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POSTTRAUMATIC GROWTH AMONG OLDER ADULTS WITH LATE-LIFE CANCER DIAGNOSES

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POSTTRAUMATIC GROWTH AMONG OLDER ADULTS WITH LATE-LIFE
CANCER DIAGNOSES

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DISSERTATION

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A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in
Gerontology in the College of Public Health
at the University of Kentucky

By
Aasha Irene Hoogland

Lexington, Kentucky

Director: Dr. Graham D. Rowles, Professor of Gerontology

Lexington, Kentucky

2016

ABSTRACT OF DISSERTATION

POSTTRAUMATIC GROWTH AMONG OLDER ADULTS WITH LATE-LIFE CANCER DIAGNOSES

Gerontological scholarship has often focused on the ways older adults deteriorate or decline with time, but it is plausible that positive change continues into and throughout old age. Late-life psychosocial growth may even be facilitated by a life-altering event such as a cancer diagnosis, a phenomenon broadly termed posttraumatic growth (PTG). PTG has been examined in a variety of general population samples, but there is a noticeable lack of research on PTG that focuses on older adults—a population for whom cancer diagnoses are particularly prevalent. Using a mixed methods design, this dissertation was designed to advance our understanding of PTG in older adults with late-life cancer diagnoses.

A population-based random sample of 56 cancer survivors was recruited, primarily, through the Kentucky Cancer Registry. The first Aim was to evaluate posttraumatic change in older adults with cancer by examining PTG and distress. Aim Two related PTG to contemporary theories of late-life transcendence to assess the extent of their covariance. Aim Three addressed the relationship between PTG and well-being, and Aim Four explored how primary coping strategies (emotion-focused, problem-focused, and meaning-focused coping) predict PTG.

The findings for Aim One indicated that older cancer survivors reported less PTG with age. No other demographic or clinical characteristics were associated with PTG. Aim Two determined a strong correlation between PTG and transcendence, but the two constructs were found to be distinct. Aim Three showed no statistical association between PTG and well-being. Finally, Aim Four revealed a relationship between problem-focused coping and PTG, even though older adults endorsed significantly more emotion-focused coping. Additional participant insights revealed an emphasis on faith, acceptance, and the importance of supportive others.

This study revealed few associations between participant characteristics and PTG, suggesting a more nuanced picture of PTG in old age than previously thought. Further, the findings for PTG and transcendence suggest PTG is not simply a hastened form of

transcendence, but rather a qualitatively different construct. Finally, open-ended responses highlighted factors not addressed quantitatively, including faith, financial constraints, and the nature and extent of social support, that need to be considered in future research on PTG.

KEYWORDS: Behavioral Oncology, Mixed Methods, Older Adults, Posttraumatic Growth, Transcendence

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July 25, 2016
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Date

POSTTRAUMATIC GROWTH AMONG OLDER ADULTS WITH LATE-LIFE
CANCER DIAGNOSES

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To Roz, I dedicate my second greatest accomplishment.

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Chapter One:
Introduction

Human development is typically discussed in the context of childhood stages, the transition into adolescence, or the changes we go through in middle age. Late-life psychological or social growth is seldom considered, perhaps due to the normative trajectories of physical (and cognitive) decline experienced in old age. In spite of increased rates of physical ailments and cognitive decline, recent theories of aging, informed by historical studies and anecdotal evidence, offer a more positive perspective of the last stage of life – a perspective that allows for continued growth even in the face decline (e.g., Baltes & Baltes, 1990; Carstensen et al., 1999; Tornstam, 2005).

Later life can bring a variety of physical, cognitive, and social challenges, and older adults are particularly susceptible to chronic illnesses. Cancer, for example, is widely known as one of the top killers of individuals in the United States; current figures indicate that adults aged 65 and older receive new cancer diagnoses ten times as often as individuals under 65 years old (Howlader et al., 2016). These diagnoses are often in addition to extant comorbidities that directly affect personal wellbeing. Recent research has suggested that the trauma associated with a cancer diagnosis (and, perhaps, the treatment or physical manifestations of the disease itself) can precede a kind of personal transformation called posttraumatic growth (PTG; Tedeschi, Calhoun, & Cann, 2007), but surprisingly little research has explored positive psychosocial growth in older adults after a cancer diagnosis. Prior empirical and observational inquiries have investigated PTG in general population samples, but there is a lack of research on PTG that focuses on older adults—the population for whom cancer diagnoses are most prevalent.

Given our limited understanding of positive change (in the form of PTG) in elderly cancer survivors, this mixed methods study was designed to investigate the manifestation of PTG in older adults with late-life cancer diagnoses (Specific Aim One), and advance understanding of how PTG is associated with contemporary theories of late-life growth (i.e., transcendence) (Specific Aim Two), well-being (Specific Aim Three), and coping strategies (Specific Aim Four). Mixed methods were used to minimize the weaknesses of both quantitative and qualitative research (e.g., rigid hypothesis testing that does not allow for a more in-depth exploration of participants' experiences, and limited generalizability, respectively). A "data-validation convergent" mixed methods design was used to take advantage of existing quantitative measures while allowing for elaboration and clarification through the use of open-ended questions (the qualitative component) (Creswell & Plano Clark, 2011).

In this dissertation, I begin by reviewing the current state of the literature on cancer, posttraumatic growth, transcendence, well-being, and coping (Chapter Two). I then explain the research design and specific methods used for this dissertation study (Chapter Three) before presenting my findings (Chapter Four). I conclude with a discussion of the findings, limitations, and final thoughts (Chapter Five).

Chapter Two:
Background and Significance

In this chapter, I review the literature that informed the genesis of my dissertation research. First, I delve into oncological studies that reveal the complexity inherent in a cancer diagnosis, and how older adults cope with cancer later in life. I then turn my attention to positive change following a traumatic experience by examining the phenomenon of posttraumatic growth (PTG) in cancer survivors. This discussion is followed by an exploration of related literature on transcendence. Finally, tying late-life change back to ways in which we cope with illness, I present brief overviews of the literature on well-being and coping before identifying the specific aims of the study.

Cancer

Throughout its life, a single cell in the human body undergoes a series of replications over time, dividing over and over again and creating new cells. As each cell approaches (but generally fails to reach) the Hayflick Limit (Garber, 2012), the theoretical number for how many times a cell can replicate itself during its lifetime, there is the possibility for mutation and the development of cancer. Decades of research on cancer epidemiology have confirmed a link between advanced age and an increased rate of cancer, in spite of the occasional occurrence of cancer in younger individuals. While research has covered much of the biological underpinnings (and consequences) of cancer, less is known about the psychological or social impact of the disease, particularly among older adults. In this section, I briefly review the biology of cancer, before delving into psychosocial aspects of living with cancer, and turning the reader's attention to older adults living with cancer.

Biology of Cancer

There are many different types of cancer, and incidence rates (see Figure 2.1), prevalence, and mortality all vary by cancer site. There is a wealth of research examining the biology and etiology of cancer across cancer sites (i.e., cancer locations), the majority of which is beyond the scope of this section. While there is a general consensus that cancer is, at its core, a biologically rooted process in which mutated cells proliferate rapidly in some part of the body where they should not exist, not all cancers are caused by the same type of mutation, and not all mutations are a product of the same factors. Further, certain lifestyle or genetic factors may be linked to one type of cancer, but irrelevant for another. Genetic factors have been repeatedly linked to one's likelihood of getting cancer (Shannon & Chittenden, 2012), but, at present, it is unclear which factors predict penetrance (i.e., an individual may have a gene that is linked to cancer, but we do not have a clear understanding of whether or not that person will develop cancer).

Endogenous variables share a tenuous association with cancer incidence, in spite of common beliefs that personality or disposition can affect whether or not one gets cancer (Ranchor, Sanderman, & Coyne, 2010; Wu, Powers, Zhu, & Hannun, 2016). For example, neither depression/depressive mood nor personality traits appear to be linked to cancer *incidence* (Dalton, Boesen, Ross, Schapiro, & Johansen, 2002), and personality does not seem to predict death from cancer (Nakaya et al., 2010). For some cancers, there are clear relationships between exogenous factors and cancer incidence (e.g., smoking and lung cancer) (Ligibel, 2012), but even the presence of such factors does not unequivocally predict cancer occurrence.

Figure 2.1
Estimated New Cancer Cases in 2016

Male	Female
Prostate 180,890 (21%)	Breast 246,660 (29%)
Lung & bronchus 117,920 (14%)	Lung & bronchus 106,470 (13%)
Colon & rectum 70,820 (8%)	Colon & rectum 63,670 (8%)
Urinary bladder 58,950 (7%)	Uterine corpus 60,050 (7%)
Melanoma of the skin 46,870 (6%)	Thyroid 49,350 (6%)
Non-Hodgkin lymphoma 40,170 (5%)	Non-Hodgkin lymphoma 32,410 (4%)
Kidney & renal pelvis 39,650 (5%)	Melanoma of the skin 29,510 (3%)
Oral cavity & pharynx 34,780 (4%)	Leukemia 26,050 (3%)
Leukemia 34,090 (4%)	Pancreas 25,400 (3%)
Liver & intrahepatic bile duct 28,410 (3%)	Kidney & renal pelvis 23,050 (3%)
All sites 841,390 (100%)	All sites 843,820 (100%)

Note: Keratinocyte cancers and in situ carcinoma (except urinary bladder) excluded. Figure from American Cancer Society (2016), Surveillance Research.

For individuals who have already received a cancer diagnosis, chronic stress has been linked to cancer progression through angiogenesis, tumor cell migration and invasion, suppression of the immune system, and circadian dysregulation (Lutgendorf, Sood, & Antoni, 2010). While we see such associations between behavioral/emotional tendencies and cancer progression, there is limited evidence for a curative effect of having a fighting spirit on survival (Watson, Haviland, Greer, Davidson, & Bliss, 1999).

In sum, we have a limited understanding of the factors that cause cancer, an issue that is complicated by the fact that different cancers have different mechanisms by which they occur. For the cancer survivor, this uncertainty regarding the causes and progression of cancer can itself lead to a great deal of emotional distress.

Psychosocial Aspects of Cancer

Cancer brings with it a variety of negative, socially-influenced interpretations and fears – this is what causes cancer to become a social construction. We ascribe particular meaning to cancer that is separate from physiological processes occurring at the cellular level. There can be a general deterioration of self-image upon being diagnosed with cancer that goes beyond the physical experience of pain. For example, many individuals diagnosed with a chronic illness experience restricted lives post-diagnosis, due to enforced treatment or treatment guidelines, periods of discomfort that prevent interaction with the outer world, or even having to attend doctor's appointments (Charmaz, 1983). This restriction can lead to social isolation (Charmaz, 1983) independent of a natural reduction in social network size that is often found with advanced age. For most, receipt of a cancer diagnosis (and the process of dealing with cancer) causes some degree of distress.

Distress. Distress is common in cancer patients, with the most severe, prevalent, and/or important symptoms or manifestations being anorexia, anxiety, cognitive problems, constipation, depression, diarrhea, dyspnea, fatigue, insomnia/sleep disturbance, nausea, neuropathy, and pain (Bower, 2008; Reeve et al., 2014). Distress, in general, is predicted by many factors including socio-demographic characteristics, prior health status, degree of social support (Andersen, 1993), and age (younger individuals

tend to report more distress than older adults; Carlson & Bultz, 2003). Distress (or lack thereof) can be shaped by personal beliefs about cancer, such as what causes cancer and how it can be treated. Personal experience with family members or close friends with cancer can also shape survivors' perceptions of their own cancer trajectories. While distress, is certainly more common among cancer patients than in the general population (Andrykowski, 2012; Stanton, 2006), doctors tend to be poor at identifying such problems (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001). This trend is troubling, especially as those who experience greater distress tend to have poor treatment adherence, quality of life, and prognoses/survival rates (Carlson & Bultz, 2003; Carmack, Basen-Engquist, & Gritz, 2011).

Depression and anxiety have been well-documented in cancer patients (Carlson & Bultz, 2003); indeed, depression may be predicted by cancer type (Massie, 2004). For example, Massie (2004) found that women with gynecological or breast cancer reported less depression and anxiety, and improved well-being compared to both men and women with other types of cancer, possibly due to the perceived significance of the illness. Anxiety, on the other hand, appears to have a weak link to cancer type (Stark et al., 2002), in spite of its prevalence. In general, rates of depression among cancer survivors vary, but it has been predicted that up to one in two survivors experience depression (Massie, 2004), with far fewer cancer survivors meeting the diagnostic criteria for an anxiety disorder (Stark et al., 2002).

While those experiencing more distress may be less apt to participate in research studies exploring the lived experience of cancer, in general, older adults with cancer who do participate in research studies tend to report less distress than younger adults with

cancer. Employing the 60-item COPE inventory with women coping with breast cancer,

Stanton, Danoff-Burg, and Huggins (2002) found that, post-surgery, most participants

exhibited a degree of acceptance of their condition, but older women in particular

reported less distress than younger women. In addition, women who exhibited active

acceptance prior to surgery were less distressed and had more vigor one year later

compared to those with low levels of acceptance. Further summary findings published a

few years later compared other studies with older breast cancer survivors and also found

that older women reported less distress than younger women (Mosher & Danoff-Burg,

2006).[1]

In spite of many cancer survivors reporting distress, such negative emotions tend

to diminish within the first two years post-diagnosis, and long-term (five years or more)

survivors' quality of life is often similar to that in the general population (Stanton, 2006).

While this diminishment is due, in part, to how much time has elapsed since the

diagnosis, it may also be related to chronological age.

Cancer in Old Age

As eloquently framed by Towsley and colleagues (2007, p. 98), "the cancer

survivor enters the cancer experience with prior life experiences that influence attitudes, a

sense of self, and choice of coping strategies." While it is difficult to predict how any one

person will react to such a diagnosis, older adults, by definition, have accumulated many

life experiences that inevitably shape their reactions to a cancer diagnosis. Further, with

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[1] While older women with cancer tend to report fewer unique needs while dealing with cancer, and a decreased need for emotional support from professional counselors as compared to younger women (Thewes, Butow, Girgis, & Pendlebury, 2004), some older women do still report higher feelings of distress when coping with cancer. For example, a review of relevant research has indicated that being a widow/er is associated with increased distress in elderly cancer patients (Mosher & Danoff-Burg, 2006), underscoring the influence of social support.

old age comes inevitable biological change, typically in the form of decline or degradation. With this decline and general "wear and tear" over time is an increased risk for physical problems or illnesses, making older adults more susceptible to experiencing physical and mental comorbidities (Pal & Hurria, 2010; Wolff, Starfield, & Anderson, 2002).

Older adults are far more likely than younger adults to receive a cancer diagnosis. As recently presented by the American Cancer Society (2016), the overall probability of receiving a cancer diagnosis between birth and 49 years of age is about 3.4% for males, and skyrockets to 34.6% for males 70 years of age and older. The probability of receiving a diagnosis by 49 years of age is somewhat lower for females at 5.4%, but this figure also increases dramatically to 26.1% for females 70 years of age and older. Older adults suffering from cancer are more likely to experience multiple morbidities (both at the time of diagnosis and after diagnosis), in addition to generally impaired physical and mental health (Smith et al., 2008). Coping with cancer and another debilitating condition (say, osteoarthritis) can limit one's ability to carry out instrumental activities of daily living, or severely limit mobility. These problems can, in turn, influence social relationships, and level of perceived control and independence. Multiple physical infirmities also carry with them an increased risk for drug overdose, and an enhanced fear of pain or other negative side effects. This fear seems to be founded in reality, considering older cancer patients (particularly African American older adults) experiencing pain are less likely to receive pain medication than younger cancer patients, and less likely to receive more potent types of pain medication than younger adults with cancer (Bernabei et al., 1998) (it should be

noted here that older adults tend to experience less pain than their younger counterparts; Mao et al., 2007).

One might expect that being closer to death and facing down a cancer diagnosis naturally leads to increased feelings of distress, but most studies do not support this notion. In fact, older women dealing with cancer tend to have better perceptions of their own personal resources, emotional strength, and social support (Mosher & Danoff-Burg, 2006). This finding is particularly notable considering more recent research has found that older women are more likely to keep their social network intact over a 6 month time period as compared to younger women coping with breast cancer (Ashida, Palmquist, Basen-Engquist, Singletary, & Koehly, 2009). It could be that maintenance of one's social network is vital to being able to cope with and adapt to a cancer diagnosis, particularly in old age. An alternative perspective in line with Taylor's (1983) third tenet of cognitive adaptation theory is that individuals faced with threat seek to gain mastery over the threat and/or over their life. In other words, reducing the degree of distress one feels could be a means of exerting control over an experience within which one may have little actual control. Limited research has been conducted with older cancer survivors (Jacobsen et al., 2016), and thus it is difficult to hypothesize the mechanisms through which older adults handle a late-life cancer diagnosis. What *is* apparent is that many cancer survivors, in spite of dealing with the struggle of the cancer experience, report finding some benefit post-diagnosis.

Posttraumatic Growth

Both social and biomedical scientists have found repeated evidence of positive (psychosocial) growth embedded within the overall context of suffering following a

cancer diagnosis (Bellizzi, 2004; Bellizzi & Blank, 2006; Cordova et al., 2007; Lechner & Antoni, 2004; Manne et al., 2004; Mystakidou et al., 2008). The term "posttraumatic growth" (PTG) reflects general positive psychological development following a traumatic event. For older individuals, the effects of the cancer experience on subsequent personal growth are less clear. To date, there has been limited exploration of how PTG is manifest and how accumulated life experiences can shape coping strategies (which, in turn, influence PTG) following a traumatic diagnosis among older adults. Studies incorporating older individuals (or those whose diagnosis occurred many years ago) tend to focus on age comparisons, or give a cursory nod to PTG later in life, likely because older adults appear to experience less PTG than their younger counterparts (Bellizzi, 2004; Bellizzi & Blank, 2006; Carboon, Anderson, Pollard, Szer, & Seymour, 2005; Manne et al., 2004; Mystakidou et al., 2008).

Posttraumatic Growth Overview and History of the Concept

Generally, PTG refers to the "extent to which survivors of traumatic events perceive personal benefits, including changes in perceptions of self, relationships with others, and philosophy of life, accruing from their attempts to cope with trauma and its aftermath" (Tedeschi & Calhoun, 1996, p. 458). It has been argued that subjective perceptions of growth following trauma may be more important than objective indices of a cancer diagnosis (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Cordova & Andrykowski, 2003; Koutrouli, Anagnostopoulos, & Potamianos, 2012). PTG involves affective (emotional), behavioral, and cognitive components (Calhoun & Tedeschi, 2004; Tedeschi & Calhoun, 1995, 2004; Tedeschi et al., 2007), and stems not from a traumatic event itself, but rather from the struggle with a traumatic event (Tedeschi, Park, &

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Calhoun, 1998). Changes evident via PTG include changes in the self, interpersonal relationships, spirituality, and overall worldview / philosophy of life (Lelorain, Bonnaud-Antignac, & Florin, 2010; Sumalla, Ochoa, & Blanco, 2009). Notably, the notion of "growth" is often not operationalized in the literature on PTG, but presumably conceived of as a universally understood phenomenon. For the purposes of this study, "growth" was defined as any self-reported positive change resulting from coping with a traumatic event.[2] This change is not defined as a return to baseline in the sense that cancer survivors simply accept the world in the same way they did pre-diagnosis, but rather that the change reflects a "comfortable, integrated assumptive world that incorporates the traumatic experience" (Janoff-Bulman, 2004, p. 30).

PTG is sometimes presented as synonymous with other, similar terms describing positive changes following a negative event. PTG represents a qualitative change that is not fundamentally similar to terms such as resilience, hardiness, optimism, positive reappraisal, and a sense of coherence (Sears, Stanton, & Danoff-Burg, 2003; Tedeschi & Calhoun, 2004). Benefit finding is perhaps the most often cited term used to describe PTG, but the two are distinct concepts. There is a wealth of evidence in the literature citing different predictors/determinants for the two terms (Andrykowski, Steffens, Bush, & Tucker, 2015; Jansen, Hoffmeister, Chang-Claude, Brenner, & Arndt, 2011; Sears et al., 2003), even though they are highly correlated (and share conceptual similarities).

Tedeschi and Calhoun (1995), who are considered the originators of the term "posttraumatic growth," have posited seven principles involved in PTG. First, if growth occurs, it is a byproduct of existing schemas being changed by traumatic events. In other

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[2] Trauma is also considered to be a "highly challenging life event" (Calhoun & Tedeschi, 2004, p. 99), synonymous with 'crisis' and anything perceived to be highly stressful (Tedeschi & Calhoun, 2004).

words, positive psychological change is precipitated by a change in fundamental views (e.g., an unexpected trauma might change how one views their degree of control over life events). Second, some world view assumptions are very resistant to change and are unlikely to give way to schema change. This principle relates to flexibility in the face of trauma; too much rigidity on the part of the traumatized individual limits the possibility of growth. Third, change after trauma must involve some kind of positive evaluation for growth to occur. Not surprisingly, it is difficult for posttraumatic growth to occur unless some benefit or positive change is perceived to be an outcome. If only negativity is maintained, then there is little potential for positive change. Fourth, the perceived nature of posttraumatic growth is dependent on the nature of the traumatic event. If the event challenges views of the self, relations with others, or with life in general, then there may be different changed schemas as a result (i.e., a changed worldview). If the struggle with a traumatic event exceeds personal resources, then it may be difficult to extract benefit(s) from this process. Fifth, personality influences the likelihood of experiencing growth. In other words, differences in temperament and how one approaches challenges in general will influence whether (and how) one perceives positive change post-trauma. Sixth, growth may occur if a traumatic event was considered to be very significant in one's life. As found in a study by Groleau and colleagues (2013), event centrality is uniquely predictive of PTG. The seventh and final principle is that growth leads to wisdom. While wisdom is difficult to define and measure, Tedeschi and Calhoun (1995) suggest that those experiencing PTG also tend to report an appreciation of paradoxes (e.g., "good can come from bad," p. 86).

There are several ways of describing PTG, including (but certainly not limited to) McMillen & Fisher's (1998) six-part model of perceived benefits, McFarland & Alvaro's six-part model of growth following threat (2000), and Armeli and colleagues' (2001) six-part model of stress-related growth. Tedeschi and Calhoun's (1996) five-part model, as indicated above, is perhaps the most widely endorsed. Their perspective on PTG was originally shaped by a review of the literature on growth following trauma, which revealed three primary categories of change: perceived changes in the self, changed relationships with others, and a changed philosophy of life (Tedeschi & Calhoun, 1995, 1996). With the aim of assessing PTG quantitatively, they constructed a 34-item scale derived from the literature that corresponded to benefits following trauma (Tedeschi & Calhoun, 1996). Following a principal components analysis, it was determined that there were five primary factors: *relating to others, new possibilities, personal strength, spiritual change,* and *appreciation of life*. These five factors were statistically represented by 21 items, leading to the development of the 21-item Posttraumatic Growth Inventory (PTGI; the correlation between the 34-item and 21-item scale was .98).

An alternate perspective on PTG has been offered by Janoff-Bulman (2004), who suggests that there may in fact be three overarching models of change following trauma that include and build upon Tedeschi and Calhoun's (1996) five-part model. The first model is that of *strength through suffering*, which may be addressed by the "*personal strength*" and "*new possibilities*" subscales of the PTGI. This model of change encapsulates a novel means of self-evaluation, and a change in world assumptions pertaining to one's self, as also posited by Victor Frankl in his seminal book entitled *Man's Search for Meaning* (1959). This is distinct from the second model of change,

psychological preparedness, which reflects a changed perspective when coping with future traumas, and is not inherently positive (unlike the dimensions in Tedeschi and Calhoun's model). Finally, *existential reevaluation* is addressed by the "*relating to others*," "*spiritual change*," and "*appreciation of life*" subscales of the PTGI. This final model focuses on meaning-making (i.e., one's inherent worth; Janoff-Bulman, 2004), and is also a core type of change suggested by Frankl (1959).

Janoff-Bulman's (and others', 2004) conceptualization of PTG incorporates non-positive change in the form of psychological preparedness, which is missing from the PTGI (Tedeschi & Calhoun, 1996). This preparedness may be akin to a paradigm shift that is not positive or negative, but simply reflects a change in perspective that allows one to cope with further change(s). That said, the PTGI is widely regarded as the "go-to" measure for PTG, and was therefore used in this study. To accommodate concerns about a lack of measurement of negative change (e.g., Aldwin & Levenson, 2004; Park, 2004), five questions were added that addressed negative change post-diagnosis.

Debate about PTG

Real vs. illusory. Concerns have been brought up regarding whether PTG is "real" or simply a byproduct of social desirability or wishful thinking. One perspective is that PTG manifests in the form of unintentional identity change. This identity change is thought to be a result of accommodation, or altering one's self to better fit one's personal environment, as opposed to assimilation, which refers to attempts to alter one's environment in order to maintain personal preferences during the coping process (Sumalla et al., 2009). Yet others believe that PTG describes changes in self-perceptions due to assimilation during the traumatic experience as opposed to changes in self-

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identity; unfortunately, so few studies have addressed belief change in individuals suffering from serious illness that it is difficult to evaluate either theory (Sumalla et al., 2009).

It is possible that PTG involves both constructive and illusory components, reflecting a degree of self-transcendence and openness to experience, but also self-deception and unrealistic optimism, respectively (Maercker & Zoellner, 2004; Taylor, 1983). It may even be that self-protection activated following a traumatic experience encourages subsequent growth (Nolen-Hoeksema & Davis, 2004). Tedeschi & Calhoun (1996) argue that the debate over whether PTG is real or illusory cannot adequately be addressed by looking at PTGI scores, since individuals might experience qualitative changes, quantitative changes, or some combination of the two (and the PTGI is a quantitative measure designed to address qualitative change).

Research has indicated that PTG is not related to social desirability (Tedeschi & Calhoun, 1996), and self-reports have been corroborated by others who know those reporting PTG (Calhoun & Tedeschi, 2004). In fact, it appears that current estimates of PTG may actually be *under*estimated (Smith & Cook, 2004). Recent research has also indicated there may in fact be neural correlates of PTG, such that there is increased neural decorrelation in the medial prefrontal cortex in veterans who have not experienced PTSD (Anders et al., 2015). This decorrelation suggests a decrease in "threat appraisal, expression of fear and/or need to actively work to inhibit conditioned fear responses" (Anders et al., 2015, p. 2018). While there may be neurological patterns of activity in individuals who report PTG, it should not be assumed that PTG only occurs in the absence of distress. There is a wealth of literature reporting positive associations between

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growth/benefits and distress in undergraduates (Tedeschi & Calhoun, 1996), caregivers of individuals with HIV (Cadell, Regehr, & Hemsworth, 2003), community-dwelling older adults (Palgi, 2015) and cancer survivors who perceive their diagnosis to be traumatic and/or a threat (Cordova et al., 2007; Jansen et al., 2011; Morris & Shakespeare-Finch, 2011; Sears et al., 2003).

Outcome vs. process. There is ongoing discussion on whether PTG is a process, an outcome, or both (Cordova & Andrykowski, 2003). Some researchers contend that PTG should be treated as an outcome of coping with trauma, and therefore, by definition, distinct from coping itself (Janoff-Bulman, 2004; Tedeschi & Calhoun, 1996, 1998, 2004). Others believe that PTG is fundamentally a means of coping, particularly considering emotion regulation and cognitive processing are necessary for changing schemas (Aldwin & Levenson, 2004). Still others believe that PTG is both an outcome and a process (Maercker & Zoellner, 2004). There is no definitive answer to this debate as of yet, although several studies have assessed the relationship between PTG and coping strategies, as described later in this chapter.

Methods of Assessment

Measurement issues. Various methodological concerns about research on PTG have arisen in recent years, including the accuracy of retrospective report, and the question of whether participants are really even capable of assessing their own PTG or teasing apart growth related to illness from growth stemming from other influential variables (Coyne & Tennen, 2010). Many studies measuring levels of posttraumatic growth do not include control groups (Sumalla et al., 2009), although it is unclear how control groups would be defined in the context of cancer, as is the relevance of the claim

that people are not capable of "accurately portray[ing]" posttraumatic growth within themselves (as argued by Coyne & Tennen, 2010, p. 23). If the primary 'variable' of interest is personal perception and interpretation of change following an adverse event, it is unclear whether an 'accurate' representation of personal change is as important as one's own subjective interpretation of the nature and importance of change.

Extant literature also suggests that there is more support for posttraumatic growth in findings stemming from qualitative interviews rather than quantitative assessment (Sumalla et al., 2009), indicating that existing quantitative measures of PTG are not able to fully assess the complexity of PTG. It is plausible that incorporating an open-ended, qualitative component within (or in addition to) a quantitative measure could add much-needed depth to quantitative data analysis by providing the potential for elaboration, clarity, and context to survey responses. It is this qualitative component that would allow for a more robust explanation of quantitative findings not otherwise measurable with a solely quantitative measure. Finally, existing measures of PTG may not adequately measure interactive effects of life events and experiences on personal development, such as growth consequent to, and dependent on, the struggle with illness (a period effect), as compared to 'normative' changes experienced as a function of growing older (an age effect).

PTGI. Despite concerns expressed above concerning quantitative assessment of PTG, there is still a consensus that the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), a qualitatively-informed instrument designed to assess perceived benefit following a traumatic experience, is the primary "go-to" instrument for measuring PTG. As mentioned previously, Tedeschi and Calhoun (1996) chose survey items that

tapped into changes within the self, interpersonal relations, and life philosophy. The general consensus is that there are five primary subscales within the PTGI: relating to others, recognizing new possibilities, spiritual change, a greater sense of personal strength and a greater appreciation of life. While the PTGI has been criticized for not assessing growth following non-traumatic events (Aldwin & Levenson, 2004), only measuring a subset of types of PTG (Janoff-Bulman, 2004), or failing to account for other variables that could influence PTG, like social support (McMillen, 2004), it is still widely used among PTG researchers.

PTG and Associated Variables

Generally, women report significantly more benefits, or positive change, than males (Bellizzi, 2004, Tedeschi & Calhoun, 1996; Thege, Kovács, & Balog, 2014; Vishnevsky, Cann, Calhoun, Tedeschi, & Demakis, 2010), although it has also been found that sex does not predict moderate to high PTG in middle-aged and older colorectal cancer survivors (Jansen et al., 2011). Race/ethnicity is not related to PTG among cancer survivors (Bellizzi & Blank, 2006; Morris & Shakespeare-Finch, 2011; Sears et al., 2003), even though some literature suggests there are racial differences in coping strategies and how much distress is felt by women with early stage breast cancer (Culver, Arena, Antoni, & Carver, 2002).

Most studies indicate no significant relationship between education and PTG (Jansen et al., 2011; Morris & Shakespeare-Finch, 2011; Mystakidou et al., 2008; Thege et al., 2014), although a recent longitudinal study of breast cancer survivors suggests education predicts PTG over time (but not beyond the level of college graduate; Danhauer et al., 2013). The association with income is also somewhat unclear, as one

study has shown a significant association with PTG (Cordova et al., 2001), while another has shown no relationship between the two (Sears et al., 2003). The findings for personality are a bit more straightforward, as PTG has been positively correlated with optimism (Tedeschi & Calhoun, 1996), religiosity/spirituality (Danhauer et al., 2013), openness to experience (Tedeschi & Calhoun, 1996), conscientiousness (Galea, 2014; Tedeschi & Calhoun, 1996), extraversion (Tedeschi & Calhoun, 1996), and agreeableness (Galea, 2014; Tedeschi & Calhoun, 1996).

Health. Physical health does not appear to be linked to PTG, considering neither physical impairment (Manne et al., 2004) nor number of comorbidities (Jansen et al., 2011) is associated with PTG. The relationship between PTG and mental health is a bit more nuanced; breast cancer survivors have been found to report similar levels of depression to healthy controls in one study (Cordova et al., 2001), while another study with a similar sample found mental health to not only improve over time, but to also predict PTG (both at baseline and over time; Danhauer et al., 2013). In a third study of breast cancer survivors, mental health was positively associated with the *relating to others* and *personal strength* subscales of the PTGI, but not the other subscales (Lelorain et al., 2010). Using the SF-36 measure, social functioning and role limitations (emotional) were not related to any PTG variables, while happiness, vitality, and mental health were related to at least two of the PTGI subscales (Lelorain et al., 2010). Finally, a recent study examining PTG in cancer survivors (including breast, colon, leukemia/lymphoma and a variety of gastrointestinal sites) found no relationship between mental health and PTG (Arpawong, Richeimer, Weinstein, Elghamrawy, & Milam, 2013).

Well-being. As with health, the relationship between PTG and well-being is unclear at best. In a sample of undergraduates, it was found that PTG correlated positively with life satisfaction (presented as well-being, but more accurately defined as life satisfaction) (Galea, 2014), while breast cancer survivors reported no changes in well-being compared to healthy controls (Cordova et al., 2001). As discussed previously, PTG and distress can (and often do) co-occur, and it is unclear how age might impact the relationship between PTG and well-being, given that many older adults report higher levels of well-being than their younger counterparts.

