THE DETERMINANTS OF QUALITY OF LIFE IN A SAMPLE OF OLDER ADULTS LIVING IN INDEPENDENT LIVING COMMUNITIES

Dissertation by

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DEDICATION

To all my family and friends who have supported me; and to all those who have given me an appreciation for the beautiful twilight of life
ACKNOWLEDGEMENTS

I would like to take this opportunity to thank all those who have helped me along this incredible journey. To my parents, I would like to say thank you for all the support (both financial and emotional), for all those late night venting sessions, and for your never wavering faith in me. To my sisters and brothers-in-law, thanks for believing in me even when I didn’t believe in myself. To my nieces and nephews, your unconditional love has gotten me through many hard times. To all my friends and family, I would like you to know that no matter how near or far, how often or how little we contact each other, your love and support have meant the world to me. I couldn’t have made it this far without each and every one of you, whether it be by a kind word, a hug, or laughing at my sarcasm and wit. I love you all, a bushel and a peck.

To all the other graduate students I have met along the way, thank you for the fun times, the frustrating times, and the “we’re never going to make it” times. I hope to remain in touch with all of you. I want to take a moment to say a special thanks to the other graduate students in my research work group. Jessica, thank you for being so supportive. I wish you all the best. Samuel, thank you for putting up with my crazy days, especially those days we trapped you in an office full of crying girls. Sorry for that. Amanda, your presence in the office has been sorely missed this last year. Your wisdom as the “senior” graduate student in our work group was a Godsend. Thank you so much. Kari, our graduate careers have been so parallel that there is not much left to be said that hasn’t already been said. I couldn’t have picked a better partner in crime these last four years. Thanks.

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I would also like to thank Presbyterian Manors of Mid-America for allowing us to be a part of this important research. Special thanks to Susan Fry, Candace Cullors, and Angela Page for all the hard work you have put into the project. And, finally, I would like to say thank you to all the participants who allowed me a little insight into their worlds. I will forever be grateful to you for inviting me into your homes and sharing your experiences with a clumsy researcher such as I.
Quality of life is an important factor that affects both the physical and mental well-being of older adults. However, there is much debate over what elements make up quality of life. The CASP-19 is a theoretically-based measurement of quality of life that includes the factors of control, autonomy, self-realization, and pleasure. The purpose of this small-scale study was to explore how older adults residing in two independent living facilities in the United States experienced quality of life: what elements they believed influence it; how these elements related to the CASP-19 factors; and what biopsychosocial variables were related to quality of life. Interviews were conducted with 24 independent living residents within two continuous care retirement communities. Each participant was asked to rate their quality of life along a visual-analog slider scale. Qualitative interviews were carried out with 12 randomly selected participants. Semi-structured interview questions included: “What are the most important factors that make you rate your quality of life there (along the slider)?” Biopsychosocial measures included Lubben’s Social Support Network Scale (LSNS), relationship quality questions, the 15-item Geriatric Depression Scale (GDS-15), UCLA Loneliness scale, and a single-item subjective health question. Themes developed from the qualitative interview included Health, Relationships, Faith/Religion, Independence, Place, Staying Active, Contentment, Altruism/Generativity, Basic Needs/Personal Security, and Future. The CASP-19 and visual analog slider scale scores were highly correlated suggesting good concurrent validity. Themes which emerged from the qualitative interviews suggest the CASP-19 had good content validity. The CASP-19 was negatively correlated with loneliness and positively correlated with positive relationship quality and subjective health.
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<tr>
<td>ADLs</td>
<td>Activities of Daily Living</td>
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<td>AL</td>
<td>Assisted Living facility</td>
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<td>CCRCs</td>
<td>Continuous Care Retirement Communities</td>
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<td>FDA</td>
<td>Federal Food and Drug Administration</td>
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<tr>
<td>HRQOL</td>
<td>Health Related Quality of Life</td>
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<tr>
<td>IADLs</td>
<td>Instrumental Activities of Daily Living</td>
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<td>IL</td>
<td>Independent Living facility</td>
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<td>IL-CCRCs</td>
<td>Independent Living in Continuous Care Retirement Communities</td>
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<td>NH</td>
<td>Nursing Home</td>
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<td>PMMA</td>
<td>Presbyterian Manors of Mid-America</td>
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<td>QoL</td>
<td>Quality of Life</td>
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<td>RCs</td>
<td>Retirement Communities</td>
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<td>RCTs</td>
<td>Randomized Control Trial</td>
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CHAPTER 1
OVERVIEW

Purpose of Study

Quality of life has been associated with several positive outcomes, including better physical and mental health (Choi & McDougall, 2009; Jacob, Abraham, Abraham, & Jacob, 2007; Kane, Lum, Cutler, Degenholtz, & Yu, 2007; Litwin & Shiovitz-Ezra, 2011; Netuveli, Wiggins, Hildon, Montgomery, & Blane, 2006; Smith, Nilsen, Ofei-Dodoo, Medvene, & DiLollo, 2014). It is possible that, even when older adults experience declines in physical or mental functioning, having protective factors that improve quality of life can alleviate the negative impact of these declines. The primary goal of this study was to contribute to the research literature by gaining a better understanding of the ways in which older adults living in Independent Living within Continuous Care Retirement Communities experience quality of life. This study used a mixed-methods approach in order to fully explore the framework of quality of life.

Studies have shown that individuals in diverse populations (i.e., those with more functional limitations, with differing socioeconomic statuses, or from minority ethnicities or cultures) may experience quality of life differently (Bowling & Stenner, 2011). These studies suggest that variables such as age, socioeconomic status, functional limitation, and life experiences may cause certain variables to have more or less of an impact on quality of life than in the general population. The first goal of this study was to understand the specific elements of quality of life in a population of Independent Living within Continuous Care Retirement Communities residents.
A second goal of the study was to examine how older adults describe their quality of life, and how these descriptions relate to items on the CASP-19, a 19-item instrument developed specifically for older adults living independently within community settings and based on four domains of needs – Control, Autonomy, Self-realization, and Pleasure (CASP). A third goal of the present study was to determine whether a selected set of biopsychosocial variables were associated with better quality of life in this population. This study focused on 1) depression, 2) health, 3) loneliness, 4) social isolation, 5) relationship quality, and 6) network size, and measured which had the strongest relationships with quality of life. This study attempted to determine if previous findings generalize to the current population of individuals residing in Independent Living within Continuous Care Retirement Communities, as this population has not been thoroughly studied and has the potential for improving quality of life through increased ability to age in intentionally designed congregate care settings. This is an especially relevant topic for community psychologists, as it is important to determine the environments that are associated with the best physical and mental wellbeing outcomes.

**Background**

This study was one part of a larger project studying the quality of life of older adults living in two independent living facilities within Continuous Care Retirement Communities. Quality of life in older adults is an important topic, especially for community psychologists whose main goal is to improve quality of life at the community level. Social isolation, poor relationship quality, depression, loneliness, poor health, and functional limitations have all been related to decreases in quality of life (Ferrans & Powers, 1985; Gilleard, Hyde, & Higgs, 2007; Kane, et al., 2003; Netuveli, et al., 2006; Prutkin & Feinstein, 2002; Smith, et al., 2014). Most research has focused on either healthy older adults living in the community or those with
extreme functional limitations or poor health who reside in nursing homes. However, there are several levels of independent living between these two extremes, and focus will shift to these levels as the population increases. The greatest number of older adults lives in community settings with varying degrees of independence. Currently, 4.1% of the older adult population are living in nursing homes (US Department of Health and Human Services, 2011), while the rest live in the community or in facilities that act as midpoints between community-dwelling and nursing home residence (such as assisted living; independent living; retirement communities; and Senior-Focused Housing).

Starting in 2011, more than 10,000 adults in America turned 65 years old each day. This trend will continue until 2030, increasing the total older adult population from 12% to 20% (Stone, Schwartz, Broderick, & Deaton, 2010). As the “Baby Boomer” generation ages, many policy workers and healthcare providers are turning their attention to this growing population, where they will live and what living arrangements are associated with the best outcomes. There is a trend in the healthcare systems of several states, including Kansas, to try to keep elderly persons on Medicaid out of nursing homes and in the community (New York Times, 2012). Because of the population increase and the shift in care from nursing homes to the community or specialized long term care facilities, it is important to understand the key determinates of quality of life of older adults living in these settings.

Continuous Care Retirement Communities are facilities that offer IL, assisted living, and nursing home options. There are 67 registered Continuous Care Retirement Communities in Kansas alone, and nearly 800 Continuous Care Retirement Communities within the US (CCRCs Online, 2014). According to AARP, Continuous Care Retirement Communities are the most expensive long-term care option, with entrance fees ranging from $100,000 - $1 million and
monthly fees from $3,000 - $5,000 (AARP, 2014). It can often be important in an older adult’s life to develop a sense of community, which is hindered when they are forced to move from place to place (Gilleard, Hyde, and Higgs, 2007). Older adults who must move from their homes into retirement communities or other “independent” communities often realize that they will eventually have to move to an assisted living or nursing home as they continue to age and lose capacity. Sense of community and aging in place have been linked to quality of life in older adults (Gilleard, Hyde, and Higgs, 2007), with better quality of life associated with an increased sense of community and staying in the same community longer. Because of this, Continuous Care Retirement Communities present a unique opportunity for older adults to develop important protective factors early on, before physical limitations make it more difficult to develop social ties.

The present study was part of a larger collaboration with Presbyterian Manors of Mid-America in two of their independent living facilities located within Continuous Care Retirement Communities. One independent living facility located within a Continuous Care Retirement Community was located within a mid-sized urban area while the other facility was located within a rural town. The project included a wait-list control design with an intervention designed to provide participants with training on specially programmed computer software intended to improve social participation. This study focused on data collected at the start of the study before the computer training intervention was initiated.
Quality of Life

Medical measures of quality of life. Our current understanding of quality of life began in 1937 in the medical field. During this time, attempts to understand the quality of life in older adults utilized functional limitation status as a proxy for quality of life. Most individuals who lived to be categorized as older adults during this era had illnesses of some sort hindering their ability to be “productive” members of society. With this mindset, the medical field began evaluating quality of life in older adults as a function of how limited they were in their productivity (Department of Social Welfare New York, 1937).

The first measurements of functional limitation merely ranked older adults according to the number of limitations individuals experienced (through ability to live independently; ability to remain mobile; and through activities of daily living) (New York Heart Association, 1939; Visick, 1948; Steinbrocker, Traeger, & Batterman, 1949; Zeman, 1947). Eventually these measurements became more refined, using different weighting systems based on current knowledge (Mahoney & Barthel, 1965; Mahoney, Wood, & Barthel, 1958). For example, one such measurement weighted frequent incontinence and inability to bathe and dress oneself as higher because of the social implications of these limitations (i.e., embarrassment).

Late in this movement to measure quality of life through functional status, researchers in the medical field started to add instrumental activities of daily living (Lawton & Brody, 1969). These differed from activities of daily living (e.g., bathing, walking, grooming, toileting, and dressing) in that they were not viewed as essential to daily life, but remained important activities
to the independence of the individual. Such activities included shopping, cooking, balancing the checkbook, and cleaning.

This trend to use health and the limitations that go along with it as a proxy for quality of life started to change around the 1960’s and early 1970’s. A few things happened during this era, the first of which was the World Health Organization’s redefining health as not just the absence of illnesses, but the complete well-being of an individual in the physical, emotional, and social arenas (World Health Organization, 1948). Although this is a significant indicator in the changing climate of the medical field, researchers did not actually start implementing this idea (by integration of social and psychological measurements into their research) until the government stepped in. The first thing that the US government did to promote the integration of social and psychological measurements into the field of quality of life research was to include such measurements in their national survey of health. Recommendation from that survey stressed the importance of including such influencing variables as emotional well-being and social participation (Linder, 1966). Next, the President’s Commission on the State and Goals of the Country addressed the incomplete understanding of quality of life through the lens of health (President’s Commission on National Goals, 1960). In the brief, the Commission put forth 84 goals for the country, only 48 of which were currently measurable (Bauer, 1966).

Medical research in illnesses such as cancer and dialysis patients started to look into the idea of “quality of survival.” Originally, research with these populations gauged their success by the amount of increased years in life expectancy for the individuals; in this manner, they concentrated on the quantity of life instead of the quality (Prutkin & Feinstein, 2002). One of the first measurements of quality of survival was a chart that included both years of survival (X-axis) and quality of survival (Y-axis; as measured by functional limitation and attitude about success.

**Integration of social and medical measures.** At this time, social and psychology research began to be integrated with the medical research. Quality of life began to be measured through social, emotional/psychological, and physical domains (Prutkin & Feinstein, 2002). Some of the first social sciences measures viewed quality of life as the balance between positive and negative affect. Another method was to measure the difference between perceived outcomes and aspirations. In this case, an individual may have high quality of life if they have high aspirations (goals) and perceive themselves as being able to or already having completed these goals (Prutkin & Feinstein, 2002).

Even with these additions, it wasn’t until the mid-1980’s that measuring quality of life along these added domains became popularized. Two things occurred at this time. In 1984, the Federal Food and Drug Administration stated that they would require quality of life as a key indicator of success in all clinical trials of anti-cancer agents (Johnson & Temple, 1985). Even more importantly, a few years later a randomized control trial reported results that found the main difference between drugs administered in the experiment was the effect on quality of life. Because of this finding in an randomized control trial setting, pharmaceutical companies began requiring these measurements as part of the experiment in order to advertise their drugs as beneficial to the quality of life of the patients (Croog, et al., 1986).

Quality of life as an outcome measure became widespread in the medical field, but also became an important variable in psychological and social research as well. Because of the difference in the scope of these fields, there was a “splitting” of focus in measures. The medical
field started concentrating on health-related quality of life, while the social sciences looked at overall well-being and life satisfaction through quality of life (Prutkin & Feinstein, 2002).

