Exploration of the Relationship between Well-Being and Burden in Family Caregivers:

A Community Based Research Project

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Abstract

Family caregivers provide long-term care to a growing population of older adults. Family caregiver research focuses on the burden and strain of this role. The aim of this study was to explore the psychological effects, both negative and positive, of being a family caregiver. This research was developed and conducted to meet an identified community need, in collaboration with two nonprofit organizations. A convenience sample of family caregivers was obtained through two nonprofit agencies that provide aging services. The levels of burden and well-being were assessed through self-report questionnaires administered electronically or by mail. The sample size for this study was small (n=11); this was not wholly unexpected due to the challenges of assessing an understudied population of people in roles which place high demands on their time. Some trends in the data suggest that higher levels of reported burden are associated with lower well-being. The two community agencies involved with this study expressed the need for further research to confirm this, and to identify positive experiences associated with caregiving, as reported by caregivers.

Exploration of the Relationship between Well-Being and Burden in Family Caregivers

According to census data from 2010 there were 40 million older adults (people over the age of 65) in the United States, which accounted for 13% of the total population. It is projected that by 2030 there will be approximately 72 million older adults accounting for 20% of the total population in the U.S (Federal Interagency Forum on Aging-Related Statistics, 2012). This substantial increase in the population of older adults will put a significant toll on the long-term health care system. As the population of older adults has grown, family caregivers have become an increasingly important population to research because they are considered the “backbone” and “bedrock” of long-term care provision (Levine et al., 2006; Wolff & Kasper, 2006). As an integral part of long-term care, family caregivers have a large economic impact. For example, Feinberg and Houser (2012) estimate that 40 billion hours of unpaid care are provided annually by family caregivers, with an economic value of $450 billion. Additionally, the average annual cost to live in a long term care facility is $61,318 compared to $13,150 to live in a community with the assistance of a family caregiver (Federal Interagency Forum on Aging-Related Statistics, 2012).

Who Are Family Caregivers?

There are over 65 million family caregivers, but researchers are inconsistent in determining the criteria for being considered a family caregiver (National Alliance for Caregiving & AARP, 2009). Some definitions focus on what caregivers do: “Informal (unpaid) family caregivers provide the majority of assistance that enables chronically disabled older people to continue to live in the community rather than in specialized care facilities” (Federal Interagency Forum on Aging-Related Statistics, 2012, p. 72). Another definition notes the type of care: “ADL [activities of daily living] and/or IADL [instrumental activities of daily living] care provided by a family member or friend or anyone with an emotional attachment to an individual who is frail, disabled, or chronically ill” (MetLife Mature Market Institute & National Alliance for Caregiving, 2007). Studies have defined caregivers based on the number of hours of care provided, status of residency with the care recipient, number of ADLs or IADLs the care recipient needs assistance with, among other qualifications (Beach, Schulz, Yee, & Jackson, 2000; Glueckauf et al., 2009; Zarit & Femia, 2008).

Just as the definitions vary, so do the caregiving experiences. Langa et al. (2001) highlighted the differences in the caregiving experience by comparing caregivers of people with dementia at various stages of severity. The study found that caregivers of people with severe dementia on average provided 46 house of care per week compared to caregivers of people with no cognitive impairments who provided 4.6 hours of care. There is a vast range of experiences within the caregiving population. Despite differences, family caregivers contribute vital services and need to be supported in providing the highest quality of care they are capable of.

Research Challenges

Researchers across disciplines have recognized the importance of family caregivers and have conducted many studies in order to more effectively support this population. Many research studies emphasize the importance of interventions, support programs, and policies that need to be developed (Montgomery, Gonyea, & Hooyman, 1985; Nabors et al., 2013; Roberto & Jarrott, 2008). However, researchers have discovered numerous methodological challenges to assessing the complexity and diversity of the caregiving experience. Sampling is noted as one of the most common challenges and one of the main reasons for inconsistencies in the research findings (Pinquart & Sörensen, 2003b). For instance, studies using convenience samples from clinical populations may be overestimating the level of distress in caregivers compared to non-caregivers.

Researchers have attempted to create more representative samples by including participants from larger or national studies; but, the inherent heterogeneity within the caregiving experience limits generalizability (Hilgeman, Allen, DeCoster, & Burgio, 2007; Noonan & Tennstedt, 1997; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Roff et al., 2004; Roth, Perkins, Wadley, Temple, & Haley, 2009; Schulz & Beach, 1999; Yates, Tennstedt, & Chang, 1999). As noted by the American Psychological Association (APA, 2014a), the caregiving experience can vary significantly depending on the relationship between the caregiver and care recipient, the type of condition the care recipient has been diagnosed with, and the age of the caregiver and care recipient. Research on family caregivers has mainly focused on care recipients with dementia, older adults, and spousal caregivers. This specificity in sampling also makes it difficult to recruit a representative sample. Lastly, most research on family caregivers relies on self-report measures (Zarit & Femia, 2008).