Social variables. Some researchers have commented that Tedeschi & Calhoun's conceptualization of PTG fails to include the influence of social support (McMillen, 2004). The findings on social support and PTG, as with so many other variables, are ambiguous, with some studies reporting no association between the two in breast (Cordova et al., 2001) and colorectal cancer survivors (Jansen et al., 2011), and a recent longitudinal study reporting a positive association both at baseline and over time in breast cancer survivors (Danhauer et al., 2013). Relationship status appears to have no significant association with PTG among a variety of cancer survivors (Jansen et al., 2011; Morris & Shakespeare-Finch, 2011; Sears et al., 2003).

Clinically-oriented variables. PTG is not associated with disease stage (Cordova et al., 2001; Cordova et al., 2007), underscoring, again, the importance of one's subjective interpretation of cancer over and above objective measures of cancer severity. PTG is also not related to whether one is receiving treatment for cancer (Morris & Shakespeare-Finch, 2011), or, if treatment has occurred or the nature/type of treatment

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(Bellizzi & Blank, 2006; Cordova et al., 2001; Cordova et al., 2007; Mystakidou et al., 2008; Sears et al., 2003).

Time since diagnosis seems to have an inconsistent association with PTG. Several studies have shown PTG to increase over time post-diagnosis, especially within the first few years after diagnosis (and even the first few months) (Cordova et al., 2001; Danhauer et al., 2013; Danhauer et al., 2015; Manne et al., 2004; Sears et al., 2003). Conversely, several studies have found that time since diagnosis is not related to PTG among cancer survivors (Bellizzi, 2004; Bellizzi & Blank, 2006; Cordova et al., 2007; Lelorain et al., 2010; Morris & Shakespeare-Finch, 2011; Mystakidou et al., 2008). An examination of articles investigating PTG and time since diagnosis suggests that those finding a significant relationship generally included samples that were within one month to a few years post-diagnosis, whereas those finding no significant relationship included participants who were generally more than five years post-diagnosis.

Age. Younger age is linked to increased PTG in cancer survivors (Bellizzi, 2004; Bellizzi & Blank, 2006; Carboon et al., 2005; Cordova et al., 2007; Danhauer et al., 2013; Manne et al., 2004, Morris & Shakespeare-Finch, 2011; Mystakidou et al., 2008), although a couple of studies have not found any such association when sampling young, middle-aged, and older cancer survivors (Sears et al., 2003) or individuals with a history of cardiovascular disease (Sheikh & Marotta, 2005). Specifically, using the PTGI, a negative association has been found between age and the *new possibilities* (Carboon et al., 2005; Danhauer et al., 2013; Mystakidou et al., 2008), *personal strength* (Carboon et al., 2005; Mystakidou et al., 2008), and *appreciation of life* subscales (Danhauer et al.,

2013; Mystakidou et al., 2008). Age effects have not been found when examining the differences in PTG by cancer site (Morris & Shakespeare-Finch, 2011).

Age appears to be inversely associated with perceiving cancer as a traumatic stressor (Cordova et al., 2007), and thus it might be that younger adults are more likely to experience (more) PTG because a cancer diagnosis (and its aftermath) are more schema-altering in youth than in old age. Existing research indicates that the oldest-old, in particular, are more apt to view illness in later life as a part of their natural life course (Ardelt, Ai, & Eichenberger, 2008; Hoogland, 2015). This is not to say that older adults do not experience PTG, but rather that the degree of change post-diagnosis is dampened in older individuals. Unfortunately, there has not been any published research to date that identifies how PTG can manifest in older adults, especially considering the multitude of theories positing a developmental trend toward psychosocial growth later in life (even in the absence of illness) (see Carstensen et al., 1999, Erikson, 1998, or Tornstam, 2005, for examples).

Transcendence

For some physically healthy older individuals, there appears to be a process of continued development in old age described as transcendence, and it is possible that a traumatic life event such as a cancer diagnosis may invite or support transcendent change. Transcendence refers to a developmental phenomenon of personal and spiritual growth in late life, posited to be facilitated by the passage of time, accumulated life crises (Tornstam, 2005), and a general shift in thinking that embraces interconnectedness (Reed, 1991b). The shift in perspective that accompanies transcendence can allow for self-derived meaning through participation in religious activities, increased generativity, and a

connection with nature (Reker & Woo, 2011). Perhaps unsurprisingly, older adults who

derive meaning from transcendent sources tend to be less depressed, more extraverted,

agreeable, and conscientious than those who derive meaning through hedonistic and

materialistic sources (Reker & Woo, 2011). Yet, there are different conceptions of

transcendence in the literature, with two primary theories encompassing this construct:

gerotranscendence and self-transcendence (in old age).

Gerotranscendence

Gerotranscendence refers to older adults shifting their priorities and focus from a

materialistic/rational paradigm to a cosmic/transcendent view, often accompanied by an

increase in life satisfaction (Tornstam, 2005). As might be expected, this shift in

prioritization and focus overlaps heavily with perception and thought processes, as the

construct of gerotranscendence is defined by a shift in how older adults think and

perceive. According to Tornstam (2005), there are three primary dimensions of

gerotranscendence: *cosmic*, *self*, and *social relations*. *Cosmic* transcendence refers to a

decreased emphasis on the passage of time, potentially evidenced by a heightened

attunement to childhood, past experiences, or earlier generations (Tornstam, 2005). The

cosmic dimension also includes a strengthened connection with one's ancestors or

heritage, and a decreased fear of death (Tornstam, 2005). Tornstam (2005) suggests

embracing the mystery in life, and rejoicing are key components of the *cosmic*

dimension. The *self* dimension encompasses the growth and development of one's self,

and a greater awareness of how the self has evolved and is evolving. This concept goes

hand in hand with a decreased emphasis on serving the self, greater importance attached

to helping others, and increased acceptance of the self. Two elements of growth of the

self are self-confrontation, and body-transcendence such that care of one's physical form continues, but is not a top priority (Tornstam, 2005). Finally, the (need for) *social relations* dimension encapsulates fewer social relationships, and an increased desire for and acceptance of solitude (Tornstam, 2005). Characteristic of this dimension is a kind of asceticism such that individuals attach less importance to material goods, and greater acceptance of the limited applicability of dualism (i.e., it is often difficult to expressly deem something "right" or "wrong," as there is often a gray area wherein one could make an argument either way).

One means of coping with a severe illness is to appreciate the fleeting nature of life and adopt a personal understanding of one's place in the greater cosmos. Through feeling an increased connection with the universe and potentially feeling a part of everything alive, there may be a degree of serenity felt in the face of illness – akin to a sense of belonging to an in-group even when one may perceive a loss of control over life circumstances. These changes are indicative of cosmic transcendence and coherence. Being able to find meaning in the face of suffering and potentially accepting one's diagnosis can result in experiences of coherent gerotranscendence (i.e., the coherence dimension of gerotranscendence).

Some individuals are able to derive meaning or contentment from assisting others, and may find greater importance in helping others as opposed to focusing on the self. This type of development is most indicative of experiencing coherence in life, as one shifts attention away from the ego and directs resources toward other individuals (e.g., focuses on the welfare of others instead of self-promotion; Tornstam, 2005). From an evolutionary perspective, it is adaptive for older adults to be more inclined to help others,

because directly offering assistance to their own progeny helps them to succeed and survive. Finally, the experience of cancer, and even medically-dictated social restrictions can lead to embracing solitude. This desire for solitude could be based in the need to avoid projected distress from members of one's support network, or potentially an adaptive shift toward focusing on non-intrapersonal and non-interpersonal matters.

Self-Transcendence

Levenson, Jennings, Aldwin, and Shiraishi (2005) have suggested that gerotranscendence can be conceived as the marriage of two concepts: self-transcendence and cosmic transcendence. As mentioned above, cosmic transcendence pertains to a decreased focus on the passage of time, a greater connection with one's own past and, potentially, other individuals who lived in the past (i.e., ancestors; Tornstam, 2005). On the other hand, self-transcendence (ST) "refers broadly to a characteristic of developmental maturity whereby there is an expansion of self-boundaries and an orientation toward broadened life perspectives and purposes" (Reed, 1991b, p. 64). This theory, which builds on the notion of postformal thought, was derived from Martha Rogers' nursing theory that contends "human beings have the potential for an awareness that extends beyond physical or temporal dimensions, and it is an awareness based upon the unitary nature of human functioning" (Coward & Reed, 1996, p. 280). As such, it is thought that this awareness leads to an expansion of conceptual boundaries that extends inwardly, outwardly, temporally, and upwardly (i.e., spiritually; Reed, 1991a, 1991b).

Self-transcendence contains two key assumptions: we are active agents within and beyond our environments, and ST is an innate developmental process (Reed, 2008), much like gerotranscendence. However, ST does not contain a cosmic component like

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gerotranscendence, as explained by Reed: "The term self-transcendence conjures up ideas of mystical or unobservable events. However, the concept as it is currently described and measured emphasizes the terrestrial rather than mystical…in accordance with lifespan developmental and nursing science theories" (Reed, 2009, p. 397). Further, this expansion, or transcendence, of boundaries is correlated with numerous personality characteristics, including decreased neuroticism, and increased openness, conscientiousness, extraversion, and agreeableness (Levenson et al., 2005). Similarly, ST has been correlated with decreased depression, increased morale, resilience and purpose, and enhanced emotional well-being (Reed, 2009). Specifically, the elements of ST that seem most relevant to well-being in old age appear to be generativity, introjectivity, temporal integration, and body transcendence (Reed, 1991a).

The key premise underlying ST is that we all have boundaries that define how we interact with others and the world around us, and, with age, there is a shift toward expanding these boundaries in several different domains, including: *inner boundaries* (having hobbies/interests, adjusting to present life situation, interest in learning, meaning in spiritual beliefs, and enjoying the pace of life), *outward* or *social boundaries* (being involved with other people in the community, sharing wisdom/experiences, helping others, and accepting help from others), *temporal boundaries* (accepting the self as time goes on, finding meaning in past experiences, and being able to move beyond things that once seemed important), and '*upward' boundaries* (accepting death as a part of life) (Reed, 1991a, 1991b). Redefining such boundaries is correlated with numerous personality characteristics, including decreased neuroticism, and increased openness, conscientiousness, extraversion, and agreeableness (Levenson et al., 2005).

Transcendence and Illness

Research has indicated increases in self-transcendence for individuals with intractable diseases, including neural/muscular, digestive, immune/blood, visual, and bone/joint diseases (Iwamoto, Yamawaki, & Sato, 2011). It should be noted that, in Iwamoto and colleagues' study (2011), participants in the experimental group were significantly older than those in the control group (*Mean* difference = 8 years). If it is the case that self-transcendence tends to increase with age (which the authors themselves discovered in this study), then it is difficult to determine whether the group difference in levels of self-transcendence was due to the presence of disease or more advanced age.

Numerous studies have indicated that transcendence increases with age (Coward, 1996; Iwamoto et al., 2011; Sadler, Braam, van Groenou, Deeg, & van der Geest, 2006; Tornstam, 2003, 2005), and that there is a link between increased levels of transcendence and increased wellbeing in individuals coping with cancer (Chin-A-Loy & Fernsler, 1998; Coward, 1991, 2003; Matthews & Cook, 2009; Meraviglia, 2004; Thomas, Burton, Griffin, & Fitzpatrick, 2010). Further, there appear to be neural correlates of self-transcendence as evidenced in recent research with cancer patients. Specifically, removing cancer-causing gliomas (either high- or low-grade) in the posterior parietal lobe leads to increases in self-transcendence that are not found when lesioning gliomas in the anterior parietal lobe (Urgesi, Aglioti, Skrap, & Fabbro, 2010). It also appears that removing meningiomas (i.e., in the meninges and not the neural tissue) does not lead to any significant changes in self-transcendence for anterior or posterior lesions (Urgesi et al., 2010). This finding is revealing as it implies that removing white matter specifically leads to an increase in ST. White matter is involved with information transmission, and

white matter hyperintensity is associated with cognitive deficits in old age. It is possible that removing sections of white matter in the posterior parietal lobe helps diminish cognitive deficits that can be found in old age, and/or buffers against cognitive interference that allows for increased transcendence of the self. A similar explanation, as posited by Urgesi et al. (2010), is that because certain temperoparietal damage can impact one's perception of his/her body in space, it is possible that transcendence is facilitated by those who are able (or forced) to "transcend the spatiotemporal constraints of the physical body" (p. 316).

Older cancer patients who are able to reflect on the past and find meaning in past experiences, or even decreased impact of negative experiences can be said to be exhibiting self-transcendence in the form of temporal transcendence. In other words, similar to elements of cosmic transcendence, the older individual has been able to transcend time and derive meaning from events and experiences regardless of when they occurred. Temporal transcendence also refers to letting go of the past as necessary. Finally, an important element of self-transcendence that applies to individuals with chronic illnesses is a decreased fear of death that accompanies greater perceived understanding or acceptance of one's mortality. Many older adults indicate this development as they grow older, but it is feasible that illness accelerates this transition to the acceptance of mortality.

While PTG is not a universal post-trauma experience, transcendence is arguably a selectively experienced phenomenon later in life as well. Predictors of transcendence range from prior life crises to being female or a parent (Tornstam, 2005), but individuals who report feeling transcendent also tend to report greater life satisfaction compared to

their less (or non-) transcendent peers. Similar to life satisfaction, well-being has also been positively linked to transcendence (Coward, 1990, 1991, 1995, 1996; Iwamoto et al., 2011; Matthews & Cook, 2009; Runquist & Reed, 2007; Tornstam, 2005), and spirituality (Fry, 2000; Meraviglia, 2004; Runquist & Reed, 2007). More specifically, transcendence/spirituality and wellbeing have been linked in cancer patients (Coward, 1990, 1991; Matthews & Cook, 2008; Meraviglia, 2004).

Well-Being

Consistent and universal operationalization of life satisfaction, well-being, and quality of life remains elusive even as research has shed light on factors that influence or are predictive of each of these constructs. The number of review articles addressing each construct, and sometimes combinations of all three, is staggering given the lack of consensus on how we should define and measure life satisfaction, well-being, and quality of life. Further, current measures do not always incorporate the influence of exogenous (and sometimes endogenous) variables on one's quality of life trajectory, directly related to notions of cumulative disadvantage or learned dependence. Existing measures often accommodate transient perceptions of one's emotional place in life without allowing for much input of long-term influences.

Conceptualizations of Well-Being

Well-being is considered to reflect "optimal psychological functioning and experience" (Ryan & Deci, 2001, p. 142). In addition to life satisfaction, well-being is thought to comprise trait affect (both negative and positive), and is perhaps best construed as an *area* of interest as opposed to a particular construct (Diener, Suh, Lucas, & Smith, 1999). This may be because well-being is inconsistently defined by well-being

researchers (Busseri & Sadava, 2011). Several interchangeable terms are used to express well-being, but these same terms are sometimes used to express *different* types of well-being. Overall, the current literature is not consistent in its operationalization of well-being, and there is an overwhelming sense that well-being is something that is understood, but not often explained.

While Diener's three-component structure of well-being is most widely accepted, there is disagreement about the nature of each component. One approach to viewing life satisfaction, positive affect, and negative affect, is to presume each component is unique and the shared variance among the three is not of interest when exploring well-being (Busseri & Sadava, 2011). In line with Diener's (1999) suggestion, this approach implies that well-being is an area of interest and not a particular psychological construct. However, some argue that the three components serve as indicator variables, or manifestations of well-being, or that all three combine to produce subjective well-being (Busseri & Sadava, 2011). There are those who feel that trait affect predicts one's life satisfaction, and that subjective well-being is akin to life satisfaction itself (Busseri & Sadava, 2011). And if the notion of well-being were not confusing enough, there are those who consider well-being to be a product of varying configurations of three components, emphasizing individual variation in well-being (Busseri & Sadava, 2011).

Another view of well-being is from Martin Seligman's theory of authentic happiness (Seligman, 2012). While not expressly stated, he includes his own notion of life satisfaction in his conception of well-being through the elements of personal meaning and a sense of accomplishment. However, diverging from prior conceptualizations of well-being, Seligman considers well-being to consist of positive emotion, engagement

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(with life), meaning, a sense of accomplishment, *and* positive relationships. While trait affect can be seen in these components, his idea of well-being expands dramatically on Diener's tripartite model.

In addition to the definitions and explanations of well-being provided by Seligman and Diener and colleagues, there is a third primary means of describing well-being that capitalizes on the duality between hedonia and eudaimonia. According to a seminal paper by Ryan and Deci (2001), hedonic well-being refers to a sense of (trait) happiness derived from pleasure, while eudaimonic well-being taps into meaning and self-actualization. These two different types of well-being are often labeled subjective well-being and psychological well-being, respectively (Keyes, Shmotkin, & Ryff, 2002). While there is some debate over the validity of psychological well-being for assessing subjective well-being (Diener et al., as stated in Ryan & Deci, 2001), recent research has evinced different neurobiological correlates for each proposed type of well-being. For example, Fredrickson and colleagues (2013) found that, while both were highly correlated with each other and inversely correlated with depression, they were associated with very different gene expressions in immune cells that were independent of age, sex, race and ethnicity, BMI, smoking status, alcohol consumption, and even minor illnesses. Specifically, hedonic well-being was associated with an increase in pro-inflammatory gene expression and a decrease in antibody gene expression (Fredrickson et al., 2013). Conversely, eudaimonic well-being was associated with *increased* expression of antibody synthesis genes, and in type I IFN response genes (Fredrickson et al., 2013), which are helpful with combatting inflammation. The authors' conclusion from this ground-breaking paper was that our immune system may actually be more in tune with the

sources of our happiness than our conscious experiences (p. 13686), and that, rather than establishing a hierarchy of well-being types, it is important to make sure one feels a sense of eudaimonic well-being (Fredrickson et al., 2013).

The odds of experiencing both high subjective and psychological well-being increase with advanced age (and education) (Keyes et al., 2002), one or both of which may be evident even after a cancer diagnosis. Perhaps surprisingly, it is unclear whether cancer survivors reporting increased well-being also report more PTG (Lelorain et al., 2010), possibly because dealing with a given trauma is likely to evoke both positive and negative affect, the latter of which could cancel out (positive) well-being (Cordova et al., 2001). It is of practical significance, therefore, to explore the effects of particular coping strategies on well-being among older adults with a recent cancer diagnosis, in part because coping might influence personal well-being in those experiencing PTG. It could even be that particular typologies of PTG are associated with particular coping strategies, or a higher likelihood of experiencing heightened well-being.

Coping with Cancer

The execution of a strategy[3] for use when dealing with a given stressor varies tremendously by person and is a product of internal, social, temporal, environmental, and physical factors. Further, the coping process is dynamic (Towsley et al., 2007); an individual can display a particular coping approach followed by a completely different one, even when the combination of the two appears to be discordant. Coping strategies can be adaptive and/or maladaptive, much like development; however, coping strategies can generally be divided into one of three categories: problem-focused, emotion-focused,

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[3] Here, "strategy" refers to specific behaviors used to deal with a specific situation, whereas a "coping style" refers to a general tendency to cope in a particular manner (Towsley et al., 2007).

and meaning-focused (Carver, Scheier, & Weintraub, 1989). Problem-focused coping refers to attempts to alter one's situation, whereas emotion-focused coping refers to attempts to reduce distress surrounding a detrimental situation (Carver et al., 1989). Finally, meaning-focused coping refers to attempts to distill meaning from a given stressor (Carver et al., 1989). While findings are not consistent, a longitudinal study assessing survival in cancer patients found that emotion-based coping was associated with increased survival (Reynolds et al., 2000).

According to Dunkel-Schetter, Feinstein, Taylor, and Falke's (1992) work with young, middle-aged, and older cancer patients, there are five patterns of emotion-based coping, as derived through factor analysis. The first, seeking or using social support, involves direct interaction with others to obtain information and express feelings (Dunkel-Schetter et al., 1992). The second pattern of coping is cognitive escape-avoidance, evidenced through hoping a miracle might happen, and praying, and typically expressed as a general reduction in internal control. Third is distancing, which involves cognitive avoidance such as not thinking of the illness itself, and not focusing on one's feelings associated with the illness. The fourth factor is focusing on the positive, as indicated by positive change following the stressful event, and the last factor (with the lowest overall factor loadings) is termed behavioral escape-avoidance, the behavioral version of cognitive escape-avoidance. An example of this last style is eating or drinking as a means of avoiding the struggle itself.

Coping in Later Life

As an individual grows older, there appears to be a normative shift in how adults approach the coping process from assimilation to accommodation (Brandtstädter &

Renner, 1990; Rothermund & Brandtstädter, 2003). Building on the life-span theory of control, older adults shift from exerting (primary) control over their external environments to exercising (secondary) control over their inner environment (i.e., their inner self, mental attitudes, etc.; Heckhausen & Schulz, 1995; Heckhausen, Wrosch, & Schulz, 2010; Rothermund & Brandtstädter, 2003), perhaps partly out of an understanding that efforts are better spent on altering personal perceptions than attempting to change one's environment.

It is generally accepted that coping is preceded by a (primary) appraisal of threat, and a subsequent (secondary) appraisal of what response should be initiated in response to the threat (Carver et al., 1989). Primary appraisal precedes secondary appraisal, but the process is non-linear in the sense that primary appraisal can also follow secondary appraisal if reappraisal is necessary (Carver et al., 1989). Generally, older adults perceive threats to be less changeable than younger adults, and adopt more of an avoidant approach during secondary appraisal of a threat (Folkman, Lazarus, Pimley, & Novacek, 1987). This tendency is evident in the existing literature such that older adults tend to employ fewer coping strategies (Deimling et al., 2006), expend less coping effort (Aldwin, Sutton, Chiara, & Spiro, 1996), engage in less support-seeing (Dunkel-Schetter et al., 1992), and use more distancing and positive reappraisal than younger adults (Folkman et al., 1987). Further, older adults tend to use more emotion-focused strategies aimed at reducing distress rather than changing external, environmental factors (Folkman et al., 1987).

Coping with an illness. The basic structure of personality tends to stay the same throughout the lifespan, and individual components can influence the ways in which one

deals with an illness. Building on the influence of temperament, there appears to be an association between extraversion and approach tendencies, and neuroticism and avoidance (Carver & Connor-Smith, 2010). A mechanism that can override both approach and avoidance, known as effortful control, is linked to both agreeableness and conscientiousness (Carver & Connor-Smith, 2010), both of which tend to increase with age (Allemand, Zimprich, & Hendriks, 2008). This association with effortful control, and, by extension, advanced age, has important implications for coping as effortful control is linked to an increased likelihood of perceiving coping with illness as a challenge (Carver & Connor-Smith, 2010). It could be that via increases in certain personality traits with age, like agreeableness and conscientiousness, older adults are better able to positively appraise a threat such as illness and cope with it in a less intrinsically harmful manner (i.e., through adaptive coping strategies). Notably, this is likely to vary by person and will be dependent on other sociodemographic variables, but at the aggregate, this could be a means through which older adults are better able to cope with illness as compared to younger adults.

Comorbidities. Coping with an illness in the absence of separate physical, social, or emotional problems is already intrinsically difficult for most individuals, but many have to contend with multiple physical complaints that put added strain on the coping process. Older individuals in particular are more likely than younger age groups to deal with disability and comorbid conditions that can tax and deplete their emotional resources and ability to cope with additional problems such as a chronic illness. With this decline and general 'wear and tear' over time is an increased risk for physical problems or illnesses, making older adults more susceptible to experiencing physical and mental

comorbidities (Pal & Hurria, 2010; Wolff et al., 2002). An additional consideration is the impact of particular morbidities on an individual's functionality (Beck, Towsley, Caserta, Lindau, & Dudley, 2009). Coping with cancer and another debilitating condition (say, osteoarthritis) can limit one's ability to carry out instrumental activities of daily living, or severely limit mobility. These problems can in turn influence social relationships, and level of perceived control and independence. Further, cancer survivors with comorbidities have been shown to receive less curative treatments than those without comorbidities (Sarfati, Koczwara, & Jackson, 2016).

Silverman, Nutini, Musa, Schoenberg, and Albert (2009) have found that individuals with heightened disease severity and/or disability tend to experience more negative reactions to osteoarthritis or ischemic heart disease, reflecting greater difficulty coping with the chronic illness in question. That said, Dunkel-Schetter and colleagues (1992) have indicated that medical factors are less related to coping ability when other sociodemographic variables are controlled, emphasizing the interactive effect of self and situation variables on the coping process. Beyond comorbidities and the effects of a particular illness with which one is trying to cope, there is a great degree of individual variability in terms of how the physical body tends to change with time.

Coping with an illness is likely to involve coping with the *symptoms* of that illness; these symptoms may be more obvious depending on the severity and manifestation of the illness, and one's degree of coping is dynamically related to the severity of symptoms and prognosis. When the severity of cancer dramatically degrades personal levels of functional independence (i.e., when one has greater difficulty carrying out activities of daily living), older patients tend to experience more depressive

symptoms (Deimling et al., 2006). Actual stage of disease also influences the role of

coping (Deimling et al., 2006), but this might be moderated by the time since diagnosis,

given that prior research has found disease stage to be unrelated to coping strategy in

individuals recently diagnosed with cancer (Edgar, Rosberger, & Nowlis, 1992). Current

stressors are not the only influences on coping with illness; one study has reported that

psychological stress in childhood has far-reaching effects even in later adulthood (Miller,

Chen, & Parker, 2011). Specifically, increased psychological stress experienced as a

child is expressly linked to increased morbidity and mortality in old age (Miller at al.,

2011), shedding new light on the experience of childhood and its long-term effects on

health, and potential choice of coping strategies.

    Role of faith. One's faith, or connection to their spiritual side, tends to increase

with age (Johnson, 2009), particularly for individuals coping with cancer (Musick,

Koenig, Hays, & Cohen, 1998). Religion/spirituality[4] provides a foundation on which

individuals can derive meaning in life, a sense of security, and an overall sense of

belonging. Most older adults tend to prefer the term 'religious' over 'spiritual' when

describing their beliefs (Feher & Maly, 1999), but the overall sentiment among older

cancer patients is that faith plays an important role in the coping process. For example, in

response to specific questions asking about the importance of religion and religious

attendance, 88% of older cancer patients indicate that religion is either very or somewhat

important to them (Balboni et al., 2007); this finding was especially apparent for African

Americans and Hispanics. In Balboni et al.'s study (2007), three-quarters of participants

indicated that their spiritual needs were either not met, or only minimally met by the

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[4] Here, I define "religion" as an institutionalized, dogmatic set of beliefs and practices involving the presence (or absence) of a higher power. "Spirituality" is more subjective/individualized, and can be maintained in the absence of religious belief and practice.

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medical system. While these findings point to the perceived importance (and unmet needs) of religious belief in the life of an older adult with cancer, they do not directly illustrate religion's relation to coping with cancer in old age.

Data from individuals with advanced cancer have indicated that almost 80% of patients endorse relying on religion to cope with their cancer symptoms in the latter stages of life (as assessed in response to a directed question about the reliance on religious coping; Phelps et al., 2009). Further, spiritual well-being in terminally ill older adults with cancer has been found to be inversely related to depression, perhaps because spiritual well-being serves as a buffer against the negative effects of depression (McClain, Rosenfeld, & Breitbart, 2003).

Employing qualitative interviews with older adults has also revealed the influential role of faith among older adults coping with cancer. Specifically, Feher and Maly (1999) conducted two-hour open-ended interviews with older breast cancer patients and discovered that, for 30 of the 33 interviewed women, faith provided emotional support during their time of illness. A subset of participants indicated further benefit from the provision of social support (through organized religion) and personal meaning. While it should be noted that participants in Feher and Maly's (1999) study were primarily Caucasian, married, and highly educated, 13 women indicated that their faith had strengthened during their experience with cancer, whereas 13 women felt it had stayed the same (the remaining 7 were not able to provide a definitive answer). While there is the potential that a social desirability bias or various sociodemographic factors impacted responses, it is certainly telling that respondents strongly felt that faith had played an influential role in the cancer coping process. It could be that a strengthened or stabilized

sense of faith serves as a means of providing meaning for the individual with cancer; through the lens of cognitive adaptation theory (Taylor, 1983), faith may serve to facilitate partial fulfilment of the search for meaning that accompanies adjustment to a threatening event.

While religiosity and/or spirituality can play a prominent role in coping with cancer in old age, this is certainly not the case for every older person dealing with cancer. Overall findings for the impact of religiosity are mixed. A review conducted on articles addressing religious and spiritual coping among individuals coping with cancer found that only seven out of 17 analyzed papers indicated beneficial effects of religious coping (Thune-Boyle, Stygall, Keshtgar, & Newman, 2006). Further, while the overall methodology varied among research articles, eight articles utilized Carver's well known COPE measure, but only one of these found psychologically beneficial effects of religious coping (Thune-Boyle et al., 2006). It is unclear whether there were any age comparisons conducted by Thune-Boyle and colleagues, or the researchers who conducted the studies under review, or whether there may have been religious or cultural differences impacting the findings. The authors of this review did, however, highlight some variation in cultural findings such that equal numbers of American studies found advantageous and disadvantageous results, while none of the European findings noted advantages of religious coping (Thune-Boyle et al., 2006). It could be that distinguishing between particular religious persuasions would reveal more meaningful differences in cancer survivorship experiences. Regardless, the state of current research is such that religious coping is not systematically measured in the same way across studies, and it is

not clear which variables 'induce' more beneficial effects of religious coping in individuals with cancer.

Shifting attitude. Sometimes there is an overall shift in attitude that can affect the coping process. While this is not necessarily unique to old age, advanced age can carry with it a shift in paradigm as a result of accumulated experience and reflection on life experiences. Often, older adults display a shift in degree of optimism, acceptance, and distress, all of which influence how they cope with a cancer diagnosis.

Optimism. Generally, Americans tend to become more optimistic with age, potentially reflecting a culturally influenced value (Fung, 2013). Older adults from East Asian countries do not tend to experience this same shift with age (Fung, 2013). Within Western cultures, young- and middle-aged adults tend to report feeling more optimistic about their life as they get older, although findings from several decades ago indicate this sentiment may wane as adults reach old age (Borges & Dutton, 1976). More recent longitudinal findings have indicated that positive affect in particular may remain stable over time, but negative affect may actually decrease with age (as measured via the PANAS measure; Charles & Carstensen, 2010). These findings suggest that older adults generally feel less negative as compared to their younger cohorts, a phenomenon termed the positivity effect, which is evidenced by for increased attention to, and memory for, positive information among older adults (Carstensen & Mikels, 2005). Given the proposed link between more positive/adaptive psychosocial functioning and illness (Antoni & Lutgendorf, 2007; Ong, 2010; Schneiderman, 2004), it is feasible that increased optimism and/or decreased negative affect in old age assists coping with illness. While we may not be able to argue that older adults are necessarily less

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pessimistic, recent evidence points to a lack of differentiation between pessimistic and optimistic attitudes, reflecting fewer affectual ups and downs in old age (Palgi, Shrira, Ben-Ezra, Cohen-Fridel, & Bodner, 2011). It is possible that this lack of affectual volatility (and potentially reactivity) results in a smoother transition to coping with cancer among older adults.

   Acceptance. Another transition that can occur in old age is a shift toward greater acceptance of life circumstances. Perhaps due to the "perpetual ambiguity" accompanying a cancer diagnosis (Hughes, Closs, & Clark, 2009), there is some evidence that older adults are prone to accepting the illness as a turning point marking old age (Esbensen, Swane, Hallberg, & Thome, 2008; Foley et al., 2006). Generally, this acceptance appears to be manifest in a positive take on the cancer experience (i.e., viewing it as a challenge). It should be acknowledged, though, that many of the studies assessing affect, optimism, and/or growth accompanying the cancer experience are subject to self-selection biases (Towsley et al., 2007). In other words, the individuals participating in these studies tend to be Caucasian, highly educated, and potentially experiencing less distress in their lives. While most studies do not definitively explore the latter point, there was one study that emerged in my literature review that explored characteristics of nonparticipants, and these individuals were found to be more likely to be older, and to report more distress than those who did participate in the research study (Balboni et al., 2007).

   In spite of the high degree of intra-variability in the coping experience, old age does bring with it unique stigmas, challenges, and experiences that likely mold the ways

in which one copes with illness. It is this experience of old age, and its interaction with a chronic illness like cancer that results in unique coping experiences among the elderly.

