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Assessing Quality of Life and Mental Health Differences Among Young
Adult Informal Caregivers and Non-Caregivers in Nebraska

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Abstract

The goal of this project is to identify differences in quality of life and mental health between younger informal caregivers and non-caregivers, ages 19-40, in Nebraska. To address this goal, a demographic and health assessment battery was disseminated to eligible participants (N=60), comprised of informal caregivers (N=30) and age-, education-, and gender-matched non-caregivers (N=30). The health assessment included reliable and validated questionnaires, including the RAND SF-36, EuroQol 5D, Kessler Psychological Distress Scale, and the General Health Questionnaire. By discovering relationships between quality of life and mental health with the length of time providing care, programming and intervention recommendations can be made to improve the health of informal caregivers in Nebraska.

1. Introduction

Advances in modern-day medicine have led to an increase in life expectancy and a growth in the population 65 years of age and older¹. In 2016, it was estimated that 49.2 million individuals living in the United States were 65 years of age or older with approximately 58% 65-74 years of age, 29% in 75-84 age group, and 13% 85 and older¹. Older age is often accompanied by disability and diminishing physical health¹. Of note, the inability to live independently was one of the top concerns reported by adults 65 years and older, behind ambulation, vision, hearing, and cognition. 7.6% of adults 65-74, 17.2% of adults 75-84, and 43.4% of adults 85 and older reported difficulties with independent living¹.

Due to the increasing number of older adults in the United States with and without disability, the role of informal caregivers has become indispensable. The National Center on Caregiving

defines informal caregivers as, “any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care”². Informal caregiving is driven by the desire to age in place, which 85% of baby boomers report as their preferred method of aging³. According to the report “Caregiving in the U.S 2015”, 43.5 million adults in the United States reported providing unpaid care to a family member or friend in 2014⁴. Of note, approximately 14.3% of adults in the United States provide care to someone 50 years of age or older⁴. In 2004, there were 170,972 caregivers in Nebraska alone, providing 183 million hours per year in care with an annual market value of \$1,817,000,000⁵.

Previous research has supported the notion that informal caregivers who provide support to individuals with disabilities are putting themselves at risk for declining health^{6, 7, 8, 9, 10, 11, 12}. Informal caregivers subject themselves to strain by providing intense care, which can result in mental and physical health complications, ultimately impacting the caregiver’s quality of life, defined as how one views their position in life, impacted by physical health, mental health, relationships, and beliefs^{10, 11, 12, 13}. Understanding the impact of caregiving on quality of life is instrumental, as a decrease in quality of life has been associated with self-reported chronic diseases, such as diabetes, hypertension, and arthritis¹⁴. Addressing the activities and behaviors associated with declining quality of life, such as those associated with caregiving, will reduce preventable disease, disabilities, and injury, improving the overall health of informal caregivers

Research also suggests that poor health outcomes of informal caregivers are impacted by certain factors, such as age^{12,15}. Therefore, the burden experienced by informal caregivers may impact subgroups of caregivers at different rates¹². While significant research has been dedicated to vulnerable older adult caregivers, 65 years of age and older, little research has focused on younger informal caregivers. It is important to study the age-related differences in caregiving, as younger caregivers often balance demanding responsibilities in conjunction with caregiving, such as school, employment, or parenting that may magnify the stress and burden associated with caregiving.

1.1 Problem Statement

Differences in quality of life and mental health between informal caregivers and non-caregivers, ages 19-40 in Nebraska.

1.2 Importance of Proposed Project

This project will contribute new information regarding poor health outcomes, specifically the quality of life and mental health, of younger caregivers. This research will begin to fill in the gap in the literature of the younger caregiving cohort. Additionally, this project will aim to identify and characterize age-related health outcomes of informal caregiving. Identifying age-related outcomes will help to foster and guide programming and interventions specific to younger caregivers. Finally, this research will open new doors for future research projects to expand upon the knowledge of informal caregivers.

