Caring for the Elderly and Their Informal Caregivers

Amber Dunn

Oswego State University

Dr. Laura Brown

Applied Research Methods in Gerontology
Abstract

This program proposal describes a twelve month, two hour a week program for informal caregivers and the elderly individuals they care for. The program combines the importance of education and support for the participants. This proposal describes that despite past program proposals, many lack the involvement of the elderly during the program process. Therefore, this program is not limited to the caregivers. Support and activities are available for the older individuals during the caregiver’s two hour sessions. Through positive results in past research, this program utilizes the creation of informal caregiver support groups, creating adult friendships and constant support, even after the formal program is over. The proposal of this program introduces both the short and long-term goals and results possible through its implementation.
I. Introduction: Caring for the Elderly and their Informal Caregivers

Statement of the problem

Relatives, friends and other people who are informal caregivers are a large proportion of the support and assistance needed by the elderly. Approximately eighty percent of the care for the elderly is provided through informal caregivers; family or friends (Ferrini, 1993) This percentage is likely to increase considering the approximately seventy eight million older individuals entering the ages of sixty five and over from the baby boomers generation; which began in January of last year (Hellmich, 2010).

Besides the obvious challenges of the baby boomer generation aging due to their size in numbers, there will also be challenges in informal caregiving due to the top heavy family tree. The top heavy family tree is explained by the birth of the baby boomers along with their many siblings. However, when the baby boomers became adults, they had few children; which will lead to less support for the baby boomers’ children if they become informal caregivers for their parents. The incoming baby boomer generation drastically emphasizes the need for education and support of informal caregivers for a better future for all involved.

Caregivers are a diverse group of people, from their cultural backgrounds, to their relationship to the person they care for. However, caregivers tend to have one thing in common, they are overworked and overwhelmed. Becoming an informal caregiver is not typically something someone aspires to be one day since it is challenging, time consuming and typically unpaid. Of the individuals who are informal caregivers, roughly one third of them spend over forty hours each week in direct care with the older
individuals they care for (Neidhardt, & Allen, 1993). The large number of hours that caretakers put into their role of caretaking truly expresses their need of support.

The drawback of caregiving is not only in the number of hours that the caregiver puts in, but many other factors affect them as well. Informal caregivers can be negatively affected financially, such as having to spend money on the older individual they care for, or even personally, by losing relationships or stirring up previous family issues. Informal caregiving is an emotional and physical drain for most. Studies have shown that the majority of caregivers tend to show signs of depression, even a major depression disorder in some cases (Mohide & Streiner, 1993). The presence of mental and physical exhaustion of caregivers emphasizes the need for programs to relieve these issues and create a healthier lifestyle for both the older individual and caregiver.

Informal caregivers play an important role in the life of the elderly (Hallberg & Hellstrom, 2004). Therefore, it is important for these caregivers to be supported and educated to maintain their caregiving role. Caregivers find themselves in a position of caring for someone they love and struggling along the way, through lack of education, resources, support, or all of the above. If these caregivers are given the care they need, it would not only benefit their own lifestyles, but the people they care for as well.

Theoretical framework

There are several different theories that could thoroughly analyze and benefit the exploration of this caregiving program. However, the Life Course Theory ideally examines the aspects necessary in this program to effectively educate and support the caregivers and elders who participate. The Life Course Theory not only examines how cohorts react differently to situations, but how people react to life transitions in the aging
process. This is a multidimensional theory that analyzes the aging process not only for
the individual but integrates family interactions as well (Alley, Bengtson, Putney, 2005)
The Life Course Theory analyzes how events and aspects of one’s life occur
simultaneously, and how that affects a person.

The Life Course Theory is supported by Bronfenbrenner’s Ecological Model.
This model expresses each of the aspects of one’s life by displaying the individual in the
center of the model and the different aspects of his or her life as rings. As the rings get
further from the individual, they become less physically or emotionally close, but that
does not mean they are not as influential. The rings are described as the micro-system
(close family), the meso-system (religious involvement), the exo-system (government),
the macro-system (beliefs and values), and finally the chrono-system (cohort). Each of
these systems plays a major role in a person’s life. Therefore, this theory thoroughly
examines the different aspects of an individual’s life and how they interact
simultaneously (Brown, 2011).