Negative Focus

Thus far the majority of research on family caregivers has been focused on the negative experiences of caregiving. In a review of the research on family caregivers, Zarit and Femia (2008) highlighted the assumption involved in the research that all caregivers are burdened by their role. This assumption is a trend throughout the research stemming from a research study on the correlates of burden (Zarit, Reever, & Bach-Peterson, 1980). Researchers frequently cite this study as very influential in research on caregiver burden (Zarit et al., 1980). For some researchers, burden is assessed as a single construct. Others have separated burden into two distinct parts: subjective versus objective experiences of burden (Montgomery et al., 1985).

Still other researchers have studied burden as a predictive factor for levels of depression or care recipient positive affect (Wilson-Genderson, Pruchno, & Cartwright, 2009). In one such study, researchers demonstrated the relationship between the level of depression in the caregiver and the quality of care provided for the care recipient (Smith, Williamson, Miller, & Shulz, 2011). Another study by Glueckauf et al. (2009) focused on reducing depression in caregivers through counseling. Other concepts assessed have been strain (Dorfman, Holmes, & Berlin, 1996), stress (Haley, Levine, Brown, & Bartolucci, 1987; Zarit, Stephens, Townsend, & Greene, 1998), stress process model (Glueckauf et al., 2012; Haley, LaMonde, Han, Burton, & Schonwetter, 2003), and compassion fatigue (Lynch & Lobo, 2012). These are just a fraction of the studies which emphasize the negative impacts of caregiving.

The negative focus within caregiving research is apparent in the limited range of scales and assessments developed to measure the caregiving experience. A recent inventory of assessment measures demonstrates the unbalanced ratio of 216 assessments on negative constructs compared to 13 assessments on positive constructs (Family Caregiver Alliance, 2012). Not only is there a limited amount of scales measuring the positives, but a scale that is labeled as “one of the few that address the positive feelings of caregiving” has been shown to have reproducibility concerns due to wording (Post, Festen, Van de Port, & Visser-Meily, 2007, p. 1051).

Intervention studies also reflect an exclusively negative focus by examining stress, depression, and dementia care (Glueckauf et al., 2009; Glueckauf et al., 2012; Pinquart & Sörensen, 2006b; Teri, McCurry, Logsdon, & Gibbons, 2005; Zarit et al., 1998). Much of this research has suggested that caregiving is correlated with negative physical and psychological health outcomes (Pinquart & Sörensen, 2003b). In a review of the physical health of caregivers, Pinquart and Sörensen (2007) found that there are different predictive factors for physical health and psychological health in caregivers. As part of the Cardiovascular Health Study, Schulz and Beach (1999) found that caregivers who reported strain had increased risk of mortality compared to non-caregivers. Another physical health study recently found an association between Alzheimer’s caregivers’ depressive symptoms and cardiovascular functioning (Mausbach et al., 2012).

Overall, the negative physical and psychological health effects of caregiving have been well documented throughout the body of research on burden, depression, and stress. In reviewing the research, Kramer (1997) noted that the focus of the research on caregiving is “…consistent with the long trend in social science research to focus on general measures of psychological dysfunction” (p. 218). While advancements have been made in the caregiving research, the “lack of attention to the positive dimension of caregiving seriously skews perceptions of the caregiving experience” (Kramer, 1997, p. 218).

Holistic Approach

A multidimensional perspective of the caregiving experience would allow researchers and practitioners to more effectively support family caregivers. As noted by Picot and colleagues, “Assessment of the rewards of caregiving is pertinent to a holistic view of the caregiving experience” (Picot, Youngblut, & Zeller, 1997, p. 33). Picot et al. defined rewards as positive perceptions of the caregiving experience; they developed the Picot Caregiver Rewards scale (PCRS) to assess those rewards. The scale was developed with the hypothesis that scores on the PCRS would be negatively correlated with scores on the Zarit Burden Interview (ZBI), the most common scale for assessing burden, and the scores on the Center for Epidemiological Studies Depression scale (CES-D). The results of the study supported the hypothesis, but highlighted that the assessment needed further development to include items on personal growth, and objective versus subjective rewards (Picot et al., 1997, p. 50).

In addition to rewards, researchers have referred to positive perceptions of caregiving as gains, benefits, and uplifts. The inconsistency in terminology perpetuates the unreliability of the research findings and suggests the need for further research. Pinquart and Sörensen (2003a) also demonstrated the need for further research on uplifts, their concept of positive perceptions. They stated that, "These uplifts may reduce the levels of CG [caregiver] burden and depression. However, the associations between uplifts and psychological outcomes are also inconsistent" (Pinquart & Sörensen, 2003a, p. 4). In order to demonstrate the associations between positive perceptions of caregiving and psychological outcomes more research is needed.

Researchers have explored multiple positive outcomes hypothesized to be involved in the caregiving experience, but each has received limited attention. Only a few studies have been conducted on topics such as resiliency (Clay et al., 2013; Nabors et al., 2013), reciprocity (Dwyer, Lee, & Jankowski, 1994; Reid, Moss, & Hyman, 2005), and positive affect (Folkman & Moskowitz, 2000). While these studies look at positive concepts, they are assessed by comparing them to concepts like burden and depression. For example, the main finding from both studies on reciprocity is that reciprocity decreases levels of burden in caregivers.