Unfortunately, most research addressing coping with cancer is conducted with younger individuals, or results are collapsed across age, obscuring possible age-based differences. Further, many published studies lack control groups and employ cross-sectional designs, making it difficult to draw inferences about developmental changes in coping as patients grow older (Mosher & Danoff-Burg, 2006). Many of these studies also focus on a narrow subpopulation of adults who are White, female, and in the early stages of cancer (Mosher & Danoff-Burg, 2006). Overall, while it has been suggested that a cancer patient's age is negatively associated with the degree and nature of care (Rose et al., 2000), there is still much research to be done on assessing coping with cancer at different stages of the age continuum.

Summary

The budding literature on positive change following a cancer diagnosis is primarily unexplored in studies of the older population for whom cancer diagnoses are especially prevalent. PTG in older adults remains largely uncharted territory, and no empirical or observational study to date has examined the relationship between PTG and transcendence. Further, existing well-being research has revealed contradictory findings. While some studies identify a positive relationship between well-being and PTG, others suggest there is no significant relationship between the two variables; how these variables are associated in an older sample of cancer survivors is unknown. Finally, it is unclear how coping strategies might relate to the presence or nature of PTG. Research has pointed to a relationship between PTG and 'active' coping (Belizzi & Blank, 2006),

problem-focused and emotion-focused coping (Maercker & Langner, 2001), and 'avoidant' coping (Nolen-Hoeksema & Davis, 2004), rendering it unclear as to which particular coping strategies are associated with PTG in an older sample.

Specific Aims

As a result of the issues presented in this chapter, this study was designed to address four specific aims:

Specific Aim One: *To describe posttraumatic change in older adults with recent cancer diagnoses in order to assess posttraumatic growth in this population*.

As presented, prior research has shown that many older adults with cancer do experience PTG, but there has been little exploration of PTG in older cancer survivors. It was hypothesized that one or more subtypes of PTG would emerge as prominent in this population. Given the lack of research on PTG in older cancer survivors, there were no other *a priori* hypotheses for this Specific Aim.

Specific Aim Two: *To identify and measure the relationship between posttraumatic change and transcendence*.

Both transcendence and posttraumatic growth appear to be conceptually similar, and thus it was hypothesized that PTG would be positively associated with transcendence. Further, it was hypothesized that the two constructs may in fact reflect a single, latent construct.

Specific Aim Three: *To explore the relationship between posttraumatic change and well-being*.

Considering PTG reflects an arguably positive phenomenon, it was hypothesized that PTG would be positively associated with well-being. As indicated, prior research has not established a definitive link between PTG and well-being with other populations.

Specific Aim Four: *To explore the relationship between posttraumatic change and coping strategies with an emphasis on posttraumatic growth*.

There is little consensus on the relationship between coping strategies and PTG, and while it was presumed that certain strategies of coping (e.g., meaning-focused coping) would be evident in individuals experiencing PTG, no particular strategy was hypothesized to be associated with PTG.

Chapter Three:
Study Design and Data Analysis

Overview

A mixed methods design was used to address the Specific Aims. Using a mailed survey, Likert-type scales were used to obtain quantitative data, and were embedded within the survey were several open-ended questions to allow for elaboration if participants wished to write down additional thoughts. These questions were intended to elicit responses that would expand on the quantitative findings. Further qualitative data were collected during recruitment phone calls. In this chapter, I first explain the rationale for using mixed methods in research studies. I then provide an explanation of the research design and specific methods used in this study. The chapter concludes with an explanation of the statistical and qualitative analyses employed during data analysis and interpretation.

Rationale

A Mixed Methods Primer

Mixed methods research combines quantitative and qualitative approaches in a single study design (Johnson & Onwuegbuzie, 2004; Johnson, Onwuegbuzie, & Turner, 2007). This combination can be at the level of data collection, analysis, or inferential techniques (Johnson et al., 2007). Mixed methods are further characterized by methodological eclecticism (allowing for a variety of different methods that may be qualitative, quantitative, or a combination of both), paradigm pluralism (embracing different ontologies of research, such as constructivism—which is generally qualitative), and an iterative focus (for example, transitioning between deduction and induction to formulate conclusions; Teddlie & Tashakkori, 2012).

Mixed methods are useful, in part, because they limit the weaknesses inherent in the use of either quantitative or qualitative methods alone. For example, Johnson and Onwuegbuzie (2004) suggest that quantitative research is weakened by strict hypothesis testing that does not explore additional phenomena revealed in the data; it does not explore possible divergence between researchers' conceptualizations of key constructs and participants' understanding or views of the same constructs. Mixed methods allow for a more subjective, in-depth exploration of participants' views of their own experiences, thereby reducing this weakness of strictly quantitative research. At the same time, a mixed methods design allows researchers to capitalize on the strengths of quantitative research, including testing established theories, and generalizing findings to larger groups of individuals.

Mixed methods also compensate for weaknesses inherent in qualitative research, such as limited generalizability to other samples or populations, and the influence of researcher biases and personality on data collection, analysis, and inference (Johnson & Onwuegbuzie, 2004). Employing a mixed methods approach can increase generalizability (as compared to what would be possible with a purely qualitative study) and dampen the subjective influence of a researcher on his/her findings (although it should be noted that no research approach is immune to researcher bias, nor is it necessarily the case that such immunity is desired). Mixed methods allow researchers to benefit from exploring complex phenomena with small samples, data that are "based on participants' own categories of meaning" (Johnson & Onwuegbuzie, 2004, p. 20), and, as a result, gain a better understanding of how participants themselves are understanding concepts of interest.

Present Study

For this study, a pragmatic theoretical paradigm was used, reflecting an emphasis on addressing the research questions (as opposed to fitting a research question to the preferred methodology), and on using more than one method of data collection and analysis (Creswell, Klassen, Plano Clark, & Smith, 2011; Creswell & Plano Clark, 2011). Specifically, I used a "data-validation convergent mixed methods" design (Creswell & Plano Clark, 2011) (see Figure 3.1). Traditional convergent designs assign equal weight to the quantitative and qualitative components, but the "data-validation" variant emphasizes quantitative methods and uses qualitative findings to elaborate and better explain the quantitative results (rather than be the focus of the study). This approach was used because there were already validated scales that represented the constructs of interest in this study (e.g., the PTGI and Brief COPE[5]). Further, existing PTG literature provided a framework from which to base hypotheses, the absence of which would have necessitated a qualitative focus. The addition of the qualitative component allowed for an enhanced understanding of the statistical findings, and also the emergence of additional considerations not captured by the quantitative methods. In sum, collecting both quantitative and qualitative data allowed for more comprehensive findings than could be attained through either method alone (Creswell, 2015; Creswell & Plano Clark, 2011; Johnson & Onwuegbuzie, 2004).

Participants were mailed a survey with primarily Likert-type questions, and embedded within were open-ended questions periodically spaced throughout the mailed survey (i.e., QUANT + qual). This layer of qualitative data collection was intended to

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[5] Here, "COPE" is used by Carver and colleagues (1989, 1997) not as an acronym, but as a means of referring to the both the full and shortened versions of their coping inventory.

provide participants with an opportunity to elaborate on their numerical responses. It should be noted that, at present, the labelling of mixed methods designs is not agreed upon among mixed methods researchers (Leech & Onwuegbuzie, 2009; Teddlie & Tashakkori, 2012). While the data-validation convergent mixed methods "label" is a very close fit for the design in this study, the label itself does not acknowledge additional qualitative data collected during recruitment.

Figure 3.1
Study Design

Procedure

Step 1	**Design Quantitative Strand and Collect Quantitative Data**	with	**Design Qualitative Strand and Collect Qualitative Data**

Step 2	**Analyze Quantitative Data** (descriptive and inferential statistics)	and	**Analyze Qualitative Data** (content Analysis that identifies and reviews emergent themes)

Step 3 — **Analyze both sets of data by combining findings by Specific Aim** (combine quantitative and qualitative responses for each specific aim)

Step 4 — **Integrate Results** (compare quantitative findings throughout study to qualitative findings throughout study)

Step 5 — **Interpretation** (evaluate combined data to answer Specific Aims and identify emergent findings)

Quantitative and qualitative methods were both used at several different stages of the research process, including the overall analytic strategy, data collection, and as a guide for making analytic inferences (Creswell & Plano Clark, 2011). Incorporating both quantitative and qualitative approaches throughout the research process is referred to as a fully mixed methods design (Leech & Onwuegbuzie, 2009), to be differentiated from a partially mixed methods design, wherein, for example, mixed methods are used at only one stage of the research process (e.g., data collection only).

<p style="text-align:center">Participant Eligibility and Recruitment</p>

Eligibility

Eligibility was initially limited to adults 60 years of age[6] and older with a cancer diagnosis within the last 3 months to five years. The lower end of this time frame was chosen to allow for a period of possible rumination following the diagnosis (Bellizzi & Blank, 2006). Rumination pertaining to one's traumatic experience is thought to be a key antecedent to PTG (Tedeschi & Calhoun, 2004), and other studies exploring posttraumatic growth (PTG) have found evidence of growth within the year after diagnosis (Carboon et al., 2005; Cordova et al., 2007; Manne et al., 2004). While there is evidence of PTG shortly after diagnosis, it also appears that PTG increases over time (Manne et al., 2004). The upper end of the time frame was chosen out of consideration for the immediacy of the struggle with cancer and a potential loss of clarity over time (Bellizzi & Blank, 2006).

Eligibility was minimally constrained by cancer site (as explained below) because it is unknown how particular types of cancer influence PTG. Coping with one type of

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[6] The age cut-off for studies involving older adults is often 60 or 65. In this study, 60 was chosen with the hope that it would be easier to find enough eligible and consenting participants.

cancer could be perceived as traumatic to one individual but non-traumatic to another with the same diagnosis. Further, some individuals may find the diagnosis itself to be traumatic, while others struggle with postoperative concerns, social stigma, or altered social relationships. In sum, while PTG concerns growth following the struggle surrounding a cancer diagnosis, the nature of that struggle is likely to vary by survivor. The only cancer type not included in this study was non-melanoma skin cancer, as it is associated with low mortality and low emotional impact (Madan, Lear, & Sziemies, 2010), thus reducing the likelihood that individuals with non-melanoma skin cancer would find their diagnoses (or the post-diagnosis period) to be traumatic. Eligibility was constrained to individuals with a single primary cancer site because individuals with multiple primary cancers have much higher mortality rates, poorer mental and physical health (on average), and presumably more complex experiences with cancer that could confound findings from individuals with a single cancer site (Andrykowski, 2012).

Sample Size Rationale

It was anticipated that recruiting 100-150 participants would allow for sufficient power to draw statistical inferences (Applied Statistics Lab, personal communication, October 6, 2014). For the primary dependent variable, PTG (as measured by the PTGI, explained below), current literature provides little information on effect sizes, which made it difficult to predict how many participants would be needed to obtain sufficient power in the study. One study with young, middle-aged, and older breast cancer survivors reported an *anticipated* effect size of .35 (alpha = .05 and power = .90) when using the PTGI, Brief COPE, and other scales (Bellizzi & Blank, 2006), in order to determine their expected sample size of 168. A separate study investigating PTG in 70 young, middle-

aged, and older breast cancer survivors (compared with 70 healthy matched controls) found increased PTG in breast cancer survivors, with effect sizes for the PTGI subscales ranging from .32 to .38 (Cordova et al., 2001). It should be noted that these effect sizes (Cohen's *d*'s) were only based on three of the five PTG subscales (relating to others, purpose in life, and appreciation for life). Because there were few existing mentions of effect sizes in the PTG literature to reference, I used an effect size of .35 to estimate an appropriate sample size.

A review of the literature on PTG in older adults (Bellizzi, 2004; Carboon et al., 2005, Cordova et al., 2001, Cordova et al., 2007; Manne et al., 2004; Mystakidou et al., 2008; Sears et al., 2003) revealed an average standard deviation of 25 points on the PTGI (with means centered around 50-55). Combined with an anticipated effect size of .35 and power of .8, it was determined that 150 participants would allow for a 95% confidence interval of +/- 5.66. In the case of substantial attrition (to the extent that 1/3 of contacted participants did not participate for any reason), data from 100 participants were expected to still allow for sufficient power to draw statistical inferences (power of .8 with a standard deviation of 25 allows for a 95% confidence interval of +/- 6.93). A power analysis was not conducted for smaller sample sizes.

Recruitment

To obtain a population-based random sample, participants were recruited through the Kentucky Cancer Registry (KCR). The KCR maintains a database of information on all reported cancer cases in the state of Kentucky, and all healthcare facilities must report any new cancer diagnoses. For this study, the KCR's Calling Team first contacted randomly selected registrants' physicians to ensure there was no reason their patient

should not be contacted for this study (e.g., death or dementia). If there was no response within two weeks, the KCR then sent each patient a letter and a response card indicating their eligibility for this research study, and asking for permission to release their contact information to me. In this letter was a short description of the study and contact information (see Appendix 1). If the response card was not mailed back (and there was no other form of contact, such as a telephone call), then the Calling Team phoned the potential participants (termed "cases") up to five times (during the day and night, and on weekends) to ask if they would release their contact information to me. No consenting participant was called more than three times. This calling process began in May, 2015, and 160 contacted individuals agreed to release their contact information. Once I received all cases' contact information, I began calling each one to solicit his/her consent to participate in this study.

Of the 160 potential participants from the Kentucky Cancer Registry, 72 were male, and 88 were female. During my initial phone calls, a few participants volunteered their age, and it became apparent that the ages in my database did not match participants' self-reported ages. I followed up with the Kentucky Cancer Registry, and it was revealed that the listed ages reflected *age at diagnosis* rather than current age. Thus, my final sample was older than initially anticipated.

I attempted contact with each of the 160 potential participants by telephone over the course of two months. I was unable to reach 21 individuals during this period, after calling some participants up to 11 times. Of those who were contacted, 21 individuals (9 females) declined to participate for the following reasons: they were not interested (12; 7.5%); they indicated that they did not have cancer (4; 2.5%); they were not able to

participate (e.g., spouse indicated the potential participant had cognitive difficulties) (3; 1.2%); they were afraid of participation (1; .6%); or they did not have enough time to complete the survey (1; .6%).[7]

After mailing surveys to the remaining 118 potential participants, 12 more individuals (6 females) declined to participate, citing that they were not interested (9; 5.6%); did not actually have cancer (1; .6%); or were not able to participate (one participant's wife called to say that the potential participant had dementia). The other declining participant wrote a letter indicating she was dealing with unrelated health problems at the time (2; 1.3%). Of the 118 who received surveys, there were a handful who eagerly discussed their experiences with me (over the phone), but did not return a survey. For example, participant #154, reflected on the phone about how her experience with breast cancer was "spiritual" and that she accepted the fact that she had cancer, even if that meant she would die from it. She had undergone a double mastectomy, and indicated that since her husband had died and she did not plan on remarrying, she had no use for her breasts anyway! Participant 217, on the other hand, had been diagnosed with a type of skin cancer (type unknown), and revealed that he had a history of cancer in his family, and that much of his cancer care (or lack thereof) was determined by financial constraints. Finally, participant 239 had been diagnosed with rectal cancer, and indicated that she felt her experience post-diagnosis was really "up to the Lord," and had been helped by her treatment plan.

In total, 51 participants recruited through the KCR returned surveys, or 31.9% of the original 160 individuals. This response rate is consistent with expected returns from

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[7] For purposes of Human Subjects Protection, only very basic, de-identified information is presented from individuals who did not provide written Informed Consent.

mailed surveys (Kaplowitz, Hadlock, & Levine, 2004). Because recruitment was much more difficult than originally anticipated, an advertisement was placed in the University of Kentucky's Osher Lifelong Learning Institute's (OLLI) e-news blast to recruit additional eligible participants in the fall of 2015. In this advertisement, eligibility was listed as being 55 years of age and older with a cancer diagnosis (at any point in time); the age cut-off was lowered from 60 years of age in an attempt to boost recruitment. The five individuals who responded to this advertisement (of the more than 1,000 individuals who received the e-mail) were all over the age of 60, but all had received initial cancer diagnoses more than five years prior to hearing about the study. In addition, one participant from the OLLI group, and one participant from the original KCR group reported having received cancer diagnoses for two different sites (breast and ovary, and lung and prostate).

Procedure

I mailed each potential participant ($N = 118$) a survey packet (see Appendix 2), two copies of the Informed Consent form (see Appendix 3) and a pre-addressed, stamped envelope for returning the survey packet. Mailings began in mid-June, and all KCR packets were mailed by mid-July. Starting approximately three weeks after mailing the first batch of surveys, I sent out follow-up letters (see Appendix 4 for an example) to the 75 individuals who had not mailed back their surveys from the first mailing. A handful of secondary follow-up letters were then sent out again to those who had still not returned surveys. Finally, surveys were re-sent to 45 initially consenting individuals in September in a final bid to recruit participants (of these, only three were returned). Of the five participants who responded to the 2015 OLLI e-news blast sent in September, four

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mailed (and returned) the surveys, and one was sent and returned the survey by e-mail (as per the participant's request).

This study was approved by the University of Kentucky's Protocol Review and Monitoring Committee (expedited review; Protocol 15-0222-P6H), and study details were uploaded onto the Markey Cancer Center's OnCore website.

Measures/Materials

Several participants were intrigued by the topic of this study, and chatted with me by phone about their personal situation and experience with cancer during recruitment. These conversations were not audio-recorded, but I took notes during each call, and used the information to better understand participants on a personal level. These notes, in conjunction with the open-ended responses in the survey, provided both context and elaboration when analyzing the survey data.

Basic Characteristics

Participants were asked to report basic demographic information such as date of birth, sex, race (American Indian, Asian, Black/African-American, Native Hawaiian or Pacific Islander, White/Caucasian, or Unknown), and ethnicity (Hispanic, Non-Hispanic, or Unknown) (see Section 1 in Appendix 2). Even though race/ethnicity has not been linked to PTG in cancer survivors (Bellizzi & Blank, 2006; Morris & Shakespeare-Finch, 2011; Sears et al., 2003), these variables were included for completeness, and also because they were required by the OnCore website (where participant accrual information is uploaded by all cancer researchers at the University of Kentucky). The chosen categories were also obtained directly from the OnCore website.

Education, while likely not related to PTG, was assessed by asking the following open-ended questions: "How many years of education have you completed?" and "What is your highest level of schooling/highest degree?" It was thought that education may be related to other variables of interest, such as coping strategies. Relatedly, income was asked in an open-ended format as a proxy for socioeconomic status. To date, there is an unclear link between income and PTG (Cordova et al., 2001; Sears et al., 2003), thus it was of interest to assess the relationship between the two variables with this sample.

Participants were also asked to report their marital status (Married, Separated, Divorced, Widowed, or Single) and living situation (living with a spouse/significant other, living with children/grandchildren, living alone, or other) in the event either variable was associated with posttraumatic growth. Extant literature, as stated in Chapter Two, has not shown a link between PTG and relationship status in cancer survivors (Jansen et al., 2011; Morris & Shakespeare-Finch, 2011; Sears et al., 2003).

Number of children was included primarily to assess whether or not participants had the experience of parenting, which may be associated with the cancer experience or PTG (literature has shown there is a link between being a parent and experiencing gerotranscendence; Tornstam, 2005). Secondary questions were asked about the number of *living* children, in part, to assess whether the loss of a child may have influenced PTG, and also the ages of participants' children. This latter question was added to ascertain whether patients were currently caring for minors (which may also have a marked impact on their experience with cancer).

Social support was assessed by asking participants to write down how many people they depend on for support. Social support has an unclear relationship with PTG

in cancer survivors, (Cordova et al., 2001; Danhauer et al., 2013; Jansen et al., 2011) and was thus presented in an open-ended format to best capture how much support participants felt they had from others (in lieu of using pre-conceived categories).

Religion and spirituality were assessed using five-point Likert items (e.g., 1 = not at all religious, and 5 = very religious; 1 = not at all spiritual, and 5 = very spiritual). In addition, participants were asked to report the religious denomination with which they identified.

In terms of clinical variables, participants were asked to report their cancer location (open-ended), cancer stage/status, and date of diagnosis. The latter question was used in place of "time since diagnosis" in case participants were better able to remember *when* they were diagnosed as opposed to how much time had passed since they were diagnosed. In order to calculate time since diagnosis, the number of months since diagnosis was calculated based on when the survey was received. Participants were also asked about prior life crises, in the event that any other major life events could have had a significant impact on their lives since receiving a cancer diagnosis (e.g., received a cancer diagnosis and spouse passed away shortly thereafter). This question was included to allow me to assess whether reported growth could have stemmed from the cancer experience or from other life events. Finally, to account for individual variability in cancer survivorship, there was one question that addressed how meaningful participants found their particular cancer diagnosis (or consequent challenge to personal integrity). Specifically, each potential participant was asked to rate the question: "How significant has a diagnosis of cancer been in your life?" on a seven-point Likert item (1 = not significant; 7 = very significant).

Health

The 12-item Short-Form Health Survey (SF-12; Ware, Kosinski, & Keller, 1996)

was used to measure overall physical and mental health (see Section 2 in Appendix 2).

The SF-12 has a test-retest reliability above .85 for the physical component summary

(PCS) and mental component summary (MCS) scores, and correlates highly (r's = .94

and above) with the widely used SF-36 (Gandek et al., 1998; Ware et al., 1996). Scores

on the PCS and MCS are typically "normed," meaning that they are compared to

population-based scores that are scored using a mean of 50 and a standard deviation of 10

(Ware et al., 1996). This norm-based scoring allows for a straightforward comparison of

one's findings with the general population. Of note, norm-based scoring of the PCS has

revealed an average score of approximately 50.8 (SD = 8.9) in the U.S. general

population, and 43.7 (SD = 11.0) for adults aged 65 to 74 (no figures were provided for

even older individuals; Gandek et al., 1998). Norm-based scoring of the MCS indicates

an average score in the U.S. general population of 50.0 (SD = 9.5), and an average score

of 52.1 (SD = 9.5) for adults aged 65-74.[8]

Posttraumatic Change

In order to assess posttraumatic growth, I used the 21-item Posttraumatic Growth

Inventory[9] (PTGI; Tedeschi & Calhoun, 1996) (see Section 4, questions 1-21 in

Appendix 2). In existing literature, the PTGI has had high internal consistency with a

Cronbach's alpha of .90 or higher (Anders et al., 2015; Brunet, McDonough, Hadd,

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[8] While the PCS and MCS scores in the general U.S. population were slightly different in Gandek et al.'s
(1998) study, the formula used to compare SF-12 findings to population-based scores assumes Ware et al.'s
(1996) figures (M = 50.00, SD = 10.00).
[9] I did not use the revised 10-item short form because, as noted by Cann et al. (2010), it is better to use the
full scale when it is of scholarly interest to focus on the subscales in addition to the overall PTG score.

Crocker, & Sabiston, 2010; Cordova et al., 2007; Lelorain et al., 2010; Manne et al., 2004; Morris & Shakespeare-Finch, 2011; Mystakidou et al., 2008; Sears et al, 2003; Sheikh & Marotta, 2005; Tedeschi & Calhoun, 1996), and in this study, the PTGI had a similar Cronbach's alpha of .96. For each scale item, participants were asked to assess the relevance of the statement, for example, "I discovered that I'm stronger than I thought I was," on a six-point scale (0 = I did not experience this change as a result of my cancer experience; 5 = I experienced this change to a very great degree as a result of my cancer experience).

The PTGI was developed to measure overall PTG and identify five general subtypes of PTG: *relating to others* (items 6, 8, 9, 15, 16, 20, and 21); *new possibilities* (items 3, 7, 11, 14, and 17); *personal strength* (items 4, 10, 12, and 19); *spiritual change* (items 5 and 18); and *appreciation of life* (items 1, 2, and 13). In this study, all subscales had acceptable Cronbach's alphas; for instance, the *relating to others* subscale had an alpha of .90, consistent with what has been reported in previous studies (alphas ranging from .85 to .92; Brunet et al., 2010; Cordova et al., 2007; Lelorain et al., 2010; Morris & Shakespeare-Finch, 2011; Sears et al., 2003; Tedeschi & Calhoun, 1996). Further, all of the seven items comprising the *relating to others* subscale had correlations of .65 or higher with the total.

The *new possibilities* subscale had a Cronbach's alpha of .89, also consistent with previous studies (alpha ranging from .84-.90; Brunet et al., 2010; Cordova et al., 2007; Lelorain et al., 2010; Morris & Shakespeare-Finch, 2011; Sears et al., 2003; Tedeschi & Calhoun, 1996). In the *new possibilities* subscale, four of the five scale items had a

correlation of .75 or higher with the total (question #14 had a correlation of .56 with the total).

The Cronbach's alpha for *personal strength* was somewhat high compared to what has been reported previously (α = .88 compared to .72-.87; Brunet et al., 2010; Cordova et al., 2007; Lelorain et al., 2010; Morris & Shakespeare-Finch, 2011; Sears et al., 2003; Tedeschi & Calhoun, 1996), and all scale items had correlations of .66 or higher with the total.

Spiritual change had a high alpha (.90), in accord with what has been found in other studies (alphas ranging from .83-.94; Brunet et al., 2010; Cordova et al., 2007; Lelorain et al., 2010; Morris & Shakespeare-Finch, 2011; Sears et al., 2003; Tedeschi & Calhoun, 1996). Finally, the *appreciation of life* subscale had an alpha of .89, also consistent with previous studies (alphas ranging from .67 to .89; Brunet et al., 2010; Cordova et al., 2007; Lelorain et al., 2010; Morris & Shakespeare-Finch, 2011; Sears et al., 2003; Tedeschi & Calhoun, 1996), and all scale items had correlations of .78 or higher with the total.

Not all researchers have used the five-factor framework when analyzing the PTGI. Some studies have measured the total score alone (see Anders et al., 2015; Manne et al., 2004 for examples), others have used a three-factor structure, and still others have assessed both the total score and the five subscales (Bellizzi, 2004; Mystakidou et al., 2008). This variability is likely due to inconsistent findings regarding the underlying factor structure of the PTGI. For example, Sheikh & Marotta (2005) found just one factor (the total score) described the majority of variance in PTG in their sample of individuals with cardiovascular disease using principal components analysis, while Tedeschi and

Calhoun's (1996) study with undergraduates and Brunet and colleagues' (2010) study with physically active breast cancer survivors found a five-factor structure (i.e., the five subscales) to provide the best fit to their data (using principal components analysis and confirmatory factor analysis, respectively). Other researchers performing confirmatory factor analyses have found that either a five-factor structure *or* a five-factor + one-factor (correlated with the five factors) provide an adequate statistical fit (Linley, Andrews, & Joseph, 2007; Taku, Cann, Calhoun, & Tedeschi, 2008). Finally, a recent study conducted with a Hungarian version of the PTGI found that the best option may in fact be a five-factor structure in combination with a single, uncorrelated factor (Thege et al., 2014). In sum, most studies on PTG look at either the total score, or the total score in combination with the five subscales. For this reason, I planned *a priori* to investigate PTG by analyzing both the total score and the five subscales.

Using the same six-point scale above, an additional five items were included to assess negative change following the cancer diagnosis (see Section 4, questions 22-26 in Appendix 2). These items were intended to compare negative change scores to (positive) growth scores, and identify negative changes stemming from cancer survivorship. Collectively, the distress items had an alpha of .84. Removing the final item ("I can't do the things I once enjoyed"), which had a correlation of .49 with the total, resulted in an alpha of .87, and thus it was not removed. Finally, an open-ended question was added at the end of this section to allow participants to write down and communicate additional thoughts and observations in completing the protocol.

Transcendence

Transcendence was measured using Reed's Self-Transcendence Scale (STS; 1986) (see Section 5, questions 1-15 in Appendix 2) and Tornstam's Gerotranscendence Scale (2005) (see Section 5, questions 16-26 in Appendix 2). I included both the STS and the Gerotranscendence Scale to allow for an assessment of whether the two scales are assessing one latent construct or two separate constructs (which has not been explored in existing literature).

For the STS, participants are asked to rate items (e.g., "At this time of my life, I see myself as: Accepting death as a part of life") on a four-point scale (0 = not at all; 3 = very much). The STS has a Cronbach's alpha of .93 (Reed, 1989), with a test-retest reliability of .95 (Reed, 1991a). The average score for the final scale item ("At this time of my life, I see myself as dwelling on past losses") was .96 (SD = .85), indicating low endorsement of dwelling on past losses.[10]

Tornstam's (2005) Gerotranscendence Scale allows for an assessment of three dimensions of gerotranscendence (*cosmic*, *self*, and *social relations*[11]) (see Section 5, questions 16-25 in Appendix 2). For this scale, participants were asked to rate items (e.g., "Feeling connected with the entire universe") on a four-point scale (0=not at all; 3=very much). As per Tornstam's (2001) study with Swedes aged 65 and older, a varimax rotated principal component analysis revealed factor loadings ranging from .51 to .89 (Tornstam, 2003, 2005). Of note, the scale's psychometric properties are unclear or

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[10] It was discovered post-defense that this item was incorrectly removed from analyses, and should have, instead, been reverse-coded. Analyses will be re-run prior to any publication of material from this component of the dissertation.

[11] Labels for the three dimensions of gerotranscendence vary in the literature, but several researchers have adopted "cosmic," "self," and a variant of "social relations" in their work (Braam, Bramsen, van Tilburg, van der Ploeg, & Deeg, 2006; Jönson & Magnusson, 2001).

unknown. I could not find a well-validated gerotranscendence measure in my literature review, and Tornstam's Scale has at least been used in other studies assessing gerotranscendence (Tornstam, 2003, 2005). In this study, the five-item *cosmic* dimension of gerotranscendence had an alpha of .71, with correlations with the total ranging from .34 to .55; removing the item with a correlation of .34 did not change the alpha for these five questions, and so it was retained.

The *self* dimension of the Gerotranscendence Scale was more problematic, as the two scale items were only marginally correlated with one another ($r = .23$, $p = .09$), and had an unacceptably low Cronbach's alpha ($\alpha = .37$). Scale item 7 ("The life I have lived has coherence and meaning") was selected to represent the *self* dimension due to greater face validity relative to scale item 6. An examination of scores for scale item 7 revealed a highly non-normal distribution, such that half of participants reported a score of 3 (thereby also reflecting a robust ceiling effect). Because of these statistical concerns, no inferential analyses were conducted for the *self* dimension.

The *social relations* dimension yielded an alpha of -.33, and the two most highly correlated scale items (8 and 10) were only marginally associated with one another ($r = .23$, $\alpha = .38$, $p = .087$). Thus, a single scale item was selected to reflect the *social relations* dimension (item 8; "I like to be by myself better than being with others") due to enhanced face validity relative to scale item 10. Finally, an open-ended question was added at the end of the transcendence section to enable participants to share any additional thoughts.

Well-Being

I obtained a quantitative assessment of wellbeing using the 8-item Flourishing Scale (FS; Diener et al., 2010; see Section 7 in Appendix 2). For the FS, participants were asked to rate each item (e.g., "I am optimistic about my future") on a seven-point scale (1 = strongly agree; 7 = strongly disagree). To maintain consistency within the statistical analyses, participants' responses were reverse-coded so higher scores reflect increased well-being.

The focus of the FS scale is on eudaimonic (psychological) well-being, which reflects a deeper sense of well-being associated with meaning in life (as opposed to more 'superficial,' or hedonic well-being). The internal consistency of the FS is high (Cronbach's alpha = .87), and the scale correlates highly with most of Ryff's (1989) psychological well-being subscales (r's range from .63 to .73 for all but the Autonomy subscale, which had an r of .43 with the FS), and Diener and colleagues' (1985) Satisfaction With Life Scale ($r = .62$) (Diener et al., 2010). In this study, the scale's Cronbach's alpha was .94. Finally, as with the other main sections of the survey, an open-ended question was added to the end of this section to enable participants to share additional thoughts.

Coping

Carver's (1997) 28-item Brief COPE was used to measure coping (see Section 6 in Appendix 2). For this scale, participants are asked to rate each item (e.g., "I've been giving up trying to deal with it") on a four-point scale (0 = I have not been doing this at all; 3 = I have been doing this a lot). This theoretically-derived measure includes two items for each of the following subscales: *self-distraction, active coping, denial,*

substance use, use of emotional support, use of instrumental support, behavioral

disengagement, venting, positive reframing, planning, humor, acceptance, religion, and

self-blame. For each subscale, items are summed to create the subscale score (e.g., items

2 and 7 comprised active coping, and thus active coping was derived by adding the scores

for items 2 and 7). Cronbach's alphas for the 14 subscales range from .50 (venting) to .90

(substance use), considered 'minimally acceptable' for use in a survey (Nunnally, 1978,

as cited in Carver, 1997). In this study, the alphas ranged from .51 (venting) to .93

(substance use), and for the subscales with relatively low alphas, all had modest inter-

item correlations of .35 and above (see Table 3.1).