1.3 Literature Review

Identifying the health implications of informal caregiving has been a trend in the healthcare community and literature. In 2011, The Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services funded the National Study of Caregiving (NSOC). This study consisted of telephone interviews with 1,742 unpaid caregivers who cared for community-dwelling older adults. Caregivers participating in this study had a mean age of 57.1, were 62.2% female, 46.1% were adult children taking care of a parent, 22.9% were taking care of spouses, and 31% had an “other” relationship to the care recipient¹⁵. 56.1% of caregivers reported caregiver burden, 12.7% acknowledged depressive symptoms on a 2-item questionnaire, and 12.8% acknowledged anxiety symptoms on a 2-item questionnaire¹⁵. The average, caregiver provided four instrumental activities of daily living or activities of daily living (IADL and ADL), 1.3 health management tasks, and 2.5 health systems tasks. In the multivariable model, caregiver burden was associated with fair and poor self-reported health, symptoms of anxiety, and assisting with more ADLs and IADLs¹⁵.

The National Alliance for Caregiving and the AARP Public Policy Institute conducted the study “Caregiving in the U.S. 2015”. This specific study interviewed 1,248 caregivers 18 years of age and older, defined as “providing unpaid care to a relative or friend 18 years or older to help them take care of themselves”⁴. Caregivers participating in the study had a mean age of 49.2, 34% of caregivers were between the age of 50 and 64, 85% of caregivers were caring for a relative, 49% reported no choice in providing care, yet only 56% of respondents were current caregivers⁴. Caregiver’s health declined over time, with 20% of caregivers providing care for 5 or more years reported fair or poor health,

opposed to 14% of caregivers providing care for less than a year⁴. 20% of caregivers attribute their worsening in health to caregiving. In this study, the burden of care was defined by hours of care provided and IADLs and ADLs performed. 40% of caregivers classified their care as highly stressful⁴. Other contributors to stressful caregiving included caring for a spouse or parent, caring for a co-resident, performing medical tasks, care duration, and burden of care⁴. Although this study comprehensively assessed characteristics of caregivers, it lacked validated quality of life and mental health metrics.

Globally, other literature has acknowledged the health implications of caregiving amongst older caregivers. In the Dutch study “The Impact of Older Person’s Frailty on the Care-Related Quality of Life of Their Informal Caregiver Over Time: Results From the TOPICS-MDS Project,” 660 older adults and their caregivers were surveyed using The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS). This data set included validated measures of health and quality of life, like the RAND SF-36¹⁶. Surveyed caregivers had a mean age of 65, were 68% female, 50% the spouse of the care recipient, and 52% of the caregivers lived with the care recipient¹⁶. Results indicated that the care recipient’s frailty over time resulted in a lower quality of life for the caregiver. Additionally, the quality of life of the caregiver was directly proportional to the psychological wellbeing of the care recipient¹⁶. Quality of life of the caregiver was inversely proportional to the number of care hours they provided¹⁶.

A gap in the literature persists, identifying and characterizing the age-related health impacts of informal caregiving. Currently, there is an emphasis in the literature on

caregivers 50 years of age and older, as this cohort has previously been viewed as vulnerable.

2. Goals and Objectives

Goal: Assess the differences in quality of life and mental health between informal caregivers and non-caregivers, ages 19-40, in Nebraska

Objective 1: Describe the demographic characteristics of young informal caregivers and non-caregivers, age 19-40.

Activity 1: Disseminate a demographics questionnaire assessing demographic information for both groups.

Activity 2: Using descriptive statistics, analyze the results of the demographics questionnaire

Objective 2: Assess and compare the quality of life of younger informal caregivers compared to non-caregivers

Activity 1: Disseminate a battery of questionnaires assessing quality of life, including the RAND SF-36 and EurQol 5D

Activity 2: Create a REDCap database to collect and store participant data

Activity 3: Use between-groups analyses to compare the quality of life metrics between informal caregivers and non-caregivers

Objective 3: Assess and compare the mental health of younger informal caregivers compared to non-caregivers

Activity 1: Disseminate a battery of questionnaires assessing mental health, including The Kessler Psychological Distress Scale and The General Health Questionnaire

Activity 2: Use between-groups analyses to compare the mental health metrics between informal caregivers and non-caregivers

Objective 4: Compare the quality of life and mental health of younger informal caregivers based on number of years providing care

Activity 1: Use within-groups analyses to compare quality of life and mental health metrics between informal caregivers who have been providing care for less than five years and informal caregivers who have been providing care for five years or longer

3. Methods

This study utilized primary survey data to assess the differences in quality of life and mental health between informal caregivers and non-caregivers, ages 19-40 in Nebraska.