Other studies have tested the relationship between positive effects and negative effects of the caregiving role. Boerner, Schulz, and Horowitz (2004) found that the positive benefits of caregiving can decrease depression and grief for the caregiver when the care recipient dies. Through studying the relationship between burden and well-being, researchers have highlighted some important distinctions regarding outcomes and predictor factors (Chappell & Reid, 2002; Stull, Kosloski, & Kercher, 1994). The relationship between the positives and the negatives of caregiving differs, which is another reflection of the heterogeneity of caregiving experiences.

Researchers of family caregivers have operationalized well-being using a variety of assessments that generally reflect a narrow definition of well-being. In a meta-analysis of the research on caregivers compared to non-caregivers, Pinquart & Sörensen (2003b) found that subjective well-being was most commonly operationalized using life-satisfaction scales, positive affect scales, or single-item happiness indicators. An earlier study by Knight, Williams, McGee, and Olaman (1998) measured well-being with a depression scale, a burden scale, and a health rating. Yates et al. (1999) operationalized well-being using a single depression scale. Haley et al. (2003) measured well-being with a life-satisfaction and a depression scale.

Psychological well-being has been operationalized in various ways including a positive affect and a depression scale (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). Broader definitions of well-being assess negative factors as demonstrated in a study by Noonan and Tennstedt (1997) in which they measured psychological well-being with scales on depression, self-esteem, mastery, role captivity, and loss of self. Lastly, one study defined psychological well-being using four items to measure "how many days per week they felt: (1) dejected or out of sorts, (2) calm, serene, and relaxed, (3) tense, irritated, or nervous, and (4) full of energy, strength, and optimism" (Perrig-Chello & Hutchison, 2010, p. 199). The reason these operationalizations are troublesome is not only due to methodological concerns, but due to the incomplete picture of caregiving these narrow definitions of well-being provide researchers.

Some suggest researchers should adopt the perspective that "there is more to mental health than the absence of pathology" (Kramer, 1997, p. 218). To operationalize psychological well-being with a depression scale is to assume that if one is free of depressive symptoms one is automatically experiencing psychological well-being. In a review of the research on the gains of caregiving, Kramer (1997) highlighted the way Ryff (1989) defined psychological well-being in order to generate "a wholesale rethinking about caregiving experiences and outcomes" (p. 218). Ryff (1989) conceptualized psychological well-being as having six dimensions including: personal growth, purpose in life, autonomy, environmental mastery, positive relations with others, and self-acceptance. This definition of well-being goes beyond simple constructs of life satisfaction, positive affect, or happiness. Through this broader conceptualization of psychological well-being research can holistically assess the caregiving experience.

Present Study

In collaboration with the Aging Coordinating Consortium's five-year strategic plan to improve aging, family caregivers were identified as a population that could be better served by local agencies, which sought to gather more information about their experiences. The purpose of the present study was to meet that community need through collaboration with CarePartners and the Council on Aging of Buncombe County. In the process of exploring research topics, assessing levels of depression in family caregivers was suggested. As outlined, however, there is extensive social science literature on depression among this population, which prompted an alternative focus on the psychological well-being of family caregivers. This study was conducted to add to the limited research on the potential benefits of caregiving. During the preliminary stages of research, the study was continually changed and adapted to fit the needs of the community. Specifically, this study used a multidimensional definition of psychological well-being to further develop the understanding of caregiving experiences. To assess the benefits, family caregivers completed two surveys; one on burden and one on psychological well-being. It was hypothesized that there would be a negative correlation between psychological well-being and burden.

Method

Participants

Potential participants were recruited through two nonprofit agencies that provide aging services in Western North Carolina, CarePartners and the Council on Aging of Buncombe County. CarePartners provides rehabilitation, home health, adult care, hospice, and palliative care. The Council on Aging of Buncombe County coordinates resources, education, and programming to support older adults. Following multiple discussions with these two community partners, a convenience sample of family caregivers was generated through flyers, posters, person-to-person solicitation at family caregiver support group meetings, referrals, emails, and mailings. In order to obtain a large sample, no exclusion criteria regarding number of hours of care provided or condition of care recipient was used. Anyone who self-identified as a family caregiver was eligible to participate. After discussions with the community partners, two versions of the survey were made available. The primary version was electronically completed while a paper version was available upon request. Further communication between the community partners and primary researcher may have increased participation by making the paper version more accessible.

Despite significant recruitment efforts and broad eligibility requirements, the final sample size was much smaller than the intended size. Of the 11 participants who completed the study, 90% (n=10) were recruited through the same nonprofit agency. On average, caregivers were 62.8 years old (SD=8.6), ranging from 42 years old to 74 years old. Most caregivers identified as female (n=9), one caregiver identified as male, and one caregiver did not provide a response. In terms of kinship, 73% (n=8) were caring for a parent and 27% (n=3) were caring for a spouse. On average care recipients were 84 years old, ranging from 65 years old to 95 years old.