**Current quality of life measures.** Two other measures for quality of life have been prevalent throughout the research in elderly populations: Kane’s QoL measurement (QOL) and Ferrans and Powers Quality of Life Index (QLI). The Kane’s QOL has been used only with congregate care living (Kane, et al., 2003; Kane, Lum, Cutler, Degenholtz, & Yu, 2007). Its measured domains are physical comfort, functional competence, privacy, dignity, meaningful activity, relationship, autonomy, food enjoyment, spiritual well-being, security, and individuality. One study found that individual’s living in nursing homes experienced decreases in quality of life with decreases in physical function, visual acuity, and social engagement and increases in depression, incontinence, and relationship conflict. They also found that being bedridden decreased quality of life (Degenholtz, Kane, Kane, Bershadsky, & Kling, 2006). Although the domains measured by this scale are very important for those living in nursing homes, they did not fit the current population because those who live in independent living facilities do not have limitations on such things as privacy.

The QLI was a good measure used in community settings, with Cronbach’s alphas ranging from .73 to .99 (Kimura & Silva, 2009). This scale measures several areas, including health, occupation, and self-acceptance, while weighting items according to how they contribute to life satisfaction (Ferrans & Powers, 1985; Hagell & Westergren, 2006). It was originally developed in a population consisting of nursing students and dialysis patients (Ferrans & Powers, 1985) and has since been used mostly with individuals experiencing health problems, such as Parkinson’s patients, hemodialysis patients, and those with incontinence (Ferrans & Powers,
1985; Ferrans & Powers, 1992; Hagell & Westergren, 2006). However, this scale contained 66 items, and was therefore too long of an instrument to use with the current study.

**CASP-19 measurement.**

**Development.** Because of the long history and diverse background of quality of life research, there is still much debate over the meaning of the term quality of life. Although some researchers still confuse the term with life satisfaction (a measurement of the experiences of past life along with the current status, often measured while engaging in life review), quality of life takes more into account. It also measures the ability to meet certain needs, regardless of limitations. Whereas an individual may be unsatisfied with life because of the fact that they have poor health, they can also be adaptable in the way they carry out their daily lives (gaining pleasure from other sources), and therefore have better quality of life.

Hyde, et al. (2003) made the argument that quality of life is still not understood well because most research on it has not been theoretically based. Instead, most research and therefore instruments that have been developed were based on the data (items such as loneliness were included because they had been found to be associated with quality of life). Although this may not seem like a bad idea, Hyde argued that having a theory-driven measurement would allow an increase in understanding of the factors that contribute to quality of life.

It is notable that Hyde referred to the “Third Age” movement as the reason quality of life moved away from only health status measurements to more diverse concepts of quality of life. The “Third Age” is the time in an adult’s life when they may begin to work less (i.e., retirement) but continue to actively participate in society through knowledge seeking or hobbies. Many individuals in older adulthood are able to maintain the health that they enjoyed in younger years, as well as remain active through traveling and social participation. Because of this, using health
related variables as a substitution for quality of life was insufficient to grasp the entirety of the concept of quality of life in late life, especially in active, community-dwelling populations. This increase in individuals who live to be older adults, and who live without any restrictions or ill health, caused researchers to become aware of the need to understand quality of life in older adults outside the framework of health in contexts other than illness or disability. That is, individuals may experience good quality of life while experiencing illness or physical limitations and that individuals may experience poor quality of life while completely healthy. It became important for researchers to understand that quality of life does not solely rely on health and vitality, but on other, numerous variables.

Hyde, et al. (2003) used Maslow’s theory of needs to inform their measurement of quality of life. Although people need to have provisions of basic life (food, shelter, safety), they will pursue other needs when these other, basic needs are met. These other needs include social interaction, achievement, and emotional stability, among others. Hyde developed a quality of life measurement that was based on four domains: Control, which is the ability to exert to some extent control over one’s own environment; Autonomy, which is the ability to reject unwanted interference in one’s own life; and Self-realization and Pleasure, which are the active and reflexive components of being human. They believed that these factors would focus attention on the positive aspects of quality of life, while also conforming to a needs satisfaction model of quality of life. Their measure was called the CASP-19 (Control – Autonomy – Self-realization – Pleasure, 19-item).

In their development of the instrument, Hyde, et al. (2003) utilized experts in the field to help develop questions, focus groups to increase the ability of participants to understand the wording of the questions, and a pool of over 260 individuals to pilot the questionnaire. They
included a six item Life Satisfaction Index to test concurrent validity \( (r = .60, p < .01) \). They also used factor analysis to ensure that the four domains loaded onto a latent variable (quality of life). All second-order factor loadings were .71 and higher.

**CASP-19 research.** Since the development of this instrument, researchers have discovered a variety of implications for quality of life. For example, Gilleard, Hyde, and Higgs (2007) conducted a study of the effects of age, aging in place, and place on quality of life in older adulthood. They found that quality of life decreases with age. Researchers also found that attachment to place increased an individual’s quality of life. However, deprivation in the area (low socioeconomic status) decreased quality of life. However, socioeconomic status did not affect attachment to place. That is, those in the most deprived areas showed just as much attachment to place as those in the least deprived areas. Also, age was found to be related to attachment to place. The older an individual was, the less likely they were to move around (residential mobility); and the longer they lived in the area, the more attached they were to it. Results also showed a significant interaction between age and place (socioeconomic status). The older adults (in their 80’s) were not affected by socioeconomic status level of place; their levels of quality of life remained lower than younger groups no matter what level of socioeconomic status they lived in. For all other age groups, socioeconomic status influenced levels of quality of life.

Netuveli, et al. (2006) found that quality of life increased with amount of close relationships, higher frequency of contact with friends, and better positive relationship quality. However, depression, anxiety, stress, worry, illness, and functional limitation due to longstanding illness have been shown to decrease quality of life. Interestingly enough, one study showed that there was a difference in the levels of quality of life of individuals with longstanding
illnesses based on the level of functional limitations experienced due to the illness. Those without limitations had higher levels of quality of life than those with limitations. Much of the research that has shown that illness is associated with lower levels of quality of life might have been improved by measuring health and illness more in depth, such as seeing what kinds of limitations health issues affected in their lives. Therefore, a second goal of the present study was to identify whether relevant psychosocial variables like social isolation, quality of relationships, loneliness, depression, and health were related to quality of life.

*CASP measures and inconsistencies.* Past research has been conducted in many different settings as to what variables impact quality of life. There is evidence that quality of life differs significantly for people from different socioeconomic levels, different ethnicities, and different functional levels. Bowling and Stenner (2011) found in their research on community-dwelling older adults living in Europe that certain measures of quality of life did not hold together in more ethnically diverse populations. For instance, the CASP-19 had good inter-item reliability within a sample of community-dwelling older adults living in Britain but did not have good inter-item reliability in a sample of community-dwelling older adults with “statistically robust sampling of people in common ethnic minority groups in Britain” (Bowling & Stenner, 2011).

Other studies also found issues with the four factor model, suggesting a 12-item, three factor structure was a better fit to the data (Sim, Bartlam, & Bernard, 2011; Wiggins, Netuveli, Hyde, Higgs, & Blane, 2008). Researchers found that the factors Control and Autonomy were not very well defined, or separate, within the data. That is, although Control and Autonomy are theoretically separate, they collapse into a single structure in the data. In a study of older adults living in retirement communities, the CASP-12 was found to have better psychometric properties than the CASP-19 (Sim, Bartlam, & Bernard, 2011). Recommendations from this study lead to
another, larger study comparing the psychometric properties of the CASP-12 and the CASP-19. In this study, a 12-item, two-factor structure was found to be the best fit for the data. This study found that Self-Realization and Pleasure also collapsed into a single factor (Sexton, King-Kallimanis, Conroy, & Hickey, 2013).

A recent, small-scale study with frail, community-dwelling older adults found that some items of the CASP-19 within the Control and Autonomy subscales do not correlate well with other items of the scale. Cronbach’s alphas were very low for both the Control and Autonomy subdomains (.49 and .13, respectively), but were acceptable for both Self-Realization and Pleasure (.76 and .79). When running a two-factor solution, however, researchers found factor loadings that closely resembled the two-factor structure found by Sexton, et al. (Smith, et al., 2014). These findings are important, as they indicate that the CASP-19 has some factor structure replication issues with different populations (such as frail older adults). It is important to understand how individuals of these populations experience quality of life differently and why certain items may not affect overall quality of life as they do in other populations. The present study was exploratory in nature, utilizing a mixed-methods approach. The qualitative analysis of quality of life took a phenomenological approach with a semi-structured interview in order to determine the key elements that influence the quality of life of older adults living in independent living facilities located within Continuous Care Retirement Communities. Because the study population was small, no psychometric testing was performed on the factor structure of the CASP-19. However, construct validity was tested based on answers given to a visual analog slider scale of quality of life. Concurrent validity was also explored using correlational analyses with biopsychosocial variables that have been previously linked to quality of life.
**Qualitative vs quantitative measures.** Given the wide variety of approaches taken to measuring quality of life, as well as the mixed findings yielded from the theoretically-based CASP-19, the present study used a mixed-methods approach. Based on suggestions for a more qualitative approach and individual population-driven methods (versus generalized instruments developed from work with different populations) by Prutkin and Feinstein (2002), this study used qualitative methods to allow the description of quality of life of the population to be led by the participants. A visual-analog slider scale was used to gather a subjective rating of quality of life, followed by a semi-structured interview. The open-ended questions of the semi-structured interview gathered information about the key determinants of quality of life and what variables may improve or worsen quality of life for older adults living in independent living facilities located within Continuous Care Retirement Communities. This approach allowed researchers to explore the specific variables that participants believed affected their quality of life and identify any variables that were not currently being measured in other scales.

Although the CASP-19 has recently shown some inconsistencies, it is a well-developed, theoretically-based instrument that includes questions measuring generativity and mattering, two important aspects of well-being in later life (Hyde, et al., 2003; Netuveli, et al., 2006). Recent studies have suggested that the two-factor, 12-item scale may be a better measurement; however, this scale has not been as thoroughly validated or researched as the original CASP-19. Due to this, we used the full CASP-19 scale.

**Biopsychosocial Variables**

**Depression.** One frequently used measurement for depression is the Geriatric Depression Scale (GDS) (Almeida & Almeida, 1999; Alpass & Neville, 2003; Hanson, et al., 2004). Higher scores on the GDS (more depressed) have been shown to be negatively correlated with quality of
life and network size and positively correlated with loneliness (Alpass & Neville, 2003; Medvene, et al., 2015). The revised 15-item version of the original 30-item GDS has been found to be a valid measure (Almeida & Almeida, 1999). In order to reduce the length of the questionnaire in total, the GDS-15 was used for this study.

**Health.** Health and quality of life have a long history, as stated previously. They are so closely linked that there are health-related quality of life measures. One question was used to measure subjective ratings of health, “how would you describe your overall health these days?” (Wen, Hawkey, & Cacioppo, 2006). This single-item measure has been used widely throughout the literature (Greiner, et al., 2004; Kawachi, Kennedy, & Glass, 1999; Kim, Subramanian, & Kawachi, 2006; Mansyur, et al., 2008; Schultz, O’Brien, & Tadesse, 2008; Subramanian, Kim, & Kawachi, 2002; Wen, Hawkey, & Cacioppo, 2006).

**Loneliness.** Past research has found that loneliness was negatively associated with emotional well-being, was a predictor of cognitive decline, was a risk factor for depressive symptoms, and posed substantial mortality risk (Litwin & Shiovitz-Ezra, 2011). The majority of studies conducted on social relationships that have a measure for loneliness have used some form of the UCLA loneliness scale (Alpass & Neville, 2003; Cacioppo, Hawkey, & Thisted, 2010; Russell, 1996; Russell, Peplai, & Cutrona, 1980). The UCLA-R (or ULS-20) was used in this study, as this form of the UCLA loneliness scale was adapted for use with older adults since the original scale showed systemic bias (due to negative wording of items) and issues with discriminant validity (due to high correlation with depression and self-esteem) in populations other than college students (Russell, 1996; Russell, Peplai, & Cutrona, 1980).

**Social support networks.** Social support networks, consisting of persons an individual interacts with and gains some form of social support from, are vital to older adults who wish to
continue living independently (US Department of Health and Human Services, 1991). There are
different ways in which these networks affect the well-being of older adults. One way is that the
social support gained from social support networks act as *buffers* to life stressors (negative
events or difficult transitions) through emotional support, information-gathering, and concrete
resources that serve to reduce the adverse effects of these stressors. The second way in which
social support networks elicit improvements is through the *main effect* on well-being through
social conformity norms by the modeling of healthy behaviors and/or encouragement from
network members to follow to better patterns of behavior. However, through either pathway,
individuals with high-quality, large social support networks fair better than those with smaller
networks or poor relationship quality (Holt-Lunstad, et al., 2010).

There are several ways in which to measure social support. The current study measured
social support networks by assessing their structural (network size) and functional characteristics
(isolation and relationship quality). Past research has found that the size (structural) of social
support networks and relationship quality (functional) were negatively correlated with mortality
(Holt-Lunstad, et al., 2010) and that relationship quality was the most significant predictor of
health (Antonucci, Fuhrer, & Dartigues, 1997). Social isolation and relationship quality
(functional) have also been significantly correlated with loneliness, depression, quality of life,
and health (Antonucci, 1986; Antonucci & Akiyama, 1995; Fiori, et al., 2006; Lubben, 1988;
Medvene, et al., 2015).

**Network size.** In Antonucci’s convoy method, participants are presented with three
concentric circles where they are asked to place people in their social support networks. People
are placed in the three circles based on how close the participants feel to them. The names and
relationships of each person (i.e. – child, friend) are recorded (Antonucci, 1986; Antonucci &
Akiyama, 1995). Network size is determined by summing the number of people participants placed in each circle.

*Isolation.* Isolation was measured using Lubben’s Social Network Scale (LSNS). This measure asks individuals to answer questions about how often they are in contact with friends and family, whether or not they have confidante relationships, living arrangements, and if they feel needed (mattering). The LSNS has been shown to be a good subjective measure of social isolation risk, and has correlated significantly with health variables (Lubben, 1988).

