# AN EXAMINATION OF THE PRECURSORS OF POSTTRAUMATIC GROWTH IN PEOPLE LIVING WITH HIV/AIDS

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# AN EXAMINATION OF THE PRECURSORS OF POSTTRAUMATIC GROWTH IN PEOPLE LIVING WITH HIV/AIDS

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Dissertation

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### ABSTRACT

Posttraumatic Growth (PTG) is a phenomenon in which some individuals who experience trauma report positive development in various aspects of their lives that surpassed their pre-trauma level of functioning (Tedeschi & Calhoun, 1996; 2004). PTG has been investigated in various populations of trauma survivors, including people living with HIV/AIDS (PLWHA) (Milam, 2002, 2004). Until this point, the research has only focused on PTG and its correlates as an outcome variable in PLWHA, however additional studies are needed to develop a better understanding of the process of PTG in PLWHA (Milam, 2006b). The current study examined the extent to which the theoretical precursors to PTG (Tedeschi & Calhoun, 2004) exist across PLWHA who report higher or lower levels of PTG. In addition, the current study attempted to address the gaps in the literature by exploring positive changes in PLWHA using a discernable theoretical framework (PTG; Tedeschi & Calhoun, 1996), a standardized assessment of growth (Posttraumatic Growth Inventory [PTGI]; Tedeschi & Calhoun, 1996), and a theoretically based qualitative methodology (grounded theory; Strauss & Corbin, 1998). The current study also explored the process for developing PTG in PLWHA by comparing the differences in coping, quality of life, and meaning-making in PLWHA who report higher or lower levels of PTG.

Results were based on a sample of PLWHA (N = 109) who completed questionnaires. Participants were screened into higher-PTG (n = 8) and lower-PTG (n = 8) 8) groups based on PTGI total growth scores, and invited to complete semi-structured interviews. The results of this study indicated that there were few discernible differences in personal narratives between the higher- and lower-PTG groups. The participants from both higher- and lower-PTG groups met criteria for the precursors of PTG. During the interviews, participants from both higher- and lower-PTG groups reported factors of PTG in their daily lives and the number of lower-PTG participants who reported each factor was similar to the number of higher-PTG participants endorsing that particular factor. Therefore, the presence or absence of theoretical precursors to PTG, and the factors of PTG, in the participants' self-reported narratives were not predicted by their scores on the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). In addition to leading to some questions about PTG and the PTGI, the results of the current study demonstrate the challenges of data analysis in a mixed method design where there is a lack of convergence in the quantitative and qualitative data.

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## CHAPTER I

# STATEMENT OF THE PROBLEM

The purpose of this study was to explore how people living with HIV/AIDS (PLWHA) cope with their disease, through the theoretical framework of the Posttraumatic Growth (PTG) model (Tedeschi & Calhoun, 2004). This chapter begins by providing a brief overview of the concepts underlying PTG. Then, it outlines some of the issues that PLWHA face including stressors related to being HIV-positive and reports of personal growth in this population. Finally, this chapter concludes with a discussion of how we can expand our understanding of how PLWHA cope with their disease by comparing PLWHA who report high levels of PTG to other PLWHA who report low levels of PTG.

# The Construct of Posttraumatic Growth

The term Posttraumatic Growth was first used by Tedeschi and Calhoun (1996) when they developed a questionnaire to measure this phenomenon; however, they had been exploring it conceptually for 12 years prior to the development of the instrument (Tedeschi & Calhoun, 2004). They had noticed that some individuals who had experienced trauma reported positive development in various aspects of their lives that surpassed their baseline level before the trauma had occurred. Through their previous work (Calhoun & Tedeschi, 1989-90), Tedeschi and Calhoun (1996) identified three broad areas of positive change that would serve as a starting point for developing the conceptual model of posttraumatic growth: changes in self-perception, changes in interpersonal relationships, and a changed philosophy of life.

Through further research, Tedeschi and Calhoun (1996) developed the Posttraumatic Growth Inventory (PTGI) which identified five factors that contributed to posttraumatic growth: New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation for Life. After examining other research and clinical data, the authors asserted that those five factors seem to be comprehensive in covering the experiences of individuals who have undergone Posttraumatic Growth (Tedeschi & Calhoun, 2004). Each of the factors paradoxically illustrates that positive change can develop out of pain or loss. It is important to realize that growth is not caused directly by the trauma itself, but rather as a result of the process of struggling with and making sense of the event (Tedeschi & Calhoun, 2004). Also, the authors note that growth in these domains does not indicate the absence or end of pain or distress, but can be present at various stages during the recovery process even when the negative effects of the event are still evident (Tedeschi & Calhoun, 2004).

There are several conditions that frequently are present that facilitate the process of Posttraumatic Growth (Tedeschi & Calhoun, 2003). First, the individual must experience a traumatic event that is severe enough to cause him or her to reconsider previously held assumptions. In this way, the event challenges the fundamental schema that the individual had regarding the nature of the world, himself or herself, or his or her goals in life. Second, the individual is able to find a way to cope with his or her feelings of distress about the event. If the person is overly absorbed in his or her emotional

reaction to the event, then he or she might not be able to question the previously held assumptions. Third, the disengagement from previous goals and assumptions must occur, because these old goals and assumptions do not account for the new information that has been gained as a result of going through the traumatic event. Fourth, the distress must persist for some time. If the individual does not experience distress for a long enough period of time, then he or she may not go through the process of reconsidering previous assumptions. Finally, new personal narratives are created that account for the changes that have occurred as a result of the event, which then leads to schema changes to account for the new information that has been learned since the trauma (Tedeschi & Calhoun, 2003).

During their research process, Tedeschi and Calhoun developed the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) to assess the benefits resulting from coping with trauma. Since its development, the PTGI has been used in several studies with various populations including college students (Tedeschi & Calhoun, 1996; Smith & Cook, 2004), cancer patients (Bellizzi & Blank, 2006; Sears et al., 2003; Widows et al., 2005), individuals with cardiac disease (Sheikh, 2004), and people living with HIV/AIDS (Milam 2006a, 2006b). These studies have assisted researchers in understanding the correlates of Posttraumatic Growth across populations. Based on these research studies and clinical examples, Tedeschi and Calhoun (2004) were able to develop a comprehensive model of Posttraumatic Growth that describes the domains in which growth occurs, examines the conditions necessary for Posttraumatic Growth to occur, considers individual characteristics that can facilitate growth, and examines the cognitive processes that underlie posttraumatic growth. Tedeschi and Calhoun (2004) concluded that after a significant stressor some people transcend their previous level of functioning and develop enhanced interpersonal relationships, a deeper meaning in life, a heightened sense of spirituality, and a greater subjective well-being. In addition, the authors describe many factors contributing to these changes including personality traits, coping styles, and cognitive processes. The current study used the Tedeschi and Calhoun model, and their description of the domains and precursors of PTG, in order to understand the characteristics that facilitate growth in PLWHA. In addition, investigating which precursors of PTG are present in PLWHA helped expand our understanding of the process of PTG.

Trauma and Posttraumatic Growth in People Living with HIV/AIDS

This section explores how Posttraumatic Growth (PTG) may apply to persons living with HIV/AIDS (PLWHA). The model of PTG may be helpful in exploring how PLWHA cope, because being diagnosed with HIV and living with this disease fits in several ways with the conceptualization of Posttraumatic Growth (Tedeschi & Calhoun, 2004). First, the experience of having HIV/AIDS can pose a significant stressor and impacts the individuals' quality of life because it affects their physical health, mental health, and social functioning. Second, having HIV/AIDS requires the person to use their coping resources to deal with major changes in health, changes in social interactions (including stigma), and grief that may accompany the HIV/AIDS diagnosis. Third, the experience of HIV/AIDS may also be traumatic because it can pose an existential crisis: shattering previously held core beliefs about the self, the self in society, religious dogma, the meaning of life, and ultimately death. Finally, living with HIV/AIDS may set into place the conditions necessary for PTG to take place. As a result of coping with their disease, PLWHA may reframe their infection and experiences in such a way that they discover purpose, positive changes, and an enhanced meaning in life. This study will therefore examine how PLWHA have coped with their disease and explore the extent to which these prerequisites to growth were present during the coping process.

## Stressors and Trauma Related to HIV/AIDS

There are more than half a million people currently living with HIV/AIDS in the United States. Specifically, at the end of 2005, the US Centers for Disease Control and Prevention (2007) estimated that 421,873 persons were living with AIDS in the United States, and an additional 215,346 persons were HIV-positive. Living with HIV/AIDS is likely to be a significant stressor because the disease affects many aspects of an individual's life. Grossman, Sullivan, and Wu (2003) give several examples of such stressors by assessing the physical, psychological, and social well-being of PLWHA through measuring the health-related quality of life (HR-QOL). Grossman, Sullivan, and Wu reported that PLWHA report a HR-QOL score that is lower than both the general population and persons with other chronic illnesses, such as cancer or depression. The authors speculated that PLWHA reporting a lower HR-QOL could be the result of the many unique HR-QOL issues that PLWHA face, including issues related specifically to the pharmacological therapy used to treat HIV/AIDS and several medical complications associated with HIV/AIDS. Additionally, there are several psychosocial factors that contribute to depression in PLWHA including social stigma, discontinuation of work or

unemployment, dependence on others, limitations in social activity or social support, and poor coping skills (Grossman, Sullivan, & Wu 2003).

Living with HIV/AIDS is also likely to be a life changing experience (Schwartzberg, 1992). Arguments have been made in the literature that this process could also be traumatic, because the individual usually has to adjust to changes in health and interpersonal relationships (Brief, Vielhauer, & Keane, 2006). In addition, there may be higher rates of previous trauma exposure and PTSD in people living with HIV/AIDS than in the general population, because many of the high risk behaviors that could expose someone to traumatic experiences could also increase the risk of HIV. The authors argued that trauma exposure, particularly sexual trauma, may increase HIV-risk behaviors such as substance abuse and high-risk sexual behaviors (Brief, Vielhauer, & Keane). Finally, the experience of having HIV/AIDS may be innately traumatic because it taps into existential questions. In the process of coping with the disease, PLWHA may experience existential anxiety as they re-examine their core beliefs about life itself.

Nilsson Schönnesson (1992) outlined the various dimensions of existential crises that PLWHA may experience. She argued that the concept of trauma can be broadly applied to HIV/AIDS because it evokes strong emotions of helplessness, powerlessness, anxieties of death, and realities of death, too. It threatens one's physical existence, because both the disease and medications to treat it can cause a wide variety of health problems and ultimately death. In addition, HIV/AIDS threatens one's social existence because of the social stigma attached to being HIV-positive and the actual or perceived social isolation that many PLWHA report. Finally, HIV/AIDS also threatens one's sexual existence because it affects one's sexual well-being, desire, and functioning. Nilsson Schönnesson concluded that coping with HIV/AIDS requires the individual to address these previously mentioned existential anxieties and adapt within the context of his or her life to the new circumstances that the illness creates. The adaptations may include changing both intrapersonal resources, such as coping skills, and interpersonal resources, such as social support.

#### New Meaning in the Aftermath of HIV/AIDS

Researchers have also found that some PLWHA report finding new meaning in life despite the challenges of living with HIV/AIDS (Massey, Cameron, Ouellette, & Fine, 1998; Mayers et al., 2005; Milam, 2004; Schwartzberg, 1993; Siegel & Schrimshaw, 2000; Siegel et al., 2005; Updegraff et al., 2002; Woods & Ironson, 1999; Woods et al., 1999a, 1999b). For example, some individuals have found meaning in their diagnosis through activism and community involvement (Massey et al., 1998; Schwartzberg, 1993); some found meaning through caring for other people (Mayers et al., 2005; Schwartzberg, 1993), and some through enhancing their spirituality (Woods & Ironson, 1999; Woods et al., 1999a, 1999b). Many of the participants in these studies reported positive changes in domains consistent with the theoretical basis of posttraumatic growth, and these themes emerged post hoc as the investigators explored how PLWHA cope with their illness. In recent years, a few studies have been published specifically looking at Posttraumatic Growth in PLWHA to examine the correlates that predict these positive changes (Milam, 2004) and qualitatively describe the positive changes that have occurred (Siegel & Schrimshaw, 2000; Siegel et al., 2005; Updegraff et al., 2002). All of the studies mentioned above have identified enhanced meaning in life,

or personal growth, as an outcome of coping with HIV/AIDS. The present study will use these works as a foundation to investigate the precursors of Posttraumatic Growth in PLWHA.

One study specifically used Tedeschi and Calhoun's (1996) Posttraumatic Growth model as an outcome variable in PLWHA. Milam (2004) quantitatively tested for the presence of Posttraumatic Growth (PTG) in PLWHA and investigated potential correlates of PTG specific to this population. In his research Milam (2004) was interested in determining if PTG existed in a diverse sample of PLWHA, if there are physical health benefits to PTG, if PTG affects mental health, if the correlates associated with PTG can predict growth longitudinally, and if PTG is associated with antiretroviral therapy (ART) adherence and reporting of medication side-effects. Summarizing Milam's study, he was able to demonstrate that PTG did exist within his sample of PLWHA (N= 434) and revealed several variables that were correlated with PTG.

Milam (2006b) summarized the literature regarding the factors that contribute to Posttraumatic Growth and the changes that occur in PLWHA. First, based on the previous research it is clear that PTG can occur in PLWHA with many reporting positive changes including increases in meaning in life, spirituality, sense of community, relationships with others, and altruistic behaviors. Second, there are several correlates that have been found to contribute to PTG in PLWHA including being on antiretroviral treatment, increased healthy behaviors, having a sense of religiosity/spirituality, being optimistic, and having lower levels of depressive symptoms. Third, across studies there are demographic variables that were found to be related to PTG in PLWHA. Some studies found that younger people and females reported higher levels of PTG (Siegel &

Schrimshaw, 2000; Tedeschi & Calhoun, 1996); other studies presented mixed evidence for socioeconomic status and ethnicity to be related to higher levels of PTG (Milam, 2004; Updegraff et al., 2002). Finally, some early evidence suggests that PTG may be related to disease progression, but it is unclear whether PTG is a result of relative wellness or if PTG influences the course of HIV/AIDS infection (Milam, 2004). Milam (2006b) concluded that although it is clear that PTG is beneficial to the health and well being of PLWHA, the underlying process and secondary benefits of PTG are still areas in need of additional study so that health care professionals can use that knowledge to assist PLWHA in adjusting to their disease and having a better quality of life.

#### Purpose of the Present Study

It is clear based on the literature that Posttraumatic Growth can occur in people living with HIV/AIDS. Most of the quantitative research has identified correlates and moderators of PTG (Milam 2004; Siegel et al., 2005; Updegraff et al., 2002), while the qualitative research has focused on the description of PTG and how it manifests in the individuals' lives (Siegel & Schrimshaw 2000; Updegraff et al., 2002). In addition, the research seems to assume that the meaning-making processes, demographic characteristics, and coping strategies of people with high levels of PTG are different from those with low PTG; however, no studies were found that directly compared PLWHA with higher levels of PTG to other PLWHA who report lower levels of PTG. The studies were commenting on the outcome of PTG by looking at what is present in people who have undergone PTG, but none of them had explored the process through which PTG developed. The present study, therefore, set out to explore the process of PTG in PLWHA by examining the theoretical precursors to PTG as outlined by Tedeschi and Calhoun (2003).

The understanding of the process of PTG could be enhanced by comparing the coping strategies and meaning-making processes between PLWHA who report higher levels of PTG and PLWHA who report lower levels of PTG. This methodology could help to identify ways in which PTG develops, how the path to PTG could have been obstructed, and shed light on additional factors in the development of PTG that may or may not be specific to PLWHA. In addition, investigating the differences in how PLWHA with higher or lower levels of PTG perceive their world and their illness can assist in understanding and describing what types of shifts, if any, occurred in these concepts since the time of their diagnosis and how this relates to the development of PTG.

The purpose of this study was to explore how PLWHA cope with and find meaning in their disease, through the theoretical framework of the Posttraumatic Growth (PTG) model. More specifically, this study was interested in examining how PTG develops in PLWHA. The existent literature has been able to establish that PLWHA can report positive changes in their lives as a result of living with their disease, describe the types of growth the PLWHA report, and identify some of the correlates that predict positive growth. There are, however, some gaps within the literature that this study addressed. First, many of the studies that describe coping, meaning making strategies, or positive life changes in PLWHA (e.g., Mayers et al., 2005; Penedo et al., 2001; Schwartzberg, 1993; Siegel & Schrimshaw, 2000; Siegel et al., 2005; Updegraff et al., 2002) do not examine these phenomena within a discernable theoretical framework. The current study used the Posttraumatic Growth model to systematically explore these related concepts. Second, many of the studies do not use a standardized assessment of growth (e.g., Mayers et al., 2005; Penedo et al., 2001; Schwartzberg, 1993; Siegel & Schrimshaw, 2000; Updegraff et al., 2002), use a lesser-known instrument (Siegel et al., 2005), or an abbreviated version of the Posttraumatic Growth Inventory (PTGI) (Milam, 2004, 2006a). The current study used the entire PTGI (Tedeschi & Calhoun, 1996), so that the underlying factors can be analyzed and the results can be compared to other studies using the PTGI. Finally, the studies that have used interview data (Siegel & Schrimshaw, 2000; Updegraff et al., 2002) do not report using a theoretically based qualitative methodology. The current study, however, used qualitative methodology based on grounded theory (Strauss & Corbin, 1998) in order to build upon Tedeschi and Calhoun's (2004) model of posttraumatic growth.

The current study also took the next step in the line of research on PLWHA and PTG. Until this point, the research has only focused on PTG and its correlates as an outcome variable in PLWHA. However additional studies are needed to develop a better understanding of the process and correlates of PTG in PLWHA (Milam, 2006b). In the current study PTG was investigated as both an outcome and a process. PTG was regarded as an outcome variable during the quantitative phase of the study, for the screening purposes of identifying PLWHA who report higher or lower levels of PTG and then dividing the sample accordingly. The PTG model was then regarded as a process for developing the qualitative phase of the study. This study began to explore the process for developing PTG by comparing the general differences in coping, quality of life, and meaning-making in PLWHA who report higher or lower levels of PTG. Specifically, this study examined the extent to which the five theoretical precursors to PTG (e.g., presence of trauma, ability to cope with distressing emotions, disengagement from pre-trauma goals, distress persists for a sufficient length of time, and development of new personal narratives; Tedeschi & Calhoun, 2004) existed across the groups of PLWHA who report high or low levels of PTG.

### CHAPTER II

## LITERATURE REVIEW

This chapter reviews the literature regarding the ways in which people may derive positive meaning out of traumatic experiences, how researchers assess this phenomenon, and more specifically how people living with HIV/AIDS could develop personal growth as a result of coping with their disease. First, the immediate physiological and psychological responses to trauma are discussed, including complications to the recovery process such as Acute Stress Disorder and Posttraumatic Stress Disorder. Second, potential positive outcomes to trauma are explored from parallel literature including resiliency, thriving, and hardiness. Third, the empirical literature regarding adversarial growth, posttraumatic growth, and stress-related growth are summarized including the ways that researchers have conceptualized and measured these phenomena across various populations. Finally, the literature related to the experiences of people living with HIV/AIDS is examined, including the stressors which this population encounters and their potential for posttraumatic growth. This chapter concludes with the rationale and research questions for this proposed study which aims to enhance our understanding of how people living with HIV/AIDS cope with some aspects of their disease, as conceptualized through the Posttraumatic Growth model. Specifically, this study examined to degree to which the theoretical precursors to Posttraumatic Growth

(Tedeschi & Calhoun, 2003) are present in people living with HIV/AIDS as they cope with their disease. This study explored the underlying process for the development of posttraumatic growth, and potential barriers to growth, by comparing the experiences of people living with HIV/AIDS who report experiencing higher levels of Posttraumatic Growth to those who are HIV-positive and report lower levels of posttraumatic growth.

## Typical Reactions to Trauma

The experience of trauma has often been assumed to produce solely negative repercussions in the victim's life. There are a wide range of stressful events that can produce a traumatic reaction in people. The most extreme examples include individuals who have experienced unusual events, major disasters involving massive death or destruction, or a significant threat to their own personal safety and life (Joseph & Williams, 2005). Other challenging circumstances such as bereavement, illness, injuryproducing-accidents, separation or divorce, relationship break up, criminal victimization, academic problems, and unwanted pregnancy can also prove to be a major life crisis and produce distress or trauma (Joseph & Williams). Although these types of difficult situations occur in many people's lives there are variations in how individuals cope in the long run with distressing thoughts, emotions, and memories.

There are many psychological processes that are common in the time following highly stressful events, which are mostly negative and disturbing (Tedeschi & Calhoun, 2004). First, people facing major life crises often experience distressing emotions such as anxiety, sadness, depression, guilt, anger, and irritability. These emotions may continue for a long time after the actual traumatic event has ended. In addition, specific fears and anxiety are common if the individual has experienced a threat to his or her personal wellbeing. Second, disturbing cognitive patterns often emerge surrounding the traumatic event. If the event was unanticipated, then the individual may experience periods of disbelief or psychological numbness. A highly threatening event can also trigger repetitive intrusive thoughts and images of the incident. Third, the individual may experience unpleasant physiological reactions related to the stressful event as a result of the prolonged activation of bodily systems. These physical symptoms can vary from person to person, but may include general discomfort, fatigue, muscle tension, and gastric symptoms. Finally, people who experience significant stressors are at an increased risk for developing psychiatric problems because the life crisis can serve as a catalyst to exacerbate current symptoms or activate latent predispositions (Tedeschi & Calhoun).

Although many people experience stressful events during their lifetime, there are variations in the intensity and duration that the impact of the event has on an individual. In order to conceptualize why some people may perceive an event as traumatic while other people may not have a similar perception, Joseph and Williams (2005) developed a psychosocial framework that integrates three theoretical principles to describe individual differences in responses to traumatic events.

First, Joseph and Williams (2005) explain that the individual's subjective appraisal, or perception, of the event is the "foundation stone" of the framework. The authors pointed out that previous trauma research had only focused on extreme events that most people would find traumatic, such as massive death and destruction. The authors argue that only studying reactions to extreme events masked the importance of the individual's subjective appraisal, or perception of the event. Understanding individual differences in the perception of trauma is not only an important consideration for research, but is also a diagnostic consideration. For example, in order to acquire a diagnosis of Acute Stress Disorder or Post-Traumatic Stress Disorder (PTSD), the individual must have been exposed to an event that threatened death or serious injury and have a response to the event that included intense fear, helplessness, or horror (American Psychiatric Association, 2000). This latter criterion helps to explain why some people perceive stressful, yet less extreme events as highly traumatic while others do not perceive the event in the same way. In other words, if an individual perceives the event as threatening and has a response of intense fear, helplessness, or horror, then he or she may report that event as more traumatic than an individual who did not have such responses to the same event. Therefore, understanding the individual's perception of an event helps to frame his or her reaction to the event within a traumatic or non-traumatic context.

The second principle that Joseph and Williams (2005) explicated, is that many of the characteristics of posttraumatic stress are part of the normal cognitive-emotional processing of new traumatic information. This process allows the individuals to change emotions and appraisals, or reconstruct schema, "through the recollection of key aspects of the traumatic experience with full emotional engagement and arousal," (Joseph & Williams, p. 427). In other words, individuals re-experience aspects of the trauma as they try to construct meaning for the event and their reactions to it. In addition, the traumatic event bombards the individual with so much information and extreme emotional arousal that immediate processing is disrupted, and therefore appraisal of the event occurs over a lengthy period of time. Joseph and Williams also stated that specific symptoms may have evolutionary origins. The immediate reactions of hyper-alertness, excessive startle response, and focused concentration could be seen as forms of "survival mode," where the individual is preparing to respond quickly to avoid further danger. Although it is not clear why intrusive and avoidant symptoms occur after a trauma, Joseph and Williams suggested that these experiences may be related to flashbulb memories, or vivid emotionally laden memories of specific events. They also speculated that we will keep information about traumatic events in "active memory" until it is integrated within our new schema about the outside world. Therefore, the intrusive and avoidant symptoms would be a normal part of the cognitive-emotional processing that helps us make sense of the new traumatic information and avoid encountering similar threats in the future.

The final principle that Joseph and Williams (2005) discussed is that the rate and intensity of cognitive-emotional processing is influenced by personality and social psychological factors. As individuals are processing traumatic information they may experience unwanted intrusive thoughts, flashbacks, or nightmares. These unintentional thoughts can then become the subject matter of additional conscious thinking such as generating further meanings, recalling past experiences, or examining prior assumptions. These conscious processes are influenced by personality, life experiences, and interactions with others, which could facilitate or hinder the successful cognitiveemotional processing of trauma.

Joseph and Williams (2005) identified the individual's attitude toward emotional expression and the quality of social support as the most important personality and interpersonal factors that influence the processing of trauma. For example, the process of appraising and re-appraising the traumatic information can lead to distressing emotions such as fear, anger, guilt, and shame. The way in which the individual copes with these

intense emotions will function to aid or impede the cognitive-emotional processing. If the individual is able to identify and express the emotions, Joseph and Williams hypothesized that processing will be facilitated because the traumatic information can be analyzed and integrated into schema. However, if the individual copes by suppressing emotions, then the processing of the traumatic information can be hindered or stagnated.

The individual's social support network can also contribute to the appraisal, meaning attribution, emotional expression, memory structure, and coping mechanisms of trauma in a positive or negative way. If the social support network encourages emotional expression and allows the individual to remember and talk about the trauma, then the cognitive-emotional processing will be facilitated. However, trauma-related emotions can be intense and distressing for other people to observe. If others try to prematurely curtail the exposure to traumatic material, such as advising the survivor to "move on," then the social network could function to promote avoidance, delay the full resolution of trauma, and increase the survivor's sense of social alienation (Joseph & Williams, 2005). Finally, the variations in social support networks should also be considered within the context of community norms, socioeconomic status, religion, and culture. These factors shape what types of emotional expressions are appropriate within various social venues and could affect the type of support the survivor will receive from his or her community.

#### An Additional Response to Trauma

It is clear, based on the previous section, that many people experience disturbing thoughts, emotions, and physical reactions as they try to process a traumatic event. Many research studies have focused on posttraumatic stress, or what can go wrong when an individual does not fully work through a traumatic event. An alternative view of trauma has been recognized in the fields of philosophy, religion, and literature for thousands of years: suffering can lead to positive transformation (Tedeschi & Calhoun, 2004). For the past 15 years the psychological literature has been exploring why it seems that for some people the process of coping with trauma leads to positive changes in their lives. Almedom (2005) pointed out that this phenomenon has been explored in parallel lines of research and is known by different construct names in other disciplines such as psychiatry, sociology, and behavioral health. Almedom advocated for more interdisciplinary research to further explore how the human spirit can rise above trauma and disaster by examining intrapersonal, interpersonal, cultural, and historical factors that contribute to or impede positive coping. This section discusses the various theories, constructs, and measurement instruments that have been used to examine this positive response to trauma. This section will highlight some of these parallel constructs including resiliency, thriving, and hardiness in order to explore how various branches of the literature describe positive changes following trauma.

#### Resiliency

The term "resilience" has been used to examine the personality characteristics, cognitive processes, emotional regulation, behavior, and coping styles of individuals overcoming adversity. Within the literature, however, there are several variations in the exact definition of resilience. For example, Agaibi and Wilson (2005) describe resilience as "the ability to adapt and cope successfully despite threatening or challenging situations" (p. 198). Others have argued that resilience is more than whether the

individual has major psychological disturbances because of a loss or traumatic event, but rather that resilient individuals do not exhibit the magnitude of difficulties that would be expected, both clinically and statistically, given the nature of the traumatic event (Miller, 2003). Despite these differences in opinion, resiliency has been examined in many developmental and longitudinal studies over the last several decades.

The ways in which resiliency was studied and conceptualized have changed over time. Richardson (2002) described the evolution of resiliency research as three separate, cumulative movements. The first explored the traits of individuals who were able to cope remarkably well despite negative circumstances, considering their developmental strengths and protective factors. The second investigated how resilience develops through an individual's experiences, as a disruptive and reintegrative process. Finally, the third examined the cognitive processes that individuals use to derive meaning and actually grow despite adversity. Each of these lines of research considered several factors that contribute to resiliency including the type of traumatic event, personal history of previous trauma, childhood development, personality traits, cognitive abilities and style, ego defenses, affect regulation, and demographic variables (Richardson, 2002).

In their literature review of *Trauma, PTSD, and Resilience* Agaibi and Wilson (2005) described the progression of resiliency research. Early studies examined children who grew up in difficult circumstances including abuse, neglect, poverty, developmental deprivations, war, extreme physical illness, or with severely impaired parents, yet turned out psychologically healthier than what had been expected. This line of research revealed that resilient children were more likely to exhibit social competence, higher self-esteem, problem-solving behavior, and effective use of resources. It was noted that nurturing and

stable care assisted children in developing these skills, and that effective parenting led to an increase in self-efficacy by modeling effective coping and problem-solving strategies. In addition, internal factors such as higher levels of intelligence and personality traits were also identified as moderators to the development of these skills. Overall, the research revealed that a combination of individual traits and environmental protective factors contributed to the development of resilience in at-risk children (Agaibi & Wilson, 2005).

Longitudinal studies confirmed these findings about childhood resiliency, and found that resilient adults had periods throughout their lives where adversity would occur, and then be followed by a period of recuperation that allowed them to gradually and cumulatively build a sense of mastery in coping (Agaibi & Wilson, 2005). As the line of research transitioned from examining childhood resiliency to investigating the experiences of trauma survivors and combat veterans, researchers began to explore the cognitive processes that led to resiliency compared to those that led to Posttraumatic Stress Disorder (PTSD). These studies found that personal characteristics such as higher intelligence, an internal locus-of-control, personal hardiness, social support, and active or problem-focused coping were related to higher levels of resiliency and fewer PTSD symptoms. In addition, individuals who were more resilient were able to use positive reappraisal, view the stressor as a challenge rather than a threat, and create personal meaning out of the traumatic situation. The exception was veterans who were exposed to heavy combat, because that group exhibited symptoms of PTSD regardless of their personal characteristics, coping styles, or cognitive processes. Agaibi and Wilson (2005) concluded their literature review by proposing a multidimensional person-environment

model to describe the process of resiliency that considered the nature of the traumatic event; the impact to personality, self, and ego structure caused by the trauma; and the activation of the physiological stress response. The current study evaluated themes that are similar to resiliency, including examining how PLWHA have coped with adversity in the past and derived meaning from these experiences.

#### Thriving

The term "thriving" has also been used in a line of literature that describes the process of individuals overcoming adversity and growing after trauma. The description of thriving in the literature actually came from the research on resiliency. O'Leary and Ickovics (1995) explained that thriving described a process that went above and beyond resilience. According to their model, when an individual is faced with a challenge there are four possible outcomes: they can succumb, survive, recover, or thrive. If the individual succumbs to the stressor then the stressor either figuratively or literally destroys them, such as death from an illness or severe psychopathology as the result of trauma. If the individual survives the stressor, then they continue to function but in an impaired manner. If the individual recovers, then they are able to return to their baseline level of social and psychological functioning. O'Leary and Ickovics argued that this is the level to which most of the resiliency literature is referring: that individuals who have faced adverse situations are able to bounce back to their pre-incident state. Individuals who thrive go above and beyond their original level of functioning and, in the process, develop an enhanced meaning in life and are able to cope better with future stressors. O'Leary and Ickovics (1995) explained that in order for thriving to take place, the stressor

needs to be profound enough to challenge the individual's pre-existing beliefs about her or his sense of purpose, meaning, or identity, and that it is in the process of rebuilding these shattered schemas that thriving occurs.

In addition to psychological functioning, the concept of thriving has also been examined within the context of physical health. Epel, McEwen and Ickovics (1998) defined physical thriving as "any physiological changes brought about as a result of facing stressors that leave one with greater physiological resilience than she or he had before facing adversity" (p. 303). They explained that this concept can refer to either having one's health status exceed its baseline level or remaining healthier than would be expected given the nature of an illness. This process occurs because when the individual faces a stressor she or he is also exposed to large amounts of stress hormones and, in turn, the body also may be triggered to release growth-promoting counter-regulatory hormones. Therefore, after the exposure to stress and periods of reduced arousal that allows for recovery, the body can become conditioned to be more resistant to future stress. Conversely, if the body is under a state of chronic stress and is not able to have periods of reduced arousal, then the levels of stress hormones remain high; this is a state that inhibits growth and increases the likelihood for disease (Epel et al., 1998).

In their study, Epel and colleagues (1998) investigated the role that psychological factors play in this hormonal stress response. Their results revealed that individuals who quickly adapted physiologically to repeated laboratory stressors had different cognitive appraisals of the stressor, had reported thriving after previous traumatic stress, and reported a greater appreciation of life and spiritual change. They concluded that the cognitive factors can moderate the body's physiological response to stress, which can

either improve the body's ability to handle future stress or shift it toward a negative stress reaction that inhibits growth, limits restorative functioning, and promotes disease. They identified specific cognitive factors that contributed to positive physiological responses to stress: a challenge as opposed to a threat appraisal of the stressor, perceived control over one's environment and resources, and high self-esteem (Epel et al., 1998). Based on this research, it would appear that thriving can be an experience where the mind and body are able to surpass their previous ability to cope with stressors and develop enhanced meaning and physiological resources to cope better with future adversity. This conceptualization of both physiological and psychological thriving led to a line of research investigating the personality traits and cognitive processes of individuals who reported an enhanced level of functioning following a traumatic experience, which will be further discussed in the following section.

## Hardiness

The term "hardiness" has been used to describe a constellation of personality features that allow certain individuals to face life's challenges with positivity and resiliency, and which also serves as a buffer from the negative effects of stress and illness (Khoshaba, 1979; Maddi & Khoshaba 1994). The construct of hardiness consists of three unique yet cumulative dimensions of how the individual views a potentially stressful event: commitment, control, and challenge. Individuals who are high in commitment view the event as something interesting or important to them, so they actively engage in the event instead of avoiding it or becoming alienated. Those who are high in control seem to have an internal locus of control, or think that they can have some influence over
the events surrounding them rather than viewing themselves as victims of life's circumstances. Finally, individuals who are high in challenge believe that wisdom and personal growth develop by learning from the positive and negative experiences in life, and not taking the comfortable, safe, and easy way out (Maddi & Khoshaba, 1994). In other words, hardy individuals would be described as those who are involved with others and the events going on around them, believe that they can choose to have influence over events in their life, and experience the positive process of learning from life events (Maddi et al., 2002).

The hardiness line of research originated in the corporate world, and examined how employees dealt with changes within the company structure that challenged their job status and security. This research also revealed that individuals high in hardiness reported lower levels of mental health concerns including anxiety and depression. This prompted Maddi and Khoshaba (1994) to investigate how hardiness was related to mental health. To do this, they examined the relationship between individuals' (N = 158) scores on a hardiness measure to their personality profile on the Minnesota Multiphasic Personality Inventory (MMPI). The results revealed that the hardiness score was a unique negative predictor of clinically significant elevations on the MMPI scales of Depression, Paranoia, Psychasthenia, Schizophrenia, Social Interest, Anxiety, and Dependency; as hardiness increased, the elevations on these scales decreased. Hardiness was found to be a unique positive predictor of Ego Strength; as hardiness increased, Ego Strength also increased. Maddi and Khoshaba concluded that hardiness appeared to tap into traits that encompass positive mental health and the opposite of psychotic tendencies.

Maddi and colleagues (2002) further investigated the relationship between hardiness and mental health by comparing individuals' hardiness scores to their personality profiles on the Minnesota Multiphasic Personality Inventory 2 (MMPI-2) (N = 69), the Millon Clinical Multiaxial Inventory III (MCMI-III) (N = 69), and the NEO Five Factor Inventory (NEO-FFI) (N = 102). The results replicated and expanded the findings from their previous study (Maddi & Khoshaba, 1994), indicating that the construct of hardiness tapped into underlying traits that positively predicted mental health. The authors concluded that across the various personality instruments, hardiness was related to positive mental health and high self-esteem (Maddi et al., 2002).

In a more recent publication, Maddi (2004) expanded his conceptualization of hardiness and its impact on coping behaviors. More specifically, he has argued that hardiness is actually a more tangible form of what humanistic psychologists have referred to as "existential courage," which affects how people choose to cope with stressors in life. Maddi explained that when people make decisions, their choices are either oriented toward the future (trying something new or unfamiliar which increases information), or oriented toward the past (holding onto what is already known and familiar). Choosing to make decisions oriented toward the past may feel safer, because it is known, but also can lead to stagnation and meaninglessness. On the other hand, making decisions oriented toward the future can be anxiety provoking because it is unknown, yet this also carries the possibility of personal growth through new information and enhanced meaning. Therefore making future-oriented decisions requires existential courage, because one is heading into the realm of the unknown. Maddi suggested that hardiness could be a good operational definition for existential courage because the "hardy attitudes" of commitment, control, and challenge are future oriented. More specifically, hardy individuals would view a stressful event as a normal frustration to development (challenge), yet a manageable (control) and worthwhile (commitment) endeavor. They are willing to become involved in, try to influence, and continue to learn from challenging and ever-changing life events. He concluded by calling for additional empirical research into existential courage, using hardiness as the operational definition and method of measurement (Maddi, 2004).

The previous section discussed three distinct branches of literature related to how individuals can attain positive outcomes despite trauma or adversity. The literature on resiliency explored how some people can cope remarkably with trauma, overcome difficult backgrounds, and not exhibit the magnitude of difficulties that could be expected of someone who had gone through similar circumstances (Agaibi & Wilson, 2005). The literature on thriving explained how some individuals are able to go beyond their previous (pre-event) level of functioning, and are able to cope better, physically and psychologically, with future stressors (Epel et al., 1998; O'Leary & Ickovics, 1995). Finally, the literature on hardiness examined the personality trait constellation that allows some individuals to cope with challenges by remaining engaged in the event, believing that they can choose to influence certain aspects of the event, and learning a life lesson from their experience (Maddi, 2004; Maddi & Khoshaba, 1994). Each of the branches of literature was able to establish that people can experience positive outcomes after trauma and offered descriptions of the various personal components that differentiated such individuals from others who did not report positive outcomes. The next section will

discuss another distinct line of research: how certain belief systems can assist in coping with adversity in a positive way.

