


EXPLORING CAREGIVING EXPECTATIONS OF
A GROUP OF COLLEGE STUDENTS

CHER R. TEUTON

To the Graduate Council:

I am submitting herewith a thesis written by Cher R. Teuton entitled "Exploring Caregiving Expectations of a Group of College Students." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Arts, with a major in Psychology.



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STUDENTS

Presented for the Master of Arts

Degree

Austin Peay State University

Cher R. Teuton

June 2003

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ABSTRACT

This study examined the expectations of caregiving among college students between the ages of 18 to 35 years. Participants ($N = 68$) completed a demographics survey and a questionnaire that consisted of three essay questions investigating their expectations of caregiving. Results indicated that out of the 68 participants, 52 listed themselves as the primary caretaker or willing to share the caregiving responsibility with another family member. The results from this study are supported by findings within existing research literature.

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CHAPTER I

INTRODUCTION

The purpose of this study was to investigate what individuals who are in the age range of 18 years to 35 years view as their future caregiving responsibilities. Many studies have been done to research characteristics of current caregivers or those who have already served in a caregiving role. However, this study is intended to examine a population who typically has not yet been faced with having to care for an elderly or chronically ill parent.

Caregiving has been defined in previous research by Miller and Mc Fall (1991) as assisting another with at least one activity of daily living. Scharlach, Sobel, and Roberts (1991) defined caregiving as physical, financial, and/or emotional support. For the purposes of this study, the definition of caregiving will consist of assisting the elderly individual with any activities of daily living and other means of support. Daily living activities include hygiene needs and feeding. Other means of support will include physical support, housekeeping, transportation needs, financial assistance or bookkeeping, and emotional support. Caregiving and caretaking will be used interchangeably throughout this paper.

More than seven million Americans perform caregiving duties for elderly friends and family members (Buglass, 1989). Although potential caregivers are often faced with the choice of placing their family member into assisted living institutions, the reality of the future is that family members themselves will

provide most of the care for the aged and ill (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). The American population over the age of 65 years is growing at an increasing rate due to the numerous advances within the healthcare system. While healthcare advances have made it possible for an individual to live longer, they have also increased the possibility of family members having to provide complex caregiving duties in the home (Canam & Acorn, 1999). The United States Bureau of Census' Statistical Brief stated that in 1995 the elderly represented one in every 25 people in 1900; by 1994 the ratio increased to one in every eight people. The Bureau of Census (1995) also predicted rapid growth of the elderly population between the years of 2010 and 2030, predicting that by the year 2050 this population will rise to 80 million people. Their predictions are based on the fact that the "baby boomer generation" will be reaching retirement age at this time.

The fastest growing group has been deemed the "oldest old" and consists of individuals who are 85 years of age and older. As a result of longer life spans, the United States Bureau of Census (1995) expects that the "baby boomers" will increase the population within this age group to 19 million people by the year 2050. According to these statistics, an overwhelming number of elderly people will be in need of care during their later years. It is likely that an increased number of family members who have elderly relatives will find themselves in a caregiving position.

Current long-term care policy and practices are built on the premise that the family is, and should be, the primary party responsible for impaired older persons (Montgomery, 1999). Tending to one's immediate family and attempting to maintain a career is an arduous task. These stresses coupled with the added pressures of caring for an elderly or ill parent is likely to cause an individual to feel overwhelmed. Additionally, many times caring for a parent whose needs are extensive causes the caregiver(s) to change priorities in reference to career choices and family matters.

In some cases, spouses of the elderly persons take on the role of caregivers until they are physically incapable of carrying out the necessary tasks. This scenario is disconcerting because the caregivers are also likely to be elderly and may not maintain their own physical and psychological health as they care for their loved one's needs. The Bureau of the Census (1995) has found that most elderly men have a spouse who is providing them with aid, but the majority of elderly women do not. It has also been reported that as many as 50% of those aged 85 and over need assistance with everyday activities (The Bureau of the Census, 1995). The 1982 National Long-Term Care Survey indicated that widowed and never married people have larger helping networks than those of married people (Barrett & Lynch, 1999).

