care partners based on relationship to care recipient

	Spouse	**Spouse**	**Spouse**	**Adult Child**	**Adult Child**	**Adult Child**
Occupational Changes	No	No	Yes	Yes	Yes	No
Neglect Physical/Mental Health	No	Yes	No	Yes	Yes	Yes
Desire for More Physical Activity	No	No	No	Yes	Yes	Yes
Interest in Using Respite Time to Exercise	No	Yes	Yes	Yes	Yes	Yes
Should Wellness/Fitness Respite Programs Exist	Yes	Yes	Yes	Yes	Yes	No

None of the spousal care partners have a desire for more physical activity participation. All of the adult child care partners confirmed having a desire for increased physical activity. However, 2/3 of the spousal care partners and all of the adult child care partners stated that they would be interested in using respite time to exercise if wellness/fitness centered respite programs existed in fitness centers/gyms.

Finally, when directly asked if exercise based wellness/fitness centered respite programs that give care recipients the opportunity to exercise should exist, all but one care partner responded yes. The single outlier in this case is the same outlier who rated their stress level as very high and believed that such programs would not make the caregiving role easier.

Discussion

Study Findings

The findings of the present study are in alignment with much of the previous research. Many of the care partners, especially those that are the adult child of their care recipient, had to retire early from their jobs and also expressed that they did not have enough time for hobbies or visiting with friends as a result of the time demands of their role. Adult child care partners also shared that they were unable to exercise as often as they would like. In total, over 50% of care partners stated that they neglect their mental and/or physical health as a result of the demands of their care-giving role. Care partners also contributed stress to the constant time in their roles and the need to be vigilant at all times. All of these factors show that care partners are under a great deal of stress from multiple sources and that respite can play a role in easing some of this stress.

The lack of time spent participating in enjoyable activities or exercising can take a toll on the mental and physical health of care partners while the constant responsibility can become exhausting. This places care partners at a higher risk for poor health outcomes. The increased risk necessitates increased physical activity as exercise can help to support both aspects of health.

When questioned specifically about physical activity care partners reported that care recipients get less physical activity in the winter and that they do not get 30 minutes or more of physical activity five days per week themselves. Much of the physical activity for both groups was attributed to activities of life or chores and taking walks outside. Wellness/fitness centered respite programs that give care recipients the chance to exercise would allow for more structured physical activity throughout the year for care partners as well as their care recipients. Furthermore, the existence of these programs would also provide more time for care partners to exercise while also enabling them to decompress. In this way, care partners would be able to have respite from providing care and attend to both their mental and physical health. Most importantly, all of the care partners, except for one outlier, expressed the need for wellness/fitness centered respite programs to be implemented, supporting the relevance of such programs.

Previous Research

Previous research has shown that caring for an individual with dementia contributes to elevated levels of stress for care partners based on various factors. Caring for an individual with dementia requires extensive amounts of time (Ory et al., 1999). Often times, as a result, care partners must make occupational changes such as retiring early. Care partners also have less time to participate in activities they enjoy or to socialize (Ory et al., 1999). Studies have shown that care partners tend to overlook their own mental and/or physical health (Cordon & Waun, 2015). As a result, care partners are at an increased risk for illness as well as depression and anxiety (Schulz & Sherwood, 2008) (Cordon & Waun). All of these factors contribute to care partner stress. Although there are various programs, such as support groups and respite, to help reduce this stress, there are not many existing programs that utilize physical activity (sörensen, Duberstein, Gill & Pinquart, 1987). Wellness/fitness centered respite programs would be beneficial for care partners as participating in physical activity can have positive impacts on both mental and physical health.

Applications

The Andover/North Andover YMCA should continue to utilize and develop Revive and Thrive as it is leading the way for the implementation of such programs. Efforts to increase the number of members in the program should be continued in order to reach more care partners through facilities such as senior centers, physician offices or the local Alzheimer’s Association chapter. Continued outreach will also raise awareness for wellness/fitness centered respite programs within communities. Extending the program to other YMCA locations will also help to reach and serve care partners in other areas.

The establishment of wellness/fitness centered respite programs in fitness centers/gyms would create another opportunity for care partners, as well as their care recipients, to exercise. Such programs could reach care partners that don’t belong to a YMCA. Wellness/fitness centered respite programs in fitness centers/gyms can also make this service accessible to areas without YMCA facilities within reasonable distance.

Having wellness/fitness centered respite programs in multiple locations would fill the need that care partners have for such programs by providing them with both respite and the opportunity to exercise if they so choose. This is supported by the fact that care partners reported that they would be interested in using respite time to exercise and that they are aware of the possible positive impacts of physical activity on care giving relationships.

Strengths

The strength of the study can be attributed to the recruitment of care partners from various sites such as the Andover/North Andover YCMA’s Revive and Thrive, Andover Memory Café and greater community. Just as care partners within communities utilize various programs, the care partners in the sample also use different services. The findings are also supported by and in alignment with previously conducted research. The findings of the present study support the continued development of the Andover/North Andover YMCA Revive and Thrive wellness/fitness centered program. Revive and Thrive should continue to be implemented, as it is an innovative program that can lead the way for other fitness centers/gyms in implementing similar programs. The expansion of such programs into other fitness-based locations will provide care partners more opportunity to exercise if they so choose.

Limitations and Future Research

Limitations of the present study include the use of convenience sampling and the small sample size. As a result, the sample was not representative of the greater population and, therefore, the findings are not generalizable.