## The Role of Religion, Spirituality, and Assumptions About the World

As stated in a previous section, how the individual perceives an event can affect whether or not that event is viewed as traumatic (Joseph & Linley, 2005). In addition, the individual's beliefs about life and the world serve as a lens through which he or she perceives experiences, and these beliefs may affect how the individual copes with a traumatic event. In fact, one branch of the literature has explored how individuals' sense of religion and spirituality helps them to cope with trauma in a more positive way. Overcash, Calhoun, Cann, and Tedeschi (1996) investigated the impact that traumatic events have on participants' empirical, or directly observable, and metaphysical assumptions about the world. In this study, quantitative measures assessing adjustment, empirical world assumptions, religious motivation, and spiritual experiences were collected from 25 people who had experienced trauma and compared to the data from 25 people who had not. Then, the individuals who had experienced trauma were interviewed to further explore the relationship between trauma and spirituality. On the quantitative measures, the trauma sample endorsed more symptoms of psychological distress, but was similar to the non-trauma group in the level of thinking that the world is safe, predictable, and controllable. The interview data revealed that the religious assumptions of the trauma group were not challenged by the trauma, and that these beliefs seemed to provide a framework for coping because the participants assimilated the trauma into their existing religious belief system. The authors concluded that the religious beliefs were more

resilient than the participants' empirical assumptions about the world, because these beliefs were less subject to empirical disconfirmation.

In a later study, Calhoun, Cann, Tedeschi, and McMillan (1998) explored the relationship between the age of an individual, her or his sense of religion or spirituality, and her or his assumptions about the world following a traumatic event (as measured by a score on the Traumatic Stress Schedule; Norris, 1990). The sample (N=223) was divided into three "generational groups:" the youngest group was people under 25, the middle group was people between the ages of 25 to 55, and the older group was people 59 years and older (with no participants ages 56-58). The results revealed a significant difference based on gender: that women across the generational groups believed that events were less random than men. The youngest group tended to view the world as less just and less benevolent than the middle or older group. On the other hand, the older group tended to view the world as more controllable and having more lucky experiences than either the younger or middle groups. The results also indicated that the traumatic events had no significant impact on the participants' assumptions about the world in any of the generational groups. The authors concluded that the core assumptions about benevolence and justice in the world are not always influenced by traumatic events, but rather may be influenced by other factors such as age.

Siegel, Anderman, and Schrimshaw (2001) conducted a literature review to explore how religion can help people positively cope with health-related stressors and adjust to chronic illnesses. They determined that religion can be more or less helpful in coping depending on where the individual falls on the extrinsic - intrinsic continuum of religious orientation. Individuals whose religiosity is extrinsic use religion as a means or tool to achieve a desired end, such as salvation, and those with an intrinsic motivation regard religion itself as an end, or they focus on God rather than the rewards obtained. An extrinsic orientation has been associated with poorer emotional adjustment to illness, while an intrinsic orientation has been associated with lower levels of depression and better subjective well-being. Siegel and colleagues also cautioned that religiosity can have some negative effects on coping with illness such as apathy, self-condemnation, feeling at odds with one's religious system, believing that God is punishing the person with illness, denial, and fatalistic attitudes.

Siegel and colleagues (2001) stated that religion shapes the way that individuals cope with illness by providing an interpretive framework, or cognitive schema, that enables them to find meaning and shape their appraisal process. Specifically, religion can enhance personal coping resources by increasing one's feelings of mastery, control, and self-worth. In addition, religious communities provide access to social support and promote social integration that can assist the individual with her or his recovery process. Siegel and colleagues concluded that religion can play a central role in the individual's ability to positively cope with, and find meaning in, stressful life events involving significant loss, health threats, and physical suffering.

The role of religion and spirituality in positive coping was further explored by Park (2004b), who investigated the relationship between religiousness and depressive symptoms in elderly people with chronic physical illness (N = 83). This study revealed that religiousness was negatively related to initial scores on depression, and further predicted the level of depression one month later, when controlling for the participants' initial depression score. Religiousness was also found to be positively related to stress-

related growth. Park concluded that religiousness may be an adaptive resource in the adjustment to chronic illness and the stressors associated with aging.

Park (2005) then integrated these findings with a model of meaning-making coping to further explain how religion can serve as a framework for coping positively with traumatic experiences, and conducted a study to test this relationship. In the meaning-making model of coping (Park & Folkman, 1997), meaning can be derived at two distinct, but related, levels. The first level is a global meaning system, which includes an individual's global beliefs and goals about the world, the self, and their interaction. The global meaning system is influenced by the individual's perceptions of stability, optimistic bias, and personal relevance. The second level of meaning is the appraised meaning of a specific event. This level is made up of a primary attribution of the event, which is its personal significance, and a secondary attribution, which evaluates what can be done about the event. The person's appraised meaning of an event is seen through the lens of her or his global meaning system. The individual experiences distress when there is a discrepancy between the global meaning system and the appraised meaning that she or he places on an event, and the amount of distress is positively related to the amount of discrepancy between these levels of meaning. For example, the amount of distress a loss creates will depend on how discrepant the appraised meaning of the event is with the global meaning or belief that "life is fair" (Park & Folkman, 1997).

Park (2005) explained that religion is often a component of the global meaning system, because it helps the person develop meaning and understanding of the world, the self, and the interaction between these aspects. More specifically, religion is often used in meaning-making coping because it can help people make causal attributions for traumatic events. Most of the time religion aids in the reappraisal of a traumatic situation by helping people see the more positive aspects of the event. This is because religious beliefs are relatively stable, and people are more likely to change their attributions of the event rather than challenge their religious beliefs. If the event is too traumatic, however, then the global meaning system of religious beliefs can be challenged and individuals must work to accommodate their schema to fit the new information, and therefore create new global meaning (Park).

Park (2005) tested this hypothesized relationship between religion, meaningmaking, and coping on a sample of 169 bereaved college students, who had experienced the death of a loved one within the past year. The results indicated that religion was a strong predictor of stress-related growth and well-being, and those relationships were partially mediated through positive reappraisal, or meaning-making coping. Park also explained that the amount of subjective distress was influenced by the amount of time that had passed since the death. Religion was found to be related to higher levels of initial distress, which Park suggested could be a result of the disturbance in the global meaning system. On the other hand, religion was related to lower levels of long term distress, which Park suggested could be related to the positive reattributions of the event that the religious beliefs facilitated. Park concluded that the results of this study supported the idea that religion is an important component of meaning-making coping, which can be used on an individual, community, or societal level to assist in the positive recovery from life's stressors.

This previous section discussed the ways in which religion, spirituality, and assumptions about the world influence how individuals perceive and cope with traumatic

events. These belief systems appear to provide a mental framework, or schema, through which the individual can find meaning and shape the appraisal process of the traumatic experience (Siegel et al., 2001). If the event is very distressing, however, then the new information gained from the event may challenge previously held assumptions within the global meaning system and be incongruent with the individual's religious beliefs (Park, 2005). The manner in which the individual resolves this incongruence is an important component of this study because it is one of the theoretical prerequisites to Posttraumatic Growth (PTG), which will be discussed in greater detail later in the chapter (Tedeschi & Calhoun, 2004). Therefore, an understanding of how these belief systems function and help the individual make sense of a traumatic event, and exploring where potential incongruencies exist, will be important to help the researcher in this study to evaluate the process of PTG in PLWHA.

### Examining Growth Following Trauma Across Multiple Studies

It is clear from the previous sections of this chapter that there have been several branches of research that have examined positive change following trauma. It seems that these different branches within the literature have been exploring similar phenomena, but using different terminology and investigating slightly different parts of the same whole. There have, however, been a few articles that try to integrate these related fields of research, examine their similarities, comment on what is known in terms of the larger picture across the literature, and identify what needs to be further defined or investigated. This section of the chapter will focus on two comprehensive articles (Helgeson, Reynolds, & Tomich, 2006; Linley & Joseph, 2004) in order to further explore the

literature on positive change following trauma, identify some of the gaps in the present literature, and comment on new directions for research.

Linley and Joseph (2004) used the term *adversarial growth* to describe the phenomenon of personal growth following a traumatic experience and conducted a literature review to explore the extent to which it has been studied empirically, the constructs developed to describe it, the methodologies and limitations of the research, and the common variables across studies. They searched three major databases (PsychINFO, PIOLTS, and Ingenta/Medline) using the specific search terms posttraumatic growth, post-traumatic growth, and stress-related growth. In addition they conducted key word searches for thriving, perceived benefit, perceived benefits, perception of benefit, positive adjustment, and positive adaptation. Finally, they reviewed the references of the publications identified during their database search to screen for any additional articles that were missed.

Through their literature review, Linley and Joseph (2004) identified 40 empirical studies that had been published on *adversarial growth* by March of 2002. There were many methods used to measure adversarial growth. The majority of the studies (N = 27) used quantitative measures that had not been used in other research, item level data, or qualitative methods. However, 12 of the articles utilized measures that had been used in previous research. Linley and Joseph identified seven instruments that had been developed to measure adversarial growth: the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1995), the Stress-Related Growth Scale (SRGS; Park, Cohen, & Murch, 1996), the Revised Stress-Related Growth Scale (RSRGS; Armeli, Gunthert, & Cohen, 2001), the Changes in Outlook Questionnaire (CiOQ; Joseph, Williams, & Yule,

1993), the Thriving Scale (TS; Abraido-Lanza, Guier, & Colon, 1998), the Illness Cognition Questionnaire (ICQ; Evers et al., 2001), and the Perceived Benefit Scales (PBS; McMillen & Fisher, 1998). All of these scales use self-report items and produce from one (SRGS) to eight (RSRGS, PBS) growth related subscales or factors. Given that the PTGI and SRGS are used to the greatest extent in the literature, they will be discussed in greater detail later in this chapter.

The studies that were included in the literature review examined adversarial growth in a wide variety of populations. The populations that were investigated included college students, survivors of natural disasters, combat veterans, victims of violent crimes, survivors of abuse, people with chronic or terminal medical conditions, bereaved individuals, parents of critically ill children, parents of murdered children, survivors of accidents, survivors of terrorist attacks, and mixed samples (Linley & Joseph, 2004). The studies that reported prevalence rates for positive changes did so by interpreting the range of positive change items that were endorsed by participants, which revealed prevalence rates for positive changes from 3% for bereaved persons to 98% for women with breast cancer. These rates may not be considered representative, however, because none of the studies used random sampling techniques (Linley & Joseph).

Linley and Joseph (2004) identified six categories of variables that were thought to be associated with adversarial growth and were investigated through the empirical studies. These categories informed the current study by identifying areas of potential differences in people living with HIV/AIDS who report high- or low- levels of posttraumatic growth. The six categories investigated across studies included Differences by Event Type; Cognitive Appraisal; Sociodemographic Variables; Personality; Coping, Social Support, and Religion; and Cognitive Processing, Affect, Quality of Life, and Psychological Distress. The authors advised that tentative comparisons could be made among studies that used the same instruments; however, most did not use published instruments and therefore comparisons across different studies should be made with caution.

The first category that was investigated was differences in adversarial growth by event type. When comparing growth across studies that used the PTGI, Linley and Joseph found that bereaved mothers scored the highest (Polatinshy & Esprey, 2000) while husbands of women with breast cancer scored lowest (Weiss, 2002). In addition, only three studies specifically investigated growth outcome by event type and two of them had nonsignificant results. The study that did find significant results (McMillen, Smith, & Fisher, 1997) found the highest levels of growth in survivors of a tornado, followed by individuals affected by a mass shooting, and finally individuals affected by a plane crash. In this study, there were differences in the degree to which the participants had first-hand interactions with the stressors. For example, the tornado destroyed an entire town and individuals from that community were sampled. On the other hand, the employees of the restaurant where the mass shooting occurred and of the hotel where the plane crashed who were both on- and off-site at the time of the incidents were sampled (Linley & Joseph). Linley and Joseph commented that the differences in growth scores could also be because of the sample's relationship to the stressor. The individual's subjective experience of the event, rather than the actual event, could actually be the factor influencing growth. Therefore, the samples from the mass shooting and plane crash had

lower mean scores of growth because of variations in the individuals' proximity to the traumatic event.

The second category that Linley and Joseph identified as a point of investigation was cognitive appraisal. Specifically the constructs of awareness, control, harm, and threat were found to be related to growth. Across studies it seemed that awareness and controllability of the event were related to higher levels of growth. The association between harm and threat, or trauma, was not as clear because a consistent linear relationship did not appear across studies. Fontana and Rosenheck (1998) described a potential curvilinear relationship between growth and trauma: that growth was highest at intermediate levels of traumatic exposure.

The third category that Linley and Joseph examined as a variable that was studied in relation to adversarial growth was sociodemographic variables. The first variable explored across many studies was gender. In general it seemed that women tended to experience higher levels of growth than men, but Linley and Joseph stated that the evidence remains mixed because some studies reported no gender difference. For example, studies that used samples of college students reporting on various events (Park et al., 1996; Tedeschi & Calhoun, 1996) or examined the differences between women with breast cancer and their husbands (Weiss, 2002) found that women reported higher levels of growth than men. On the other hand, a study of bereaved parents reported a nonsignificant gender effect (Polatinsky & Esprey, 2000). This study had a relatively small sample size (N= 67) and while the results were nonsignificant the trend in the data was in the direction of mothers reporting more growth (Linley & Joseph). The second variable explored was age, with younger participants generally reporting more growth across studies than older respondents. The authors stated that there could be confounds for age effects such as the results being skewed by outlier scores of younger participants (Polatinsky & Esprey, 2000); the older participants might have been more concerned by the imminence of their death than growth (Davis, Nolen-Hoeksema, & Larson, 1998); and the younger participants with chronic illnesses may have been more motivated to adapt to their conditions because they believe they have a longer life ahead of them (Evers et al., 2001). Finally, Linley and Joseph identified a study that linked higher income and education to increased growth (Updegraff, Taylor, Kemeny & Wyatt, 2002); however, they cautioned that most samples were from people of low socioeconomic status so the "higher" income and education was actually closer to the national average.

The fourth category that Linley and Joseph noted in their literature review as a variable that was studied in relation to adversarial growth was personality. The studies that used the Big Five personality constellation found extraversion, openness to experience, agreeableness, and conscientiousness to be positively associated with growth while neuroticism is negatively associated (Tedeschi & Calhoun, 1995). It also seemed that people with higher self-esteem and optimism reported higher levels of growth (Abraido-Lanza et al., 1998). Finally, self-efficacy and hardiness were both associated with growth, while sense of coherence was not (Linley & Joseph).

The fifth category that Linley and Joseph discussed in their literature review as a variable that was studied in relation to adversarial growth was coping, social support, and religion. Across studies, problem-focused coping seemed to be related to growth, including acceptance and positive reinterpretation (Armeli et al., 2001; Evers et al., 2001). In addition, religious activities and intrinsic religiousness were also related to

growth (Park et al., 1996; Tedeschi & Calhoun, 1996). The role of social support, however, remains unclear because the results were mixed. In general, social support alone was not found to be related to growth. On the other hand, using social support within the context of emotion-focused coping and satisfaction with social support were both related to growth (Park et al., 1996). Linley and Joseph concluded that the causal nature of the relationship between social support and growth was unclear; appropriate social support could promote growth or enhanced interpersonal relationship could be the result of growth.

The final category that Linley and Joseph identified across the studies they reviewed was cognitive processing, affect, quality of life, and psychological distress. Several researchers found that rumination, intrusions, and avoidance were associated with growth (Calhoun, Cann, Tedeschi, & McMillen, 2000; Cordova, Cunningham, Carlson, & Andrykowski, 2001). While these behaviors are also associated with Posttraumatic Stress Disorder, the authors explained that these cognitive processes may be necessary to help the individual reconstruct his or her worldview that was shattered by the trauma. Across studies, positive affect was associated with growth while negative affect was negatively associated (Abraido-Lanza et al., 1998; Evers et al., 2001). The authors pointed out that in many studies, negative affect may actually be overlapping with neuroticism, and said that one study found nonsignificant results for negative affect in a partial correlation that controlled for neuroticism (Linley & Joseph). Notably, quality of life, depression, anxiety, and pre-existing mental health diagnosis were all found not to be related to growth (Best et al., 2001; Frazier et al., 2001; Updegraff et al., 2002). Finally, the diagnosis of PTSD received mixed results. In one study, a PTSD diagnosis was

negatively associated with positive life changes 2 weeks following a sexual assault but not 1 year following the assault (Frazier et al., 2001). Another study, however, found that a PTSD diagnosis was positively related to stress-related growth (Pargament, Smith, Koening, & Perez, 1998).

In addition to the six categories of variables that have been examined across studies, Linley and Joseph also commented on what empirical studies have found related to the long term effects of adversarial growth. They identified five longitudinal studies that examined variables associated with adversarial growth and found that only positive affect, negative affect, and self-efficacy were significantly associated longitudinally with growth. One study (Abraido-Lanza et al., 1998) found nonsignificant associations between growth and pain experience, level of disability, age, length of time with the illness, self-esteem, acculturation, acceptance, and emotional support over a 3-year period. In addition, Abraido-Lanza and colleagues used path analysis to determine that social support and acceptance of illness did not predict thriving; however, positive affect did. Another study (King, Scollon, Ramsey, & Williams, 2000) found nonsignificant associations with growth and optimism, self-esteem, life satisfaction, sense of coherence, and ego development over a 2-year period. In contrast, Davis and colleagues (1998) found that only optimism predicted "benefit finding" among bereaved persons. Park and colleagues (1996) used multiple regression to identify six significant individual predictors of stress-related growth in a 6-month follow up: positive reinterpretation, intervening positive life events, acceptance coping, intrinsic religiousness, initial stressfulness of the event, and social support satisfaction. Contrary to the previously mentioned longitudinal studies, positive affect was found to be nonsignificant. Finally, McMillen and colleagues

(1997) found that participants who thought they were going to die and had a pre-existing mental health diagnosis were more likely to perceive benefits 3 years after a tornado, a mass shooting, and a plane crash. Linley and Joseph concluded, "that greater traumatic experience, dealt with by means of positive reinterpretation and acceptance coping, in people who are optimistic, intrinsically religious, and experience more positive affect, is likely to lead to reports of greater adversarial growth" (Linley & Joseph, 2004, p. 17).

Linley and Joseph concluded their comprehensive literature review by discussing methodological considerations and future avenues of investigation. First, they explained that there is a need for greater methodological rigor and the use of well-validated measures. The comparison of adversarial growth across studies was difficult, given that many of the studies used unpublished measures. In addition, the currently published measures vary in the number of underlying factors that contribute to adversarial growth. Second, they expressed the need for additional studies examining the longitudinal and developmental effects of adversarial growth. Third, they recognize that the lack of preevent data makes it difficult to assess how much change has occurred, and recommend collateral assessment of both behavioral and psychological indicators. They also recommended that future studies do not rely heavily on self-report measures that do not allow for negative responses in addition to growth items. Fourth, they acknowledged that the associations that empirical research has found between psychosocial variables and growth have been small, and encourage researchers to identify new variables related to growth. They pointed out that there are many conceptual overlaps between adversarial growth and other constructs such as reinterpretation coping and resiliency. They recommended the development of a comprehensive theoretical model that accounts for

many of the mediating and moderating variables that are involved. Finally, they encouraged researchers and clinicians to consider the therapeutic application of concepts from the adversarial growth literature, such as the co-existence of growth and distress in the survivors of trauma. The findings of Linley and Joseph's (2004) literature review helped to inform the current study by identifying variables related to Posttraumatic Growth and highlighting the limitations within the literature that the current study built upon.

In an effort to better define the amount of growth that was measured across studies, Helgeson, Reynolds, and Tomich (2006) conducted a meta-analysis that further examined the outcome of growth following a trauma or stressor. Several of the studies mentioned by Linley and Joseph (2004) were included in this meta-analysis. Helgeson and colleagues had three primary goals for their meta-analysis. First, the purpose of the meta-analysis was to explore the relationship between benefit finding and well-being. Second, Helgeson's team wanted to examine which correlates of benefit finding are most likely to predict growth. The specific correlates included: the demographic variables of age, race, and gender; the stressor characteristics of objective compared to subjective severity, and time since the trauma; the personality traits of optimism, religiosity, and neuroticism; and, finally, the coping strategies of positive reappraisal, acceptance, and denial. Finally, they wanted to examine five potential moderators between benefit finding and health: time since the stressful event, the nature of the traumatic event, the outcome measures used to assess benefit finding, the demographic variable of race, and the demographic variable of gender (Helgeson et al., 2006).

The studies for the meta-analysis were identified using the reference list from Linley and Joseph (2004) and electronic databases, such as PsychINFO and Medline, using the search terms *positive life changes, benefit finding, posttraumatic growth*, and *stress-related growth* (Helgeson et al., 2006). This literature review identified 235 studies that were published through April 2005. The articles were then screened using the following criteria: the research was on an adult population (over 18 years old), the work included a clear measure of benefit finding, the participants had experienced a stressful event, and the work included a measure of physical or mental health. This narrowed the article pool down to 87 studies that were published in 77 articles. The authors noted that more than half of the studies were published within the last five years (Helgeson et al., 2006).

In order to explore the relationship between benefit finding and well-being, effect sizes were calculated for the mental and physical health outcome measures across the studies. This was done in order to see if benefit finding actually produced a positive change in the participants' mental or physical health. The results revealed that benefit finding was related to the mental health outcomes of less depression (r = -.09; p < .001), greater positive well-being (r = .22; p < .001), and more intrusive-avoidant thoughts about the event (r = .18; p < .001). The authors noted that the results seem contradictory: benefit finding resulted in less depression but more intrusive-avoidant thoughts. These findings, however, appear to reflect the cognitive processing and the participants' attempts at finding meaning in the trauma rather than acting as indicators of mental health outcomes. In the meta-analysis, benefit finding was only compared to one physical health outcome, reports of physical well-being, which did not achieve significant results and

appeared to be unrelated. In addition, benefit finding was not related to anxiety, global distress, or quality of life. The authors speculated this was because each of these variables was measuring more than one construct (Helgeson et al., 2006).

In order to investigate the types of correlates that could predict benefit finding, effect sizes were also calculated for the demographic, stressor characteristic, personality, and coping style correlates. The results indicated that most of the effect sizes were small. The demographic variables of gender (r = -.08; p < .001), race (r = .11; p < .001), and age (r = -.07; p < .001) reached statistical significance. Higher rates of benefit finding occurred in women, non-White individuals, and younger participants. The stressor characteristics of objective severity (r = .07; p < .001) and perceived threat of the stressor (r = .14; p < .001) also were statistically significant. The personality trait of religiosity achieved a small effect size (r = .17; p < .001), while optimism had a medium effect size (r = .27; p < .001). Interestingly, neuroticism was unrelated to benefit finding. Finally, all of the coping strategies had statistically significant relationships with benefit finding. Acceptance coping (r = .20; p < .001) and denial (r = .16; p < .001) both had small effect sizes while positive reappraisal (r = .38; p < .001) demonstrated a medium to large effect size, and was the largest effect size in the meta-analysis (Helgeson et al., 2006).

Finally, Helgeson and colleagues tested moderator relationships between benefit finding and health. Several of the moderator relationships also were found to be statistically significant. The amount of time that passed since the event was a significant predictor for less depression ( $\beta = ..42$ ; p < .001), greater anxiety ( $\beta = ..59$ ; p < .05), more positive well-being ( $\beta = ..62$ ; p < .001), and greater global distress ( $\beta = ..30$ ; p < .001). Benefit finding was related to more positive affect and less depression when more than 2

years had passed since the event; however, benefit finding was related to more global distress and less anxiety when less than 2 years had passed. The type of outcome measure used to assess benefit finding was also a significant predictor of global distress ( $\beta = -.41$ ; p < .001), intrusive-avoidant thoughts ( $\beta = -.31$ ; p < .05), and subjective physical health  $(\beta = .32; p < .05)$ . Well-established measures such as the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), the Stress-Related Growth Scale (Park et al., 1996), the Benefit Finding Scales (BFS; Mohr et al., 1999; Tomich & Helgeson, 2004), and the Perceived Benefits Scale (PBS; McMillen & Fisher, 1998) had stronger effect sizes. The authors further explain that gender was not found to be a significant moderator because some of the studies were about women with breast cancer, and therefore this confound of gender and type of stressor produced mixed and non-significant results. Finally, the racial composition of the sample served as a moderator for benefit finding depending on what percentage of the sample was of racial minority participants. For samples that consisted mostly of Caucasian participants, the racial composition of the sample predicted increased depression ( $\beta = .63$ ; p < .001), decreased positive well being ( $\beta = -.56$ ; p < .001) .001), and increased global distress ( $\beta = .40$ ; p < .001). However, in the samples with higher percentages of racial minority participants, benefit finding was related to better mental health outcomes. For example, if 25% or more of the participants in the sample were racial minorities, then benefit finding was related to better health and less distress; however, if the sample had less than 25% minority participants then benefit finding was related to more distress. In addition, benefit finding was related to lower levels of depression, higher levels of positive affect, and reduced distress only in samples that had higher percentages of minority participants. The authors concluded that it is possible that

persons who are racial minorities engage in more benefit finding than Caucasians, but more research is needed to understand this phenomenon (Helgeson et al., 2006).

Helgeson and colleagues (2006) pointed out some limitations of the current empirical literature and areas for future growth in this line of research. First, they explained that benefit finding needs to be better defined because many of the studies used different assessment instruments and conceptualizations, making it difficult to compare the results across studies. In addition, the researchers from the various studies may not be measuring the same phenomenon. It is unclear if high reports of benefit finding are a result of the person actually changing as a result of the event, or if benefit finding is a coping mechanism for dealing with extreme stress and is only the individual's change in perception. Second, there needs to be a clearer distinction between benefit finding as a process and an outcome. For example, benefit finding immediately after the stressor could be a coping process; however, later on in recovery, benefit finding could be an outcome. Finally, Helgeson and colleagues (2006) explained that benefit finding did not seem to be a linear process and encouraged the use of longitudinal studies to explore other temporal models.

At the end of their meta-analysis, Helgeson and colleagues (2006) came to four primary conclusions about benefit finding and growth following a stressful experience. First, they stated that benefit finding is clearly related to less depression, more positive affect, and more intrusive and avoidant thoughts about the stressor. Second, the results were stronger for well-established instruments. The authors cautioned that even though these instruments had good psychometric properties, they were not sophisticated enough to distinguish between actual growth, or objectively measurable growth, and only perceived growth as a coping mechanism. Third, benefit finding is more likely to be related to better mental health when more time, such as 2 years, has elapsed since the event. Finally, the direction of the relationship between mental health and benefit finding is still unclear. It is not known whether benefit finding leads to better mental health, or if better mental health leads to benefit finding. Taken collectively, it is clear that some individuals do experience positive change following adversity; however, more research needs to be done to clarify the process.

There are several findings from Helgeson and colleagues' (2006) meta-analysis that were helpful in shaping the current study, and helped the current study to take the next step in the literature. First, Helgeson and colleagues point out that benefit finding after a traumatic event clearly does exist and has been found to be related to decreased depression, increased positive affect, and increased avoidant/intrusive thoughts. The current study examined differences in these and other indicators of mental health and quality of life, in PLWHA who report higher or lower levels of PTG. Second, Helgeson and colleagues explain that the construct of benefit finding needs to be more clearly defined in research; that researchers need to make a distinction as to whether benefit finding is being studied as a process or outcome. The current study examined the construct of benefit finding through the well-established theoretical model of Posttraumatic Growth (PTG; Tedeschi & Calhoun, 1996). Also, in this study the concept of PTG was applied as both an outcome and a process. PTG was regarded as an outcome variable during the quantitative phase of the study, for the screening purposes of identifying PLWHA who report higher or lower levels of PTG and then dividing the sample accordingly. The PTG model was then regarded as a process during the

qualitative phase of the study. Helgeson and colleagues' meta-analysis also revealed that better results for the measurement and effects of benefit finding were found with wellestablished instruments. The current study used the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), which is the most widely used and well validated instrument in the current literature. Finally, Helgeson and colleagues explain that there needs to be a distinction between actual and perceived changes made when participants report finding benefits after trauma. In order to assess for actual changes as opposed to responding in a socially desirable manner, the current study included a measure of social desirability. More details about how the current study expanded upon the extant literature appears at the end of this chapter and a discussion of the specific methodology of the current study appears in Chapter 3.

The next section of this chapter further discusses some of the empirical articles, conceptual models, and instruments that were used in the Linley and Joseph's (2004) literature review and Helgeson and colleagues (2006) meta-analysis. This section specifically focuses on the works that are most relevant to the current study. The next section will begin by reviewing the two most commonly used instruments used to measurement benefit finding in the literature: the Stress-Related Growth Scale (SRGS; Park, Cohen, & Murch, 1996) and the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). Having familiarity with these instruments and the theory behind them will assist the reader in evaluating the various studies that appear later in this chapter, which explore benefit finding in diverse populations including PLWHA. Then, since the current study uses the theory of Posttraumatic Growth, the next section will go into greater detail in discussing the theoretical model of Posttraumatic Growth, the precursors

necessary for Posttraumatic Growth to occur, and review some of the literature that assesses Posttraumatic Growth across various populations.

Specific Instruments Designed to Measure Growth Following Trauma

Through their literature review, Linley and Joseph (2004) identified several authors whose research examined the phenomenon of personal growth following a trauma or stressor. Each line of research acknowledged that this type of growth can occur; however, the research groups developed slightly different conceptualizations for the process of and the factors that contribute to growth. As a result of these conceptual differences, each research group developed its own measurement of growth. In this next section, the two most widely used instruments, the Stress-Related Growth Scale (SRGS; Park, Cohen, & Murch, 1996) and the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), will be reviewed including their conceptual background, measurement apparatus, and populations that have been examined.

There are three distinct reasons why the SRGS and PTGI will be reviewed in such detail in this section. First, in each case the development of the instrument preceded the formulation of the theoretical model for growth. In other words, the authors (Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996) noticed post hoc that participants in previous research studies were reporting personal growth or finding benefits after a traumatic event, then the authors developed an instrument to measure the level of growth, and based on the results of the instrument development studies the authors developed a theoretical framework to explain how the growth occurred. Second, the Stress-Related Growth Scale (SRGS; Park, Cohen, & Murch, 1996) and the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) are the two most widely used and well established instruments in the literature (Helgeson et al., 2006; Linley & Joseph, 2004). Therefore, many of the studies discussed later in this chapter that describe growth following trauma in specific populations, including PLWHA, use either the SRGS or the PTGI and familiarity with these instruments may help the reader to evaluate the studies. Third, the current researcher had to make a decision as to which instrument and theoretical framework to use in its methodology and therefore a careful review of each instrument and branch of literature was necessary to facilitate the decision making process. In this section the SRGS will be discussed briefly in order to illuminate some of its limitations and psychometric problems that led to it being excluded from the current study. This section will then conclude with a discussion of the development of the PTGI, which is the instrument and theoretical model that will be used in the current study.

### Stress-Related Growth

The concept of Stress-Related Growth was developed by Park, Cohen, and Murch (1996). These researchers also noticed the discrepancy in the theoretical literature surrounding individuals' responses to stressors: the focus on negative outcomes precluded the exploration of the possibility that people can "grow" from stressful events. They also noted the empirical evidence which indicated that many people who experienced significant stressors reported positive outcomes in addition to negative ones including improved self-concepts, coping skills, and interpersonal relationships. In order to clarify the relationship between stressors and positive outcomes Park and colleagues (1996) sought to develop an instrument to assess and predict Stress-Related Growth.

# The Stress-Related Growth Scale

Park, Cohen, and Murch (1996) developed the Stress-Related Growth Scale (SRGS) to assess and investigate the determinants of stress-related growth. Based on the previous work of Schaefer and Moos (1992), the SRGS explores the relationship between how an individual copes with a life stressor and the amount of growth an individual reports as a result of coping with that experience. It was developed in three specific studies. In the first study the SRGS was created with a college student population, the internal and test-retest reliabilities were calculated, and the total scale and subscale constructs were explored using factor analysis. The second study investigated the validity of the scale. The final study investigated the personality, event-related, coping, and environmental variables that contribute to the participants' responses on the SRGS. This series of studies produced a unidimensional measure for Stress-Related Growth (Park et al., 1996).

The SRGS is the second most widely used measure in the literature, after the PTGI (Armeil et al., 2001; Kesimci et al., 2005; Park & Fenster, 2004a; Roesch et al., 2004). Despite its popularity, there have been problems with the SRGS related to its factor structure and interpretation. Since the development of the SRGS, there has been some controversy as to whether Stress-Related Growth was even a unidimensional construct. Armeli, Cimbolic, and Cohen (2001) suspected that Stress-Related Growth could be a multidimensional construct since prior research, like the development and use of the PTGI (Tedeschi & Calhoun, 1996), revealed that growth was multifaceted. The authors also noted that they wanted to develop a revised version of the Stress-Related Growth Scale (RSRGS) that would allow responses to assess both positive and negative

change, instead of using the solely positively-worded items of the original SRGS (Armeil et al., 2001). After conducting factor analysis, Armeli and colleagues (2001) concluded that Stress-Related Growth is better described by a multidimensional model. They found that the seven factors of treatment of others, religiousness, personal strength, belongingness, affect-regulation, self-understanding, and optimism better describe the underlying dimension of that construct.

The controversy surrounding the factor structure of the Stress-Related Growth Scale was revisited by Roesch, Rowley, and Vaughn (2004). These authors wanted to determine if a unidimensional or multidimensional model best represented the SRGS and if a multidimensional model were more appropriate then how many meaningful factors exist. In order to conduct the factor analysis, the authors had to drop several poorly loading items from the SRGS, depending on the number of factors they defined in each model. Roesch and colleagues (2004) concluded that the dimensionality of the SRGS was highly unstable. The original unidimensional structure found by Park et al. (1996) was not replicated in following studies. The seven-factor solution found in Armeli et al.'s (2001) validation study was not replicated in this study because there were problems with internal consistency and redundant factors. Roesch and colleagues suspect that the number of factors that emerge in a particular study depends on the number and types of items used; their 29-item version of the SRGS only shared 8 of the 19-items that Armeli et al. used in their analysis. Roesch and colleagues stated that the number of factors interpreted from the SRGS in future studies could vary depending on the goals of the research. They explained that the three-factor model could be used to assess global dimensions of growth, while the seven-factor solution could describe more specific

aspects of growth (Roesch et al., 2004). Due to the difficulties in establishing the number of factors in the SRGS, it was decided that this measure will not be used in the current research project.

### Posttraumatic Growth

The term of Posttraumatic Growth was first used by Tedeschi and Calhoun (1996) when they developed a questionnaire to measure this phenomenon; however, they had been exploring it conceptually for 12 years prior to the development of the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 2004). They had found that some individuals who had experienced trauma reported positive development in various aspects of their lives that surpassed their baseline level before the trauma had occurred. Through their previous work (Calhoun & Tedeschi, 1989-90) Tedeschi and Calhoun (1996) identified three broad areas of positive change that would serve as a starting point for developing the conceptual model of Posttraumatic Growth: changes in self-perception, changes in interpersonal relationships, and a changed philosophy of life.

### The Posttraumatic Growth Inventory

Tedeschi and Calhoun (1996) developed the Posttraumatic Growth Inventory to measure the level of positive growth and help clarify the underlying structure of this phenomenon. Based on their previous work and a literature review, they developed 34 items that referred to positive changes in perception of self, relationships with others, and philosophy of life that happened as a result of the participants' attempts to cope with a trauma. Participants were asked to consider a crisis from their life and rate the degree to which change had occurred as a result of that crisis. Responses were in a 6-point Likerttype scale ranging from 0 ("I did not experience this change as a result of my crisis") to 5 ("I experienced this change to a very great degree as a result of my crisis"), with intermediate scores indicating "a very small degree (1), a small degree (2), a moderate degree (3), and a great degree (4)," (Tedeschi & Calhoun, 1996, p. 459).

The questionnaires were administered to 604 undergraduate students (199 men, 405 women) who were taking psychology classes at a large university in the southeastern United States and had experienced a "significant life event" during the past five years. Most participants ranged in age from 17 to 25 (92%) and 95% of the sample was single. The participants reported a wide range of life events including bereavement (36%), injury producing accidents (16%), separation or divorce of parents (8%), relationship break up (7%), criminal victimization (5%), academic problems (4%), and unwanted pregnancy (2%). The amount of time that had passed since the event varied: less than 6 months ago (22%), between 7 and 12 months ago (16%), between 13 and 23 months ago (17%), between 2 and 4 years ago (32%), and more than 4 years ago (13%) (Tedeschi & Calhoun, 1996).

A principle component analysis (PCA) with varimax rotation was conducted on the original 34 items, which produced a "very high" internal consistency ( $\alpha = .94$ ) and six factors with eigenvalues greater than one. Tedeschi and Calhoun (1996) asserted that five of the six factors were easily interpretable and therefore the 21 items from those factors were kept for further analysis. The 21 items accounted for 55% of the common variance, had a loading greater than 0.5 on one factor, and had loadings of less than 0.4 on the remaining four factors. Another PCA with varimax rotation was conducted on the remaining 21 items, which produced a five factor solution that was identical to the original PCA, which accounted for 62% of the common variance. The Pearson product-moment correlation (r = .98) indicated that there was no significant loss of information when the number of items was reduced from 34 to 21. The final five factors were named Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation for Life (Tedeschi & Calhoun, 1996).

On the overall scale, women reported finding more benefits (M = 75.18, SD =21.24) than men (M = 67.77, SD = 22.07) (t(1,590) = 3.94, p < .001), with women scoring higher on every factor except New Possibilities, which was not significantly different between women and men. The internal consistency for all 21 items was  $\alpha = .90$ , although individual factor internal consistencies varied: New Possibilities ( $\alpha = .84$ ), Relating to Others ( $\alpha = .85$ ), Personal Strength ( $\alpha = .72$ ), Spiritual Change ( $\alpha = .85$ ), and Appreciation for Life ( $\alpha = .67$ ). The authors said that the corrected item-total correlations, which examine the correlation of each individual item with the total score across the remaining items, were in the moderate range (r = .35 to r = .63). The Pearson productmoment correlations among the factors ranged from r = .27 to r = .83, and the correlations of the individual factors with the total PTGI score ranged from r = .62 to r =.83, which Tedeschi and Calhoun (1996) stated are an indication of some overlap yet separate contributions by each factor. Finally, a sample of 28 college students was selected, using the same method as previously mentioned, to establish test-retest reliability over a two month period. The test-retest reliability for the entire PTGI was "acceptable" at r = .71; however, the individual factor reliabilities ranged from r = .37 to r = .74 (Tedeschi & Calhoun, 1996).

Tedeschi and Calhoun (1996) recognized that perceiving benefits could be the result of some other intrapersonal tendency and not the result of coping with trauma. To examine concurrent and discriminant validity, Tedeschi and Calhoun compared their PTGI to a measure of social desirability and to demographic and situational variables, such as age and time since the traumatic event occurred. The authors used the Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1960) to examine the correlation between the PTGI and social desirability. The findings revealed no significant relationship between the PTGI and social desirability; in fact the factor Appreciation for Life was found to be negatively correlated (r = -.15, p < .01). Finally, there appeared to be no significant relationship between the ages of the participants or the time since the event occurred and the PTGI score (Tedeschi & Calhoun, 1996).