*Relationship quality.* Finally, measures of relationship quality provided by social support network members were taken. The questions included in the current study asked about the perceived positive and negative quality of social relationships for seven specific categories of contacts, including Presbyterian Manors of Mid-America friends, Presbyterian Manors of Mid-America staff, spouse, children, outside/community friends, and relatives (Fiori, et al., 2006). Participants were asked to answer seven questions for the individual with whom they had the most contact from each category.

**Goals of Study**

The goal of the present study was to answer the following research questions: 1) what elements of quality of life are most important to older adults living in independent living facilities located within Continuous Care Retirement Communities?, 2) do these elements correspond with factors that are currently being measured on the CASP-19?, 3) does the CASP-19 measurement have good concurrent validity with the visual-analog rating of quality of life?, and 4) what social, mental, and physical health variables are related to quality of life in this population and which ones have the strongest relationships?
Method Overview

This study used an exploratory, mixed-methods design involving both quantitative and phenomenological qualitative methods. Ninety-minute interviews were carried out with each of 24 older adults residing in two independent living facilities located within Continuous Care Retirement Communities (15 from Newton; 9 from Wichita). Interviews were carried out by graduate and undergraduate students, from June 9, 2014 through June 27, 2014. All students were trained in interviewing techniques; however, one researcher carried out the initial 16 interviews (11 interviews at Newton and 5 interviews at Wichita) until saturation was reached for the qualitative quality of life questions. Saturation was reached when participants no longer presented any new statements, categories, or themes during their interviews. The first two interviews at Newton were not included in the qualitative data set since researchers had not yet obtained permission from the IRB to record the interviews. Another two interviews at Wichita were not included in the data set due to outside influences (emotional stress on the participants lead researcher to decide not to conduct the qualitative part of the interview). Therefore, a total of 12 interviews were included in the qualitative data set, while 24 were used in the quantitative data set.

Participants

Study participants were recruited from the population of two independent living facilities located within Continuous Care Retirement Communities who met the study criteria. Both Continuous Care Retirement Communities were run by the same company, Presbyterian Manors of Mid-America. This company had a previous relationship with Dr. Louis Medvene and
approached him wanting to find out more about a previous student’s dissertation (Carissa Coleman) and how they could partner with Wichita State University (WSU) on a project.

Participants were initially identified as eligible for the study by Presbyterian Manors of Mid-America staff, meeting the following criteria: living in congregate independent living housing units, English-speaking, non-computer users, cognitively-able to participate, medically stable at entry, and living in the current independent living facility for at least 1 month. Following initial identification, staff along with graduate students conducted several information/recruitment meetings in order to gauge interest in the study. Residents were approached by individual staff members. If residents expressed interest in the study to the staff members, their names were given to a graduate student who followed up with the resident to gain informed consent and schedule interviews and training sessions.

At the first Presbyterian Manors of Mid-America facility, there were a total of 44 residents asked to participate. Of those residents, about one-third (15) said yes and the other two-thirds (29) said no, giving a response rate of 34%. There were various reasons residents decided not to participate. Reasons included no interest, no time to participate, no desire to learn something new, being scared of computers, and not wanting to be “part of a study.”

At the second Presbyterian Manors of Mid-America facility, there were a total of 31 residents asked to participate. Of those residents, twenty-two said no and nine said yes, giving a response rate of 29%. This particular facility was constructing a new building and remodeling other buildings during the recruitment period, so the residents were hesitant to undertake a project that required a time commitment. They also chose not to participate due to lack of interest in the computer portion of the larger study.
Procedures

Once residents gave informed consent, interviews were carried out in the apartments of 24 participating independent living facilities located within Continuous Care Retirement Communities residents in Sedgwick and Harvey Counties, Kansas. The first part of the interview gathered data on social support network’s functional and structural qualities. The second part of the interview collected data on quality of life, depression, loneliness, and health status. The third part of the interview collected data on computer use and interest. This study focused on data collected during the first and second parts of the interview. Interviews were conducted by two-person graduate and undergraduate student teams.

Measures

Quality of life.

Qualitative. A visual-analog slider scale was shown to participants in order to gauge their subjective ratings of quality of life (See Appendix A; Prutkin & Feinstein, 2003). The scale was marked in standardized intervals with numbers which ranged from 0 – 10 (0 = “Worst,” 10 = “Best”). Participants were asked to rate their quality of life, with the end labeled “0, Worst” being the worst possible quality of life they could imagine, and the opposite end labeled “10, Best” being the best possible quality of life they could imagine. After the interview, researchers measured the participant’s mark from the beginning of the scale in centimeters (cm, the full length of the scale was 22 cm). Following the visual-analog rating was a semi-structured, topic interview. Participants were asked “What are the most important factors that make you rate your quality of life there,” “What might possibly make it better,” and “What might possibly make it worse?” Although the interviewer engaged in individual probing during interviews when participants went off topic or had trouble thinking of answers, no standardized prompts were
developed. Two pilot interviews were conducted to determine if the questions were easy to understand and if the information elicited from the interview was appropriate to the research questions.

**Quantitative.** The quantitative instrument that was used to measure quality of life was the CASP-19 model (See Appendix B; Hyde, et. al., 2003). The CASP-19 measure has been found to have a strong relationship with the Life Satisfaction Index ($r = 0.63, p = 0.01$) and includes four factors that have been shown to be important for well-being in later life: control (Cronbach’s alpha = 0.59), autonomy (Cronbach’s alpha = 0.65), pleasure (Cronbach’s alpha = 0.74), and self-realization (Cronbach’s alpha = 0.77) (Hyde, et. al., 2003). The measure included items such as “I feel satisfied with the way my life has turned out” and “I feel that my life has meaning.” Responses were coded on a 4-point Likert scale (0 = often, 1 = sometimes, 2 = not often, and 3 = never). Some items were reverse coded, so that higher scores meant higher quality of life. The subscales were determined by summing individual items (control subscale = 4 items; autonomy, pleasure, and self-reliance subscales = 5 items each). Overall scores were determined by summing these subscale scores, with possible scores ranging from 0 – 57 on a 58-point scale.

**Depression.** The instrument that was used to measure depression was the GDS-15 (See Appendix C; Almeida & Almeida, 1999). The original 30-item measure has been used throughout the research literature as a tool to measure depression in the elderly, but in order to make the interview process and questionnaire as simple as possible, the revised 15-item version of the original 30-item GDS was used here. Almeida and Almeida (1999) found that the GDS-15 item with a cutoff point of 4 had high validity, measured through sensitivity (92.7) and specificity (65.2) ratings when compared to the ICD-10 criteria for detecting depression. It has also been found to have high internal consistency reliability, with a Cronbach’s alpha of .76 (Van
Items included “Are you basically satisfied with your life” and “Do you feel pretty worthless the way you are now?” Responses were coded as “yes” or “no.” Answers indicating depression were coded as “1” and those indicating no depression were coded as “0.” Scores for individual items were then summed. Possible scores ranged from 0 – 15 on a 16-point scale, with higher scores meaning higher rates of depression. Because of the exploratory nature of this project and the interest in both subclinical and clinical levels of depression, participant scores on the GDS were left in their raw form; no cutoffs were used.

Health status. In order to assess the overall health status of the HCBS population, one question was “how would you describe your overall health these days?” (Wen, Hawkley, & Cacioppo, 2006). Responses were coded on a 5-point Likert scale (1 = excellent, 2 = very good, 3 = good, 4 = fair, 5 = poor). This item was reverse scored so that higher scores meant better health ratings.

Loneliness. The instrument that was used to measure loneliness was the UCLA-R loneliness scale (See Appendix D; Russell, 1996). The internal consistency reliability of the 20-item scale has been found to be very high, with a Cronbach’s alpha of .90, and the discriminant validity is 76.7% when compared to similar measurements (Hays & DiMattero, 1987). Items included “How often do you feel that you lack companionship” and “How often do you feel outgoing and friendly?” Responses were coded on a 4-point Likert scale (1 = never, 2 = rarely, 3 = sometimes, and 4 = always). Some items were reverse coded so that higher scores meant more loneliness. Scores for the individual items were summed, and possible scores ranged from 20 – 80 on a 61-point scale.
Social support networks. The questions for social support networks involved the use of three instruments, Antonucci’s Hierarchical Mapping Technique (See Appendix E; Antonucci, 1986; Antonucci & Akiyama, 1995), Lubben’s Social Network Scale (LSNS; See Appendix F; Lubben, 1988), and quality of relationships questions (See Appendix G; Fiori, et al., 2006).

Network size. Antonucci’s Hierarchical Mapping Technique was used to determine participants’ social convoys (Antonucci & Akiyama, 1995). Participants were asked to place individuals they have contact with into one of three categories: people they “cannot imagine life without,” people who are “not as close, but still important,” or people “who have not been mentioned, but are still important enough to be part of their network.” Individuals within the participants’ networks were summed to determine network size.

Social isolation. Lubben’s Social Network Scale (LSNS) included 10 questions that ask about the frequency and nature of contact with friends and family, confidant relationships, and helping others (Lubben, 1988). Based on their responses to Lubben’s Social Network Scale, elderly persons can be categorized as “Isolated”, at “High Risk for Isolation”, at “Moderate Risk for Isolation”, and at “Low Risk for Isolation.” Questions included “How many relatives do you see or hear from at least once a month” and “When you have an important decision to make, do you have someone you can talk to about it.” Each item was answered on a 5-point Likert scale (1 = agree, 2 = somewhat agree, 3 = neither agree nor disagree, 4 = somewhat disagree, and 5 = disagree), with higher scores indicating more isolation. Individual items were summed to create the isolation variable, with possible scores ranging from 0 – 50 on a 51-point scale. Because of the exploratory nature of this project and the interest in all levels of isolation, participant scores on the LSNS were left in their raw form; no groupings were used.
**Relationship quality.** Perceived quality of relationships was measured using seven items, including 5 positive quality questions and 2 negative quality questions, for seven categories of relationships. Questions included “I enjoy being with [Person name/relationship]” and “[Person name/relationship] gets on my nerves” (Fiori, et al., 2006). Each item was answered on a 5-point Likert scale (1 = agree, 2 = somewhat agree, 3 = neither agree nor disagree, 4 = somewhat disagree, and 5 = disagree). All items for both the positive and negative quality scales were reverse coded, so that higher scores meant more positive and more negative relationship quality, respectively. The five positive items for each category (total of 35) were averaged to determine their positive relationship quality. The two negative items for each category (total of 12) were averaged to determine their negative relationship quality.

**Demographics.** Included in the survey were demographic questions (See Appendix H). These included questions about age (year of birth), sex, marital status (ever married or never married), race (African American, Caucasian, Hispanic/Latino, Asian, or Other), and education level (no high school, high school, high school diploma, some college, technical college, Associate’s, Bachelor’s, Master’s, Doctorate, or Professional degree). The average of participants was 85. Three-fourths of the study population was female, and all participants were Caucasian. See Table 1 for an overview of demographic information.

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<td>Living Arrangements (%)</td>
<td></td>
</tr>
<tr>
<td>Old old (85+)</td>
<td>79.3</td>
<td>Alone</td>
<td>70.8</td>
</tr>
<tr>
<td>Marital Status (%)</td>
<td></td>
<td>Spouse/Relative</td>
<td>29.2</td>
</tr>
<tr>
<td>Widowed</td>
<td>62.5</td>
<td>Sex (%)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>25.0</td>
<td>Female</td>
<td>75.0</td>
</tr>
<tr>
<td>Divorced or other</td>
<td>12.5</td>
<td>Male</td>
<td>25.0</td>
</tr>
</tbody>
</table>

*Note. N = 24.*
Data Analysis Plan

Descriptive statistics were run for the structural and functional characteristics of social support networks (total network size, isolation, positive relationship quality, and negative relationship quality) and physical and mental health variables (quality of life, depression, health status, loneliness).

Research Question 1: What elements of quality of life are most important to older adults living in independent living facilities located within Continuous Care Retirement Communities?

Data collected from qualitative interview conversations were transcribed. Next, two coders, working independently of each other, went through the data in order to develop codes (meaningful units) and themes (categories). The purpose of two coders was to ensure validation of coding of the researcher, who was influenced due to previous experience in the quality of life field. First, the transcripts were read in order to identify all codes described by the participants. Next, coders organized these meaningful units into categories based on how well the individual codes matched other codes. This was an iterative process, and categories changed frequently as more interviews revealed new codes. After organizing the codes into separate categories, coders came up with names for these broader units of data, or themes.

Finally, once both coders were satisfied with the way they had organized the data, they began to meet together to review the data together. During these sessions, both coders discussed each interview, which meaningful units they included as codes, and under which themes they placed each code. When there was a disagreement between the ways each coder organized the data, coders discussed the reasons each had for the differences until a consensus was reached. After finalizing both the codes and themes, the researcher met with participants to verify that the
meaningful units were interpreted correctly. One participant had moved out of the facility and therefore could not be reached. However, all other participants agreed with coding of data, so all data were included. Finally, the themes that emerged during segmenting and coding were analyzed in order to determine if they corresponded with concepts or factors included in the CASP-19.

Research Question 2: Do these elements correspond with factors that are currently being measured?

Themes and subthemes developed under research question 1 were analyzed by the researcher in order to determine any explicit and implicit references to the CASP-19 sub-scales or factors. Specific themes or subthemes that related directly to CASP-19 factor items were labeled “explicit references.” “Implicit references” were defined as meaningful units or themes or sub-themes which seemed to imply one of the four factors.

Next, individual codes were analyzed in order to determine if each of them fit with one of the four CASP-19 factors or if they fell into an “other” category. The researcher coded each of the 174 items. The second coder analyzed 35 items (20%). Reliability analysis was determined by the percent of matching codes (CASP-19 or “Other”).