Table 3.1
Brief COPE Subscale Items

Scale	α	p	r
Active coping	0.73	<.0001	0.57
Planning	0.55	0.004	0.38
Positive Reframing	0.85	<.0001	0.74
Acceptance	0.74	<.0001	0.6
Humor	0.76	<.0001	0.62
Religion	0.88	<.0001	0.79
Use of Emotional Support	0.59	0.002	0.41
Instrumental Social Support	0.69	<.0001	0.53
Self-Distraction	0.71	<.0001	0.55
Denial	0.6	0.0006	0.45
Venting	0.51	0.008	0.35
Substance Use	0.93	<.0001	0.89
Behavioral Disengagement	0.58	0.002	0.41
Self-Blame	0.62	0.0005	0.46

Problem-focused coping has been derived from five of the COPE's subscales:

active coping, *planning*, *suppression of competing activities*, *restraint coping*, and

seeking of instrumental support (Carver et al., 1989). In the Brief COPE, both *restraint*

coping and the *suppression of competing activities* were removed as they proved to be

either redundant or provided little information not already addressed by *active coping* (Carver, 1997). Thus, I planned *a priori* to aggregate scores from *active coping* (items 2 and 7), *planning* (items 14 and 25), and *use of instrumental social support* (called *seeking of instrumental support* in the COPE; items 10 and 23) as a means of measuring PF coping. Collectively, these three subscales had an alpha of .77.

Emotion-focused coping has been derived by aggregating scores from five of the COPE's subscales: *seeking of emotional support, positive reinterpretation and growth, acceptance, denial,* and *turning to religion* (Carver et al., 1989). All five of these subscales are present in the Brief COPE, and were used here to derive an aggregated score for emotion-focused coping: *use of emotional support* (items 5 and 15), *positive reframing* (called *positive reinterpretation and growth* in the COPE; items 12 and 17), *acceptance* (items 20 and 24), *denial* (items 3 and 8), and *religion* (called *turning to religion* in the COPE; items 22 and 27). In this study, the Cronbach's alpha for the five subscales that comprise emotion-focused coping was .61. The denial subscale was negatively correlated with the other subscales ($r = -.06$), and removing the denial subscale led to an alpha of .69. Consequently, emotion-focused coping was assessed using the four remaining subscales.

Finally, meaning-focused coping was derived by assessing *positive reframing* (used by Park, Zlateva, & Blank, 2009). Notably, there is overlap between meaning-focused coping and emotion-focused coping, and thus emotion-focused coping was also analyzed without the overlapping subscale (*positive reframing*). The Cronbach's alphas for emotion-focused coping without the positive reframing or denial subscales, and for

meaning-focused coping were .77 and .85, respectively. Finally, an open-ended question was added at the end of this section to enable participants to share additional thoughts.

Future Time Perspective

Carstensen and Lang's (1996) unpublished 10-item Future Time Perspective (FTP)[12] scale was used to measure participants' perceptions of the amount of time they have left in life, and any resultant effects on their personal goals or motivations (see Section 3 in Appendix 2). The psychometric properties for the full scale were not readily apparent, but at least one study found the scale's Cronbach's alpha to be .8 (Bal, Jansen, van der Velde, de Lange, & Rousseau, 2010). For this scale, participants were asked to rate each item (e.g., "Many opportunities await me in the future") on a seven-point scale (1 = very UNTRUE for you; 7 = very TRUE for you).

<div align="center">

Data Analysis

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Quantitative Data

I entered all raw survey data into Excel, and imported a separate, "clean" file into SAS 9.4 that included some additional basic characteristics and variables (e.g., in addition to "date of birth," I added "current age"). Composite variables were created for overall PTGI, each of the five subscales of PTG, self-transcendence and gerotranscendence (meaning, the three dimensions of gerotranscendence as separate variables), and all subscales used for emotion-focused coping, problem-focused coping, and meaning-focused coping. Additional data cleaning was carried out using SAS 9.4.

Specific aim one. To describe posttraumatic growth, I ran descriptive analyses on the participant characteristics to get a better sense of who my participants were (e.g., age

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[12] Carstensen and Lang's (1996) unpublished manuscript was titled "Future Orientation Scale," but the scale is referred to as the "Future Time Perspective Scale" (see Lang & Carstensen, 2002).

range, gender breakdown, etc.), followed by descriptive analyses on the PTG composite variable and each of the five subscales. I then ran simple/multiple linear regressions with overall PTG (and, separately, the subscales) as the dependent variable, and significantly correlated demographic/contextual variables as the independent variables.

Specific aim two. To identify and measure the relationship between posttraumatic growth and transcendence, I first examined the bivariate relationships between PTG and both types of transcendence. Then, with an eye toward assessing the degree to which the two constructs represent one underlying factor, I used confirmatory factor analyses with AMOS software (Arbuckle, 2014), as confirmatory factor analyses take into account measurement error. The confirmatory factor analyses used only the STS and PTGI items; the gerotranscendence items were not included given their low internal consistency and unanticipated results (e.g., high scores for enjoying meetings with new people).

Three participants were removed from the analyses since these three did not complete one or more components of the surveys (likely due to turning the page and missing those questions). I loaded all of the STS items (not including the final scale item which did not correlate well with the other STS items) and all of the PTGI items onto a single latent factor. For the second model, the STS items were loaded onto one latent factor (self-transcendence) and the PTGI items were loaded onto a second latent factor (PTG). These factors were allowed to covary. The χ^2-difference test was applied to assess improvement in model fit over the initial, single factor model.

After examining transcendence and PTG, I assessed the relationship(s) between distress and transcendence using correlations.

Specific aim three. To explore the relationship between posttraumatic change and wellbeing, I first examined well-being in the context of the participants' characteristics (i.e., through descriptive analyses). I then correlated the composite well-being variable with the composite PTG score and with each of the 5 subscale scores.

Specific aim four. Finally, I explored the relationship between posttraumatic growth and coping by first examining each of the 14 coping styles and the three coping strategies (emotion-focused, problem-focused, and meaning-focused) with the demographic and clinical characteristics. I then ran two general linear models, first with problem-focused coping and emotion-focused coping, and the second with problem-focused coping, emotion-focused coping without positive reframing, and meaning-focused coping. These general linear models allowed me to assess how different coping strategies were related to PTG by identifying which strategy was most predictive of PTG.

Qualitative Data and Mixed Methods Contributions

Thirty-four participants (60.7%) responded to the open-ended questions (not counting individuals who wrote "No" or "N/A"). I employed a standard recursive approach to the analysis of qualitative data involving open, axial and selective coding procedures (Charmaz, 2006; Corbin & Strauss, 1990). I read through all the open-ended responses several times and grouped them by question (e.g., all responses following the PTGI were assessed together) for analysis. I then read through each response again and assigned labels to each response. These labels were then reviewed and grouped into themes. For each Specific Aim, the qualitative findings were presented by themselves, and then combined with the quantitative findings by relating themes that emerged in both the quantitative and qualitative analyses. I explored overarching themes revealed through

both individual sets of analyses, and through combining the results from both analyses, as

a final component of the mixed methods design (see Chapter Five).

Chapter Four:
Findings

Both quantitative and qualitative data are analyzed in this chapter to address each Specific Aim. First, the sample is described in terms of sociodemographic and clinical characteristics. Then, PTG is examined (Specific Aim One) through analysis of the PTGI and the post-hoc distress items for all participants. To identify and measure the relationship between transcendence and posttraumatic change (Specific Aim Two), the transcendence items were then analyzed and compared to the PTGI and distress items. Next, the relationship between well-being and PTG is assessed (Specific Aim Three). This chapter concludes with an examination of the relationship between coping strategies and PTG (Specific Aim Four).

Sample Characteristics

Descriptive Statistics

Demographic characteristics. The fifty-six participants ranged in age from 62 to 87 years old ($M = 72.45$, $SD = 6.62$), and the majority were female (60.7%) (see Table 4.1). Most were Caucasian (91.1%) and 32 participants indicated they were not Hispanic (although 21 did not indicate whether they were Hispanic or not). The majority of participants were married (71.4%) or widowed (16.1%), and living either with a spouse or significant other (71.4%), or alone (25.0%).

Education levels varied. It was not possible to obtain an average education level in years due the variability in responses (e.g., "12+" versus "12" versus "14"). A visual inspection of the data led to categorization into five groups: less than high school; high school diploma or equivalent; less than four years of college; Bachelor's degree or equivalent; and graduate work/degree. Over a third of the sample had achieved a high

school diploma (35.7%), and a large percentage had gone to college for some length of time (not resulting in a 4-year degree; 19.6%). Another third had completed graduate work or achieved a graduate degree (32.1%).

The average household income was $51,050 ($SD$ = $36.117). Of those who recorded their income (n = 42), the responses varied from $10,000 to $200,000 with roughly half the sample earning between $35,000 and $74,999. Because responses were sometimes vague or not clearly defined (e.g., "$75,000+"), responses were categorized according to the U.S. Census Bureau's groupings for ease of interpretation.

Table 4.1
Demographic Characteristics

Variable	*Mean*	*Median*	*SD*	*n*	*%*
Age	72.45	70.5	6.62		
Sex (Female)				34	60.70%
Race					
White/Caucasian				51	91.10%
Black/African-American				5	8.90%
Ethnicity					
Non-Hispanic				32	91.40%
Unknown				3	8.60%
Marital Status					
Married				40	71.40%
Separated				1	1.80%
Divorced				3	5.40%
Widowed				9	16.10%
Single				3	5.40%
Living Situation					
Spouse/significant other				40	71.40%
Children/grandchildren				2	3.60%
Alone				14	25.00%
Education					
Less than high school				2	3.60%
High school diploma or equivalent				20	35.70%
< 4 years of college				11	19.60%

Table 4.1 (continued)

Education (continued)					
Bachelor's degree or equivalent				5	8.90%
Graduate work/degree				18	32.10%
Income	$51,050	$44,100	$36,117		
Less than 10k				-	-
$10,000-14,999				4	9.50%
$15,000-24,999				4	9.50%
$25,000-34,999				3	7.10%
$35,000-49,999				12	28.60%
$50,000-74,999				10	23.80%
$75,000-99,999				3	7.10%
$100,000-149,999				5	11.90%
$150,000-199,999				-	-
$200,000+				1	2.40%
Social Support	7.13	6	5.04		
0 members				1	1.90%
1 member				4	7.70%
2 members				4	7.70%
3 members				3	5.80%
4 members				7	13.50%
5 members				6	11.50%
6 members				4	7.70%
7 members				1	1.90%
8 members				2	3.90%
9 members				1	1.90%
10 members				11	21.20%
> 10 members				8	14.30%
Number of Children	2.73	2	1.43		
Religiosity	3.72	4	1.31		
Low religiosity				20	37.00%
High religiosity				34	63.00%
Spirituality	3.94	4	1.19		
Low spirituality				18	33.30%
High spirituality				36	66.70%

Fifty-two participants recorded the number of individuals who provide support, with responses varying widely from 0 to "at least 25." The average number of individuals who provide support was 7 ($Mdn = 6$; $SD = 5$). Further, most participants had living

children (94.6%), with an average of almost 3 children per individual ($SD = 1.43$).

Number of children varied from zero to six. Three participants had a deceased child.

Finally, religiosity and spirituality scores were high, averaging 3.72 ($SD = 1.31$)

and 3.94 ($SD = 1.19$) on the five point-scale, respectively, with a median of 4 for both.

Responses for the 54 participants who reported their religiosity and spirituality levels

varied from one to five, with scores clustered in two distinct groups (see Figures 4.1 and

4.2). Because of this clustering, both variables were analyzed as continuous (i.e., using

the raw data) *and* binary variables reflecting low (responses of 1, 2, or 3) and high values

Figure 4.1
Distribution of Religiosity Scores
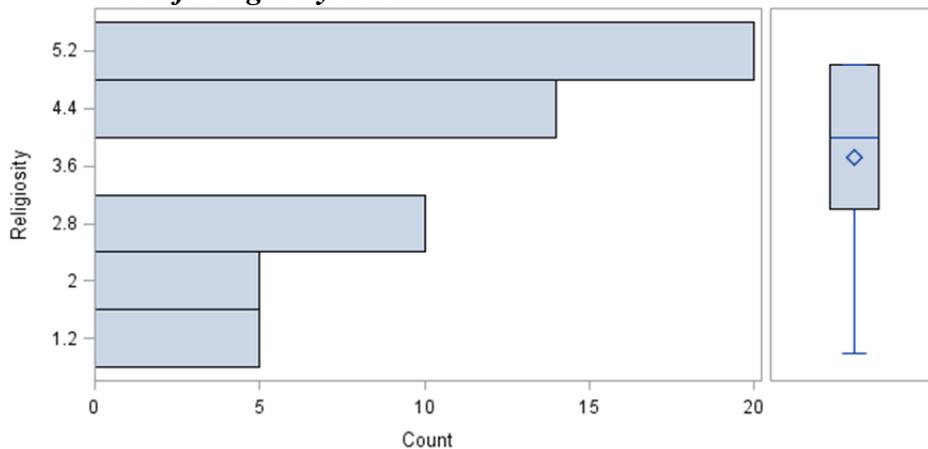
Figure 4.2
Distribution of Spirituality Scores
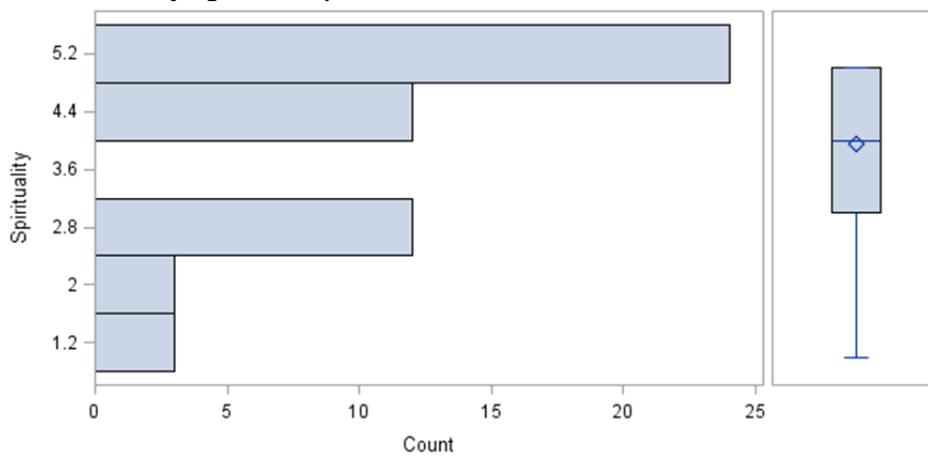
(responses of 4 or 5). Re-categorizing each variable revealed that two-thirds of the sample reported high religiosity and high spirituality.

Clinical characteristics.

Cancer site. Cancer sites were grouped into 12 categories: bladder; blood and bone; breast; cervix; colon; lung; ovary; prostate; skin; stomach; throat and tongue; and thyroid. Participants reported a wide range of cancer diagnoses, with half of the sample reporting either breast, blood, or bone cancer (See Table 4.2). Four participants indicated they had cancer in two sites, including three participants recruited through the KCR (participant 202 wrote "Lung/ Prostate" which was coded as "lung;" participant 230 wrote "breast metastes [sic] to bone" which was coded as "breast;" participant 232 wrote "ovarian, peritoneal" which was coded as "ovary;" and participant 304 recorded "ovarian

Table 4.2
Clinical Characteristics

Variable	Mean	Median	SD	n	%
Cancer Location					
Breast				15	26.8%
Blood and Bone				12	21.4%
Prostate				7	12.5%
Skin				5	8.9%
Colon				3	5.4%
Lung				3	5.4%
Ovary				3	5.4%
Stomach				2	3.6%
Throat and Tongue				2	3.6%
Thyroid				2	3.6%
Bladder				1	1.8%
Cervix				1	1.8%
Months since Diagnosis	36.71	33.00	19.76		
Cancer Significance	5.38	6.00	1.88		
Life Crises					
Old life crisis (pre-cancer)				23	53.5%
Recent life crisis (post-diagnosis)				8	20.9%

and breast," which was coded as "ovary").

 Time since diagnosis. The time since diagnosis was assessed by taking the month

and year of diagnosis, and calculating the elapsed time in months (as of survey

completion). A scatterplot of the data revealed three outliers: participants 305 (363

months), 302 (166 months), and 303 (122 months) (see Figure 4.3). All three of these

participants were recruited through the OLLI e-news blast, for which the advertisement

did not specify that participants needed to have received a cancer diagnosis within five

years of the diagnosis. Because the elapsed times since diagnosis for these three

participants were well beyond 2 standard deviations out from the mean, their data were

not included in analyses including time since diagnosis.

Figure 4.3
Distribution of Time since Diagnosis Scores
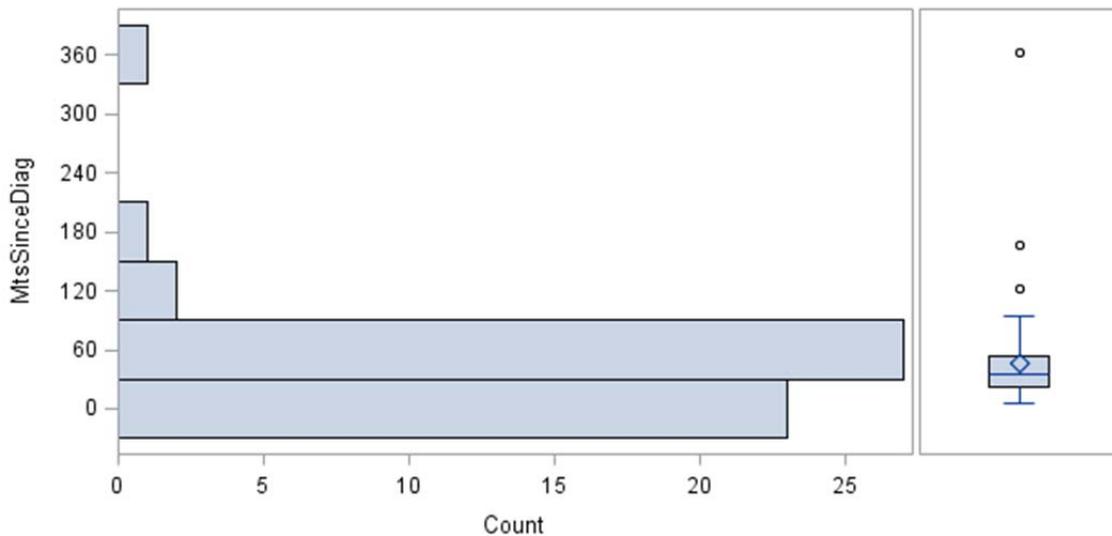
 On average, the remaining participants (51 who responded to this question)

received a cancer diagnosis 37 months prior to survey completion (*SD* = 20 months), with

a median of 33 months. The range of responses varied from six to 95 months. Of these

participants, six indicated their cancer diagnosis was received more than five years prior

to participating in the study (ranging from 65 to 95 months); four of these six had been recruited by the KCR. Because these six individuals' responses were not more than two standard deviations above the mean, their data were retained for the subsequent analyses with this variable.

Cancer stage/status. In the survey, participants were asked to report their cancer "stage/status", but they appeared to interpret this question in different ways. For example, some indicated that the cancer was gone, but did not state what stage they were in upon diagnosis. Others put down a stage (e.g., Stage III) but it was unclear whether they were currently in that stage, or originally diagnosed with that stage. Still others indicated what treatment they had received. Given the wide variability in participant interpretation of this question and inconsistency in responses, it was not possible to categorize or compare the responses in a meaningful way for statistical analyses, and these data were not included in analyses.

Cancer significance. The personal impact of a cancer diagnosis (and, feasibly, the survivorship period to date) was evaluated through a single question (on a scale of 1-7, "How significant has a diagnosis of cancer been in your life?"). Reponses were high ($M = 5.38$, $SD = 1.88$) ($Mdn = 6.00$), with only two individuals reporting a one out of seven (these two had bladder cancer and bone cancer).

Participants also reported any life crises they had experienced, and these were then coded as "old" life crises that occurred before the cancer diagnosis (e.g., "My appendix ruptured when I was 8 months pregnant and I had peritonitis before I was diagnosed…" and "My husband died in December of 2006…"), and "recent" life crises that likely co-occurred with or followed the cancer diagnosis (e.g., "Terminal illness and

death of spouse due to idiopathic pulmonary fibrosis…I was the primary caregiver throughout her illness and through mine"). This binary assortment was intended to allow for an assessment of growth in participants who also experienced other traumatic events (or life crises) during the same time period, in the event that their cancer survivorship experience was shaped by other important life events. For most of the participants' responses, it was challenging to assess whether the crisis co-occurred with the cancer diagnosis (e.g., "divorce ruined my health and my future"). Overall, thirteen participants declined to answer the question, ten indicated "no" or "none," and an additional three wrote "N/A." In sum, of the 43 who responded to this question, 23 indicated they had experienced a life crisis prior to receiving a diagnosis. A total of eight participants recorded non-cancer-related life crises that clearly co-occurred with their cancer survivorship.

Summary. Participants were somewhat older than anticipated due to issues with recruitment through the KCR (i.e., they recruited individuals who were 60 or older at the time of diagnosis, instead of at present). Consistent with the general populace of Kentucky, participants were overwhelmingly Caucasian, religious or spiritual, and had a variety of levels of education. Consistent with older populations, participants were primarily female, and either married or widowed, living with their spouse or significant other, or living alone. Income was approximately normally distributed, and social support networks ranged in size with a fairly normal distribution centered at six individuals. One third of the sample reported 10 or more members in their social support system.

Compared to national and state-wide frequencies, participants in this sample reported higher rates of breast and blood or bone cancer, and lower rates of lung and

colon cancer (see Figure 4.4). Higher rates of breast cancer may have been due, in part, to

older women being especially amenable to discussing their experience with cancer;

indeed, much of the research on PTG and cancer survivorship has been conducted with

breast cancer survivors (e.g., Cordova et al., 2001; Cordova et al., 2007; Danhauer et al.,

2013; Lelorain et al., 2010; Manne et al., 2004; Mystakidou et al., 2008; Sears et al.,

2003). The relatively low rates of lung cancer may be due to low rates of survival among

lung cancer patients, and, perhaps more relevantly, distress related to cancer survivorship

(e.g., treatment, and management of symptoms) that predisposed participants to not be

Figure 4.4
Percentage of Diagnoses by Cancer Site in the Study Sample, Kentucky, and the United States
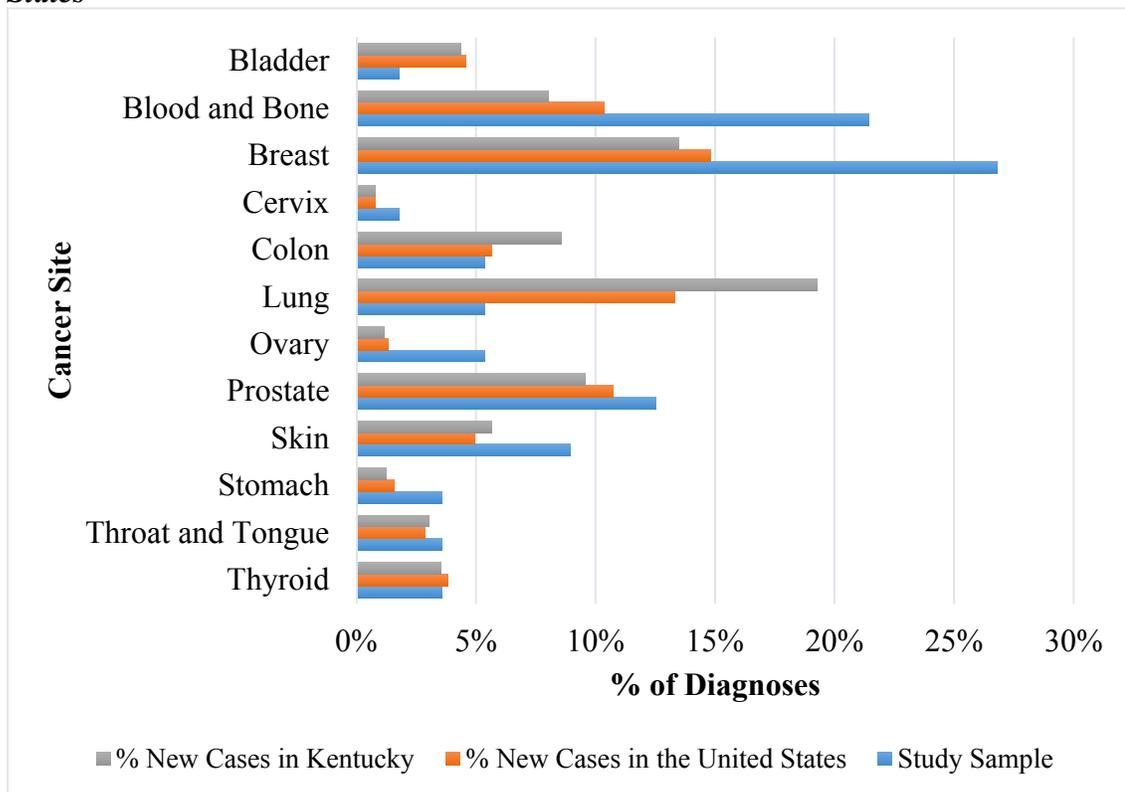
Note. Data for Kentucky and the United States reflect anticipated new cancer diagnoses by cancer site for 2016 as a function of all new cancer diagnoses (1,685,210 in the United States, and 25,720 in Kentucky).
Source: American Cancer Society. *Cancer Facts & Figures 2016*. Atlanta: American Cancer Society; 2016.

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interested in study participation. The greater percentage of blood and bone cancer survivors is not readily explainable and may simply be due to chance. Similarly, a greater percentage of ovarian and stomach cancer is not readily interpretable due to few participants reporting such cancer locations (ovary: three participants; stomach: two participants).

Inferential Statistics

To evaluate bivariate relationships among the demographic and clinical variables, Pearson's *r* correlations were run with the ratio, interval, and binary variables (see Table 4.3), and Spearman's ρ was run with the ordinal variables. For completeness, the Spearman's ρ correlations for the ratio, interval, and binary variables are also included in Table 4.3.

There were negative associations between age and education ($\rho = -21, p = .12$), and age and income ($\rho = -.43, p < .01$). Having experienced a prior life crisis was associated with being male ($r = -.29, p = .05; \rho = -.29, p = .05$) and being White/Caucasian, although this failed to reach statistical significance ($r = .24, p = .12; \rho = .24, p = .12$). There was also a marginally significant relationship between being unmarried and experiencing a recent life crisis ($r = -.28, p = .07$).

Being married was significantly and positively correlated with higher education ($\rho = .31, p = .02$) and higher income ($\rho = .51, p < .001$). In turn, both education and income were highly correlated with one another ($\rho = .58, p < .0001$). Social support was significantly associated with being married ($\rho = .32, p = .02$), and higher levels of education ($\rho = .48, p < .001$) and income ($\rho = .55, p < .001$).

Table 4.3

Bivariate Correlations between Demographic and Clinical Variables (Pearson's r and Spearman's ρ)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
	1	0.08	0.13	-0.21	0.39	0.03	-0.25	-0.02	-0.13	-0.44	0.13	-0.05	0.15	-0.21	-0.43	-0.19
1. Age		0.56	0.34	0.12	<.01	0.85	0.07	0.89	0.35	<.001	0.40	0.73	0.29	0.12	<.01	0.17
	56	56	56	56	56	54	54	54	54	55	43	43	51	56	42	53
	0.05	1	0.00	0.27	0.25	0.04	-0.09	-0.02	-0.08	-0.01	-0.29	0.05	0.20	0.06	0.08	0.13
2. Sex - Male	0.71		0.97	0.05	0.07	0.76	0.54	0.90	0.56	0.96	0.05	0.74	0.15	0.65	0.64	0.35
	56	56	56	56	56	54	54	54	54	55	43	43	51	56	42	53
	0.16	0	1	0.22	-0.09	0.13	-0.08	0.02	-0.09	-0.07	0.24	0.01	0.13	-0.02	0.08	0.00
3. Race - White	0.23	0.97		0.11	0.52	0.33	0.54	0.89	0.52	0.62	0.12	0.96	0.37	0.87	0.64	0.99
	56	56	56	56	56	54	54	54	54	55	43	43	51	56	42	53
	-0.21	0.27	0.22	1	0.09	0.05	-0.12	0.12	-0.09	-0.02	-0.11	-0.28	-0.03	0.31	0.51	0.32
4. Marital Status - Married	0.12	0.05	0.11		0.51	0.71	0.38	0.37	0.53	0.87	0.50	0.07	0.85	0.02	<.001	0.02
	56	56	56	56	56	54	54	54	54	55	43	43	51	56	42	53
	0.36	0.15	-0.1	0.08	1	0.17	-0.17	0.22	-0.08	0.00	-0.17	-0.02	0.18	-0.15	-0.17	0.10
5. Number of Children	0.01	0.26	0.45	0.58		0.21	0.21	0.11	0.54	0.97	0.28	0.88	0.20	0.26	0.29	0.47
	56	56	56	56	56	54	54	54	54	55	43	43	51	56	42	53
	0.03	0.02	0.08	0.03	0.11	1	0.64	0.87	0.59	-0.19	0.05	-0.06	0.12	-0.22	-0.18	0.03
6. Religiosity	0.85	0.86	0.57	0.85	0.45		<.0001	<.0001	<.0001	0.17	0.76	0.72	0.42	0.12	0.26	0.83
	54	54	54	54	54	54	53	54	53	53	41	41	50	54	42	52
	-0.2	-0.12	-0.07	-0.13	-0.22	0.64	1	0.60	0.87	-0.15	-0.01	0.09	-0.04	0.00	-0.04	0.10
7. Spirituality	0.14	0.37	0.62	0.33	0.12	<.0001		<.0001	<.0001	0.30	0.97	0.58	0.79	0.99	0.81	0.47
	54	54	54	54	54	53	54	53	54	53	41	41	49	54	41	52
	0.01	-0.02	0.02	0.12	0.19	0.87	0.63	1	0.63	-0.14	0.06	-0.18	0.07	-0.19	-0.06	-0.04
8. High Religiosity	0.95	0.9	0.89	0.37	0.17	<.0001	<.0001		<.0001	0.32	0.72	0.26	0.64	0.16	0.69	0.78
	54	54	54	54	54	54	53	54	53	53	41	41	50	54	42	52

Table 4.3 (continued)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
9. High Spirituality	-0.08	-0.08	-0.09	-0.09	-0.14	0.56	0.87	0.63	1	-0.25	0.03	0.07	-0.12	-0.06	0.04	0.06
	0.58	0.56	0.52	0.53	0.33	<.0001	<.0001	<.0001		0.07	0.85	0.66	0.41	0.65	0.82	0.67
	54	54	54	54	54	53	54	53	54	53	41	41	49	54	41	52
10. Significance	-0.51	-0.03	-0.1	-0.01	-0.04	-0.2	-0.12	-0.14	-0.22	1	-0.02	-0.09	-0.03	0.04	-0.10	-0.18
	<.0001	0.84	0.45	0.97	0.76	0.16	0.41	0.31	0.11		0.91	0.55	0.85	0.75	0.52	0.20
	55	55	55	55	55	53	53	53	53	55	43	43	51	55	41	52
11. Old Life Crises	0.2	-0.29	0.24	-0.11	-0.1	0.06	0.07	0.06	0.03	0.01	1	-0.21	-0.09	0.21	0.07	-0.11
	0.19	0.05	0.12	0.5	0.51	0.72	0.67	0.72	0.85	0.96		0.18	0.59	0.17	0.70	0.51
	43	43	43	43	43	41	41	41	41	43	43	43	40	43	32	40
12. Recent Life Crises	-0.1	0.05	0.01	-0.28	-0.08	-0.04	0.11	-0.18	0.07	-0.07	-0.21	1	0.24	0.17	0.17	0.15
	0.53	0.74	0.96	0.07	0.6	0.79	0.51	0.26	0.66	0.67	0.18		0.14	0.26	0.36	0.34
	43	43	43	43	43	41	41	41	41	43	43	43	40	43	32	40
13. Time since Diagnosis	0.13	0.16	0.15	-0.01	0.05	-0.05	-0.07	0.03	-0.14	-0.10	-0.03	0.21	1	-0.10	0.04	-0.04
	0.37	0.26	0.29	0.96	0.71	0.74	0.62	0.84	0.35	0.49	0.86	0.19		0.47	0.81	0.80
	51	51	51	51	51	50	49	50	49	51	40	40	51	51	39	48
14. Education	-	-	-	-	-	-	-	-	-	-	-	-	-	1	0.58	0.48
	-	-	-	-	-	-	-	-	-	-	-	-	-		<.0001	< .001
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	56	42	53
15. Income	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	0.55
	-	-	-	-	-	-	-	-	-	-	-	-	-	-		< .001
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	42	41
16. Social Support	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	53

Note: Pearson's *r* correlations are presented in the bottom left (*r, p, n*) and Spearman's *ρ* correlations are presented in the upper right (*ρ, p, n*).