To assess further for concurrent and discriminant validity, Tedeschi and Calhoun (1996) examined the relationships between the PTGI and personality characteristics. They used the Life Orientation Test to investigate optimism (LOT; Scheier & Carver, 1985), the NEO Personality Inventory to investigate Neuroticism, Extraversion, Openness to Experience, Agreeableness, and Conscientiousness (NEO; Costa & McCrae, 1985), and a three-item measure to examine religious participation (Pressman, Lyons, Larson, & Strain, 1990). The PTGI was found to be positively correlated with optimism (r = .23), religiosity (r = .25), and all of the factors of the NEO except Neuroticism (Extraversion, r = .29; Openness, r = .21; Agreeableness, r = .18; and Conscientiousness, r = .16) (Tedeschi & Calhoun, 1996). In addition, Extraversion was the only NEO factor that was found to be positively correlated with each PTGI factor. Finally, three specific facets of the NEO demonstrated a strong relationship to all PTGI factors and total score: the Extraversion facets of Activity (r = .31 with PTGI total) and Positive Emotions (r = .34 with PTGI total), and the Openness to Experience facet of Feelings (r = .28 with PTGI total) (Tedeschi & Calhoun, 1996).

To investigate the construct validity of the PTGI, Tedeschi and Calhoun (1996) wanted to determine that the PTGI tapped into benefits that were unique to individuals who had experienced traumatic events compared to people who had only experienced ordinary life events. A sample of 194 participants was recruited using methods similar to the methods described in the previous section. These participants completed the PTGI, with instructions that asked them to rate changes that occurred within the past year, and the Traumatic Stress Schedule (TSS; Norris, 1990), which is a screening instrument designed to assess the incidence and effect of traumatic events. The responses to the TSS were used to identify participants who had not experienced any traumatic events and participants who reported at least one intensely traumatic event within the past year. The questionnaires of 117 respondents were selected for analysis based on the TSS scores; 54 (23 men and 31 women) reported at least one severely traumatic event and 63 (32 men and 31 women) reported none. The data were then analyzed using a 2 (gender) X 2 (severe trauma or no trauma) design (Tedeschi & Calhoun, 1996).

Tedeschi and Calhoun (1996) conducted a gender X severity of trauma analysis of variance (ANOVA) with the PTGI total score as the dependent variable. The results indicated that women reported more PTG (M = 81.60; SD 21.09) than men did (M = 70.15; SD 21.87) (F(1,113) = 10.69, p < .001), and participants who experienced severe trauma reported more PTG (M = 83.16; SD = 19.27) than those who did not (M = 69.75; SD = 20.47) (F(1,113) = 12.33, p < .001), while the gender X severity of trauma

interaction was not significant (Tedeschi & Calhoun, 1996). A gender X severity of trauma multivariate analysis of variance (MANOVA) was conducted with the five PTGI factors as dependent variables. The results reiterated that women reported more benefit than men did (F(53,5) = 3.68, p < .01), that participants who experienced severe trauma reported more benefits than those who did not (F(53,5) = 3.61, p < .01), and that the gender X severity of trauma interaction was not significant (Tedeschi & Calhoun, 1996).

Univariate tests were conducted to examine differences in factor scores between groups. The analysis revealed that women had higher scores than men for the New Possibilities factor (F(1,113) = 6.15, p < .05), the Relating to Others factor (F(1,113) = 6.93, p < .01), the Personal Strength factor (F(1,113) = 4.96, p < .05), and the Spiritual Change factor (F(1,113) = 14.09, p < .001). The Appreciation of Life factor was not significant across gender. Participants who had experienced severe trauma had higher scores than those who did not for the New Possibilities factor (F(1,113) = 6.54, p < .05), the Relating to Others factor (F(1,113) = 4.95, p < .05), the Personal Strength factor (F(1,113) = 4.95, p < .05), the Personal Strength factor (F(1,113) = 9.23, p < .01), and the Appreciation of Life factor (F(1,113) = 17.58, p < .001). The Spiritual Change factor was not significant across trauma severity (Tedeschi & Calhoun, 1996).

Since the development of the Posttraumatic Growth Inventory, researchers have been able to assess the presence, type, and extent of benefits people perceive as a result of coping with trauma. As the PTGI has been used in more studies with various populations, some researchers began to question whether asking about benefits following a trauma could actually create the illusion of growth. Specifically, Smith and Cook (2004) wondered if the process of linking the questions on the PTGI to a specific traumatic event could lead respondents to overestimate their growth through self-enhancing thinking, rather than have the participant think about general life changes.

Smith and Cook (2004) assessed the validity of the PTGI by using two different administration methods: one with instructions linking the PTGI questions to a specific traumatic event (linked group) and one with instructions to complete the PTGI in reference to general life changes that occurred over the past four years (unlinked group). A total of 344 participants was recruited from a large, urban university (N = 93) and a jury pool sample (N= 251) that drew from the county in which the university was located. The authors noted that the participants from the two data collection sites were "statistically similar" across demographic variable except for age, with the jury pool being older (M = 42.1 years, SD = 11.6) than the university pool (M = 26.4 years, SD = 5.9), t(272) = 11.38, p < .01 (Smith & Cook, 2004).

The questionnaire packets contained both the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) and the Traumatic Stress Schedule (TSS; Norris, 1990). The TSS was used to categorize participants into event exposure groups, differentiating between participants who had experienced traumatic versus non-traumatic events. This screening identified 85 participants who had experienced traumatic events and 191 who had experienced non-traumatic events. Smith and Cook (2004) then varied the instructions to the PTGI and the order that it appeared in the questionnaire packets between the linked and unlinked methods. In the linked method the PTGI was left with its original instructions and participants were asked to consider the extent to which they had changed as the result of a specific event that occurred within the last four years. In this condition, the PTGI was administered after the TSS. In the unlinked method the PTGI was administered before the TSS and participants were instructed to think generally about the past four years and indicate the amount of personal changes that had occurred without any reference to a specific traumatic event (Smith & Cook, 2004).

The results were analyzed using a multivariate analysis of covariance (MANCOVA) to statistically control for the age differences in the university and jury pools. With the age controlled, Smith and Cook (2004) conducted a 2 (method) X 2 (event exposure) MANCOVA with the five PTGI subscales as the dependent variables. The authors found both a significant main effect for method and significant interactions for method and event exposure (Pillai's Trace = .05, F (5, 267), p < .05), and stated that they only interpreted the interaction (Smith & Cook, 2004). Follow-up ANCOVAs were conducted with each factor of the PTGI as a dependent variable. The results indicated that for the unlinked group only, respondents who were exposed to traumatic events reported greater growth in Personal Strength (M = 17.35, SD = .75) and Relating to Others (M = 26.70, SD = 1.25) than participants who were not exposed to traumatic events. Smith and Cook (2004) concluded that although the PTGI appears to be a sound instrument for assessing for growth after a traumatic experience, it could actually be underestimating the amount of growth in the realms of Personal Strength and Relating to Others. Smith and Cook's finding, that linking the PTGI to a specific event is an appropriate way to assess for personal growth following a traumatic experience, will help to inform the current study exploring the development of Posttraumatic Growth by specifically linking the PTGI to the event of being diagnosed as HIV-positive.

The previous section discussed the development of two instruments designed to measure growth following a traumatic event: the Stress-Related Growth Scale (SRGS;
Park, Cohen, & Murch, 1996) and the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). The development of each instrument served as a starting point for the generation of theoretical models that explain the process of growth. Tedeschi and Calhoun (1996) initially developed the Posttraumatic Growth Inventory (PTGI) to investigate 3 areas of positive change that the authors observed in trauma survivors: changes in self perception, interpersonal relationships, and philosophy of life. Further investigation of the PTGI revealed five underlying factors of change: Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation for Life (Tedeschi & Calhoun). The next section of this chapter will discuss the theoretical model of Posttraumatic Growth (PTG) that Tedeschi and Calhoun developed as an extension of their work on the PTGI including an explanation of the theory of PTG and the prerequisites necessary for PTG to occur. Finally, since the current study used the PTG model to explore how PLWHA cope with their disease, the next section will also review the literature concerning how the theory of PTG has been applied to people coping with other medical conditions.

#### The Conceptual Model of Posttraumatic Growth

The current study will explore how people living with HIV/AIDS (PLWHA) cope with and find meaning in their disease, through the theoretical framework of the Posttraumatic Growth (PTG) model. More specifically, this researcher was interested in examining how PTG develops in PLWHA by examining the precursors to PTG in this population. In this study the concept of PTG was applied as both an outcome and a process. PTG was regarded as an outcome variable during the quantitative phase of the study, for the screening purposes of identifying PLWHA who report higher or lower levels of PTG and then dividing the sample accordingly. Therefore, the 5-factor theoretical model of PTG was used to describe how the PLWHA are coping with their disease. The PTG model was then regarded as a process during the qualitative phase of the study. Specifically, this study examined the extent to which the theoretical prerequisites to PTG (Tedeschi & Calhoun, 2004) exist across the groups of PLWHA who report higher or lower levels of PTG. This section of the chapter will explain how Tedeschi and Calhoun developed the theory of Posttraumatic Growth from their work on the PTGI, discuss the five factors of PTG, and explicate the prerequisites that are necessary for PTG to occur.

The Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) has assisted the development of a conceptual framework for assessing benefits resulting from coping with trauma. Since its development, the PTGI has been used in several studies with various populations and has assisted researchers in understanding the underlying mechanism of Posttraumatic Growth across populations. Based on these research studies and clinical examples, Tedeschi and Calhoun (2004) were able to develop a model of Posttraumatic Growth that describes the domains in which growth develops, examines the conditions necessary for Posttraumatic Growth to occur, considers individual characteristics that can facilitate growth, and examines the cognitive processes that underlie posttraumatic growth.

The domains of Posttraumatic Growth were originally defined in the development of the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) as the five factors that emerged from that 21-item instrument. After examining other research and clinical data, the authors asserted that those five factors seem to be comprehensive in covering the experiences of individuals who have undergone Posttraumatic Growth (Tedeschi & Calhoun, 2004). Each of the factors paradoxically illustrates that positive change can develop out of pain or loss. It is important to realize that growth is not caused directly by the trauma itself, but rather by the process of struggling with and making sense of the event (Tedeschi & Calhoun, 2004). Also, the authors note that growth in these domains does not indicate the absence or end of pain or distress, but can be present at various stages during the recovery process even when the negative effects of the event are still evident (Tedeschi & Calhoun, 2004).

The first domain of Posttraumatic Growth is an increased appreciation for life in general. Many individuals who have struggled with life crises experience a shift in priorities, and reconsider what is important in life. They may begin to take notice of the "little things," or have recognition of what was taken for granted before the event. The second domain of growth is the development of closer, more meaningful interpersonal relationships. As a result of going through trauma, the individual may feel more empathy and a greater sense of connection with others, especially toward people who share difficult circumstances. Paradoxically, the deepening of some relationships can occur while others fade or are lost, as the individual discovers who are their "real friends." The third domain of Posttraumatic Growth is an increased sense of personal strength. As the individual becomes aware of his or her vulnerability as a result of the trauma, he or she can also realize that bad things in life can be overcome and hence smaller obstacles appear less intimidating. The fourth domain of growth is the realization of new possibilities for a person's life, or that the individual can decide to take a new path in life.

Some people may decide to change careers or establish new personal goals. Finally, the fifth domain is growth in spiritual or existential matters. Religious individuals could experience a deeper sense of spirituality and religious commitment, while non-religious individuals may become more engaged in contemplating fundamental existential questions (Tedeschi & Calhoun, 1996, 2004).

There are five conditions that frequently are present that allow the process of Posttraumatic Growth to occur (Tedeschi & Calhoun, 2003). First, the individual must experience a traumatic event that is severe enough to cause him or her to reconsider previously held assumptions. The event challenges the fundamental schema that the individual had regarding the nature of the world, himself or herself, or his or her goals in life. Second, the individual is able to find a way to manage the initial debilitating distress of the event. If the person is absorbed in his or her emotional reaction to the event, then he or she might not be able to question the previously held assumptions. Third, the disengagement from previous goals and assumptions must occur, because they do not account for the new information that has been gained as a result of going through the traumatic event. Fourth, the distress must persist for some time. If the individual does not experience distress for a long enough period of time, then he or she may not go through the process of reconsidering previous assumptions. Finally, new personal narratives are created that account for the changes that have occurred as a result of the event, which then leads to schema changes to account for the new information that has been learned since the trauma (Tedeschi & Calhoun, 2003).

Tedeschi and Calhoun (2004) also identified three individual characteristics that could influence the development of posttraumatic growth. First, they reiterated findings from the development of the PTGI and identified certain personality traits as being related to posttraumatic growth. They reaffirmed that all five factors from the PTGI were related to the Big Five trait of extraversion, that the PTGI factors of new possibilities and personal strength were related to the Big Five trait of openness to experience, and that the NEO facets of activity, positive emotions, and openness to feelings were most strongly related to the total PTGI score (Tedeschi & Calhoun, 1996, 2004). Tedeschi and Calhoun explained that individuals who have these characteristics will be more aware of positive emotions during challenging circumstances, be able to process information about the adverse situation more efficiently, and perhaps produce the schema change necessary for posttraumatic growth. They also pointed out that a relationship between neuroticism and Posttraumatic Growth has not been established at this time. Finally, they restated that a "modest correlation" (r = .23) was found between optimism and PTGI scores in the original instrument development (Tedeschi & Calhoun, 1996; 2004). They explained that this correlation indicates that although optimism and Posttraumatic Growth are separate concepts, they may be related in that optimism influences the cognitive process by which schemas are restructured to integrate new post-trauma information and develop an awareness of positive change.

The second individual characteristic Tedeschi and Calhoun (2004) discussed that would have an influence on the development of Posttraumatic Growth is the individual's way of managing the initial distressing emotions. When facing the initial trauma, debilitating emotions often flood the individual. It is critical, however, for these emotions to be managed sufficiently to allow some constructive cognitive processes to occur so that the necessary changes in schema can happen. The distress the individual faces is important because it keeps the cognitive process active so that the assumptive world is tested and new schemas are created to accommodate the traumatic information (Tedeschi & Calhoun, 2004). The third individual characteristic that Tedeschi and Calhoun discussed that influences Posttraumatic Growth is support and disclosure. Supportive others can help facilitate the Posttraumatic Growth process by offering a setting for the individual to share her or his experiences in an emotionally safe environment. The process of self-disclosure can help the individual explore her or his previously held assumptions, receive feedback from others, and confront questions of meaning as she or he constructs new schemas. In addition, the sharing of narratives can result in deeper levels of intimacy between people because of the emotionally charged content (Tedeschi & Calhoun, 2004).

Throughout the discussion of the domains of and prerequisites necessary for posttraumatic growth, Tedeschi and Calhoun (2004) highlighted the role of cognitive processing. Specifically, they assert that people who report growth usually disengage from certain basic assumptions that no longer fit their worldview and attempt to reconstruct new schemas, goals, and meaning that integrate new post-trauma information. In order for this reconstruction to take place, a persistent cognitive process occurs that allows the individual to derive some positive meaning from the negative events. A central component of the cognitive process underlying Posttraumatic Growth is similar to rumination. According to Martin and Tesser's (1996) description, rumination is a type of thinking that is conscious, is based upon a specific theme, and happens spontaneously although it could be indirectly cued from the environment because it is connected to salient goals. Ruminations can refer to the past, present, or future and represent positive

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or negative events. Although having repetitive, intrusive thoughts related to a traumatic event is part of the normal response to trauma (Joseph & Williams, 2005), the cognitive process similar to rumination that facilitates Posttraumatic Growth is a deliberate course of action (Tedeschi & Calhoun, 2004).

Calhoun and colleagues (2000) investigated whether the amount and timing of ruminations, religious participation, and openness to religious change made a difference in the levels of posttraumatic growth. They found that the more deliberate rumination individuals reported experiencing soon after the event, the more Posttraumatic Growth they reported. This neutral or constructive cognitive processing helps the individual contemplate previously held assumptions, construct meaning from the event, and integrate the information into a new schema. However, ruminations that were primarily intrusive, negative, and continued for long periods of time after the event were not linked to increased Posttraumatic Growth (Calhoun et al., 2000). Therefore, it would appear that the cognitive process of reviewing event-related information early in the recovery process is helpful in creating Posttraumatic Growth because it allows the individual to make sense of the traumatic information and reframe it in a positive manner. In addition, their results revealed that, although the amount of religious participation did not independently predict growth, individuals with high levels of openness to religious change experienced more growth. The authors concluded that these results suggest that individuals whose posttraumatic cognitive processes includes significant attempts at meaning making are the most likely to experience posttraumatic growth.

The previous section explained how Tedeschi and Calhoun (1996, 2004) developed a theoretical model of Posttraumatic Growth based on their work on the PTGI.

When an individual undergoes PTG, positive changes may occur in five domains: Appreciation for Life, Relating to Others, Personal Strength, New Possibilities, and Spiritual Change. In addition, Tedeschi and Calhoun (2003) identified prerequisites to growth, or conditions that would be necessary for growth to occur: having a traumatic experience that is severe enough to challenge previously held assumptions about the world, the individual is able to manage his or her distress, there is disengagement from previously held goals, the distress must persist for some time, and new personal narratives are created to accommodate the new traumatic information. In addition, the authors (Tedeschi & Calhoun, 2004) identified individual characteristics that could influence the development of PTG including the Big Five personality traits of extraversion and openness to experience, optimism, the ability to cope with stressful emotions, and social support with self-disclosure. Finally, the authors (Calhoun et al., 2000; Tedeschi & Calhoun, 2004) explained how the cognitive process of reviewing event-related information early in the recovery process is helpful in creating Posttraumatic Growth because it allows the individual to make sense of the traumatic information and reframe it in a positive manner. The next section in this chapter will review the literature that applies Tedeschi and Calhoun's theory of PTG to people who are coping with various medical conditions. If the model of PTG can be applied to individuals who are coping with medical conditions, then perhaps the findings of these studies can inform the development of the current study which focused specifically on people coping with HIV/AIDS.

## Posttraumatic Growth in People with Medical Conditions

A significant source of stress for many people is the process of coping with the diagnosis of and treatment for a chronic or terminal medical condition (Linley & Joseph, 2004). Experiencing the symptoms from the illness, going through rigorous medical treatments, and facing potential changes in physical or cognitive abilities may be stressful enough to cause the individual to challenge previously held assumptions about life and make it necessary for the restructuring of schema. Therefore, the process of a severe medical condition could serve as a context for posttraumatic growth. In this next section, the relationship between Posttraumatic Growth and medical illness will be explored. An expanded discussion specifically related to people living with HIV/AIDS, however, will occur later on in this chapter.

One population that has been researched in relation to Posttraumatic Growth (PTG) has been individuals with cancer. One can generate predictions about how individuals diagnosed with cancer could find benefits concurrent with their condition, using Tedeschi and Calhoun's model of PTG. According to theoretical principles of posttraumatic growth, one would expect that individuals who had a more severe diagnosis would report greater levels of Posttraumatic Growth because their assumptive world would be presented with greater challenges, which would make it necessary to reconstruct schema and integrate new trauma-related information. It should be noted that this prediction assumes that PTG follows a linear pattern of development. If the relationship between severity of diagnosis and PTG is curvilinear, then individuals with more severe diagnosis could report lower levels of PTG if the prerequisite of managing distressing emotions is not met (Tedeschi & Calhoun, 2004). In addition, individuals who

have had cancer for a longer period of time would be expected to report more Posttraumatic Growth because they would have had more time to participate in the cognitive processes that would allow them to reconstruct schema to acknowledge the positive aspects of their situation. Finally, it would be expected that individuals who possess the personality traits of optimism, extraversion, and openness to experiences to report more Posttraumatic Growth because they would be more likely to be aware of positive aspects of their recovery. Next, a few of the studies exploring PTG in individuals with cancer will be discussed in order to see how well the PTG model (Tedeschi & Calhoun, 2004) fits with the coping patterns of this population.

Sears and colleagues (2003) examined benefit finding, positive reappraisal coping, and Posttraumatic Growth in women with early stages of breast cancer. The participants completed self-report questionnaires at a baseline survey (N = 92), 3-month follow up survey (N = 92), and 12-month follow up survey (N = 60). In addition, structured interviews were conducted after the participants completed the baseline survey (N = 77). Sears and colleagues' study revealed mixed support for Tedeschi and Calhoun's (1996) model of Posttraumatic Growth in this population of women with breast cancer. Posttraumatic Growth was found to be prevalent within the sample; 83% of the women perceived at least one benefit from their experience, most commonly within the domain of their relationships with others. Consistent with theoretical expectations, both illness-related stress and time since diagnosis were significantly related to increased rates of posttraumatic growth. Specifically, individuals who reported more stress in reaction to cancer, or more engagement with the stressor, and who had a longer period of time to process information about their illness reported more posttraumatic growth. The authors

also noted that illness-related stress uniquely predicted posttraumatic growth. In addition, participants who used positive reappraisal coping at the beginning of the study reported more Posttraumatic Growth at the 12-month follow up. Therefore, the authors concluded that effortful and regular use of benefit-related information was more beneficial to the participants' level of growth than just simply identifying benefits. Finally, contrary to theoretical expectations, characteristics such as education, optimism, and hope were not predictive of Posttraumatic Growth (Sears et al., 2003).

Bellizzi and Blank (2006) also found similar predictors of Posttraumatic Growth in breast cancer survivors (N = 224). These researchers, however, only investigated three factors of the PTGI: Relationships with Others, New Possibilities, and Appreciation for Life. Bellizzi and Blank explained that they only used items from these three factors because those were the areas of growth that were most often reported by breast cancer survivors. Consistent with theoretical predictions, women who reported a high intensity of stress at the time of diagnosis and had more serious forms of breast cancer reported higher levels of Posttraumatic Growth in all three areas. In addition, women who used active, adaptive coping strategies also reported high levels of Posttraumatic Growth in all three areas. Contrary to expectations, yet consistent with the findings of Sears and colleagues (2003), hope and optimism did not predict Posttraumatic Growth. Several demographic variables were found to be related to Posttraumatic Growth. Younger women and women who were employed reported more growth in all three areas. Women who did not attend college and women who were married reported more growth in their relationships with others and purpose in life, but not appreciation for life. Finally, having

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children, ethnicity, and time since diagnosis were not found to be predictive of Posttraumatic Growth (Bellizzi & Blank, 2006).

Individuals with other types of cancers were also surveyed to examine the level of Posttraumatic Growth they have experienced. Widows, Jacobsen, Booth-Jones, and Fields (2005) investigated the predictors of Posttraumatic Growth in 72 individuals with cancer; data were collected through self-report measures from these individuals both preand post-bone marrow transplant. Results indicated that the average participant endorsed PTGI items to what the authors refer to as a "moderate degree," or an average of 14.70 out of 21 items. The only demographic variables that were found to have significant relationships with Posttraumatic Growth were age and education, in that younger and less well-educated individuals reported higher levels of posttraumatic growth. Contrary to the authors' prediction, clinical variables such as cancer diagnosis, length of hospitalization, and time since transplantation, were found to have a nonsignificant relationship to posttraumatic growth. In addition, greater social support, post-transplant levels of PTSD symptomatology, and actual pre- and post-bone marrow transplant levels of actual, or objective, psychological stress were found not to be significantly related to higher reports of posttraumatic growth. Notably, the post-bone marrow transplant recollection of psychological stress, the recollection of concern for life, and positive reappraisal coping were found to be significantly related to higher levels of posttraumatic growth. Widows and colleagues speculated that this supports the theoretical notion that the individual's subjective appraisal of an event, instead of the actual event, is more important in deriving positive meaning from the trauma. In other words, the authors of this study suspected that the perception of change that is attributed to a past negative psychological status is

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related to posttraumatic growth, more than the actual amount of change in the psychological status that have occurred (Widows et al., 2005).

The process of Posttraumatic Growth has also been researched in populations with other physical diseases or disability. Sheikh (2004) investigated the roles of personality, social support, and coping in Posttraumatic Growth in individuals with cardiac disease. A sample of 110 individuals who had a history of cardiac arrest was obtained from the United States and the United Kingdom. Sheikh wanted to examine the extent to which personality and social support predict posttraumatic growth, as mediated through coping resources. Specifically, the authors hypothesized that Extraversion and Social Support positively influence Posttraumatic Growth through the mediating variable of Problem-Focused Coping.

Results indicated that Extraversion was the only personality variable that significantly predicted posttraumatic growth. Contrary to predictions, Social Support was not found to be a significant predictor (Sheikh, 2004). Consistent with Tedeschi and Calhoun (1996), there was no relationship between Neuroticism and posttraumatic growth. When testing the mediation hypothesis, Sheikh found that Emotion-Focused Coping did not mediate the relationship between Extraversion or Social Support and posttraumatic growth. Further, Problem-Focused Coping only served as a partial mediator for Extraversion, and no mediation relationship was found for Social Support (Sheikh, 2004). This study seems to support the idea that innate personality features, such as Extraversion, significantly influence coping styles and an individual's likeliness to experience Posttraumatic Growth in populations with cardiac disease.

The literature discussed in this section revealed how Tedeschi and Calhoun's model of Posttraumatic Growth (PTG) can be applied to people coping with medical conditions. Across the studies, most of the individuals with cancer reported some personal growth as a result of coping with their disease (Bellizzi & Blank, 2006; Sears et al., 2003; Widows et al., 2005). Contrary to theoretical predictions, optimism and hope were not found to be predictive of PTG (& Blank, 2006; Sears et al., 2003). Also, all of the studies found that illness-related stress, or the amount of perceived stress, and active positive reappraisal coping were related to higher levels of PTG (Bellizzi & Blank, 2006; Sears et al., 2003; Widows et al., 2005). Although these studies were working with PTG as an outcome variable, the results are consistent with theoretical predictions regarding the prerequisites for the process of developing PTG (Tedeschi & Calhoun, 2004). In other words, the individual's subjective experience was so stressful that it challenged his or her previously held assumptions about the world. The individual who then engages in positive reappraisal coping is able to construct a new personal narrative that integrates the stressor-related information with the context of personal growth. The studies about PTG in individuals with medical conditions helped to inform the current study of PTG in PLWHA because they establish that PTG can occur as a result of coping with disease. In addition, the previously discussed studies provide some insight into how the coping strategies for illness-related distress might serve as a prerequisite for the development of PTG.

Trauma and Personal Growth in Persons Living with HIV/AIDS (PLWHA)

Thus far, this chapter has examined how researchers have tried to conceptualize and measure the way individuals can undergo personal growth as a result of their traumatic experience. Based on this literature, it appears that after a significant stressor some individuals transcend their previous level of functioning and develop enhanced interpersonal relationships, a deeper meaning in life, a heightened sense of spirituality and a greater subjective well-being. There are many factors contributing to these changes including personality traits, coping styles, and cognitive processes.

This final section will explore how Posttraumatic Growth (PTG; Tedeschi & Calhoun, 2004) may apply to persons living with HIV/AIDS (PLWHA). Tedeschi and Calhoun's (2004) model of posttraumatic growth, as outlined in a previous section in this chapter, is appropriate for this population because being diagnosed with HIV and living with this disease fits with the conceptualization of Posttraumatic Growth in several ways. This section will review theoretical and empirical articles that demonstrate how the experience of living with HIV/AIDS can be conceptualized through Tedeschi and Calhoun's model. First, the experience of having HIV/AIDS can pose a significant stressor and impacts the individual's quality of life because it affects her or his physical health, mental health, and social functioning. This section will first review articles that explore illness-related stressors and quality of life in PLWHA (Grossman, Sullivan, & Wu, 2003; and WHOQOL HIV Group, 2003a). Second, living with HIV/AIDS requires the person to use their coping resources extensively to deal with the changes in health, changes in social interactions (including stigma), and grief that may accompany the HIV/AIDS diagnosis. This section will then review articles that explore coping and grief

in PLWHA (Brashers, Neidig, & Goldsmith, 2004; Penedo et al., 2001; Schwartzberg, 1992; Sikkema et al., 2003). Third, the experience of HIV/AIDS may also be traumatic because it can pose an existential crisis; shattering previously held core beliefs about the self, the self in society, religious dogma, the meaning of life, and ultimately death. This section will also review articles exploring how living with HIV/AIDS can be perceived as a traumatic experience and existential crisis (Brief, Vielhauer, & Keane, 2006; Frankl, 1984; Mayers, Naples, & Nilsen, 2005; Nilsson Schönnesson, 1992; Schwartzberg, 1993; Woods & Ironson, 1999; Woods et al., 1999a, 1999b; Yalom, 1980). Finally, living with HIV/AIDS provides an opportunity for individuals to develop Posttraumatic Growth by reframing their infection and experiences in such a way that they discover purpose, positive changes, and an enhanced meaning in life. This section will finally review articles that have specifically explored Posttraumatic Growth in persons living with HIV/AIDS (PLWHA) (Milam 2004, 2006a; Siegel & Schrimshaw, 2000; Siegel et al., 2005; Updegraff et al., 2002).

## HIV/AIDS as a Stressor Affecting Quality of Life

Quality of Life (QOL) is a global term that reflects the individual's subjective well-being across multiple domains including economic status, social functioning, health status, and life satisfaction. Health-related quality of life (HR-QOL) has been recognized by the medical community for many years, understanding the need to assess the physical, psychological, and social well-being of a patient and not just the absence of illness (Grossman, Sullivan, & Wu, 2003). In an effort to offer more holistic patient care, especially for those with severe illness, many medical settings began assessing patients' HR-QOL. These inventories often include assessments of physical, emotional, cognitive, and social functioning; self-care and mobility; symptoms; and the patient's subjective view of his or her health (Grossman et al., 2003). These screenings have been helpful for medical staff to not only track disease progression, symptoms, and response to treatment, but also to identify additional psychosocial or physical concerns. Examining the patient's HR-QOL also helps to enhance therapeutic communication, which can facilitate a discussion of treatment concerns, such as medication side-effects, that can interfere with the patient's treatment adherence and treatment outcome (Grossman et al., 2003).

Grossman, Sullivan, and Wu (2003) discussed the importance of tracking HR-QOL specifically in PLWHA. The authors pointed out that many PLWHA report an HR-QOL score that is lower than both the general population and persons with other chronic illnesses, such as cancer or depression. These authors speculated that this could be to the result of the many unique HR-QOL issues that PLWHA face, which cut across many QOL domains. In addition, these HIV-specific issues are often not addressed in general HR-QOL inventories.

There are three primary areas of HIV-specific symptoms that traditional QOL inventories do not address (Grossman, Sullivan, & Wu, 2003). First, there are issues related specifically to the pharmacological therapy used to treat HIV/AIDS. Adherence to antiretroviral therapy is crucial to delay disease progression; however, the side-effects of the medications (abnormal fat distribution, nausea, taste perversion, anorexia, insomnia, anxiety, confusion, vision problems, and sexual dysfunction) can worsen the patient's HR-QOL. Second, there are several medical issues associated with HIV/AIDS that affect HR-QOL including malnutrition, chronic diarrhea, anemia, fatigue, and chronic pain or neuropathy. Finally, there are psychosocial factors for PLWHA that impact their HR-QOL and contribute to depression including social stigma, discontinuation of work or unemployment, dependence on others, limitations in social activity or social support, and poor coping skills. Grossman, Sullivan, and Wu (2003) concluded that it is important for clinicians to assess HR-QOL in PLWHA using specific inventories designed for use with this population so that all of these HIV-specific concerns can be addressed, which increases the chances of treatment adherence and better treatment outcomes.

Recognizing the importance of HR-QOL in PLWHA and the limitations in the measurement of this construct, the World Health Organization (WHO) developed a quality of life instrument (i.e., the WHOQOL-HIV) to assess these HIV-specific issues in a standardized, cross-cultural manner. The WHOQOL-HIV was developed internationally in three stages: the qualitative phase (WHOQOL HIV Group, 2003a), the pilot test (WHOQOL HIV Group, 2003b), and the international field test (WHOQOL HIV Group, 2003b), and the international field test (WHOQOL HIV Group, 2004). Since the WHOQOL-HIV was used in the current study, the process of the development and validation of the WHOQOL-HIV is discussed in greater detail in the Instruments section of Chapter 3.

## Coping, Grief, and HIV/AIDS

The experience of living with HIV/AIDS can introduce or exacerbate stressors from several domains of people's lives, and therefore they must use their coping resources to attempt to manage their level of discomfort. The way in which individuals cope with a stressor can affect their subjective well-being, and ultimately whether they come through the situation below, at the baseline of, or above their previous level of functioning. Although the literature on coping is outside the scope of this chapter, this next subsection briefly highlights how some PLWHA cope with the stressors of HIV/AIDS and the grief that can accompany having HIV/AIDS or dealing with HIV/AIDS related losses.

One factor that can affect coping is the underlying beliefs or attitudes a person possesses about life. Penedo and colleagues (2001) examined the relationship between dysfunctional attitudes, coping style, and depression in HIV-positive men (N = 115) who have sex with men (MSM). Dysfunctional attitudes were described as core beliefs that are global, rigid, and overgeneralized to life circumstances that affect how an individual copes with a stressor, such as perfectionism or the need for constant approval by others. These dysfunctional attitudes are often associated with higher levels of depression and distress, higher use of avoidance and denial coping, and lower use of problem solving skills. The results revealed that higher levels of dysfunctional attitudes were consistently and significantly related to higher levels of depression, less use of adaptive coping, and higher levels of maladaptive coping strategies such as avoidance and disengagement. Finally, the use of adaptive or maladaptive coping strategies mediated the relationship between depression and dysfunctional attitudes, which was independent of the participants' HIV disease status or recent negative life events. The authors concluded that interventions that focus on both enhancing adaptive coping and reducing dysfunctional attitudes would help reduce depression and distress in HIV-positive MSMs (Penedo et al., 2001).

Another coping strategy that can be used is seeking social support. Brashers, Neidig, and Goldsmith (2004) examined how social support affects how PLWHA cope with uncertainty about health, identify, and interpersonal relationships. Qualitative data were collected from six focus groups (N = 33; 29 men, 4 women). The focus groups identified several ways in which social support was helpful. First, social support helped with information gathering because the support person could serve as a source of information, evaluate information, or assist in information gathering. The support person could also serve as a buffer against overwhelming information; for example the support person may not want to discuss their partner's HIV-status or treatment and thus facilitate the PLWHA's avoidance coping strategies. Second, the support person could provide instrumental support and a sense of stability. Third, if the support person was a peer who was also HIV-positive he or she could allow for ventilation of stress and acceptance or validation. Fourth, he or she could help facilitate new skill development, such as decision making or self-advocacy skills. Finally, the support person could encourage a new perspective on problems and facilitate reappraisal of the situation (Brashers et al., 2004).

The focus groups also identified several ways that social support hindered the PLWHA's attempts at coping. First, some PLWHA stated that when they accepted help from another it reduced their feelings of self-directed control over their circumstances. Second, if the PLWHA was receiving social support from a peer who was also HIV-positive there was a significant risk that the peer could become ill or die, leading to feelings of grief and loneliness. Third, the PLWHA may want a different level of support than the support person wants to give. Fourth, some PLWHA feared that disclosing their HIV-status and asking for support would lead to stigmatization and additional relationship ambiguity or rejection. Finally, the support person may experience anxiety,

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which would turn the PLWHA's focus away from getting support and on to managing their support person's discomfort (Brashers et al., 2004).

The authors concluded that although social support can be a helpful resource in coping with HIV/AIDS, it may not come without complications. The focus group members who believed that they were able to use their social support systems well had developed strategies for managing some of the potential downfalls. The successful social support management strategies included developing an active or self-advocating orientation, reframing less than optimal support attempts, accepting the lack of support, withdrawing from bad social situations, selectively choosing support persons, and maintaining healthy relationship boundaries (Brashers et al., 2004).

One unique component of coping with HIV/AIDS is dealing with AIDS-related grief and loss. The experience of losing someone to AIDS when one is also HIV-positive poses challenges that exceed conventional grief theories. Schwartzberg (1992) highlighted how grief in HIV-positive gay men can be unique. Because HIV/AIDS was initially concentrated in the gay community, many PLWHA experienced multiple or overlapping AIDS-related losses, and stage-models of grieving do not accommodate these types of losses. Schwartzberg pointed out that the grief process may not be finite if the individual is unable to make sense of the deaths. For example, a gay man living with HIV/AIDS may be simultaneously in different stages of the grief process while trying to cope with and grieve multiple AIDS-related losses. He may be mourning the dead, nursing the ill, dealing with his own personal health, and trying to maintain optimism for those who are HIV-negative all at the same moment in time.

The grieving process in the gay community may differ significantly from the majority culture. Schwartzberg (1992) explained that the AIDS epidemic within that community came to represent a double stigma--both against being gay and being HIVpositive. In some cases, experiencing the stigma related to HIV/AIDS re-activated internalized homophobia that had previously been suppressed. Also, grieving within the gay community could be an isolating and private experience because some of the PLWHA were no longer connected with more traditional support systems of family and church communities. In addition, the AIDS epidemic signified the loss of a way of life for the gay community, which can add to the sense of grief, because their patterns of socializing, relationships, and sexuality changed as a result of the crisis. Finally, Schwartzberg stated that PLWHA need to find meaning and make sense of HIV/AIDS, both in themselves and in their communities, to effectively grieve. Many gay men have developed meaning in the HIV/AIDS crisis by political activism, community involvement, caring for the ill, and enhancing their sense of spirituality (Schwartzberg, 1992).

In a related empirical article Sikkema, Kochman, DiFranceisco, Kelly, and Hoffmann (2003) explored the relationship between AIDS-related grief and coping in PLWHA. Their sample of PLWHA (N = 268) was diverse in terms of race, gender, sexual orientation, and substance abuse history. All of the participants had experienced the loss of a partner, lover, spouse, or close friend to AIDS within the past two years. Sikkema and colleagues also stated that AIDS-related grief may be different than other grief for three reasons. First, HIV/AIDS heavily affected certain subpopulations where multiple losses within their social networks were common, such as gay men or IV drug users. Second, HIV/AIDS tended to affect a disproportionate number of younger people. Finally, there are multiple layers of stigmatization, in addition to HIV/AIDS, within these subpopulations including being gay, sexual promiscuity, or drug use (Sikkema et al., 2003).

The results revealed that many participants indicated that difficulty in coping with AIDS-related grief was one of their most severe life stressors, and most had experienced multiple AIDS-related losses. The participants' average scores on grief reaction measures, depressive symptoms, and traumatic stress were higher than the average scores of the general population. Measures of grief reactions were the most severe in racial/ethnic minorities; however, there was no significant difference across gender or sexual orientation. Measures of traumatic stress were highest in women and racial/ethnic minorities. The patterns of substance abuse differed across demographic groups; men were more likely to report using alcohol and marijuana, while racial/ethnic minorities were more likely to report cocaine use and a history of IV drug use (Sikkema et al., 2003).