Measures

There were two primary measurements used in this study. The Zarit Burden Interview (Zarit et al., 1980), which assessed the variable of burden and the Psychological Well-Being Scale (Ryff, 1989), which assessed the variable of well-being in family caregivers. The Zarit Burden Interview (ZBI) scale originated as a 29-item questionnaire and was developed to measure subjective impact of caregiving (Zarit et al. 1980). The most commonly used form of the scale has 22-items (Zarit, Orr, & Zarit, 1985; see Appendix A), which is frequently used by agencies who are providing aging services (APA, 2014b). In the 22-item version each item represents a feeling that the caregiver is asked to endorse using a 5-point scale, ranging from 0 (Never) to 4 (Nearly Always). Hébert, Bravo, and Préville (2000) offer these score interpretations as guidelines: 0 – 21 (little or no burden), 21 – 40 (mild to moderate burden), 41 – 60 (moderate to severe burden), and 61 – 88 (severe burden).

In a review of the research on dementia caregivers, Pinquart and Sorensen (2006) found that the ZBI has been used to assess burden in 32 studies. Additionally, Hébert et al. (2000) found that scores on the ZBI were unrelated to factors such as age, gender, living situation, and marital status among other factors, which demonstrated the broad potential applications of the scale with the caregiving population. This scale has shown good internal consistency (alpha=0.91) and test-retest reliability (0.71) (Hébert et al., 2000). The 22-item version of the ZBI scale was chosen for this study due to its widespread use, brevity, and good psychometric values.

The Psychological Well-Being Scale (PWB) originated as a 120-item questionnaire with 20-items per dimension of psychological well-being (Ryff, 1989). The dimensions, or sub scales, include: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. Since the development of the original scale various versions have been created, which differ on the number of items per sub scale and on the items that overlap. The original scale "showed high internal consistency and test-retest reliability as well as convergent and discriminant validity with other measures" (Ryff & Keyes, 1995, p. 720).

Many studies (Abbott, Ploubidis, Huppert, Kuh, & Croudace, 2009; Cheng & Chan, 2005; Kafka & Kozma, 2002; Van Dierendonck, 2004) have been conducted to analyze the validity of the structure of conceptualizing psychological well-being with six factors. The sample sizes and analysis methods of these studies differ; but, they all conclude that despite some flaws the PWB is a valid measure of psychological well-being. The version used in this study was the 42-item PWB scale (See Appendix B). Participants respond to each item on a seven-point scale ranging from 1 (Strongly Agree) to 7 (Strongly Disagree). There is an almost even balance between positively worded and negatively worded items on the scale. Some items were reverse scored so that high scores reflect high psychological well-being.

There are no scoring guidelines provided for defining high or low well-being. The 42-item version of the PWB scale was used in a study that focused on testing the construct validity of the six factor model of psychological well-being by conducting a factor analysis of the items included on the scale (Abbott et al., 2006). The study supported the construct validity of the Psychological Well-Being Scale. Most studies assessing the psychometric properties of the PWB have focused on construct validity with little attention to the reliability of the scale (Abbot et al., 2006; Cheng & Chan, 2005; Kafka & Kozma, 2002; Ryff & Keyes, 1995; Springer, Hauser, & Freese, 2006; Van Dierendonck, 2004). A psychometric evaluation of the reliability of the 42-item version demonstrated that the PWB adequately measures psychological well-being, but the precision is weak at measuring high levels of psychological well-being (Abbott et al., 2009).

These assessment strategies were used due to their accepted validity in the social sciences. More intentional collaboration with community partners may have led to the utilization of different assessment techniques. Especially, due to the low level of participation, qualitative information may have been more useful to meeting the identified community need.

Procedure

This study was approved by the Social Sciences Review Board at the associated institution. Interested participants were instructed through an information sheet (See Appendix C) to directly access the electronic version of the survey or to contact the researcher for a physical copy to be mailed to them. The electronic version of the survey was powered through an online survey software that maintained confidentiality by not collecting I.P. addresses. For both the electronic and paper versions of the survey, participants completed the Informed Consent Form (See Appendix D), demographic questions, the PWB, and the ZBI in this order. Participation was voluntary with no rewards or incentives provided. It took approximately 45 minutes to participate in the study.

Results

The research objective of the present study was to explore the relationship between psychological well-being and burden. The researchers hypothesized that there would be a negative correlation between psychological well-being, measured by the PWB, and burden, measured by the ZBI. The average score on the PWB was 217 (s= 37.8) with a minimum score of 147 and a maximum score of 259. The highest possible score on the PWB is 294. The average score on the ZBI was 43 (s= 15.7) with a minimum of 21 and a maximum of 60. The highest possible score on the ZBI is 88. A Pearson’s correlational test was run to determine the relationship between the PWB scores and ZBI scores. The results from the correlational test were insignificant (r= -.348). As seen in Figure 1, an insignificant, weak negative correlation was found between scores on the PWB and the ZBI.