Religiosity and spirituality were highly correlated with one another ($r = .64$, $p <$ .0001; $\rho = .64$, $p < .0001$), as would be expected, and there was a marginal relationship between age and spirituality ($\rho = -.25$, $p = .07$) that was nonsignificant when examining the Pearson's r correlation.[13] Furthermore, religiosity was negatively associated with education such that less educated individuals reported higher levels of religiosity, but this relationship failed to reach significance ($\rho = -.22$, $p = .12$). Conversely, there was no statistically meaningful relationship between spirituality and education ($p = .99$).

Cancer significance was inversely related with age, such that younger participants found their cancer diagnosis to be more personally significant than older participants ($r = -.51$; $p < .001$; $\rho = -.44$, $p < .001$). Cancer significance was also associated with high spirituality, but this relationship failed to reach statistical significance ($r = -.22$, $p = .11$; $\rho = -.25$, $p = .07$). Finally, an exploratory ANOVA examining cancer significance by cancer category was nonsignificant ($p = .23$).

Summary. Older participants tended to be less educated with lower incomes as compared to their younger counterparts. Married participants also tended to be more educated with higher incomes than nonmarried participants. There was a robust positive association between education and income, and both, in turn, were linked to greater social support, indicating that participants from higher SES backgrounds felt they could rely on more supportive others than those from lower SES backgrounds. Participants, by and large, were highly religious and spiritual, and older participants reported being more spiritual than their relatively younger counterparts. There was no statistical relationship between spirituality and education, but less educated individuals generally reported

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[13] It is feasible that the skew in the spirituality scores (which trended toward higher scores) were better assessed using Spearman's ρ, considering Pearson's r is less robust to outliers.

higher levels of religiosity. In terms of clinical variables, younger participants reported greater perceived significance of their cancer diagnosis (and/or overall experience), and participants reporting the highest levels of spirituality tended to feel their cancer was more significant.

<div align="center">**Specific Aim One**</div>

Posttraumatic Growth

Posttraumatic growth was assessed by first evaluating total scores calculated from the Posttraumatic Growth Inventory (PTGI). Three participants appeared to have turned a survey page and missed the last four questions of the PTGI, all of the distress questions, and the entirety of the STS, and four additional participants did not complete all questions of the PTGI. Across the 49 participants who completed all of the PTGI questions, total PTG was high with a mean of 53.98 (*SD* = 28.68) and a median of 62 out of 105 possible points. Average PTG (which included all participants' responses) was 2.74; multiplying this score by the total number of questions (21), yielded an average score of 57.54, indicating that scores were high even among those who did not complete all PTGI questions.

Mean scores were highest for two of the three scale items for *appreciation of life*: "An appreciation for the value of my own life," (*M* = 3.55, *SD* = 1.66; on a scale from 0 to 5) and "Appreciating each day" (*M* = 3.55, *SD* = 1.86) (see Table 4.4). Four of the seven items for *relating to others* also had high mean scores ranging from 3.02 to 3.16 ("Having compassion for others," "I accept needing others," "I learned a great deal about how wonderful people are," and "Knowing that I can count on people in times of

trouble"). Scores were generally lowest for the *new possibilities* (*Means* ranging from

1.84 to 2.71) and *spiritual change* subscales (*Means* ranging from 2.48 to 2.71).

Table 4.4
Scores on the Posttraumatic Growth Inventory (PTGI) (range = 0 to 5)

#	Question	*Mean*	*SD*
1	My priorities about what is important in life.	2.98	1.80
2	An appreciation for the value of my own life.	3.55	1.66
3	I developed new interests.	1.84	1.62
4	A feeling of self-reliance.	2.30	1.81
5	A better understanding of spiritual matters.	2.71	1.89
6	Knowing that I can count on people in times of trouble.	3.02	1.81
7	I established a new path for my life.	1.96	1.75
8	A sense of closeness with others.	2.63	1.80
9	A willingness to express my emotions.	2.36	1.75
10	Knowing I can handle difficulties.	2.88	1.85
11	I'm able to do better things with my life.	2.35	1.74
12	Being able to accept the way things work out.	2.96	1.90
13	Appreciating each day.	3.55	1.86
14	New opportunities are available which wouldn't have been otherwise.	1.88	1.83
15	Having compassion for others.	3.16	1.90
16	Putting effort into my relationships.	2.71	1.98
17	I'm more likely to try to change things which need changing.	2.71	1.70
18	I have a stronger religious faith.	2.48	2.02
19	I discovered that I'm stronger than I thought I was.	3.23	1.79
20	I learned a great deal about how wonderful people are.	3.02	1.68
21	I accept needing others.	3.04	1.64

Posttraumatic growth and demographic characteristics. Individual Pearson's

correlations (all run separately in order to maximize the effective sample size) with the

ratio, interval, and binary sociodemographic variables (age, sex, race, number of children,

religiosity, spirituality) revealed a significant negative relationship between age and PTG

($r = -.43$, $p = .002$). A simple linear regression revealed that age negatively predicted total

PTG ($b = -1.83$, $t(47) = -3.26$, $p = .002$) ($R^2 = .18$). Spearman's Rho rank correlations

with education and income were nonsignificant.

Box plots and one-way ANOVAs (with post-hoc LSD tests) were used to compare the relationships between overall PTG and the remaining categorical variables (sex, race, marital status, living situation, and social support). All ANOVA results were nonsignificant and PTG did not differ significantly across levels of any of these variables (even when dichotomizing religiosity and spirituality into low and high categories).

Posttraumatic growth and clinical characteristics. Individual Pearson's r correlations with the ratio, interval, and binary cancer-related variables (life crises, cancer significance, and months since diagnosis) revealed a significant relationship between PTG and cancer significance ($r = .30$, $p = .04$). There was no significant relationship between PTG and time since diagnosis. Removing the three outliers with very long times since diagnosis (see previous section) and re-running the correlation with overall PTG suggested that PTG declined over time, although this trend failed to reach significance ($r = -.24$, $p = .11$).

PTG did not differ across all cancer sites, or across cancer sites reported by at least five participants (i.e., "breast" – 15 participants, "blood and bone" – 12 participants, "prostate" – 7 participants, and "skin" – 5 participants). There was also no significant relationship between PTG and having experienced a life crisis before or since the cancer diagnosis.

Finally, a multiple linear regression with age and cancer significance (selected because they were significantly correlated with total PTG) revealed only age was significantly associated with overall PTG ($b = -1.57$, $t(45) = -2.34$, $p = .02$) ($R^2 = .186$).

Posttraumatic Growth Subscales

To better compare scores on each of the subscales, all subscale scores were normed to allow for more easily interpretable scores (see Figure 4.5). For example, the *relating to others* subscale has 35 possible points, and thus the normed *relating to others* score was calculated as the unadjusted mean score (19.53) / the total possible points (35) to create a normed score of .56. All statistical analyses were performed on the unaltered (e.g., non-normed) data.

Figure 4.5
Normed PTGI Subscale Scores
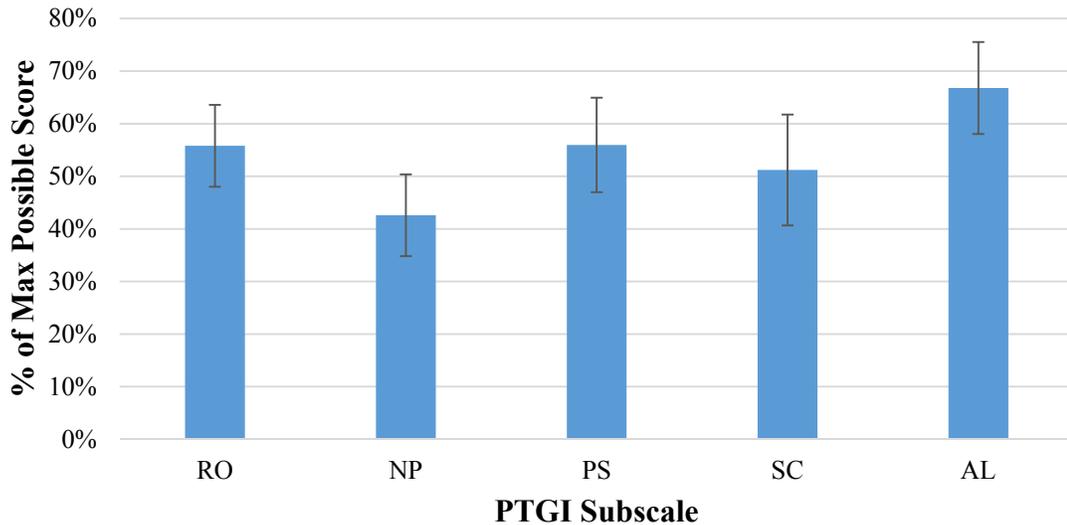
Note. Error bars represent 95% confidence intervals. RO = *relating to others*; NP = *new possibilities*; PS = *personal strength*; SC = *spiritual change*; AL = *appreciation of life*.

Relating to others. Across participants, the mean score was 19.53 ($SD = 10.01$) and the median score was 22 out of 35 possible points. Most participants reported some change in this subscale, as removing participants who recorded all zeros for the *relating to others* subscale ($n = 3$) revealed a mean score of 20.7 ($SD = 9.03$) (a minimal change from the unadjusted mean of 19.53).

Age was negatively correlated with *relating to others* ($r = -.28, p = .045$). No other bivariate relationships were statistically significant.

New possibilities. Across participants, the mean score for *new possibilities* (NP) was 10.65 (*SD* = 7.12) and the median was 12 out of 25 possible points. Scores were heavily zero inflated, meaning that several participants (*n* = 12) indicated "0" for these questions, reporting that they felt no change in the form of new possibilities. Removing those who recorded all zeros for the NP subscale revealed a mean score of 13.69 (*SD* = 4.76).

Age was negatively correlated with NP, although this relationship was only marginally significant ($r = -.23, p = .094$). Married participants reported higher NP scores than non-married participants ($r = .29, t(52) = -2.15, p = .04$), and a one-way ANOVA with post-hoc LSD tests suggested that this result was primarily due to the difference in responses between married participants and single participants (although there were only three single participants). Further, a one-way ANOVA revealed a significant difference in NP scores based on living situation, such that those living with a spouse or significant other reported higher NP scores ($F(2, 51) = 3.77, p = .03$).

Finally, there was a nonsignificant trend such that time since diagnosis was negatively associated with NP after removing the three outliers with very long times since diagnosis ($r = -.22, p = .125$). There were no other statistically significant relationships between NP and the sociodemographic or clinical variables.

Personal strength. The mean score for the *personal strength* (PS) subscale was 11.19 (*SD* = 6.40) and the median was 14 out of 20 possible points. Removing the

participants who reported only zeros for the PS subscale ($n = 7$) revealed a mean score of 12.89 ($SD = 4.99$).

Age was negatively correlated with PS ($r = -.28$, $p = .045$). A one-way ANOVA with post-hoc LSDs suggested a difference in PS based on living situation ($F(2,50) = 2.26$, $p = .115$) whereby individuals living with a child or grandchild had lower scores compared to those living with a spouse or living alone. No other bivariate relationships were statistically significant.

Spiritual change. The two-item *spiritual change* (SC) subscale mean was 5.12 ($SD = 3.77$) and the median was 5.5 out of a possible 10 points. Scores for this subscale varied widely, with an interquartile range of 1.0 to 9.0 and a bimodal distribution with modes at 0 and 10. Removing participants who only recorded zeros for the SC subscale revealed a mean score of 6.65 ($SD = 2.85$).

SC was negatively correlated with age ($r = -.33$, $p = .02$) and positively correlated with spirituality ($r = .27$, $p = .05$). Collapsing spirituality and religiosity into binary variables (i.e., scores of 3-5 were high and scores of 1 and 2 were low) also revealed a significant relationship between SC and high spirituality ($r = .29$, $p = .04$) and a marginally significant relationship between SC and high religiosity ($r = .27$, $p = .058$). Time since diagnosis, when removing the three outliers, was marginally correlated with SC ($r = -.27$, $p = .07$), suggesting there was less spiritual change as more time passed since the cancer diagnosis. When running a multiple linear regression with age, high spirituality, and high religiosity, only age remained significant ($b = -.16$, $t(45) = -2.04$, $p = .05$).

Appreciation of life. The mean *appreciation of life* (AL) score was 10.02 (*SD* = 4.81) with a median of 11 out of 15 possible points. Most participants reported high scores, with 25% of respondents reporting 14 or 15 total points. Removing participants who only recorded zeros for the AL subscale revealed a mean score of 11.02 (*SD* = 3.77).

AL was negatively correlated with age (*r* = -.52, *p* < .0001) and positively correlated with being married (*r* = .28, *p* = .04). A one-way ANOVA with post-hoc LSDs revealed a significant difference in AL scores based on living situation, such that individuals living with a child or grandchild generally reported lower AL scores than those living with a spouse or significant other, or living alone. Finally, after removing outliers, time since diagnosis was negatively associated with AL, (*r* = -.31, *p* = .03), and cancer significance was positively associated with AL (*r* = .47, *p* = .0003). A multiple linear regression with age, marital status (as a binary variable), time since diagnosis, and cancer significance, revealed that AL was still significantly associated with cancer significance (*b* = .78, *t*(46) = 2.21, *p* = .03), and marginally associated with age (*p* = .08) and being married (*p* = .099). The relationship between AL and time since diagnosis trended toward statistical significance (*p* = .13). Collectively, these variables explained a third of the variance in AL (R^2 = .36).

Distress

The PTGI items were highly correlated with the distress items (α = .96). Overall, participants reported low levels of endorsement for each distress item, as mean scores ranged from 1.11 ("I had difficulty relating to my family in the same way") to 2.82 ("I felt my cancer diagnosis to be a threat to my life") (see Figure 4.6).

Threat to life. Participants reported a mean score of 2.82 ($SD = 2.02$) and a median score of 3 for feeling like they were no longer able to do the things they once enjoyed. Scores varied, with an interquartile range of 1-5, and a plurality of respondents marking the highest possible score. One participant wrote a note on the survey stating "at first" next to a score of 5.

Feeling the cancer diagnosis was a threat to life was negatively associated with age ($r = -.46$, $p = .0006$) and positively associated with cancer significance ($r = .56$, $p < .0001$). A linear regression with both age and significance revealed that only cancer significance remained statistically significant ($b = .48$, $t(48) = 3.00$, $p = .004$) ($R^2 = .34$). While cell sizes were very small for most of the cancer categories (e.g., 2 and 3), LSD tests revealed significant differences in responses such that participants with lung cancer reported higher scores for feeling the cancer diagnosis was a threat to life than those with stomach cancer or thyroid cancer.

Figure 4.6
Posttraumatic Distress Scores

Note. Error bars represent 95% confidence intervals.

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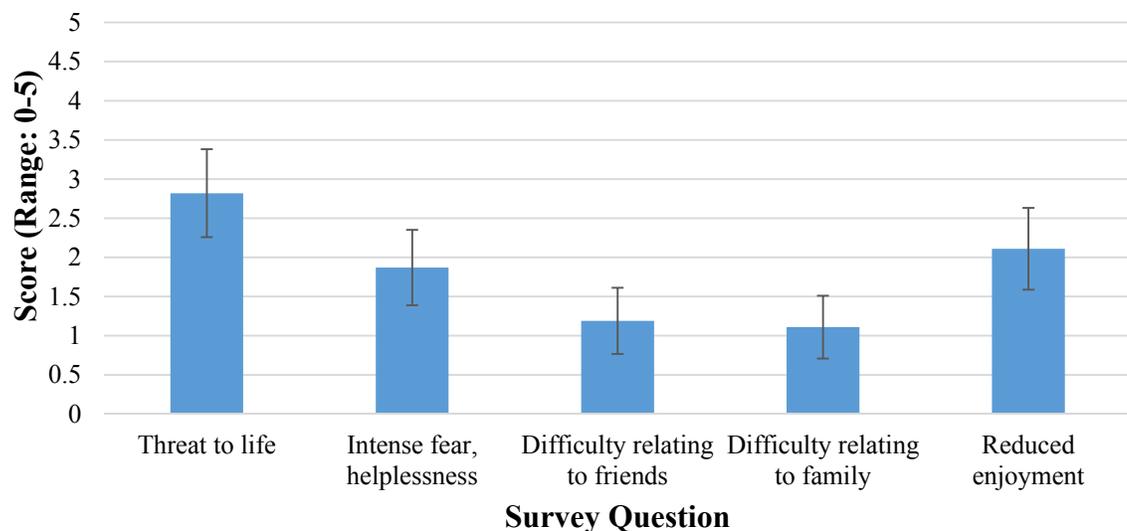
Fear and helplessness. The average score for feeling fear and helplessness was low at 1.87 (SD = 1.77) with a median score of 1. The interquartile range spanned the entire range of possible responses, and half of participants indicated either a 0 or a 1. One participant wrote "for 10 days only" next to a response of 5 for this question.

There was a negative relationship with age (r = -.27, p = .055) and a positive relationship with cancer significance (r = .52, p < .0001). While failing to reach statistical significance, there were also trends in the data such that feeling fear and helplessness was associated with lower education (ρ = -.21, p = .13). A linear regression with age and cancer significance revealed a highly significant association between fear and helplessness and cancer significance (b = .48, t(49) = 3.56, p < .001), but no meaningful relationship with age (p = .99).

Difficulty relating to friends. The mean score for having difficulty relating to friends was 1.19 (SD = 1.49), with a median of 0 (indicating a floor effect). Half of participants recorded a 0, and the interquartile range was small, ranging from 0 to 2.

There was a marginal relationship between difficulty relating to friends and being younger (r = -.24, p = .08) and male (r = .23, p = .10). Experiencing difficulty relating to friends trended toward being negatively associated with education (ρ = -.22, p = .11), and was significantly associated with having fewer members in one's social support system (ρ = -.32, p = .03). In terms of medical characteristics, there was a significant relationship with cancer significance (r = .33, p = .02). A linear regression revealed both social support (p = .05) and cancer significance to be statistically significant (b = .23, t(44) = 2.16, p = .04). A post-hoc general linear model adding age and sex revealed that these

two variables washed out the relationship with cancer significance ($p = .24$), as sex was significantly associated with difficulty relating to friends ($b = .91$, $t(42) = 2.41$, $p = .02$).

Finally, there was a trend toward differences in responses based on cancer category ($F(11,41) = 1.64$, $p = .12$). LSD tests revealed this trend was driven by greater difficulty relating to friends for those with throat and tongue cancer (even though there were only two participants with those types of cancer), and lung cancer (for whom there were three participants).Throat and tongue cancer may predict difficulty relating to friends due to disfigurement and/or speech issues that hinder communication with others (and may promote feelings of shame or embarrassment). The association with lung cancer may be due, in part, to feelings of stigma or shame on the part of the individual with lung cancer.

Difficulty relating to family. The results for having difficulty relating to family were similar to those for having difficulty relating to friends. Participants reported a mean score of 1.11 ($SD = 1.47$) and a median score of 0 for having difficulty relating to family. Half of participants did not endorse feeling any difficulty relating to family, and the interquartile range of responses ranged from 0 to 2.

Difficulty relating to family was negatively associated with social support ($\rho = -.30$, $p = .03$) and trended toward a negative association with education ($\rho = -.22$, $p = .12$). Having difficulty relating to family was also positively correlated with cancer significance ($r = .31$, $p = .03$), and negatively associated with sex, such that males felt more difficulty relating to family ($r = .28$, $p = .046$). A multiple linear regression with sex, social support, and cancer significance ($R^2 = .32$) revealed significant associations with sex ($b = .92$, $t(43) = 2.40$, $p = .02$) and cancer significance ($b = .22$, $t(43) = 2.19$, $p = $

.03), and a marginally significant relationship with social support ($p = .06$). There was also a marginal association with cancer type ($F(11,41) = 1.96, p = .059$) driven primarily by participants with throat and tongue cancer, and lung cancer. Participants with prostate cancer also reported significantly higher scores than participants with breast cancer, even though the mean and median scores for both sets of individuals were below the midpoint of the scale (indicating that participants with prostate and breast cancer generally reported low scores on this scale).

Overall, while having difficulty relating to family was not related to age, it was associated with being male, having fewer members in one's social support system, and perceiving the cancer experience as more significant. Difficulty relating to family members was linked to throat and tongue, and lung cancer, conceivably via the same mechanisms listed previously. It is likely that the differences in responses found between breast and prostate cancer were due to sex differences, such that female respondents found less difficulty in relating to family members than did male respondents.

Reduced enjoyment. Participants reported a mean score of 2.11 ($SD = 1.90$) and a median score of 2 for feeling reduced enjoyment. Again, many participants did not endorse this statement at all, recording a score of 0.

Spirituality was negatively correlated with feeling reduced enjoyment ($r = -.29, p = .04$), and positively correlated with cancer significance ($r = .38, p = .006$). There was a significant negative association with social support ($r = -.38, p = .007$), and a trend toward significance with education ($r = -.21, p = .13$). A multiple linear regression with spirituality, significance, and social support revealed only cancer significance ($b = .28$, $t(42) = 2.48, p = .02$) and social support ($p < .001$) remained significant. For social

support, individuals with 3-5 members in their support system had marginally less enjoyment than those with 0-2 members in their social support system ($p = .09$). Finally, while a one-way ANOVA with cancer category was not significant, there were significant differences in responses such that individuals with lung cancer reported higher scores than those with thyroid or skin cancer, and those with blood and bone cancer reported higher scores than those with skin cancer.

Overall, reduced enjoyment was associated with being having fewer members in one's social support system, and feeling increased cancer significance. Higher scores for individuals with lung cancer may have been due to symptoms associated with lung cancer (e.g., breathing problems), social concerns (e.g., difficulty relating to others and/or feelings of shame), or with treatment (e.g., chemotherapy).

Open-Ended Responses

A total of 24 participants (42.9%) recorded responses to the open-ended question at the end of the PTG section. Several of these participants indicated that their cancer experience was overshadowed (or influenced) by other events such as comorbidities, other life crises, and financial issues. For instance, participant 170 wrote that "*some of my responses are influenced by my chronic back pain in addition [to] dealing with cancer.*" Other participants remarked on the negative lasting effects of both the cancer and cancer treatment; participant 169 stated "*...after 4 ½ years free and clear I continue to have memory recall difficulties I associate with chemo/radiation therapy.*" Participant #127 confessed "*my reasons for negative answers comes [sic] from treatment only (which I found I didn't need!)*"

Several participants reflected feeling a greater appreciation of life and of others, and of the time left to live. For example, participant 133 stated "*...having physical problems does give you a greater appreciation of what you <u>do</u> have...*" and participant 149 stated "*I felt my diagnosis was a wake-up call about life in general. I'm more aware that we all have limited time in this life.*" Similarly, many participants indicated they felt a greater acceptance of death, stating "*we all tend to put death out of our minds but this experience brought it home to me*" (participant 149), and "*I feel I accepted what I faced and just got on with it. Just another part of living is dying*" (participant 213). Participant 230 remarked that "*prior to the diagnosis I actually feared death, but almost to the day of diagnosis I let the fear go. I finally realized it is what you do with your life in the short time we have on earth.*"

Many participants reflected on their reliance on faith and on other people. Participant 162 noted that "*family and friends were very supportive and concerned and very attentative [sic] to me and my family,*" and participant 105 wrote:

> "*For ten days, I thought I had eight months to live. My inner body felt as if a motor were turning. My husband and I cried a lot. He had to come to grips with possibly losing me. I had researched Triple negative breast cancer on the internet and felt that my prognosis wasn't good. I prayed fervently to Jesus Christ on the 9th night and awoke on the 10th morning with peace. It came that if there is a day appointed to be born and a day to die, then I could do nothing to change that. I relied on Christ my Lord to walk me through the journey.*"

Finally, participant 208 suggested that it is difficult to tease apart changes due to cancer, and changes due to getting older by stating "*how much is age related? How much is cancer related?*"

Summary

Older age was associated with less overall PTG, lower scores on each of the PTG subscales, and decreased cancer significance (although this latter relationship was nonsignificant when controlling for participants' age). Scores on the subscales were highest for *appreciation of life*, *personal strength*, and *relating to others*, consistent with the open-ended responses highlighting appreciation of life, acceptance of life situation (and death), and support from others. Generally, other demographic and clinical variables were not statistically associated with PTG, particularly after controlling for age. The only exception was for *appreciation of life*, which was associated with cancer significance and being married (and trended toward an association with time since diagnosis).

Scores on the distress items were low, particularly for experiencing difficulty relating to family and friends. These low scores were due, in part, to many participants indicating no change (i.e., "0"), perhaps due to greater acceptance, as reflected in the open-ended responses. Increased cancer significance was linked to all distress items with the exception of difficulty relating to friends. Decreased social support was linked to the relational distress items, namely difficulty relating to friends and family, and experiencing reduced enjoyment. An unanticipated outcome was the relationship between distress and sex, such that being male was linked to having difficulty relating to friends and family members. Overall, when controlling for other variables, neither age nor religiosity or spirituality were associated with distress. This latter result is especially noteworthy, given participants' emphasis on their faith not only in the open-ended responses, but also in their overall religiosity and spiritualty scores. Finally, participants

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with lung cancer tended to score higher for all of the distress items with the exception of fear and helplessness.

Specific Aim Two

To identify and measure the relationship between posttraumatic change and transcendence, I first evaluated self-transcendence and its association with posttraumatic growth. I then analyzed gerotranscendence and its association with posttraumatic growth, and assessed the relationship between transcendence and posttraumatic distress.

Self-Transcendence

Across participants, the mean self-transcendence (ST) score was 35.54 ($SD =$ 6.09) (removing the final question resulted in a mean of 34.6 with a standard deviation of 6.35) out of 45 possible points, but the distribution of scores was heavily skewed such that half of the sample scored between 32 and 39. Mean scores were highest for "Accepting myself as I grow older" ($M = 2.65$, $SD = .59$), "Having an ongoing interest in learning" ($M = 2.62$, $SD = .71$), and "Adjusting well to my present life situation" ($M = 2.58$, $SD = .57$) (see Table 4.5).

After removing the final question and two outliers more than two standard deviations below the mean (with total scores of 18 and 19), ST was positively associated with high religiosity ($r = .28$, $p = .059$), spirituality ($r = .37$, $p = .01$) and high spirituality ($r = .34$, $p = .02$), and education ($r = .31$, $p = .03$). There was no significant association with age, but there was a marginally significant relationship with sex, such that females tended to report higher ST ($r = -.26$, $p = .068$). No other bivariate relationships were significant.

Table 4.5
Self-Transcendence Scale (STS) Scores (range = 0 to 3)

#	Question	Mean	SD
1	Having hobbies or interests I can enjoy.	2.49	0.82
2	Accepting myself as I grow older.	2.65	0.59
3	Being involved with other people or my community when possible.	2.42	0.84
4	Adjusting well to my present life situation.	2.58	0.57
5	Adjusting to changes in my physical abilities.	2.40	0.69
6	Sharing my wisdom or experience with others.	2.36	0.83
7	Finding meaning in my past experiences.	2.32	0.87
8	Helping others in some way.	2.55	0.67
9	Having an ongoing interest in learning.	2.62	0.71
10	Able to move beyond some things that once seemed so important.	2.43	0.75
11	Accepting death as a part of life.	2.60	0.72
12	Finding meaning in my spiritual beliefs.	2.44	0.89
13	Letting others help me when I may need it.	2.32	0.61
14	Enjoying my pace of life.	2.32	0.70
15	Dwelling on my past losses.	0.96	0.85

A multiple linear regression with high religiosity and spirituality, education, and sex, revealed nonsignificant relationships between ST and high religiosity and spirituality. Being female (b = -2.76, $t(37)$ = -2.01, p = .05) and having more education (p = .047) was associated with higher ST scores.

Posttraumatic growth and self-transcendence. PTG was significantly associated with ST (r = .39, p = .008), without controlling for any other variables. A simple exploratory linear regression revealed that, controlling for spirituality, this association was still significant (b = .06, $t(40)$ = 2.43, p = .02). An ANOVA with ST and marital status trended toward significance ($F(43,47)$ = 2.00, p = .11), and LSD tests revealed divorced participants reported lower ST than non-divorced participants. When examining PTG by subscale, it was found that ST was positively correlated with the *relating to others* (r = .40, p = .005), *new possibilities* (r = .38, p = .009), *personal*

strength ($r = .28$, $p = .055$), and *spiritual change* ($r = .31$, $p = .04$) subscales. No other

bivariate relationships were significant.

Table 4.6
Confirmatory Factor Analysis Standardized Regression Weights for a Single Latent Factor and Two Latent Factors

Scale	Scale Item	Single Factor	Two Factors
STS			
	Having hobbies or interests I can enjoy.	0.00	0.61
	Accepting myself as I grow older.	-0.01	0.62
	Being involved with other people or my community when possible.	0.34	0.80
	Adjusting well to my present life situation.	0.07	0.66
	Adjusting to changes in my physical abilities.	0.13	0.49
	Sharing my wisdom or experience with others.	0.23	0.65
	Finding meaning in my past experiences.	0.38	0.61
	Helping others in some way.	0.01	0.61
	Having an ongoing interest in learning.	0.07	0.69
	Able to move beyond some things that once seemed so important.	0.22	0.46
	Accepting death as a part of life.	0.04	0.32
	Finding meaning in my spiritual beliefs.	0.22	0.36
	Letting others help me when I may need it.	0.35	0.37
	Enjoying my pace of life.	0.25	0.62
PTGI			
	My priorities about what is important in life.	0.82	0.83
	An appreciation for the value of my own life.	0.68	0.69
	I developed new interests.	0.72	0.72
	A feeling of self-reliance.	0.73	0.74
	A better understanding of spiritual matters.	0.69	0.69
	Knowing that I can count on people in times of trouble.	0.69	0.69
	I established a new path for my life.	0.79	0.79
	A sense of closeness with others.	0.77	0.77
	A willingness to express my emotions.	0.75	0.74
	Knowing I can handle difficulties.	0.85	0.85
	I'm able to do better things with my life.	0.89	0.89
	Being able to accept the way things work out.	0.86	0.87
	Appreciating each day.	0.83	0.83
	New opportunities are available which wouldn't have been otherwise.	0.60	0.60

Table 4.6 (continued)

Having compassion for others.	0.65	0.66
Putting effort into my relationships.	0.82	0.83
I'm more likely to try to change things which need changing.	0.81	0.81
I have a stronger religious faith.	0.72	0.72
I discovered that I'm stronger than I thought I was.	0.72	0.72
I learned a great deal about how wonderful people are.	0.71	0.70
I accept needing others.	0.67	0.66

To better assess whether PTG and ST reflect a similar construct, I then ran a confirmatory factor analysis with all ST items (not including the final scale item) and all PTG items as indicator variables that loaded onto a single latent factor. The model provided a suboptimal fit to the data, as shown by the standardized regression weights (see Table 4.6) ($\chi^2(560) = 1339.13$, $p < .001$; $\chi^2/df = 2.39$; CFI = .49; RMSEA = .16, 90%CI = .15-.18). The standardized regression weights for ST were very low (all under .4); optimally, standardized regression weights should be .7 or higher (Kline, 2010). In fact, the weights for scale items 1 and 2 were near zero and actually negative.

In the second model, the ST items were loaded onto a single latent factor (ST) and the PTG items were loaded onto a second latent factor (PTG) ($\chi^2(559) = 1167.39$, $p < .001$; $\chi^2/df = 2.09$; CFI = .60; RMSEA = .15, 90%CI = .13-.16). The χ^2-difference test indicated this second model provided a better fit to the data ($\chi^2_D(1) = 171.74$, $p < .0001$). Across models, the standardized regression weights for PTG were essentially equivalent, but the ST weights were much better for the second model (and very poor in the first model). Together, these results indicate not only that PTG and ST reflect different constructs, but they also suggest greater psychometric validity for the PTGI compared to the STS.

Gerotranscendence

Scores on the Gerotranscendence Scale ranged from .76 ("My life feels chaotic and disrupted") to 2.36 ("The life I have lived has coherence and meaning") (see Table 4.7). Scores for two of the items ("My life feels chaotic and disrupted" and "I like meetings with new people") were reverse-coded, consistent with what is found in the literature, and Cronbach's alphas were tabulated for the *cosmic*, *self*, and *social relations* dimensions of gerotranscendence (see Chapter Three).