Future studies should obtain larger samples that are representative of the greater community to allow for conclusive, generalizable results. More extensive recruitment that is open to care partners with relationships to care recipients besides being a spouse or adult child may aid in obtaining a larger sample. Further recruitment extension to neighboring communities and programs may be helpful as well.

Conclusion

Care partners are under a high amount of stress that places them at an increased risk of poor mental/physical health outcomes. The care partners in this sample have expressed the need for wellness/fitness centered respite programs to be more widely utilized although further research is necessary to conclude if this need is expressed within the greater community. However, the expressed need for wellness/fitness centered respite programs by care partners supports the continuation and development of the Andover/North Andover YMCA’s Revive and Thrive program.

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Appendix A

Consent Form

MERRIMACK COLLEGE

INFORMED CONSENT

CONSENT TO PARTICIPATE IN RESEARCH PROJECT ENTITLED: Assessment of Care Partner Needs for Dementia Centered Wellness/Fitness Programs

Principal Investigator(s): Mary McKeown

You are invited to take part in a research study examining the need of dementia care partners (caregivers) for wellness/fitness centered respite programs, which provide care recipients with the opportunity to participate in physical activity. You have been asked to be in this study because you are a care partner of an individual who has early stage dementia.

<u>Procedures</u>: If you choose to participate in the study, you will be asked to participate in an interview. The interview contains questions about your relationship to the care recipient as well as the effects of the caregiving relationship. These effects include stress levels, mental and physical impacts as well as information pertaining to the care partner's social life and physical activity along with that of the care recipient. The interview will take approximately 60 minutes to complete.

For the accuracy of data collection and to ensure that remarks made are accurate, this session will be audio recorded. These recordings will be transcribed with no personal identifiers included and then destroyed. If you are not comfortable being audio recorded please inform the investigator prior to starting the interview. It is your right to not be recorded if you so choose. You may at any time ask the investigator conducting the interview to turn off the recorder. If there are certain questions you have answered that are recorded but after the fact feel uncomfortable, you may ask to have that content erased from the recording.

<u>Benefits</u>: This study may be of no direct benefit to you, but it will improve our knowledge of the level of need of dementia care partners for wellness/fitness based respite programs. The questions may help you to see a need for such a program and further explore opportunities for physical activity participation for yourself and the care recipient.

Potential Risks: There are no inherent physical risks in the procedures themselves, and it is not anticipated that participants will experience risks in completing the interview. Participants will not be exposed to any more risk of harm or discomfort than those ordinarily encountered in daily life. Occasionally, an individual may be more aware of ongoing stresses as a result of completing the interview. If this is the case, you are free to discontinue completing the interview at any time. In addition, information about supportive professional counseling services will be made available should you be interested.

Confidentiality: The information from the interview will be used for research purposes only. Your responses will be identified by a number and the identity of any participant will be kept confidential. In addition, your name will not be used in any reports or publications of this study.

Freedom of Choice to Participate: You are free (1) to decide whether or not to participate, (2) whether or not to be recorded (at any time) if you choose to participate and also free (3) to withdraw from the study at any time. A decision not to participate will not adversely affect any interactions with the investigator or any representative/employee of Merrimack College.

Questions: Before you sign this form, please ask any questions on any part of this study that is unclear to you. You may take as much time as necessary to think this over. At any point in the study, you may question the Principal Investigator about the study (include name, phone number, and email address). In addition, you are free to contact the Institutional Review Board Chair, with any questions (irb@merrimack.edu).

Consent: This project has been explained to me to my satisfaction and in language I can understand, and I have received a copy of this consent form. I understand what my participation will involve and I agree to take part in this project under the terms of this agreement. I understand that I am not giving up my legal rights by signing this form.

____ ____________________

Signature of Participant Date

____

Printed Name of Participant

____ ____________________

Signature of Investigator/Designee Obtaining Informed Consent Date

Interview

1. What is your relationship to your care recipient?
2. How many hours per week do you spend providing care?
3. How long have you provided care to the care recipient?
4. Do you utilize any respite programs? If so what kind?
5. If so, does the respite program allow you time to exercise if you so choose?
6. How many hours per day are you NOT providing care?

   _Less then 1 hour _1-3 hours _4-5 hours _More then 5 hours
7. Have you had to make any occupational changes or retire early as a result of your caregiving role?
8. How would your rate your stress levels?

   _Very Low _Low _Moderate _High _Very High
9. How would you rate your overall life satisfaction?

   _Very Low _Low _Moderate _High _Very High
10. Do you neglect your own physical and/or mental health?
11. What factors contribute to your levels of stress/strain?
12. Have you developed any mental/physical ailments since becoming a care partner?
13. Are you aware of the possible positive impacts of physical activity on your care recipient or the caregiving relationship?
14. Has your care recipient had any losses in strength or balance?
15. Does the physical weakness of the care recipient make activities of daily life increasingly difficult (dressing, sitting, standing up, bathing, ect.)?

16. How many days per week does the care recipient get 30 minutes or more of physical activity?

    _One day or less _1-2 days _3-5 days _More then 5 days

17. Do you wish you had more time to exercise?
18. How many days per week do you get 30 minutes or more of physical activity?

    _One day or less _1-2 days _3-5 days _More then 5 days

19. Have you had to give up any activities you find enjoyable?
20. Do you think there should be exercise based respite programs in which your care recipient has the chance to be physically active?
21. Do you think such a program would make your caregiving role easier?
22. If such programs existed in a fitness center/gym, would you be interested in using the time to exercise?