3.1 Study Population

All participants were healthy adults, ages 19-40 residing in Nebraska. The lower limit of the age range was determined by Nebraska's definition of an adult, being 19 years of age. The upper limit of the age range was determined by the age at which age-related changes in the brain are accelerating¹⁷. Participants were excluded if they had less than two years of high school education or were unable to comprehend written and spoken English. Participants were also excluded if they self-reported neurological or psychiatric diagnoses. Participants in the caregiver group were a current adult caregiver. There was no requirement for the amount of care provided

or the total duration of time the caregiver had been providing care. Differences in the amount of care provided were addressed in analyses.

Participants were recruited from the University of Nebraska registries, past studies on aging, caregiver coalitions, and from the community. Two main sources of recruitment through the University of Nebraska system were the Aging Brain and Emotion Lab at The University of Nebraska-Omaha and the Mind & Brain Health Labs at the University of Nebraska Medical Center. Aging Brain and Emotion Lab participants who meet inclusion criteria who previously enrolled in the study, “Social Decision Making Across the Lifespan,” IRB #204-17-EP, were recruited. The Mind & Brain Health Registry, IRB #398-15-EP, housed in the Mind & Brain Health Labs was used to recruit younger informal caregivers and non-caregivers across the state of Nebraska. Recruitment fliers were distributed to caregiver coalitions across Nebraska, including Nebraska Lifespan Respite Network, Jefferson County Health and Life Hospital, and Caregiver Support Services Omaha. Fliers were also distributed around UNMC at the Home Instead Center for Successful Aging, the UNMC Neurology Clinic, and the UNMC Movement Disorders Clinic.

3.2 Sample Size

Since this was a pilot study for feasibility, a convenience sampling approach was used. This study enrolled 60 participants, including 30 informal caregivers and 30 non-caregivers. The target sample size was guided by the recommendation that pilot studies should aim to recruit 30 participants per group¹⁸. A total of 68 participants were recruited, but eight were lost to attrition.

3.3 Data Collection Methods

Once participants were recruited and agreed to participate in the study, they were taken through the consent process. Unlimited time was allocated for the process of consent, which took place over the phone or in dedicated lab space. After consent was obtained, participants were directed to the questionnaire battery comprised of the following forms:

- Demographic and Identification Intake:
 - The Demographic and Identification Intake form collected information about the participant, such as age, date of birth, gender, marital status, education level, address, phone number, and email address.
- Caregiver Characteristics:
 - National Study on Caregiving Questionnaire: a subset of questionnaires were selected from the National Study on Caregiving. The selected questions focused on aspects of caregiving, such as years of caregiving, type of care provided, caregiver's relationship to care recipient, use of respite care, etc.
- Quality of Life:
 - RAND SF-36: This self-report questionnaire assessed quality of life, defined by eight domains; physical functioning, limitations due to physical health, limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health. The RAND SF-36 is widely used amongst adult patients to evaluate health outcomes.
 - EuroQol 5D (EQ-5D): This questionnaire assesses five domains of health; mobility, self-care, usual activities, pain and discomfort, and anxiety and

depression. The EQ-5D has good psychometric properties and captures various aspects of quality of life.

- Mental Health:
 - Kessler Psychological Distress Scale (K10): This questionnaire is a self-report questionnaire assessing anxiety and depressive symptoms a person experiences in a 4-week timeframe to provide a measure of general distress.
 - General Health Questionnaire (GHQ): This questionnaire is a validated and reliable self-report screening tool to identify symptoms of psychiatric conditions. The GHQ is valid for adults of all ages.