Research Question 3: Does the CASP-19 measurement have good concurrent validity with the visual-analog rating of quality of life?

A Pearson product moment correlation was run to determine if the CASP-19 score was related to the visual-analog ratings of quality of life. This correlation was believed to measure the construct validity of the CASP-19.

Research Question 4: What social, mental, and physical health variables are related to quality of life in this population and which ones have the strongest relationships?
Pearson product-moment correlations were run on the structural and functional social support network variables and the physical and mental health outcome variables in order to determine the relationships among the variables.
CHAPTER 4

RESULTS

Descriptive statistics were run for the structural and functional characteristics of social support networks (total network size, isolation, and overall perceived quality of support) and physical and mental health variables (depression, loneliness, health status, quality of life). See Table 2 for correlations.

Table 2. Correlations with Means, SD, Range, and Cronbach’s Alpha.

<table>
<thead>
<tr>
<th>Measure</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. CASP-19 QoLb</td>
<td>.73a</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Visual Analog QoLc</td>
<td>.66***</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Depressiond</td>
<td>-.37</td>
<td>-.33</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Subjective Healthε</td>
<td>.51*</td>
<td>.34</td>
<td>-.15</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Lonelinessf</td>
<td>-.58**</td>
<td>-.41*</td>
<td>.20</td>
<td>-.26</td>
<td>.80a</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Isolationg</td>
<td>.02</td>
<td>.12</td>
<td>.07</td>
<td>-.03</td>
<td>.33</td>
<td>.45a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Positive Relationship Qualityb</td>
<td>.67***</td>
<td>.55**</td>
<td>-.02</td>
<td>.49*</td>
<td>-.41*</td>
<td>-.34</td>
<td>--</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Negative Relationship Qualityi</td>
<td>-.22</td>
<td>-.47*</td>
<td>.08</td>
<td>.05</td>
<td>.25</td>
<td>-.05</td>
<td>-.34</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>9. Network Size</td>
<td>-.22</td>
<td>-.40</td>
<td>-.10</td>
<td>-.32</td>
<td>.17</td>
<td>-.18</td>
<td>-.25</td>
<td>.27</td>
<td>--</td>
</tr>
</tbody>
</table>

| M         | 42.46 | 16.40 | 1.92  | 3.17  | 36.79 | 19.67 | 4.81  | 1.48  | 23.92 |
| SD        | 5.33  | 3.01  | 1.38  | .76   | 6.23  | 6.15  | .19   | .42   | 15.23 |
| Range     | 31.0- | 10.5- | 0.0-  | 1.0-  | 27.0- | 8.0-  | 4.48- | 1.0-  | 2.0-  |
| 52.0      | 21.0  | 5.0   | 4.0   | 46.0  | 38.0  | 5.0   | 2.25  | 1.0   | 2.25  |

Note. \( n = 24 \).

*p < .05; **p < .01, p < .005

aCronbach’s alpha

bCASP-19 QoL: CASP-19 model, scored so higher scores mean better QoL, 58-point scale ranging from 0 – 57.

cVisual Analog QoL: slider scale rating of QoL, higher ratings mean better QoL, 11-point scale ranging from 0 – 10 (converted to cm, with scale ranging for 0 cm – 21 cm).

dDepression: 15-item Geriatric Depression Scale (GDS-15), scored so higher scores mean more depression, 16-point scale ranging from 0 – 15.

eSubjective health: 1-item scale, reverse scored so that higher scores mean better health ratings, 5 point scale ranging from 1 – 5.

fLoneliness: Revised version of the UCLA (UCLA-Rev), scored so that higher scores mean more loneliness, 61-point scale ranging from 20 – 80.

gIsolation: Lubben Social Network Scale (LSNS), reverse scored so higher scores mean more isolation, 51-point scale ranging from 0 – 50.

hPositive Relationship Quality: 30-item scale derived from Fiori, et al (2006), 5 questions repeated for each of six relationship types, scored so that higher scores mean more positive relationship quality, composite 5-point scale ranging from 1 – 5.

iNegative Relationship Quality: 12-item scale derived from Fiori, et al (2006), 2 questions repeated for each of six relationship types, scored so that higher scores mean more negative relationship quality, composite 5-point scale ranging from 1 – 5.
Elements of Quality of Life

Research Question 1: What elements of quality of life are most important to older adults living in independent living facilities located within Continuous Care Retirement Communities?

Qualitative analysis of the quality of life interviews revealed 10 main themes participants identified as important elements of quality of life. Themes included Health, Relationships, Faith/Religion, Independence, Place, Staying Active, Contentment, Altruism/Generativity, Basic need/Personal security, and Future. Several main themes were also grouped into several subthemes. A total of 26 theme/subthemes were developed. Saturation of themes was reached after the eighth interview; however, four more interviews were conducted to ensure no more themes would emerge from the data (see Figure 1). See Table 3 for a full listing of themes, subthemes, and examples of coding units.

Table 3. Themes, Subthemes, and Exemplar Codes.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th># of Codes</th>
<th>Exemplar Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health (n = 11)</td>
<td>Limitations caused by</td>
<td>37</td>
<td>The ability to be with my beloved grandchildren, it (health) might draw them close but I would feel like I can't respond like I would like to. (W-04)</td>
</tr>
<tr>
<td></td>
<td>(n = 7)</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Deterioration (n = 6)</td>
<td>11</td>
<td>Well if I'd get worse shape than I'm in right now (would make quality of life worse)...I think (health) that's why your quality of life isn't where you want it to be. (N-13)</td>
</tr>
<tr>
<td></td>
<td>General (n = 4)</td>
<td>5</td>
<td>Well I can only think of is health things (would make quality of life worse)...Well obviously if you have a stroke or Alzheimer's that can happen, dementia and there's just a lot of things can happen. (N-11)</td>
</tr>
<tr>
<td></td>
<td>Positive outlook</td>
<td>5</td>
<td>Oh health...Right now I'm about as good of health as I have been in a long time. (N-05)</td>
</tr>
<tr>
<td></td>
<td>Of family/loved ones</td>
<td>7</td>
<td>I'd like to be in control of it (health issues of family) but I know I can't. (N-03)</td>
</tr>
<tr>
<td></td>
<td>(n = 2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationships</td>
<td>Benefits (n = 7)</td>
<td>31</td>
<td>We don't really know, always understand what the doctors are saying to us or what's going on. We have two nurses in the family...and my daughter in Springfield, she's a nurse. She was tremendously good for us and helped us understand (N-11)</td>
</tr>
<tr>
<td>(n = 11)</td>
<td>Connectedness (n = 5)</td>
<td>12</td>
<td>You're in contact with people and that's good. You got to have that...well I'm hoping this computer thing is going to be more contact and easier...I think I need more communication for me. (N-11)</td>
</tr>
</tbody>
</table>

29
<table>
<thead>
<tr>
<th>Table 3. continued</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships (continued)</td>
</tr>
<tr>
<td>Faith/Religion (n = 9)</td>
</tr>
<tr>
<td>Independence (n = 8)</td>
</tr>
<tr>
<td>Place (n = 7)</td>
</tr>
<tr>
<td>Staying Active (n = 6)</td>
</tr>
<tr>
<td>Contentment (n = 6)</td>
</tr>
<tr>
<td>Altruism/ Generativity (n = 4)</td>
</tr>
<tr>
<td>Future (n = 3)</td>
</tr>
</tbody>
</table>

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>Sickness in some of the relatives...if they passed away. (N-06)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>I just want them (kids) to have a good life...be(ing) happy. (N-03)</td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>Wherever I am, the Lord is in my life and He's the One that I follow. He's my shepherd, He's my constant companion so it's the spiritual aspect that makes the difference...The Lord's been with us. (W-08)</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>I'm as free as I need to be to do the things I care to do....Freedom to do what I'm able to do. (W-04)</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>If my wife would get busy...well I could more or less do what I wanted to do too. You know she gets pretty frustrating. (N-15)</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>I can dress myself and take my own baths and fix some food if I want myself. (N-04)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>You don't want to have to depend on anyone else paying your way...well you always worked hard and you saved your money and you don't want to depend on somebody else. (W-02)</td>
</tr>
<tr>
<td></td>
<td>22</td>
<td>But here, if my health did get bad, I could move from here to assisted living or worse than that they have an area where they take care of you until you die, where they do everything for you. (N-04)</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>They're all friendly, courteous, and just nice to be around. (N-06)</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Interplay of people because we're coming from all different backgrounds and so really it broadens you a little. (W-08)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Food is good. (W-04)</td>
</tr>
<tr>
<td></td>
<td>25</td>
<td>I try to exercise. I just finished therapy and you know it's something I work on...it's my problem with walking and my legs and so. (N-13)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>I don't have a wood workshop. 'Til I get it, I won't be normal...relax and do it. (N-15)</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>His problem (husband's health) has made it very different for both of us (have to be home more and not as active). (N-09)</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Keep current (by reading newspapers). (N-09)</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>To not just dwell on that but to realize this is the point of life we're in and we can make of it what we will...I'm going to make the best of it here. (W-08)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>I feel sorry for the people that have to be (not on the go). That's why I go visiting them and trying to cheer them up. (N-08)</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>...not having to worry about the money or a place to live. (N-04)</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>We're a partnership and he (husband) does a lot...if he outlives me it won't be a problem but if I outlive him it will be a problem. (N-09)</td>
</tr>
</tbody>
</table>

Note. N = 12; n = number of participants who mentioned the theme or subtheme during their interview.

*# of Codes: individual codes that were organized under each theme (bold text) and subtheme (non-bold text).
Health. Health was a very prevalent feature of participants’ lives. All but one participant mentioned some aspect of health during their interview. The only one who didn’t was the shortest interview and final interview. This participant mentioned some health issues briefly during other parts of the questionnaire. He stated that his children pressured him and his wife to move into the facility because of his failing health, and that he wasn’t happy about it. However, during the qualitative interview, nothing about his health was mentioned and the limitations placed upon his activities and hobbies were blamed on moving to a new place and away from things like his wood workshop. Subthemes for health were limitations caused by, deterioration, general, positive outlook, and of family/loved one.

Limitations caused by. Seven participants talked about things that they were limited in doing because of their health, and that this was an important element that contributed to their quality of life. During his interview, one participant said: *that (worsening health) would really restrict me because then I wouldn't be doing much of anything...outside of walking.* Another participant mentioned being limited also: *the ability to be with my beloved grandchildren, it (health) might draw them close but I would feel like I can't respond like I would like to.*
**Deterioration.** Six participants talked about deterioration of health as an important element that contributed to their quality of life. During her interview, one participant said: *well if I'd get worse shape than I'm in right now (would make quality of life worse)...I think (health) that's why your quality of life isn't where you want it to be.* Another participant said: *if I were to be seriously organically ill, apart from just parts of the body that don't work anymore...If I had any more senior moments, that would discourage me.*

**General.** Four participants talked about their health in general as an important element that contributed to their quality of life. During her interview, one participant said: *well I can only think of is health things (would make quality of life worse)...Well obviously if you have a stroke or Alzheimer's that can happen, dementia and there's just a lot of things can happen.* One of the married participants mentioned: *if one of us had a change of health.*

**Positive outlook.** Four participants talked about their health in a positive way. During his interview, one participant said: *oh health...Right now I'm about as good of health as I have been in a long time.* Another participant also mentioned health in a positive light: *my health (lymphoma cancer, detached retina) hasn't stopped me, fortunately.*

**Of family/loved ones.** Two participants talked about the health of their loved ones as an important element that contributed to their quality of life. During her interview, one participant said: *I'd like to be in control of it (health issues of family) but I know I can't.* She also mentioned that: *my youngest granddaughter has a health problem but I've put her in God's hands and the doctor's hands.* Another participant, when asked what could make her rate her quality of life lower, stated: *if he gets so that he loses more strength in his legs and he's not able to walk well at all and he still wants to be here. I'd say he's going to go kicking across the street.*
**Relationships.** Almost all participants mentioned relationships as important to their quality of life. The only participant who didn’t mention relationships was much more focused on his health issues. However, he did mention limitations caused by health issues in activities that he previously engaged in with his daughter. Therefore, although his codes were not categorized under this particular theme, it seems that relationships might have also been important to him as well. Subthemes for relationships included benefits, connectedness, loss of loved one, and wanting better for others.

**Benefits.** Seven participants talked about the benefits received from relationships with others as an important element that contributed to their quality of life. During her interview, one participant said: *well I think your friends and your support system...they're there for you when you need help and somebody to lean on and help you out you know.* When asked what could make his quality of life better, another participant said: *oh companionship...to be close friends and be showing a little affection.*

**Connectedness.** Five participants talked about remaining connected with others as an important element that contributed to their quality of life. During her interview, one participant said: *well they (family) communicate, they call, they're always sending you know cards....You're in contact with people and that's good. You got to have that...well I'm hoping this computer thing is going to be more contact and easier...I think I need more communication for me.* Another participant mentioned staying connected with people: *I enjoy people...I like to be around people.*

**Loss of loved one.** Five participants talked about the loss of a loved one as an important element that contributed to their quality of life. During her interview, one participant said: *well gradually as your friends pass away, you feel like you're kind of lonely. You lose one friend after*
another. When asked what could make her quality of life decrease, another participant said: if I were to lose any of them (family) through accidents or health or something.

**Wanting better for others.** Four participants talked about wanting better for others as an important element that contributed to their quality of life. During her interview, one participant said: I wish I could make their lives better...I just want them (kids) to have a good life...be happy. When asked what could make his quality of life better, another participant mentioned: she (wife) feels she is tied down here (with me)...If she had some yard work to do or you know flowers and stuff. She likes that.

**Faith/religion.** Nine participants mentioned faith or religion as an important element that contributed to their quality of life. No subthemes were developed for this category. During her interview, W-08 said: wherever I am, the Lord is in my life and He's the One that I follow. He's my shepherd, He's my constant companion so it's the spiritual aspect that makes the difference...The Lord's been with us. Another participant said: …and our church does that (supports us). It's a very important part of our life...and then just our beliefs you know...We believe in God and a Christian life.