The Life Course Theory describes the challenges for the informal caregiver in
terms of his or her role status. The three challenging role situations are role strain, role
conflict, and role overload. An adult child who is caring for their parent who abused
them during their childhood may feel conflicted between events of the past and their
feeling of obligation to care for their parent. Sibling conflicts may also occur during the
caregiving process. If one adult child is the caregiver and feels as though their siblings
are not performing their share of the caregiving, this may cause role strain along with
strain in the overall family system (Power, Robertson-Tchabo, Smith, & Tobin, 1995; p.
Each of the examples is a description of role strain. Avoiding role strain is crucial to maintaining a satisfactorily family dynamic.

Role conflict on the other hand, occurs when two roles a person holds are clashing. An individual who is an informal caregiver and works a full-time career may experience role conflict. Through this experience, the individual may be at work, but receive a call that his or her parent is sick and needs a ride to the doctor. If an informal caregiver frequently receives phone calls from or for the elderly person they care for, his or her boss may become less tolerant or flexible of the situation, increasing stress in balancing both roles (Brown, 2011).

The final challenging role position is role overload, where an individual is overwhelmed. An individual with role overload may be a parent, spouse, employee, friend, and a caregiver. With the challenge of being in role overload, the individual tends to sacrifice his or her own time and money to keep up with all of his or her role responsibilities. Despite the differences between the separate role challenges, each of them is challenging and should be addressed to avoid detrimental stress (Brown, 2011).

Through the Life Course Theory, older individuals who participate in the program not only will be likely to gain a healthier and happier lifestyle as they age, but also will have the opportunity to assess to personal issues with their family. As discussed previously, as older adults age and need assistance, there may be previous family tensions that need to be addressed. The family can work calmly and productively together in the caregiving process with this program.

The Life Course Theory examines how this caregiving program not only benefits the elderly, but also the people who care for them. While the program will benefit the
individual’s health and well-being, it will also benefit the family system through therapy and developing communication.

*Review of the Literature*

In the aspect of informal caregiving, many programs have been created to educate and support the well-being of the caregivers. Researchers, Scultz, Smyrnios, Schultz and Grbich (1993) introduced an educational and support program to observe the long-term impact on caregivers. The year long program provided their services and later observed the results of participants increased knowledge, improved psychological well-being, and a stable anxiety level. Although this program was effective in creating a long-term educational and support program, it lacked the formation of an informal support group after program completion. Even though the program ended, the participants’ need of emotional support continues.

On the other hand, there have been studies to form informal support groups for caregivers. Dr. David Haber (1984) created a church-based program for African American informal caregivers. Although the twelve hour program was set to train and educate caregivers, its sole purpose was to assist the caregivers in creating a mutual help group after program completion. Three of the eight churches successfully formed a help group. The help groups created fund-raisers, newsletters, health screenings and other aspects to benefit caregivers and the elderly. Informal support groups are a beneficial response to the end of a program. However, this program lacked a satisfactory time length to give participants the opportunity to learn and become comfortable with the training. In addition, although this program had benefits to its restrictions, the constraint
of the participants as religious African Americans could exclude a lot of informal caregivers who could need the assistance and support too.

The diversity of informal caregivers seems immeasurable at times, between cultures, gender, age and many other variables. Therefore, research has been performed to examine the different characteristics of caregivers to eventually tailor programs to those differences. An example of this research is done by Cathy Martin (2011) focusing on caregiving, race, and gender differences. This research reflected that African Americans tend to be less burdened by caregiving compared to Caucasian caregivers. In addition, women, who tend to be caregivers more often than men, tend to report, negative effects of caregiving rather than positive benefits. Although this research was not instilled into a program, the results are useful to determining who are burdened the most and may need more training or motivation; helping to determine program structure.