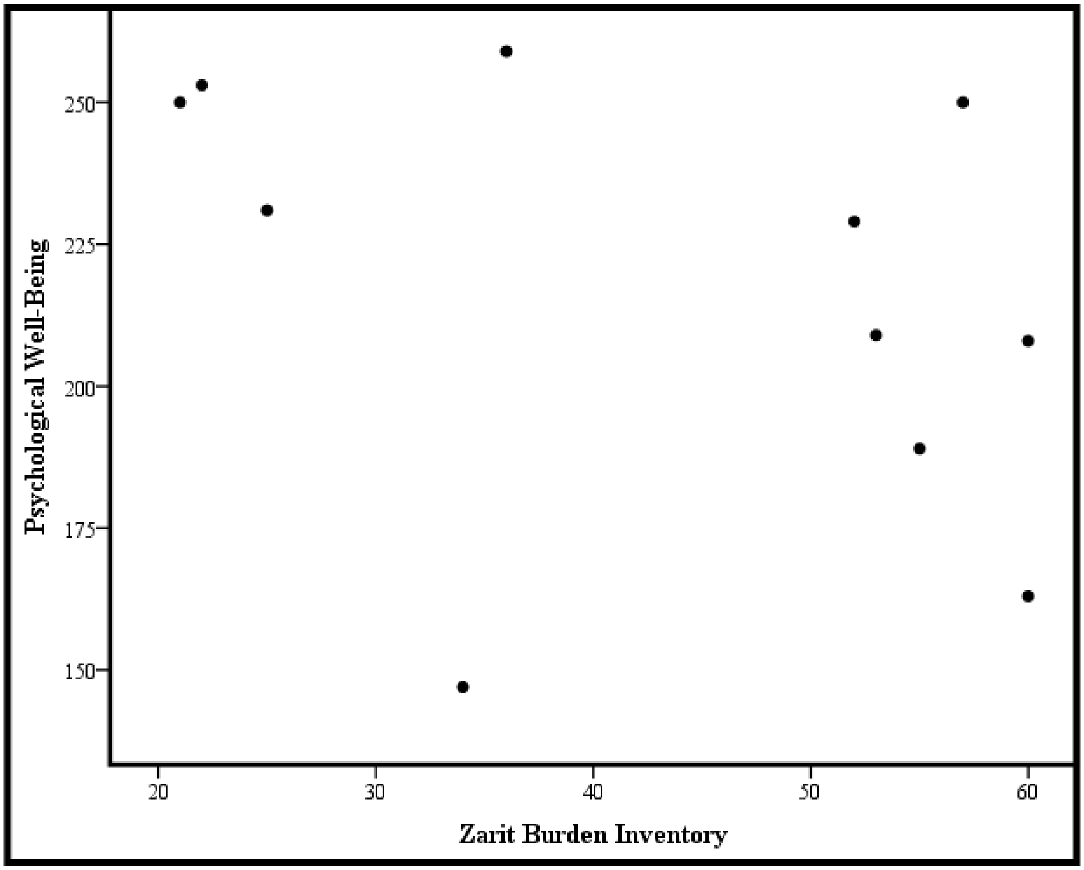

Figure 1. Mean scores on the Psychological Well-Being scale and the Zarit Burdern Interview. There is an insignificant negative correlation between the mean scores of each assessment.

Discussion

The purpose of the present study was to explore the relationship between burden and psychological well-being, with the intention to respond to a community need for information about family caregivers. The results were inconclusive due to sample size, but this was not wholly unexpected. Sampling is a key methodological challenge to studying family caregivers (APA, 2014a; Zarit & Femia, 2008). Despite the lack of significance, the data suggest a negative relationship between psychological well-being and burden which suggests that family caregivers with higher burden have lower psychological well-being. This reflects the findings of Picot et al (1997), which found a negative correlation between the rewards of caregiving and burden. However, psychological well-being and rewards of caregiving are two distinct concepts that should not be assumed to be equal. Further research is needed to fully understand the relationship between the variables.

While this research study is inconclusive, it demonstrates the extent of the unknown concerning the caregiving experience. This study provided a preliminary exploration of the psychological well-being of family caregivers by intentionally focusing on the positives of caregiving. Another strength of this study was the holistic conceptualization of psychological well-being. Compared to other studies psychological well-being was operationalized with six dimensions instead of only measuring one factor, for instance happiness.

This study's most notable limitation is the sampling issue. The sample was too small to run a significant correlational analysis or to analyze a specific sub scale of the PWB. For example, prior research suggests that family caregivers would score highly on the purpose in life dimension of the PWB (Kramer, 1997). Not only was the sample small, it was also not representative due to 90% (n=10) of the participants being recruited through the same nonprofit agency. These concerns highlight the need to assess the methods used to recruit family caregivers from the community.