**Independence.** Eight participants mentioned some aspect of independence during their interviews. The subthemes for independence included freedom, autonomy, activities of daily living, and dependence (on others).

**Freedom.** Five participants talked about freedom as an important element that contributed to their quality of life. During her interview, one participant said: when we go get groceries, he goes, and I would like to do those things myself sometimes. Just freedom...because he picks a lot. I don't get to do that. It's weird. Another participant mentioned: well when you get to this age you don't have choices, what you do. You do what you have to do. I mean that's all.
Autonomy. Four participants talked about autonomy as an important element that contributed to their quality of life. During his interview, one participant said: getting to do what I want to do...If my wife would get busy...well I could more or less do what I wanted to do too. You know she gets pretty frustrating. Another participant said: I can't go everywhere I want to go to when I want to.

Activities of daily living. Four participants talked about their ability to perform activities of daily living as an important element that contributed to their quality of life. During his interview, one participant said: try it (brushing teeth with eyes closed) and then you'll know what frustration is. I mean daily living is a lot of things that's frustrating...and I start to do something and I can't see...Daily living is a lot of things that's frustrating. Another participant mentioned: I was getting to the point where I didn't want to keep up house. I didn't want to dust, you know those kinds of things. You lose interest in a lot of that stuff.

Dependence. Three participants talked about dependence on others as an important element that contributed to their quality of life. During her interview, one participant said: you don't want to have to depend on anyone else paying your way...well you always worked hard and you saved your money and you don't want to depend on somebody else. Another participant mentioned: if I had to give up car...I'd be a little bit more lost...couldn't do what I want to do...(I would) have to rely on someone else.

Place. Seven participants mentioned some aspect of place as an important facet of their quality of life. Subthemes included being cared for/cared about, atmosphere, friendship, and food.

Being cared for/cared about. Five participants talked about the feeling of being cared for or about as an important element that contributed to their quality of life. During his interview,
one participant said: *security here - I feel at home here...The kind of security that a child feels in his father's arms.* Another participant mentioned: *staff have residents' interests at heart... they're kind with us and understanding.*

**Atmosphere.** Four participants talked about the atmosphere where they were living as an important element that contributed to their quality of life. During his interview, one participant said: *community here is really neat.* Another participant mentioned: *they're (people in facility) all friendly, courteous, and just nice to be around.*

**Friendship.** Three participants talked about the friendships of other residents that they had made or already had before moving into the facility as an important element that contributed to their quality of life. During her interview, one participant said: *I think it's just the interchange, interplay of people because we're coming from all different backgrounds and so really it broadens you a little bit if you take the time to get interested in others.* The same participant also said: *here it's almost like family.* Another participant mentioned: *I'm content with where I live and how I'm cared for, and the advantages of friendship here.*

**Food.** Two participants talked about the food within and around the facility as an important element that contributed to their quality of life. During his interview, one participant said: *we like eating places. They have pretty good selection there.* When asked what some of the most important elements of his quality of life were, another participant said: *the food is good.*

**Staying active.** Six participants mentioned staying active as an important element to their quality of life. Subthemes developed for staying active included mobility, hobby, socialization, and learning/intellectual stimulation.

**Mobility.** Five participants talked about their mobility as an important element that contributed to their quality of life. During her interview, one participant said: *I try to exercise.*
just finished therapy and you know it's something I work on...it's my problem with walking and my legs and so. Another participant talked about one of her experiences before moving into the facility: this last winter was really tough because the weather was bad, you're caught in the house and you can't get out.

**Hobby.** Four participants talked about their hobbies as important elements that contributed to their quality of life. During his interview, one participant said: *I love to play golf.* In fact I played golf for 70 years...and this year I'm not playing...because I can't see...I'd play golf (if I could see). Another participant, who had recently moved out of his home, said: *I don't have a wood workshop. 'Til I get it, I won't be normal...relax and do it.*

**Socialization.** Four participants talked about their ability to socialize as an important element that contributed to their quality of life. During her interview, one participant said: *yeah more ways of getting out and doing things. I really don't do that. I spend all my time with my husband. All of it. Another participant mentioned: I do not like to stay at home...I like to be around people.*

**Learning/intellectual stimulation.** Only one participant talked about learning and intellectual stimulation; however, it was a very important element to her, as she mentioned it several times with four separate codes falling under this category. During her interview, this participant said: *yeah keeping up with reading and we get three newspapers. We get the USA Today because the Wichita Eagle doesn't give us what we're looking for very much but we read it and then we're getting the Kansan here which is a hand-me-down from three people. So I keep current. She also mentioned that she loved to play bridge because you never played the same game twice and …it's a stimulating game.*
Contentment. Six participants mentioned contentment as an important element that contributed to their quality of life. During her interview, one participant said: *to not just dwell on that but to realize this is the point of life we're in and we can make of it what we will...I'm going to make the best of it here.* Another participant stated that: *it could be much worse...I can't complain too much.*

Altruism/generativity. Four participants mentioned altruism and generativity as important elements that contributed to their quality of life. According to one participant, an important aspect of her quality of life was having *someone else to think about, not just myself...Love to help people.* Another participant mentioned passing things on to the next generation: *yeah, that's the story of my life but who wants my books (genealogy that she has put together).*

Basic needs/personal security. Three participants mentioned basic needs or personal security as important to their quality of life. One participant mentioned that: *well the foundation has helped me pay the bills...that would be disastrous if something happened to that.* One participant talked about needs that the facility was meeting, and when asked to specify which ones those were, she stated: *your need to stay alive.*

Future. Three participants talked about the future as an important element that contributed to their quality of life. During her interview, one participant said: *we're a partnership and he (husband) does a lot...if he outlives me it won't be a problem but if I outlive him it will be a problem.* Another participant stated: *I don't think that's (rate quality of life better) going to happen...It's a downhill slide from here.* Although this participant presented a negative view of the future, other participants had a more positive or even variable view of the future. For instance, one participant stated: *It'll get better (in general).*
Case studies. During the review process of the qualitative data, several participants seemed to exemplify certain themes; that is, their interviews and therefore data seemed to focus on certain themes more so than others. Because there were other parts to this study that included questions related to quality of life, the researcher decided to present four case studies based on the top four most frequently mentioned themes, drawing information from observation notes and open-ended questions from other sections of the questionnaire.

Health. N-05 (whom we will refer to as Henry) was a widowed male in his early 90’s. He had previously been living next to his daughter, but they had been discussing his moving into a long-term care facility for six months before he moved into the facility. He said that the reason they were talking about it is that several things had “come up,” but he never gave specifics. The deciding element in his move was actually that his granddaughter needed to move closer to her mother (his daughter), so he moved out of his house so she could live there. Five of the seven friends he listed in his social support network were residents, although he only had one friend who lived at the facility when he moved in.

Henry mentioned his health issues during almost every part of his interview. He had developed macular degeneration, which restricted his vision to the point of interfering with his daily life. He could no longer read or play golf, both activities that he loved severely. However, he was very adaptive. He received special audio books from a library in another town so that he could still enjoy “reading.” He explained that he listened to the books about two to three hours a day. Even so, he was still restricted. He mentioned that he and his daughter used to go to the library and pick out a book each. Then, once they had read their books, they would switch and read each other’s. This was a fond memory for him, and his vision problems prevented him from enjoying this activity.
He also mentioned that he no longer drove during high traffic times or at night because of his poor eye sight. This restricted him from being able to go to The Lodge where most of his contact with his outside friends had taken place. Most of his friends living outside the facility would play cards at The Lodge during the evening. This was often when he would have attended and socialized. Because of his failing eye sight, he was no longer able to engage in this activity.

Henry mentioned activities of daily living as one of the most frustrating things he had to face, and which was impacted by his vision the most. During the interview, he asked the primary interviewer to imagine trying to brush her teeth with her eyes closed (walking into the bathroom, finding the toothpaste and toothbrush, getting the toothpaste onto the toothbrush, and then brushing without stabbing yourself in the face).

Although his vision was deteriorating and his health wasn’t what he wanted it to be, Henry was able to make accommodations in order to have good quality of life. He only drove during certain times; and he went to Envision (a company who specializes in helping individuals with vision problems) and was referred to a library in Emporia where he could get recordings of narrated books.

**Relationships.** N-09 (whom we will refer to as Isabel) was a married woman in her late 80’s. Her husband had installed one of the first IBM computers, and one of her nephews had also patented some of the technology used in smartphones today. Because of this, her family was very excited for her to be a part of the study for the computer training purposes. Isabel was very talkative; she had a story for nearly every question (even the closed-ended ones). She had never used computers before, and wasn’t much interested in them. However, she felt the need to start taking more control over certain aspects of her life (such as the finances) because of her husband’s failing health. According to the secondary interviewer, *she seemed very upbeat and*
very involved in many groups, but she was very concerned about her husband's health. This may be one of the reasons that she is now willing to learn to use the computer.

For Isabel, relationships were very important. She and her husband had lived in several different metropolitan areas, including Washington, D.C. and Saint Louis, Missouri. They were well traveled, both within the US and internationally, and used to high society. They moved to their current location because one of their daughters lived nearby and convinced them to move into the facility. However, their daughter moved to another state soon after they moved in. The community that they now reside in is mostly a farming community, and they have had issues developing deep and meaningful friendships because the other residents do not share their interests.

One of the most interesting things Isabel mentioned during other parts of her interview was about the possibility of losing her husband and her loss of friends. When interviewers asked her about some of the reasons she moved into the facility and if her family or friends had an impact on the decision or if her relationships with her friends had changed since moving in, she told interviewers that she was a the age where she was losing friends left and right. She told them that her husband had woken up in the middle of the night recently and told her that he didn’t think he was going to make it to his next birthday (90th). She said he had stated: *I am not going across the street (to the “Big House”).* The “Big House” is how resident refer to the skilled nursing unit. She also said that he would probably shoot himself before he’d go over there. Because of these losses of friends and the worry of losing her husband, relationships are a very important element in the quality of life of Isabel.

**Faith/religion.** W-08 (whom we will refer to as Sue) was a widowed female in her mid-eighties. Sue was a very religious person, and she mentioned several times how much she liked
to help others because it helped her to keep an outward focus instead of being consumed by her own problems. The secondary interviewer described her as follows: *she seemed bright and understood most everything. Unlike some of the other participants, she did not share a lot of stories. Even so, she fully answered open-ended questions and seemed very optimistic and heavily reliant on the spiritual aspect of her life as a source of hope or reassurance. She said that her life was about as close to perfect as it could be given that life has “ripples.”*

Sue was very independent. She decided to move into the facility when she started having health problems. She and some of her friends decided to look into different facilities and they all liked the one she currently resides in. She also mentioned that moving into the facility was good because she wouldn’t have to call her children so often.

As independent as she was, Sue also believed that her faith sustained her, and that she had a higher power she could rely on. She believed that being content with life was a key element to happiness. She believed not that she needed everything to go her way, but that being satisfied with where she was in life was the best way to live

*Independence.* N-04 (whom we will refer to as Paul) was a divorced male in his early eighties. He is confined to a motorized chair and is on oxygen. Paul had previously had a bad experience with another facility. In the facility he lived in before Presbyterian Manors of Mid-America, he told interviewers that he was not allowed to eat outside of the times the staff told him to, he couldn’t have a refrigerator in his room to keep snacks in, and they forced him to take a shower twice a week with staff persons present and didn’t acknowledge his request for male staff. Paul had been a reporter for the Los Angeles Times and they had a foundation set up for the retirees. A woman from the foundation helped him to find another facility that would better suit his needs and independent nature.
Because of his previous experience, he was very grateful for the assistance of the foundation and also conscientious of what would happen if he lost the funds from them. According to the primary interviewer, “He is much happier at PM(MA) because he can do things when he wants to do them, and he can have a refrigerator and prepare his own meals and take a shower by himself.” Paul felt very strongly about his independence. Paul had a prior experience that limited his independence. Because of this, he was very thankful for his current situation that allowed him to be more independent.

Themes, Codes, and the CASP-19

Research Question 2: Do these elements correspond with factors that are currently being measured?

**Control.** Hyde et al. defined control as “the ability to actively intervene in one’s environment” (p. 187, 2013). Items for the Control factor included “My age prevents me from doing the things I would like to,” “I feel that what happens to me is out of my control,” “I feel free to plan for the future,” and “I feel left out of things.” The paragraphs below present residents’ explicit and implicit references to “control.”

**Explicit themes.** One theme explicitly related to control was Health. One participant mentioned: *I'd like to be in control of it (health issues of family) but I know I can't.* For this participant, not having control over her own health and the health of her family was detrimental to her quality of life. Another theme that was related to control was Independence. One participant stated: *I can dress myself and take my own baths and fix some food if I want myself.* This participant felt that the ability to perform activities of daily living independently were especially important to his quality of life.
Another theme that was related to control was the Future theme. In this theme, the participants talked about either their lack of control over how things will be in the future or their fear of what will happen in the future. For example, one participant said: *I don't think that's (rate quality of life better) going to happen...It's a downhill slide from here.* This particular participant did not feel she had much control over her future.

**Implicit themes.** Other themes had certain elements that were related to control. These themes were more implicitly related to control. These themes included Relationships and Staying Active. One participant mentioned: *I wish I could make their lives better...I just want them (kids) to have a good life...be happy.* Although this code was organized under the Relationships: Wanting Better for Others theme, this participant talked about how she would like to be able to actively intervene in her children’s life in order to make them happy. Another participant stated that: *well I, of course being 93 is changed too but I’m restricting myself to driving. It’d be my age why I have to restrict what I do. I mean that’s just normal.* Although this code was organized under the Staying Active: Mobility theme, this participant was also talking about how his age limited his ability to actively engage in his environment.