Higher levels of grief severity were related to the loss of a spouse/partner or close family member, a history of IV drug use, and depressive symptoms; however, the severity of grief was not significantly related to the level of perceived social support or current use of mental health services. The severity of grief was also related to coping strategy. Those with severe grief reactions were more likely to use escape-avoidance and self-controlling coping strategies. Contrary to the hypothesis, positive-reappraisal coping and help-seeking were not associated with measures of lower grief severity. The authors concluded that AIDS-related grief creates significant mental health issues that should be addressed with interventions that consider the unique needs of PLWHA (Sikkema et al., 2003). The articles from the previous section (Brashers et al., 2004, Penedo et al., 2001, Schwartzberg, 1992, and Sikkema et al., 2003) helped to inform the current study by examining how communities that experience many HIV/AIDS-related losses cope with the resulting grief.

# HIV/AIDS as a Trauma and Existential Crisis

Living with HIV/AIDS is also likely to be a life changing experience (Schwartzberg, 1992). Arguments have been made in the literature that this process could also be traumatic, because the individual will have to adjust to changes in health and interpersonal relationships (Brief, Vielhauer, & Keane, 2006). In addition, there may be higher rates of previous trauma exposure and PTSD in people living with HIV/AIDS than in the general population, because many of the high risk behaviors that could expose someone to traumatic experiences could also increase the risk of HIV. The authors argued that trauma exposure, particularly sexual trauma, may increase HIV-risk behaviors such as substance abuse and high-risk sexual behaviors (Brief, Vielhauer, & Keane). Finally, the experience of having HIV/AIDS may be innately traumatic because it taps into existential questions. In the process of coping with the disease, PLWHA may experience existential anxiety as they re-examine their core beliefs about life itself.

Nilsson Schönnesson (1992) outlined the various dimensions of existential crises that PLWHA may experience. She argues that concept of trauma can be broadly applied to HIV/AIDS because it evokes strong emotions of helplessness, powerlessness, anxieties of death, and realities of death, too. It threatens one's physical existence, because both the disease and medications to treat it can cause a wide variety of health problems and ultimately death. In addition, HIV/AIDS threatens one's social existence because of the social stigma attached to being HIV-positive and the actual or perceived social isolation that many PLWHA report. Finally, HIV/AIDS also threatens one's sexual existence because it affects one's sexual well-being, desire, and functioning. Nilsson Schönnesson concludes that coping with HIV/AIDS requires the individual to address these existential anxieties and adapt within the context of his or her life to the new circumstances that the illness creates. The adaptations may include changing both intrapersonal resources, such as coping skills, and interpersonal resources, such as social support.

Another way to explain how existential anxiety can be generated by the experience of having HIV/AIDS is by using Yalom's (1980) theoretical framework. According to Yalom, human beings struggle with four primary existential anxieties: the fear of death, the fear of freedom which includes personal responsibility and choices, the fear of isolation, and the fear of meaninglessness. Having HIV/AIDS may evoke the fear of death because until recent improvements in medical treatment AIDS was considered a terminal illness. It may generate the fear of freedom because the individual may feel responsible for contracting the disease because of high risk behavior, and may encounter many choices in health behaviors during the treatment process. In addition, the disease may bring to mind the fear of isolation because of the social stigma, or fear of social rejection, often associated with HIV/AIDS. Finally, the experience of living with HIV/AIDS may evoke fear of meaninglessness because previously held assumptions of health, spirituality, and a just world could be challenged. In a similar vein, Frankl (1984) explained that if there is going to be meaning in life there also has to be meaning in

suffering. The individual living with HIV/AIDS has to, therefore, not only reconstruct meaning in his or her life after the diagnosis, but also derive meaning or purpose for his or her suffering that is caused by the illness.

There have been a few articles that investigated how PLWHA cope with these existential anxieties and attempt to develop meaning in their illness. Schwartzberg (1993) qualitatively examined the meaning that HIV-positive gay men placed on their HIV infection and how well they were able to integrate HIV into the structure that they use to assign meaning to their entire world. In this study, he was able to identify four patterns of meaning-making: shattered meaning, high meaning, defensive meaning, and irrelevant meaning. The way in which the men made meaning out of their disease affected their cognitive processes and how they coped with HIV/AIDS.

Schwartzberg (1993) found that those who were able to assign high levels of meaning to HIV and integrate that meaning into other aspects of their lives were able to use HIV as a catalyst for a new appreciation for life. For this group, HIV represented personal growth, spiritual growth, and belonging. Participants who assigned a defensive meaning to HIV also spoke of HIV as a catalyst for personal growth, which is similar to the high levels of meaning group, but their primary representation of HIV was that of punishment. Schwartzberg expressed concern that this group's inconsistent belief system would not be able to sustain them in times of crisis. Finally, participants who were unable to ascribe meaning to their HIV infection presented as embittered, bewildered, and clinically depressed. It therefore appears as if individuals who were able to find meaning behind their HIV infection were able to utilize more positive coping strategies than those who had not ascribed meaning, or had ascribed negative meaning, to their disease (Schwartzberg, 1993).

Coping with existential anxiety has also been examined in other subpopulations of PLWHA. Mayers, Naples, and Nilsen (2005) enquired about existential loneliness, anxiety, helplessness, guilt, and authenticity in low-income, HIV-positive mothers. Of the nine women who were interviewed, five contracted HIV from IV drug use and the remaining four became infected by a sexual partner. All of the women had given birth to at least one HIV-positive child. The women had been HIV-positive for a minimum of four years. They were selected for interviews because they were part of an earlier study and seemed to exhibit a heightened sense of existential loneliness.

The first theme in the results related to the women's experiences of existential anxiety, loneliness, and isolation. The women's sense of existential anxiety seemed to differ depending on how they contracted HIV. The women who were exposed to HIV through an infected partner reported experiencing more initial fear of death after diagnosis, and this fear was magnified when they found out that one of their children was also HIV-positive. Women who contracted HIV through substance abuse reported less death anxiety and reframed HIV as a second chance in life, because it gave them a reason to get sober. These women seemed to initially develop more meaning in life, which reduced their existential anxiety. All of the women reported that caring for their HIV-positive children helped reduce their sense of isolation. Caring for the child's needs made the women maintain contact with the outside community, because they needed to take the child for treatment, and increased the women's sense of intimacy with their children. Many of the women seemed to cope with these anxieties by using denial as a defense

strategy, minimizing the impact that HIV has on their lives and only confronting the disease as issues arise (Mayers et al., 2005).

The second theme was related to how the women coped with choice, or responsibility, and guilt. Many women discussed choices and responsibility in terms of medical care, for both themselves and their children, including what type of medication regimen can be tolerated, and treatment adherence. Another issue related to choice was self-disclosure about one's HIV status, specifically when to tell the child about the mother's and the child's own HIV status. There was a fear that if the child was told too soon, she or he might naively share the HIV status with others who do not understand and be exposed to the shame and stigma associated with HIV/AIDS. All of the women reported some degree of guilt for transmitting HIV to their child; however the degree of guilt was influenced by whether they believed that the infection was a result of a characterlogical flaw or of behavioral origin. Finally, many of the women used projection to cope with the anxieties created by choice, such as saying that it was the health care professionals' fault that their child was HIV-positive because they did not prevent the transmission during birth (Mayers et al., 2005).

The third theme in the results was related to how the women coped with feelings of vulnerability and helplessness, and how they attempted to regain control of their lives. Many women reported using some sort of reframing technique to reinterpret events as being an important part of life, view the circumstances as ones where they received special protection, or find other reasons to be hopeful. They would also enhance their self-esteem by seeing themselves as survivors, explaining that living in poverty was worse than being HIV-positive. Many women reported that they wanted to teach others

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about HIV/AIDS. Some of the women focused on the universality of chronic illness, comparing their experiences with HIV/AIDS to others who have had cancer or diabetes. Finally, many women reported that their sense of spirituality assisted them in coping with their illness and maintaining a sense of optimism (Mayers et al., 2005).

The final theme that emerged in the data was related to the women's sense of authenticity and meaning. Many of the women reported that their experiences living with HIV/AIDS, specifically caring for their HIV-positive children, allowed them to shift their priorities to the present rather than focusing on past issues. The authors speculated that the children were the most protective factor for the women, and the most potent meaning-giving source, because caring for the child gave the women a sense of purpose. In addition, the women identified other meaning-giving variables including spirituality, reframing their way of coping, reconnecting with previously estranged extended family and friends, and teaching others about HIV by sharing their experiences (Mayers et al., 2005).

One resource that many individuals use to cope with existential anxiety is religion or spirituality. Individuals with chronic or life-threatening illnesses may use their sense of religion or spirituality to better cope with their condition and assist them in answering existential questions that medical science cannot. Woods and Ironson (1999) examined how medically ill patients describe their spirituality or religiosity, and how it helps them to cope, by conducting semi-structured interviews with 60 individuals diagnosed with cancer (n = 20), myocardial infarction (n = 20), or HIV/AIDS (n = 20). The authors found that both spiritual and religious individuals indicated that their beliefs helped them to cope with their illness by giving them a greater sense of well-being, an idea of right and wrong, a feeling of connection with God, and a belief that their spirit will live on in some form.

This study also revealed distinct differences between individuals who identified as religious compared to spiritual. Individuals who identified themselves as spiritual described a relationship with a higher dimension or divinity within one's self; and that the self was a part of God, of life, and not apart from other people. They were also more likely to reply that they did not believe that they could judge others. On the other hand, religious individuals reported focusing more on a belief system, the answers were more absolute, and they reported more feelings of security in knowing that they would be "saved" if they followed God's rules. Religious individuals also reported that they saw God as more judgmental and reported a more negative view of others who had different belief systems than themselves (Woods & Ironson, 1999).

Woods and Ironson (1999) noted that compared to the other illness categories, participants with HIV/AIDS were most likely to self-identify as spiritual (70%) and most likely to be alienated from traditional religion, with only 10% identifying as religious. The remaining participants with HIV/AIDS self-identified as both spiritual and religious. The authors concluded that because some of the early high-risk groups for HIV/AIDS were gay men and IV drug users, they might not have found the support they needed from traditional religion because those behaviors were not approved of within the religious community. In order to find support and guidance they might have had to redefine their belief system and therefore turned to spirituality (Woods & Ironson, 1999).

Understanding that individuals with HIV/AIDS are more likely to be spiritual compared to religious does not, however, explore what role religiosity plays in the

diverse subpopulations of PLWHA. Woods, Antoni, Ironson, and Kling (1999a, 1999b) conducted two studies to further examine the role of religiosity and well-being in PLWHA. The first one (Woods et al., 1999a) examined the relationship between religiosity, depression, and immune status in 106 HIV-positive gay men. The second study (Woods et al., 1999b) replicated the first study, but used a sample of 33 HIVpositive African American women; the African American women were also assessed for anxiety in addition to depression.

In both studies (Woods et al., 1999a, 1999b), two factors of religiosity were identified through factor analysis: religious coping and religious behaviors. Religious coping was described in a similar manner to Woods and Ironson's (1999) construct of spirituality, such as placing trust in God and finding comfort; and religious behavior was similar to their construct of religiosity, such as attending religious services. An interesting distinction between the two subpopulations, however, was that the percentage of variance accounted for by each factor was reversed. In the sample of gay men, religious coping accounted for 48.4% of the variance, while religious behavior accounted for 21% (Woods et al., 1999a). In the sample of African American women, however, religious coping accounted for 23.4% of the variance, while religious behavior accounted for 42.3% (Woods et al., 1999b). The authors noted that these differences in factor endorsements highlight the fact that although the presence of each religious factor exists across the subpopulations, each has a different level of importance or serves a different function within each subpopulation (Woods et al., 1999b).

The relationships between the religious factors, depression, and immune response exhibited some similarities and differences across the subpopulations. In both samples, religious coping was significantly related to lower levels of depression, and also lower levels of anxiety in the African American women sample. In the gay male sample, religious behavior was significantly related to better immune functioning, as evidenced by higher CD4 counts and percentages; however, this relationship was not found in the sample of African American women. The authors speculated that within the gay male sample, increased church attendance could bring them into contact with more social support and therefore enhance their health-related behaviors; however, in the African American women population this may not increase interaction with peers or family members (Woods et al., 1999b).

Another difference between the subpopulations was revealed by the examination of mediator relationships. In the gay male sample, the relationship between religiosity, depression, and immune status was not mediated by either self-efficacy or active coping (Woods et al., 1999a). In contrast, within the African American female sample that relationship was found to be mediated by an active coping style (Woods et al., 1999b). The authors concluded that both studies demonstrate the effect of religion on improving general well-being and coping with depression in PLWHA. In addition, there are at least two distinct ways in which individuals conceptualize religiosity and use it to cope with illness: as an internal way to conceptualize situations and an external behavioral presentation (Woods et al., 1999b). The previously mentioned studies (Woods et al., 1999a; 1999b) found that spirituality is an important component of coping for PLWHA, however different communities of PLWHA report different conceptualizations of spirituality. This information was used to inform the current study to examine how spirituality influences the process of Posttraumatic Growth in PLWHA. Until this point, the current section has reviewed articles that demonstrated how PLWHA as a population can be appropriately studied using Tedeschi and Calhoun's (2004) model of posttraumatic growth, because the experience of living with HIV/AIDS can be stressful enough to trigger the process of posttraumatic growth. The previously reviewed studies explored illness-related stressors and quality of life issues in PLWHA, coping and grief related to HIV/AIDS, and perceiving the experience of living with HIV/AIDS as a trauma or existential crisis. The following section will review articles specifically related to posttraumatic growth, or stress related growth, in PLWHA.

## Studies of Posttraumatic Growth in People Living with HIV/AIDS

Several studies were outlined above that demonstrate that many PLWHA do perceive positive changes in their lives since diagnosis, which in turn helps them to cope more effectively with the illness. Some individuals found meaning in their diagnosis through activism and community involvement (Massey, Cameron, Ouellette, & Fine, 1998; Schwartzberg, 1993), others found meaning through caring for others or children (Mayers et al., 2005; Schwartzberg, 1993), and some through enhancing their spirituality (Woods & Ironson, 1999; Woods et al., 1999a, 1999b). Many of the participants in these studies reported positive changes in domains consistent with the theoretical basis of Posttraumatic Growth, and these themes emerged post hoc as the investigators explored how PLWHA cope with their illness. In recent years, a few studies have been published specifically looking at Posttraumatic Growth and Stress-Related Growth in PLWHA to examine the process and correlates through which these positive changes occur. In the final section of this chapter, the studies specifically investigating Posttraumatic and Stress-Related Growth in PLWHA are reviewed as a way to frame the current study which serves as an extension of the extant literature.

Quantitative testing for the presence of Posttraumatic Growth (PTG) in PLWHA and an investigation of its correlates was undertaken by Milam (2004). In his research Milam was interested in determining if PTG existed in a diverse sample of PLWHA, if there are physical health benefits to PTG, if PTG affects mental health, if the correlates associated with PTG can predict it longitudinally, and if PTG is associated with antiretroviral therapy (ART) adherence and reporting of medication side-effects. Participants were recruited from six outpatient clinics in California. They filled out surveys assessing demographics, health behaviors, dispositional optimism/pessimism, Posttraumatic Growth, depression, religiosity, and medical information at two separate times. It should be noted that Milam used an 11-item measure to assess PTG, which was derived from the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) and then modified by the investigator to allow participants to endorse both positive and negative changes. There was significant attrition between data collection times; at Time 1 there were 835 participants who produced complete data while at Time 2, 434 complete follow-up protocols were collected. The author explained that the attrition of usable data was due to incomplete responses and an inability to contact some of the participants for follow-up. The mean follow-up time for the Time 2 data collection was 1.57 years (Milam, 2004).

The results indicated that PTG was prevalent in the PLWHA sample; 59% of the participants reported moderate to high levels of PTG. In the correlational analysis, several demographic variables were associated with higher levels of PTG: being younger,

female, non-European American, healthy, having an undetectable viral load, being on ART therapy, and being HIV-positive for a shorter amount of time. In addition, several health-related behaviors were also found to be related to higher levels of PTG: not using illicit drugs for the past 3 months, avoiding tobacco and alcohol, and maintaining a healthy diet and exercising. Finally, PTG was found to be positively correlated with optimism, and inversely related to pessimism and depression (Milam, 2002, 2004).

Posttraumatic Growth was also entered into two hierarchical multiple regression models, one at Time 1 and the other at Time 2, in order to determine the strength and uniqueness of the relationships with the previous variables and to explore the predictors of PTG over time. At Time 1, PTG had significant positive relationships with non-European American ethnicity, maintaining a healthy diet, and optimism; and significant negative relationships with age, female gender, alcohol consumption, depression, and pessimism. In addition, lower levels of depression and higher religiosity at Time 1 were significant predictors of higher PTG scores at Time 2. There were several variables that were correlated with PTG; however, these variables did not predict PTG over time including optimism, pessimism, time since diagnosis, age, Time 1 disease status (as measured by CD4 cell counts and viral load), antiretroviral therapy (ART), and healthrelated behaviors (Milam, 2002, 2004).

To further clarify this longitudinal model, Milam compared the sum of positive changes score across several variables that were thought to predict PTG over time. After making these comparisons in positive change scores between Time 1 and Time 2 data, Milam found that religiosity remained a significant predictor of PTG over time; however, depression did not. In order to better assess the relationship between depression over time and changes in PTG, the sample was split into 4 subgroups: those who gained PTG between Time 1 and Time 2, those who lost PTG, those who maintained PTG, and those who never experienced PTG. The post hoc analysis revealed that depression at Time 2 was the lowest in those who maintained PTG and gained PTG, and therefore Milam concluded that changes in PTG seemed to be related to the level of depression over time (Milam, 2002, 2004).

Summarizing Milam's study, he was able to demonstrate that PTG did exist within the sample of PLWHA and reveal several variables that were correlated with PTG. There were many factors that were related to the presence of PTG at Time 1. Demographic variables that predicted higher levels of PTG included being younger, female, non-European American, healthy, having an undetectable viral load, being on antiretroviral therapy (ART), and being HIV-positive for a shorter amount of time. Behavioral variables related to PTG included not using illicit drugs for the past 3 months, avoiding tobacco and alcohol, and maintaining a healthy diet and exercising. Finally, the characterological variables related to increased PTG included high levels of optimism, and low levels of pessimism and depression (Milam, 2002, 2004). Although these variables predicted the presence of PTG at Time 1 as an outcome measure, many of these relationships did not predict PTG longitudinally. Only religiosity consistently predicted PTG over time; and the level of depression predicted changes in PTG over time for individuals who maintained PTG and gained PTG between Time 1 and Time 2. Milam concluded that although the results for the longitudinal analysis did not support demographics, medical status, or optimism-pessimism as predicting PTG over time, this study did not examine several psychosocial variables that would be theoretically related
to predicting PTG longitudinally including coping strategies, stress levels, social support, perceived control, or sense of coherence (Milam, 2002, 2004).

In another study, that appeared to be from a subset of his previous data, Milam (2006a) further explored the relationship between PTG and disease status by examining changes in viral load and CD4 counts over time. Milam (2006a) also examined optimism, pessimism, and ethnicity as potential moderators between PTG and disease status. In addition, depressive symptoms and health behaviors, such as antiretroviral therapy (ART) adherence, diet, exercise, illicit drug use, and tobacco and alcohol use, were examined as potential mediators. Participants were recruited from six HIV clinics in California. A total of 412 diverse PLWHA completed questionnaires assessing demographics, optimism, pessimism, and PTG at two data collection times: a baseline and 19-month follow-up. At each data collection time, the participants' viral load and CD4 levels were obtained from their medical charts.

The results revealed several correlational relationships; higher levels of PTG were reported in women, Hispanics, those who did not use illicit drugs or alcohol, those with lower pessimism, fewer depressive symptoms, lower viral loads at Time 1 and Time 2, and higher levels of optimism. The regression analysis indicated that PTG was not associated with viral load; however, there was a significant interaction between PTG, pessimism, and viral load. For those scoring low in pessimism, PTG was inversely related to viral load, and PTG was positively related to viral load for those scoring high in pessimism. The regression analysis also revealed that PTG was not associated with CD4 count, but there were two significant interactions. The first interaction was ethnicity, with Hispanics who reported higher levels of PTG having higher CD4 counts. The second interaction was with optimism, with PTG being positively related to CD4 counts in those with low optimism, and inversely related to CD4 in those with high optimism. In the regression analysis of depressive symptoms and health behaviors, there were no significant relationships or interactions. Because there were no relationships established, depressive symptoms and health behaviors could not be examined as potential mediators (Milam, 2006a).

Milam (2006a) concluded that having higher levels of PTG encouraged better physical adaptation to HIV over time, particularly for Hispanics and those with low levels of optimism and pessimism, and that these relationships were not explained by depressive symptoms or health behaviors. The author speculated that these results could be related to cultural variables among Hispanic participants, specifically religious change or openness, because the significance of the interaction was greatly reduced in this group when religious items were removed from the analysis. This is consistent with previous research (Woods et al., 1999a, 1999b), which indicated that religiosity and religious coping are related to PTG and, based on these results, spirituality may play a greater role in the underlying process of PTG that has previously been studied.

Milam (2006a) also commented that the results indicated that the relationship between disease status and PTG appears to be moderated by pessimism and optimism; however, the results are mixed. In individuals who reported low levels of pessimism PTG had a positive relation with viral load; or in other words higher levels of PTG was related to lower viral load numbers. The results for optimism were split. Participants who reported low levels of optimism demonstrated a positive impact of PTG on CD4 counts (high levels of PTG were related to high CD4 counts) while those with high optimism

indicated a negative impact of PTG on their CD4 counts (high levels of PTG were related to lower CD4 counts). The author speculated that this could be related to a curvilinear relationship between optimism and CD4 counts, or that individuals with extremely strong positive or negative expectations about health are likely to experience a negative impact on their health because their expectations cannot be met. Either way, Milam concluded that these findings offer evidence that pessimism and optimism should be examined as constructs separate from each other, rather than assessed as a continuum.

There are many strengths and limitations to Milam's (2004, 2006a) studies. In both of his studies, Milam was able to obtain the largest sample of diverse participants found thus far in the literature (Milam, 2004, Time 2 n = 434; Milam, 2006a, n = 412). Milam (2004) stated that the data were collected as part of a larger study that examined sex behaviors, and therefore some potential participants (n = 495) were excluded because they reported no sexual activity within the last 3 months prior to data collection. Given that the number of excluded individuals is larger than the samples that were analyzed, it would have been interesting to see how the results would have been similar or different if these individuals were included. Another strength of Milam's studies is that he was able to assess for many correlates and moderators of PTG, at both baseline and longitudinally (approximately 1.5 years later). This helps to shed light on how PTG changes over time and which factors seem to be predictive of long-term PTG.

Unfortunately, Milam (2004, 2006a) did not assess for the relationship between PTG and other variables that have been identified in the literature (Linley & Joseph, 2004) including coping strategies, stress levels, social support, perceived control, or sense of coherence; the current study, however, will explore these relationships qualitatively. Another limitation is that although Milam (2004, 2006a) did use the PTG model, he used an 11-item measure to assess PTG, which was derived from the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) and then modified by the investigator to allow participants to endorse both positive and negative changes. In addition to questions about the psychometric properties of this shortened scale, the abbreviated scale also did not allow for the analysis and comparison of the five underlying factors of PTG. A final limitation of Milam's (2004, 2006a) studies is due to their quantitative nature; they do not explore the process of the development of PTG including the way in which the participants derive meaning from their experiences. The current study built upon these limitations in Milam's work by using the complete PTGI to quantitatively assess growth within the sample, which permitted the analysis and comparison of the five underlying factors of PTG. In addition, the current study used qualitative data to explore the process for developing PTG and some of the variables associated with this process including coping strategies, stress, and social support.

Because HIV/AIDS cuts across many demographic lines, some authors have investigated how individuals in various subpopulations perceived positive growth since their infection. Siegel and Schrimshaw (2000) examined the presence of Stress-Related Growth in women living with HIV/AIDS by interviewing 54 ethnically diverse women. Stress-Related Growth was prevalent among the sample, with 83% of the women reporting at least one positive change since their diagnosis. The women reported personal growth in several domains such as their health behaviors, a renewed sense of spirituality, improved interpersonal relationships, an enhanced view of the self, increased value in life, and rediscovery of career or personal goals. Also, in comparison with other

populations where Stress-Related Growth was studied, the HIV-positive women reported the greatest amount of personal change in their health behaviors including their eating habits, exercising, following their treatment regimen, avoiding tobacco and alcohol, becoming sober, and engaging in safer sex practices. The authors noted that all of the women who reported change acknowledged that they were under significant stress including stigma, disability, and psychological distress; Stress-Related Growth also persisted while their health was deteriorating. The authors concluded that the perception of finding benefits or positive changes after being diagnosed with HIV/AIDS might be an important part of coming to terms with the diagnosis and the ramifications of future treatment; however, they said more research into this process is needed (Siegel & Schrimshaw, 2000).

Although Siegel and Schrimshaw's (2000) study appears to be one of the earliest studies in the literature that qualitatively assessed Stress-Related Growth in women living with HIV, it had some significant areas of strengths and limitations. One of its strengths is the qualitative methodology, which provides an in-depth exploration of the domains in which the women experienced growth. Also, the authors took great care in obtaining an ethnically diverse sample (18 African American women, 17 Puerto Rican women, and 19 European American women) that was evenly matched across ethnic groups for additional demographic characteristics including women with- and without children, with- and without a romantic partner, with- and without a history of substance abuse, and being HIV-positive for varying lengths of time. This method, however, led to a non-random sample and some women were excluded from the study including those over 45 years old, Latina women who were not Puerto Rican, and those who reported drug use within the last 6 months (Siegel & Schrimshaw, 2000). The data were actually a sub-set (n = 54) from one of the authors' previous studies examining women's adaptation to living with HIV/AIDS (N = 146). Siegel and Schrimshaw explained that they did not use the entire data set because saturation for themes of growth was reached after analyzing 54 interviews, which were randomly selected accounting for equal representation across ethnicity. Interestingly, the authors reported no significant differences in the levels of growth across ethnic groups (Siegel & Schrimshaw, 2000).

There were other limitations in Siegel and Schrimshaw's (2000) study that were related to the methodology and procedures. First, the authors reported that the women completed questionnaires of standardized mental health and psychosocial measures; however they failed to mention what instruments were included in the questionnaire packets. More specifically, since the original study was not focusing on Stress-Related Growth, the authors did not include a formal measure of this phenomenon (Siegel & Schrimshaw). Second, the authors did not attempt to determine whether the reports of growth were actual or perceived. They did not obtain any corroborating reports (such as from significant others), include assessments of social desirability, or explore positive reappraisal coping. Third, the authors did not discuss any negative experiences related to HIV that the participants reported during the interview process. Finally, the Siegel and Schrimshaw did not report using a theoretically-based qualitative methodology for their data analysis, but rather explained that the transcripts were coded for themes by the researchers and then double-checked by computer software that did a key word search of the transcripts for portions of text related to growth. The current study alleviated the previously mentioned limitations by measuring Posttraumatic Growth with the

Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), screening for social desirability using the Marlowe-Crowne Social Desirability Scale (M-C SDS; Crowne & Marlowe, 1960), using open-ended questions in the qualitative phase of the study so that participants may report positive and negative experiences, and analyzing the qualitative data using grounded theory (Strauss & Corbin, 1998).

Siegel, Schrimshaw, and Pretter (2005) continued the line of research reported in Siegel and Schrimshaw (2000) by further exploring the correlates of Stress-Related Growth in women living with HIV/AIDS. Using a sample of 138 ethnically diverse women, Siegel and colleagues examined the relationship between Stress-Related Growth and stressor characteristics, individual resources, social resources, and cognitive coping strategies. Also, the authors examined positive and negative affect as both potential predictors and confounds for growth. They were specifically interested in whether reports of growth reflected actual change, or were just an emotionally focused coping strategy involving positive reappraisal of the stressor (Siegel et al., 2005).

The results indicated that Stress-Related Growth was significantly related to race/ethnicity, depressive affect, positive reappraisal coping, and emotional support, the combination of which explained 49% of the variance in the authors' statistical model (Siegel et al., 2005). African American women reported significantly more growth than the European American women, which could be because of their socioeconomic status, multiple stressors in daily life, and more previous opportunities for Stress-Related Growth. In addition, participants who reported depressive affect reported significantly less growth. None of the stressor characteristics was found to be related to growth, including disease stage, symptoms, or time since diagnosis. The authors speculated that

this was the result of HIV/AIDS being such a feared disease and that the stress associated with receiving the diagnosis was strong enough to trigger a re-evaluation of one's world view regardless of one's current disease stage or symptoms. Neither perceived control over health nor self-esteem were related to growth in this sample. Only one of the social resources was found to be related to growth, emotional support. Finally, positive reappraisal coping significantly predicted growth. The authors concluded that Stress-Related Growth is not just a form of positive reappraisal coping, because several other factors contributed to growth even after positive reappraisal was partitioned out of the model. Stress-Related Growth appeared to be an adaptive component of coping that was related to affect-regulation strategies in women living with HIV/AIDS, in an effort to assuage illness-related stressors (Siegel, Schrimshaw, & Pretter, 2005).

In their follow-up study, Siegel and colleagues (2005) improved upon some of the limitations of Siegel and Schrimshaw (2000). They were able to obtain a larger sample (N = 138) of ethnically diverse women (53 African American women, 47 Puerto Rican women, and 38 European American women) (Seigel et al., 2005). In addition, the Seigel et al. (2005) study quantitatively explored the relationship between Stress-Related Growth and stressor characteristics, individual resources, social resources, and cognitive coping strategies, as well as how positive and negative affect influenced reports of growth. Therefore, the authors reported the details of the instruments they used to assess these constructs including the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977; Weissman et al., 1977), selected items from the revised Ways of Coping questionnaire (WOCQ; Folkman & Lazarus, 1988; Lazarus & Folkman, 1984), the Rosenberg Self-Esteem Scale (Rosenberg, 1965), and the Health Specific Locus-of-

Control Questionnaire (HLC; Lau & Ware, 1981). One potential limitation of their scale selection is that some of their instruments were not current or commonly used in this specific branch of literature (Lau & Ware, 1981; Rosenberg, 1965). Another limitation is that the authors did not include measures of variables that have been empirically related to growth including spirituality (Park et al., 1996; Woods et al., 1999a & 1999b; Calhoun et al., 2000) or dispositional optimism (Park et al., 1996; Tedeschi & Calhouh, 1996; Antoni et al., 2001; Milam, 2002, 2004). In addition, Siegel et al. (2005) quantitatively measured Stress-Related Growth by using both the Psychological Thriving Scale (TS; Abraido-Lanza et al., 1998) and additional items that were generated based on their previous (Siegel & Schrimshaw, 2000) study. Like the previously mentioned instruments, the Psychological Thriving Scale has not been commonly used in the literature to measure Stress-Related Growth and it has only been used in two other published studies (Abraido-Lanza et al., 1998; Joseph et al., 2005).

Siegel and colleagues (2005) also investigated whether the level of growth the participants reported reflected actual change or was merely a perception of growth. This was done by considering the participants' emotional state at the time of the study (using the CES-D) and assessing the participants' coping strategies (using the WOCQ), particularly the use of positive reappraisal coping. The results did indicate that depressive affect predicted growth, with participants who indicated higher levels of depression reporting lower levels of growth than the rest of the sample. The interpretation of this relationship, however, is limited by the cross-sectional nature of the data; so it is unclear if depression made it more difficult for the participants to recognize growth or what the temporal relationship is between depression and growth (Siegel et al., 2005). The results

also indicated that positive reappraisal coping was a positive predictor of growth. The authors contend that growth might be more than just positive reappraisal coping because other factors such as depressive affect, ethnicity, and social support continued to predict growth once coping style was accounted for in the model. A significant limitation to this finding, however, is that positive reappraisal coping was measured using only one item from the positive reappraisal subscale of the WOCQ (Siegel et al., 2005). An additional limitation to determining whether the reported level of growth reflected actual changes was that the authors did not obtain any corroborating reports of change (such as from significant others) or include assessments of social desirability (Siegel et al., 2005). The current study used the Marlowe-Crowne Social Desirability Scale (M-C SDS; Crowne & Marlowe, 1960) in order to help determine if the participants are actually reporting growth or merely responding in a socially desirable manner.

Updegraff, Taylor, Kemeny, and Wyatt (2002) investigated the perceived benefits and negative changes that occurred since diagnosis in the lives of 189 women living with HIV/AIDS who were of lower socioeconomic status (SES). The women identified several positive changes including becoming closer to others, focusing more on family, feeling stronger, having increased self-worth, and wanting to live life to the fullest. In addition, the women reported more negative than positive changes in romantic relationships and body image, as well as marginal negative changes in social relationships. Benefit finding was strongly related to socioeconomic resources, and those with relatively more education and a higher income reported more positive changes such as depression and anxiety were not related to socioeconomic resources, but rather to having more stressors in life,

lower optimism, and declining health. Notably, social support did not predict positive or negative changes in this study. The authors concluded that in this sample, benefit finding was most strongly predicted by socioeconomic resources and that because both positive and negative changes were reported they may actually be a part of separate underlying processes in PLWHA (Updegraff et al., 2002).

There are several areas of strengths and limitations to Updegraff and colleagues' (2002) study. One area of strength is that they did interview a large number of women (n = 189) of diverse ethnicities (90 African American women, 62 European American women, and 37 Latina women), who were of lower socioeconomic status (SES). The authors explained that the purpose of this study was to explore the relationship between benefit-finding and SES; by assessing both positive and negative HIV-related changes and evaluating the extent to which SES predicted these changes (Updegraff et al., 2002). The authors, however, did not give a clear operational definition of what they considered to be "lower socioeconomic status," but rather assessed education level as a dichotomous variable (completed high school or not) and measured income in monthly dollar amounts. The authors reported that 36% of their sample did not complete high school and the median monthly income fell below the federal poverty line, however, they did not comment on the range of income or economic resources for the entire sample (Updegraff et al., 2002). This creates some limitations in the interpretation of the results related to SES and generalizability to the population of PLWHA. First, the meaning of the authors' comparisons between participants with higher-SES and lower-SES within their sample is unclear. The authors did not explain how they divided the sample into such categories and to what magnitude the lower-SES group was disadvantaged. Second, it is difficult to

generalize how SES affects benefit finding in the general population of PLWHA because the sample in this study consisted entirely of women of lower SES.

There were also some significant limitations to how Updegraff and colleagues (2002) conceptualized, measured, and analyzed benefit finding in their study, which makes it difficult to compare their results to other studies in the literature. First, they did not use a consistent or current theoretical framework to explore this phenomenon, which they referred to as "benefit finding" in some parts of the article and "stress-related growth" in others. The authors did not use the current models of Stress-Related Growth (Park et al., 1996) or Posttraumatic Growth (Tedeschi & Calhouh, 1996) in their study, but rather a combination of the Conservation of Resources theory (Hobfoll, 1989) and Cognitive Adaptation theory (Taylor, 1983) as a rationale for their study. The current study addressed this inconsistency in Updegraff and colleagues' research by using Tedeschi and Calhoun's (1996, 2004) model of posttraumatic growth. Second, Updegraff and colleagues (2002) did not use a standardized measure of growth, but rather created a score based on the total number of changes reported within each interview transcript. The current study addressed this limitation by using the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) to measure growth in the sample. Finally, the authors did not use a specific, theoretically-based qualitative methodology. In their description of the transcript analysis process, Updegraff and colleagues (2002) simply stated that the transcripts were assessed by 2 trained coders, who summed the number of positive and negative changes reported by each participant across each interview question. After the analysis of 20 interviews, discrepancies in the coders' scoring were discussed and the coding guidelines were refined. The inter-rated reliability was then calculated after the

review of an additional 20 interviews (r2 = .94, F(541, 541) = 18.10, p < .001). Updegraff and colleagues did not comment on how themes within the transcripts were extracted and analyzed (although they do identify the types of growth the women reported) or how a saturation point was reached within the data. Interestingly, Updegraff and colleagues (2002) commented that follow-up interview data had been collected six months later; however these were not analyzed or used in this study. The current study addressed this limitation by using qualitative methodology based on grounded theory (Strauss & Corbin, 1998), which gave a clear description of how the data are coded, themes within the transcripts are extracted and analyzed, and the saturation point within the data is reached.

The factors that contribute to Posttraumatic Growth and the changes that occur in PLWHA are summarized in a chapter written by Milam (2006b), that was based on a literature review and his research. First, Milam concludes that PTG can occur within PLWHA and many report positive changes including increases in meaning in life, spirituality, sense of community, relationships with others, and altruistic behaviors. Second, there are several correlates that have been found to contribute to PTG in PLWHA: being on antiretroviral treatment, increasing healthy behaviors, having a sense of religiosity/spirituality, being optimistic, and having lower levels of depressive symptoms. Third, there are demographic variables that were found across studies to be related to increased PTG in PLWHA including being younger and female (Siegel & Schrimshaw, 2000; Tedeschi & Calhoun, 1996); other studies presented mixed evidence for socioeconomic status and ethnicity being related to PTG (Updegraff et al., 2002; Milam, 2004). Finally, some early evidence suggests that PTG may be related to disease

progression, but it is unclear whether PTG is a result of relative wellness or if PTG influences the course of HIV/AIDS infection (Milam, 2004). Milam (2006b) concluded that although it is clear that PTG is beneficial to the health and well being of PLWHA, the underlying process and secondary benefits of PTG are still areas in need of additional study so that health care professionals can use that knowledge to assist PLWHA to adjust to their disease and have a better quality of life. What is needed is to further examine how the theoretical model of PTG (Tedeschi & Calhoun, 1996; 2003), including the precursors to growth, applies to PLWHA in order to explore the underlying process of PTG. The current study addressed this need by examining the extent to which the precursors to growth (Tedeschi & Calhoun, 2003) exist across groups of PLWHA who report higher or lower levels of PTG.

### The Present Study

It is clear, based on the literature, that Posttraumatic Growth can occur in people living with HIV/AIDS, and that there may be several health and psychological benefits from experiencing PTG. Most of the quantitative research has identified correlates and moderators of PTG (Milam 2004; Siegel et al., 2005; Updegraff et al., 2002), while the qualitative research has focused on individuals describing what the outcome of PTG looks like in their lives (Siegel & Schrimshaw 2000; Updegraff et al., 2002). In addition, the research would suggest that the meaning-making processes, demographic characteristics, and coping strategies of people with higher levels of PTG could be different than those with lower PTG; however, there were no studies to the knowledge of this researcher that directly compared PLWHA with higher levels of PTG to those with lower levels of PTG. In fact, since the studies to date are based on correlational data, there is little information about how PLWHA who report lower levels of PTG can even be described. In addition, the studies to date have reviewed PTG and its correlates by looking at what is present in people who have undergone PTG, but none of them have explored the process through which PTG developed.