Table 4.7
Gerotranscendence Scale Scores (range = 0 to 3)

#	Question	Mean	SD
1	I feel connected with the entire universe.	1.30	0.91
2	I feel that I am a part of everything alive.	1.70	0.99
3	I can feel a strong presence of people who are elsewhere.	1.33	1.10
4	Sometimes I feel like I live in the past and present simultaneously.	1.00	1.03
5	I feel a strong connection with earlier generations.	1.44	0.92
6	My life feels chaotic and disrupted.	0.76	0.82
7	The life I have lived has coherence and meaning.	2.36	0.82
8	I like to be by myself better than being with others.	1.27	0.98
9	I like meetings with new people.	2.09	0.92
10	Being at peace and philosophizing by myself is important for my well-being.	2.05	0.99

Cosmic. The distribution of scores for *cosmic* transcendence was approximately normal, with a mean of 1.35 (*SD* = .68) (possible scores ranged from 0 to 3), and the highest score (albeit a relatively low score) was for "I feel that I am a part of everything alive." Two participants did not circle any responses for the five *cosmic* items (but they did mark responses for other transcendence scale items), and one (209) simply wrote several question marks next to the *cosmic* items. Another participant (231), wrote that in reference to scale item 5, his "connection with earlier generations is more historical than

empathetic." Finally, participant 105 indicated that their connection with the universe (item 1) reflected a connection with "God."

Cosmic transcendence was significantly associated with self-transcendence ($r = .49$, $p = .0006$), and for the demographic variables, *cosmic* transcendence was marginally associated with education ($r = .26$, $p = .06$), and significantly associated with marital status ($F(50,53) = 4.43$, $p = .008$), such that married participants reported significantly higher *cosmic* transcendence scores than single participants, but significantly lower scores than widowed participants. Single participants also reported significantly lower scores than widowed participants. Further, the relationship with cancer category trended toward significance ($F(42,53) = 1.57$, $p = .14$), revealing higher scores for ovary, prostate, and breast cancer survivors than blood and bone cancer.

Posttraumatic growth and cosmic transcendence. *Cosmic* transcendence was highly correlated with total PTG ($r = .57$, $p < .0001$). A multiple linear regression with total PTG, education, and marital status revealed only significant associations between *cosmic* transcendence and total PTG ($b = .01$, $t(38) = 5.20$, $p < .0001$) and marital status ($p < .01$) such that *cosmic* transcendence scores were higher for widowed participants than married participants ($b = .47$, $t(38) = 2.25$, $p = .03$), but lower for single participants compared to married participants ($b = -.90$, $t(38) = -2.73$, $p < .01$).

When examining each of the PTG subscales, it was found that *cosmic* transcendence was positively and significantly correlated with all five of the subscales (*relating to others*: $r = .49$, $p < .001$; *new possibilities*: $r = .65$, $p < .0001$; *personal strength*: $r = .62$, $p < .0001$; *spiritual change*: $r = .41$, $p < .01$; *appreciation of life*: $r = .42$, $p < .01$).

Self. The mean scores for scale items 6 (when reverse-coded) and 7 were 2.24 (*SD* = .82) and 2.36 (.82), respectively, reflecting a fairly high endorsement for each item. As indicated in Chapter Three, further analyses were not run for the *self* dimension given the low correlation between the two scale items, and the ceiling effect and non-normal scores found for scale item 7.

Social relations. The three scale items for the *social relations* dimension yielded an alpha of -.33, in part, because item 9 ("I like meetings with new people") was heavily endorsed (*M* = 2.09, *SD* = .92; i.e., before it was reverse-coded). In other words, it was expected, as per Gerotranscendence Theory, that participants would mark low scores for enjoying meetings with new people, but the reverse was true in this sample. Furthermore, the two remaining items were only marginally correlated with each other (*r* = .23, α = .38, *p* = .087), perhaps because item 8 ("I like to be by myself better than being with others") received a low endorsement (*M* = 1.27, *SD* = .98). As indicated in the previous chapter, scale item 8 was selected as most representative of the *social relations* dimension, in spite of heavy zero inflation (i.e., many participants recorded "0"), and subsequent statistical analyses were performed on this single item.

Given the non-normality of responses to item 8, Spearman's ρ was used to evaluate bivariate relationships with continuous variables. Higher scores for the social relations dimension of gerotranscendence was significantly associated with being female (ρ = -.34, *p* = .01) and having experienced a prior life crisis (ρ = .41, *p* < .01), and marginally associated with cancer significance (ρ = .25, *p* = .067). No other bivariate relationships were significant. A linear regression with sex and prior life crises revealed only sex remained significant (*b* = -.88, *t*(40) = -3.20, *p* < .01). These statistical

relationships were maintained when adding cancer significance to this model (i.e., sex was still statistically significant; $p < .01$).

Posttraumatic growth and social relations. The *social relations* dimension was significantly and positively correlated with total PTG ($\rho = .37$, $p = .01$). For the subscales, *social relations* was significantly and positively correlated with *new possibilities* ($\rho = .27$, $p = .049$) and *spiritual change* ($\rho = .34$, $p = .01$), and marginally associated with *personal strength* ($\rho = .24$, $p = .096$) and *appreciation of life* ($\rho = .29$, $p = .10$).

Posttraumatic Distress and Transcendence

Bivariate correlations between the distress items and self-transcendence (after removing the two outliers mentioned previously) revealed no significant relationships (all p's $> .05$). For gerotranscendence, there were no significant relationships between *cosmic transcendence* and each of the distress items, but there were several positive associations between *social relations* and the distress items. The *social relations* dimension of gerotranscendence was significantly and positively associated with feeling more fear and helplessness ($\rho = .29$, $p = .03$), difficulty relating to friends ($\rho = .35$, $p = .01$), and difficulty relating to family ($\rho = .31$, $p = .02$). There was also a marginally significant association between *social relations* and feeling cancer was a threat to life ($\rho = .25$, $p = .07$).

Open-Ended Responses

A total of nine participants (16.1%) responded to the open-ended question asking for additional comments. One participant (169) indicated that the GS question 10 was more relevant in the context of faith, such that "*telling others how Christ literally pulled from death and continues to give me strength [to] live, love, and enjoy life.*" Another

participant (151) also mentioned pulling strength from their faith, stating "*I have always, from childhood on, always had a strong religious faith. This is a continuing source of structure and support and strength.*"

Consistent with the higher scores on GS question 8 on being around others, a couple of participants remarked on the importance of their social interactions, e.g., "*There are times when I need to be alone to rest my brain! I am the epicenter of a large extended family. They all count on me for advice. I like it that way, but sometimes, it becomes exhausting. I retreat to my bedroom once in a while to simply regroup…*" (participant 105).

Summary

Scores for self-transcendence were high, and positively associated with being female and having more education. Self-transcendence was positively correlated with overall PTG, and all subscales but *appreciation of life*. This relative collinearity did not translate into both variables reflecting a single underlying construct, as a confirmatory factor analysis revealed they are indeed two separate phenomena.

Gerotranscendence was difficult to analyze given issues with the scale itself (both statistical issues, and concerns expressed on the part of participants). Greater *cosmic* transcendence was linked to higher education, and being widowed (or married), and certain types of cancer (such as breast, ovary, and prostate cancer), but not age. *Cosmic* transcendence was also highly correlated with PTG (including the five subscales), even when controlling for education and marital status. Females and individuals who had experienced a prior life crisis scored higher on the *social relations* dimension of gerotranscendence. PTG was significantly and positively associated with *social relations*,

and there was a significant association between this dimension of transcendence and the *new possibilities* and *spiritual change* subscales. Perhaps surprisingly, there were no statistically significant relationships between the *social relations* dimension and social support. Qualitatively, participants did note the importance of social interactions. Open-ended responses also revealed a focus on strength through faith, even though religiosity and spirituality did not emerge as significant indicators of the variables of interest when controlling for other demographic variables (e.g., sex).

Finally, there were no statistically meaningful relationships between the distress items and self-transcendence or *cosmic* transcendence. The *social relations* dimension of gerotranscendence was significantly associated with more fear and helplessness, and difficulty relating to both friends and family.

<div align="center">**Specific Aim Three**</div>

In order to explore the relationship between posttraumatic change and well-being, I first examined the distribution of well-being scores, and the relationships between well-being and participant characteristics. I then evaluated the associations between PTG and well-being, and distress and well-being.

Well-Being

When reverse-coded (so higher scores would reflect increased well-being), the average score for well-being was 48.33 ($SD = 9.63$). Two outliers were removed (with scores of 8 and 14), and the resulting correlation was .85 with an average score of 49.77 ($SD = 6.26$). In accord with the high mean score, there was a ceiling effect such that half of the sample scored 50 or higher out of 56 possible points. Scores were highest for scale items 8 ("People respect me;" $M = 6.48$, $SD = .77$), 6 ("I am a good person and live a

good life;" *M* = 6.40, *SD* = .99), and 1 ("I lead a purposeful and meaningful life;" *M* =

6.35, *SD* = .89) (see Table 4.8).

Well-being was negatively correlated with having experienced a recent life crisis

(r = -.37, p = .02) and positively correlated with increased education (r = .36, p = .008).

Well-being was marginally associated with marital status ($F(47,51)$ = 2.28, p = .075), and

LSD tests revealed that divorced participants reported significantly lower well-being

scores than all other participants. An ANOVA with cancer category was not significant (p

= .21), but LSD tests revealed that participants with lung cancer reported significantly

lower well-being compared to all other participants with exception of those with blood

and bone cancer. No other bivariate relationships were significant.

Table 4.8
Reverse-Coded Well-Being Scores (range = 1 to 7)

#	Scale Item	Mean	SD
1	I lead a purposeful and meaningful life.	6.35	0.89
2	My social relationships are supportive and rewarding.	6.19	1.08
3	I am engaged and interested in my daily activities.	6.17	1.11
4	I actively contribute to the happiness and well-being of others.	6.17	1.15
5	I am competent and capable in the activities that are important to me.	5.85	1.59
6	I am a good person and live a good life.	6.40	0.99
7	I am optimistic about my future.	6.15	1.11
8	People respect me.	6.48	0.77

Posttraumatic Change and Well-Being

Well-being was not significantly associated with either total PTG or the PTG

subscales (all p's < .45), but was significantly negatively associated with difficulty

relating to friends (r = -.37, p = .01), difficulty relating to family (r = -.36, p = .01), and

reduced enjoyment (r = -.33, p = .02).

Open-Ended Responses

Twelve participants (21.4%) responded to the final, open-ended question. Here, a few participants acknowledged the negative impact of other life events such as comorbidities (e.g., participant 193 has Black Lung and Chronic Obstructive Pulmonary Disorder-COPD). One participant (175) indicated that they "*have had so many misfortunes at the same time – it was hard to deal with all of them at the same time – so I retreaded [sic] into myself – dealing only [with] what was major at that particular time – I am somewhat numb and slowly coming out of my "funk.""*

Others commented on the value of their social relationships/social support system, and the reliance on their faith. For example, participant 192 indicated that "*God has brought me through this crisis and I am here to help others.*" Similarly, participant 105 wrote:

> "*I am saved by the Grace of Jesus Christ, my Lord and Savior. He walks me through each day. He is always on my mind. When I hear birds singing, I attribute it to a free gift from God Almighty who sustains me and gives me "butterfly kisses" (not original). I live a great life. Breast cancer was a bump in the road that just slowed me down a bit.*"

Still others mentioned that they do not dwell on their cancer; participant 162 stated "*I am a very active person and respond to my daily activites [sic] and chores. Basically I am a very healthy individual. I do not dwell on the situation which occurred two-half years ago.*" Participant 169 also noted that "*to a great degree happiness is a personal choice. I see myself more as a spiritual cheerleader. Through Christ we receive forgiveness over and above all our past.*"

Summary

Well-being scores were very high across participants, and associated with higher education and not having experienced a recent life crisis. There were no statistically meaningful relationships between PTG and well-being, but lower well-being was associated with having more difficulty relating to friends and family, and experiencing less enjoyment. In the open-ended section, participants noted the negative impact of other life events and comorbidities, even in light of relatively high well-being scores. They also remarked on the importance of their social relationships and faith, and electing to have a positive outlook in spite of having a cancer diagnosis.

Specific Aim Four

The last specific aim was to explore the relationship between posttraumatic growth and coping. To do this, coping was first assessed by examining scores on each of the 14 subscales from the Brief COPE, and then analyzing coping in terms of problem-focused, emotion-focused, and meaning-focused strategies. Then, each coping strategy was analyzed in the context of its relationship with posttraumatic growth.

Coping Styles

Participants employed acceptance more than any other coping style ($M = 4.42$, $SD = 1.91$), and there was also strong endorsement of religion as a coping style ($M = 3.91$, $SD = 2.15$). Generally, participants indicated that they were not using (illicit) substances ($M = .27$, $SD = 1.09$), denial ($M = .48$, $SD = 1.14$), behavioral disengagement ($M = .50$, $SD = 1.10$), self-blame ($M = .93$, $SD = 1.44$), or venting ($M = 1.13$, $SD = 1.15$) as coping strategies (see Table 4.9).

Table 4.9
Scores on the Brief COPE Subscales (range = 0 to 6)

Coping Subscale	*Mean*	*SD*
Active Coping	3.17	1.97
Planning	2.25	1.71
Instrumental Social Support	2.38	1.93
Emotional Support	3.25	1.99
Positive Reframing	2.67	2.03
Acceptance	4.42	1.91
Denial	0.48	1.14
Religion	3.91	2.15
Humor	1.40	1.71
Self-Distancing	2.18	1.91
Venting	1.13	1.15
Substance Use	0.27	1.09
Behavioral Disengagement	0.50	1.10
Self-Blame	0.93	1.44

Problem-Focused Coping

Problem-focused coping yielded an average score of 7.74 (SD = 4.65) out of 18 possible points, and was negatively associated with age (r = -.28, p = .04). Problem-focused coping was positively associated with cancer significance (r = .28, p = .04), education (r = .32, p = .02), and being male (r = .25, p = .067). There was also a marginal relationship with recent life crises (r = .27, p = .09). No other bivariate relationships were significant, but a nonsignificant ANOVA with cancer category with follow-up LSD tests revealed that participants with prostate cancer tended to use more problem-focused coping than those with breast, or blood and bone cancer.

Posttraumatic growth and problem-focused coping. Problem-focused coping was significantly and positively associated with overall PTG (r = .55, p < .0001), *relating to others* (r = .38, p = .006), *new possibilities* (r = .42, p = .002), *personal strength* (r = .35, p = .01), and *appreciation of life* (r = .44, p = .001), but not *spiritual change* (p = .22).

Emotion-Focused Coping

  Emotion-focused coping with positive reframing. As indicated in the previous chapter, emotion-focused coping has been assessed by aggregating several of the coping subscales, including *positive reframing. Positive reframing* is also used as a single item measure of meaning-focused coping, which was of theoretical interest in the context of cancer survivorship and PTG for this study. As such, emotion-focused coping was first analyzed with the *positive reframing* subscale, and then analyzed without it to provide an assessment of emotion-focused coping that was separate from meaning-focused coping.

  The average score for emotion-focused coping with the *positive reframing* (PR) subscale but without the *denial* subscale was 14.19 ($SD = 5.84$) out of 24 points with a median of 15. The distribution of scores was fairly normally distributed, but there were four participants whose scores were more than two standard deviations from the mean (they scored either 0 or 1 for emotion-focused coping) (see Figure 4.7). These participants were excluded from all other analyses for emotion-focused (PR) coping. Removing these individuals yielded an average score of 15.31 ($SD = 4.47$) with a median of 15.

  Emotion-focused (PR) coping was significantly correlated with spirituality ($r = .58, p < .0001$) and marginally correlated with religiosity ($r = .25, p = .085$). A significant ANOVA ($F(3,30) = 4.45, p = .01$) with post-hoc LSD tests revealed that skin cancer survivors (among those reporting the most commonly cited cancers) reported less emotion-focused (PR) coping than participants with breast or prostate cancer. Similarly, individuals with blood and bone cancer reported significantly less emotion-focused (PR) coping than individuals with prostate or breast cancer.

Figure 4.7
Distribution of Emotion-Focused Coping Scores with the Positive Reframing Subscale
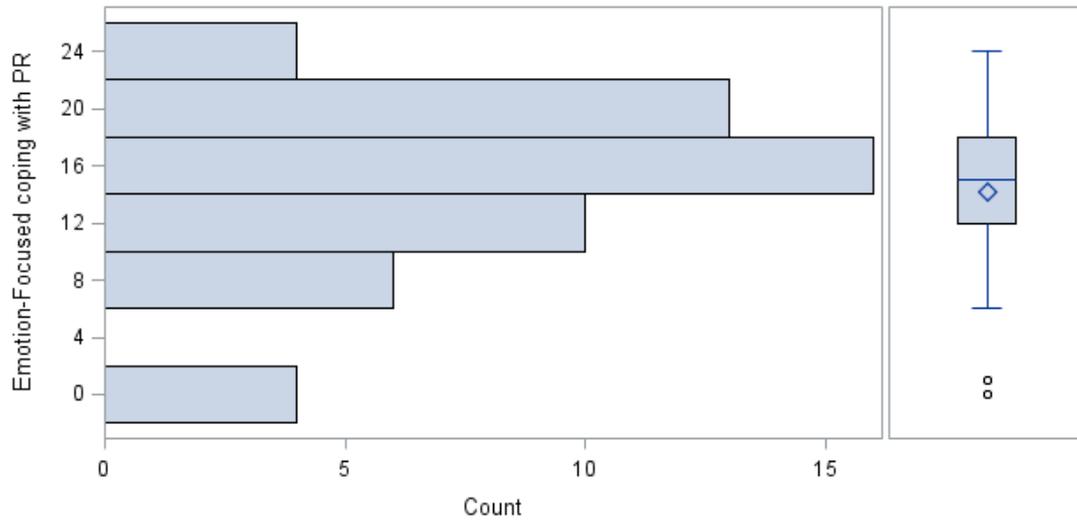
Posttraumatic growth and emotion-focused (PR) coping. Emotion-focused (PR) coping was marginally associated with overall PTG ($r = .27, p = .077$), *relating to others* ($r = .27, p = .065$), and *new possibilities* ($r = .27, p = .06$). No other bivariate relationships were significant.

Emotion-focused coping without positive reframing. Emotion-focused coping without the positive reframing or denial subscales (no-PR) had an average score of 11.58 ($SD = 4.62$) out of 18 possible points with a median score of 12. There were no outliers for the emotion-focused (no-PR) analyses.

Emotion-focused (no-PR) coping was significantly positively correlated with spirituality ($r = .37, p < .01$) and high spirituality ($r = .39, p < .01$). There was not a significant association with religiosity, but there was a marginally significant association with high religiosity ($r = .25, p = .077$), indicating this coping strategy was associated with generally higher scores on the religiosity scale.

Cancer significance was marginally associated with emotion-focused (no-PR) coping ($r = .26, p = .058$), and there was a marginally significant ANOVA with cancer

category ($F(11,43) = 1.95$, $p = .059$) that revealed significantly lower scores for blood and bone cancer survivors as compared to breast, ovary, prostate, colon, and throat and tongue cancer survivors. Similarly, skin cancer survivors reported lower scores than prostate and breast cancer survivors. Running the ANOVA only with the most frequently reported cancer sites revealed a significant association ($F(3,35) = 4.88$, $p < .01$) in the manner described above.

Posttraumatic growth and emotion-focused (no-PR) coping. Emotion-focused (no-PR) coping was significantly and positively associated with overall PTG ($r = .36$, $p = .01$), *relating to others* ($r = .28$, $p = .05$), and *new possibilities* ($r = .27$, $p = .05$). There was also a marginally significant relationship between emotion-focused (no-PR) coping and *spiritual change* ($r = .24$, $p = .097$), but no significant relationships with *personal strength* or *appreciation of life*.

Meaning-Focused Coping

The average score for meaning-focused coping was 2.67 ($SD = 2.03$) out of six possible points with a median of three. Scores varied from 0 to 6, with many reporting "0" (see Figure 4.8).

Meaning-focused coping was significantly positively associated with spirituality ($r = .32$, $p = .03$) and high spirituality ($r = .35$, $p = .01$). Cancer significance and having a recent life crisis were both significantly associated with meaning-focused coping ($r = .31$, $p = .03$; $r = .33$, $p = .03$, respectively). While not statistically significant, individuals with more education tended to use more meaning-focused coping ($r = .21$, $p = .137$). No other bivariate relationships were significant.

Figure 4.8
Distribution of Scores for Meaning-Focused Coping
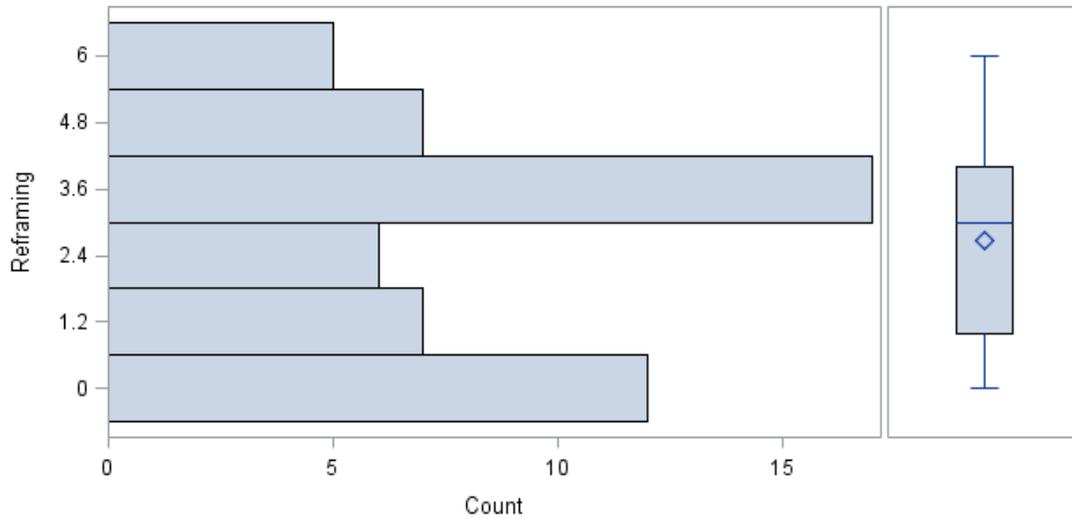
Posttraumatic growth and meaning-focused coping. Meaning-focused coping was significantly and positively associated with overall PTG ($r = .54$, $p < .0001$), and all five of the subscales: *relating to others* ($r = .41$, $p = .003$), *new possibilities* ($r = .37$, $p = .006$), *personal strength* ($r = .41$, $p = .003$), *spiritual change* ($r = .39$, $p = .006$), and *appreciation of life* ($r = .35$, $p = .01$).

PTG and All Three Coping Strategies

General linear models were used to assess the relative contributions of each coping strategy to overall PTG. In the first model, problem-focused coping, emotion-focused (no-PR) coping, and meaning-focused coping were added with all demographic and clinical predictors that were statistically associated with at least one coping strategy (i.e., $p < .11$). These included age, sex, education, spirituality, religiosity, cancer significance, recent life crises, and cancer categories. Collectively, these variables explained more than three-quarters of the variance in overall PTG ($R^2 = .87$) ($p = .08$). Removing the variable with the highest nonsignificant p-value (religiosity), yielded an R^2 of .86 ($p = .048$). With this model, overall PTG was significantly predicted by problem-

focused coping ($b = 4.23$, $t(10) = 2.95$, $p = .01$), but not emotion-focused (no-PR) coping ($p = .33$) or meaning-focused coping ($p = .35$).

In the second model, I included problem-focused coping and emotion-focused coping with the positive reframing subscale (PR) in addition to the statistically significant and marginally significant demographic and clinical variables (see above) as predictors. The four outliers mentioned previously were removed, and meaning-focused coping was not included (because it was already subsumed in the emotion-focused coping with *positive reframing* variable). Collectively, these variables did not sufficiently explain the variance in overall PTG ($p = .17$). Retaining only the demographic and clinical variables significantly related to at least one coping strategy (p values of .05 or less) improved model fit ($p = .10$). A visual examination of each independent variable's contribution to the model led to removing cancer significance and spirituality (each had p values over .5). The resultant model was significant ($p = .04$) and explained more than half the variance in overall PTG ($R^2 = .67$). Controlling for all other variables in the model, problem-focused coping significantly predicted overall PTG ($b = 3.85$, $t(18) = 3.23$, $p < .01$), whereas emotion-focused (PR) coping did not ($p = .34$).

Overall, problem-focused coping was significantly associated with higher PTG when controlling for both emotion-focused coping (measured both with and without the positive reframing subscale) and meaning-focused coping. This association with PTG was evident even in light of most participants endorsing emotion-focused coping (without positive reframing) significantly more than problem-focused coping (see Figure 4.9).

Figure 4.9
Normed Coping Strategy Scores
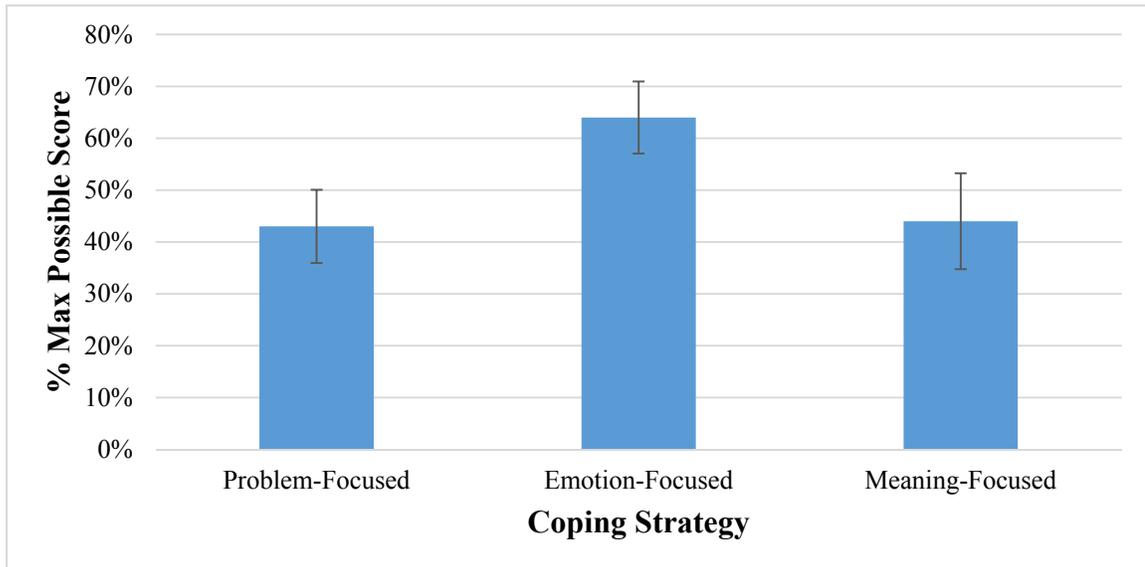
Note. Emotion-focused coping does not include the *denial* or *positive reframing* subscales.

Open-Ended Responses

A total of 13 participants (23.2%) responded to the coping open-ended question.

Several indicated they don't experience major problems from their cancer, and they

reflected on doing well overall; for example, participant 304 stated "*this was a difficult*

section because I feel I am no longer coping with cancer…there is SO much going on in

our lives – retirement, traveling, moving to Lex…cancer totally takes a back seat."

Relatedly, participants reflected on the importance of their faith and supportive

others, and having a positive outlook. Participant 105 indicated:

> *"people tell me that I "got through" breast cancer treatment better than*
> *anyone they have seen. Some say they can't believe how positive I am*
> *about it all. I just went about my business of substitute teaching without*
> *much down time at all. I did what my doctors told me to obtain the very*
> *best outcome…I relied on God and knew that if I only had eight months to*
> *live (typical TNBC [or, triple-negative breast cancer] outcome), then I*
> *would make the best of each day."*

Only one participant (230) reported feeling self-blame due to not visiting a doctor upon detecting a lump in her breast. She noted that she was ultimately diagnosed with stage IV breast cancer.

Summary

Participants reported emotion-focused coping more so than either problem-focused or meaning-focused coping. This finding is in accord with the open-ended responses highlighting acceptance, the importance of faith, and having a positive outlook, all components of emotion-focused coping. Emotion-focused coping, both with and without the *positive reframing* subscale, was positively and significantly associated with spirituality and cancer type. Generally, participants with breast or prostate cancer reported more emotion-focused coping than individuals with other cancers, such as blood or bone, or skin cancer. There was also a positive correlation between emotion-focused coping and PTG (including the *relating to others* and *new possibilities* subscales).

Problem-focused coping was associated with being younger, more educated, and feeling the cancer experience was more significant. Problem-focused coping was significantly associated with PTG (including all subscales but *spiritual change*), to such an extent that it significantly predicted PTG when controlling for relevant demographic variables and the other coping strategies (which, when added to the statistical model, were no longer statistically associated with PTG).

Meaning-focused coping was significantly and positively associated with having experienced a recent life crisis, feeling the cancer experience was more personally significant, spirituality, and PTG. As indicated, this latter association with PTG was nonexistent when controlling for the other coping strategies.

Participant Responses to Open Ended Concluding Question

Twenty participants (35.7%) responded to the final, open-ended question soliciting additional comments not addressed elsewhere in the survey. Consistent with the high levels of religiosity and spirituality (and the other open-ended comments), participants noted a reliance on their faith. For instance, participant 205 detailed how difficult it was to treat her triple-negative invasive ductal carcinoma, and how

> *"...there is nothing else that can be done except the use of experimental drugs. This is partly what helped me turn it all over to God. If man cannot come up with a plan, I knew that God can, so I placed my whole life in his hands. If He was going to take care of it, then I wouldn't have to worry, so I didn't after that day."*

Participants noted the importance of having a support system in place. Participant 144 indicated, "*luckily I have a lot of support from family and friends…which makes me feel positive about life. I have the most supportive husband who always says "we are in this together."*" Similarly, participant 149 reflected on a concern for others, noting "[I]… *don't fear death as much as leaving my family behind.*"

Several participants stated that their cancer had actually had limited impact on their life to date; participant 187 noted that "*having cancer had very little impact on my life. However, this is mainly because my cancer was not actually life-threatening.*" Similarly, participant 198 reflected, "*I don't consider my [thyroid] cancer to be in the same category as others with more serious ones…I just consider my episode a bump in the road.*"

Many participants reported that their problems really stem from other life events and comorbidities. Participant 157 said "*…most of my problems are not because of cancer,*" and admitted that it was difficult to answer some of the questions that had

"…*more than one answer.*" Participant 211 also stated, "…*breast cancer was nothing*

compared" to dealing with "…*a nodule in the middle lobe of my right lung.*" Conversely,

some participants reflected on how their cancer experience had a marked negative effect

on their life due to side effects from treatment. For example, participant 127 stated

"…*treatment much worse for me than any diagnosis. Made me worse rather than better*

and it wasn't necessary…could have avoided a lot of discomfort and uncertainty."

Participant 151 noted that cancer brought "*unpredictable diarrhea [that] has been a*

source of anxiety."

Not reflected in the quantitatively-oriented components of the surveys was an

emphasis on finances and the financial burden incurred from having a cancer diagnosis.

For example, participant 186 wrote that she was:

> "…*not prepared for the financial part cancer has played…no supplement*
> *health insurance has burden[ed] me. No way I'll ever be able to pay*
> *14,000 back to hospital doctor. I'll be dead. Feeling very guilty that I*
> *can't pay my debts! On my mind daily.*"

Participant 151 noted gratefulness over their medical coverage, given that the tablet they

must take costs over $5,000 per month, and stated that without sufficient insurance,

"…*the financial burden would have significantly altered most of my responses.*"

Finally, a recurrent theme in responses to this concluding section of the

questionnaire was that of gratefulness and reflection. For example, participant 147 noted

"…*by having my prostate removed, certain problems arise and one has to deal with the*

changes that occur. Your [sic] thankful to be alive." Participant 260 explained:

> "*None of us know what tomorrow may bring. As of today, at age 80 I am*
> *enjoying life greatly. I am thankful to God for the light of each new day,*
> *for the food he allows me to enjoy, for my lovely wife of 56 years, my*
> *children, their spouses, grandchildren, a host of wonderful friends, and all*
> *of life's many wonderful blessings. God is good.*"

Similarly, participant 229 reflected on a family history of cancer, relating that one sister

died from breast cancer, and two other siblings have had thyroid cancer for 20 years. He

concluded,

> *"Information, family support, faith and optimism laced w/ a realistic*
> *assessment of the situation are critical to dealing w/cancer on daily basis.*
> *Also, the support and encouragement provided by the medical*
> *professionals is essential to cancer management."*

Chapter Five:
Discussion and Conclusion

While there is a growing body of literature on posttraumatic growth (PTG) in cancer survivors, little attention has been paid to PTG in older adults, the population that is most likely to receive a cancer diagnosis. This dissertation was designed to examine PTG in late-life cancer survivors with a recent diagnosis in order to contribute to our psycho-oncological and gerontological knowledge base on this topic. In this concluding chapter, I situate the findings for each specific aim within the context of the current understanding of PTG to show how the findings build on or support what we already know about PTG. I then critically evaluate the findings by considering several unanticipated themes that emerged during the study. I end the chapter by presenting limitations of the study and considering future directions for research on PTG.