The participant was given the opportunity to skip any questions without being penalized for an incomplete response. Additionally, participants were given the opportunity to take frequent breaks during the survey assessment to eliminate boredom and fatigue. All participants completed the entire survey battery, and no data was missing from the dataset.

3.4 Administrative Resources

The following administrative resources were utilized to accomplish the study goals. The UNMC library provided access to online journal databases, such as PubMed, for literature reviews and accessing the questionnaires used in the survey battery. Research Electronic Data Capture (REDCap) was the web-based software platform used to develop the electronic consent and survey intake form. REDCap was also used to support data capture of participant's information. UNMC Outlook email was used to contact eligible research participants, to provide a safe and secure mode of communication. For the participants who wished to complete the survey over the

phone, office space in UNMC was dedicated to data collection. The office space had a UNMC landline and a locked door for privacy. Finally, Microsoft Excel and Tableau were used for data analysis and data visualization.

3.5 Ethics

The protection of human subjects, both safety and confidentiality, was imperative to this project. To ensure the protection of research participants, the IRB-approved protocol documenting the study personnel, the background of the project, the purpose for conducting research, project methods, privacy and confidentiality, the method of informed consent, and data safety and security was followed. All eligible participants who agreed to participate in the study were required to sign the IRB-approved consent form once they have had the protocol explained to them. Eligible participants had unlimited time to review the consent form and ask questions that arose during the consent period. To maintain participant confidentiality, consent and study procedures took place in a quiet room with a door or in the privacy of the participant's home. Additionally, each participant was assigned a subject identification number, which served as their identification throughout the project. Participants' names will not be associated with their data or any study materials in the future. All data will remain de-identified, and the key linking identifiable data to de-identifiable data will remain in a locked filing cabinet or on a password protected server. Only personnel listed on the IRB will have access to the data to ensure privacy and confidentiality. All data is housed on REDCap, a secure website for developing and managing survey data behind the UNMC firewall.

3.6 Data Analysis

Descriptive statistics were computed in SPSS to describe the characteristics of younger caregivers and their comparison participants. For between-group analyses, comparing caregivers and non-caregivers, two-tailed t-tests were used to test for significance in differing survey responses. For within-group analyses, caregivers were split into two groups, those providing care for less than five years and those providing care for five or more years. Two-tailed t-tests were used to test for significance in survey responses as a factor of the length of time providing care. The two-tailed t-test was chosen as the statistical test since the analyses aim to compare continuous data sets for two unique populations. The two-tailed t-test allowed us to test the possibility that there was an effect in either direction, positive or negative.

4. Results

This project collected quality of life and mental health information on informal caregivers and non-caregivers, ages 19-40 in Nebraska. We report the following findings.

4.1 Describe the Characteristics of Younger Informal Caregivers and Age-, Education-, and Gender-matched Non-Caregivers

Characteristics of informal caregivers and non-caregivers are provided in Table 1. A total of 60 participants completed the study, 30 informal caregivers and 30 non-caregivers. Informal caregivers had an average age of 32.9, were 67% female, 86.7% were college graduates, and 33% were married. Non-caregivers had similar demographic makeup with an average age of 29.9, 73% female, 76.7% college graduates, and 37% were married. Informal caregivers primarily cared for parents (60%), 13% reported using respite care, and 6.7% attended support

groups. Informal caregivers provided an average of 2.67 hours of care each day and assisted with approximately two ADLs and three IADLs.