The purpose of this study was to explore how PLWHA effectively cope with and find meaning in their disease, through the theoretical framework of the Posttraumatic Growth (PTG) model. Specifically, this study explored the process for the development of PTG by examining the extent to which the theoretical precursors to PTG (Tedeschi & Calhoun, 2003) exist across groups of PLWHA who report higher or lower levels of PTG. Until this point, the literature has been able to establish that some PLWHA report positive changes in their lives as a result of living with their disease, describe the types of changes the PLWHA report, and identify some of the correlates of positive growth. There are, however, some gaps within the literature that this study attempted to address. First, many of the studies that describe coping, meaning making strategies, or positive life changes in PLWHA (Mayers et al., 2005; Penedo et al., 2001; Schwartzberg, 1993; Siegel & Schrimshaw, 2000; Siegel et al., 2005; and Updegraff et al., 2002) do not examine these phenomena within a consistent theoretical framework. The current study used the Posttraumatic Growth model to systematically explore coping, meaning making, and positive growth in PLWHA. Second, many of the studies do not use a standardized assessment of growth (Mayers et al., 2005; Penedo et al., 2001; Schwartzberg, 1993; Siegel & Schrimshaw, 2000; and Updegraff et al., 2002), use a lesser known instrument (Siegel et al., 2005), or use an abbreviated version of the Posttraumatic Growth Inventory (PTGI) (Milam, 2004, 2006a). The current study used the entire PTGI, so that the underlying factors could be analyzed and the results could be compared to other studies using the PTGI. Finally, the studies that have used interview data (Siegel & Schrimshaw, 2000; Updegraff et al., 2002) do not report using a theoretically based qualitative methodology. The current study used qualitative methodology based on grounded theory (Strauss & Corbin, 1998).

The current study also took the next step in the line of research on PLWHA and PTG. Until this point, the research has only focused on PTG as an outcome measure and examined the correlates of PTG in PLWHA, however, additional studies are needed to develop a better understanding of the process for developing PTG in PLWHA (Milam, 2006b). The current study began to explore the process for developing PTG by comparing the differences in coping, quality of life, and meaning-making in PLWHA who report higher or lower levels of PTG. More specifically, the current study explored the extent to which the theoretical precursors to PTG (Tedeschi & Calhoun, 2003) exist across groups of PLWHA who report higher or lower levels of PTG.

There are several reasons why a person living with HIV/AIDS might not develop PTG. Tedeschi and Calhoun (2003) identified many conditions necessary for PTG to develop including having a traumatic experience that is severe enough to challenge previously held assumptions about the world, being able to manage distress, disengaging from previously held goals, the distress persisting for some time, and creating new personal narratives to accommodate the new traumatic information. Having a low level of PTG fundamentally implies that these conditions for PTG were not met (Tedeschi & Calhoun, 2003); however, to our knowledge, this assumption has not been formally tested in the literature.

There are several ways in which a PLWHA may not develop the precursors for PTG. First, it is possible that in individuals with low PTG, finding out they are HIVpositive was not traumatic or stressful enough that it challenged their previously held assumptions about life (Tedeschi & Calhoun, 2003). If the situational meaning that the individual places on the event does not challenge, or is not incongruent with, her or his global meaning or belief system then the event will not be as distressing (Park & Folkman, 1997). For example, if the person were an IV drug user she or he might have a global belief that drugs can expose you to dangerous diseases or situations. Perhaps then, becoming HIV-positive as a result of drug use would not challenge her or his beliefs, but rather confirm them and the infection could be seen as a result of risky behavior.

Second, if the event were traumatic, the individual with low PTG might not have been able to effectively manage his or her debilitating distress (Tedeschi & Calhoun, 2003). Managing distress is a crucial component for PTG because the individual needs to be able to process the information about the trauma and make meaning out of it either by looking at it from his or her old global meaning system, or reconstructing his or her global meaning system to incorporate this new information. Being unable to manage the distress could happen as a result of lacking effective coping skills, or relying heavily on maladaptive coping strategies such as substance abuse. It is also possible that the person's social environment is chaotic, and that new stressors are continually emerging, so he or she is not able to devote time or energy to coping effectively. He or she might not have the level of social support necessary to manage multiple stressors. Finally, the person's health or quality of life might be so poor that he or she is unable to cope with multiple stressors.

A third precursor within Tedeschi and Calhoun's (2003) theory regarding the development of PTG is that the trauma is so disruptive that the individual must disengage from previous goals and assumptions about life. It is possible that being diagnosed with HIV/AIDS would not pose an obstacle to previous life goals, for some individuals, or that the individual did not have clearly defined goals before their diagnosis. The fourth condition that Tedeschi and Calhoun identified for the development of PTG is that the distress must persist for some time; long enough for the individual to begin challenging her or his assumptions about life (Tedeschi & Calhoun, 2003). If the person with HIV remains relatively healthy, or asymptomatic, and is able to maintain a good quality of life, then the distress from diagnosis may not last long enough to initiate PTG.

The final condition necessary for PTG to occur is that the person is able to create a new life narrative, or reconstruct his or her sense of global meaning to integrate the new trauma-related information (Tedeschi & Calhoun, 2003). For whatever reason, the low PTG individuals may not be able to find meaning in their disease. Because many individuals use religion or spirituality to inform their sense of global meaning (Park, 2005), it is possible that some PLWHA may have difficulty integrating information within their previous global meaning system if they contracted the disease through some taboo behavior, such as drug use, homosexuality, or sexual promiscuity. Others may have difficulty integrating fragmented pieces of information about their assumptions about life, and the new information about their diagnosis, into a comprehensive narrative. Finally, the individual's social support network might not encourage the discussion and

processing of trauma-related information, so the individual is not able to assign meaning to the events.

#### **Research Questions**

The purpose of this study was to explore how PLWHA cope with and find meaning in their disease, through the theoretical framework of the Posttraumatic Growth (PTG) model. More specifically, this study was interested in examining how PTG develops in PLWHA. To date, the existent literature has been able to establish that some PLWHA report positive changes in their lives as a result of living with their disease, to describe the types of growth the PLWHA report, and to identify some of the correlates that predict positive growth. There are, however, gaps within the literature that this study will address. First, many of the studies that describe coping, meaning making strategies, or positive life changes in PLWHA (Mayers et al., 2005; Penedo et al., 2001; Schwartzberg, 1993; Siegel & Schrimshaw, 2000; Siegel et al., 2005; Updegraff et al., 2002) do not examine these phenomena within a discernable theoretical framework. The current study used the Posttraumatic Growth model to systematically explore these related concepts. Second, many of the studies do not use a standardized assessment of growth (Mayers et al., 2005; Penedo et al., 2001; Schwartzberg, 1993; Siegel & Schrimshaw, 2000; Updegraff et al., 2002), use a lesser known instrument (Siegel et al., 2005), or use an abbreviated version of the Posttraumatic Growth Inventory (PTGI) (Milam, 2004, 2006a). The current study used the entire PTGI (Tedeschi & Calhoun, 1996), so that the underlying factors could be analyzed and the results could be compared to other studies using the PTGI. Finally, the studies that have used interview data (Siegel

& Schrimshaw, 2000; Updegraff et al., 2002) do not report using a theoretically based qualitative methodology. The current study, however, used qualitative methodology based on grounded theory (Strauss & Corbin, 1998).

The current study also took the next step in the line of research on PLWHA and PTG. Until this point, the research had only focused on PTG and its correlates as an outcome variable in PLWHA, however, additional studies are needed to develop a better understanding of the process of PTG in PLWHA (Milam, 2006b). In the current study the concept of PTG was applied as both an outcome and a process variable. PTG was regarded as an outcome variable during the quantitative phase of the study, for the screening purposes of identifying PLWHA who report higher or lower levels of PTG and then dividing the sample accordingly. The PTG model was then regarded as a process during the qualitative phase of the study. This study began to explore the process for developing PTG by comparing the differences in coping, quality of life, and meaningmaking in PLWHA who report higher or lower levels of PTG. Specifically, this study examined the extent to which the theoretical precursors to PTG (Tedeschi & Calhoun, 2003) exist across the groups of PLWHA who report higher or lower levels of PTG.

To the best of our knowledge, comparing PLWHA who report higher or lower levels of PTG has not been attempted previously; therefore this section was framed as research questions rather than as study hypotheses. The first set of research questions assessed for the presence of the precursors of PTG, and is derived from Tedeschi and Calhoun's (2003) description of these five precursors. The second set of research questions explored the degree to which the experience of being diagnosed and living with HIV/AIDS is traumatic for the participants. These questions were derived from Tedeschi and Calhoun's (2003) description of the precursors to PTG, specifically regarding how the individual perceives and copes with the traumatic experience, and Joseph and William's (2005) description of how variability of individuals' perceptions of traumatic events affects coping. The third set of research questions explored the five factors of PTG and was derived from the five factors of the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). This in-depth exploration helped to identify additional qualitative differences in the five factors of PTG between the groups PLWHA who report high or low levels of PTG. The fourth set of research questions evaluated the participants' health-related quality of life and was derived from works such as Grossman, Sullivan, and Wu (2003), and Milam (2004, 2006a), which suggest that the PLWHA's perception of his or her health may affect PTG. Finally, the fifth set of research questions examined how social desirability was related to reports of PTG. These questions were derived from works that have also explored whether reports of PTG were influenced by social desirability (Tedeschi & Calhoun, 1996).

## Research Question 1: Precursors for Posttraumatic Growth

How have the precursors for PTG (Tedeschi & Calhoun, 2003) been encountered in PLWHA?

*Question 1A:* In what ways, if any, has HIV-related trauma challenged previously held beliefs (i.e., beliefs about life, self, or others) in PLWHA?

*Question 1B:* How were PLWHA able to manage any distressing emotions brought on by HIV-related trauma?

*Question 1C:* How long have the distressing emotions, from the HIV-related trauma, endured?

*Question 1D:* In what way did PLWHA disengage from previous (i.e., pre- HIV diagnosis) goals?

*Question 1E:* How was the PLWHA able to construct a new personal narrative of his or her life, post-HIV diagnosis?

*Question 1F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the precursors of PTG (Tedeschi & Calhoun, 2003)?

## Research Question 2: Perception of Traumatic Experiences

To what extent were being diagnosed as HIV-positive and living with HIV/AIDS perceived as traumatic experiences? How did these perceptions affect coping?

*Question 2A:* To what degree do PLWHA perceive being diagnosed as HIV-positive as a traumatic experience?

*Question 2B:* If being diagnosed as HIV-positive was a traumatic experience, what was the intensity of this traumatic experience?

*Question 2C:* If being diagnosed as HIV-positive was a traumatic experience, what was the duration of this traumatic experience?

*Question 2D:* If being diagnosed as HIV-positive was a traumatic experience, what types of strategies have PLWHA used to cope with this traumatic experience?

*Question 2E:* To what degree do PLWHA perceive living with HIV/AIDS as a traumatic experience?

*Question 2F:* If living with HIV/AIDS has been a traumatic experience, what has been the intensity of this traumatic experience?

*Question 2G:* If living with HIV/AIDS has been a traumatic experience, what has been the duration of this traumatic experience?

Question 2H: If living with HIV/AIDS has been a traumatic experience, what

types of strategies have PLWHA used to cope with this traumatic experience?

*Question 21:* What other types of traumatic experiences have occurred within the lives of PLWHA?

Question 2J: How did PLWHA cope with other types of traumatic experiences?

*Question 2K:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the perception of HIV as a traumatic event and the affects on coping?

Research Question 3: Personal Changes Within the Five Factors of Posttraumatic Growth Since Becoming HIV-Positive

Using the model of Posttraumatic Growth (PTG; Tedeschi & Calhoun, 1996; 2004), what types of changes occurred within the life of PLWHA since the time of his or her diagnosis?

*Question 3A:* What types of changes have occurred in how the PLWHA views her or his purpose in life?

*Question 3B:* What types of changes have occurred in the interpersonal relationships of PLWHA?

*Question 3C:* What types of changes have occurred in how the PLWHA views her- or himself?

*Question 3D:* What types of changes have occurred in the personal goals, or dreams, of PLWHA?

Question 3E: What types of changes have occurred in the spirituality of PLWHA?

*Question 3F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding changes that occurred within the lives of PLWHA since the time of his or her diagnosis?

## Research Question 4: Perceptions of Quality of Life

To what extent has living with HIV/AIDS affected quality of life?

Question 4A: How has living with HIV/AIDS affected the quality of life (i.e.,

perception of health and well-being) in PLWHA?

*Question 4B:* What are the differences between those who report higher or lower levels of PTG in their responses to the question regarding quality of life?

### Research Question 5: Social Desirability and Reports of Posttraumatic Growth

In what way does social desirability affect reports of PTG?

Question 5A: How is social desirability related to quantitative measurement of

PTG?

*Question 5B:* How is social desirability related to qualitative reports of increased levels of PTG?

*Question 5C:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding social desirability?

# CHAPTER III

# METHODOLOGY

This chapter outlines the research process used in this study. First, it describes how people living with HIV/AIDS were recruited through social service agencies throughout Ohio. Second, it reviews the instruments used to collect quantitative data about demographics, quality of life, posttraumatic growth, and social desirability. Then, it explains the qualitative data collection along with the rationale for the semi-structured interview questions. Third, it discusses the two-phase data collection procedure, including the process of contacting participants, distributing and coding questionnaire packets, and scheduling interviews.

# Participants

Participants were recruited through agencies that provide services for people living with HIV/AIDS in the Ohio HIV Care Consortia regions of Akron/Canton, Cleveland (including Lorain), Columbus, Toledo, and Youngstown. The Ohio HIV Care Consortia was established to coordinate HIV support services and funding from the Ryan White Comprehensive AIDS Resources Emergency act (C.A.R.E.) throughout the state. There are 11 Consortium regions, and each region is required to have 25% of the Consortium membership be HIV service consumers. In a previous research project, the researcher found that the regions of Akron/Canton, Cleveland, Columbus, Toledo, and Youngstown had the largest and most active Consumer Advisory Panel (CAP) groups and were the most open to assisting with research projects. In addition to participants from these regions, 3 participants were recruited from the Dayton area through snowball sampling (i.e., participants were asked if they knew others who might be interested in participating in the project, and then were given information so that the interested party could contact the researcher).

Potential participants were identified through case managers, agency staff, and snowball sampling. Individuals were eligible to participate if they were at least 18 years of age and HIV seropositive (asymptomatic, symptomatic, or had AIDS). A total of 109 individuals were recruited for the screening phase of this study, which consisted of completing a questionnaire packet that collected demographic information and included assessments of quality of life, posttraumatic growth, and social desirability.

This number of participants was necessary because the sample was divided into quartiles for the interview portion of the study based on participants who reported higher or lower levels of Posttraumatic Growth in the intial contact. Because there is considerable variability among populations in scores of posttraumatic growth, no preestablished cutoff scores have been established for the Posttraumatic Growth Inventory (L. Calhoun, personal communication, 2006). Therefore, in this study the participants' reports of Posttraumatic Growth were considered higher or lower relative to the rest of the sample (how the sample was stratified will be presented in the Results section). In other words, this approach ensured that there was a large enough pool of potential interviewees who reported higher or lower levels of Posttraumatic Growth to allow saturation to be reached during the interview phase of the study (data saturation is

discussed in greater detail later in this chapter). The participants in the questionnaire sample ranged in age from 18 to 70 years (M = 45.71, SD = 9.45, Mode = 47). The participants in the interview sample ranged in age from 34 to 60 years (M = 48.37, SD = 6.83, Mode = 47). The number of participants recruited by region and their sex is presented in Table 1 for the entire questionnaire sample and in Table 2 for the interview sample. Demographic information is presented in Table 3 for the entire questionnaire sample, in Table 4 for the interview sample with higher-PTG, and in Table 5 for the interview sample with lower-PTG.

Table 1. Ouestionnaire Sample (n=109) by Sex and Region

Quebuloiman	te Builipie (ii	10))0),	oon and	region	•			
Variable	Region:	1	2	3	4	5	6	Total
Men		13	22	24	7	11	3	80
Women		3	9	5	3	9	0	29
Total	l	16	31	29	10	20	3	109

*Note*. Region Code Numbers: 1= Akron/Canton; 2 = Cleveland; 3 = Columbus; 4 = Toledo; 5 = Youngstown; 6 = Dayton.

Table 2.

Interview Sample (n=16) by Sex and Region

		- j ~ • • •						
Variable	Region:	1	2	3	4	5	6	Total
Men		4	2	2	0	3	0	11
Women		0	3	1	0	1	0	5
Tota	1	4	5	3	0	4	0	16

*Note*. Region Code Numbers: 1= Akron/Canton; 2 = Cleveland; 3 = Columbus; 4 = Toledo; 5 = Youngstown; 6 = Dayton.

	Frequency	Percent	Cumulative Percent
HIV Status			
Asymptomatic	38	34.9	51.4
Symptomatic	10	9.2	13.5
AIDS	26	23.9	35.1
Total	74	67.9	100.0
No Answer	35	32.1	
Sexual Orientation			
Heterosexual	19	17.4	19.6
Homosexual	39	35.8	40.2
Bisexual	6	5.5	6.2
Other	33	30.3	34.0
Total	97	89.0	100.0
No Answer	12	11.0	
Hispanic/Latino Origin			
Yes	13	11.9	12.1
No	92	84.4	86.0
Don't know	2	1.8	1.9
Total	107	98.2	100.0
No Answer	2	1.8	

Table 3. Demographic Information for Questionnaire Sample (N = 109)

		Frequency	Percent	Cumulative Percent
Race				
	African American	39	35.8	37.1
	Caucasian	50	45.9	47.6
	Asian American	1	0.9	1.0
	Biracial	2	1.8	1.9
	Other	13	11.9	12.4
	Total	105	96.3	100.0
	No Answer	4	3.7	
Religi	on			
	Christian	74	67.9	74.0
	Jewish	1	0.9	1.0
	Muslim/Islam	1	0.9	1.0
	Buddhist	4	3.7	4.0
	No Religion	9	8.3	9.0
	Other	11	10.1	11.0
	Total	100	91.7	100.0
	No Answer	9	8.3	

Table 3. Demographic Information for Questionnaire Sample (N = 109) – Continued.

	Frequency	Percent	Cumulative Percent
Sex			
Male	6	75.0	75.0
Female	2	25.0	25.0
Total	8	100.0	
HIV Status			
Asymptomatic	3	37.5	50.0
Symptomatic	1	12.5	16.7
AIDS	2	25.0	33.3
Total	6	75.0	100.0
No Answer	2	25.0	
Sexual Orientation			
Heterosexual	2	25.0	33.3
Homosexual	1	12.5	16.7
Other	3	37.5	50.0
Total	6	75.0	100.0
No Answer	2	25.0	

Table 4. Demographic Information for Interview Sample Participants with Higher-PTG (n = 8)

	Frequency	Percent	Cumulative Percent
Hispanic/Latino Origin			
Yes	1	12.5	14.3
No	5	62.5	71.4
Don't know	1	12.5	14.3
Total	7	87.5	100.0
No Answer	1	12.5	
Race			
African American	3	37.5	42.9
Caucasian	3	37.5	42.9
Other	1	12.5	14.3
Total	7	87.5	100.0
No Answer	1	12.5	
Religion			
Christian	5	62.5	83.3
Other	1	12.5	16.7
Total	6	75.0	100.0
No Answer	2	25.0	

Table 4. Demographic Information for Interview Sample Participants with Higher-PTG (n = 8) -Continued.

		Frequency	Percent	Cumulative Percent
Sex				
Mal	e	5	62.5	62.5
Fen	nale	3	37.5	37.5
Tota	al	8	100.0	
HIV Status				
Asy	mptomatic	4	50.0	66.7
Syn	nptomatic	2	25.0	33.3
Tota	al	6	75.0	100.0
No	Answer	2	25.0	
Sexual Orie	entation			
Het	erosexual	2	25.0	25.0
Hor	nosexual	4	50.0	50.0
Oth	er	2	25.0	25.0
Tota	al	8	100.0	100.0
Hispanic/L	atino Origin			
Yes		1	12.5	12.5
No		7	87.5	87.5
Tota	al	8	100.0	100.0

Table 5. Demographic Information for Interview Sample Participants with Lower-PTG (n = 8)

Table 5. Demographic Information for Interview Sample Participants with Lower-PTG (n = 8) – Continued.

	Frequency	Percent	Cumulative Percent
Race			
African American	4	50.0	50.0
Caucasian	3	37.5	37.5
Other	1	12.5	12.5
Total	8	100.0	100.0
Religion			
Christian	5	62.5	62.5
Buddhist	1	12.5	12.5
No Religion	1	12.5	12.5
Other	1	12.5	12.5
Total	8	100.0	100.0

## Instruments

This section will review the various instruments used in this study, including information regarding their development, validity, and reliability.

# World Health Organization's Quality of Life HIV - Brief

Demographic information and the participant's perspective on his or her current quality of life were collected through the WHOQOL-HIV BREF, which is a 31-item instrument reflecting the domains of the original 120-item WHOQOL-HIV. The WHOQOL-HIV was based on a generic cross-cultural assessment of Quality of Life (QOL) that was developed by the World Health Organization (WHO) collaborative: the World Health Organization Quality of Life - 100 (WHOQOL-100). This original instrument consisted of 100 items that assessed 25 facets. These facets were then subsumed under six broad domains: physical, psychological, level of independence, social, environmental, and spiritual. A general QOL score, the "G" facet, could also be calculated. The WHOQOL-100 was then expanded into the WHOQOL-HIV to address HIV-specific issues (WHOQOL HIV Group, 2003a, 2003b, 2004).

The qualitative and pilot phases of development revealed five new HIV-specific facets including symptoms of HIV, social inclusion, death and dying, forgiveness, and fear of the future (WHOQOL HIV Group, 2003a, 2003b). The international field test revealed that the inclusion of these new facets expanded upon the spirituality domain, indicating the importance of existential aspects to QOL in PLWHA. In addition, the results of the field test demonstrated good psychometric properties ( $\alpha$  values for domains ranged between 0.70 and 0.90) and good discriminant validity (WHOQOL HIV Group, 2004). The WHOQOL HIV Group concluded that this new international instrument is an appropriate tool for researchers and healthcare providers to assess the impact that HIV/AIDS has on people's physical, social, and psychological well-being, as well as the environmental and existential aspects of their lives (WHOQOL HIV Group, 2004).

The WHOQOL-HIV-BREF is based on the WHOQOL-BREF, which is a 26-item short version of the WHOQOL-100. An additional five HIV-specific items were added to the WHOQOL-HIV-BREF so that the HIV-specific facets explored in the WHOQOL-HIV would be assessed. Participants are asked to consider how each item has affected their life within the past two weeks. Responses are rated on a 5 point Likert-type scale ranging from 1 (low, negative perceptions) to 5 (high, positive perceptions). There have been no published studies to date evaluating the psychometrics of the WHOQOL-HIV-BREF, but there is information about its parent instruments. The analysis of the WHOQOL-HIV demonstrated good internal consistency, with the alpha values for domains ranging between 0.70 and 0.90, and 0.93 for the HIV/AIDS specific module (WHOQOL HIV Group, 2003a, b, 2004). The WHOQOL-BREF also demonstrated good internal consistency, with all of its alpha values greater than 0.70 in the entire international sample of over 11,000 individuals (Skevington, Lofty, & O'Connell, 2004). For the present study, the internal consistency was good ( $\alpha = 0.93$ ).

### Supplemental Demographic Information

Additional demographic information that does not appear on the WHOQOL-HIV-BREF, such as viral load, CD4 count, antiretroviral treatment, current living arrangements, relationship status, sexual orientation, employment status, and belief system (religion/spirituality), was assessed on a separate demographic sheet (see Appendix B).

#### Posttraumatic Growth Inventory

The participant's level of Posttraumatic Growth (PTG) was ascertained using the PTGI. This 21-item scale assesses personal growth through five factor-analytically derived subscales: Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation for Life. Responses are made on a 6-point Likert-type scale
ranging from 0 ("I did not experience this change as a result of my crisis") to 5 ("I experienced this change to a very great degree as a result of my crisis"), with intermediate scores indicating "a very small degree (1), a small degree (2), a moderate degree (3), and a great degree (4)," (Tedeschi & Calhoun, 1996, p. 459). The internal consistency for all 21 items was  $\alpha = .90$ , while individual factor internal consistencies varied: New Possibilities ( $\alpha = .84$ ), Relating to Others ( $\alpha = .85$ ), Personal Strength ( $\alpha =$ .72), Spiritual Change ( $\alpha = .85$ ), and Appreciation for Life ( $\alpha = .67$ ). The internal consistency for the current study was excellent ( $\alpha = 0.97$ ).

Tedeschi and Calhoun (1996) stated that the corrected item-total correlations, which examine the correlation of each individual item with the total score across the remaining items, were in the moderate range (r = .35 to r = .63). The Pearson productmoment correlations among the factors ranged from r = .27 to r = .83, and the correlations of the individual factors with the total PTGI score ranged from r = .62 to r =.83, which the authors said are an indication of some overlap yet separate contributions by each factor. For the current study, the total PTGI score was significantly correlated with each factor ranging from r = .69 to r = .95 (p < 0.01); and there were significant correlations among the factors ranging from r = .61 to r = .85 (p < 0.01).

To examine concurrent and discriminant validity, Tedeschi and Calhoun (1996) compared their PTGI to a measure of social desirability and to demographic and situational variables, such as age and time since the traumatic event occurred. The authors used the Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1960) to examine the correlation between the PTGI and social desirability. The findings revealed no significant relationship between the PTGI and social desirability and, in fact, the factor Appreciation for Life was found to be negatively correlated (r = -.15, p < .01). In addition, there appeared to be no significant relationship between the ages of the participants or the time since the event occurred and the PTGI score (Tedeschi & Calhoun, 1996).

To assess further for concurrent and discriminant validity, Tedeschi and Calhoun (1996) examined the relationships among the PTGI and personality characteristics. They used the Life Orientation Test to investigate optimism (LOT; Scheier & Carver, 1985), the NEO Personality Inventory to investigate Neuroticism, Extraversion, Openness to Experience, Agreeableness, and Conscientiousness (NEO; Costa & McCrae, 1985), and a three-item measure to examine religious participation (Pressman, Lyons, Larson, & Strain, 1990). The PTGI was found to be positively correlated with optimism (r = .23), religiosity (r = .25), and all of the factors of the NEO except Neuroticism (Extraversion, r = .29; Openness, r = .21; Agreeableness, r = .18; and Conscientiousness, r = .16) (Tedeschi & Calhoun, 1996). Extraversion was the only NEO factor that was found to be positively correlated with each PTGI factor. Finally, three specific facets of the NEO demonstrated a "strong" relationship to all PTGI factors and total score: the Extraversion facets of Activity (r = .31 with PTGI total) and Positive Emotions (r = .34 with PTGI total), and the Openness to Experience facet of Feelings (r = .28 with PTGI total) (Tedeschi & Calhoun, 1996).

To investigate the construct validity of the PTGI, Tedeschi and Calhoun (1996) compared scores from the PTGI to responses from the Traumatic Stress Schedule (TSS; Norris, 1990), which is a screening instrument designed to assess the incidence and affect of traumatic events. Results indicated that participants who experienced severe trauma reported more benefits than those who did not (F(53,5) = 3.61, p < .01). Specifically, participants who had experienced severe trauma had higher scores than those who did not experience trauma for the New Possibilities factor (F(1,113) = 6.54, p < .05), the Relating to Others factor (F(1,113) = 4.95, p < .05), the Personal Strength factor (F(1,113) = 9.23, p < .01), and the Appreciation of Life factor (F(1,113) = 17.58, p < .001). The Spiritual Change factor was not significant across trauma severity (Tedeschi & Calhoun, 1996).

#### Marlowe-Crowne Social Desirability Scale

The participants' tendencies to respond in a socially desirable way were measured using the Marlowe-Crowne Social Desirability Scale. Given that the construct of Posttraumatic Growth is assessing for positive changes and perceptions about life, it was important to gauge to what extent the participant has the need "to respond in culturally sanctioned ways" (Crowne & Marlowe, 1960, p. 354). The M-C SDS was developed using a college student sample; however, it also has been used with other populations (see Barger, 2002, for an overview).

The original M-C SDS consists of 33-items; 18 items are keyed true and 15 keyed false to reduce response set interpretations. The authors reported that these 33-items discriminated between high and low scorers at the .05 level, and that the scale demonstrated good internal consistency ( $\alpha = .88$ ) and test-retest correlation (r = .89). In addition, the authors stated that the M-C SDS demonstrated good convergent validity; with positive correlations with the Edwards Social Desirability Scale (Edwards, 1957) and the validity scales of the MMPI (Meehl & Hathaway, 1946), and negative correlations with the MMPI clinical scales (Crowne & Marlowe, 1960; Fordyce, 1956).

Several short versions of the M-C SDS have been developed (Strahan & Gerbasi, 1972); however, more recent investigations into the psychometric properties of these short versions caution that they do not appear to be measuring equivalent constructs to the original scale and discourage their use based on empirical and conceptual arguments (Barger, 2002; Beretvas, Meyers, & Leite, 2002). In light of this evidence, the original 33-item M-C SDS was used in the present study. For the present study, the internal consistency of the M-C SDS was good ( $\alpha = 0.85$ ).

### Semi-Structured Interview

Interview questions were developed by the investigator based on the conditions necessary for the development of Posttraumatic Growth (PTG; Tedeschi & Calhoun, 2003) and the five factors of PTG as defined in the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996). Open-ended questions were used to assess PTG as both a process and an outcome. PTG was conceptualized as a process when examining the extent to which the precursors of growth were present differently across participants with higher or lower PTGI scores. PTG was conceptualized as an outcome when examining to what extent PTG is present differently across groups and how the specific factors of PTG manifest in each participant's life. A sample interview question about the precursors of PTG included: "How did your goals in life change after you found out you were HIVpositive?" A sample interview question about the factors of PTG included: "How has your sense of spirituality changed since you found out that you are HIV-positive?" In addition, scaling questions were asked in order to compare the participants' recollection of distress across interviews and groups. One sample scaling questions was: "On a scale of 1 to 10, with 1 being lowest and 10 being highest, how distressing was it for you when you first found out you were HIV-positive?"

Appendix E provides the initial interview questions that were used with all participants. Participants were also asked if there is anything else they would like to tell the interviewer that might add to understanding their specific experience. The interviews lasted approximately 45-90 minutes, depending on the amount of time each participant needed to share his or her story. In order to assess for the appropriateness and clarity of the interview questions, one pilot interview was conducted with an HIV-positive volunteer at a local HIV-service organization. This individual was asked to provide feedback about the main interview questions and overall interview process (Fassinger, 2005). The feedback given did not change the final question list.

In addition to the main interview questions, participants were asked to provide basic demographic information about their sex, age, ethnicity/race, relationship status, sexual orientation, quality of life, education, occupation, and belief system (religion/spirituality), as well as other information about their HIV-status (CD4 and viral load) and treatment in order to confirm the data collected in the WHOQOL-HIV-BREF.

# Researcher as Instrument

In qualitative research, the researcher herself is often regarded as an instrument of data collection because of the interaction with the participants during the interview process. As a result of this dynamic, the researcher's underlying beliefs about the world and the subject matter may influence data collection. Although the effects of the researcher cannot be completely eliminated, they should be acknowledged through a

process known as "bracketing," which entails becoming aware of one's implicit assumptions and predispositions about the project's topic of inquiry (Morrow, 2005). In addition, the influence of the researcher was monitored in this study through the review of the researcher's data collection journal and the use of a research team during the data analysis process (Morrow, 2005).

Those who write about the bracketing process recommend that the researcher explore his or her emotional involvement with the topic (Morrow, 2005). In the current study of Posttraumatic Growth in PLWHA, the researcher did differ from many of the participants on several demographic variables: the researcher is female, in her late 20's, of Slavic descent, heterosexual, and a secular humanist. The researcher is not HIVpositive and does not have a history of substance abuse; however, she has had family members who have died from complications related to AIDS. In addition, the researcher has been a primary care giver to a relative with a chronic and debilitating illness for several years and, therefore, she is familiar with some of the biopsychosocial needs of an individual with acute medical illness.

In this study, the qualitative data were analyzed with the assistance of a research team and therefore the bracketing process also needed to be completed for them. The research team members examined ways in which they were similar to or different from the study population, their experiences with HIV/AIDS, and experiences with PTG. The first research team member was male, in his mid 20's, of mixed race/Puerto Rican descent, gay, and does not identify with a particular religion. The research team member is not HIV-positive and does not have a history of substance abuse. He did have previous experience working with HIV. He was an HIV test counselor at a university's wellness

center administering Orasure Advanced HIV tests to students and attended a 2 day seminar about HIV and prevention. In addition, the research team member had experiences caring for family members with chronic illnesses (i.e., cancer). This project was his first experience with PTG and he previously had little familiarity with PTG.

The second research team member was female, in her mid 20's, of Scandinavian descent, heterosexual, and a secular humanist. This research team member is not HIV-positive and does not have a history of substance abuse. She has had a few family members who lived with chronic illness. This project was her first academic experience with HIV or PTG, and she previously had little familiarity with PTG or exposure to people living with HIV/AIDS.

Another important area of exploration in the bracketing process is the researcher's knowledge and presuppositions about the topic based on an awareness of the literature and previous work (Morrow, 2005). In addition to writing the literature review for the current study (Chapter 2), the researcher has worked with PLWHA in previous projects including data collection for grant-funded research and her Masters Thesis. The researcher has also developed familiarity with the Posttraumatic Growth model (Tedeschi & Calhoun, 1996), by facilitating PTG-themed group therapy with combat veterans who had received treatment for PTSD for a minimum of 2 years. The other members of the research team had little previous experience with PTG. In addition, one of the research team characteristics were kept within the principal investigator's awareness during the interview process and considered by the research team during the data analysis in order to monitor the researcher/interviewee interaction.

#### Procedure

Before data collection began, one pilot questionnaire packet and interview were given to an HIV-positive volunteer from a local HIV service organization to gauge the amount of time necessary for completing the survey and interview, and to gain feedback about this process. Data collection for the project itself occurred in two phases. First, participants were identified through agencies that provide services to people living with HIV/AIDS (PLWHA) in the Ohio HIV Care Consortia regions of Akron/Canton, Cleveland, Columbus, Toledo, and Youngstown. The researcher and a dissertation cochair contacted case managers and other agency staff in these regions, inquired whether they believed agency clients may want to participate in the study, and provided materials to distribute so that, if the agency staff or clients knew others who would like to participate, the recruits could contact the primary researcher directly (i.e., snowball sampling). The researcher informed potential participants that the purpose of the study was to explore how PLWHA have coped with being HIV-positive. The potential participants were informed about the requirements of the study, which included being HIV-positive and over 18 years of age. They also were informed that this first phase of the study consisted of a questionnaire packet, which took approximately 30 minutes to complete. The packet included a demographic questionnaire, the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), the Marlowe-Crowne Social Desirability Scale (M-C SDS; Crowne & Marlowe, 1960), and World Health Organization's Quality of Life- HIV- Brief (WHOQOL-HIV BREF) instrument (World Health Organization, 2003a, 2003b, 2004). A sample of 106 people living with HIV/AIDS was drawn from the six consortia regions. In addition, 3 questionnaires were completed by participants in the

Dayton area who were recruited by the snowballing method, which gave a grand total of 109 participants.

The researcher then explained that some participants may be invited to participate in the second phase of the project, which would consist of a 45-90 minute interview. Only the participants from the highest and lowest quartiles of Posttraumatic Growth were invited to participate in the qualitative component of the study; however, at the time of data collection the scores and quartile rankings for the PTGI were not known yet and therefore all participants were informed about the potential to participate in the second phase of the study. Participants were asked to fill out a contact information sheet at the end of the questionnaire packet so that if the participant was identified as a potential interview candidate then he or she could be contacted and invited to participate in the qualitative phase of the study. At the time of collection, the contact information sheet was removed from the questionnaire and stored in a separate envelope to remove any potential identifying information from the raw data. Each questionnaire packet and contact sheet was coded so that interested participants who were identified as belonging in the higher or lower Posttraumatic Growth group could be contacted at a later date and invited to participate in an interview. The coding system consisted of a 3-digit number, with the first digit identifying the region and the last two digits being the participant number. This system was used to link the questionnaire packet, contact information, and interview transcript together. This allowed the data to be separated into higher and lower PTG groups, participants to be contacted for interviews, and the data to be analyzed according to higher and lower PTG groups. Each type of data (questionnaire, contact information, and interview transcript) was stored separately in locked filing cabinets to

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protect the confidentiality of the participants. For the first phase of the project, participants were compensated \$10 for completing the questionnaires.

The primary purpose of the questionnaires was to screen the sample for individuals who reported higher and lower levels of Posttraumatic Growth on the PTGI. This screening process entailed calculating quartile scores using the SPSS statistical software package, based on the PTGI total score, to select those reporting higher (top 25% of the sample) and lower levels (bottom 25% of the sample) of Posttraumatic Growth. One of the dissertation co-chairs conducted the screening process to identify potential interviewees within the higher and lower level PTG groups. This dissertation co-chair then presented the researcher with a list of interview candidates that omitted their group membership coding in order to reduce the likelihood of potential bias within the interview (the group membership coding was re-established after the initial qualitative coding of the interviews by the research team was complete). The researcher then contacted these individuals by phone and set up an interview. The interviews took place at the local HIV-service organizations, The University of Akron, a reserved conference room at a local library, or the participant's residence, depending on which location was the most comfortable for the participant. The interviews were conducted by the researcher, a female Slavic American graduate student in counseling psychology. The interviews took approximately 45-90 minutes to complete. The interviews were semistructured and additional follow-up questions were asked when appropriate in order to clarify the participant's responses. If a participant's response to a question included information regarding questions that would be covered later in the interview, then when

the subsequent question was asked the interviewer noted that the question content had been addressed and asked if the participant wanted to add any additional information.

Interviews were audio-recorded and transcribed by the researcher with the assistance of a digital recorder and transcription software. Each transcript had identifying information removed and was coded with the number that corresponded to the participant's questionnaire packet. Participants had the option of receiving their transcript before data analysis to confirm the accuracy of their responses and contribute to the trustworthiness of the data (Fassinger, 2005). At the time the interviews were collected none of the participants requested transcripts of their interview; however, they were given an additional copy of the informed consent that had contact information for the researcher. In addition, participants were informed that the final results of this study would be shared at the HIV-service organizations where data were collected and that the participants are welcome to attend those events. Participants were compensated \$10 for their participation in the second phase of the project. Participants were treated in accordance with the Ethical Principles of Psychologists and Code of Conduct (American Psychological Association, 2002). This project has been approved by The University of Akron Institutional Review Board.