**Autonomy.** Hyde et al. defined autonomy as “the right to be free from unwanted interference of others” (p. 187, 2013). Items for the Autonomy subscale included “I can do the things that I want to do,” “Family responsibilities prevent me from doing what I want to do,” “I feel that I can please myself with what I can do,” “My health stops me from doing the things I want to do,” and “Shortage of money stops me from doing the things I want to do.” The paragraphs below present residents’ explicit and implicit references to “autonomy.”

**Explicit themes.** The themes that were related to autonomy were Independence and Basic Needs/Personal Security. In regard to Independence, one participant stated: *when we go get*
groceries, he goes, and I would like to do those things myself sometimes. Just freedom...because he picks a lot. I don't get to do that. It's weird. This participant was spending a lot of time with her husband and felt that he didn’t give her enough autonomy in certain activities. In relation to Basic Needs/Personal Security, one participant felt it was important to have sufficient funds to move on to where you want to be. Being able to make those decisions about personal needs was very important for several participants.

**Implicit themes.** Other themes had certain elements that were related to autonomy. These themes were more implicitly related to autonomy. These themes included Health, Place, and Staying Active. In regard to Health, one participant stated that their quality of life would decrease if they get moved to assisted living. The decreased independence due to health was an important element for this participant. In relation to Place, one participant mentioned that: but here, if my health did get bad, I could move from here to assisted living or worse than that they have an area where they take care of you until you die, where they do everything for you. For this participant, having someone help him maintain some amount of autonomy (even while he was losing some of his independence) was important to his quality of life. Finally, as far as Staying Active, one participant mentioned that: his problem (husband's health) has made it very different for both of us (have to be home more and not as active). For this participant, she felt she needed to be home with her husband even though he wasn’t able to get out as often because of his health, and this limited her ability to socialize and stay active.

**Self-realization.** The Merriam-Webster dictionary defines self-realization as “fulfillment by oneself of the possibilities of one’s character” (“Merriam-Webster online,” 2015). Hyde et al. refer to self-realization as the “active…processes of being human” (p. 187, 2013). Items on the Self-Realization subscale included “I feel full of energy these days,” “I choose to do things that I
have never done before,” “I feel satisfied with the way my life has turned out,” “I feel that life is full of opportunities,” and “I feel that the future looks good for me.” The paragraphs below present residents’ explicit and implicit references to “self-realization.”

**Explicit themes.** The theme related to self-realization was **Future.** One participant stated that: *it'll get better (in general).* For this participant, he held onto the hope that things would get settled in his personal life (as he and his wife had just moved) and he would be able to find fulfillment in the near future as that happened.

**Implicit themes.** Other themes had certain elements that were related to self-realization. These themes were more implicitly related to self-realization. These themes included **Health**, **Independence**, **Contentment**, and **Altruism/Generativity.** In regard to **Health**, one participant mentioned that, if her health got worse, she was *afraid I'd sit and do nothing.* For her, worsening health would play an important part in her quality of life by preventing her from reaching fulfillment through activities. For **Independence**, one participant mentioned that: *you don't want to have to depend on anyone else paying your way...well you always worked hard and you saved your money and you don't want to depend on somebody else.* For her, if she had to depend on someone else, she would lose a little bit of who she had worked so hard to become: an independent woman.

In regard to **Contentment**, one participant said: *to not just dwell on that but to realize this is the point of life we're in and we can make of it what we will...I'm going to make the best of it here.* For this participant, contentment allowed her to gain satisfaction and enjoyment from her life. In relation to **Altruism/Generativity**, a participant stated that she needed *someone else to think about, not just myself...(I) love to help people.* For her, helping others allowed her to have a greater sense of self.
**Pleasure.** The Merriam-Webster dictionary defines pleasure as “a feeling of happiness, enjoyment or satisfaction: a pleasant or pleasing feeling; activity that is done for enjoyment; something or someone that causes a feeling of happiness or satisfaction” (“Merriam-Webster online,” 2015). Hyde et al. refer to pleasure as the “reflexive processes of being human” (p. 187, 2013). Items on the Pleasure subscale included “I look forward to each day,” “I feel that my life has meaning,” “I enjoy the things that I do,” “I enjoy being in the company of others,” and “On balance, I look back on my life with a sense of happiness.” The paragraphs below present residents’ explicit and implicit references to “pleasure.”

**Explicit themes.** The themes that were related to pleasure were Relationships, Place, and Staying Active. As far as Relationships, one participant stated: *they (surrounding family) have supported us and kept us, you know, within reach...I think that's why we're so happy because we have kids that are with us and around us and that's all we need.* It was her family members being close to them and staying in contact that allowed her to be happy and take pleasure in life. In relation to Place, one participant stated that an important aspect of her quality of life was *campus life...Wonderful campus. They have so many opportunities. The newspaper comes right to my door.* For her, having things within her immediate environment in which she could take pleasure was very important to her quality of life. In regard to Staying Active, one participant said: *well I like to spend time in my backyard and I'll be going to ball games this fall.* For him, engaging in activities that he enjoyed was very important to his quality of life, especially since he had experienced an interruption in many of these activities due to moving into the facility.

**Implicit themes.** Other themes had certain elements that were related to pleasure. These themes were more implicitly related to pleasure. These themes included Health, Independence, and Altruism/Generativity. In relation to Health, one participant said: *well I can't do the things I
would like to do. Health reasons…I can’t walk like I need to and just generally I just can’t do the things that I used to do. For him, his poor health was limited the things he could take pleasure in, which was in turn decreasing his quality of life. As far as Independence, one participant mentioned that he enjoyed getting ice cream either in a cone or a Styrofoam bowl anytime you want. It was his ability to do things without others telling him when he could or couldn’t do them that brought him pleasure. In regard to Altruism/Generativity, one participant stated: I volunteered out there in the library...I really liked it. The ability to volunteer somewhere that gave her purpose and that she could take pleasure in had been important to her quality of life.

**Individual coding units.** Of the 35 codes used in the reliability analysis, the raters agreed on 69%. Forty seven of the codes were rated as “Other.” These units included codes such as Yeah, that's the story of my life but who wants my books (genealogy) and She (wife) feels she is tied down here (with me). Of the 174 coding units, 127 codes (73%) fit under the CASP-19 factors. The units included There's nothing you can, whatever happens is going to happen (Control), I couldn't even have a coffee maker (at the previous facility) (Autonomy), On any given day I could go way down the list there (quality of life rating) (Self-realization), and They're all friendly, courteous, and just nice to be around (Pleasure).

**CASP-19.** Overall, the factors of the CASP-19 measure of quality of life were well represented within the qualitative data. Control, Autonomy, and Pleasure were especially important for the participants to experience. Control was related explicitly to three themes and implicitly to two themes. Autonomy was related explicitly to two themes and implicitly to three themes. Pleasure was related explicitly to three themes and implicitly to three themes. Self-Realization, however, was not as well represented within the data as the other three factors, having only one small theme (Future) explicitly related to it, though there were four themes
implicitly related to this factor. Future had an n of three, indicating that only three participants felt that their quality of life was affected by something directly related to the items on the Self-Realization factor.

The majority of the individual coding units fell within the scope of the CASP-19 factors. This representation of the four factors of the CASP-19 within the qualitative data gave some indication of the content validity of the CASP-19. The content validity was explored more thoroughly in the discussion section.

**CASP-19 Validity**

*Research Question 3:* Does the CASP-19 measurement have good concurrent validity with the visual-analog rating of quality of life?

The visual analog quality of life slider scale was significantly positively correlated with the CASP-19 scores ($r (23) = .66, p < .001, R^2 = .44$). Because the visual analog quality of life slider scale had powerful face validity, the strong relationship (44% shared variance) between it and the CASP-19 provided some support for the concurrent validity of the CASP-19.

**Biopsychosocial Variables**

*Research Question 4:* What social, mental, and physical health variables are related to quality of life in this population and which ones have the strongest relationships?

The visual analog quality of life slider scale was negatively correlated to loneliness ($r (23) = -.41, p < .05, R^2 = .17$), negative relationship quality ($r (23) = -.47, p < .05, R^2 = .22$), and network size ($r (23) = -.40, p = .05, R^2 = .16$), and positively correlated to positive relationship quality ($r (23) = .55, p < .01, R^2 = .30$). The CASP-19 was also negatively related to loneliness ($r (23) = -.58, p < .01, R^2 = .34$) and depression ($r (23) = -.37, p = .07, R^2 = .14$), and positively
related to positive relationship quality ($r (23) = .67, p < .001, R^2 = .45$) and subjective health ($r (23) = .51, p < .05, R^2 = .26$). See Table 2 for a summary of correlations.
CHAPTER 5
DISCUSSION

The purpose of this study was to determine the most important elements of quality of life for older adults living in independent living facilities located within Continuous Care Retirement Communities using qualitative methods. Also of interest was examining how closely the content of the qualitative study corresponded with the factors and items of the CASP-19 -instrument. Quantitatively the study explored whether the CASP-19 had good concurrent validity with a visual analog slider scale of quality of life and the extent to which standardized measures of biopsychosocial variables correlated with the CASP-19. Overall, findings supported the validity of the CASP-19 measurement of quality of life. Content validity was indicated through the qualitative analysis of the themes that corresponded with the CASP-19 factors, and the high correlation of the CASP-19 with the visual analog slider scale indicated high concurrent validity. The following sections discuss in detail how the results of this study relate to previous research findings and what conclusions can be made about the research questions.

Elements of Quality of Life

Research Question 1: What elements of quality of life are most important to older adults living in independent living facilities located within Continuous Care Retirement Communities?

Themes overview. As the qualitative analysis showed, the majority of individuals within our sample felt that elements such as Health, Relationships, Faith/Religion, Independence, and Place were very important to their quality of life. Although most researchers agree that health is related to quality of life (Prutkin & Feinstein, 2002), the exact way in which people’s health affects their quality of life is still debated. For example, Kane’s QOL questionnaire included a domain that measured the individual’s physical comfort: that they were relatively free of
discomfort and pain, and the pain and discomfort they did encounter was being acknowledged and addressed by staff persons (Kane, et al., 2003). Ferrans and Powers’ QLI included a subdomain measuring health and functioning: items on this subdomain measured individual’s ratings of satisfaction and importance of thirteen areas, including health, energy, sex life, and worries. Another subdomain, the family subscale, included ratings of satisfaction and importance of family health (Ferrans & Powers, 1985). The subthemes found in this population point to possible protective factors of having a positive outlook on health and having good health in general, while possible risk factors may be the limitations caused by their health, the fear or frustration of deteriorating health, and the heartache or worry of having loved ones with poor health. Findings indicating that health was an important element in quality of life were consistent with previous research.

Another theme that had several subthemes was Relationships. Many researchers have found social support to be important to quality of life (Antonucci, 1986; Antonucci & Akiyama, 1995; Fiori, et al., 2006; Holt-Lunstad, et al., 2010; Lubben, 1988; Medvene, et al., 2015). The current study found that relationships were important due to the benefits participants received from them (both emotional and tangible benefits) and the connectedness they had with their loved ones. Potential risk factors included loss of loved ones and worry caused by wanting better for others. Kane’s QOL questionnaire included a domain that measured the individual’s relationships: that they were able to have meaningful relationships and social interactions with others (Kane, et al., 2003). Ferrans and Powers’ QLI included two subdomains measuring relationships, the social and economic subscale and the family subscale: items on these subdomains measured individual’s ratings of satisfaction and the importance of areas such as friends, emotional support, children, and spouse/lover/partner (Ferrans & Powers, 1985).
Findings indicating that relationships were an important element in quality of life were consistent with previous research.

Faith/Religion was another important element for quality of life. Participants mentioned not only being able to engage in religious activities (such as attending church) but also being able to have fellowship with others of their faith and experiencing the feeling of comfort they took from their higher power. Kane’s QOL questionnaire included a domain that measured the individual’s spiritual well-being and whether their needs were being met (Kane, et al., 2003). Ferrans and Powers’ QLI included a psychological/spiritual subdomain: items on this subdomain measured individual’s ratings of satisfaction and importance of areas such as piece of mind and faith in God (Ferrans & Powers, 1985). Findings indicating that faith or religion was an important element in quality of life were consistent with previous research.

Researchers have also found that Independence is an important element in quality of life (Kane, et al., 2003; Kane, et al., 2007; New York Heart Association, 1939; Visick, 1948; Steinbrocker, et al., 1949; Zeman, 1947). In the current study, Independence was another theme that had several subthemes. The elements that contributed to the importance of independence were participant’s ability to be free to make their own choices, have autonomy in those decisions, have the ability to engage in the things that they enjoy, and not have to rely or be dependent on others. Kane’s QOL questionnaire included items that measure the individual’s independence through the domains of functional competence (the ability to remain independent) and autonomy (their willingness and ability to make the decisions in their lives; Kane, et al., 2003). Ferrans and Powers’ QLI included specific items that measured independence: ability to take care of oneself, ability to take care of family, and control (Ferrans & Powers, 1985).
Findings indicating that independence was an important element in quality of life were consistent with previous research.

Place was also an important element for older adults. Gillett, et al. (2007) found that attachment to place was related to quality of life. In the current population, participants felt that being cared for and about, the atmosphere of Presbyterian Manors of Mid-America, the friendships they made there, and even the quality of the food contributed to their quality of life. Kane’s QOL questionnaire included domains related to Place, such as privacy; dignity; food enjoyment; and safety, security, and order (Kane, et al., 2003). Privacy and dignity were not mentioned within the current population, although these may be especially important for nursing home residents. Ferrans and Powers’ QLI included specific items that measured Place: neighborhood and home (Ferrans & Powers, 1985). In the current population, Place was especially important to residents who were, for the most part, able to choose their location before having outside influences (health, children, spouse) swayed this decision (Nilsen, 2015).

Findings indicating that place was an important element in quality of life were consistent with previous research.