Table 1. Descriptive Characteristics of Informal Caregivers and Non-Caregivers, ages 19-40		
Characteristic	Caregiver	Non-Caregiver
Total Sample, N=60	30	30
Age, Mean (SD)	32.9 (9.1)	29.9 (8.9)
Female, N (%)	20 (67)	22 (73.3)
College Graduate, N (%)	26 (86.7)	23 (76.7)
Married, N (%)	10 (33)	11 (37)
Caregiver-specific Characteristics	Caregiver	
Relationship to care recipient, N (%)		
Parent	18 (60)	
Sibling	4 (13.3)	
Other	8 (26.7)	
Used respite care, N (%)	4 (13.3)	
Attended caregiver support group, N (%)	2 (6.7)	
Hours per day spent caregiving, Mean (SD)	2.67 (1.53)	
Type of assistance, Mean (SD)		
ADL	2.1 (1.34)	
IADL	3.1 (1.45)	

4.2 Assess and Compare the Quality of Life of Younger Informal Caregivers to Non-Caregivers

Quality of life characteristics of informal caregivers and non-caregivers are presented in Table 2.

With an alpha threshold of 0.05, there was no significant difference detected in energy/fatigue ($p=0.769$), emotional wellbeing ($p=0.539$), social functioning ($p=0.239$), or pain ($p=0.081$) from the RAND SF-36. No significant difference in quality of life ($p=0.250$) was detected from the EQ-5D.

Table 2. T-Test Results Comparing Quality of Life Characteristics of Informal Caregivers to Non-Caregivers			
Characteristic	Caregiver, Mean (SD)	Non-Caregiver, Mean (SD)	P-Value
Energy/Fatigue ¹	55.33 (24.24)	57.5 (20.54)	.769
Emotional Wellbeing ¹	68.80 (22.13)	72.93 (18.46)	.539
Social Functioning ¹	75.00 (28.74)	85.42 (24.14)	.239
Pain ¹	76.83 (21.28)	87.92 (13.45)	.081
Quality of Life ²	76.80 (19.29)	83.20 (11.34)	.250
¹ RAND SF-36, scores range from 0-100, a higher score indicates better health, ² EQ-5D, scores range from 0-100, a higher score indicates better quality of life			

4.3 Assess and Compare the Mental Health of Younger Informal Caregivers to Non-Caregivers

Mental health characteristics of informal caregivers and non-caregivers are presented in Table 3.

With an alpha threshold of 0.05, there was no significant difference detected in general health (0.971) or distress (p=0.275) measured from the General Health Questionnaire and Kessler Psychological Distress Scale, respectively. It should be noted that the mean distress score for informal caregivers is approaching 20, which is the scoring threshold for “mentally well”.

Table 3. T-Test Results Comparing Mental Health Characteristics of Informal Caregivers to Non-Caregivers			
Characteristic	Caregiver, Mean (SD)	Non-Caregiver, Mean (SD)	P-Value
General Health ¹	25.33 (10.94)	25.47 (12.45)	.971
Distress ²	19.60 (6.43)	17.37 (6.14)	.275
¹ General Health Questionnaire, scores range from 0-90, a lower score indicates better health, ² Kessler Psychological Distress Scale, scores range from 0-50, scores <20 indicate likely well.			

4.4 Compare the Quality of Life and Mental Health of Younger Informal Caregivers Based on Number of Years Providing Care

A comparison of quality of life and mental health characteristics are presented in Table 4.

Caregivers who provided less than five years of care self-reported a mean energy/fatigue level of 50, emotional wellbeing of 59.2, social functioning of 67.5, pain of 76.25, and quality of life of

73.3. These same caregivers had a mean distress rating of 21.2, indicating not “mentally well,” and had a mean general health rating of 28.7 on a 90-point scale. Caregivers who provided five years or more of care self-reported a mean energy/fatigue level of 66.0, emotional wellbeing of 88.0, social functioning of 90.0, pain of 78.0, and quality of life of 83.8. These same caregivers had a mean distress rating of 16.4 and had a general health rating of 18.6. When comparing characteristics of informal caregivers based on length of time providing care, significant findings emerged. With an alpha threshold of 0.05, emotional wellbeing differed significantly ($p=0.002$), where caregivers providing care for less than five years reported significantly lower scores. Additionally, the general health differed significantly ($p=0.033$), where caregivers providing care for less than five years reported worse health.