Additionally, the length of the survey may have limited the ability of those in the caregiving role to participate. The sampling issues involved in this study significantly limit generalizability; however, issues of generalizability are common in research on family caregivers due to the enormous variety within the population. Also despite the holistic operationalization of psychological well-being, the PWB was not specific to caregiving. Thus, the PWB may not be a clear indicator of the positive aspects of specifically caregiving. PWB may not be an indicator of the caregiving role experience, but a reflection of the overall context of the person who is the caregiver (Kramer, 1997, p. 219). Despite these limitations the present study has the potential to further research on the positives of caregiving.

As this study has shown, researching family caregivers is challenging. Based on the sampling issues of this study the researcher suggests evaluating the methods used for recruitment of family caregivers. Additional collaboration with family caregivers could provide insight on this challenge. Understanding the time constraints of caregivers from a caregiver’s point of view could be used to define more useful assessment tools. Also, more qualitative data collection methods may more accurately describe the positives of the caregiving experience due to the heterogeneity of the population. In addition to researching solutions for sampling challenges, future research could assess differences in psychological well-being between family caregivers utilizing support groups compared to no support services. Lastly, researching how psychological well-being and the positives of caregiving change over time could be beneficial. Academia, practitioners and the public could all benefit from further research into the caregiving experience and its positive factors.

Regardless of the inconclusive data, the most important strength of this research comes from the relationships that were developed in order to conduct this community-based research. Without the collaboration from the surrounding community this research would not have been possible or pursued. Increased communication and more time spent in discussions may be useful in the future for conducting research aimed at addressing community-identified issues. However, time constraints not only affect family caregivers, but also staff who support community agencies. Identifying the most effective modes of communication with community partners from the outset may help to address the limitations identified in this research study.

Conclusion

Researchers have recognized the importance of family caregivers in the long term health care system but have yet to holistically understand the caregiving experience. The majority of research conducted on family caregivers has focused on the negative effects of being a caregiver, such as burden, strain, and depression. The present study explored the positive effects of being a caregiver through a community based research project. While the results proved to be insignificant, a weak negative correlation suggests that there is a negative relationship between burden and psychological well-being. This study was unable to provide holistic information on family caregivers in the community but the collaboration on which it is based was a step forward toward that goal. The lack of research on the benefits of caregiving skews the perception that caregiving is an exclusively negative experience. The insignificance of the current study’s results and the limited research on the benefits of caregiving demonstrate the need for further research. Further research could better inform academia, clinical practitioners, family caregivers, and the public on the full range of caregiving experiences.

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Appendix A

Zarit Burden Interview (ZBI)

Survey #2:

Please circle the response the best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid of what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Appendix B

Psychological Well-Being Scale (PWB)

Survey #1

The following set of questions deals with how you feel about yourself and your life. Please remember that there are no right or wrong answers.

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Neither	Agree Slightly	Agree Somewhat	Strongly Agree
1. I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.							
2. In general, I feel I am in charge of the situation in which I live.							
3. I am not interested in activities that will expand my horizons.							
4. Most people see me as loving and affectionate.							
5. I live life one day at a time and don't really think about the future.							
6. When I look at the story of my life, I am pleased with how things have turned out.							
7. My decisions are not usually influenced by what everyone else is doing.							
8. The demands of everyday life often get me down.							

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Neither	Agree Slightly	Agree Somewhat	Strongly Agree
9. I think it is important to have new experiences that challenge how you think about yourself and the world.							
10. Maintaining close relationships has been difficult and frustrating for me.							
11. I have a sense of direction and purpose in life.							
12. In general, I feel confident and positive about myself.							
13. I tend to be influenced by people with strong opinions.							
14. I do not fit very well with the people and the community around me.							
15. When I think about it, I haven’t really improved much as a person over the years.							
16. I often feel lonely because I have few close friends with whom to share my concerns.							
17. I don’t have a good sense of what it is I’m trying to accomplish in life.							
18. I feel like many of the people I know have gotten more out of life than I have							
19. I have confidence in my opinions, even if they are contrary to the general consensus.							

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Neither	Agree Slightly	Agree Somewhat	Strongly Agree
20. I am quite good at managing the many responsibilities of my daily life.							
21. I have the sense that I have developed a lot as a person over time.							
22. I enjoy personal and mutual conversations with family members and friends.							
23. My daily activities often seem trivial and unimportant to me.							
24. I like most parts of my personality.							
25. It’s difficult for me to voice my own opinions on controversial matters.							
26. I often feel overwhelmed by my responsibilities.							
27. For me, life has been a continuous process of learning, changing, and growth.							
28. People would describe me as a giving person, willing to share my time with others.							
29. I enjoy making plans for the future and working to make them a reality.							
30. In many ways I feel disappointed about my achievements in life.							

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Neither	Agree Slightly	Agree Somewhat	Strongly Agree
31. I tend to worry about what other people think of me.							
32. I have difficulty arranging my life in a way that is satisfying to me.							
33. I gave up trying to make big improvements or changes in my life a long time ago.							
34. I have not experienced many warm and trusting relationships with others.							
35. My attitude about myself is probably not as positive as most people feel about themselves.							
36. I judge myself by what I think is important, not by the values of what others think is important.							
37. I have been able to build a living environment and a lifestyle for myself that is much to my liking.							
38. I do not enjoy being in new situations that require me to change my old familiar ways of doing things.							
39. I know that I can trust my friends, and they know they can trust me.							
40. Some people wander aimlessly through life, but I am not one of them.							
41. When I compare myself to friends and acquaintances, it makes me feel good about who I am.							