Caregiver Burden/Stress/Positive Aspects

Caregivers possess various characteristics that have been identified as playing a major role in determining how burdensome and/or stressful caregivers

view their roles, such as gender, availability of support systems, relationship to care recipient, perception of care recipient's symptoms, and attitude or behavior toward care recipient. Mui's (1995) research of wife and husband caregivers found that both spouses encountered considerable amounts of emotional, financial, and physical strain. The causes that affected the amount of stress encountered included role conflict, caregiving role demand, coping resources, and care recipient characteristics. Hughes, Giobbie-Hurder, Weaver, Kubal, and Henderson (1999) tested 1570 caregivers of veterans that qualified for formal home care situations. Caregivers of Caucasian spouses expressed the greatest burden, while African American and Indian/Alaskan caregivers reported the lowest amount of burden (Hughes, et al., 1999). This study also reported the highest caregiver burden was expressed by those with the lowest education levels while caregivers with higher education levels reported the least amount of burden. The causes of increased burden in relation to education level or race was not discussed, only findings of their cross-sectional study to assess the needs of caregivers to enhance their quality of life were stated.

Furthermore, caregivers are at higher risk of developing mental health problems and are subject to social, economic, and health based problems (Murray, Schneider, Banerjee, & Mann, 1999). Since the majority of caregivers are women, it is often assumed that caregiving is an extension of their roles as wife and mother (Bull, 2001). Many women are finding themselves in a position of caring for an elderly parent as well as their own children, thereby increasing the

chance of emotional burden and stress (Buglass, 1989). The demand for elder care is steadily growing. However, the number of available caregivers is decreasing due to the increased number of women in the workforce and higher divorce rates (Frederick & Fast, 1999). More family members are being called upon to share caregiving duties. Within some families that have extended to four generations or more, the young adult members are now becoming a part of the caregiving population (Dellman-Jenkins, Blankemeyer, & Pinkard, 2000).

Caregiver support groups have been shown to be useful in the areas of morale, information and social support in a study conducted by Kaasalainen, Craig, and Wells (2000). Their study formally evaluated caregiver support programs and their effect on the participants. The study followed 23 female caregivers through their first two weeks of support group attendance. The women were given morale, social support, and demographic questionnaires prior to their attendance of the support group and again after two weeks of participating in the support group. Results from this study suggest that available social support positively influences the morale of caregivers.

Caregiving is not only comprised of negative or burdensome aspects. Caretakers also experience positive aspects associated with caretaking. Many caregivers have higher self-esteem, which may be a result of meeting filial or marital obligations by preventing the person they are helping from being institutionalized (Huston, 1990). Nijboer, Triemstra, Tempelaar, Sanderma, and van der Bos (1999) found that caregivers with a low level of education were more

likely to have higher self-esteem regardless of low income, to be living with only the care recipient, to experience a distressed relationship, to engage in a high level of recipient dependency, and have a high involvement in caregiving tasks.

The Industry of Caregiving

The costs of caring for an elderly relative can be tremendous. The estimated national economic value of informal caregiving was \$196 billion in 1997, formal home care was found to be \$32 billion, and nursing home care was \$83 billion (Arno, Levine, & Memmott, 1999). If an individual does not have savings or a health plan, the responsibility of care falls on the family. If a plan is in place, it is likely that it is not adequate for long term care needs. Many companies are realizing that job performance of caregiving employees is likely to decrease, allowing for issues such as reductions in work productivity and increased absences to arise. Employees in caregiving roles surveyed by Transamerica Life reported emotional strain, physical and financial stress, and less time for self care (Buglass, 1989). Some employed caregivers reported reducing their working hours or having discontinued employment completely due to the demands of caring for a relative (Sullivan & Gilmore, 1991).