Understanding the distinct differences of informal caregivers is one great way to comprehend how to create a program to benefit them. However, structuring a program for these differences may ignore the simpler aspects of caregiving. Programs that assist formal caregivers allow one to understand the needs of the elderly and how the formal caregivers can achieve those needs. In a program by Wells, Dawson, Sidani, Craig, and Pringle (2000) they focused on dementia patients and decreasing their frustrations and the caregivers' stress levels. Although the program successfully decreases some of the patients’ frustrations, caregivers' stress levels remained high. This program lacked the benefit of a de-stressing program for caregivers. In addition, considering these caregivers are paid, one can only imagine the stress levels of informal caregivers if they participated in this program.
An important factor in increasing life satisfaction in older adults with decreasing functioning ability is to maintain independence when possible. In terms of those who are informal caregivers for those individuals, adult day care can be a form of respite care. Researchers Strain, Chappell, and Blandford (1987) created an adult day care program for the well-being of elders and their informal caregivers. Fortunately, the program showed an increase in life satisfaction for both the elderly and their caregivers. Although the program was effective, it did not reach a large number of people, therefore conveying the importance of recruiting participants.

Creating an effective program for informal caregivers can sometimes be just as simple as interviewing participants to understand what they believe they need the most in a program. This is precisely what researchers Hagen, Gallagher, and Simpson (1997) did. Through participation in this educational and support program, caregivers’ felt supported by their community and more prepared for their roles as caregivers. Despite its success, this program lacked the involvement of the elder individuals, such as providing an activity or support program for them to partake in.

There are many aspects in society that have changed since caregiving has begun. However, one of the most significant is the aspect of technology. Technology has influenced the way we live our lives and can be used as an advantage. Some researchers have utilized technology as a way to assist informal caregivers (Magnusson, Hanson, Brito, Berthold, Chambers, & Daly, 2002). These researchers utilized education and support online and through video phone, interacting with professionals and other informal caregivers. Although technology is a great form of communication, this should be used as
a last resort, whereas these researchers utilized this program for all caregivers, even those who could have attended a program in person.

Proposed Program

There are many programs that are intended for caregivers. However, the majority of the programs fail to provide for both the caregivers and the elders they care for. In addition, not all of the programs represent the importance of education and emotional support for caregivers and the older individuals. A scheduled session with training and therapy will occur within this program. Similar to Dr. Haber’s (1984) help group at the end of the program, this program will give participants the ability to form an informal support group. This support group will be less like Dr. Haber’s (1984) and instead will be a social support group for the participants. The combination of the formal educational support program and the informal support group may be the ideal blend. This program will give the elderly the opportunity to have scheduled meetings with people who will listen, giving them the opportunity to share their life stories; a crucial aspect to the aging process. This program also utilized Magnusson, Hanson, Brito, Berthold, Chambers, and Daly’s (2002) idea of web cam technology. However, this program will only provide the live video chat technology for those who cannot attend, allowing the program to be accessible to all.
Impact Model

**Purpose Statement:** To provide informal caregivers support and education through their caregiving of older individuals to benefit their well-being, and giving the elderly opportunities to interact with others and gain support and education through the aging process to benefit their well-being.

**Target Population:** Informal caregivers caring for older individuals at the ages of 65+, in Oswego, New York, seeking education and support through their caregiving process.

**Implementation Goals:**
1. Obtain grant from AARP
2. Rent space for weekly program meetings
3. Determine the curriculum for each meeting
   4. Hire professional educators
   5. Hire professional counselors
   6. Hire general staff
7. Hire general director of program
8. Advertise to recruit participants
9. Organize transportation for participants if needed
10. Organize and train employees
11. Purchase food and supplies
12. Schedule a meeting time for participants each week
13. Schedule a meeting time for family therapy if necessary

**Intermediate Goals:**
1. Monitor participant attendance
2. Update staff training
3. Hold monthly staff meetings
4. Maintain food and supplies for program
5. Update curriculum/Restructure to family needs
6. Maintain rental of meeting location
7. Budget spending