The next chapter will present the results of the current study. It will begin by orienting the reader to the context of this study with a review of the research questions. The chapter then will review the quantitative results by explaining how the data were analyzed and used to divide the participants into groups reporting higher and lower levels of posttraumatic growth. The chapter will continue and review the qualitative results including how the data were interpreted using grounded theory. The chapter will end with

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a description of the answers to the research questions that integrate information from the quantitative and qualitative sections.

#### CHAPTER IV

# RESULTS

This chapter begins with a review of the research questions, to help the reader frame the results within the context of the questions. The chapter then explains how the quantitative data were analyzed, how the participants were divided into groups reporting higher and lower levels of posttraumatic growth, and how the qualitative data were interpreted using grounded theory. The chapter ends with a description of the answers to the research questions.

#### **Review of the Research Questions**

In order to re-orient the reader to goals of the current study, the research questions are listed again below. These questions are intended to provide a context that the reader can keep in mind as she or he reviews the quantitative and qualitative results. At the end of this chapter, the research questions will be answered along with integrated information from across the Results section.

### Research Question 1: Precursors for Posttraumatic Growth

How have the precursors for PTG (Tedeschi & Calhoun, 2003) been encountered in PLWHA?

*Question 1A:* In what way, if any, has HIV-related trauma challenged previously held beliefs (i.e., beliefs about life, self, or others) in PLWHA?

*Question 1B:* How were PLWHA able to manage any distressing emotions brought on by HIV-related trauma?

*Question 1C:* How long did the distressing emotions, from the HIV-related trauma, endure?

*Question 1D:* In what way did PLWHA disengage from previous (i.e., pre- HIV diagnosis) goals?

*Question 1E:* How was the PLWHA able to construct a new personal narrative of his or her life, post-HIV diagnosis?

*Question 1F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the precursors of PTG (Tedeschi & Calhoun, 2003)?

#### Research Question 2: Perception of Traumatic Experiences

To what extent were being diagnosed as HIV-positive and living with HIV/AIDS perceived as a traumatic experience? How did these perceptions affect coping?

*Question 2A:* To what degree do PLWHA perceive being diagnosed as HIV-positive as a traumatic experience?

*Question 2B:* If being diagnosed as HIV-positive was a traumatic experience, what was the intensity of this traumatic experience?

*Question 2C:* If being diagnosed as HIV-positive was a traumatic experience, what was the duration of this traumatic experience?

*Question 2D:* If being diagnosed as HIV-positive was a traumatic experience, what types of strategies have PLWHA used to cope with this traumatic experience?

*Question 2E:* To what degree do PLWHA perceive living with HIV/AIDS as a traumatic experience?

*Question 2F:* If living with HIV/AIDS has been a traumatic experience, what has been the intensity of this traumatic experience?

*Question 2G:* If living with HIV/AIDS has been a traumatic experience, what has been the duration of this traumatic experience?

*Question 2H:* If living with HIV/AIDS has been a traumatic experience, what types of strategies have PLWHA used to cope with this traumatic experience?

*Question 21:* What other types of traumatic experiences have occurred within the lives of PLWHA?

*Question 2J:* How did PLWHA cope with other types of traumatic experiences? *Question 2K:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the perception of HIV as a traumatic event and the affects on coping?

Research Question 3: Personal Changes Within the 5 Factors of Posttraumatic Growth Since Becoming HIV-Positive

Using the model of Posttraumatic Growth (PTG; Tedeschi & Calhoun, 1996; 2004), what types of changes occurred within the life of PLWHA since the time of his or her diagnosis?

*Question 3A:* What types of changes have occurred in how the PLWHA views her or his purpose in life?

*Question 3B:* What types of changes have occurred in the interpersonal relationships of PLWHA?

*Question 3C:* What types of changes have occurred in how the PLWHA views her- or himself?

*Question 3D:* What types of changes have occurred in the personal goals, or dreams, of PLWHA?

Question 3E: What types of changes have occurred in the spirituality of PLWHA?

*Question 3F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding changes that occurred within the lives of PLWHA since the time of his or her diagnosis?

# Research Question 4: Perceptions of Quality of Life

To what extent has living with HIV/AIDS affected quality of life?

Question 4A: How has living with HIV/AIDS affected the quality of life (i.e.,

perception of health and well-being) in PLWHA?

*Question 4B:* What are the differences between those who report higher or lower levels of PTG in their responses to the question regarding quality of life?

Research Question 5: Social Desirability and Reports of Posttraumatic Growth

In what way does social desirability affect reports of PTG?

*Question 5A:* How is social desirability related to quantitative measurement of PTG?

*Question 5B:* How is social desirability related to qualitative reports of increased levels of PTG?

*Question 5C:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding social desirability?

### Data Analysis

The data analysis is discussed in separate sections according to the quantitative and qualitative methodologies.

#### Quantitative

The responses collected from the questionnaire were analyzed using the SPSS statistical software package. The total growth score and individual factor scores (Table 6) were calculated on the PTGI (Tedeschi & Calhoun, 1996). The PTGI does not have a published cutoff score for what would be considered high- or low-levels of Posttraumatic Growth. During a personal communication, Calhoun (2006) explained that the scale authors' hesitation to develop cutoff scores is because the emphasis of this construct has been on the individual's perception of personal transformation and change.

One of my main personal resistances [to developing cutoff scores for the PTGI] is that it is still possible for a person to show no change or even deterioration in several areas, but experience an important, at least from that person's own perspective, positive transformation in another area (L. Calhoun, personal communication, 2006).

In other words, the individual may score low compared to the general population in some areas of Posttraumatic Growth but the person may report experiencing positive personal transformation. Therefore, Calhoun (personal communication, 2006) recommended using quartile scores within the sample of this study to select those reporting higher (top 25% of the sample) and lower levels (bottom 25% of the sample) of Posttraumatic Growth to proceed to the second phase of the study.

The quartile scores were calculated on SPSS, based on the PTGI total score, along with descriptive statistics (mean, standard deviation, maximum score, minimum score, and range) (see Table 6). The analysis of the questionnaire sample revealed the PTGI total growth quartile scores for the higher-PTG group to be 89 and higher, and less than 50 for the lower-PTG group. The PTGI total score, along with descriptive statistics (mean, standard deviation, maximum score, minimum score, and range) for the quartiles are presented in Table 7 for the higher-PTG quartile, and Table 8 for the lower-PTG quartile.

The M-C SDS (Crowne & Marlowe, 1960) scores were summed using SPSS and then correlated with the PTGI total scores in order to describe the response styles within the quartiles and to determine whether social desirability may be accounting for differences in PTGI scores across the quartiles. The MC-SDS was intended to help add dimensions to the discussion of the differences in participants who reported higher or lower levels of PTG. The responses from the World Health Organization's Quality of Life- HIV- Brief (WHOQOL-HIV BREF) instrument (World Health Organization, 2003a, 2003b, 2004) were scored using SPSS and produced domain scores reflecting the perception of quality of life in the following areas: physical, psychological, level of independence, social, environmental, spiritual, and general QOL score or the "G" facet. The descriptive statistics (mean, median, mode, and standard deviation) from the WHOQOL-HIV BREF were used to further examine the differences between PLWHA who reported higher and lower levels of PTG and help to inform the discussion. The descriptive statistics for the PTGI factor and total growth scores, the M-C SDS, and the WHOQOL-HIV BREF are reported in Table 6 for the entire questionnaire sample, in Table 7 for the higher-PTG quartile, in Table 8 for the lower-PTG quartile, in Table 9 for the interview sample with higher-PTG, and in Table 10 for the interview sample with lower-PTG.

Scale	М	SD	Minimu	m Maximu	m Range
PTGI					
Total Growth	67.68	26.39	0.00	105.00	105.00
Relating to Others	21.45	9.36	0.00	35.00	35.00
New Possibilities	15.69	7.09	0.00	25.00	25.00
Personal Strength	13.36	5.60	0.00	20.00	20.00
Spiritual Change	6.44	3.22	0.00	10.00	10.00
Appreciation of Life	e 10.74	4.07	0.00	15.00	15.00
M-C SDS	18.88	6.42	0.00	32.00	32.00
WHOQOL-HIV					
Total QOL	83.16	16.39	43.40	112.60	69.20
Physical	13.39	3.54	6.00	20.00	14.00
Psychological	13.86	3.18	5.60	20.00	14.40
Independence	13.31	3.66	5.00	20.00	15.00
Social Relationship	13.40	3.97	4.00	20.00	16.00
Environment	14.14	2.84	5.00	20.00	15.00
Spirituality	15.07	3.68	5.00	20.00	15.00

Table 6. Descriptive Statistics for the PTGI, M-C SDS, and WHOQOL-HIV BREF- Questionnaire Sample (N = 109)

Scale	М	SD	Minimu	m Maximu	m Range
PTGI					
Total Growth	97.82	5.23	90.00	105.00	15.00
Relating to Others	31.74	2.86	24.00	35.00	11.00
New Possibilities	23.19	2.11	18.00	25.00	7.00
Personal Strength	19.07	1.44	16.00	20.00	4.00
Spiritual Change	9.34	1.30	5.00	10.00	5.00
Appreciation of Life	e 14.48	1.19	10.00	15.00	5.00
M-C SDS	21.07	6.35	12.00	32.00	20.00
WHOQOL-HIV					
Total QOL	92.90	12.52	63.10	110.90	47.80
Physical	13.96	3.66	7.00	20.00	13.00
Psychological	16.02	2.68	9.60	20.00	10.40
Independence	14.22	3.45	8.00	20.00	12.00
Social Relationship	16.11	3.14	7.00	20.00	13.00
Environment	15.54	1.89	9.50	18.50	9.00
Spirituality	17.04	3.35	7.00	20.00	13.00

Table 7. Descriptive Statistics for the PTGI, M-C SDS, and WHOQOL-HIV BREF- Quartile with Higher-PTG (n = 27)

Scale	М	SD	Minim	ım Maximu	m Range
PTGI					
Total Growth	30.85	16.31	0.00	50.00	50.00
Relating to Others	9.26	6.24	0.00	19.00	19.00
New Possibilities	6.03	4.47	0.00	13.00	13.00
Personal Strength	6.52	5.12	0.00	20.00	20.00
Spiritual Change	3.63	3.30	0.00	10.00	10.00
Appreciation of Life	5.41	3.79	0.00	14.00	14.00
M-C SDS	15.89	7.58	0.00	31.00	31.00
WHOQOL-HIV					
Total QOL	77.50	20.52	43.40	112.60	69.20
Physical	12.93	4.24	6.00	20.00	14.00
Psychological	12.65	3.66	5.60	18.40	12.80
Independence	12.89	4.46	5.00	20.00	15.00
Social Relationship	12.22	4.73	4.00	20.00	16.00
Environment	13.59	3.53	6.00	19.50	13.50
Spirituality	13.22	4.03	5.00	20.00	15.00

Table 8. Descriptive Statistics for the PTGI, M-C SDS, and WHOQOL-HIV BREF- Quartile with Lower-PTG (n = 27)

Table 9.

Scale	М	SD	Minimum	Maximum	Range
Years HIV+	14.25	5.95	6.00	24.00	18.00
PTGI					
Total Growth	97.25	4.89	92.00	105.00	13.00
Relating to Others	31.50	3.30	24.00	35.00	11.00
New Possibilities	22.88	2.42	18.00	25.00	7.00
Personal Strength	19.38	1.41	16.00	20.00	4.00
Spiritual Change	8.63	2.07	5.00	10.00	5.00
Appreciation of Life	e 14.88	0.35	14.00	15.00	1.00
M-C SDS	20.88	5.82	12.00	28.00	16.00
WHOQOL-HIV					
Total QOL	89.68	14.41	63.10	107.90	44.80
Physical	13.00	3.70	8.00	18.00	10.00
Psychological	14.80	2.90	9.60	18.40	8.80
Independence	12.75	2.55	9.00	16.00	7.00
Social Relationship	16.88	4.32	7.00	20.00	13.00
Environment	15.38	1.06	14.00	17.50	3.50
Spirituality	16.88	4.61	7.00	20.00	13.00

Descriptive Statistics for the Years HIV+, PTGI Plus Factors, M-C SDS, and WHOQOL-HIV BREF Plus Factors- Interview Sample with Higher-PTG (n = 8)

Table 10.

HIV BREF Plus Factors- Interview Sample with Lower-PTG $(n = 8)$					
Scale	М	SD	Minimum	Maximum	Range
Years HIV+	10.29	5.02	3.00	17.00	14.00
PTGI					
Total Growth	32.62	15.56	2.00	47.00	45.00
Relating to Others	9.00	6.09	0.00	18.00	18.00
New Possibilities	8.38	4.31	0.00	13.00	13.00
Personal Strength	4.38	3.46	0.00	10.00	10.00
Spiritual Change	3.75	3.81	0.00	10.00	10.00
Appreciation of Life	7.13	4.22	2.00	14.00	12.00
M-C SDS	15.38	5.32	8.00	23.00	15.00
WHOQOL-HIV					
Total QOL	71.55	23.33	43.40	112.60	69.20
Physical	11.88	5.00	7.00	20.00	13.00
Psychological	11.80	4.21	6.40	17.60	11.20
Independence	10.75	4.92	5.00	20.00	15.00
Social Relationship	12.13	5.38	4.00	20.00	16.00
Environment	13.13	3.57	9.00	19.00	10.00
Spirituality	11.88	4.52	5.00	18.00	13.00

Descriptive Statistics for the Years HIV+, PTGI Plus Factors, M-C SDS, and WHOQOL-HIV BREF Plus Factors- Interview Sample with Lower-PTG (n = 8)

The investigator of this study was also intersted in the relationship between indicators of posttraumatic growth, social desirability, and quality of life; therefore, the participants' responses on the PTGI, M-C SDS, and WHOQOL-HIV BREF were correlated. The correlations between the PTGI, M-C SDS, and WHOQOL-HIV BREF are presented in Table 11 for the entire questionnaire sample, in Table 12 for the interview sample with higher-PTG, and in Table 13 for the interview sample with lower-PTG. Results for the questionnaire sample indicated that the PTGI was significantly correlated with the M-C SDS (r = 0.31; p < 0.01) and the WHOQOL-HIV BREF (r = 0.27; p < 0.01) (Table 11). Results for the lower-PTG group revealed that the PTGI was correlated with the M-C SDS (r = 0.78; p < 0.01) only and not the WHOQOL-HIV BREF (Table 13). There was no significant relationhip between the PTGI, M-C SDS, and WHOQOL-HIV BREF for the higher-PTG group (Table 12).

Table 11.

Correlations between the PTGI, M-C SDS, and WHOQOL-HIV BREF- Questionnaire Sample (N = 109)

	PTGI	M-C	WHOQOL-HIV-BREF- total
	total	SDS	QOL
PTGI total			
Pearson Correlation	-	0.31**	0.27**
Significance (2-tailed)	-	0.001	0.005
M-C SDS			
Pearson Correlation		-	0.09
Significance (2-tailed)		-	0.330
WHOQOL-HIV-BREF- total			
QOL			
Pearson Correlation			-
Significance (2-tailed)			-

*Note*. PTGI= Posttraumatic Growth Inventory, M-C SDS= Marlowe-Crowne Social Desirability Scale, and WHOQOL-HIV BREF = World Health Organization's Quality of Life HIV- Brief. \*\* = Correlation is significant at the 0.01 level (2-tailed).

Table 12.

Correlations between the PTGI, M-C SDS, and WHOQOL-HIV BREF- Intervie	W
Sample with Higher-PTG $(n = 8)$	

	PTGI	M-C	WHOQOL-HIV-BREF- total
	total	SDS	QOL
PTGI total			
Pearson Correlation	-	-0.35	-0.35
Significance (2-tailed)	-	0.402	0.395
M-C SDS			
Pearson Correlation		-	-0.38
Significance (2-tailed)		-	0.358
WHOQOL-HIV-BREF- total			
QOL			
Pearson Correlation			-
Significance (2-tailed)			-

Table 13.

Correlations between the PTGI, M-C SDS, and WHOQOL-HIV BREF- Interview Sample with Lower-PTG (n = 8)

	PTGI	M-C	WHOQOL-HIV-BREF- total
	total	SDS	QOL
PTGI total			
Pearson Correlation	-	0.78*	0.23
Significance (2-tailed)	-	0.002	0.580
M-C SDS			
Pearson Correlation		-	0.30
Significance (2-tailed)		-	0.472
WHOQOL-HIV-BREF- total			
QOL			
Pearson Correlation			-
Significance (2-tailed)			-

*Note*. PTGI= Posttraumatic Growth Inventory, M-C SDS= Marlowe-Crowne Social Desirability Scale, and WHOQOL-HIV BREF = World Health Organization's Quality of Life HIV- Brief. \* = Correlations is significant at the 0.05 level (2-tailed).

### Qualitative

The interviews were analyzed in the order in which they were collected, and none of the research team members knew the group membership (i.e. higher- or lower-PTG) of any of the interviews during the initial phases of the qualitative analysis process. The research team was made aware of the group membership of the interviews during the final "selective coding" stage of analysis, to investigate whether any pattern formed based on group membership.

For the qualitative analysis, the interviews were divided into 3 theoretically derived sections. The first section, "*The Past and HIV*," explored the participants' lives before they were HIV-positive and what happened to them when they were first diagnosed. This section was intended to examine the presence or absence of the precursors to PTG. The second section, "*Other Stressful Experiences*," investigated whether the participants had experienced other stressful or traumatic events and how they coped with these events. This section explored whether the participants had experience of the attraction, which could then affect how they coped with and perceived their HIV infection. The third section, "*Currently Living with HIV*," focused on how the participants had been currently coping with the disease. This section looked for the presence or absence of changes in the participants' lives including, but not limited to, the factors of PTG.

The interview data were analyzed using grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Glaser and Strauss described the purpose of grounded theory as "the discovery of theory from the data systematically obtained from social

research" (p. 2). Grounded theory uses flexible hypotheses and broad questions to guide the investigation process. As the investigative process unfolds, themes that emerge from the data help to generate theory that is grounded in the data. The categories that are generated through this research process are developed from the data, rather than preconceived concepts. Essentially, the investigation stays grounded within the data throughout the research process.

Grounded theory has been used successfully by other researchers in counseling psychology (e.g., Gomez et al., 2001; Noonan et al., 2004; Richie et al., 1997; Timlin-Scalera, Ponterotto, Blumberg, & Jackson, 2003; see Fassinger, 2005, and Creswell et al., 2007, for overviews) and is appropriate to use with the study's participants because they have had the experience of living with HIV/AIDS and had the personal challenge of learning to cope with, and make personal meaning of, their disease. Thus, the current study used grounded theory to explore and compare the components and precursors of Posttraumatic Growth in PLWHA who report higher and lower levels of PTG because the topic requires an in-depth and descriptive examination of these processes that quantitative questionnaires alone could not fulfill.

The analysis team consisted of the researcher and two other graduate students who reviewed interview data from a sample of PLWHA who reported higher or lower levels of posttraumatic growth. As part of the training process, the team studied the procedures of grounded theory as described by Glaser and Strauss (1967), Strauss and Corbin (1998), and Fassinger (2005). The team practiced conducting grounded theory on an unrelated, existing transcript regarding HIV guest speakers. The researcher has conducted qualitative research previously for her Masters Thesis and consulted with other researchers who had experience with qualitative methodology about how to train the analysis team.

After the interviews were transcribed, the team analyzed the interviews and separated the dialogue into appropriate categories related to the question-specific themes. A total of 16 PLWHA were interviewed: eight reporting higher levels of PTG and eight reporting lower levels of PTG. The total number of participants that is appropriate for a qualitative study using grounded theory depends on when the data seems to converge, or saturate, and no new themes emerge. The literature and experience indicates that saturation often happens with approximately eight to 10 interviews (Morrow & Smith, 2000). After eight interviews were collected from each group, or 16 total interviews, it seemed that no new themes were emerging and therefore saturation had been reached.

Throughout the analysis process, the research team met on a regular basis to discuss the data and move toward consensus about the coding of the data. Care was taken to ensure that all team members felt comfortable sharing their views in the group. Furthermore, all team members' feedback on the data was solicited so that no one member dominated the group. The team members read and analyzed (using line-by-line coding) each interview transcript as well as identified the meaning units (concepts) before they met as a group. It should be emphasized that none of the research team members knew the group membership (i.e. higher- or lower-PTG) of any of the interviews during the qualitative analysis process. The primary researcher became aware of the group membership of the last 2 interviews because she had to call nearly every potential participant in the lower quartile before enough interviews had been collected from that group. The group identity of the last 2 interviews was withheld from the other members of the research team. The research team was made aware of the group membership of the interviews during the final "selective coding" stage of analysis, to investigate whether any pattern formed based on group membership.

Grounded theory methodology is intended to reduce the data and generate themes using open, axial, and selective coding that result in core categories and substantive level grounded theory, which tell an interrelated story line (Fassinger, 2005; Morrow & Smith, 2000; Strauss & Corbin, 1998). The first level of coding is open coding (see Figure 1), which consists of breaking down the transcript into smaller units of meaning (concepts), labeled using descriptors similar to the words of the participant, and then examined for alternative interpretations or the context surrounding the meaning. This process was performed on each transcript to identify phenomena and place these phenomena into categories. The categories were formed based on similarity of concepts found in the data and each category was given tentative names by the research team.

The second level of coding is axial coding (see Figure 1), which allows the researchers to put the data back together by making connections among categories (Strauss & Corbin, 1998). During this process, comparisons are used to identify the properties of each category, group categories into more encompassing "key" categories (themes) (see Figure 1), and explain the relationships between categories and the subcategories within each category (Fassinger, 2005; Morrow & Smith, 2000; Strauss & Corbin). The research team also identified the properties, or specific characteristics, of each category. Then, the team identified the dimension of each category, or where those data should be relatively positioned along a continuum of the entire data set (Fassinger, 2005). In other words, all of the concepts within a category are placed on a continuum

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that helps to describe and define the content of that category; and that continuum is referred to as a dimension. For example, the dimensions of the category "Family" might include the various dynamics between the participants and their families including No Disclosure (of HIV status to family), Family Rejecting (family rejects participant after HIV-positive), and Family Supportive.

The final stage of grounded theory analysis is selective coding. In the selective coding stage, the researchers are supposed to generate a "core" category that integrates all of the other categories derived from the data (see Figure 1). This core category is intended to create "an explanatory whole" or a description of the data in narrative form (Strauss & Corbin, 1998, p. 146). The research team did attempt to complete the selective coding step; however, the data from the current study did not generate a core category. Details for the decision that a core category failed to form will be discussed later in this chapter. Finally, the research team conducted a parallel phase of analysis. During the parallel analysis process, answers to each interview question from the original transcripts were summarized, the concepts (see Figure 1) generated in the qualitative analysis were reviewed, and then this information collectively informed the answers to some of the research questions. Because no core category formed, this step was necessary in order to develop an alternative way to answer the study's research questions.



Figure 1. Levels of Coding in Grounded Theory- Read from Bottom (Level 1) Up

Throughout the data analysis process, the researcher shared the team's progress and decision making with an auditor. One of the dissertation co-chairs (not the one who provided the PTGI ratings) served as the auditor. The auditor examined each transcript and discussed with the researcher whether categories were properly created using grounded theory methodology and provided any feedback that may be helpful. The auditor then returned the transcripts, with comments, to the researcher, who reviewed the comments and discussed them with the research team.

In grounded theory the researcher is a tool for the analysis because of the interaction between the researcher and the data (Glaser & Strauss, 1967). Given this interaction, it is important for the researcher to record objective information (e.g., the participant was late to the interview) and keep a personal memo of her or his thoughts and feelings during the data collection processes. More specifically, Fassinger (2005) described memos as a crucial part of the process because they create a record of analytic questions and decisions, as well as the insights, emotions, choices, assumptions, category formation rationale, and hunches of the researcher. It is highly recommended that investigators make memos throughout the investigation (Fassinger 2005; Glaser & Strauss; Strauss & Corbin, 1998). The researcher kept memos and then shared these memos with the research team and auditor during the data analysis process.

In summary, the analysis of the interview questions first produced concepts, which consists of breaking down the transcript into smaller units of meaning and labeling them using descriptors consistent with the words of the participant. Comparable concepts were then grouped together to create categories. The categories were formed based on similarity of concepts found in the data. The research team also identified the dimension of each category, or where those data should be relatively positioned along a continuum of the entire data set (Fassinger, 2005). Finally, the categories are grouped into more encompassing themes (alternatively known in some of the literature as "key categories") (Fassinger, 2005; Morrow & Smith, 2000; Strauss & Corbin, 1998) (see Figure 1). The interviews were analyzed for categories and themes in each section: "*The Past and HIV*," "*Other Stressful Experiences*," and "*Currently Living with HIV*." The categories and themes generated for each section were then compared across interviews. A summary of the categories and themes that emerged during the analysis is presented in Table 14. In order to be included in the analysis, the categories needed to be endorsed by 3 or more participants to ensure appropriate representation and fairness of perspectives (Morrow, 2005). Each section is presented below along with the categories and themes that emerged. Representative participant quotes are included to illustrate the themes. In addition, these quotes help explain the dimensions of a specific category (see Figure 2).

Because the interviews were analyzed using a parallel process in 3 different sections (i.e., "*The Past and HIV*," "*Other Stressful Experiences*," and "*Currently Living with HIV*"), some of the same categories and themes appeared in more than one section. For example, the theme "Coping Strategies" emerged across all three sections because many of the participants discussed coping throughout the interviews. In addition, similar sounding categories emerged in different sections during the analysis; however, those categories had differing dimensions (i.e. content) and had somewhat different connotations, and therefore were classified under different themes. For example, the category of Vocational/Socioeconomic Status emerged in both "*The Past and HIV*" and "*Currently Living with HIV*" sections, because some participants brought up topics related to vocational and economic issues. However, the dimension (i.e., content) of the Vocational/Socioeconomic Status category varied between the sections, and therefore it was classified in a different theme from one section to the other. In other words, in the section "*The Past and HIV*" vocational and economic issues were discussed within the

context of Negative Life Experiences, while in the section "*Currently Living with HIV*" vocational and economic issues were discussed within the context of Coping Strategies.

Table 14.Categories and Themes by Section of Interview

Section	Theme (Number of Participants	<b>Categories in each Theme</b>
	<b>Reporting; Higher-PTG, Lower-</b>	(Number of Participants
	PTG)	<b>Reporting; Higher-PTG, Lower-</b>
		PTG)
1. The Past	1A. Coping Strategies (16; 8H,	Coping (15; 8H, 7L)
and HIV	8L)	Spirituality (7; 4H, 3L)
		Resources/Support (5; 2H, 3L)
		Destructive Coping(4; 3H, 1L)
		Nostalgia (3; 1H, 2L)
	1B. Negative Life Experiences	Negative Feelings/ Reactions (13;
	(15; 7H, 8L)	7H, 6L)
		Stress (11; 5H, 6L)
		Negative Societal Reaction (7; 4H,
		3L)
		Alienation/ Isolation (5; 3H, 2L)
		Vocational/ SES (4; 1H, 3L)
		Legal (3; 2L, 1H)
	1C. Interactions with Others (13;	Family (8; 4H, 4L)
	7H, 6L)	Interpersonal Relationships (6; 3H,
		3L)
		Disclosure (5; 2H, 3L)
	1D. Health/Treatment/Intervention	Health/Treatment/Intervention (13;
	(13; 5H, 8L)	5H, 8L )
	1E. No Change (5; 3H, 2L)	No Change (5; 3H, 2L)
<u>2. Other</u>	2A. Coping Strategies (14; 7H,	Coping (14; 7H, 7L)
<u>Stressful</u>	7L)	Spirituality (4; 1H, 3L)
<b>Experiences</b>		Resources/Support (4; 3H, 1L)
	2B. Negative Life Experiences	Stress (9; 5H, 4L)
	(10; 6H, 4L)	Negative Feelings/ Reactions (4;
		3H, 1L)
	2C. Interactions with Others (7;	Family (4; 2H, 2L)
	3H, 4L)	Interpersonal Relationships (4; 1H,
		3L)
	2D. Health/Treatment/Intervention	Health/Treatment/Intervention (6;
	(6; 2H, 4L)	2H, 4L)
Table 14. Categories and Themes by Section of Interview - Continued

Categories and Themes by Section of Interview - Continued		
<b><u>3. Currently</u></b>	3A. Coping Strategies (14;	Coping (14; 6H, 8L)
living with HIV	6H, 8L)	Spirituality (12; 6H, 6L)
		Vocational/SES (5; 1H, 4L)
	3B. Interactions with Others	Interpersonal Relationships (11;
	(13; 6H, 7L)	4H, 7L)
		Family (6; 3H, 3L)
		Disclosure (3; 1H, 2L)
	3C. Healthcare (12; 5H, 7L)	Health/Treatment/Intervention (12;
		5H, 7L)
	3D. Negative Life	Stress (8; 3H, 5L)
	Experiences (11; 3H, 8L)	Negative Feelings/Reactions (5;
		1H,4L)
		Negative Societal Reaction (5; 1H,
		4L)
	3E. Personal Transcendence	Altruism (6; 3H, 3L)
	(9; 5H, 4L)	New Attitude (4; 3H, 1L)
		Education (3; 2H, 1L)
	3F. No Change (6; 4H, 2L)	No Change (6; 4H, 2L)
	3G. Reflecting on Life (5;	Concerns for the Future (3; 1H,
	2H, 3L)	2L)
		Nostalgia (3; 2H, 1L)



Figure 2. Relationship Between Categories and Dimensions

## Section One: "The Past and HIV."

The five themes that emerged in section one, the number of participants who reported them, and the categories in each theme are reported in Table 14. Each theme is described below, followed by the categories that comprise each theme, and the dimensions that help define the categories.

All 16 participants endorsed the theme *Coping Strategies*, and gave several examples of types of coping, which were further broken down into categories. The first category, Coping, had a dimension that reflected ways of thinking about HIV and another dimension that involved activities. One participant explained, "Mentally, the healing is [important] as much as the medicine is working. You can sit and get into that pity party...So, the way of thinking has a great deal to do with it" (Higher-PTG participant). Another participant explained, "Instead of looking at it as a negative, I almost look at is as a positive because it gave me the time to slow down" (Lower-PTG participant). Other participants explained that they tried to control their thoughts and not think about HIV, "Anything to take my mind off of thinking about it. It was really, really hard, but that's how I did it" (Lower-PTG participant). Finally, some participants described doing activities to cope, such as walking their dogs or doing chores. One participant explained, "When I'm at home I try to do a few little things around here. I have these puzzles. I can do some praying and read some books or something. Read a western or watch TV" (Lower-PTG participant).

The second category under the theme *Coping Strategies* was Destructive Coping. The participants who endorsed this category described coping techniques that seemed to be ultimately maladaptive. Some participants reported using substances to cope. One participant explained, "I did the best that I knew how to do, and that was self-medicate myself to stuff it and run" (Higher-PTG participant). Another participant stated, "I tried it, drinking, smoking marijuana, I tried it. That kept me from thinking about that I was positive, but as soon as that high went down the same problems came back" (Lower-PTG participant). Other participants became obsessively involved in activities, "I was a workaholic. I was a churchaholic. Anything that I did was to the extreme" (Lower-PTG participant). Some participants reported isolating themselves in their homes, "There was a point where I became a recluse. I wouldn't even open the shades of my windows" (Higher-PTG participant).

The third category under the theme *Coping Strategies* was Spirituality. Many participants who spontaneously mentioned Spirituality described it as a source of strength. "I pretty much fell into my faith" (Lower-PTG participant). Another participant reported "It made me believe more in God" (Higher-PTG participant). Other participants described prayer as an important component of coping, "Yeah, and the only hopeful thing that I had was my prayers. I just kept praying. That's all that I could do" (Lower-PTG participant). Some participants described HIV as being part of God's plan for them, "I still believe in God, and God has his place in time for everything. Sometimes I wonder, why me? And then again, I know why me. There's a reason for it" (Lower-PTG participant).

The fourth category in *Coping Strategies* was Resources/Support. In this category, participants described how they tried to get support from community resources. One participant commented about the decision to apply for social security disability, "So I just supported myself with social security, basically, because I had paid so much into it that I

got a decent return" (Lower-PTG participant). Another participant used community resources that recommended that she attend the healing weekend workshop, "I started going to group sessions that they were having at the AIDS Task Force. There was a guy there and he told me that I needed to go to a healing weekend. So I went" (Higher-PTG participant). Other participants explained that identifying community resources could be challenging, "You will get a support team built around you but you really have to dig and find what resources are available, because they are not advertised" (Lower-PTG participant).

The fifth category in the *Coping Strategies* theme was Nostalgia. Participants who reported content related to Nostalgia seemed to be focusing on their life before HIV as a way of coping and avoiding thinking about HIV. One participant commented, "Oh. It was beautiful. I used to get dressed and go out to parties and go out to the bar. It was beautiful. It was a good life" (Higher-PTG participant). Another participant explained, "I had a good job. It seemed like everything was going okay... I had a good job, good health, all the right things" (Lower-PTG participant). One participant described focusing on life before HIV and the changes that have occurred since living with HIV, "But I was always busy, happy, and doing things. But now, uh-uh [no]" (Lower-PTG participant).

The next theme, *Negative Life Experiences*, was endorsed by 15 of the 16 participants. This theme consisted of six categories. In the first category, Negative Feelings / Reactions, the participants described times of powerful negative emotions including shock, devastation, anger, fear, and depression. One participant explained the intensity of the emotions, "Shocking? It's like a nuclear explosion. It's devastating, because it's complete shock" (Higher-PTG participant). Another participant explained, "I think it was the worst thing that ever happened to me in my life" (Lower-PTG participant). One participant described feeling suicidal, "I was really going to throw myself out of that window. I was really depressed for a long time. It was the lowest point of my life. The lowest I've ever been" (Lower-PTG participant). Finally, one participant explained that he went through stages of negative emotions, "I never went to denial, and I did go through the fear, but I would always go right back to the anger" (Higher-PTG participant).

The second category in *Negative Life Experiences* was Stress. Many of the participants described being under a great deal of stress after they were first diagnosed. Some participants described the stress as growing. One participant explained, "It seems like all the problems take over instead of good things" (Higher-PTG participant). Another participant stated, "The stressors were mounting, stress was constant" (Higher-PTG participant). Finally, another participant described the stress as being more intense when he was ill, although it was always there: "Well, first it took about a month for the medication to really kick in. I was very stressed during that time, because I was very sick... It keeps you a bit under stress all the time" (Lower-PTG participant).

The third category in *Negative Life Experiences* was Negative Societal Reaction. In this category, participants described negative reactions from society toward individuals living with HIV/AIDS. Some of the participants did not realize that the public was still very misinformed, "I was different, because I didn't know the real stigma of AIDS. I didn't understand what was going to take place and what was going to happen, and how I was going to be treated" (Lower-PTG participant). Many participants explained that negative reactions were based on public misinformation about HIV, "That's why I said, they're not ignorant people, but they are ignorant to the facts. A lot of people, I think the

reason they are scared is because they don't know the facts" (Higher-PTG participant).

Some participants experienced negative feelings in response to how society reacted to

HIV:

It gave me a dim look on the world because of the way the world stigmatize[s] HIV and AIDS. They didn't really talk so much about HIV as they did AIDS. Then it was strictly AIDS. Then it was associated only with homosexuality. It was associated with being a menace to society. It was always shunned down on. You were alienated. People didn't have a lot of education about it. So they didn't know whether it was appropriate for you to kiss someone or whether to be around them. Would they catch it from you touching them, looking at them, or whatever? With their lack of knowledge, it made me look at the world as saying ewww. It will stand back and get away from me. I wanted to reach out to the world, but I was afraid. (Higher-PTG participant)

Other participants thought of the public reaction as an opportunity for education:

It didn't discourage me at all, but it just made me realize how important what I was doing was, talking to the kids first. Because if they act like that, then the adults act like that, and that's basically the problem in the world, is that no one understands. What they don't understand, they're scared of, and they won't learn more about it. (Lower-PTG participant)

Finally, some participants described the public reaction as kind of a collective denial,

which could prove to be dangerous for HIV prevention:

Society is walking around pretending like it doesn't exist. And there are a lot of people, I mean, there are probably quite a bit of people out there who are positive, who either aren't admitting it and spreading it further... But really, the stigma needs to come down, and we need to protect people. This disease is not going to go away because people are hiding it. (Lower-PTG participant)

The fourth category in *Negative Life Experiences* was Alienation / Isolation.

Participants who endorsed this category described feeling alone and misunderstood by

other people. One participant recalled talking to his father about HIV:

He did not understand it or do anything about it...but at that point I felt that he didn't understand it, and I would like [to be] talking to someone [about HIV], and I really had no one to talk to. (Higher-PTG participant)

Another participant explained, "I had no one to talk to, no one to ask questions to"

(Higher-PTG participant). Some participants reported socially withdrawing from others

because of bad experiences:

There was a point where I became a recluse. I wouldn't even open the shades of my windows. Every time you turned around it seemed like someone was turning their back on you. So, the last thing that you want to do is see anybody. I would do my job and go home. My mother lived across the street, and she never even saw me. She's the one who brought it to my attention. She said, "Do you know that you're living in a cave?" I had not paid attention to it, I just blocked everybody out. (Higher-PTG participant)

Further, some participants reported withdrawing because they felt they were treated differently from everyone else, "You're still being labeled as different. You lose a lot of people you love, who you thought was your friends, even family members. So, I just stick to myself." (Lower-PTG participant)

The fifth category in *Negative Life Experiences* was Legal, which included interactions with the legal system in a negative way. One participant explained that his HIV status could further complicate his legal issues, "If you get in a fight, and you have HIV, they can get you for attempted murder, even if you're defending yourself" (Lower-PTG participant). Two participants reported filing lawsuits against professionals for violating HIPAA laws and illegally revealing the participants' HIV status. One participant stated, "I asked you to keep your mouth quiet, but she would not do it. I lost over half of my clientele. I had to take her to court and put a gag order on her" (Higher-PTG participant). Another participant stated, "So, that HIPAA law don't mean a thing to them. Something really terrible happened to me. My wife found a friend at my lawyer's office, and she read my records to my wife" (Lower-PTG participant). Finally one

participant reported being the victim of a crime because of his HIV status, "And then a

year to the day that I was diagnosed, I was the victim of a hate crime" (Higher-PTG

participant).