A smaller number of residents mentioned the other themes: Staying Active, Contentment, Altruism/Generativity, Basic Needs/Personal Security, and Future. Staying Active was an important element for several of the participants. Being able to engage in meaningful activity was found to be important in previous research (Kane, et al., 2003; Kane, et al., 2007). In the current population, participants found it important to remain mobile (or able to engage in the activities they enjoyed, such as walking), to be able to continue engaging in hobbies, to have opportunity to socialize during these activities, and to continue to be intellectually stimulated. Kane’s QOL questionnaire included domains related to Staying Active, such as functional
competence, meaningful activity, and individuality (Kane, et al., 2003). Ferrans and Powers’ QLI included specific items that measured Staying Active: energy (fatigue), things for fun, and achievement of personal goals (Ferrans & Powers, 1985). Findings indicating that staying active was an important element in quality of life were consistent with previous research.

Contentment was an important element for several of the participants. These participants felt that it was important for them to remain content in their lives, to focus on the good and not the bad. Kane’s QOL questionnaire did not include any domains related to Contentment (Kane, et al., 2003). Ferrans and Powers’ QLI included two specific items that measured Contentment: happiness and life satisfaction (both in general) (Ferrans & Powers, 1985). Findings indicating that contentment was an important element in quality of life were slightly different from previous findings. Contentment, as explained by the participants in the study, was more than just being satisfied with how life turned out, but being content and accepting where life has taken you and that this is the point of life we're in and we can make of it what we will.

Altruism/Generativity was an important element for some of the participants. These participants enjoyed being able to do things that helped others or that would help the next generations retain some pride in their heritage. Kane’s QOL questionnaire did not include any domains related to Altruism/Generativity (Kane, et al., 2003). Ferrans and Powers’ QLI included only one specific item that measured Altruism/Generativity: usefulness to others (Ferrans & Powers, 1985). Altruism and generativity have not been measured well in either Kane’s QOL or the QLI. However, findings indicating that altruism and generativity were important elements in quality of life were consistent with previous research that have found altruism and volunteering were related to well-being in older adults (Thomas, 2010). Previous research has shown that the importance of generativity increased as individuals aged (Stewart, Ostrove, & Helson, 2001), and
that these processes improved positive social engagement (Cox, Wilt, Olson, & McAdams, 2010).

Basic Needs/Personal Security was an important element for a few of the participants. For these participants, having a place to live and the finances to meet their basic needs was very important to their quality of life. Kane’s QOL questionnaire included items that measure the individual’s independence through the domain of safety, security, and order (Kane, et al., 2003). Ferrans and Powers’ QLI included specific items that measured Basic Needs/Personal Security: job/not having a job and financial needs (Ferrans & Powers, 1985). Findings indicating that basic needs and personal security were important elements in quality of life were consistent with previous research.

Future was an important element for a few of the participants. The three participants who mentioned the future discussed the worries they had about the future and their forecasts of how things would turn out for them. Kane’s QOL questionnaire did not include any domains related to Future (Kane, et al., 2003). Ferrans and Powers’ QLI included specific items that measured Future: chances for living as long as they would like and chances for a happy future (Ferrans & Powers, 1985). Findings indicating that future was an important element in quality of life were consistent with previous research.

**Individual differences.** There were a large number of individual differences evident in the qualitative data. Although only half of the participants mentioned Staying Active during their interviews, there were a total of 25 codes which fell under this theme. Comparatively, the only two themes with more codes were Health (37) and Relationships (31). This may be why previous studies have found inconsistencies in differing populations (Bowling & Stenner, 2011). People may or may not have similar elements that affect their quality of life; they may also place more
importance on certain elements to a degree that other people do not. For instance, Paul placed a lot of importance on Basic Needs/Personal Security because his independence was directly linked to his ability to afford the facility he currently resided in. On the other hand, half the participants did not mention Basic Needs/Personal Security as important elements to their quality of life.

Overall, many of the elements that have been previously found in the research were also found in the current study to varying degrees. The more common themes have been well represented in previous instruments. However, the themes that were not mentioned by the majority of participants were not as likely to be measured explicitly in Kane’s QOL or Ferrans and Powers QLI.

Themes, Codes, and the CASP-19

Research Question 2: Do these elements correspond with factors that are currently being measured?

Control. Themes explicitly related to the Control factor were Health, Independence, and Future. One theme that related to Control was Health. An item on the Control subscale states, “I can do the things I want to do.” One of the subthemes of Health was in relation to the limitations caused by poor health. Participants felt that their health negatively affected their quality of life when it limited their ability to engage in certain activities. For example, one participant said, Well I can't do the things I would like to do. Health reasons…I can’t walk like I need to and just generally I just can't do the things that I used to do. Independence was also explicitly related to Control. One item on the Control subscale is “My age prevents me from doing the things I would like to.” Participants felt that not only their health but their age restricted their ability to engage in meaningful activity and to be able to make their own choices and live independently. One
participant in the current study stated *Well when you get to this age you don't have choices, what you do. You do what you have to do. I mean that's all.*

Another item on the Control subscale of the CASP-19 states: “I feel free to plan for the future.” Participants in the current study expressed their feelings of doubt and worry about what would happen in the future. Although one participant mentioned the inability to plan for the future, *there's nothing you can, whatever happens is going to happen,* other participants mentioned the future in another context. One participant talked about the plans she was trying to make for the future but how worried she was about those plans: *We're a partnership and he (husband) does a lot...if he outlives me it won't be a problem but if I outlive him it will be a problem.* One of the main reasons this participant joined the study was because her husband did the checkbook and all the things online and she felt a need to learn some things so that she could take over as his health got worse.

Themes that were implicitly related to Control were Relationships and Staying Active. In both these themes, some participants mentioned their desire to be in control of the situation or their lack of choices due to outside circumstances. Overall, Control was well represented within the data. The qualitative interviews confirmed the importance of Control. As this has been seen in other populations as well, I believe it is an important aspect to include on quality of life instruments used with older adults.

**Autonomy.** Themes explicitly related to the Autonomy subscale were Independence and Basic Needs/Personal Security. One item on the Autonomy subscale of the CASP-19 states “I can do the things I want to do.” Participants felt that their ability to remain independent was important, and outside influences that decreased their independence included health-related issues, family interference, or other micro and exosystem influences. One participant stated,
Residents’ statements included in the Basic Needs/Personal Security theme also related well to the Autonomy subscale. One item on this scale stated “Shortage of money stops me from doing the things that I want to do.” This theme included needs such as shelter and food, but most participants also mentioned money and the security of knowing things were taken care of. For example, one participant said, *Well the foundation has helped me pay the bills...that would be disastrous if something happened to that.*

The themes that were implicitly related to Autonomy were Health, Place, and Staying Active. Many of the participants felt that their health issues (either current or in the future) created problems with maintaining their autonomy. On the other hand, some residents recognized that the facility they were in would allow them to adjust their level of independence and need for care as their health worsened. Because of this knowledge, residents attributed Place as important to their quality of life. For them, knowing that the transition to more care and less independence would happen within the facility gave them some measure of assurance and lessened their fears. Overall, Autonomy was well represented within the data. The qualitative interviews confirmed the importance of Autonomy. As this has been seen in other populations as well, I believe it is an important aspect to include on quality of life instruments used with older adults.

**Self-realization.** One theme explicitly related to the Self-realization factor was Future. One sample item on the Self-Realization subscale of the CASP-19 states “I feel that the future looks good for me.” Participants who had codes under the Future category either made statements about their negative or positive views of the future. For example, one participant
stated *I don't think that's (rate quality of life better) going to happen...It's a downhill slide from here.*

There were several themes implicitly related to Self-realization: Altruism/Generativity, Contentment, Health, and Independence. For the themes Altruism/Generativity and Contentment, participants felt that being able to give back to society or being happy with their life in any situation gave them better quality of life. More subtly, the ability to reach fulfillment was related to Health and Independence as the aging process and health issues prevented some people from being able to reach said fulfillment.

Overall, Self-Realization was mentioned relatively infrequently by the residents. Although certain themes such as Altruism/Generativity and Contentment would seem to be more explicitly related to Self-Realization, they are not captured in the items of the subscale. Altruism/Generativity may also be seen as one step higher on Maslow’s hierarchy of needs: This theme could potentially fall under the self-transcendence, or highest motivational level one step above self-realization (Koltko-Rivera, 2006). For this specific population, a rewording or broadening of the Self-Realization items might have served better. For instance, items could read: “I have sufficient energy to accomplish my goals,” “The things that I do give me a sense of fulfillment,” or “I’m looking forward to the future.” As this population was extremely homogenous, no generalizations were made. More research should be conducted to determine the specific relationship of Self-Realization to other populations.

**Pleasure.** Themes explicitly related to the Pleasure factor were Relationships, Place, and Staying Active. A sample item on the Pleasure subscale of the CASP-19 states “I enjoy being in the company of others.” Participants frequently talked about being in relationships, staying in contact with loved ones, what benefits they felt were important that they gleaned from those
relationships, and the fear of losing someone important to them. One participant mentioned that
*Well they (family) communicate, they call, they're always sending you know cards....You're in
contact with people and that's good. You got to have that...well I'm hoping this computer thing is
going to be more contact and easier...I think I need more communication for me.*

Staying Active was also explicitly related to Pleasure. One item on the subscale stated “I
enjoy the things that I do.” Participants talked not only of the activities they currently engage in
but the activities that they could no longer attend due to a variety of reasons. One participants
stated that *My daughter and I would go to the library and I'd check out two books and she'd read
one and I'd read the other and we would trade and I can't do that anymore (vision problems).*

Themes implicitly related to Pleasure were Altruism/Generativity, Health, and
Independence. The ability to engage in activities that were pleasing or enjoyable was hampered
by health issues and decreasing independence. When participants were able to focus outward on
others, however, they were able to feel a sort of self-worth and enjoyment. Overall, the Pleasure
was well represented within the data. The qualitative interviews confirmed the importance of
Pleasure. As this has been seen in other populations as well, I believe it is an important aspect to
include on quality of life instruments used with older adults.

**Content validity.** As discussed, the CASP-19 factors were found within the qualitative
analysis. In fact, several themes were related to each of the four factors. This provides some
evidence of the content validity of the CASP-19. However, there were some areas where the
themes and factors did not completely match up. For instance, although many of the main themes
could be related to a factor, some of the subthemes were not. Health: Deterioration was an
important theme for half of the participants. Although the CASP-19 measure does have an item
related to health (“My health stops me from doing the things that I want to do”), this does not
capture the worry people feel about their declining health. Although the item “I feel that the future looks good for me” might possibly capture some of this, the item itself is too broad to really be a good indicator.

Three-fourths of the participants mentioned Faith/Religion as important to their quality of life. Admittedly, this population was very religious, but other populations with religious affiliations may also have a strong relationship between their participation in the faith community or associated rituals and their quality of life. Participants also discussed Altruism/Generativity as an important factor, but the CASP-19 has no items that directly measure this. Another area not captured by the CASP-19 is Contentment. Although life satisfaction is captured on the CASP-19, the participants in this study were referring to contentment as the ability to accept the good and the bad parts of life and make the best of it. This is a fine difference from life satisfaction, but an important one. Although some individuals may not be satisfied with how life has turned out, they may choose to move on with their life and not concentrate on the things that have gone wrong.

Another area in which the CASP-19 does not capture the content of the themes expressed by the participants in this study is how much the participant’s quality of life depended on others. In Health: Of Family/Loved Ones, Altruism/Generativity, Relationships: Wanting Better for Others, and Relationships: Loss of Loved One, we found that the quality of life of loved ones was very important to the participant’s own quality of life. The CASP-19 measure is very egocentric; that is, all questions are concerned with the impact of issues on the individual. However, this study found that participants had worries about what impacted those they loved. More “other-centered” questions might be able to capture this part of quality of life.
The CASP-19 factors capture much of what the qualitative analysis found to be important to participant’s quality of life. Although there are a few subthemes not captured explicitly and a few items that may be too broad or too narrow in focus, the scale is still a good measure of overall quality of life. The current study indicates that the CASP-19 may have good content validity for this population. As previously stated, because of the homogeneity of the sample and the nature of qualitative research, these findings cannot be generalized to other populations. Implications of these findings for future research are discussed in detail below.

**Concurrent Validity**

*Research Question 3:* Does the CASP-19 measurement have good concurrent validity with the visual-analog rating of quality of life?

The visual-analog slider scale of quality of life and the CASP-19 scores were highly positively correlated. Because of the large effect size ($r = .66, p < .01$), the data indicate that the CASP-19 did measure quality of life in the current sample. Although the CASP-19 has shown some internal consistency issues in past research (Sexton, et al., 2013; Sim, et al., 2011), the findings here suggest it is a valid measurement.

**Biopsychosocial Variables**

*Research Question 4:* What social, mental, and physical health variables are related to quality of life in this population and which ones have the strongest relationships?

The CASP-19 was positively correlated to subjective health and positive relationship quality and negatively correlated to loneliness. Inconsistent with previous research, the CASP-19 was not related to depression or isolation. The correlation with isolation was very small ($r = .02$). This may be due to the environment of the independent living facilities located within Continuous Care Retirement Communities in which the participants lived. Residents in these
facilities may not count staff and other residents as close friends or confidantes (both integral items on the isolation scale used), but may still feel embedded in an environment enriched with opportunities to socialize and interact. There were also only two participants who were at high risk for isolation or isolated (8.3%). The majority of participants were at low risk (54.2%) or moderate risk (37.5%) for isolation. This limited variance in the LSNS may explain the lack of correlation. Although the CASP-19 was not significantly related to depression, the correlation coefficient was moderate \( (r = -0.37) \). This is notable because there was very little variance in depression scores and almost all participants had no depressive symptoms (95.8%). In a larger sample, a correlation coefficient of that size would have been statistically significant.