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Neither	Agree Slightly	Agree Somewhat	Strongly Agree
42. I sometimes feel as if I've done all there is to do in life.							

Appendix C

Information Sheet for Potential Participants

Interested in Participating?

What is this research study about?

This research study is exploring the effects of being a family caregiver. The study is being conducted in cooperation with CarePartners, Council on Aging, and the Aging Coordinating Consortium. The overall purpose is to gain a comprehensive understanding of what it is like to be a family caregiver in Buncombe County.

Am I allowed to participate?

If you are a family caregiver you are eligible to participate.

Why should I participate?

The results of this study will be used to inform service providers like CarePartners and the Council on Aging on the effects of being family caregivers. This study will assess the positives and negatives of being a family caregiver, which could directly improve the resources and support systems available in Buncombe County. Not only could you experience a direct benefit in the improvement of the services provided to you, but your participation could improve the relationships of future family caregivers with their service providers.

How long will it take to participate?

Approximately, 40-45 minutes.

What is involved in participating?

Participating involves completing personal information questions and questions related to caring for your care recipient. Your personal information and responses will be kept confidential.

Ready to participate? The survey will only be available until March 5th, 2014.

The survey is available online at this link:

https://www.surveymonkey.com/s/Family_Caregiver_Research

Note: If you don't have access to a computer the survey can be mailed to you by calling the researcher, Deanna Dragan, at 610-507-8392.

If you have questions please call the researcher at the above contact or email (ddragan@warren-wilson.edu).

Appendix D

Informed Consent Form

Informed Consent to Participate in Research

Title of Research Study: An Exploration of the Effects of Being a Family Caregiver

The purpose of this study is to gain a better understanding of both the positive and negative effects of being a family caregiver. Your participation will help to improve the understanding of family caregivers by service professionals and potentially improve the resources provided as support for family caregivers. First, you will complete some personal information questions that will allow the researcher to contact you following completion of the study. Secondly, you will be asked to respond to statements regarding caregiving. Participating in this study will require approximately 40-45 minutes and should be completed in one sitting. If you have a need to stop the survey please return to finish it as soon as possible. While there are no known risks to participating in this research study, some participants may experience discomfort as a result of responding to questions related to caregiving. Your participation is completely voluntary and if you feel uncomfortable, or do not wish to continue at any point during the survey you may discontinue without penalty. Your personal information will only be known to the researcher and your responses will remain confidential. The results of this study will be shared publicly, but in general terms to protect the confidentiality of your identity. If you would like to discuss any discomforts you experience or have any questions about participating you can contact the researcher listed below.

Researcher Name: Deanna Dragan	Supervisor: Dr. Bob Swoap
Telephone Number: 610-507-8392	Telephone Number: 828-771-3706

As the participant, I have been fully informed of the above-described procedure and the benefits and risks that are involved in participating in this study. I have received a copy of this entire document (attached after this page in the packet). I have voluntarily given permission for my participation in this study. I confirm that I am at least 18 years of age and by signing I am consenting to participate.

____________________________________	____________
Signature of Participant	Date

It’s Not Always about the Final Product:
The Challenges and Rewards of Community-Based Research

Deanna Dragan
Warren Wilson College

My undergraduate career has instilled in me a passion to serve the community. At Warren Wilson College engaging in service is a graduation requirement, but for me it evolved into a personal commitment to be involved in my community. I have worked closely with many community partner organizations. Over the last three years I have engaged in direct service, completed a summer internship, coordinated event planning, participated in a strategic planning committee, and facilitated service opportunities through communication with community partners. My service experiences have informed the direction of my future career plans, enhanced my academic learning, and drawn me closer to people in the community.

Based on the variety of ways in which I have engaged in service, I eventually felt I was ready to tackle a sustained relationship with a community partner. As such, I approached the idea of a community-based research project with confidence. This confidence was short lived, as I soon found that I had underestimated the challenges of conducting community-based research. Despite these challenges, I now feel even more strongly about the importance of developing and completing community-based research projects.

From the fall of 2013 through the spring of 2014, I conducted a research project in partnership with two nonprofit organizations on the psychological effects of being a family caregiver. I began this research as a course within my psychology major. While most of my peers chose college students as their participants, my interests in psychology were focused on older adults. With very limited resources allotted for my research, much like all undergraduate research, I was prompted to utilize community partner connections to reach the older adult population. I decided to complete a community-based research project not just to access participants, but because I wanted this research to serve a purpose beyond course credit. In this way, the research felt more meaningful and gave me strong motivation to dedicate my time to the project.