Gender Differences in Caregivers

Women are predominately considered to be the caregivers of the family; however, many men also take on this role. Husbands of ill wives, sons of mothers and fathers, and brothers find themselves in positions that require them to become caregivers. Male caregivers have been shown to report fewer

psychiatric symptoms and experience less stress than women (Yee & Shulz, 2000). Males also scored lower on the Zarit's Burden Interview than women (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002). The research suggests male caregivers are reluctant to admit negative feelings toward caregiving and may be less likely to report symptoms of depression or distress than their female counterparts. Males expect to be asked for their help as opposed to women who are more likely to volunteer their help, except during times of crisis or transition (Matthews & Heidorn, 1998). Men in Australia, interviewed for reasons they took on a caregiving role for a spouse, replied in terms of commitment, reciprocity, duty, love, and fairness (Cahill, 2000). Stoller (1990) reported men did fewer tasks regarding caregiving overall. Male caregivers were also less likely to perform tasks such as cooking, light chores, and laundry. Stoller also reported that males are more likely to abandon their caregiving role when the responsibilities increase or become more demanding. Males are also more likely to maintain activities outside of their caregiving roles to help them cope (Archer & MacLean, 1993).

Past Research

Past research has indicated that caretakers are at a high risk for mental health problems and that the comprehensive burden of caring has social, economic and health based elements (Schneider, Murray Banerjee, & Mann, 1999). Wallhagen and Strawbridge (1995) found that current caregivers were less likely to want to be cared for by family. Although the adult descendant

caregivers were generally supportive of family care, almost half of the participants stated they did not want family taking care of them once they became dependent (Wallhagen & Strawbridge, 1995). Marks (1996) found that gender, age, education, ethnicity, marital status, and professional status are indicators of the possibilities of caregiving. Several factors have been shown to significantly contribute to a woman's possibility of providing care for her elderly parent. These include age, marital status, education level, number of living parents, parental age, and geographic proximity (Himes, Jordan, & Farkus, 1996). Himes et al. reported never married women are at a much greater risk of caregiving than currently married women; however, divorced or widowed women share the same risk. Proximity to the parent in need of less than 15 miles also increased the likelihood of a daughter providing care, whereas women with two living parents decreased their chance of becoming a caregiver.

Limitations of Existing Research

Few researchers have investigated the events and circumstances preceding the onset of caregiving (Sorensen & Zarit, 1996). Donaldson and Burns (1999) have acknowledged that caregivers' own characteristics play a major role in determining how burdensome and stressful they find their role. The characteristics they have found that influence the perception of burden include gender, support systems, relationship to care recipient, perception of the care recipient's illness, and the attitudes toward the care recipient. However, the

literature does not contain research relevant to young people's expectations of caretaking.

Present Research

Since there is a lack of research involving the expectations of caregiving for young adults, this study investigated the expectations of caregiving of college students between the ages of 18 years to 35 years to contribute to the literature information regarding this age range.

CHAPTER II

METHODS

Participants and Design

There were a total of 68 participants utilized for this study. Participants were both males and females between the ages of 18 years to 35 years. Participation was voluntary and anonymous, as the informed consent was filed separately from the questionnaire. All participants received extra credit slips for participating in this research.

This study used a descriptive, non-experimental design. The survey method was used to identify themes presented by the respondents in the questionnaire and said themes were categorized according to similarity. Raters included the examiner and one professor involved with the research committee and one colleague who has earned a Masters degree in Clinical Psychology. The raters blindly and separately examined original copies of the questionnaires and extracted themes presented among the responses.

Measures

Demographics. Each participant was asked to answer questions regarding his or her major area of study, age, and gender. Additionally, each participant was asked to list the birth order of his or her family (including self with siblings) (see Appendix A). This information was kept separate from the questionnaire to ensure blind rating.

Expectations of Becoming a Caretaker. In order to assess expectations of becoming a caregiver, participants completed a self-report questionnaire. The questionnaire consisted of three essay-type questions that examined the participant's view on caretaking and his or her expectations of caring for an elderly or ill relative (see Appendix A).

Procedure

After obtaining permission from the Institutional Review Board, professors within the Psychology Department were contacted in person to schedule appointments for the administration of the questionnaire to those students who chose to participate after class time. It should be noted that the professors were not involved in the recruitment process or present during the administration of any measures.