Specific Aim One

My first aim was to describe posttraumatic change in older adults with late-life cancer diagnoses. Posttraumatic growth in samples including young, middle-aged, and older adult cancer survivors, has varied tremendously from 43.76 ($SD = 16.21$; Mystakidou et al., 2008) to 64.1 ($SD = 24.8$; Cordova et al., 2001) when measured using the PTGI. Bellizzi (2004) assessed PTG levels in cancer survivors citing a variety of cancer sites and ages, and found that adults aged 55 and older reported PTG scores of 38.23 ($SD = 22.25$) on average. Within this limited comparative framework, results from this study suggest somewhat high levels of PTG ($M = 53.98$; $SD = 28.68$). This finding alone is notable, especially considering PTG is generally higher among younger and middle-aged adults, who tend to be the targeted age groups for research on cancer

survivorship. Even in this study with older adults, younger participants reported higher scores than older participants.

Apart from age, PTG was not predicted by demographic characteristics, contrary to what has been found in the literature to date. For example, prior studies have found positive associations between PTG and being female (Bellizzi, 2004; Tedeschi & Calhoun, 1996; Thege et al., 2014; Vishnevsky et al., 2010), and religious or spiritual (Danhauer et al., 2013), but neither association was apparent in this study. Clinically, participants experienced more PTG when their diagnosis and cancer experience was more personally significant, but cancer significance declined with age (consistent with Cordova et al., 2007), suggesting cancer was less impactful among the eldest older adults.

PTG Subscales

There is debate over the utility of assessing PTGI using both the overall score and the subscale scores (see Chapter Three). To contribute to this discussion I tested the hypothesis that one or more PTG subtypes would emerge as most prominent. On the PTGI, scores were highest for *appreciation of life* (e.g., the PTGI items with the highest scores were "an appreciation for the value of my own life," and "appreciating each day"). Qualitatively, participants also noted an enhanced appreciation of life, and acceptance, supporting a general theme of appreciation. Beyond this subscale, participants also reported relatively higher scores for *personal strength* and *relating to others*, with the lowest scores for *new possibilities*. Relatively low scores for *new possibilities* may be a product of a shortened future time perspective, considering older cancer survivors likely assess that there is less time in life and necessarily fewer opportunities for there to be new possibilities left in life. Collectively, these findings appear to provide support for Janoff-

Bulman's (2004) argument that PTG can be in the form of existential reevaluation, as evidenced through higher scores for the *appreciation of life*, *relating to others*, and *spiritual change* subscales.

Distress

Participants reported low levels of distress, especially for the relational variables (difficulty relating to friends and family), but those who felt greater cancer significance also experienced more distress. In line with the PTG findings, participants' acceptance of their situation may have translated into decreased feelings of distress. Perhaps surprisingly, time since diagnosis was not associated with feelings of distress, even though existing research has suggested that more time since initial diagnosis results in reduced distress (Stanton, 2006).

Males, and individuals with less social support, tended to acknowledge more difficulty relating to friends and family. No other participant characteristics were associated with distress. Faith was not related to distress using the quantitative measure, but participants did comment on their faith in response to several of the open-ended questions. Several participants also implicated other life factors that had a substantial influence on their daily life, such as comorbid conditions, and family or financial problems.

Finally, there was some association between cancer type and distress, particularly for individuals with lung cancer. The association with cancer type must be interpreted with caution though, considering there were very few participants with lung cancer.

Conclusion

Across participants, PTG was high, and distress was low. Being younger predicted more PTG, but had little bearing on participants' experience of distress, regardless of how long ago they had received a cancer diagnosis. While one goal of this research was to identify factors that predicted PTG, there were few characteristics that predicted PTG on the PTGI, suggesting that in this population, the manifestation of PTG is more nuanced than previously thought. It may also be the case that positive change post-diagnosis is more common in older adults given their age and already shortened future time perspective. This suggestion is tempered by the understanding that many individuals will not have the opportunity, capacity, or perhaps even temperament for experiencing PTG, but also bolstered by the nature of this study sample (a population-based random sample that confers a degree of generalizability). It is possible that participants were already experiencing changes in their worldview that limited the potential for growth over and above this "normative" change. This sentiment was reflected by participant 208, who queried, "*How much is age related? How much is cancer related?*"

Specific Aim Two

My second aim was to identify and measure the relationship between posttraumatic change and transcendence. Considering transcendence is a tenuously defined construct, I used both self-transcendence and gerotranscendence to obtain a more comprehensive measurement. I hypothesized that PTG would be positively associated with transcendence, and that PTG and transcendence reflect a single latent construct.

Consistent with my first hypothesis, self-transcendence was highly correlated with PTG. Self-transcendence was also higher among females and individuals reporting higher levels of education. As indicated by a confirmatory factor analysis, the two variables truly reflected two different constructs in spite of their high covariance. It may be inferred that PTG reflects a path of coping post-diagnosis that is not simply a form of hastened transcendence, but rather a separate type of change that is unique to dealing with trauma. The findings from the confirmatory factor analysis also indicated that PTG loaded more heavily onto the PTGI than self-transcendence did on the STS, suggesting enhanced psychometric validity for the PTGI. In other words, it is likely that the PTGI did a better job of assessing posttraumatic growth than the STS did for self-transcendence.

Gerotranscendence was assessed by evaluating two of the three dimensions on the Gerotranscendence Scale (*cosmic* and *social relations*), given measurement issues with the third dimension (*self*). *Cosmic* transcendence was associated with self-transcendence, higher levels of education, and having been in a relationship (i.e., currently widowed or currently married), potentially reflecting the importance of intimate partnerships on existential evaluations. Unlike self-transcendence, *cosmic* transcendence was not associated with sex. The *social relations* dimension was associated with being female, and having experienced a prior life crisis. Perhaps surprisingly, there was no link between *social relations* and social support, but again, given this dimension was assessed using a single scale item, these results should be viewed provisionally. Finally, both dimensions of gerotranscendence were associated with greater PTG.

Distress

There were no meaningful relationships between distress and self-transcendence or *cosmic* transcendence. The association between the *social relations* dimension of gerotranscendence and the social distress items (i.e. difficulty relating to friends and family; and feeling fear or helplessness) may reflect withdrawal on the part of some participants, although scores for the *social relations* item and distress were very low (suggesting this may be a spurious association).

Conclusion

As hypothesized, both self-transcendence and *cosmic* transcendence were associated with PTG, although PTG reflected a different underlying construct than self-transcendence. There were few associations (significant at an alpha of .05) between participant characteristics and transcendence, contrary to what has been found in the literature in other populations. For example, cosmic transcendence has been positively associated with being older, female, and having a higher income (Tornstam, 2005), none of which were found in this study. Transcendence has also been linked to age (Coward, 1996; Iwamoto et al., 2011; Sadler et al., 2006; Tornstam, 2003, 2005), but there was no such link within this study sample. Finally, there were few meaningful associations between transcendence and distress.

Specific Aim Three

There is little consensus on the nature of the relationship between well-being and PTG. Older adults tend to report higher well-being (Keyes et al., 2002), and there are robust positive associations between well-being and transcendence (Reed, 2009; Tornstam, 2005), but it is unclear whether individuals reporting growth following trauma

also report greater well-being (Lelorain et al., 2010). Thus, my third specific aim was to shed light on these two variables in older cancer survivors.

Well-being was high, especially among those who were more highly educated, and those who had not experienced a recent life crisis. Contrary to my hypothesis, there was no significant statistical association between well-being and PTG. This finding could be partly due to participants experiencing distress in some form that limits the bidirectional influence of PTG on well-being (as per Cordova et al., 2001). There was also little variability in well-being scores (i.e., a ceiling effect), which made it difficult to quantitatively tease apart the relationship between PTG and well-being. From a qualitative standpoint, several participants noted feeling a degree of acceptance with their life situation, and joy at still being alive and being able to spend time with loved ones. These comments support the quantitative results but do not necessarily reflect an association between PTG and well-being. Rather, the open-ended comments connote generally greater life satisfaction among those who were inclined to provide comments.

In terms of distress, lower well-being scores were associated with experiencing less enjoyment and more difficulty relating to friends and family. It is plausible that there was no significant relationship with the other two distress items (feeling the cancer was a threat to life, and feeling fear and helplessness) because those are more likely to be influenced by the nature of the cancer diagnosis (e.g., advanced lung cancer with a short-term prognosis), which could not be adequately assessed given the sample size and distribution of cancer sites in this study (i.e., few participants with cancer diagnoses reflecting poor prognoses).

Conclusion

In sum, PTG and well-being were not statistically related in this study. There are several possible explanations for this lack of association, including insufficient incorporation of the distress and struggle that precipitate PTG (and may thus cancel out the effects of well-being on PTG), and a ceiling effect for the well-being scores. It may also be the case that well-being is associated with PTG for individuals with certain types of cancer, but it was beyond the scope of this study to assess this quantitatively.

Specific Aim Four

The final specific aim was intended to shed light on the relationship between PTG and coping strategies. Extant research has shown older adults use fewer coping strategies (Deimling et al., 2006) and more emotion-focused strategies in order to reduce distress (Folkman et al., 1987). It was hypothesized that older adults with cancer would gravitate toward a particular coping strategy (e.g., meaning-focused coping).

Participants' scores were highest for acceptance (a component of problem-focused coping) and religion (a component of emotion-focused coping), consistent with the open-ended comments through the survey that emphasized turning to faith and accepting one's life circumstance. Prior research has also found acceptance and religion to be significant correlates of PTG (Bellizzi & Blank, 2006; Danhauer et al., 2013; Lelorain et al., 2010); these same studies found correlations between PTG and multiple coping styles. Scores were lowest for arguably maladaptive coping strategies, including using illicit substances, behavioral disengagement, and self-blame.

Emotion-Focused Coping

Overall, participants endorsed emotion-focused coping (*use of emotional support*, *acceptance*, and *religion*) more than either problem-focused or meaning-focused coping. This result is in accord with the well-documented positivity effect whereby older adults have more positive appraisals and memories for events (Mather & Carstensen, 2005), and experience less affective distress and reactivity (Charles & Carstensen, 2010). Such changes in behavior and thought processes may be due to prioritizing emotion regulation over and above other motivating influences, such as knowledge acquisition (Carstensen, 2006). This finding also aligns with Folkman and colleagues' (1987) seminal study citing emotion-focused coping as the coping strategy most often used by older adults. Emotion-focused coping is also associated with increased survival in cancer patients (Reynolds et al., 2000). In this sample, emotion-focused coping was associated with PTG, being spiritual, and with certain types of cancer, such as breast or prostate cancer. It is possible that emotion-focused coping was facilitated by having a somewhat better prognosis (as compared to, say, throat and tongue cancer), although it is difficult to evaluate this without knowing the cancer stage for each participant.

Meaning-Focused Coping

Meaning-focused coping (*positive reframing*) was significantly and positively correlated with PTG. Participants who were more spiritual, felt increased cancer significance, and had experienced a recent life crisis, were more likely to report meaning-focused coping. The relationship with recent life crises is noteworthy, as it indicates that participants were less likely to endorse this strategy unless something unrelated to their cancer had recently occurred.

Problem-Focused Coping

Participants who were younger, more educated, and felt their cancer was more significant reported more problem-focused coping (*active coping*, *planning*, and *use of instrumental social support*). Problem-focused coping was also significantly associated with PTG, as previously shown in the literature (Bellizzi & Blank, 2006; Danhauer et al., 2013; Lelorain et al., 2010). Of the three coping strategies, problem-focused coping was most predictive of PTG when controlling for relevant demographic variables. It is difficult to say that problem-focused coping is therefore the most adaptive; this finding may better reflect the relationship between active coping (as compared to passive coping) and psychosocial growth such that passive forms of coping may not facilitate PTG.

Conclusion

This study provides further evidence that all three primary coping strategies are associated with PTG, but problem-focused coping appears to explain most of the variance in PTG when factoring in both emotion-focused and meaning-focused coping.

<center>New Insights</center>

This research generated several unanticipated findings. These additional insights were gleaned during recruitment phone calls, data entry, statistical and qualitative analyses, and while writing up my findings. In this section I detail not only methodological challenges, but also themes relevant to older adults and cancer survivorship.

Measurement Challenges

Transcendence. Transcendence is a difficult concept to operationalize. Researchers have defined transcendence as expanding conceptual boundaries (Reed,

1991b) and shifting views from a materialistic to a cosmically-oriented paradigm (Tornstam, 2005). My conceptualization of transcendence is that it reflects psychological and social changes whereby individuals focus less on themselves, more on others' welfare, more on meaning *in* and *of* life, and on openness and interconnectedness. Understandably, a tenuously defined construct such as transcendence is difficult to measure; face validity is difficult to evaluate and reliability can be questionable. This research reinforced the difficulties inherent to measuring transcendence using previously used measures, as measurement issues arose with both the Self-Transcendence Scale (STS) and the Gerotranscendence Scale.

Self-Transcendence Scale. The Self-Transcendence Scale (STS) is comprised of 15 items, which collectively had an acceptable alpha of .83. However, the last question ("At this time of my life, I see myself as dwelling on past losses") received much lower scores on average when compared to other scale items, indicating very low endorsement of this particular item. I removed the final item, and results from the confirmatory factor analysis indicated that the remaining 14 items only moderately loaded onto a single underlying construct. In other words, while the items reflected self-transcendence, they did not do a great job of representing self-transcendence, especially not when compared to how well the PTGI reflected a single underlying construct (which I and other researchers term "posttraumatic growth"). It is plausible that tweaking the scale, especially for older adults or older adults with cancer, would result in a more accurate representation of self-transcendence.[14]

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[14] As indicated previously, it was discovered after the dissertation defense that the final scale item should have been reverse-coded. Future work with this data will involve re-analyses using the full scale with the final item reverse-coded.

Gerotranscendence Scale. Gerotranscendence was far more difficult to evaluate than self-transcendence. The scale items for *cosmic* transcendence cohered reasonably well ($\alpha = .71$), even though a few participants noted that the questions were confusing (or they simply did not respond to those scale items). Scores for *cosmic* transcendence were quite low, on average, potentially reflecting some participants' difficulty with interpreting the scale items.

The *self* dimension of gerotranscendence, measured using just two questions, was virtually uninterpretable. The two items, which were expected to be highly correlated, were only marginally correlated, with a very low alpha (.37). An attempt at using a single item to measure this dimension was diminished due to a large ceiling effect in scores for the chosen scale item (#7). Initial analyses (not presented in this dissertation) also reflected non-normal distributions of residuals when analyzing this single item with other variables, and thus I decided to not pursue any further analyses for the *self* dimension of gerotranscendence.

The *social relations* dimension of the Gerotranscendence Scale was highly problematic. Of the three scale items, scores for only two (# 8 and #10) were in the expected direction. Gerotranscendence Theory (Tornstam, 2005) posits that older adults will gradually embrace a need for solitude, and it was thus expected that scores for "I like meetings with new people" (item #9) would be low. In this sample, scores were unexpectedly high, thereby profoundly limiting the coherency of the *social relations* items. While I conducted exploratory analyses with item #8 (detailed in Chapter Four), it may be that the findings for item 9 are most novel. Specifically, it may be that older *cancer survivors* are less likely to withdraw from others (meaning, compared to older

adults in general) precisely because they often seek social support as a means of coping with cancer. The research on social support and cancer reflects an often (but not always!) positive influence of others on our coping experience (Schroevers, Helgeson, Sanderman, & Ranchor, 2010; Wortman, 1984), and several open-ended responses pointed to the importance of supportive others, as detailed later in this chapter.

Overall, the problems with the Gerotranscendence Scale are not entirely unexpected. Braam and colleagues (2006) have detailed how the scale itself has undergone revision, and other researchers have had difficulty drawing conclusions for the *self* and *social relations* dimensions (including Tornstam; see Tornstam, 1997). Attempts at revising the scale overall have not resulted in a reliable or valid instrument to date (see Cozort, 2008 for an example); this study provides further evidence that the Gerotranscendence Scale has limited applicability for measuring gerotranscendence.

Meaning-focused coping. There is a rich literature on the ways in which individuals find meaning in stress (e.g., Frankl, 1959). Victor Frankl, who wrote about life in a concentration camp during World War II, and the ways in which man (not sex-specific, but in the human sense) extracts meaning as a way of coping with extreme stress, explained how we can reach a point of evaluation in our lives where we create or find meaning as a means of explaining our own existence. This coping approach would appear to be highly relevant not only in the context of cancer survivorship, but also for individuals in general who reasonably anticipate a shortened time to death. It might therefore be surprising that, when designing this study, it was not readily apparent how to measure meaning-focused coping. I did not find a reliable scale to assess meaning-focused coping, and thus I elected to use a two-item subscale from the Brief COPE

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(*positive reframing*), as previously used in the literature (see Park et al., 2009). It is unlikely that this simple subscale adequately captured the complexity of meaning-focused coping, and thus related conclusions should be interpreted cautiously. Further, this subscale was a component of emotion-focused coping (Carver et al., 1989), which directly calls into question how to meaningfully tease apart meaning-focused coping from emotion-focused coping. My analyses included emotion-focused coping "proper" with the *positive reframing* subscale, and emotion-focused coping without *positive reframing* in order to attempt to evaluate both coping strategies (emotion-focused and meaning-focused) without redundancies, but it is unclear whether this is the most appropriate means of assessing emotion-focused and meaning-focused coping.

Psychosocial Growth over Time

A consistent finding in this research was that of a robust, negative relationship between PTG and age. Other demographic variables that were initially statistically correlated with PTG became nonsignificant when accounting for the influence of age. This finding was unexpected, as I thought older adults would report more positive change overall. However, a critical review of the literature highlights that this trend is remarkably consistent with what we know from existing psycho-oncological and gerontological studies, as explained below.

There are no published studies examining PTG in (only) older adult cancer survivors, but samples of young, middle-aged, and older adult cancer survivors have shown that younger individuals report more PTG (Bellizzi, 2004; Cordova et al., 2007; Danhauer et al, 2013; Manne et al., 2004; Morris & Shakespeare-Finch, 2011; Mystakidou et al., 2008; Sears et al., 2003). While this sample was age-restricted, the

variability in PTG as a function of age may reflect the individual differences between participants that is a maxim of gerontological research. In other words, participants were all older adults, but it would be incorrect to assume that all older adults experience cancer in the same way.[15] Older adults are a heterogenous group, as "older adult" is simply a form of age stratification and not a means of grouping individuals by personality, worldviews, socioeconomic status, or health (as examples). In truth, individuals are likely to become less similar with age as they accumulate more life experiences that are shaped by their own unique histories. As stated by Ferraro (1990), "…traits may vary over the life course, but standard deviations on such traits will often be larger in the advanced years" (p. 332). For the older cancer survivor who perceives his or her diagnosis (or cancer experience) as traumatic, this perception is likely to be shaped not only by prior life events and personal beliefs, but also by personal resources. For example, an individual with a low socioeconomic status, few friends, and limited access to medical treatment is going to have a remarkably different cancer experience than a highly educated socialite with a large social circle and reliable, consistent medical care. These are but a few factors that affect the lived experience of cancer, but these factors are bound to be wide-ranging in their influence on cancer survivors in older adulthood.

In this study, participants perceived their cancer experience as less "significant" as a function of age. While the express meaning of "significance" can be debated, it is apparent that cancer was less influential for older participants, especially when considering the freely written comments throughout the survey. Several participants noted acceptance of their situation, and a release of anxiety brought on by embracing

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[15] This assumption would still be questionable if participants had reported only one cancer site (e.g., breast), especially considering research has shown that the relationship between age and PTG is not influenced by cancer site (Morris & Shakespeare-Finch, 2011).

their faith. These findings build on my pilot study, where older participants were more accepting of a hypothetical cancer diagnosis, and by and large not as emotionally affected by the thought of death happening sooner than anticipated (Hoogland, 2015). These findings are also in accord with Ardelt et al.'s (2008) assertion that elderly individuals tend to view illnesses in old age as a somewhat expected, natural part of the life course.

Andrykowski and colleagues (2008) have suggested that there are several illness trajectories following a cancer diagnosis (see Figure 5.1). Initially, there is a generally reliable decline in psychological health that can either continue (resulting in deterioration), or improve over time. This improvement, should it occur, can lead to an increase in functioning that is below the cancer survivor's level of functioning pre-diagnosis (impairment), at the same level (recovery), or at an increased level of functioning (growth, or PTG). By definition, then, PTG is an assessment of the degree of positive change between the cancer survivor's psychological functionality pre-diagnosis, and after experiencing a decline, or paradigmatic shift, post-diagnosis. For older adults, this difference in functioning may be reduced in comparison to younger adults because their psychological health is already on an upward trajectory. Indeed, research has shown that older adults tend to experience less negative affect than younger adults (Charles & Carstensen, 2010), they adapt to life stressors when they have the resources to do so (e.g., Baltes & Baltes, 1990), and they are less distressed or personally impacted by late-life illness such as cancer (Ardelt et al., 2008; Carlson & Bultz, 2003; Cordova et al., 2007; Hoogland, 2015). Some of this shift in perspective may be due to a realistically shortened future time perspective.

Figure 5.1
Illness Trajectories following a Cancer Diagnosis
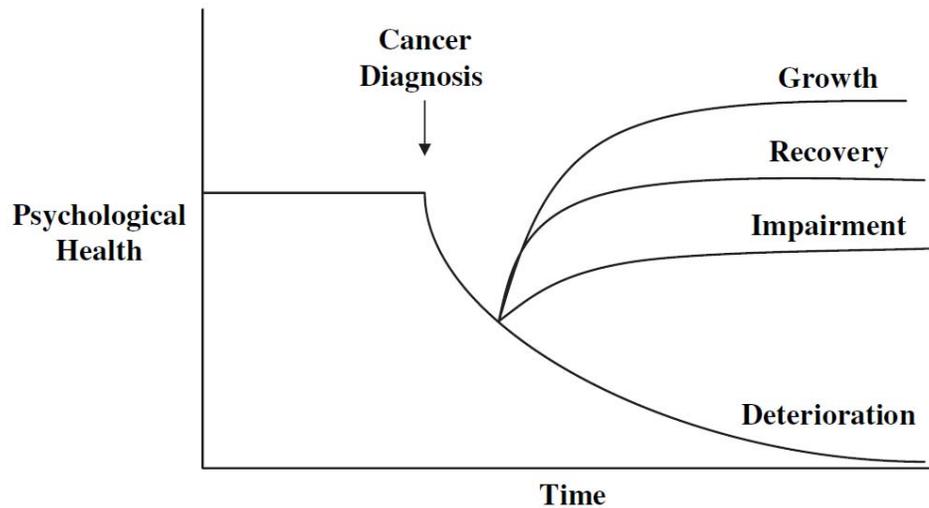
Note. Image from Andrykowski, Lykins, & Floyd (2008).

Future time perspective. As individuals grow older, they place less emphasis on the number of years lived, choosing instead to focus on other indicators of time and life stage. Older adults tend to shift their focus from time lived to time *left* in life, and this shift may explain age-related differences in attitudes (Carstensen, 2006). Older adults or younger adults coping with a terminal illness will tend to experience a limited future time perspective as they anticipate fewer years to death, while healthy younger adults will often experience a more open-ended future time perspective.

Worsening health is certainly a common trend with advancing age, and has been shown to predict fewer developmental or aspirational motives (Kooij & Van De Voorde, 2011). Declining health is likely to limit one's future time perspective; as such, it is reasonable to presume that reduced time left to live would reduce one's prioritization of developmental motives. Put simply, it is not beneficial to focus on long-term goals when there is a diminishing likelihood that one will even be alive to achieve those goals. It is perhaps for this reason that older adults generally use fewer coping strategies with age,

potentially reflecting a heightened degree of acceptance of one's circumstances (Deimling et al., 2006). Similarly, research has suggested that older adults tend to view troublesome situations as less changeable than younger adults, which may reflect a pattern of engaging in more positive reappraisal (Folkman et al., 1987). These notions are certainly supported by this study's findings; many participants reflected on positive evaluations of their current life situation, which were likely due, in part, to the role of religiosity and spirituality in their lives.

Ceding Control

Older adults generally report high levels of religiosity, and individuals in more rural areas, such as the majority of Kentucky, place a heavy emphasis on their faith. In this study, participants were highly religious and spiritual, consistent with the demographics of the region. Neither religiosity nor spirituality were expressly associated with many other variables, perhaps because there was so little variance in religiosity and spirituality scores (thereby limiting my ability to make statistical inferences). Qualitatively, participants consistently commented on a reliance on "Jesus Christ," and "God," especially as a means of reducing their anxiety by ceding control to a higher power. In other words, many participants were acknowledging a reduction in perceived control over their cancer experience. Perceived control refers to individual perceptions of control in various domains of life; generally, we either perceive that we have control over events (internal control), or we believe that there is something external to us that exerts control over said events (external control; Rotter, 1966).

An individual's sense of control is influenced by several factors that include sex/gender, SES, culture, and race. For example, women tend to experience a lower sense

of internal control than men, although there is great variability among individuals (Schaie & Willis, 2010). Understandably, those who have a lower SES perceive less internal control, likely due to the hardships they continually have to face (Schaie & Willis, 2010).

External control is generally split in the literature into "chance" and "powerful other" control (Levenson, 1974). Chance locus of control involves perceiving behaviors or events to be determined by fate, luck, or as the term suggests, mere chance (Levenson, 1974). A powerful other locus of control entails believing that a powerful individual or being (e.g., doctor or God) has power over behaviors or events (Levenson, 1974). This form of control can be most relevant when coping with a severe, debilitating illness, as recent research has highlighted the importance of religiosity and spirituality with respect to physical health in cancer survivors (Jim et al., 2015).

Individuals who are more confident in their ability to manage their health and cope with illness tend to possess a higher internal locus of control (Jacobs-Lawson, Waddell, & Webb, 2011). It is perhaps unsurprising, then, that growing older is associated with increased powerful other and chance health loci of control, perhaps due to ceding some responsibility for their health to others or fate (Jacobs-Lawson et al., 2011). From a transcendent perspective, it is feasible that older adults become more aware of their interconnectedness with others and potentially higher beings, thus allowing themselves to cede personal control to these other entities (i.e., friends, family, or God), such as participant 105, who reflected, "*He walks me through each day. He is always on my mind. When I hear birds singing, I attribute it to a free gift from God Almighty who sustains me…*" Notably, there is not necessarily a normative course for control beliefs in old age; many individuals feel less internal control, but this is not a universal trend.

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For older adults with cancer, the shift to an external locus control may reflect not only a natural tendency, but also a coping strategy (Balboni et al., 2007; Feher & Maly, 1999) and a way to derive meaning from the cancer experience (Taylor, 1983). This assertion is supported not only by the high well-being scores in this study, but also the high endorsement of religion as a coping style (especially compared to the other coping styles evaluated in the Brief COPE)

Importance of Supportive Others

Like religion, social support was generally not linked to PTG quantitatively, but many participants noted the importance of having a support system in coping with cancer. This combination of findings was not entirely unexpected, considering that the nature of the relationship between social support and coping with cancer is unclear (Cordova et al., 2001; Danhauer et al., 2013; Jansen et al., 2011). It is possible that, for some individuals, supportive others actually increase stress and potentially limit feelings of self-mastery (Revenson, Wollman, & Felton, 1983). Further, the role and benefit of supportive others may differ depending on the treatment status of the cancer survivor (Revenson et al., 1983).

Financial Constraints

Several participants noted the impact of finances on their health decisions. For example, one individual with whom I spoke during recruitment (and did not end up returning a survey), stated that she needed a hysterectomy in her 20's, but was not able to afford more than an ovarian cyst removal. Not having the insurance coverage for the hysterectomy led to a later diagnosis of endometriosis, with concomitant symptoms. Her frustration with the insurance system was palpable, and she felt that her health problems

could easily have been mitigated were it not for her financial situation both early on and later in life.

Another individual (who also did not return a survey) reflected on having to stop seeing some doctors due to associated costs, including $40 co-pays for each visit. Participant 151 noted that the medication for her cancer cost over $5,000 a month – a prohibitive expense for most individuals without insurance. These concerns were not captured by the closed-ended questions but emerged as a legitimate and sometimes major concern that influenced not only cancer treatment, but also how participants viewed their cancer experience.

In the framework of Maslow's Hierarchy of Needs (1943), individuals must satisfy lower level needs before moving up the theoretical hierarchy to higher based needs. At the lowest level is physiological need, and the theory is that this need must be satisfied before safety needs can be fulfilled, and subsequent love, esteem, and self-actualization needs (Maslow, 1943).[16] There is a general fixedness to Maslow's theory, such that individuals who struggle to satisfy, say, physiological and safety needs do not have the luxury of seeking out higher order needs such as the need for self-actualization. For cancer survivors who grapple with financial need, it may be more challenging to experience PTG and higher-order states like self-transcendence. Conversely, there are numerous instances of individuals with arguably few resources who are in fact able to derive meaning in their life circumstance, thus satisfying "lower" needs may not be a prerequisite for achieving higher levels of being (Frankl, 1959).

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[16] This is not to say that self-actualization is the highest level need in Maslow's Hierarchy; in later years he specifically identified a higher-level need of self-transcendence (Maslow, 1971). In his view, self-transcendence is thought to involve setting aside personal needs in order to assist others and/or a higher being, while self-actualization refers to realizing one's own potential (Koltko-Rivera, 2006, p. 306).

Limitations

Measurement Issues

As indicated previously, measuring constructs such as self-transcendence, gerotranscendence, and meaning-focused coping proved to be difficult. Thus, while I have presented tentative conclusions based on my findings with these variables, it must be emphasized that findings need to be interpreted in the context of measurement challenges. For example, meaning-focused coping was relatively de-emphasized compared to emotion-focused coping, but this may be an artifact of insufficient measurement of meaning-focused coping, or of overlapping conceptualizations of these two forms of coping.

Kentucky Cancer Registry

I encountered several challenges while working with the Kentucky Cancer Registry (KCR). During the recruitment phone calls, a few individuals (most of whom declined participation) adamantly denied having cancer, one of whom was particularly irate over being associated with a cancer registry. The KCR indicated that the individuals on the registry were incorrect, and did in fact have cancer diagnoses. Other individuals could not be reached because the phone numbers were disconnected, or the addresses were invalid.

By June, a few participants had volunteered their ages over the phone, and when I cross-referenced the KCR database, I realized that the reported ages in the database did not align with what my participants were reporting. After contacting the KCR, I was told that the KCR database maintained information on participants' age at diagnosis, and the randomly selected sample was chosen based off of how old individuals were when they

were diagnosed. This discrepancy meant that participants were recruited based on being 60 years of age or older at the time of diagnosis instead of 60 years of age or older based on the time of recruitment. As a result, the recruited sample was older than anticipated. This age difference had unknown effects on the study results, but it is feasible that the anticipated sample age constraints would have resulted in less attrition, at a minimum.

Self-Selection and Participant Responses

One unanticipated circumstance that arose during the data collection phase involved participants reflecting interest in the study, and then not participating after being mailed surveys. None of the participants who were especially talkative and revealing during recruitment phone calls returned surveys. One potential participant who was very friendly on the phone ended up sending a letter back explaining that upon viewing the survey, she decided she was not able to participate. For a few others, their spouses called to say the potential participants would not be participating. Reasons varied from none to explaining the spouse was not mentally capable of participation (e.g., due to dementia; although the KCR screened for cognitive status, there was no way to assess cognitive change since receiving a cancer diagnosis).

A concern with self-report is response bias, which may have been especially evident in this study. Participants may have offered desirable responses or responses they felt I would want to see in part because they did not have a strong rapport with me. Conversely, allowing participants to complete surveys on their own time likely reduced the chance they would record socially desirable responses, and may have provided them with a sense of anonymity that increased openness. Similarly, as with any study utilizing retrospective report, there is the potential for a loss of clarity over time. In this study,

there were few statistical associations with time since diagnosis, but the nature of participants' individual posttraumatic growth trajectories post-diagnosis was unknown (and the study design did not allow for an explanation of how participants' individual experiences may have changed over time). Further, assessing certain dynamic participant characteristics like social support and income at the time of survey completion did not necessarily reflect how these variables may have changed before study participation (and after diagnosis).

Generalizability

Because this study employed a cross-sectional design, age-related findings reflect age *differences* as opposed to age *changes*. Without a within-subjects design, any changes in PTG or transcendence manifestation cannot be definitively attributed to changes over time given the influence of both cohort and age effects (Schaie & Caskie, 2005). Also, while my intent was to compare findings across cancer sites, most participants reported either breast or blood and bone cancer, limiting the generalizability of cancer site-specific findings.

<div align="center">

Future Directions

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This study is the first step along a path that may eventually lead to interventions to be used by clinicians to ameliorate or at least compensate for the distressing news that is a diagnosis of cancer. This research has shown that older adults have the capacity for PTG after a cancer diagnosis, and that even in the face of other life events and distress stemming from their cancer, they can still experience high levels of well-being, contentment, and overall acceptance with their life situation. Future research may yet

reveal how such positive change contributes to enhanced quality of life in older cancer survivors.