After discussing my research interests with multiple people, I was connected with the Aging Coordinating Consortium, a committee with a five-year strategic plan to improve aging in Buncombe County, NC. The committee invited me to a meeting to see how my research interests might align with the goals of its strategic plan. Simply sitting in on one of the meetings was a greater learning experience than quite a few of my academic courses. I was in a room with people dedicated to solving the issues I felt most passionate about. It was a truly inspiring experience just to be in the same room with them.

The research question was developed based on these agencies’ need to know more about the family caregivers in the area. By aligning my time and energy with the needs of this committee, I served a real function in moving the strategic plan forward. I attended multiple meetings in order to fine tune and communicate my research objective and procedures for reaching it. One of the first challenges in this process was the fact that the group met only once a month, during one of my classes. This foreshadowed a persistent challenge throughout this project, which was staying on schedule with my course deadlines while not imposing on my community collaborators’ time.

The Council on Aging of Buncombe County and CarePartners, two members of the Aging Coordinating Consortium, offered to collaborate with me on research focused on family caregivers. Developing the research procedures required many phone calls, emails, and visits to these two nonprofit organizations. This was particularly challenging because I was trying to synthesize different sources of input with my own ideas for how to assess family caregivers. It was often difficult to make decisions because of the conflicting ideologies at play. For example, based on my academic training in psychology I leaned toward quantitative research methods instead of qualitative methods. Looking back, I wish I could have spent more time collaborating with my community partners to develop my research plans, without the pressure of my course timeline. With more intentional conversations around their needs as nonprofits, I might have gotten a better understanding of the value of qualitative interviews for their purposes.

Additionally, while I was motivated by the idea of giving back to the community, this was a daunting project due to the scale of the strategic plan. The Aging Coordinating Consortium's plan addresses the needs of the entire county, but because of limited resources and time I had to shrink the scale of the research. In addition, collaborating with my community partners was much more time intensive than I expected and required many more firm decisions from me than I had anticipated. Reflecting on this, I think I had assumed that the community partners would provide a clear direction for the research rather than the wide scope of issues they presented. This gave me some freedom in developing my research, but was also overwhelming.

Furthermore, differing ideologies around research complicated my decision making about which aspects of family caregiving to assess. The Aging Coordinating Consortium and the two community partners often urged me to assess levels of depression in family caregivers. However, I was more interested in psychological well-being, which, unlike depression, has not been well studied in the literature surrounding family caregivers. It appears well documented in previous research that most caregivers are burdened by the role to at least some degree. A gap exists in research regarding the benefits or positive experiences associated with the caregiving role. Thus, navigating between what I thought might best serve the needs of the community and what my community partners saw as being in their best interests was a great learning experience. Navigating these conflicting ideas was further complicated by the additional pressure of conducting research for an academic course in the discipline of psychology. I found myself relying on my own initiative and communicating with my community partners succinctly in order to move the project forward on pace with my timeline.

One of the most important lessons I took away from this experience is the value of adaptability. Many times I found myself wondering what the next step was, or what the community partners would need from me next. There were no procedures or guidelines for how to make this project come to fruition. In the beginning it frustrated me to have no structure, but ultimately it forced me to adapt to the needs of my collaborators.

One of the key moments when I had to learn to adapt was when the research study struggled to recruit participants. My intention when I began this community-based research project was to give back to the community. I had high hopes for how this research could be beneficial, but when only eleven caregivers participated, I had to adjust my strategies and my expectations. Through this process I learned which methods were more and less successful at reaching the family caregiver population. I may not be able to present clear results on the experiences of family caregivers to the Aging Coordinating Consortium, but I believe that learning this was a step forward.

Throughout this process of collaboration I was looking for a model to follow or guidelines for next steps. Now I realize that trying to organize the process of community-based research into a rigid model might limit the diversity of the opportunities for knowledge development. I found that I could develop a model based on my experience, but just as each community partner differs, so does the process of collaboration. As long as one approaches the community partner with humility and is ready to adapt, I feel that a project can be successful.

Overall, this experience significantly increased my skills in communicating and adapting. More importantly, it challenged me to reevaluate what it means to work with a community partner and what it means to do community-based research. I now have a greater appreciation for the hard work and commitment that community partners contribute to a project like this. It is not a simple task to volunteer for a community-based research project but I am grateful my community partners dedicated their time. I learned that sometimes a project is still successful even if the initial goals are not met; a collaboration has been created and a partnership developed.

I know now that the value of community-based research is in the process of community collaboration itself. I learned much more about the community, community partners, and myself by working through the challenges of conducting this research than I had ever hoped for. When I began this project I was looking for a way to serve a purpose in my community and I now feel that working with the community in this sustained way has renewed my sense of purpose to engage in service. For me, the bottom line is that it’s not always about the final product of community-based research, sometimes it’s about coming together to learn through the process.

~

I would like to thank Dr. Bob Swoap for his continuous support and guidance through this project. I would also like to thank the Psychology Department and the Service Program Staff at Warren Wilson College for their networking connections. Lastly, I would like to thank the Council on Aging of Buncombe County, CarePartners, and the Aging Coordinating Consortium for the dedication and energy they brought to this project.