Participants completed the informed consent document (Appendix B) prior to completing the questionnaire. Next, each participant completed the questionnaire, which took approximately 15 minutes. Following the completion of the questionnaire, participants received a debriefing statement (Appendix C) and extra credit slips for their participation.

CHAPTER III

RESULTS

This study included the use of a questionnaire and a qualitative analysis of the data. Validity and reliability issues in qualitative research are addressed by a focus on the trustworthiness of the conclusions drawn from the data.

According to Williamson, Softas-Nall and Miller (2003), trustworthiness is “developed by emphasizing credibility, consistency, confirmability, and communicability” (p. 25). Credibility was assured by the examiner keeping all responses as they were written in their original form. Consistency was demonstrated as several common themes were extracted from the data.

Consistency occurs when the same core concepts and themes consistently emerge across different cases. Confirmability was enhanced by a thorough explanation of how the themes emerged from the data, as confirmability concerns how the results are obtained from the data and how the results could be replicated.

Communicability issues were addressed by the examiner who explained the processes clearly and in a manner the reader could understand.

Trustworthiness was enhanced by the use of several qualified examiners who reviewed the data and congruence of their themes. Triangulation of the data occurred as the data was carefully collected, processed by the researcher and two qualified reviewers, and the integrity of the themes presented were scrutinized. This process verified triangulation of the data, as the researcher and reviewers

thoroughly examined and coded the questionnaires, discussed their findings, and agreed upon the themes presented in each questionnaire. The data was further triangulated by considering the findings in light of the literature review.

All participants' informed consent documents and questionnaires were separated after collection in order to assure the anonymity of the participants. Each questionnaire was reviewed by the researcher to determine whether or not the completed questionnaire met the criteria for inclusion in the study. Appropriate questionnaires were then typed and copies were provided to the other two examiners. Each examiner analyzed the responses for themes associated with the participant's anticipation of caregiving.

Once each examiner completed their review of the data, a meeting with the researcher was held to discuss their findings. After a thorough examination of each participant's demographic data and essay responses, themes were named and each participant's responses were categorized into the themes they represented. During the meeting, the researcher and both examiners agreed upon the themes that were presented and triangulated their data by discussing each theme in detail. A consensus on each theme was met among the examiners and researcher at the conclusion of the meeting. The researcher used this information to help clarify the list of themes that were identified from the data.

Participants included 47 (69%) females and 21 (31%) males ranging in ages from 18 to 34 years with a mean age of 23 years. The 24 different majors

represented among the participants were primarily comprised of nursing, psychology, biology, and home health provider majors. Out of the 68 participants, 52 listed themselves as the primary caretaker or willing to share the caregiving responsibility with another family member. The most common reason provided for the expectation of caregiving was being the oldest in the family (see Table 1). However, three participants indicated that the youngest sibling would assume caregiving responsibilities within their families. The reviewers felt that the predominant theme found among participants in relation to what types of services they expected to provide were activities of daily living, which included activities such as hygiene and feedings (see Table 2). In contrast, only two participants stated that they were not expecting to provide any kind of care in the future, and only one participant identified providing services such as meeting spiritual needs, making life decisions, and providing stability for those whom they expect to provide care.

Additionally, six of the female participants identified that a male sibling would be the primary caretaker within their family other than themselves, while four male participants identified that a female sibling would assume the role of the primary caregiver. In contrast, six participants stated that they would share the responsibility of caregiving with another sibling regardless of gender.

CHAPTER IV

DISCUSSION

This study examined the expectations of caregiving of 68 individuals who were between the ages of 18 to 35 years. The results of this study provided insight into the views of one age group of participants as they consider their potential roles as caregivers for elderly family members. As indicated by the results, most participants believed that they would perform caregiving duties in their lifetime for a family member. While the predominate theme related to the expectation of caregiving throughout this study was based on birth order, various other themes, such as relative relationship between expected caregiver and recipient, level of responsibility, previous training, and sense of duty, were present throughout this study as well. The predominate themes related to expected duties were providing assistance with activities of daily living, emotional, financial, and physical support, as well as providing transportation and housing for the recipient. Additionally, some respondents also identified such duties as providing stability, facilitating the spiritual needs of the recipients, and making major life decisions.