The final category in Negative Life Experiences was Vocational / Socioeconomic

Status. Participants who endorsed this category described losing their jobs or careers once

they found out they were HIV-positive, which in some cases resulted in having to adjust

to less income or a lower socioeconomic status. One participant explained:

I was called into my immediate supervisor's office, who was the CFO, who also gave the approval to the third-party insurance payer, approvals and denials for payment for various things, that my department was being taken into a different direction and my services were no longer needed. So now I'm faced with no livelihood. I was like, "God... I lost my job." I'm dealing with a virus that could kill me. I'm trying to take medications that are supposed to make this virus subside so that I can continue to live. Now I have no means to support myself and no insurance on top of that. (Higher-PTG participant)

Another participant reported having to stop working out of concerns for the clientele:

I dealt with behaviorally challenged people. I miss that and I miss my people that I worked with very much. But, I had to worry about them, and then that started becoming a concern. Because what if one of them bit me or scratched me? Their hands went in their mouth all the time. (Lower-PTG participant)

The next theme that emerged, Interactions with Others, was endorsed by 13

participants and included 3 categories. The first category was Family. Some of the

participants reported that their families were supportive of them when they first found out

they were HIV-positive. One participant explained, "When I first found out, me and my

husband had just gotten married and he stuck by my side. I told my family and they never

took it negative...They accept me as if nothing was wrong" (Lower-PTG participant).

Other participants explained that they were concerned about infecting other family

members, "At that point in time, when she was pregnant [participant's wife], it was a big concern...A huge burden, but now she's fine [pointing to baby in room]. She [baby] doesn't have anything, and I thank God for that" (Lower-PTG participant). Some of the participants discussed family members who also were HIV-positive or had passed away from AIDS. One participant stated, "I had like my 2 uncles, who died from AIDS" (Lower-PTG participant). Another participant discussed concerns for her husband, who is also HIV-positive, "Then, I guess I was concerned more about how he was" (Higher-PTG participant). Finally, some participants reported that their families were rejecting of them, which was very hurtful. One participant explained, "The first people that hurt me is my family. Now, not all of my family, but the main ones that was in my life every day, and they turned away from me" (Lower-PTG participant). Another participant reported, "Because not only did I have my clientele walk away from me, but I had part of my family walk away too. That didn't hurt me, it made me angry" (Higher-PTG participant).

The second category in *Interactions with Others* was Interpersonal Relationships. This category described changes to romantic relationships and friendships. Some of the participants reported losing relationships and going through a divorce or breakup after finding out they were HIV-positive. One participant described breaking up with her fiancée, whom she believes infected her with HIV, after finding out that he was keeping his HIV-status a secret from her. "He [fiancée] was [HIV-] positive, all of that time. So I was engaged and when I found out and everything, I broke that off" (Lower-PTG participant). Another participant responded when asked what his life was like when first diagnosed, "umm, going through a divorce, dealing with my sexuality" (Lower-PTG participant). Some participants reported that they had friends who were also HIV- positive, and who helped them get information and resources. "Thank goodness I have had a good group of people around me and I did have a friend who was positive. That person helps me through a lot of it and gave me a lot of information" (Higher-PTG participant). Another participant reported making a friend in the HIV community:

There was a person already in the area who had HIV, but I didn't know it, in my neighborhood. So I finally met this person, I met him at the health department when I went for our checkups. So I met this person and I was like oh, you live across the street from me. That person took me under his wing and he educated me. (Lower-PTG participant)

Finally, some participants explained that their relationships with friends did not change, "As far as the way I socialized or whatever with my friends, ain't nothing changed about that" (Higher-PTG participant).

The third category in *Interactions with Others* was Disclosure. This category described participants' concerns about disclosing their HIV status, how they decided to disclose, and to whom. Some participants expressed concern about telling their children they were HIV-positive and when to talk about it. One participant explained, "Because, the only difference is, at the time I had to figure out how I was going to tell my kids...Actually, I still didn't tell them until about eight years ago" (Higher-PTG participant). Another participant stated, "I have a daughter. I really didn't want to lay this on her at that point. She does know now, she's 16, but before she was 14 and it was just a little bit too much then" (Lower-PTG participant). Another participant expressed regret for not telling his family sooner:

So I carried around not disclosing to my family, and here they were the most easiest [to disclose to] and [the] most supportive. I wasted all them years that I could've had that support. So I suggest people disclosing to their support system early in their recovery. (Lower-PTG participant) Some participants reported that they had to think carefully about to whom they were going to disclose their HIV status. "Because if you're going to tell the truth, you have to weigh who you're going to tell the truth to. There's consequences on telling the truth" (Lower-PTG participant). Another participant explained:

I was lucky enough to find it [social support] inside my family, so going outside my family is when I noticed that you can't tell everybody everything. You pick and choose who you want to know, and who you don't want to know. If you tell them, you best be prepared for the outcome because you never know where that information is going to go. I know they always say, "I'm not going to tell anybody. This is just between me and you." But, we live in the real world and how often is that the case? (Lower-PTG participant)

Finally, a few participants reported that other people did not respect confidentiality and disclosed the participants' HIV status without permission. One participant stated, "I have had one friend who thought he would be ignorant and tattled to a few people" (Lower-PTG participant). Another participant's husband told people her HIV status because he was angry, "So, because I would not go along with him, and I don't even remember what we were arguing about, he jumped up and told everybody in the house" (Higher-PTG participant).

The next theme that emerged was *Health/Treatment/Intervention*, which was endorsed by 13 participants. This theme had one category, Health / Treatment / Intervention, which consisted of information about symptoms, illnesses, medication, and the treatment process. Many of the participants described getting ill with mysterious symptoms and doctors were unsure of their illness:

I found out in April of 1997 that I was positive, because I was displaying a number of symptoms with regard to chronic fatigue to the point of confusion. It was like Mono, no energy, wanting to sleep all time sleeping through an alarm clock, profuse night sweats, heart palpitations, enlarged lymph nodes. I had gone to one of our area clinics and that's the satellite of one of our hospitals, and I was basically given a prescription for two weeks worth of antibiotics and sent on my way. They said if my symptoms persist I should see my family doctor. So, and naturally of course, I ended up going to see my family doctor, and he was kind of baffled as to what the symptoms were. (Higher-PTG participant)

Another participant described being so ill that he ended up in the hospital, "I found out from the doctor and the next thing I knew, I was in the hospital" (Lower-PTG participant). Some participants explained that they did not have any health problems initially after diagnosis, "So, like I said, I really didn't... I guess because I wasn't really sick" (Higher-PTG participant). Many of the participants reported challenging side effects from HIV medication, "I had a bad reaction from the AZT medicine, which is the only thing that they had available to time, so I refused to take that because of the harsh side effects" (Higher-PTG participant). Some of the participants reported experiencing depression and seeking medication to cope with the depression, "Well, the depression medication that they put me on at the time wasn't helping. They gave me Prozac, and I think the Prozac was too strong" (Lower-PTG participant). Finally, some participants explained that they had difficulties getting referrals for HIV treatment in their community.

As a matter of fact, the doctor who told me I was positive told me that I had to find another doctor to help me with no recommendation. I had no idea. I knew nothing about it, and I had no idea about what doctor to go look for. (Higher-PTG participant)

The last theme in the "*The past and HIV*" section was *No Change*, which was endorsed by 5 participants. This theme consisted of one category, No Change, which described a global feeling that their lives did not change when they found out they were HIV-positive. More specific areas where change did not occur, such as within their family, were discussed in the previous sections of related categories. One participant commented, "Nothing really nothing has changed. It just happens" (Higher-PTG participant). Another participant acknowledged that some might think it is unusual that he has not experienced much change, "Actually my life is pretty much, this may sound strange, but I guess my life seems pretty much the same" (Lower-PTG participant). One participant explained that he resisted letting his life change, "It really didn't change when I first found out. Because I was in denial. I didn't let it change" (Lower-PTG participant). Finally, one participant explained that because she was not ill, her daily routine did not change:

So, like I said, it really didn't. I guess because I wasn't really sick...Everything was the same, there was no difference. Other than the fact that I knew, but my lifestyle didn't change none. I went to work every day, came home and played with the grandkids or whatever. So nothing ever changed. (Higher-PTG participant)

In conclusion, the section "*The past and HIV*" examined what the participants' lives were like before HIV and how their lives changed, if at all, once they became HIVpositive. The purpose of asking participants about their lives before HIV was to investigate whether the precursors to PTG (Tedeschi & Calhoun, 2003) were present, including having a traumatic experience that is severe enough to challenge previously held assumptions about the world, being able to manage distress, disengaging from previously held goals, the distress persisting for some time, and creating new personal narratives to accommodate the new traumatic information. The personal narratives of the participants varied as to the amount of change that they recalled after coping with the initial shock of finding out they were HIV-positive. The next section "*Other stressful experiences*" explores how the participants coped with other stressors compared to coping with HIV. Theoretically, if the person had already coped with a previous traumatic event, then he or she may be more prepared to cope with HIV.

## Section Two: "Other Stressful Experiences."

The four themes that emerged in section two, the number of participants who reported them, and the categories in each theme are reported in Table 14. Fourteen of the participants reported experiencing another stressful or traumatic event in their lives before becoming HIV-positive. Death of a family member, including some deaths associated with HIV/AIDS, was the most commonly reported stressor with five participants reporting this issue. Acute, life-threatening personal illness was reported by three participants. Surviving sexual abuse or sexual assault was reported by two participants. Going through a lengthy divorce was reported by two participants. Surviving domestic violence was reported by one participant. Finally, the daily stressors of the family's schedule were reported by one participant.

The first theme under "*Other Stressful Experiences*" was *Coping Strategies*, which was endorsed by 14 participants. This *Coping Strategies* theme consisted of ways that the participants used to cope with the non-HIV-related stressors. The first category in this theme was Coping. The dimensions of this category (Coping) described ways in which participants thought about the stressor, and activities they did to cope with the stress. Some participants described just going through the stress and living their daily lives. One participant stated, "So I started living day by day and really not let nothing bother me" (Higher-PTG participant). Another participant said, "I just had to go through it" (Higher-PTG participant). In a similar vein, some participants explained that they either did not know what to do at the time or they did nothing at all. One participant described his reaction after a death in the family, "I was 11, and I was still a child. I would just run around. I didn't know what was going on" (Higher-PTG participant). Another participant explained in relation to his acute illness, "mentally there is no coping because you are lying there going a little insane" (Lower-PTG participant). Some participants described falling into addictive behaviors as a way of coping, "I tried to do the drug thing" (Higher-PTG participant). Another participant explained, "I think I was already an addict because of the sexual abuse" (Lower-PTG participant). Finally, one participant commented, "I probably had my spells of trying to anesthetize myself" (Lower-PTG participant).

Some participants coped with their stressors by concentrating on daily life. One participant explained, "I focused on my job, my duties and responsibilities at work, and my mother who was elderly and widowed" (Higher-PTG participant). Another participant explained that she cleared out her schedule to care for herself, "When it's too stressful, I just cut that day out because I can always count on my mom to pick up or my husband" (Lower-PTG participant). Participants who previously went through acute and severe illnesses reported relying on their healthcare providers to cope. One participant stated, "I guess, by me knowing that I had good doctors. All the doctors I had were, like I said we had relationships, instead of me being just a file" (Higher-PTG participant). Another participant said, "I kept yelling for them to come and give me my shot. [laughs] That was the main thing because I wanted that Demerol. I wanted that shot to make my pain go away" (Lower-PTG participant). Another participant explained that she cut her hair preparing for cancer treatment, "I know how it makes people bald. So it was kind of like transitioning myself from long hair down to shorthair to no hair. That way, it wouldn't be so drastic when it started to fall out" (Higher-PTG participant). In addition, participants with prior illnesses explained that having a positive attitude was another important component of coping. One participant explained:

Like I said, the first or the initial thing was, oh this is a breeze. I guess that's just how I cope with the stuff. Because I got this armor around me that at first. I always tell people not to worry until its time to worry. I don't worry about things a lot. (Higher-PTG participant)

Another participant with acute illness stated, "I just stayed positive. I didn't care what anybody else said. I'm going to make it through this. That's what I was going to tell everybody" (Lower-PTG participant).

The second category in Coping Strategies was Resources / Support. Participants

who endorsed this category described getting support from social service organizations.

One participant described how people from her substance abuse treatment program

supported her during her mother's illness and death, "We pulled the cord on her. People

from AA, my sponsor, and different people at rehab were at the hospital with me. We

said a prayer and then we pulled the cord on her" (Higher-PTG participant). Another

participant explained how a support group assisted him in learning how to cope:

It was a number of things, because I was in a support group, and that's going back to people. I had a lot of people to help me. I started learning how to talk about my feelings. I started reaching out and saying I can't do this anymore I need help. (Higher-PTG participant)

Finally, another participant described how she utilized social services and the emotional support of her sister to get out of a domestic violence situation:

So, I just got connected. Well, it seems like I was always attracted to the wrong man. He would end up being just like the one I had before. I had my sister and I talk to her a lot about it. She was like, this man ain't right. You need to just leave

him alone. So, I talked with my sister and I had to get the system involved. That's how I coped with that. I had to get the system involved to get him out of my life. (Lower-PTG participant)

The third category in *Coping Strategies* was Spirituality. In some of the dimensions in this category, participants described their religious beliefs as a source of strength. One participant explained, "I got to the point that I didn't even like myself. I've had more, I felt like I deserve more, and I wanted more. I got on my knees and I prayed for God to help me" (Higher-PTG participant). The same participant described surrendering to God in order to cope with the death of her mother, "Well, I prayed, and I left it up to God. I asked Him to guide me. I know that He's not going to fail me. I just asked Him to lead and guide me. I just surrendered my whole self" (Lower-PTG participant). Another participant described his spirituality:

Really I think, what helped me was my deep rooted spirituality... Because no matter where I went or how far down I got, there is always something. Something inside of me...I had to get back up. Even though, I tried to do away with my life, God didn't want me to leave here. (Lower-PTG participant)

Another dimension of the Spirituality category entailed a participant coping with the religion of his family and comparing that to his different sense of spirituality. One participant explained that he became aware of the differences between his spiritual beliefs and those of his family when he was recovering in the ICU from an acute medical illness, and he believed that he would die without medical intervention:

I remember my aunts coming to see me. I had this one aunt who would come in there, and she was trying to tell me that they should take all of this stuff off of me, and that I don't need that blood. All of that junk. I was looking at her like, "What? Are you insane?" I guess she was some kind of Christian Scientist, or some junk like that. They don't believe in medical stuff like that... So, I think that your religion is a little far fetched on that side. You have to have a little more science than that. Like her, where does the science come in?... For them, God is the science. (Lower-PTG participant) The second theme in the "*Other Stressful Experiences*" section was *Negative Life Experiences*, which was endorsed by 10 participants. The first category in this theme was Stress, in which participants described other non-HIV-related stressful events and gave the events a stress rating on a 10 point scale. Of the 14 participants who reported experiencing a non-HIV-related stressful event, only nine of the participants elaborated on the stressor in a manner that would allow their responses to be included in this category. Many of the participants reported a rating of the stressor on a 10 point scale, with 1 meaning low stress and 10 meaning high stress. Seven of the participants rated the non-HIV-related stressor at a level of 7/10 or higher, one participant rated the stress as a 5/10, and one participant rated the stress as a 2-3/10. In addition, the participants described many different types of stressors including the death of a loved one, acute medical illness, divorce, sexual assault or abuse, and domestic violence.

The second category in *Negative Life Experiences* was Negative Feelings / Reactions. This category described specific negative emotions that the participants experienced in response to the non-HIV-related stressor. One participant described grief and loss after the death of his cousin, "My cousin was killed in Vietnam and that really hurt because he was more than a cousin. He was like my brother. He was a friend. He was everything" (Higher-PTG participant). Some participants reported emotional numbness as a response to grief, "Oh yeah, then I was just out of my head. I was just numb. I didn't know whether to cry or to laugh. I was just there I just existed. It was really hard to accept, really hard" (Higher-PTG participant). Another participant reported that the seriousness of her cancer did not hit her until after she cried, "Well, after I got all of my crying out and everything, it just really hit me how serious it was" (Higher-PTG participant).

The third theme in the "*Other Stressful Experiences*" section was *Interactions with Others*, which was endorsed by seven participants. *Interactions with Others* was divided into two categories. The first category, Family, is based on participants' descriptions of how their family members were involved in their non-HIV-related stressors. One participant recalled his mother's assisting him to understand his acute illness:

She took everything off, the gown, the gloves everything. They told my mom that I was on my death bed. I had an IV. When I was told that there, [about being on his death bed] that was when the whole thing really hit. (Higher-PTG participant)

Another participant described his non-HIV stressor as watching his father develop

Alzheimer's dementia and pass away:

My father who was living had passed away. He developed Alzheimer's and during that time I had to take care of him so that was an enormous stress. I saw a healthy man go down, have strokes, be in and out of the hospital. (Higher-PTG participant)

Another participant described her other stressor as death and illness of family members.

She spontaneously mentioned the death of her brother from AIDS-related complications,

even though she was asked about other stressors not related to HIV, "My brothers dying.

I have two brothers who died. One from the overdose of drugs and the other from the

AIDS. And now my mom, she has Alzheimer's now, and is sick and had a stroke"

(Lower-PTG participant). Finally, one participant described her family as being a source

of strength and support during a difficult time, "My brother, bless his heart and may he

rest in peace, he passed away a year ago from cancer. He was my hero because he was right there every day" (Lower-PTG participant).

The second category in *Interactions with Others* was Interpersonal Relationships, which included the reactions to the non-HIV stressor by other people in the participants' lives. This category had two dimensions: positive or negative reactions from other people. One participant explained that interacting with others while she had cancer helped her to cope:

I mean, here's people that's in worse shape than me and if they can deal with it then I can too. Then, I would sit up and try to laugh and talk and keep people, and I do that everywhere that I go, even with the drivers that come to pick me up to take me to the doctors' appointments. (Higher-PTG participant)

Some of the participants explained that other people were not helpful or supportive

during stressful times. One participant explained, "I knew I was still surrounded by all

kinds of negative people... Because I was isolated all by myself and I felt so alone, like

nobody didn't care or love me in the world" (Lower-PTG participant). Another

participant reported that people who he helped in the past would not repay his kindness:

You ask for help from all of these people who you thought were your friends. And they're not your friends... All the people you bought dope for, all the people who you bought a six pack for, all the people who you let lay up in your house and smoke and fuck, and suck and lay with women and lay with guys. It didn't mean a damn thing. (Lower-PTG participant)

The fourth theme in the "Other Stressful Experiences" section was Health /

Treatment / Intervention, which was endorsed by six participants. Health / Treatment /

Intervention had one category, Health / Treatment / Intervention. The dimensions of this

category included descriptions of acute illnesses that were identified as the non-HIV

stressor, the treatment of these illnesses, or somatic responses to the non-HIV stressor.

Some of the participants identified acute illness as their primary non-HIV stressor. One participant reported having meningitis as his non-HIV stressor, "I went to the hospital and they didn't do crap for me, so I went home. And then Tuesday night, the next night, I went back there and that's when they found out that I had spinal meningitis" (Higher-PTG participant). Another participant identified cancer as her non-HIV stressor.

It had already started into the second stage. So, I had probably been in the first stage for a while in that year between tests. So then he started telling me that it went into the second stage and then he sat me down and was telling me the same four stages again, and the seriousness of it. I guess right then was when it really hit me. And it hit me. I'm talking about that I was sitting there in that office and I cried. I mean, it just really clicks then. (Higher-PTG participant)

Another participant identified severe appendicitis as his non-HIV-related stressor, and

also described the treatment, which involved hospitalization and a long recovery:

I had appendicitis, and almost died from that. I was positive that I was going to make it and stuff like that. The doctors were saying that I had a 50-50 chance of making it... He [his father] took me down to the hospital and for 3 days they could not tell what was wrong. So the guy [hospital staff] had just shaved me and they had me ready for surgery and then it just broke. I let out a big yell and he [hospital staff] said to get a nurse, doctor, or somebody. The next thing you know, I was in surgery. They took it out, and they thought they got all of the juices and all of the stuff out of me. But I guess this thing, it was lying across my intestines and had pinched them off and the muscles in that spot stayed pinched. The poison got into my intestines too and created ulcers on the outside and on the inside. (Lower-PTG participant)

For other participants, a somatic response was discussed as a result of or in reference to

their non-HIV stressor. For example, one participant developed migraine headaches in

relation to domestic violence, "I got beaten. Getting away, getting out of that, and

surviving that...And I had to go through that step and that process. It left me with severe

migraine headaches for 10 years" (Lower-PTG participant).

In conclusion, the section "*Other Stressful Experiences*" reviewed how participants coped with non-HIV-related stressors in order to compare their coping strategies to how they coped with HIV. In addition, surviving another traumatic event could put being diagnosed as HIV-positive in a different perspective than if a person never experienced other severe stressors. The personal narratives of the participants revealed a variety of events including death of a family member, acute personal illness, assault, divorce, and daily stressors of the family's schedule. The participants also varied in how similar coping with those events was to coping with HIV. The next section, "*Currently Living with HIV*" examines participants' current lives; what changes, if any, have occurred as they adjusted to living to HIV; and explores the presence or absence of PTG.

## Section Three: "Currently Living with HIV."

The seven themes that emerged in section three, the number of participants who reported them, and the categories in each theme are reported in Table 14. Each theme is described below, followed by the categories that comprise each theme, and the dimensions that help define the categories.

The first theme in "*Currently Living with HIV*" was *Coping Strategies*, which was endorsed by 14 participants. The first category in *Coping Strategies* was called Coping, which consisted of ways that participants currently cope with HIV. The Coping category has two dimensions: one cognitive and one behavioral. Many of the participants reported that adjusting the way that they think about HIV helps them to cope. Some participants reported focusing only on the positive aspects of life. One participant stated, "What you need to do is you need to take your circumstances and you need to extract a positive from what ever circumstances you are dealt" (Lower-PTG participant). Another participant explained, "Yeah, behind every cloud there is a silver lining. And I don't try to concentrate anymore on the bad, because that can honestly get you even sicker" (Lower-PTG participant). Other participants focused their attention on making each day important. One participant stated, "Before I didn't give a damn, come what may. Now each day is very important to me" (Higher-PTG participant). Another participant explained:

Every day, every breath is a blessing. From now [pause to demonstrate time passing], that time [during the pause], I can never go back to. That breath I can never go back and take again, because it's gone. You have to live with the now. (Lower-PTG participant)

Some participants reported coping by trying not to think about HIV, "Putting the fact that you have it out of your head, so that you're not thinking about it all the time, made a big difference." (Lower-PTG participant). Other participants focused their attention on how fortunate they are because others have it worse, "A lot of people, I know there are some that might have been worse off situation, than I came from." (Higher-PTG participant). Finally, some participants reported focusing only on what they can control, "Focus on reality, and don't focus on things that you have no control over." (Lower-PTG participant.)

Many participants discussed the behavioral dimension of the Coping category. Some participants reported that participating in other activities helped them cope with HIV. One participant explained, "I just do the little things that I like to do. I like growing plants. I go over to my mom's house and mess around in her flower beds. I plant her garden and trim her small trees" (Lower-PTG participant). Participants who had past substance abuse problems reported that their recovery program has also helped them cope with HIV. One participant explained, "I try to be involved, stay on the wagon. The only thing I drink now is a Pepsi and I never smoked cigarettes. Now I get high off of life" (Higher-PTG participant). Finally, some participants discussed organizing their affairs as a way of coping with HIV. One participant stated, "I don't want to be a burden on my family and I don't have any insurance. So what can you do about it? So I have it paid off now. I went and pre-paid for all of my funeral arrangements" (Lower-PTG participant). Another participant explained, "I really do focus much more on getting my house set up because I'm going to give my house to my daughter. It will be paid for and everything so that's something for her" (Lower-PTG participant.)

The second category in *Coping Strategies* was called Spirituality, which consisted of the ways that spirituality, religious beliefs, and involvement with the faith community helped the participants to better cope with living with HIV. Some of the participants explained that their belief in God has increased since they have been living with HIV. One participant stated, "Well, it made me realize that I became more spiritual... It made me do a lot of thinking about life and the meaning of life" (Higher-PTG participant). Another explained about his spirituality, "It has deepened. I have become more spiritual. That has been a healing for me" (Higher-PTG participant.)

Some participants reported that their sense of spirituality helped them to cope with HIV because it assisted them in making meaning out of being HIV-positive, or discovering a purpose behind their HIV infection. One participant explained: I equate it with a lot of times people look for their passion in life and my passion was chosen for me....You have to realize that with in every dark cloud there is a silver lining, and you have to look for the silver lining. There is a purpose for my being infected, and if that is part of the plan of the Divine Creator, so be it. Karma, maybe, call it what you will, but there is a purpose. What you need to do is you need to take your circumstances and you need to extract a positive from whatever circumstances you are dealt. (Higher-PTG participant)

Another participant stated:

From my religious standpoint, right after I got infected and a few years after I started getting out again I read the book *Purpose Driven Life*. In that book, it basically tells you that the Lord has something in store for you, and you have to go through trials and tribulations to figure out what it is. I've told everybody, even new diagnosed patients, HIV wasn't a death sentence to me, it was more like a blessing to me because it made me go out and try things that I normally wouldn't try. (Lower-PTG participant)

Some participants decided to become involved with ministry or outreach into their

community. This participant explained that his decision to go into the ministry came from

God:

It has affected some of my goals. But I believe that my goals were just what they were: my goals. They were not God's goals. I really do, I believe they were just my goals. I was like, I'm going to do this and God thought differently. My goals have changed tremendously. I did not intend to go into the ministry. If you would've told me that I would be working at the treatment center that I went through almost 9 years later, helping other addicts and alcoholics and people freshly diagnosed with HIV, I would've told you that you're crazy. (Higher-PTG participant)

For some participants, the process of working though their religious beliefs while

learning to live with HIV produced changes in how they thought about spirituality. Some

of these participants reported that keeping their sense of spirituality while maintaining

distance from the organized religion was the balance that they had chosen. One

participant stated, "I think I've been placed here to do something, but I don't think it's in

church...I talked to God all the time. I don't think you have to go to church to do that"

(Lower-PTG participant). Another participant pointed out the impact that being HIV-

positive and gay has in some church communities:

I don't go to a church because being HIV is one issue, and being gay is another issue. And the churches don't want to hear about that. So, if you can't accept me as I am then I'm not coming to your building. My faith and everything is still very strong. (Higher-PTG participant)

Some participants reported that they developed a new understanding of the divine while

trying to make sense of living with HIV. One participant stated:

You wonder why God has done this to you. Then, later on, you find that you do something, [and then] you don't even believe in it, because it's like why would somebody [God] let this happen to you? Then, it becomes a point of that you want his help so you start to talk to Him. So I say, what if God is an alien? (Lower-PTG participant)

Another participant changed religion from Christianity, which he grew up with, to

Buddhism. He explained his rationale for the switch:

I got a better sense that my religion does work, as long as you do it. Other than that, I see religion, and I always have, as control. Everybody wants to control you with the Bible, and all that. That book is about control... Buddhism is reason, and reason is what you have to have. But religion, it doesn't coincide with science. If they can't intermingle with each other, then it's not a real religion to me. I don't think that religions should be religion, they should be philosophies. It should be a philosophy that you believe in, not a religion. (Lower-PTG participant)

Finally, one participant reported that she no longer has religion in her life, "I don't

believe in God anymore" (Lower-PTG participant).

The third category in Coping Strategies was called Vocational/Socioeconomic

Status. This category had two dimensions, which consisted of participants describing the

shift they made relating to work behavior and changes in thinking about money. Some

participants reported they had stopped working since they began living with HIV. One

participant stated, "I would say the biggest, major change is from working to not

working" (Lower-PTG participant). Another participant explained that work was the area of his life that HIV affected the most, "I mean, in a way it didn't interfere with a lot except I can't work" (Higher-PTG participant). One participant explained that the economic change was one of the most stressful adjustments to living with HIV, "The biggest stress is making sure that you're monetarily able to pay your bills. That's my biggest stress right now. I've had to really learn where to go and when to go and you have to have somebody help you coordinate that" (Lower-PTG participant). Another participant reported that he wanted to find work but discrimination interferes with employment, "For such a long period the issue of disclosure was a factor because it controls employment opportunities. It limits them, it shouldn't legally, but it does realistically" (Higher-PTG participant).

Other participants described a shift in the way that they think about money. For these participants, having less cash flow taught them that they do not need many material possessions. One participant explained:

It was a shift. Materialism went out the window. I was no longer concerned with wealth, self gain, or material wealth in the way of possessions. Yes, I wanted financial security, but just enough to exist. I need my needs met, nothing lavish. (Higher-PTG participant)

Finally, another participant explained this change in the terms of a shift in values:

I was making and enormous salary and now I don't make nothing like what I used to. It was a total reality check. I'm starting to learn that my values in life have changed...I used to have money, but I found out that money doesn't bring me joy, peace, and happiness. It's good to have. I mean, I would love to have an abundance of it. But when I did have it, it didn't bring me what I have today. It sounds a little crazy because I have less than what I had then, as far as financial stuff goes, but I'm more happy and at peace. (Higher-PTG participant) The second theme in "*Currently Living with HIV*" was *Interactions with Others*, which was endorsed by 13 participants. The first category in *Interactions with Others* was called Interpersonal Relationships, which consisted of participants describing their relationships with people other than family members since they have been living with HIV. Some participants reported others in their lives responding in a supportive way. One participant explained, "Some brought me closer together because we are all in the clubs, the prayer groups, [and we] are all HIV [positive]" (Lower-PTG participant). Another participant described intense support from one person:

Well, the first person that I told was [Name deleted], and that is why I consider him to be my family and my best friend. He stuck by me and he then is the support. A moral support, an emotional supporter, he hasn't wavered. It didn't affect him or his view of me and I pulled from his strength quite a bit. (Higher-PTG participant)

Other participants described the reaction from others as more neutral. One participant reported that although he noticed a change in how his neighbors interact with him, it has not been negative. "I've been very fortunate because I have no one who has been negative [to me]. Several of my neighbors know [my HIV status]. I've been very lucky. My neighbors knew me. I never have changed. I feel like it's other people who changed, not me" (Lower-PTG participant). Another participant explained that living with HIV has affected his romantic partner, "That for me was not as bad as it was for my partner. It was worse on him" (Higher-PTG participant).

Some of the participants explained that living with HIV led them to reflect about how they treat other people in their lives. One participant explained, "I need to talk to people a little differently, and love people a little differently. (Crying) respect people a little more differently" (Higher-PTG participant). Another participant stated, "The best way to treat people is to treat them how you want to be treated" (Higher-PTG

participant).

Other participants reported a change in how they interact with others. One

participant described a shift in how he interacts with others from when he was first

diagnosed as HIV-positive, to transitioning to living with HIV:

Initially everybody walked away and closed doors but now there's no problems, none at all. We have our motto that you can't catch AIDS from hugging. If you treat it like a chronic illness, then people are more open. People used to be shutting me out but now I open the door. (Higher-PTG participant)

A few participants reported that they do not interact with other people much since they

have been living with HIV. One participant reported limiting her social life to only

certain kinds of people:

It changed because of my social life. I'm still single, I'm not married, I've never been married. My social life is now on the back burner. I've been celibate for 16 years. I got my friends. [Now] there are no men in my life. I'm not dating or anything. I'm trying to stay positive and deal with positive people. I rule out any negativity that I recognize or can find. I just rid it out. I won't allow any negativity in my home or in my life, regardless of how they feel because I don't look at that anymore. (Lower-PTG participant)

Another participant reported that she has practically isolated herself because she fears a negative response from other people, "It got worse. I just, I can't have a boyfriend. I don't want people to know. People that do know turned their backs on me. So the way I changed is that I just stay to myself in my house" (Lower-PTG participant). One participant explained that lifestyle changes led to him to not socialize as much as he used to, "I really don't go out and see people anymore because I don't go to the bars. I quit drinking, so there's no need for that anymore. I don't just run around and have conversations with anybody" (Lower-PTG participant). Finally, one participant reported

that he does not have contact with his friends because of their health conditions, "You know, most of the friends I had now they're dead or dying. If they are still alive and I don't see them too often but I hear they're good" (Higher-PTG participant).

The second category in *Interactions with Others* was called Family, which consisted of how participants interacted with their families after being diagnosed as HIVpositive. This category had dimensions of feeling closer to family, leaving a positive legacy for children, and continued negative reactions of family. Many of the participants described more positive interactions and becoming closer to their family since living with HIV. One participant explained the process:

You know what, they have become more valued. Whereas, I'm closer to my loved ones, to my family. I have more compassion. I have more unselfishness. I think before my attitude was that I love them. I care for them, they were my family and my people, but what can you do for me? In this sense, if I do this for you then you should do something for me. Now my compassion has changed and I really value the time that I have with them. I like talking with them, I like being with them and they like being with me. They've seen a tremendous change in my life and they like me [laughs]. They've seen me grow. Whether I knew it or not, because I didn't know, they noticed the change. (Higher-PTG participant)

Another participant explained that he feels close to his family and even though they do

not openly discuss his HIV status, he believes he educates his family about HIV:

While we were always a close knit family, very close, I think we're closer now. We have become a lot closer pretty much. Everybody in my family knows about it and while we don't talk about it very much they don't look at me sideways either. They're not scared to touch me or hug or kiss me. It's not that [pauses as if thinking], it brought us closer together as a family and I think, in some sense, I educate my family about it better. You can hear about it all the time but it never affects you until it hits home. (Lower-PTG participant)

Some participants reported that their children give them continued meaning in life

and hope. One participant stated, "My purpose in life, I guess, is to... basically leave

some type of positive legacy for my kids" (Lower-PTG participant). Another participant

stated, "So now, anymore, I concentrate on my daughter, my home, and concentrate on the future knowing that my daughter is going to have a future. That's kind of what keeps me going" (Lower-PTG participant).

Some of the participants reported continued negative interactions with some family members. One participant stated, "There's one of my nephews who just can't deal with me. He stereotypes me and just, it's sad. Well, I think that had been hidden in the closet and just hasn't gotten out there yet" (Lower-PTG participant). Another participant explained, "I had a couple of family members that ran the other way. Even to this day, I have one brother whose children are not allowed within 10 feet of me, even now" (Higher-PTG participant). Finally, one participant explained that HIV had affected his family almost like a penalty, "No, I have discovered no meaning. It was just like maybe a punishment, but you know, my wife died. And why should she get punished? It was like her punishment, so I don't know" (Higher-PTG participant).

The third category in *Interactions with Others* was called Disclosure, which consisted of what participants think about sharing their HIV status with others, now that they have been living with HIV. For some participants, disclosure was seen as part of a larger solution for HIV awareness. One participant explained:

Disclosure is not an issue to me, to be a voice for a voiceless sector of our community....You can't hide your identity. The community of HIV-infected individuals needs a voice.... It made me have the decision to think about [whether or not to disclose my HIV-status]. Disclosure is fine and anonymity is not and I'm going to help. I've always been a believer that if you're not part of the solution you're part of the problem. I just wanted to be part of the solution. You can't be part of the solution if you remain anonymous. (Higher-PTG participant)

For other participants, disclosure is not as much of an obstacle as it used to be. One participant stated:

Although it has a lot of stigma with it, I don't think that it's as bad. Only because, and I'm not saying that you can write it on your shirt or go out and tell everybody in the world that you're positive, but its not as bad of a death sentence as it used to be. (Lower-PTG participant)

Some participants explained that disclosure happens on a need to know basis. One

participant stated:

One was a neighbor and it was his brother and he called me up and asked me about it [HIV status]. I told them yeah it's true. He said that he just wanted to know in case there was some kind of emergency. (Lower-PTG participant)

Finally, another participant described the potential limits to confidentiality with disclosure, "[When] dealing with HIV, disclosure there is so much more than that. I've learned that it's more than just telling one person" (Lower-PTG participant).

The third theme in "*Currently Living with HIV*" was *Health / Treatment / Intervention*, which was endorsed by 12 participants. The only category in *Health / Treatment / Intervention* was called Health / Treatment / Intervention, which consisted of information about symptoms, illnesses, medication, and the treatment process that the participants have experienced since they have been living with HIV. This category produced three dimensions: healthcare services, medication strategies and side effects, and other illnesses.

Many of the participants discussed the process of obtaining healthcare services, such as physician appointments. One participant explained, "So the main thing is to get a good health provider that does both your general health and your HIV health. I have a doctor who does both. So I don't need to take out 2 visits" (Lower-PTG participant). Another participant explained his general strategy for health since he has been living with HIV: Following up on doctors' appointments, making sure that I take my meds, I really try to be conscious about taking my meds. Just being healthier if I have a choice. If I can find a product that offers a little bit of help towards better immunity, I think I do better. You really have to start and be aware of your health. To take it upon yourself, because even with doctors it's still an assembly line process. You're in, they check you for this, this is the symptom, this is the diagnosis. It might not even be anything like that, but you have to be proactive toward your health. (Lower-PTG participant)

Other participants discussed their strategies for taking HIV medication and medication

side effects. One participant explained, "All of the pills that I took, I would just think of

them as vitamins" (Higher-PTG participant). Another participant reported this strategy

for taking his medication:

Taking all the pills themselves. I was frustrated. Taking the pills and stuff. I said, "I don't like taking these pills," so I cut down. Then I put them in a pillbox that had each day on it. That kind of wore me out. I have to take these the rest of my life. I have them lined up. I tell my friends I had to take my pills, and I can take them like eating Skittles [Candy]. (Lower-PTG participant)

Other participants reported experiencing troublesome side effects from their HIV

medication. One participant explained, "Yeah was helpful, but that's a medication now

that's giving me trouble" (Higher-PTG participant). Another participant explained that

the medication side effects are the worst part about being HIV-positive:

My only problem is the side effects from the medication. My neuropathy and that kept getting worse and worse over time. The pain from the stupid neuropathy, that is what drives me nuts and I wish I could just make it go away. I could just chant one time and make it all go away. Then I wouldn't feel any of this pain anymore, because I can't do what I used to do. That's kind of depressing to me but I got to just live with it. (Lower-PTG participant)

Many of the participants reported having other medical conditions in addition to

HIV. Examples include diabetes, high blood pressure, stroke, fatigue, mobility problems,

renal disease, and dental problems. One participant explained, "I now have full-blown

AIDS, but my counts are not detectable and I'm doing great. The biggest issue I have now

is my blood pressure and weight. My HIV is not an issue today" (Lower-PTG participant). Another participant reported, "The diabetes is actually the cause for me to go on disability, not the HIV. HIV truthfully, has not been a reason" (Lower-PTG participant). Finally, many of the participants reported that they do not think of HIV as a terminal disease because they are getting good medical care. One participant stated, "HIV is not going to kill me. HIV is not a death sentence. It was at first, and they were dying because they did not get detected early enough. Now we're getting detected earlier. So we're getting better healthcare" (Higher-PTG participant). Another participant explained, "Then, of course, when you found out that it was no longer a death sentence then you can get up and do something. Then that was a big weight lifted instead of sitting around and just waiting" (Lower-PTG participant.)