**Outcome Goals**

**Short term:**
1. Identify caregivers’ needs
2. Identify family therapy needs
3. Discuss feelings and stress
4. Increase day to day happiness
5. Increase day to day caregiving potential
6. Positive interaction with other adults

**Long term:**
1. Increase caregiver life satisfaction
2. Increase elderly life satisfaction
3. Increase elderly longevity
4. Improve family relationship
5. Provide long-term group support
6. Create new adult relationships of caregivers
II. Methods

Participants

The participants will be any persons who are informal caregivers for older individuals and are unpaid for their caregiving. Participants will be recruited through the local Oswego newspaper and through television commercials. The community members who participate will be recruited based on their desire to have education and support throughout their caregiving process. In addition, the participants must be willing to involve the elderly individual they care for in the program and be willing to form a community support group at the end of the program. There will be a restriction of thirty participants for every session and if necessary, another program session will be formed to accommodate for caregiver participants. Additional participants will be placed on a waiting list and will also serve as the comparison group. A small program group will be instilled to ensure participants have quality of education and support to give them the opportunity to form friendships in an intimate setting.

Procedures

This educational and support program will run for one year, with groups meeting once every week for two hours. Prior to the start of the program, participants will have a one-on-one session with a program counselor. Many informal caregivers may be caring for a relative that they have ongoing issues with from their past. Through meeting with the program counselor, participants will have the opportunity to discuss their feelings of the person they care for and even the chance to discuss these feelings with the older individual if possible. This pre-program counseling will give the participant the chance to attend the program with an open mind and able to care for the older individual with the
past behind them. Participants will then start their weekly meeting. The first hour will be spent conversing and reflecting upon their week and troubles; creating a support system. The second hour of the program, participants will have an educational session about a particular topic to benefit their caregiving ability. The caregivers program session will give them a form of respite care at some points, where they will be able to take a break from caregiving, a crucial part of caregivers well-being (Minichiello & Coulson, 2005; p. 199). While participants are in their two hour sessions, the older individuals they care for will be in sessions as well. In the older individual session they will have the opportunity to have conversation, talk about their days, or troubles. For the rest of the session, the older individuals will do an activity, board game, watch a film or do a craft together that they would enjoy.

Participants will have the opportunity to have additional one-on-one counseling sessions if needed to benefit their well-being and ability to be a better caregiver. To decrease stress levels and create a connection between caregivers and those they care for, there will be a few field trips with the program staff, caregivers, and older individuals. At the end of the year, program participants will be given the opportunity and encouragement to create a long-term support group. Support groups will allow the participants to have a positive closure to the end of the program and also allow participants to have long-term support and possibly friendships.

Participants, who are not able to attend the program sessions for whatever reason, may be included through a live video chat. However, means of transportation will be offered for all participants, therefore, lack of physical attendance may be due to a disability or an older individual who is bed ridden. It is encouraged that participants
attend the meetings in-person, but those who cannot attend in-person, due to special circumstances, will not be excluded but involved through the web cam system.

Measures

There will be several forms of measurement to assess the program to ensure program success and participant satisfaction. First, the program participants will be compared to the group of people on the waiting list. The group on the waiting list will perform all of these same measures as the program groups to assess program success. Once participants are recruited, they will be given a pre-test to assess their needs of education based on the individual they care for. The Older Americans Resources and Services, OARS (Duke University, 1978) preexisting instrument for measuring the pre-test and post-test will be utilized, as it was used in Dr. Haber’s (1984) study (See Appendix A). In addition, the pre-test will assess the participants’ need of support based on their self-assessment of their own stress levels.

Participants in the program will be asked to keep a journal in which they will log in every day. Each day participants will be asked to write the activities they performed with the person they care for, their personal assessment of their capability in caregiving, their stress level and overall happiness. Journals will be brought to each program session and will allow participants to reflect upon their week. The program director and staff will look over the journals each day to seek improvement in the participants’ daily attitudes and happiness.