Commensurate with Montgomery (1999), this study supports the notion that family members are the primary party responsible for providing care for their elderly parents. As found within this study, Himes et al. (1996) also found proximity to be a predictor for performing caregiving duties. Finally, comparable

with Donaldson & Burns' (1999) findings, this study indicated that an individual's perception of burden was based on his/her emotional relationship to the care recipient.

Limitations of the Present Study

Conclusions drawn from the present research are limited to the institution and area in which participants were recruited. While differences may be found among individuals from different universities and areas, it is possible that some suppositions could be made in reference to those universities and areas that are similar. In addition, generalizability of this study cannot be assumed. This study represents the opinions of the research participants, which may or may not reflect the opinions of the larger population of individuals aged 18 to 35 years. The study may provide the impetus for future studies that might be more generalizable.

In conclusion, this study examined the expectation of caregiving in individuals who were 18 to 35 years of age. Results indicated that most participants expected to provide some type of caregiving duties in their lifetime, either solely or jointly with other siblings. The specific themes that emerged throughout the research were supported by past research. Future research should further examine caregiving expectations by asking specific questions based on participants' anxiety levels, as well as delving deeper into the rationale of why an individual would expect to give care.

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TABLES

Table 1.
Themes Presented

<i>Theme</i>	<i>N</i>
Oldest	19
Self more responsible/training/experience	18
Sharing caregiving responsibilities	17
No other sibling capable	14
Sense of duty	10
Only child	9
Proximity	8
Other emotionally closer to parent	7
No care to be provided	2

Table 2.
Expected Duties

<i>What does caregiving mean to you?</i>	<i>N</i>
Activities of daily living (hygiene and feedings)	31
Emotional support	23
Financial support	16
Physical support	12
Transportation	12
Provide housing	11
Provide companionship	8
Housekeeping	7
Medical care	4
Nursing home/ In home healthcare	3
Time consumption	3
Providing recreation	2
Providing stability	1
Decision making	1
Spiritual needs	1

APPENDIXES

APPENDIX A

EXPECTATION OF BECOMING A CARETAKER QUESTIONNAIRE

APPENDIX A
Expectation of Becoming a Caretaker Questionnaire

Background Information

Major: _____

Your Gender: M or F

How many siblings do you have?

Please list them in birth order by gender and age including yourself in the list. (Please begin with first-born.)

_____ M or F _____ AGE _____

_____ M or F _____ AGE _____

_____ M or F _____ AGE _____

_____ M or F _____ AGE _____

_____ M or F _____ AGE _____

_____ M or F _____ AGE _____

_____ M or F _____ AGE _____

_____ M or F _____ AGE _____

_____ M or F _____ AGE _____

Who in your family do you think will assume the most responsibility of your parent(s) care when they have aged and require assistance?

Please explain in detail how you arrived at your answer to the previous question.

What does the responsibility of caretaking mean to you (i.e. tasks you will have to perform, emotional issues/concerns)?

APPENDIX B

INFORMED CONSENT

APPENDIX B

Informed Consent Document

You are being asked to participate in a research study. This form is designed to provide you with information about this study. You may ask the researcher listed below about this study or you may call the Office of Grants and Sponsored Research, Box 4517, Austin Peay State University, Clarksville, TN 37044, (931) 221-7881 with questions about the rights of research participants.

1. TITLE OF RESEARCH STUDY

Caregiving Expectations of Psychology Majors

2. PRINCIPAL INVESTIGATOR

Cher R. Teuton, Graduate Student, Austin Peay State University, Psychology Department, Clarksville, TN.

3. THE PURPOSE OF THE RESEARCH

This study has been designed to investigate the caregiving expectations of psychology majors and their expectations of providing care to their aging parents. There are no right or wrong answers. You should answer each question according to your own beliefs and feelings. You are being asked to respond as honestly and as accurately as possible to each question on the questionnaire.