Research on PTG (and transcendence) would benefit from a deeper embrace of the multi-dimensional nature of individual personalities and experiences. It is helpful to assess PTG using quantitative measures and to compare findings across studies using the PTGI, but this study's findings reinforce the fact that older cancer survivors are likely to cope with cancer in different ways, and the PTGI is unlikely to be able to adequately assess the depths of individual experiences. Consistent with previous literature, adding in the qualitative component provided needed elaboration on participant's numerical responses, and it is evident that further exploration using a qualitative lens would provide a more comprehensive picture of older cancer survivors' experiences with cancer. The fact that several participants were open to speaking on the phone during the recruitment phone calls but unwilling to complete the mailed questionnaires, in and of itself, suggests that a predominantly quantitative approach may not be most appropriate for PTG research. Put simply, it is still unclear how and why certain older adults experience PTG after (or while) coping with cancer. Adopting an even more exploratory or grounded-theory approach using qualitative methodologies would allow behavioral oncologists and gerontologists to better understand the antecedents and consequences of PTG.

In addition to modifying how we assess PTG, this research has reinforced that cancer survivors, and individuals in general, are not unidimensional, and can be seemingly self-contradictory when responding to survey questions. For example, it is possible that the older cancer survivor can exhibit gerotranscendence by de-emphasizing the self, feeling increased concern for others, and through a heightened acceptance of life

circumstances, but still enjoy being around important others, such as close family members and friends. Similarly, it is possible for an older cancer survivor to feel distress and lower functional well-being, in conjunction with greater contentment with their life as a whole. Existing measures of PTG do not allow for these self-contradictions, which often emerge through qualitative or mixed methods research that does not force responses to close-ended questions. Mixed methods research may be uniquely advantageous for revealing such contradictions, as direct comparisons can be made between forced responses to Likert-type questions, and free-flowing responses to open-ended questions.

One complication inherent to this research is that older adults have almost surely dealt with previous life traumas that impact how they cope with a cancer diagnosis. It is also to be expected that many older adults will deal with traumas unrelated to their own cancer, post-diagnosis. It may not be possible to completely tease apart growth stemming from a cancer diagnosis (and experience) from growth following other life events, but PTG research would likely benefit from a more in-depth exploration of concurrent and subsequent traumas that exert significant effects on older cancer survivors. In addition, future research in this area would benefit from examining additional factors that were not comprehensively evaluated in this dissertation. For example, it is likely that PTG and even transcendence is directly influenced by the extent to which individuals perceive a relatively long, or pain-free future life. PTG may vary based on participants' perceived time to death, regardless of participant age. This notion is supported by a recent study suggesting that older adults with recent cancer diagnoses alter their treatment decisions based on their cancer diagnosis and reduced future time perspective (Hannum & Rubinstein, 2016). Similarly, cancer progression may serve to predict PTG, particularly

in the context of cancer type, as both factors will directly (and, perhaps interactively)

influence how long participants can expect to live, and expect to live with an acceptable

quality of life, as determined by the cancer survivor. Further, assessing growth in

individuals who are not very religious or spiritual may add needed depth to these

analyses, as one's religious or spiritual beliefs may serve as a buffer that limits the

distress felt following a cancer diagnosis. As indicated in this chapter, participants noted

a heavy emphasis on factors not addressed in the PTGI, including the role of faith, the

extent of their financial concerns, an increased acceptance with their life circumstance,

and the crucial role of supportive others. PTG researchers should strive to incorporate

each of these factors when evaluating the nature and extent of posttraumatic change.

Conclusion

Aging is a lifelong process that necessarily involves accumulated experiences.

These experiences, and our appraisals of our experiences, shape the ways in which we

view and respond to threats. Invariably, a multitude of factors coalesce to provide a

unique coping experience for each individual, and older adults, who have accrued many

experiences over a lifetime, cope with illnesses in ways that are shaped by their personal

histories. For some older adults, there is the potential for growth after receiving and

grappling with the implications of a cancer diagnosis. It would be incorrect, and

potentially harmful, to suggest that all older adults do or should exhibit PTG. The

experience of cancer often leads to distress, deterioration, and, many times, death, and it

is unknown what factors truly predict one's path to PTG, especially in old age. Further, it

is unknown how PTG is associated with quality of life. What *is* known is that some

individuals discover an inner strength and sense of purpose that was not possible before

the cancer diagnosis. The task at hand for behavioral oncologists and those who seek greater understanding of positive developmental change, is to develop an understanding of the circumstances in which an older person's experience with cancer is transformed into a compensating opportunity for growth.

The Kentucky Cancer Registry

The Kentucky Cancer Registry is a statewide population-based registry established by state legislature in 1991. All Kentucky hospitals, outpatient clinics, freestanding treatment centers, non-hospital pathology labs, and physician offices are required to report each diagnosis of cancer to the central registry.

Keeping patient information confidential is a high priority at the Kentucky Cancer Registry. Personal information is not released to anyone at any time without the proper authorization as directed by law. KCR is recognized as the state's designated entity for the collection of cancer incidence data. As such, we closely monitor data access and utilize the latest methods to insure the security of the data.

KCR was established to assist in the search for ways to prevent cancer or detect it in an early stage. Some cancers can be prevented by avoiding or reducing risk factors. Many other cancers can be cured when found early and appropriately treated. By systematically collecting information on all cancer patients diagnosed and treated in Kentucky, KCR provides a valuable tool for determining where specific types of cancer are being prevented, detected early, and appropriately treated. This information is essential for determining where prevention or early detection programs are needed in Kentucky, and which individuals are at higher risk for cancer. Without this information and information gathered through research studies, it would not be possible to effectively target our efforts in cancer prevention, detection, and treatment.

For information, please call KCR at: 859.219.0773 or visit our website: www.kcr.uky.edu.

Living with Cancer Study

Cancer research typically involves young and middle-aged adults, but less is known about what it is like to live with cancer as an older adult. This is surprising, especially considering that older adults are diagnosed with cancer 10 times as often as young and middle-aged adults. Researchers at the University of Kentucky are interested in what it is like to live with cancer as an older adult.

This study will consist of one survey (to be mailed to you, should you agree to participate) to be completed at your convenience, and a possible follow-up in-person interview. The survey will include questions about your particular cancer diagnosis and how it has affected you (if at all) since receiving your diagnosis, and your overall life satisfaction.

For more information or if you have questions about the study, please feel free to email the lead investigator, Aasha I. Hoogland at aan226@uky.edu, or call at (859) 218-0148.

Living with Cancer Study Survey

Thank you for participating in this important study! If you have signed the Consent form ("**Consent to Participate in a Research Study**"), please complete this survey in one sitting (if at all possible).

A few reminders:
- Please use a **pen** to fill out this survey.
- Please note that many of the pages are **double-sided**.
- **Take your time** and answer as honestly as possible.
- If you have any questions or if you experience difficulty completing this survey, please feel free to contact Aasha I. Hoogland at (859) 218-0148.

When you are finished,
- Please use the provided stamped and addressed envelope to mail the following back to Aasha I. Hoogland at the University of Kentucky:
  - The completed **survey**, AND
  - The **signed Consent form** (the additional copy of the form is for your own records).

Section 1: Personal Characteristics
--Please use a pen to fill out this section.--

1. **Date of Birth**: _____

2. **Sex**: _____

3. **Zip Code**: _____

4. **Race:** (*circle one*)

    a. American Indian

    b. Asian

    c. Black/African-American

    d. Native Hawaiian or Pacific Islander

    e. White/Caucasian

    f. Unknown

5. **Ethnicity:** (*circle one*)

    a. Hispanic

    b. Non-Hispanic

    c. Unknown

6. **How many years of education have you completed?** _____

    a. What is your highest level of schooling / highest degree?

    _____

7. **Marital Status**: (*circle one*)

    a. Married

    b. Separated

    c. Divorced

    d. Widowed

    e. Single

8. **Living situation**: (*circle one*)

    a. Living with spouse/significant other

    b. Living with children/grandchildren

    c. Living alone

    d. Other: (*please explain*)

    _____

9. **Number of children**: _____

10. **Number of *living* children**: _____

11. **Ages of *living* children:** _____

12. **Approximate number of people you can depend on for support** (i.e., people that you rely

    on for advice, help, comfort, etc.): _____

13. **Approximate Household Income**: $ _____

14. **What religious denomination do you identify with**? _____

15. **Using the following scale, how religious are you?** (*circle the most appropriate number*)

1	2	3	4	5

    Not at all religious   Very religious

16. **Using the following scale, how spiritual are you?** (*circle the most appropriate number*)

1	2	3	4	5

    Not at all spiritual   Very spiritual

Cancer/Crisis-related questions

17. **Cancer location** (e.g., lung, prostate, etc.): _____

18. **Date of diagnosis** (months and years): _____

19. **Cancer stage/status** (e.g., Stage II, in remission): _____

    _____

    _____

20. How **significant** has a diagnosis of cancer been in your life? (*circle the appropriate number*)

1	2	3	4	5	6	7

    Not Significant   Very Significant

21. **Have you experienced any prior life crises or turning points (e.g., death of a spouse)?**

If so, please describe: _____

_____

_____

_____

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_____

_____

Section 2: Health
--Please use a pen to circle your response.--

1. **In general, would you say your health is excellent, very good, good, fair, or poor?**
   a. Excellent
   b. Very good
   c. Good
   d. Fair
   e. Poor

2. **How does your health now limit you in moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? Would you say you are limited a lot, a little or not at all?**
   a. Yes, limited a lot
   b. Yes, limited a little
   c. No, not limited at all

3. **How about climbing several flights of stairs? Would you say your health limits you a lot, a little, or not at all?**
   a. Yes, limited a lot
   b. Yes, limited a little
   c. No, not limited at all

4. **Thinking about the past four weeks, have you accomplished less than you would like as a result of your physical health?**
   a. Yes
   b. No

5. **During the past four weeks, were you limited in the kind of work or other activities you could do as a result of your physical health?**
   a. Yes
   b. No

6. **During the past four weeks, how much did pain interfere with your normal work including both work outside the home and housework?**
   a. Extremely
   b. Quite a bit
   c. Moderately
   d. A little bit
   e. Not at all

7. **How much of the time during the past four weeks did you have a lot of energy?**
   a. None of the time
   b. A little of the time
   c. Some of the time
   d. Good bit of the time
   e. Most of the time
   f. All of the time

8. **In the past four weeks, did you accomplish less than you would like as a result of an emotional problem, such as feeling depressed or anxious?**
   a. Yes
   b. No

9. **During the last four weeks, did you have trouble doing work or other activities as carefully as usual as a result of an emotional problem, such as feeling depressed or anxious?**
   a. Yes
   b. No

10. **How much of the time during the past four weeks have you felt calm and peaceful?**
    a. None of the time
    b. A little of the time
    c. Some of the time
    d. Good bit of the time
    e. Most of the time
    f. All of the time

11. **How much of the time during the past four weeks have you felt downhearted and blue?**
    a. All of the time
    b. Most of the time
    c. Good bit of the time
    d. Some of the time
    e. A little of the time
    f. None of the time

12. **During the last four weeks, how much of the time has your physical health or emotional problems interfered with your social activities, like visiting with friends, relatives, etc.?**
    a. All of the time
    b. Most of the time
    c. Good bit of the time
    d. Some of the time
    e. A little of the time
    f. None of the time

Section 3: Time Perspective
--Please use a pen to circle your response.--

Read each item and, as honestly as you can, answer the questions: "How true is this of you?" Circle the appropriate number next to each statement using the scale below.

Circle the appropriate number on the scale below, where **1** means the statement **is very untrue** for you and **7** means that the statement is **very true** for you.

1 - - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - - 5 - - - - - - - 6 - - - - - - - 7
Very UNTRUE   **Very TRUE**
for you   **for you**

1.	Many opportunities await me in the future.	1	2	3	4	5	6	7
2.	I expect that I will set many new goals in the future.	1	2	3	4	5	6	7
3.	My future is filled with possibilities.	1	2	3	4	5	6	7
4.	Most of my life lies ahead of me.	1	2	3	4	5	6	7
5.	My future seems infinite to me.	1	2	3	4	5	6	7
6.	I could do anything I want in the future.	1	2	3	4	5	6	7
7.	There is plenty of time left in my life to make new plans.	1	2	3	4	5	6	7
8.	I have the sense time is running out.	1	2	3	4	5	6	7
9.	There are only limited possibilities in my future.	1	2	3	4	5	6	7
10.	As I get older, I begin to experience time as limited.	1	2	3	4	5	6	7

Section 4: Dealing with Cancer – Part I
--Please use a pen to circle your response.--

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your crisis, using the following scale.

0 = I did **not** experience this change as a result of my crisis.
1 = I experienced this change to a **very small** degree as a result of my crisis.
2 = I experienced this change to a **small** degree as a result of my crisis.
3 = I experienced this change to a **moderate** degree as a result of my crisis.
4 = I experienced this change to a **great** degree as a result of my crisis.
5 = I experienced this change to a **very great** degree as a result of my crisis.

1.	My priorities about what is important in life.	0	1	2	3	4	5
2.	An appreciation for the value of my own life.	0	1	2	3	4	5
3.	I developed new interests.	0	1	2	3	4	5
4.	A feeling of self-reliance.	0	1	2	3	4	5
5.	A better understanding of spiritual matters.	0	1	2	3	4	5
6.	Knowing that I can count on people in times of trouble.	0	1	2	3	4	5
7.	I established a new path for my life.	0	1	2	3	4	5
8.	A sense of closeness with others.	0	1	2	3	4	5
9.	A willingness to express my emotions.	0	1	2	3	4	5
10.	Knowing I can handle difficulties.	0	1	2	3	4	5
11.	I'm able to do better things with my life.	0	1	2	3	4	5
12.	Being able to accept the way things work out.	0	1	2	3	4	5
13.	Appreciating each day.	0	1	2	3	4	5
14.	New opportunities are available which wouldn't have been otherwise.	0	1	2	3	4	5
15.	Having compassion for others.	0	1	2	3	4	5
16.	Putting effort into my relationships.	0	1	2	3	4	5
17.	I'm more likely to try to change things which need changing.	0	1	2	3	4	5
18.	I have a stronger religious faith.	0	1	2	3	4	5

19.	I discovered that I'm stronger than I thought I was.	0	1	2	3	4	5
20.	I learned a great deal about how wonderful people are.	0	1	2	3	4	5
21.	I accept needing others.	0	1	2	3	4	5
22.	I felt my cancer diagnosis to be a threat to my life.	0	1	2	3	4	5
23.	I felt intense fear, helplessness, or horror.	0	1	2	3	4	5
24.	I had difficulty relating to my friends in the same way.	0	1	2	3	4	5
25.	I had difficulty relating to my family in the same way.	0	1	2	3	4	5
26.	I can't do the things I once enjoyed.	0	1	2	3	4	5

If there is anything else you would like to share in this section, feel free to do so here: _____

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Section 5: Dealing with Cancer – Part II
--Please use a pen to circle your response.--

Please indicate the extent to which each item below describes you. There are no right or wrong answers. I am interested in your frank opinion. As you respond to each item, think of how you see yourself <u>at this time of your life</u>. Circle the number that is the best response for you.

0 = not at all
1 = very little
2 = somewhat
3 = very much

At this time of my life, I see myself as:

1.	Having hobbies or interests I can enjoy.	0	1	2	3
2.	Accepting myself as I grow older.	0	1	2	3
3.	Being involved with other people or my community when possible.	0	1	2	3
4.	Adjusting well to my present life situation.	0	1	2	3
5.	Adjusting to changes in my physical abilities.	0	1	2	3
6.	Sharing my wisdom or experience with others.	0	1	2	3
7.	Finding meaning in my past experiences.	0	1	2	3
8.	Helping others in some way.	0	1	2	3
9.	Having an ongoing interest in learning.	0	1	2	3
10.	Able to move beyond some things that once seemed so important.	0	1	2	3
11.	Accepting death as a part of life.	0	1	2	3
12.	Finding meaning in my spiritual beliefs.	0	1	2	3
13.	Letting others help me when I may need it.	0	1	2	3
14.	Enjoying my pace of life.	0	1	2	3
15.	Dwelling on my past losses.	0	1	2	3

Please rate how poorly or well each statement agrees with your own experiences/feelings.

16.	I feel connected with the entire universe.	0	1	2	3
17.	I feel that I am a part of everything alive.	0	1	2	3
18.	I can feel a strong presence of people who are elsewhere.	0	1	2	3
19.	Sometimes I feel like I live in the past and present simultaneously.	0	1	2	3
20.	I feel a strong connection with earlier generations.	0	1	2	3
21.	My life feels chaotic and disrupted.	0	1	2	3
22.	The life I have lived has coherence and meaning.	0	1	2	3
23.	I like to be by myself better than being with others.	0	1	2	3
24.	I like meetings with new people.	0	1	2	3
25.	Being at peace and philosophizing by myself is important for my well-being.	0	1	2	3

If there is anything else you would like to share in this section, feel free to do so here: _____

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Section 6: Dealing with Cancer – Part III
--Please use a pen to circle your response.--

These items deal with ways you've been coping with the stress in your life since you found out you had cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. **I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you are doing it.** Use these response choices:

> **0** = I have **not** been doing this at all
> **1** = I have been doing this a **little** bit
> **2** = I have been doing this a **medium** amount
> **3** = I have been doing this a **lot**

Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1.	I've been turning to work or other activities to take my mind off things.	0	1	2	3
2.	I've been concentrating my efforts on doing something about the situation I'm in.	0	1	2	3
3.	I've been saying to myself "this isn't real."	0	1	2	3
4.	I've been using alcohol or other drugs to make myself feel better.	0	1	2	3
5.	I've been getting emotional support from others.	0	1	2	3
6.	I've been giving up trying to deal with it.	0	1	2	3
7.	I've been taking action to try to make the situation better.	0	1	2	3
8.	I've been refusing to believe that it has happened.	0	1	2	3
9.	I've been saying things to let my unpleasant feelings escape.	0	1	2	3
10.	I've been getting help and advice from other people.	0	1	2	3
11.	I've been using alcohol or other drugs to help me get through it.	0	1	2	3
12.	I've been trying to see it in a different light, to make it seem more positive.	0	1	2	3
13.	I've been criticizing myself.	0	1	2	3
14.	I've been trying to come up with a strategy about what to do.	0	1	2	3

15.	I've been getting comfort and understanding from someone.	0	1	2	3
16.	I've been giving up the attempt to cope.	0	1	2	3
17.	I've been looking for something good in what is happening.	0	1	2	3
18.	I've been making jokes about it.	0	1	2	3
19.	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	0	1	2	3
20.	I've been accepting the reality of the fact that it has happened.	0	1	2	3
21.	I've been expressing my negative feelings.	0	1	2	3
22.	I've been trying to find comfort in my religion or spiritual beliefs.	0	1	2	3
23.	I've been trying to get advice or help from other people about what to do.	0	1	2	3
24.	I've been learning to live with it.	0	1	2	3
25.	I've been thinking hard about what steps to take.	0	1	2	3
26.	I've been blaming myself for things that happened.	0	1	2	3
27.	I've been praying or meditating.	0	1	2	3
28.	I've been making fun of the situation.	0	1	2	3

If there is anything else you would like to share in this section, feel free to do so here: _____

_____

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Section 7: Well-being and Lived Experience
--Please use a pen to circle your response.--

Below are 8 statements with which you may agree or disagree. Using the 1–7 scale below, indicate your agreement with each item by indicating that response for each statement.

1 - **Strongly agree**
2 - Agree
3 - Slightly agree
4 - Neither agree nor disagree
5 - Slightly disagree
6 - Disagree
7 - **Strongly disagree**

1.	I lead a purposeful and meaningful life.	1	2	3	4	5	6	7
2.	My social relationships are supportive and rewarding.	1	2	3	4	5	6	7
3.	I am engaged and interested in my daily activities.	1	2	3	4	5	6	7
4.	I actively contribute to the happiness and well-being of others.	1	2	3	4	5	6	7
5.	I am competent and capable in the activities that are important to me.	1	2	3	4	5	6	7
6.	I am a good person and live a good life.	1	2	3	4	5	6	7
7.	I am optimistic about my future.	1	2	3	4	5	6	7
8.	People respect me.	1	2	3	4	5	6	7

If there is anything else you would like to share in this section, feel free to do so here: _____

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<u>Section 8: Additional Thoughts</u>

If there is anything else you would like to share that has not been covered already, feel free

to do so here: _____

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Please use the provided stamped and addressed envelope to mail this completed survey
AND the signed Consent form ("**Consent to Participate in a Research Study**") back to
Aasha I. Hoogland at the University of Kentucky.

Appendix 3:
Consent to Participate in a Research Study

Living with Cancer Later in Life – Part I

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?

You are being invited to take part in a research study about living with cancer later in life. If you volunteer to take part in this study, you will be one of up to 200 people to do so.

WHO IS DOING THE STUDY?

The person in charge of this study is Aasha Hoogland, Doctoral Candidate, of University of Kentucky, Department of Gerontology. She is being guided in this research by Graham D. Rowles, PhD. There may be other people on the research team assisting at different times during the study.

WHAT IS THE PURPOSE OF THIS STUDY?

By doing this study, we hope to learn how older adults of various ages deal with a cancer diagnosis later in life.

ARE THERE REASONS WHY YOU SHOULD NOT TAKE PART IN THIS STUDY?

If you do not want to participate in this study, then you should not participate.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

The survey (included with this form) can be completed at a place of your choosing. The survey is expected to take up to 90 minutes to complete.

WHAT WILL YOU BE ASKED TO DO?

You are asked to complete the provided survey and mail the entire packet, including a signed consent form, back to the University of Kentucky using the provided pre-stamped and pre-addressed envelope. You may retain a (provided) copy of the consent form for your records. We request that you try to complete the survey in one sitting, if possible. You are free to skip or omit answering any questions if you choose.

You may also be asked to participate in a follow-up interview upon survey completion. If so, participation would be voluntary.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life, although it is possible you may find some questions

we ask you to be upsetting or stressful. In addition to the risks listed above, you may experience a previously unknown risk or side effect.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?

There is no guarantee that you will get any benefit from taking part in this study. Your willingness to take part, however, may, in the future, help society as a whole better understand this research topic.

DO YOU HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

IF YOU DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?

There are no costs associated with this study.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?

We will make every effort to keep confidential all research records that identify you to the extent allowed by law.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be personally identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private.

Officials from the University of Kentucky may look at or copy pertinent portions of records that may identify you, but we will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. All data will be stored in a secure room and/or a password-protected computer.

CAN YOUR TAKING PART IN THE STUDY END EARLY?

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.

ARE YOU PARTICIPATING OR CAN YOU PARTICIPATE IN ANOTHER RESEARCH STUDY AT THE SAME TIME AS PARTICIPATING IN THIS ONE?

You may take part in this study if you are currently involved in another research study.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?

You will not receive any rewards or payment for taking part in the study.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind. If you have questions, suggestions, concerns, or complaints about the study, you can contact the investigator, Aasha Hoogland at (859) 218-0148. If you have any questions about your rights as a volunteer in this research, contact the staff in the Office of Research Integrity between the business hours of 8am and 5pm EST, Mon-Fri at the University of Kentucky at 859-257-9428 or toll free at 1-866-400-9428. Please keep the second copy of this consent form for your records.

POTENTIAL FUTURE USE

Do you give your permission to be contacted in the future by Aasha Hoogland regarding your willingness to participate in future research studies about cancer?

Yes   No   _____Initials

_____   _____
Signature of person agreeing to take part in the study   Date

_____
Printed name of person agreeing to take part in the study

_____   _____
Name of [authorized] person obtaining informed consent   Date

_____
Signature of Principal Investigator or Sub/Co-Investigator

DATE

Dear XXXXXX,

Thank you for agreeing to participate in my dissertation study titled "Living with Cancer." Recently, you were sent a **survey** packet (and two additional forms – one certifying that you agree to participate in this study, and one for your own records) including questions about how a cancer diagnosis has affected you.

I would be grateful if you would consider completing the survey and mailing it back using the stamped and pre-addressed envelope provided in the original packet with the survey. Your responses will help me to better understand how older individuals handle having a cancer diagnosis, and will ultimately be used to help other individuals who are coping with a cancer diagnosis.

Please feel free to contact me either by e-mail (aan226@uky.edu) or telephone (859-218-0148) if you have any questions, concerns, or comments about this study. As a reminder, participation is completely voluntary, and your personal information will be stored separately from your survey responses. I very much appreciate your helping me with my study.

If you have already mailed back your survey, please disregard this letter.

I look forward to hearing from you!

Kind regards,

Aasha I. Hoogland
PhD Candidate in Gerontology
University of Kentucky

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Aasha Irene Hoogland

EDUCATION

2016-	H. Lee Moffitt Cancer Center	Tampa, FL

Postdoctoral Research Fellow

2011-2016	University of Kentucky	Lexington, KY

Doctor of Philosophy in Gerontology
- Advanced to Candidacy October, 2014

2012	University of Kentucky	Lexington, KY

Graduate Certificate in Applied Statistics

2009-2011	Wake Forest University	Winston-Salem, NC

Master of Arts in General Experimental Psychology

2007-2008	Georgia State University	Atlanta, GA

Bachelor of Arts in Psychology
- Magna cum laude

2004-2006	Florida International University	Miami, FL

Undeclared

PROFESSIONAL EXPERIENCE

2016	Research Assistant	University of Kentucky

Appalachian Center for Cancer Education, Screening, and Support (ACCESS)

2014-2016	Primary Instructor	University of Kentucky

Aging in Today's World

2013-2014	Graduate Teaching Assistant	University of Kentucky

Aging in Today's World

2009	Graduate Teaching Assistant	University of Kentucky

Introductory Psychology; Effective Parent-Child Relations; Cognition

SCHOLASTIC AND PROFESSIONAL HONORS

Dissertation Funding Awards

Medical Center/Provost's Office Scholarship, University of Kentucky (UK) 2015
College of Public Health Academic Excellence Scholarship (UK)..............................2015

College of Public Health Floyd Wright Scholarship (UK)..2015
Department of Behavioral Science Pilot Funding Award (UK) 2014

<div align="center">Scholarships/Assistantships/Fellowships</div>

Donovan Scholarship in Gerontology (UK) 2015-2016
Donovan Scholarship in Gerontology (UK) 2014
Donovan Scholarship in Gerontology (UK) 2013-2014
Schmidlapp Fellowship in Gerontology (UK)... 2013-2014
Kentucky Opportunity Fellowship (UK) 2012-2013
Kentucky Opportunity Fellowship (UK) 2011-2012
William Randolph Hearst Assistantship, Wake Forest University (WFU) 2010-2011
William Randolph Hearst Minority Scholarship (WFU)..................................... 2009-2011
Elizabeth A. Kenny Scholarship in Psychology, Georgia State University 2009
Florida Medallion Scholar 2004-2006
Presidential Scholarship, Florida International University.................................. 2004-2006

<div align="center">Other Awards</div>

Student Travel Scholarship, College of Public Health (UK)..2015
Best Research Poster Presentation, College of Public Health Research Day (UK).......2015
Graduate Student Travel Award (UK)...2014
Behavioral and Social Sciences Student Travel Award, Gero. Society of America......2014
Graduate Student Travel Award (UK)...2012
Summer Research Grant, Wake Forest University...2010
Dean's List, Georgia State University 2008
Faculty Scholar, Georgia State University...2007
International "Super Student" Tuition Waiver, Georgia State University........... 2007-2008

SCHOLARSHIP

Peer-Reviewed Journal Articles

Hoogland, A.I., & Hoogland, C.E. (2016). Learning by listing: A content analysis of students' perceptions of older adults and grandparents. *Gerontology and Geriatrics Education*.

Hoogland, A.I. (2015). Continuity of change: The dynamic of beliefs, values, and the aging experience. *Journal of Aging Studies, 32*, 32-39.

Zanjani, F., **Hoogland, A.**, & Downer, B. (2013). Alcohol and prescription drug safety in older adults. *Drug, Healthcare and Patient Safety, 5*, 13-27.

Oral Presentations

Hoogland, A.I. (2016). *Emerging from the storm: Posttraumatic growth in late-life cancer survivors*. Paper to be presented at the 68th Annual Meeting of the Gerontological Society of America, New Orleans, LA.

Hoogland, A.I. (2016). *Health considerations in late-life cancer survivors*. Presentation at the College of Public Health Research Day during the 11th Annual Center for Clinical and Translational Science (CCTS) Spring Conference, Lexington, KY.

Schoenberg, N.E., **Hoogland, A.I.**, Hoogland, C.E., Bardach, S.H., & Tarasenko, Y. (2016). *A culturally-appropriate, contextually-grounded CBPR physical activity intervention for rural residents: Explaining unanticipated intervention outcomes*. Presentation at the 76th Annual Meeting of the Society for Applied Anthropology, Vancouver, BC, Canada.

Hoogland, A.I. (2015). *Group-based vs. individuated perceptions of older adults in the United States: A case study*. Symposium paper presented at the 41st Annual Meeting of the Association for Gerontology in Higher Education, Nashville, TN.

Hoogland, A.I. (2014). *The continuity of change: Beliefs and values among older adults*. Presentation at the 67th Annual Meeting of the Gerontological Society of America, Washington, D.C.

Zimmerman, L., Armistead, L., **Anderson, A.** & King, C. (2009). *NVivo 8 and YouTube: Coding interactive internet communities as a team*. Symposium presentation at the 12th Biennial Conference of the Society for Community Research and Action, Montclair State University, NJ.

Poster Presentations

Hoogland, A.I., Hoogland, C.E., Schoenberg, N.E., & Bardach, S.H. (2015). *Health behavior change in older adults in rural Appalachia*. Poster presentation at the 68th Annual Meeting of the Gerontological Society of America, Orlando, FL.

Brown, J.A. & **Hoogland, A.I.** (2015). *Cultivating meaningful relationships through senior digital gameplay*. Poster presentation at the 68th Annual Meeting of the Gerontological Society of America, Orlando, FL.

Hoogland, A.I. (2015). *A comparison of group-based and individuated perceptions of older adults*. Poster presented at the College of Public Health Research Day during the 10th Annual Center for Clinical and Translational Science (CCTS) Spring Conference, Lexington, KY.

Hoogland, A.I. (2014). *Psychosocial change in old age: An assessment of beliefs and values.* Poster presented at the College of Public Health Research Day during the 9th Annual Center for Clinical and Translational Science (CCTS) Spring Conference and 4th Annual ATRN Summit, Lexington, KY.

McCarthy, V. L., Bowland, S., Rowles, G. D., Linfield, K. J., Thibault, J., Wilson, J., Bockweg, A., & **Hoogland, A.** (2013). *Facilitating self-transcendence: Developing an intervention to enhance optimal aging.* Poster presentation at the 66th Annual Meeting of the Gerontological Society of America, New Orleans, LA.

Brown, J.A., **Hoogland, A.I.**, & Schuier, M.W. (2013). *An exploration of socioemotional selectivity theory within senior digital gameplay.* Poster presentation at the 66th Annual Meeting of the Gerontological Society of America, New Orleans, LA.

Hoogland, A. & Zanjani, F. (2012). *Alcohol use and prescription drug safety in older adults.* Poster presented at the 65th Annual Meeting of the Gerontological Society of America, San Diego, CA.

Hoogland, A. & Zanjani, F. (2012). *Music recognition in individuals with Alzheimer's disease.* Poster presented at the College of Public Health Research Day during the Public Health Systems & Services Research Keeneland Conference, Lexington, KY.

Hoogland, A. & Zanjani, F. (2012). *Musical memory in individuals with Alzheimer's disease.* Poster presented at the 23rd Annual Southeastern Student Mentoring Conference in Gerontology & Geriatrics, Atlanta, GA.

Anderson, A. & Jennings, J. (2010). *The effects of aging and time of day on alerting, orienting, and executive function.* Poster presented at the 2010 Wake Forest University Psychology Department's Graduate Student Colloquium, Wake Forest University, NC.

Zimmerman, L., Armistead, L., **Anderson, A.** & King, C. (2010). *YouTube persuasion during the primaries and presidential debates: Global discourse about the 2008 U.S. election.* Poster presentation at the 33rd Annual Scientific Meeting of the International Society of Political Psychology, San Francisco, CA.

Zimmerman, L., Armistead, L., **Anderson, A**. & King, C. (2010). *Health care during the U.S. primaries: Persuasion on YouTube.* Poster Presentation at the 8th Biennial Society for the Psychological Study of Social Issues Convention, New Orleans, LA.

King, C., **Anderson, A.**, Cavrak, S. & Kleider, H. (2009). *Crime scene typicality: Shifting attention and the criminal stereotype.* Poster presented at the 3rd Annual Georgia State Undergraduate Research Conference (GSURC), Georgia State University, GA.