A weekly program evaluation will be given to give participants the opportunity to reflect on the program events and allow them to share any ideas they have to make the next session better (See Appendix B). In addition, each week participants will be asked
about their feeling of support and companionship they feel from other participants, to ensure success in the program goal of caregiver support, along with positive interaction with other adults. This evaluation will include both open and closed ended questions. The weekly program evaluation will also quiz participants on the educational information they learned in that weekly session to ensure increase in the knowledge of caregiving.

After completion of the twelve month program, participants will be given a post-test to assess caregiver life satisfaction, elderly life satisfaction, caregiver and older individual relationship assessment, and overall program assessment. Again, the post-test will be very similar to the pre-test, utilizing the Older Americans Resources and Services, OARS, (Duke University, 1978) preexisting measurement. All of the evaluations will be given in paper format, unless the participant is utilizing the live chat system, their evaluations will be sent through e-mail to the program director.

At the end of the program, participants will be given the opportunity and space to create a long-term support group. Program staff will be updated by a group leader of the support group each week to assess the success of the group and the practice of a regularly scheduled meeting. Once again, the participants in the small support group will be compared to the waiting list group once a month. The participants and the comparison group will receive an evaluation of the support group (See Appendix C). The evaluation will assess the participants in terms of their feelings of support levels and overall happiness.

Methodology

When participants attend the weekly sessions, the hired counselors will run the one hour support session, along with other counselors being available if the participants
need additional support. All of the counselors will rotate running the weekly sessions. The second half of the session will be run by the professional educators teaching different topics relevant to caregiving. Presentations will be administered through power points and hands on activities when possible. Educational sessions will include role playing for participants to understand how to handle difficult situations in the caregiving process.

During the two hour process, the general staff members will be running the older individuals’ session. These employees will introduce and supervise a conversation and support group. Once the employee senses that participants are ready to move on from the support group, the employee will introduce the entertaining activity, such as a movie, board game, or any other activity the elderly are interested in, if applicable.

Throughout each weekly session, the program director will be present supervising and assessing group productivity. Also, the director will reestablish food and supplies for the weekly program. The program director will hold monthly staff meetings to guide employees and make any necessary changes. Staff meetings will also be the opportunity for staff members to discuss possible issues in the program that can be changed.

III. Results

If the results come out as anticipated, the program will have both short term and long term benefits. Primarily, the benefit of the program is to decrease caregiver stress and increase ability to administer care. Positive results would indicate caregivers having an increase in day-to-day happiness, life satisfaction, and ability to discuss feelings of stress more easily. In addition, anticipated results are caregivers feeling supported throughout the program and through their support group. Positive results would also show participants creating positive relationships with the fellow participants. The
program will also allow the caregiver and older individual to discuss any issues they have had in the past and look toward a better relationship in the future. Anticipated results will increase the older individual’s life satisfaction as well.

IV. Discussion

As previously discussed, informal caregiving for the elderly is a common form of caregiving and plays an important role in the lives of the elderly. However, without support and education, informal caregivers may be doing more harm than good. Therefore, it is imperative that this program be implemented to mend the issues informal caregiving can have.

Through past research and the knowledge we will learn from the application of this program, we will have a better understanding of solutions that successfully educate and support caregivers. For example, we will be able to understand if the combination of educational presentations, that are dictated to the participants’ needs, and support groups from other participants will effectively decrease stress and increase caregiving capabilities. In addition, we will have a better comprehension of what the elderly, at different levels of capability, need to have a decrease in stress and increase in happiness, from their participation in this program.

Along with the separate needs of the caregiver and the older individual, we can also understand the family needs. Participants’ will have the opportunity to discuss past feelings and unresolved issues they have had together. In these family sessions, we will be able to understand the needs participants have and the time required to address family issues.
Although it is essential to learn new information through the implementation of this program, it is only valuable if it is utilized with the understanding of participants' educational and supportive needs, we will be able to spread the new knowledge to more individuals. In addition, even though this data is geared toward informal caregivers and the individuals they care for, the information could be adjusted to be shared with institutions and other organizations. With the program results, other institutions can gain understanding of the importance of involving and supporting family members about their loved ones.