4. PROCEDURES FOR THIS RESEARCH

You will be asked to complete a questionnaire. The questionnaire will ask you to list the birth order of you and your siblings as well as asking three questions regarding your views on caretaking for your parents. You will be asked to respond in an essay format. The questionnaire should take approximately 15-20 minutes to complete. If you are not a psychology major, please turn in all questionnaire materials to the examiner.

5. POTENTIAL RISKS TO YOU

There are minimal risks associated with participation in this study. One risk may be feeling discomfort due to some of the items on the questionnaire. If this happens, please let the examiner know.

Your name will only appear on this informed consent and will not be associated with the survey. All data will be kept secure in a locked cabinet. The identity of participants will never be revealed in any published or oral presentation of the results of this study. The data collected from the study will be made public only in summary form, which makes it impossible to identify individual participants.

6. POTENTIAL BENEFITS TO YOU OR OTHERS

As a participant in the study, you will be contributing to science and helping researchers gain insight into the expectations of college students on caregiving for their parents. In order to receive extra credit for participation, if you must be enrolled in a psychology class at Austin Peay State University.

Please read the statements below. They describe your rights and responsibilities as a participant in this research project.

1. I agree to participate in the present study conducted by Cher R. Teuton, a graduate student in the Department of Psychology at Austin Peay State University, and supervised by Dr. Stuart Bonnington, a faculty member in the Department of Psychology at Austin Peay State University. I have been asked to complete a questionnaire.
2. I have been informed in writing of the procedures to be followed and about any risks that may be involved. I have also been told of any benefits that may result from my participation. Ms. Teuton and Dr. Bonnington have offered to answer any questions I may have regarding the procedures. Ms. Teuton can be contacted at (931) 221-7233 between 9 a.m. and 4 p.m., M-F. In addition, I have been informed that I can contact the Office of Grants and Sponsored Research, Box 4517, Austin Peay State University, Clarksville, TN 37044, (931) 221-7881 with questions about the rights of research participants if I so choose.
3. I understand that I may withdraw from participation at any time without any penalty or prejudice. I understand that my answers are kept separate and confidential from my identifying information and cannot be retrieved once I release them to the examiner. I also understand that any data obtained from me will be excluded from the study and destroyed if I withdraw prior to handing in the questionnaires to the examiner with the other participants. Upon withdrawal, the examiner will destroy all materials in reference to my participation.
4. I realize that by signing this form, I willingly consent to participate in the current study. I also acknowledge that I have been given a copy of this form for my records.

Name (Please print)

Signature

Date

APPENDIX C

DEBRIEFING STATEMENT

APPENDIX C

Debriefing Statement

As previously stated, there are no right or wrong answers affiliated with the items you have just answered. We were interested in the honest self-evaluation pertaining to your expectation of becoming a caretaker. No deception was used at any time during the study.

As previously stated, your answers are entirely confidential and your name will not be attached to or recorded with any of the data. Your name will only appear on the informed consent document and will not be associated with the questionnaire. All data will be kept under lock and key in a secure office. Finally, the data will only be made available through averages and will in no way identify any individual who has chosen to participate.

Furthermore, the informed consent documents will be stored separately from the data collected. Thank you again for your participation. If you have any questions please feel free to ask now or call at a later time. Once again, I can be reached at (931) 552-9028 between 10 a.m. and 3 p.m., M-F. You can also contact Dr. Bonnington at (931) 221-7234 between 9 a.m and 4 p.m., M-F.

VITA

Cher Renee Teuton was born in Ocala, Florida on October 1, 1974. She attended elementary school at College Park Elementary and Grace Episcopal Day School. Additionally, Cher attended North Marion Middle School. She graduated from North Marion High School in June of 1992.

During the fall of 1992 Cher attended Eastern Kentucky University. In May of 1993, she left EKU and enlisted in the United States Army in December of 1994. While in the military, she continued her education at Hawaii Pacific University. After serving her enlistment, Cher graduated with a Bachelor's of Arts Degree in Psychology from Hawaii Pacific University in August of 2000.

Immediately following her graduation from Hawaii Pacific University, Cher enrolled in the Clinical Psychology graduate program at Austin Peay State University. She is currently finishing her degree.