**Limitations**

There are limitations to the current research. The very nature of qualitative research prevents this study from being generalizable. The purpose was not to gather evidence that can be generalized to other populations, but discover the meaning of quality of life in a sample of older adults living in independent living facilities located within Continuous Care Retirement Communities to gain a more in-depth view of what are the important elements of quality of life for people with this shared experience (living in this type of facility). Gaining this knowledge, future researchers may be able to explore the possibilities of the presence of these themes in other populations. Other populations should include older adults living in independent living facilities located within Continuous Care Retirement Communities in other regions, both rural and urban, with varying sociodemographics and backgrounds. Other population might also include those living in other housing, such as senior focused housing and other subsidized housing options. Grounded theory methods could be used in future studies in order to develop an instrument measuring quality of life that is based on the population under study.
Implications and Future Research

This study found the CASP-19 to be a good instrument in measuring quality of life. The large correlation with the visual analog slider scale of quality of life gave evidence that the CASP-19 was indeed measuring quality of life in the current sample. Analysis of themes developed in the qualitative data also showed that the things participants found to be important to their quality of life were related to the factors of the CASP-19. There was, however, a lack of explicit relationships for some of the factors, especially Self-Realization. Although participant talked about things that were related to Self-Realization, the specific items on the subscale did not measure precisely what participants found important. This may be why the factor structure of the CASP-19 has shown issues in previous research. How each of these factors influences individual populations may be vastly different; for example, individualistic and collective societies may have extremely different ideas about the pathways to Self-Realization. In future studies that intend to use the CASP-19 with new populations (where it has not been used extensively), qualitative methods should be used in order to develop new items or refine existing items on the scale. These mixed methods approaches can help to ensure that the CASP-19 measure captures the ways in which the factors of Control, Autonomy, Self-Realization, and Pleasure affect the quality of life in these individuals. For populations where the CASP-19 has already been rigorously tested, or for studies that do not have the resources for qualitative interviews, a single-item visual analog scale may give evidence of the goodness of fit in the population under study. Even in these studies, however, qualitative methods could benefit the researchers by allowing them to make adjustments to the quantitative measurement (CASP-19) in order to improve or increase the correlation between CASP-19 scores and the visual analog rating of quality of life.
REFERENCES
REFERENCES


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APPENDIX A

QUALITY OF LIFE VISUAL ANALOG SCALE

Note. Scale has been formatted and resized to fit portrait orientation; original was printed on landscape orientation for participants.
APPENDIX B

CASP-19

The following questions are measuring your quality of life. For each of the following statements, please indicate how often you feel the way described.

-My age prevents me from doing the things I would like to.
0 = often  1 = sometimes  2 = not often  3 = never

-I feel that what happens to me is out of my control.
0 = often  1 = sometimes  2 = not often  3 = never

-I feel free to plan for the future.
0 = often  1 = sometimes  2 = not often  3 = never

-I feel left out of things
0 = often  1 = sometimes  2 = not often  3 = never

-I can do the things that I want to do.
0 = often  1 = sometimes  2 = not often  3 = never

-Family responsibilities prevent me from doing what I want to do.
0 = often  1 = sometimes  2 = not often  3 = never

-I feel that I can please myself with what I can do.
0 = often  1 = sometimes  2 = not often  3 = never

-My health stops me from doing the things that I want to do.
0 = often  1 = sometimes  2 = not often  3 = never

-Shortage of money stops me from doing the things that I want to do.
0 = often  1 = sometimes  2 = not often  3 = never
- I look forward to each day.

0 = often  1 = sometimes  2 = not often  3 = never

- I feel that my life has meaning.

0 = often  1 = sometimes  2 = not often  3 = never

- I enjoy the things that I do.

0 = often  1 = sometimes  2 = not often  3 = never

- I enjoy being in the company of others.

0 = often  1 = sometimes  2 = not often  3 = never

- On, balance, I look back on my life with a sense of happiness.

0 = often  1 = sometimes  2 = not often  3 = never

- I feel full of energy these days.

0 = often  1 = sometimes  2 = not often  3 = never

- I choose to do things that I have never done before.

0 = often  1 = sometimes  2 = not often  3 = never

- I feel satisfied with the way my life has turned out.

0 = often  1 = sometimes  2 = not often  3 = never

- I feel that life is full of opportunities.

0 = often  1 = sometimes  2 = not often  3 = never

- I feel that the future looks good for me.

0 = often  1 = sometimes  2 = not often  3 = never
APPENDIX C
GERIATRIC DEPRESSION SCALE

The following questions are a measure of depressive symptoms. Please think back on how you have felt in the PAST WEEK when answering each question.

- Are you basically satisfied with your life?
  1 = yes    2 = no

- Have you dropped many of your activities and interests?
  1 = yes    2 = no

- Do you feel that your life is empty?
  1 = yes    2 = no

- Do you often get bored?
  1 = yes    2 = no

- Are you in good spirits most of the time?
  1 = yes    2 = no

- Are you afraid that something bad is going to happen to you?
  1 = yes    2 = no

- Do you feel happy most of the time?
  1 = yes    2 = no

- Do you feel helpless?
  1 = yes    2 = no

- Do you prefer to stay at home, rather than going out and doing new things?
  1 = yes    2 = no
-Do you feel you have more problems with your memory than most?
   1 = yes  2 = no

-Do you think it is wonderful to be alive?
   1 = yes  2 = no

-Do you feel pretty worthless the way you are now?
   1 = yes  2 = no

-Do you feel full of energy?
   1 = yes  2 = no

-Do you feel that your situation is hopeless?
   1 = yes  2 = no

-Do you think that most people are better off than you are?
   1 = yes  2 = no
APPENDIX D

UCLA-R LONELINESS SCALE

The following questions measure how lonely you feel. Please indicate how often you feel the way described.

- How often do you feel that you are “in tune” with the people around you?
  1 = never  2 = rarely  3 = sometimes  4 = always

- How often do you feel that you lack companionship?
  1 = never  2 = rarely  3 = sometimes  4 = always

- How often do you feel that there is no one you can turn to?
  1 = never  2 = rarely  3 = sometimes  4 = always

- How often do you feel alone?
  1 = never  2 = rarely  3 = sometimes  4 = always

- How often do you feel part of a group of friends?
  1 = never  2 = rarely  3 = sometimes  4 = always

- How often do you feel that you have a lot in common with the people around you?
  1 = never  2 = rarely  3 = sometimes  4 = always

- How often do you feel that you are no longer close to anyone?
  1 = never  2 = rarely  3 = sometimes  4 = always

- How often do you feel that your interests and ideas are not shared by those around you?
  1 = never  2 = rarely  3 = sometimes  4 = always

- How often do you feel outgoing and friendly?
  1 = never  2 = rarely  3 = sometimes  4 = always
-How often do you feel close to people?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel left out?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel that your relationships with others are not meaningful?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel that no one really knows you well?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel isolated from others?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel you can find companionship when you want it?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel that there are people who really understand you?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel shy?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel that people are around you but not with you?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel that there are people you can talk to?

1 = never  2 = rarely  3 = sometimes  4 = always

-How often do you feel that there are people you can turn to?

1 = never  2 = rarely  3 = sometimes  4 = always
APPENDIX E

ANTONUCCI HIERARCHICAL MAPPING TECHNIQUE

This is the first part of our social support network questions. We would like to find out more about the people you interact with, how close you feel to them, and how important they are to you. We ask that you think of people in your life that you would consider part of your social support network. As you think of them, we will place them in three different groups, represented by concentric circles. The definition of each group is as follows:

- **Inner circle-** “People to whom you feel so close that it is hard to imagine life without them.”
- **Middle circle-** “People to whom you may not feel quite that close, but who are still very important to you.”
- **Outer circle-** “People whom you haven’t already mentioned but who are close enough and important enough in your life that they should be placed in your personal network.”

Feel free to make changes as we go along (i.e. – if you feel that one of the names in the inner circle should go in the outer circle instead, feel free to move it to the outer circle). Please list off the people who belong in your social support network now.

Take the first 10 social support network members named in the hierarchical mapping exercise (regardless of the circle they were put into), and answer the following questions about the structural and functional characteristics of their support.
This is the second part of our social support network questions. We would like to know more about what kinds of people and groups that make up your network.

*Family Networks*

- How many relatives do you see or hear from at least once a month?

  0 = none  
  1 = one  
  2 = two  
  3 = three or four  
  4 = five thru eight  
  5 = nine or more

- How often do you see or hear from the relative with whom you have the most contact?

  0 = less than monthly  
  1 = monthly  
  2 = few times a month  
  3 = weekly  
  4 = few times a week  
  5 = daily

- How many relatives do you feel close to? That is, how many of them do you feel at ease with, can talk to about private matters, or could call on for help?

  0 = none  
  1 = one  
  2 = two  
  3 = three or four  
  4 = five thru eight  
  5 = nine or more

*Friends Networks*

- Do you have any close friends? That is, do you have any friends with whom you feel at ease, can talk to about private matters, or could call on for help? If so, how many?

  0 = none  
  1 = one  
  2 = two  
  3 = three or four  
  4 = five thru eight  
  5 = nine or more

- How many of your friends do you see or hear from at least once a month?

  0 = none  
  1 = one  
  2 = two  
  3 = three or four  
  4 = five thru eight  
  5 = nine or more
- How often do you see or hear from the friend with whom you have the most contact?

<table>
<thead>
<tr>
<th>Score</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>less than monthly</td>
</tr>
<tr>
<td>1</td>
<td>monthly</td>
</tr>
<tr>
<td>2</td>
<td>few times a month</td>
</tr>
<tr>
<td>3</td>
<td>weekly</td>
</tr>
<tr>
<td>4</td>
<td>few times a week</td>
</tr>
<tr>
<td>5</td>
<td>daily</td>
</tr>
</tbody>
</table>

**Confident Relationships**

- When you have an important decision to make, do you have someone you can talk to about it?

<table>
<thead>
<tr>
<th>Score</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
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<tr>
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<td>seldom</td>
</tr>
<tr>
<td>2</td>
<td>sometimes</td>
</tr>
<tr>
<td>3</td>
<td>often</td>
</tr>
<tr>
<td>4</td>
<td>very often</td>
</tr>
<tr>
<td>5</td>
<td>always</td>
</tr>
</tbody>
</table>

- When other people you know have an important decision to make, do they talk to you about it?

<table>
<thead>
<tr>
<th>Score</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
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<td>seldom</td>
</tr>
<tr>
<td>2</td>
<td>sometimes</td>
</tr>
<tr>
<td>3</td>
<td>often</td>
</tr>
<tr>
<td>4</td>
<td>very often</td>
</tr>
<tr>
<td>5</td>
<td>always</td>
</tr>
</tbody>
</table>

**Helping Others**

a. Does anybody rely on you to do something for them each day? For example:

shopping, cooking dinner, doing repairs, cleaning house, providing childcare, etc.

NO- if no, score “0”; go on to “b”.

YES- if yes, score “5”; go to next section

b. Do you help anybody with things like shopping, filling out forms, doing repairs, providing childcare, etc.?

<table>
<thead>
<tr>
<th>Score</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>never</td>
</tr>
<tr>
<td>1</td>
<td>seldom</td>
</tr>
<tr>
<td>2</td>
<td>sometimes</td>
</tr>
<tr>
<td>3</td>
<td>often</td>
</tr>
<tr>
<td>4</td>
<td>very often</td>
</tr>
</tbody>
</table>

**Living Arrangements**

Do you live alone or with other people?

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>live alone</td>
</tr>
<tr>
<td>1</td>
<td>live with other unrelated individuals</td>
</tr>
<tr>
<td>4</td>
<td>live with relatives or friends</td>
</tr>
<tr>
<td>5</td>
<td>live with spouse</td>
</tr>
</tbody>
</table>
APPENDIX G

RELATIONSHIP QUALITY

-Which (category, such as child) do you have the most contact with? ______________________

Thinking of (person named above):

-I feel [Person name/relationship] supports me, that (he/she) is there when I need (him/her).

5 = Agree  4 = Somewhat agree  3 = Neither agree or disagree
2 = somewhat disagree  1 = disagree  NA

-I enjoy being with [Person name/relationship].

5 = Agree  4 = Somewhat agree  3 = Neither agree or disagree
2 = somewhat disagree  1 = disagree  NA

-[Person name/relationship] gets on my nerves.

5 = Agree  4 = Somewhat agree  3 = Neither agree or disagree
2 = somewhat disagree  1 = disagree  NA

-I feel that [Person name/relationship] believes in me. (p. 13)

5 = Agree  4 = Somewhat agree  3 = Neither agree or disagree
2 = somewhat disagree  1 = disagree  NA

-When [Person name/relationship] is having a hard time, I want to help (him/her).

5 = Agree  4 = Somewhat agree  3 = Neither agree or disagree
2 = somewhat disagree  1 = disagree  NA

-[Person name/relationship] makes too many demands on me. (p. 14)

5 = Agree  4 = Somewhat agree  3 = Neither agree or disagree
2 = somewhat disagree  1 = disagree  NA
-I feel [Person name/relationship] encourages me in whatever I do.

5 = Agree   4 = Somewhat agree   3 = Neither agree or disagree
2 = somewhat disagree   1 = disagree   NA
APPENDIX H

DEMOGRAPHICS

- Year of birth ____________
- Sex (observe) ____________
- Race or cultural group(s) that you identify with (all that apply):
  1 = African American  2 = Caucasian  3 = Hispanic/Latino  4 = Asian  5 = Other
- # of Sons ______
- # of Daughters ______
- # of Grandchildren ______
- # of Great Grandchildren ______
- # of Brothers ______
- # of Sisters ______
- # of Living Siblings ______
- Have you ever been married?  1 = Y  2 = N
- If yes, is your spouse still living?  1 = Y  2 = N  98 = DK
- If you were ever married, are you divorced or separated?  1 = divorced  2 = separated
- Do you have a significant other?  1 = Y  2 = N
- How long have you and spouse/partner been together? ______
- Educational level: (circle highest level of educational achievement)
  1 = No high school  2 = Some High school  3 = HS Diploma/GED
  4 = Some College  5 = Technical  6 = Associate’s
  7 = Bachelor’s  8 = Master’s  9 = Doctorate
  10 = Professional