The results of family therapy in this program are an additional aspect that can be utilized to benefit other circumstances. For example, this information can be shared with family counselors so they can utilize the experience of this program with their own clients. These results may benefit counselors in appreciating the time and need of family therapy through the aging process.

This program is significant not only in the benefit to individuals, but also in the big picture results. The future can hold many positive changes with the support of this program. After many years, this program can influence the American cultures perspective of the elderly. Today within our culture, the elderly are perceived as disposable and many are entered into nursing homes way before needed; if ever needed at all. However, this program can demonstrate to our youth today, who one day will be caring for their parents, the possibility of informal caregiving. Showing our culture the possibility and benefits of informal caregiving, aging within our culture may not be as feared or ignored.
With the incoming increase in population of the elderly as the baby boomers age, the level of support and education needed for informal caregivers will increase as well. Considering the baby boomers had fewer children, their children may need more support in the informal caregiving process; due to their lack of siblings to share the responsibility with. The stress of informal caregiving can be immeasurable at times. Yet, as a culture, we should not allow the vastness of the issue overwhelm us. Instead, by tackling the issues of informal caregiving one step at a time, such as the implementation of this program, will create an increase in life satisfaction for the caregivers and the elderly they care for, creating a future all can look forward to, rather than fear.
References


http://www.geri.duke.edu/index.php?option=com_content&view=article&id=141&Itemid=73


Appendix A

The OAR questionnaire from Duke University (1978) is unavailable to view without cost, however, a description of the measurement can be found at the following website:

Appendix B

Weekly program evaluation:

This evaluation is for program participants only:

Directions: For the following questions, please use the 1-5 scale to choose the answer that applies most to you.

1- Strongly Agree 2-Agree 3-Neutral 4- Disagree 5-Strongly Disagree

1. I feel capable of dealing with the illness/situation discussed _________

2. I am very afraid of having to experience the illness or situation discussed ____

3. I feel that this session was beneficial to myself as an informal caregiver ______

4. With the information discussed I feel as though I can utilize ideas with the elderly individual I care for ______

5. I feel as though I can express my opinions freely with others in the group____

6. I feel as though the other participants within the group judge me negatively for my opinions____

7. I feel a lot of support from the other participants in the program ______

8. I consider the fellow participants to be like friends ______

Please briefly answer the following questions to the best of your ability:

1. Please list three new pieces of information that you learned this session:

2. Please list three pieces of information that you have learned about today that you already knew:

3. Please list three pieces of information that you can utilize based on what you learned today:

4. What did you enjoy about this session?
5. What did you not enjoy about this session?

6. What could we do to improve about this session?

This evaluation is for the waiting list group only:

Directions: For the following questions, please use the 1-5 scale to choose the answer that applies most to you.

2- Strongly Agree 2-Agree 3-Neutral 4- Disagree 5-Strongly Disagree

9. I feel capable of dealing with the illness/situation discussed ________

10. I am very afraid of having to experience the illness or situation discussed ____

11. I feel that I could benefit from this information as an informal caregiver_______

12. With the information discussed I feel as though I could utilize ideas with the elderly individual I care for _______

13. I feel as though I can express my opinions freely with others in my life____

14. I feel as people judge me negatively for my opinions____

15. I feel a lot of support from others______

16. I have friends to support me______
Appendix C

Support group evaluation:

This section for support group members and waiting list group:

Please answer the following questions to the best of your ability based on the 1-5 scale.

1- Strongly Agree 2-Agree 3-Neutral 4- Disagree 5-Strongly Disagree

1. I feel as though I have the support of others in my life____
2. The support I have in my life decreases my stress ____
3. I feel as though I have people to talk to about my feelings ____
4. I would be happier if I had more support in my life____
5. I feel very happy and satisfied with my life____

This section for support group members only:

Please answer these questions to the best of your ability:

1. What do you enjoy about the support group this month?
2. What did you not enjoy about the support group this month?
3. What could we do to improve the support group this month?