Table 4. T-Test Results Comparing Quality of Life and Mental Health Characteristics of Informal Caregivers by Years Providing Care			
Quality of Life Characteristic	Caregiver <5 years, Mean (SD) N=20	Caregiver ≥5 years, Mean (SD) N=10	P-Value
Energy/Fatigue ¹	50.0 (24.26)	66.0 (22.75)	.242
Emotional Wellbeing ¹	59.2 (20.37)	88.0 (9.38)	.002
Social Functioning ¹	67.5 (31.84)	90.0 (13.69)	.079
Pain ¹	76.25 (18.38)	78.0 (28.69)	.905
Quality of Life ²	73.3 (18.85)	83.8 (20.30)	.364
Mental Health Characteristic	Caregiver <5 years, Mean (SD)	Caregiver ≥5 years, Mean (SD)	P-Value
Distress ³	21.2 (6.97)	16.4 (4.03)	.117
General Health ⁴	28.7 (11.83)	18.6 (4.33)	.033

¹RAND SF-36, scores range from 0-100, higher score indicates better health, ²EQ-5D, scores range from 0-100, higher score indicates better quality of life, ³Kessler Psychological Distress Scale, scores range from 0-50, scores <20 indicate likely well, scores ≥20 indicate mental dysfunction, ⁴General Health Questionnaire, scores range from 0-90, lower score indicates better health

5. Discussion and Conclusion

This pilot yields findings that contribute novel insight to the quality of life and mental health of young, informal caregivers. Differences in quality of life and mental health exist between caregivers based on length of time the caregiver has been providing care. The relative “health” of informal caregivers providing care for five years or longer may mask any differences in quality of life and mental health between informal caregivers and non-caregivers.

There seems to be a paradoxical pattern emerging from the data, in that informal caregivers who have been providing care for less than five years have a lower quality of life and emotional wellbeing scores, compared to caregivers who have been providing care for five years or longer. This could be a result of being unaccustomed to caregiving, not abiding by a care routine, being in denial about having to care for another adult, or other factors related to the unfamiliarity of caregiving. It should be noted that the scores for quality of life and mental health were derived from brief questionnaires, in some cases a single question. Therefore, further research studies with larger sample sizes and more robust questionnaire batteries are needed to better understand the relationship between caregiving and quality of life and mental health.

To address the decreasing quality of life among caregivers providing care for less than five years, behavioral and educational interventions should be offered to informal caregivers, especially focusing on those who are new to caregiving. Of note, behavioral and educational interventions in the form of support services would aim to improve the quality of life and mental health. Support services may include caregiving educational classes on ADL and IADL care, accessing services for the care recipient, support groups for informal caregivers, respite care, and

individual therapy or counseling for informal caregivers. Additionally, Nebraska could implement nationally recognized community-based health interventions for caregivers, such as REACH OUT, an evidence-based program to promote the growth and adoption of caregiver interventions.

Several limitations merit acknowledgment. Since a convenience sample was used to demonstrate feasibility, the sample size was too small to yield significance. Additionally, participants were recruited from local registries and coalitions, reducing the generalizability of all Nebraska residents, specifically those in Western Nebraska, due to the homogenous sample. Due to the sensitivity of many mental health questionnaires, the Kessler Psychological Distress Scale was selected as a proxy for burden and depression, where a more robust questionnaire, like the Beck Depression Inventory, may have been a more reliable measure of mental health. For brevity, brief mental wellness and quality of life questionnaires were selected to avoid response fatigue, which limited the analyses that could be conducted due to the minimal amount of data collected. In a future study, a longer questionnaire battery consisting of multiple measures of mental health and quality of life should be administered. Another limitation of this study was that physical health was not directly assessed. Previous research on older caregivers indicates physical health implications of caregiving^{10, 11, 12, 13}. Future studies should include metrics on physical health and self-reported chronic disease to assess the physical health impact of caregiving in younger adults. Finally, incentives in the form of monetary compensation should be given to research participants as compensation for their time. Compensating research participants may help to increase recruitment and aid in preventing attrition.

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