The fourth theme in "*Currently Living with HIV*" was *Negative Life Experiences*, which was endorsed by 11 participants. The first category was called Stress, which consisted of descriptions of how stressful the participants thought it is to be living with HIV and other issues that are currently stressful in their lives. Many of the participants reported a rating of the stressor on a 10 point scale, with 1 meaning low stress and 10 meaning high stress. Only one participant rated the stress for currently living with HIV as 10/10. Seven of the participants rated the stress from living with HIV at a level of 5/10 or lower. One participant explained, "Living with HIV is not stressful. Dealing with the system is stressful. Dealing with the welfare. Dealing with the discrimination. Dealing with the process of getting what you need and when you need it." (Lower-PTG participant). Another participant explained:

Today, when I get stressed it's not because of my disease, it's because of something my kids have done, or my husband has done, or a test at school that I'm cramming for and I'm all out of whack about. (Lower-PTG participant)

The second category in *Negative Life Experiences* was called Negative Feelings / Reactions, which consisted of specific negative emotional reactions that participants reported related to currently living with HIV. Some participants expressed fear. One participant explained, "It's painful to think about HIV. We're all going to die, but it just brings that to the forefront. Maybe that's a good thing, because I'm living with in that moment. I was so scared of dying" (Higher-PTG participant). Another participant stated, "If I get cut and I was out somewhere, then I get kind of scared a little bit. Sometimes I'm clumsy" (Lower-PTG participant). Other participants reported feeling as if their life was over after HIV, "Initially, I felt like I didn't have one [a life]. And in 2000 is when I totally collapsed and could not work anymore" (Higher-PTG participant). One participant reported feeling bad about herself, "What did I discover about myself? That I was stupid...I could have avoided it all by using protection" (Lower-PTG participant). Finally, one participant described the frustration he experiences because of his neuropathy:

All of these little things with my hands, like I build puzzles but I can only do them for so long because of my hands. I can't hold or turn over the pieces sometimes. It gets frustrating because I can't stand there, and I can't sit right. (Lower-PTG participant)

The third category in *Negative Life Experiences* was called Negative Societal Reaction, which consisted of descriptions of negative reactions in the community toward people living with HIV, which the participants have noticed since they have been living with HIV. One participant explained, "HIV is not as bad as it was before, but it still carries a stereotypical thing in the community" (Higher-PTG participant). Another participant stated, "Right, how they perceive you changes. Now all of a sudden you've got cooties" (Lower-PTG participant). One participant described continued discrimination within the medical community, "Some nurses don't [resist discriminating]. There is still a hidden discrimination. Some nurses come to me, and they probably don't mean nothing by it, but they ask, 'how did you contract it?'" (Lower-PTG participant). Finally, one participant described how he deals with reactions from the community, "Initially I couldn't tolerate the prejudices, but now I am much more tolerant because I try to look at it from their point of view and see why are they feeling the way they are to make them react the way they are" (Higher-PTG participant).

The fifth theme in "*Currently Living with HIV*" was *Personal Transcendence*, which was endorsed by nine participants. The *Personal Transcendence* theme is unique to the "*Currently Living with HIV*" section, and it captures descriptions of the participants surpassing previous levels of thinking and behaving to adapt to living with HIV. The first category in *Personal Transcendence* was called Altruism, which consisted of descriptions of the participants reaching out or volunteering within their community. Many participants reported that helping others is therapeutic for themselves. One participant explained:

The meaning is that so much of the time human beings are caused to hold secrets and not show their true selves and we get caught up in trying to obtain material wealth and stature in our lives for recognition and what have you. That's not the true meaning of a successful life. It's basically making a positive beneficial impact on other people's lives around you that gives your life meaning. And to watch those people progress and develop into productive citizens and continue that theory. It's just a growing process. It's like planting a seed and watching it grow. (Higher-PTG participant)
Another participant stated, "That's what makes me happy, doing things for other people.

It helps me in return, not that I expect anything" (Lower-PTG participant). One

participant explained that helping others in the community is new for him:

Yeah, because I used to take from the community, and now I'm putting back into it. That's another flip the script. I guess you call me an advocate, but I don't even call me an advocate. I would just call myself a person who cares. (Higher-PTG participant)

Finally, one participant described how volunteerism enhances her coping with HIV:

I help out with the homeless shelter, I do baking and cooking for that every month. I'm always active doing what I can. That's my biggest thing, that's what helps me. What helps me cope with having AIDS is that I help others. Talking to someone every day on the phone, giving counsel to them. Someone who just got newly diagnosed, being a peer person to them. (Lower-PTG participant)

The second category in *Personal Transcendence* was called New Attitude, which

consisted of descriptions of how participants changed their thinking as a result of learning to live with HIV. Many participants who endorsed this category described being thankful for each day. One participant stated, "I mean, just the fact that, just make the best out of every day. The fact that I am still living and not sick...because I have other conditions not related to this and I'm not sick" (Lower-PTG participant). Another participant reported wanting to try new things, "Now the sky is the limit and I'm going to reach for it. I'm open to do any- and everything. My whole outlook today is that I live each day as though it was my last" (Higher-PTG participant). One participant explained that being near to death helps him to appreciate life, "A lot [changed] because knowing that I'm not going to die, going through the period where I thought I was going to, and now that I'm not I cherish every minute" (Higher-PTG participant). The participants who endorsed this category also reported having a new attitude toward other people. One participant

stated:

I may have a little more compassion now, and a little more understanding about other people's situations... I've always been a compassionate person, but now I think I'm more compassionate, and things that used to piss me off I can just push them aside. I don't do [get angry easily] anymore. (Lower-PTG participant)

Finally, one participant reported:

I don't try to hold no grudges anymore. Things that I used to fall out with a person about, things they would say or do, and I would be mad at them forever. I don't even let it make me mad at all anymore. (Higher-PTG participant)

The third category in Personal Transcendence was called Education, which

consisted of participants making efforts to educate their community about HIV. One

participant explained:

I've told everybody, even newly diagnosed patients, HIV wasn't a death sentence to me, it was more like a blessing to me because it made me go out and try things that I normally wouldn't try. I have a story to tell to other young girls who are on the same path that I was on. It opened up by eyes to a lot of things and it made me realize that, yeah, between 15 and 21 you get to have a whole bunch of fun but at the same time you could be actually destroying what you have as an adult because you're focusing so much on those years. I guess that would be it, it helped me stay focused and my purpose is that I have been taking a lot of young girls under my belt. (Lower-PTG participant)

Another participant explained that he has been able to help others with HIV after learning

more about it himself:

I educated myself, and helping other people helps the patient themselves. So I try to get all of our patients involved one way or another. I have them doing group projects, or whatever, so they're not sitting at home thinking about 'poor me.' (Higher-PTG participant)

Finally, one participant explained that one of his new goals has been to educate his

community about HIV, "Goals to strengthen education with regard to transmission,

outreach and education, and making available information as far as services available to individuals" (Higher-PTG participant).

The sixth theme in "Currently Living with HIV" was No Change, which was mentioned by six participants. This theme consisted of one category, No Change, which described a feeling that certain areas of their lives have not changed since they have been living with HIV. Some participants described a global feeling of not experiencing change. One participant stated, "I'm not that different. Nothing is different other than I take my medicine every day" (Higher-PTG participant). Other participants reported no change in their sense of community. One participant stated, "My community, well, I don't think it has. I mean, I'm social, everybody knows me. And shovel snow for people is things I [sometimes] do. I talk to people, nothing changed as far as my social life goes" (Lower-PTG participant). Some participants reported no change in their appreciation for life, "You know, nothing changed in that sense, I mean anybody could die at any time" (Higher-PTG participant). Another participant reported no change in his values since he has been living with HIV, "I still have the same values in that I believe that anybody shouldn't kill anybody" (Higher-PTG participant). Finally, one participant reported no change in meaning for living with HIV, "Meaning? There's no meaning to any disease. What does it mean to you? The disease is very meaningful to the virus itself. You are their most important thing, and that's what they need, a host" (Lower-PTG participant).

The seventh theme in "*Currently Living with HIV*" was *Reflecting on Life*, which was endorsed by five participants. The first category in *Reflecting on Life* was called Concerns for the Future, which consisted of participants describing planning for or

thinking about the future. One participant described planning for his estate for his daughter:

I try to let things be known, and I need to finish out getting a will, that is a very important thing. You've got to start and plan for when you're not going to be here. You definitely realize that you have a finite point but I think a lot of people think that they're infinite...I have set down to organize a lot of things, so that if something occurs, which is my demise, so that what I have goes to who I would like to have it. Being able to show my daughter things [about my wishes]. (Lower-PTG participant)

Another participant explained the difficulty in thinking about the future because he was

unsure about surviving, "To tell you the truth, I haven't done anything 'cause I'm

thinking, what will happen to me. I don't know if I'm going to live or die. I really don't"

(Higher-PTG participant). Finally, another participant explained that he did not feel like

he could make new goals for the future, "I guess I can't have a house and I can't own

nothing. I have no goal to get a better car [laughs], maybe just a better bicycle" (Lower-

PTG participant).

The second category in Reflecting on Life was called Nostalgia, which consisted

of participants focusing on aspects of their lives before they were HIV-positive. One

participant explained:

Oh, I was wild and crazy. I used to make people laugh and do crazy stuff... They are like, 'wow this guy is different.' And I am different. I'm not wild like that, running the streets. I'm more grown-up than a youngster. (Higher-PTG participant)

Another participant explained that he had a different way of thinking about life after he

got out of prison and before he was HIV-positive:

I was in prison, I've been out of prison since 1999. I did 10 years before that. Once I got out of prison I was just footloose and fancy free. I didn't care about nothing, I didn't care about nobody. I didn't care if nobody cared that I didn't care. (Lower-PTG participant) In conclusion, the section "*Currently Living with HIV*" examined participants' everyday lives to assess whether the participants reported changes consistent with PTG. Many of the participants reported continuing efforts at coping and concerns about healthcare, vocational issues, and interpersonal relationships. Some participants continued to report negative experiences and stressors related to living with HIV. Other participants explained that their lives had taken on new meaning focusing on helping others. Finally, some participants stated that their lives had not changed very much since living with HIV.

#### *Core Category.*

The final stage of grounded theory analysis is selective coding. In the selective coding stage, the researchers are supposed to generate a "core" category that integrates all of the other categories derived from the data (see Figure 1). This core category is intended to be reductionistic and create "an explanatory whole" or a description of the data in narrative form (Strauss & Corbin, 1998, p. 146). First, the team made an effort to examine the categories and themes specifically across and within the 3 sections of the interviews (i.e., "The past and HIV," "Other stressful experiences," and "Currently living with HIV."). Given the similarity of categories and themes in all 3 sections, which appeared to closely reflect the content of the interview questions and not the spontaneous responses of the participants, no consensus on a meta-level core category could be reached. Second, it was speculated that the factors of PTG could have emerged as core categories. However, given the qualitative similarities between the higher- and lower-PTG groups in their endorsement of categories, no pattern materialized that resembled

PTG. Therefore, although the research team attempted to complete the selective coding step, the data from the current study did not generate a core category

## Answering the Research Questions

In this section, the research questions are answered with information gleaned from the quantitative and qualitative results, and the questions are additionally informed by the parallel analysis discussed in the next paragraph. Because the information necessary to answer the research sub-questions (e.g., *Question 1A, Question 1B*) came from multiple sources within the data analysis, the main research questions (e.g., *Research Question 1*, *Research Question 2*) are answered first in order to assist the reader. During the writing of the Results it was discovered that some of the research sub-questions are redundant based on the data used to answer those particular sub-questions. To keep the reader oriented, the redundant research sub-questions will be stated in their original order; however, the reader will be referred to the sub-question where the relevant data were originally presented (e.g., Question 1C, Question 2C). In addition, some of the subquestions (i.e. Question 1F, Question 2K, & Question 3F) served as comparisons between the higher- and lower-PTG groups, within the context of the main research questions (e.g., *Research Question 1, Research Question 2*). To keep the comparisons within the proper context, the answers to the comparative sub-questions are presented along with the content to which the sub-question is referring (e.g., providing information to answer *Question 1A* and *Question 1F* in the same paragraph).

Originally, the principal investigator thought that the research questions could be answered by examining the core category and themes that were generated through the grounded theory analysis. However, because there were few qualitative differences between the higher- and lower-PTG groups based on the rate of category endorsement by each group, and no core categories formed, the research team conducted a parallel phase of analysis in order to gather information to address some of the research questions. During the parallel analysis process, answers to each interview question from the original transcripts were summarized, the concepts (see Figure 1) generated in the qualitative analysis were reviewed, and then this information collectively informed the answers to some of the research questions. This additional step was necessary in order to develop an alternative way to address some of the research questions of this study, which would have gone unanswered using the results of the grounded theory analysis alone.

#### Research Question 1: Precursors for Posttraumatic Growth

How have the precursors for PTG proposed by Tedeschi and Calhoun (2003) been experienced by PLWHA? Tedeschi and Calhoun identified many conditions necessary for PTG to develop including: having a traumatic experience that is severe enough to challenge previously held assumptions about the world, being able to manage distress, disengaging from previously held goals, the distress persisting for some time, and creating new personal narratives to accommodate the new traumatic information. Information from the section "*The past and HIV*" was used to answer *Research Question 1: Precursors for Posttraumatic Growth.* 

*Question 1A:* In what way, if any, has HIV-related trauma challenged previously held beliefs (i.e., beliefs about life, self, or others) in PLWHA? (Precursor of PTG; Tedeschi & Calhoun, 2003)

*Question 1F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the precursors of PTG (Tedeschi & Calhoun, 2003)?

Addressing *Question 1A* and *Question 1F*, there was significant variation among participants in the degree to which being diagnosed as HIV-positive challenged previously-held beliefs. Some of the participants reported there was no change or no challenge to beliefs (5 participants; 3 higher-PTG, 2 lower-PTG). There were participants in both the higher-PTG and lower-PTG who reported developing a negative outlook (2 participants; 1 higher-PTG, 1 lower-PTG) and becoming aware of stigma (2 participants; 1 higher-PTG, 1 lower-PTG). Participants with higher-PTG reported becoming more spiritual (1 participant), questioning God (1 participant), and becoming less materialistic (1 participant). Participants with lower-PTG reported questioning authority figures (1 participant), having people turn against them (1 participant), and becoming more selective about disclosing one's HIV status (1 participant).

*Question 1B:* How were PLWHA able to manage any distressing emotions brought on by HIV-related trauma? (Precursor of PTG; Tedeschi & Calhoun, 2003)

*Question 1F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the precursors of PTG (Tedeschi & Calhoun, 2003)?

The data used to answer *Question 1B* can also be used to answer the redundant *Question 2D*. In reference to *Question 1B*, the participants reported how they attempted to manage distressing emotions. Some participants identified adaptive coping strategies including planning what to do, seeking social services or social support, engaging in

activities, and turning to spirituality. Other participants described various emotional reactions including numbness, yelling, and crying. A few participants acknowledged maladaptive strategies including illicit drug use, social isolation, and ignoring their stress. *Question* 1F further breaks down how participants chose to manage distressing emotions and the number of participants who chose each method. To answer *Question* 1F, participants from both higher- and lower-PTG reported relying on maladaptive strategies including using illicit drugs (5 participants; 3 higher-PTG, 2 lower-PTG) and social isolation (3 participants; 2 higher-PTG, 1 lower-PTG), as well as emotional reactions (5 participants; 1 higher-PTG, 4 lower-PTG). The higher-PTG participants reported the coping strategies of planning and engaging in activities (2 participants). The lower-PTG group identified seeking social services of social support (4 participants) and turning to spirituality (3 participants).

*Question 1C:* How long did the distressing emotions, from the HIV-related trauma, endure? (Precursor of PTG; Tedeschi & Calhoun, 2003)

*Question 1F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the precursors of PTG (Tedeschi & Calhoun, 2003)?

The data used to answer *Question 1C* can also be used to answer the redundant *Question 2C*. To address *Question 1C*, the participants reported the length of time they felt distress after their diagnosis. Six of the participants reported experiencing acute stress for less than one year after diagnosis. Another six participants reported experiencing stress for 1-5 years. One participant reported experiencing stress for over 10 years. Two participants reported that they are still experiencing acute distress today (one participant

HIV+ for 13 years, other participant HIV+ for over 20 years). One participant did not answer the question, even after redirection by the researcher. To answer *Question 1F*, four of the participants with higher-PTG experienced acute stress for less than one year, two participants reported stress for 1-5 years, and two participants reported stress for more than 10 years (Table 15). The lower-PTG group had four participants reporting stress for 1-5 years, one participant reporting continual stress, and two participants reporting stress for less than one year. One participant from the lower-PTG group did not answer the question, even after redirection from the researcher (Table 15). In addition, there was a difference in the number of years that participants in each group have been HIV-positive, with the higher-PTG participants being HIV-positive longer (M = 14.25years) than the lower-PTG participants (M = 10.29 years).

Table 15.								
Duration of Stress after HIV diagnosis- by PTG Group (n=16)								
PTG group	Years:	< 1	1-5	>5	<b>Continual Stress</b>	No Response		
Higher-PTG		4	2	2	0	0		
Lower-PTG		2	4	0	1	1		

Question 1D: In what way did PLWHA disengage from previous (i.e., pre- HIV

diagnosis) goals? (Precursor of PTG; Tedeschi & Calhoun, 2003)

Question 1F: What are the differences between those who report higher or lower

levels of PTG in their responses to the questions regarding the precursors of PTG

(Tedeschi & Calhoun, 2003)?

To address Question 1D and Question 1F, participants reported whether finding

out they were HIV-positive affected their goals in life. Most of the participants explained

that becoming HIV-positive did affect their goals, with 12 participants reporting a change in their goals after becoming HIV-positive (6 higher-PTG, 6 lower PTG). Four of the participants reported no change in life goals (2 higher-PTG, 2 lower-PTG). Specific details about how the goals changed are provided in a later section (*Question 3D*) of the results section.

*Question 1E:* How was the PLWHA able to construct a new personal narrative of his or her life, post-HIV diagnosis? (Precursor of PTG; Tedeschi & Calhoun, 2003)

*Question 1F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the precursors of PTG (Tedeschi & Calhoun, 2003)?

In response to *Question 1E* and *Question 1F*, participants were asked in what ways their life changed after they found out they were HIV-positive and in what ways they were personally different. Six of the participants reported that their lives did not change after finding out they were HIV-positive (4 higher-PTG, 2 lower-PTG). The remaining 10 participants (4 higher-PTG, 6 lower-PTG) reported their lives did change in a number of ways including feeling devastation/depression (1 higher-PTG, 2 lower-PTG), losing a job (1 higher-PTG, 1 lower-PTG), becoming more isolated (2 lower-PTG), becoming more sexually cautious (2 higher-PTG), becoming ill from HIV or medication side effects (1 higher-PTG), losing relationships (1 lower-PTG), and becoming fearful for family members (1 lower-PTG).

In regard to whether participants felt personally different after being diagnosed as HIV-positive, 3 of the participants reported no change. Seven of the participants reported negative changes including drug use, denial, experiencing stigma or discrimination, isolation, losing a job, and becoming more negative toward life. Two of the participants reported becoming more spiritual. Other participants reported that their lives had slowed down, they became more aware of other people's needs, and spent more time with their children. One participant reported going back to college. To address *Question 1F*, both the higher- and lower-PTG groups had participants who reported no change (2 higher-PTG, 1 lower-PTG), becoming more spiritual (2 higher-PTG, 1 lower-PTG), using illicit drugs (2 higher-PTG, 1 lower-PTG), isolation (1 higher-PTG, 1 lower-PTG), and spending more time with children (1 higher-PTG, 1 lower-PTG). The lower-PTG participants reported the additional items of losing a job (2 participants), experiencing stigma/discrimination (2 participants), becoming negative about everything (1 participant), slowing down (2 participants), and going back to school (1 participant).

# Research Question 2: Perception of Traumatic Experiences

To what extent were being diagnosed as HIV-positive and living with HIV/AIDS perceived as a traumatic experience? How did these perceptions affect coping? Data from all three sections of the interviews (i.e., "*The past and HIV*," "*Other stressful experiences*," & "*Currently living with HIV*") were used to answer *Research Question 2: Perception of Traumatic Experiences*, because this question examined the perception of stress or trauma during various points in time. Data from "*The past and HIV*" were used to answer the sub-questions related to being first diagnosed as HIV-positive. Data from the section "*Other stressful experiences*" were used to address the sub-questions that were related to whether the participants experienced other traumas in their lives that were not HIV-related and how the participants perceived these events. Data from the section

*"Currently Living with HIV"* were used to answer the sub-questions that were related to living with HIV today.

*Question 2A:* To what degree do PLWHA perceive being diagnosed as HIV-positive as a traumatic experience?

*Question 2B:* If being diagnosed as HIV-positive was a traumatic experience, what was the intensity of this traumatic experience?

*Question 2K:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the perception of HIV as a traumatic event and the affects on coping?

In reference to *Question 2A*, 10 of the participants reported that finding out they were HIV-positive was a traumatic experience. The remaining six participants reported that finding out they were HIV-positive was stressful, but their stress significantly improved when their health improved. In reference to *Question 2B* and *Question 2K*, participants were asked to rate their stress on a 10-point scale, with one being low stress and 10 being high stress. More than half of the participants rated their stress as 10/10 (9 participants; 6 higher-PTG, 3 lower-PTG), 4 participants rated their stress as 7-9 (all lower-PTG), and three rated their stress at five or below (2 higher-PTG, 1 lower-PTG) (Table 16).

Table 16. Stress Rating of HIV diagnosis on 10-Point Scale - by PTG Group (n=16)								
PTG group	Rating:	$\leq 5$	7-9	10				
Higher-PTG		2	0	6				
Lower-PTG		1	4	3				

*Question 2C:* If being diagnosed as HIV-positive was a traumatic experience, what was the duration of this traumatic experience?

*Question 2C* was determined to be a redundant question, and therefore the data were used to answer *Question 1C*. Please refer to *Question 1C* above for a detailed account.

*Question 2D:* If being diagnosed as HIV-positive was a traumatic experience, what types of strategies have PLWHA used to cope with this traumatic experience?

*Question 2D* was determined to be a redundant question, and therefore the data were used to answer *Question 1B*. Please refer to *Question 1B* above for a detailed account.

*Question 2E:* To what degree do PLWHA perceive living with HIV/AIDS as a traumatic experience?

*Question 2F:* If living with HIV/AIDS has been a traumatic experience, what has been the intensity of this traumatic experience?

*Question 2K:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the perception of HIV as a traumatic event and the affects on coping?

In reference to *Question 2E* and *Question 2K*, 10 of the participants reported that living with HIV is a stressful experience (4 higher-PTG, 6 lower-PTG). The remaining six participants reported that living with HIV is no longer stressful (4 higher-PTG, 2 lower-PTG). In reference to *Question 2F* and *Question 2K*, participants were asked to rate their stress on a 10-point scale, with one being low stress and 10 being high stress. Two participants rated their stress at a high level of 10/10 (1 higher-PTG, 1 lower-PTG), half of the participants rated their stress at a moderate level of 4-6/10 (8 participants; 3 higher-PTG, 5 lower-PTG), and six participants rated their stress at low level of 0-2/10 (4 higher-PTG, 2 lower-PTG) (Table 17).

Table 17.								
Stress Rating of Living with HIV on 10-Point Scale - by PTG Group (n=16)								
PTG group	Rating:	0-2	4-6	10				
Higher-PTG		4	3	1				
Lower-PTG		2	5	1				

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*Question 2G:* If living with HIV/AIDS has been a traumatic experience, what has been the duration of this traumatic experience?

*Question 2K:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the perception of HIV as a traumatic event and the affects on coping?

To address *Question 2G* and *Question 2K*, the participants were asked about how long their HIV-related stress has lasted. Five of the participants reported that they are still in a high level of distress that has persisted since they were diagnosed as HIV-positive (5 participants; 3 higher-PTG, 2 lower-PTG). Other participants reported that their stress gradually diminished as they adapted to HIV and their medication began controlling their HIV (5 participants; 3 higher-PTG, 2 lower-PTG). Some participants were unsure about how the stress has changed or did not directly answer the question (4 participants; 2 higher-PTG, 2 lower-PTG). Finally, some participants reported that living with HIV has not been stressful at all for them (2 lower-PTG participants). *Question 2H:* If living with HIV/AIDS has been a traumatic experience, what types of strategies have PLWHA used to cope with this traumatic experience?

*Question 2K:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the perception of HIV as a traumatic event and the affects on coping?

To address *Question 2H* and *Question 2K*, the participants reported how they attempted to manage distressing emotions related to living with HIV. Participants from both the higher- and lower-PTG groups reported coping by paying close attention to their health and following their physician's instructions (6 participants; 3 higher-PTG, 3 lower-PTG), keeping busy with other tasks (5 participants; 1 higher-PTG, 4 lower-PTG), maintaining a positive attitude (5 participants; 4 higher-PTG, 1 lower-PTG), helping others (3 participants; 2 higher-PTG, 1 lower-PTG), and getting family or social support (3 participants; 2 higher-PTG, 1 lower-PTG). In addition, a participant with higher-PTG reported coping by prioritizing stressors (1 participants), getting more education about HIV (1 participant), and isolating themselves (1 participant).

*Question 21:* What other types of traumatic experiences have occurred within the lives of PLWHA?

*Question 2K:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the perception of HIV as a traumatic event and the affects on coping?

To address *Question 2I*, 14 participants (7 higher-PTG, 7 lower-PTG) identified other stressful events in their lives; two participants (1 higher-PTG, 1 lower-PTG) denied

any additional stressors or traumatic experiences. The types of experiences reported included grief/loss, divorce, personal illness, surviving assault, and a busy schedule. Regarding *Question 2K*, there was some overlap with the types of experiences reported by the higher-PTG and lower-PTG groups. Members of both groups reported events related to grief/loss (5 participants; 4 higher-PTG, 1 lower-PTG), divorce (3 participants; 1 higher-PTG, 2 lower-PTG), and personal illness (3 participants; 2 higher-PTG, 1 lower-PTG). One notable difference was that members of the higher-PTG group reported grief/loss more frequently than lower-PTG participants (4- higher-PTG, 1 lower-PTG). The lower-PTG group reported additional types of traumatic events including surviving assault (3 participants) and a busy schedule (1 participant).

Question 2J: How did PLWHA cope with other types of traumatic experiences?

*Question 2K:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding the perception of HIV as a traumatic event and the affects on coping?

If the participants reported an additional stressor or traumatic experience that was not related to HIV, then they were also asked about how they coped with that experience. To address *Question 2J* and *Question 2K*, participants reported several coping strategies including social or family support (4 participants; 2 higher-PTG, 2 lower-PTG), not knowing what to do or doing nothing (4 participants; 2 higher-PTG, 2 lower-PTG), focusing on other responsibilities (3 participants; 1 higher-PTG, 2 lower-PTG), trusting their medical care providers (2 participants; 1 higher-PTG, 1 lower-PTG), spirituality (1 participant, higher-PTG), drug use (1 participant, lower-PTG), minimizing the problem (1 participant, higher-PTG), keeping a fighting attitude (1 participant, higher-PTG), and

withdrawal from activities (1 participant, lower-PTG). To further address *Question 2J* and *Question 2K*, participants were asked how similar their coping strategy for the other stressor was to how they coped with HIV-related stress. Of the 14 participants who identified non-HIV-related stressors, seven participants reported strategies similar to coping with HIV (4 higher-PTG, 3 lower-PTG), three participants reported strategies different than coping with HIV (1 higher-PTG, 2 lower-PTG), and four participants reported an unclear relationship between coping strategies (2 higher-PTG, 2 lower-PTG).

# Research Question 3: Personal Changes Within the Five Factors of Posttraumatic Growth Since Becoming HIV-Positive

The intent of this research question was to use the model of Posttraumatic Growth (PTG; Tedeschi & Calhoun, 1996, 2004), to identify types of changes that occurred within the life of PLWHA since the time of his or her diagnosis. Information from the section "*Currently Living with HIV*" was used to answer *Research Question 3: Personal Changes Within the Five Factors of Posttraumatic Growth Since Becoming HIV-Positive*.

The participants were asked a general question about changes that occurred in their lives since they have been living with HIV to see what types of changes the participants would spontaneously report. Participants from both higher- and lower-PTG groups reported negative global changes (4 participants; 2 higher-PTG, 2 lower-PTG), a more positive attitude (3 participants; 2 higher-PTG, 1 lower-PTG), and sobriety (2 participants; 1 higher-PTG, 1 lower-PTG). The higher-PTG group reported changes related to increased spirituality (3 participants), increased community involvement (2 participants), increased openness to new things (1 participant), and decreased materialism (1 participant). Two of the higher-PTG participants reported no change in their life since they have been living with HIV. The lower-PTG group members reported changes related to a decrease in employment or financial stability (5 participants), a decrease in overall quality of health (2 participants), a decrease in social interactions (2 participants), and a decrease in anger (1 participant).

*Question 3A:* What types of changes have occurred in how the PLWHA views her or his purpose in life?

*Question 3F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding changes that occurred within the lives of PLWHA since the time of his or her diagnosis?

To address *Question 3A* and *Question 3F*, participants were asked about any personal meaning that they have discovered since they have been living with HIV. Six participants from both the higher-PTG and lower-PTG groups reported no change or no discovery of meaning (3 higher-PTG, 3 lower-PTG). In addition, participants from both the higher-PTG and lower-PTG groups reported finding meaning in HIV as part of God's plan for them (3 participants; 1 higher-PTG, 2 lower-PTG), helping others (2 participants; 1 higher-PTG, 1 lower-PTG), leaving a positive legacy for their children (2 participants; 1 higher-PTG, 1 lower-PTG). Participants with higher-PTG reported developing meaning in finding more value in life (2 participants), being a better person (1 participant), and that HIV is a punishment from God (1 participant). Participants with lower-PTG reported developing meaning in becoming a more humble person (1 participant) and that HIV has made their life much worse (1 participant).

To further address *Question 3A* and *Question 3F*, participants were asked whether their appreciation for life had changed. Most of the participants reported that their appreciation for life had changed since they have been living with HIV (13 participants; 6 higher-PTG, 7 lower-PTG). In addition, participants were asked how their priorities in life had been affected by living with HIV. Participants from both higher- and lower-PTG groups reported that their priorities had changed to focusing on family (7 participants; 3 higher-PTG, 4 lower-PTG), accepting more financial responsibility (2 participants; 1 higher-PTG, 1 lower-PTG), and not worrying about things that are outside of their personal control (2 participants; 1 higher-PTG, 1 lower-PTG). Participants with higher-PTG also reported their priorities changed to helping others in the community (2) participants), taking better care of themselves and their health (2 participants), and becoming more spiritual (2 participants). Two participants with higher-PTG reported no change in priorities. Participants with lower-PTG reported their priorities changed to better organizing their lives or personal affairs (3 participants), educating others about HIV (1 participant), maintaining sobriety (1 participant), and not being sexually promiscuous (1 participant).

*Question 3B:* What types of changes have occurred in the interpersonal relationships of PLWHA?

*Question 3F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding changes that occurred within the lives of PLWHA since the time of his or her diagnosis?

To address *Question 3B* and *Question 3F*, participants were asked about changes in their interpersonal relationships and relationships with the community. Participants

from both higher- and lower-PTG groups reported varying levels of changes in interpersonal relationships including having some people in their lives reject them while other relationships grew stronger (6 participants; 4 higher-PTG, 2 lower-PTG), developing a closer bond with only family members and not friends (3 participants; 2 higher-PTG, 1 lower-PTG), and having no change in relationships (4 participants; 2 higher-PTG, 2 lower-PTG). In addition, participants with lower-PTG reported changes regarding not trusting others after being rejected by those who were close to them (2 participants) and having friendships becoming closer, but not family relationships (1 participant).

Participants from both higher- and lower-PTG groups also reported varying levels of change relating to their interactions with the community. Half of the participants reported that they are more involved with the community including HIV-service organizations (8 participants; 4 higher-PTG, 4 lower-PTG), other participants reported no change in community involvement (5 participants; 3 higher-PTG, 2 lower-PTG), and some participant reported being less involved with the community and more withdrawn (3 participants; 1 higher-PTG, 2 lower-PTG).

*Question 3C:* What types of changes have occurred in how the PLWHA views her- or himself?

*Question 3F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding changes that occurred within the lives of PLWHA since the time of his or her diagnosis?

To address *Question 3C* and *Question 3F*, participants were asked to discuss whether they are personally different since they have been living with HIV. Participants

from both higher- and lower-PTG groups reported no personal changes since living with HIV (4 participants; 1 higher-PTG, 3 lower-PTG). In addition, participants from both groups also reported personal changes including being more compassionate toward others (3 participants; 2 higher-PTG, 1 lower-PTG), more altruistic (3 participants; 2 higher-PTG, 1 lower-PTG), more altruistic (3 participants; 2 higher-PTG, 1 lower-PTG), more altruistic (2 participants; 1 higher-PTG), feeling stronger (2 participants; 1 higher-PTG, 1 lower-PTG), and liking life more than before (2 participants; 1 higher-PTG, 1 lower-PTG). Participants with higher-PTG also reported becoming less materialistic (1 participant) and wiser (1 participant). Participants with lower-PTG reported becoming more quiet (1 participant); more cautious (1 participant); more honest (1 participant); and more socially blunt, or less likely to "sugar coat" things (1 participant).

To further address *Question 3C* and *Question 3F*, participants were asked to discuss what, if anything, they have discovered about themselves since they have been living with HIV. Participants from both higher- and lower-PTG groups reported no personal discoveries since living with HIV (4 participants; 2 higher-PTG, 2 lower-PTG). In addition, participants from both higher- and lower-PTG groups reported feeling stronger since living with HIV (2 participants; 1 higher-PTG, 1 lower-PTG). Participants with higher-PTG reported discovering that they are more spiritual (3 participants), less selfish and materialistic (2 participants), more tolerant of others (1 participant), and less likely to concentrate on negative thoughts (1 participant). Participants with lower-PTG reported varying levels of self-discovery including negative health changes (2 participants), negative self-assessments such as being "neurotic" or "stupid" (2

participants), that they still have a few good things left to offer (1 participant), and that they refuse to accept negative labels from other people (1 participant).

*Question 3D:* What types of changes have occurred in the personal goals, or dreams, of PLWHA?

*Question 3F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding changes that occurred within the lives of PLWHA since the time of his or her diagnosis?

To address *Question 3D* and *Question 3F*, participants were asked about how living with HIV has affected their goals in life. Most of the participants from both higher-PTG and lower-PTG reported that their goals have been influenced by living with HIV. Many of the participants reported change (7 participants; 4 higher-PTG, 3 lower-PTG); some of the participants reported negative changes, or they had to give up some goals (5 participants; 2 higher-PTG, 3 lower-PTG); and some participants reported no change in goals (4 participants; 2 higher-PTG, 2 lower-PTG). The new goals that were common between higher- and lower-PTG groups were getting new items (e.g., homes, appliances, cars) (4 participants; 2 higher-PTG, 2 lower-PTG) and leaving a positive legacy for their children (2 participants; 1 higher-PTG, 1 lower-PTG). Participants in the higher-PTG group reported the additional goal of community program development (2 participants). Participants in the lower-PTG group reported the additional goals of getting more education (2 participant), becoming more organized (1 participant), maintaining sobriety (1 participant), and becoming more spiritual (1 participant). *Question 3E:* What types of changes have occurred in the spirituality of PLWHA? *Question 3F:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding changes that occurred within the lives of PLWHA since the time of his or her diagnosis?

To address *Question 3E* and *Question 3F*, participants were asked about how living with HIV has affected their spirituality. Participants in both the higher and lower-PTG groups reported becoming more spiritual (8 participants; 5 higher-PTG, 3 lower-PTG), having no change in spirituality (3 participants; 2 higher-PTG, 1 lower-PTG), and having the same spiritual beliefs but no longer attending religious services (2 participants; 1 higher-PTG, 1 lower-PTG). Participants from the lower-PTG group reported more incidents of moving away from religious beliefs including questioning the nature of God (1 participant), no longer believing in God (1 participant), and becoming skeptical of Christianity and focusing on Buddhism (1 participant).

# Research Question 4: Perceptions of Quality of Life

The purpose of this research question was to assess to what extent has living with HIV/AIDS affected quality of life. This question was intended to help inform the discussion by examining alternative factors that could influence the amount of change that people living with HIV/AIDS perceive in their lives. The quantitative data were used to answer *Research Question 4: Perceptions of Quality of Life.* The data can be found earlier in the chapter in Table 6, pg. 7; Table 9, pg. 10; and Table 10, pg. 11.

*Question 4A:* How has living with HIV/AIDS affected the quality of life (QOL; i.e., perception of health and well-being) in PLWHA?

*Question 4B:* What are the differences between those who report higher or lower levels of PTG in their responses to the question regarding quality of life (QOL)?

To answer research *Question 4A*, Table 6 established the base rate of quality of life for the entire questionnaire sample. The WHOQOL-HIV BREF has facet scores that range from 4 to 20, and a total QOL score ranging from 24 to 120. For the current study, the mean facet scores for the questionnaire sample ranged from M = 13.31 to M = 15.07, with a total QOL score M = 83.16 (see Table 6, pg.7). To answer research *Question 4B*, the responses to the WHOQOL-HIV BREF from the lower-PTG group were compared to the higher-PTG group and the entire questionnaire sample. Results indicated that lower-PTG group scored below the higher-PTG group and the questionnaire sample on all domains of quality of life and the total QOL score (see Table 6, pg.7; Table 9, pg. 10; & Table 10, pg. 11). In addition, the higher-PTG group scored above the questionnaire sample on the psychological, social relationship, environment, and spirituality domains, as well as the total QOL score (see Table 6, pg. 7; Table 9, pg. 10; & Table 10, pg. 11).

## Research Question 5: Social Desirability and Reports of Posttraumatic Growth

In what way does social desirability affect reports of PTG? The quantitative data and memo notes were used to answer *Research Question 5: Social Desirability and Reports of Posttraumatic Growth.* The data can be found earlier in the chapter in Table 6, pg. 7; Table 9, pg. 10; Table 10, pg. 11; Table 11, pg. 12; Table 12, pg. 13; and Table 13, pg. 13.

*Question 5A:* How is social desirability related to quantitative measurement of PTG?

*Question 5B:* How is social desirability related to qualitative reports of increased levels of PTG?

*Question 5C:* What are the differences between those who report higher or lower levels of PTG in their responses to the questions regarding social desirability?

The PTGI was significantly correlated with the M-C SDS. To answer research *Question 5A*, significant correlations were found for the questionnaire sample (r = 0.31; p < 0.01), and the lower-PTG group (r = 0.78; p < 0.01) (Table 11, pg. 12 & Table 13, pg. 13). There was no significant relationhip between the PTGI and M-C SDS for the higher-PTG group (Table 12, pg. 13). To answer research *Question 5C*, the responses to the M-C SDS from the lower-PTG group were compared to the higher-PTG group, as well as the entire questionnaire sample. Results indicated that on the M-C SDS the higher-PTG group scored the lowest. Although this result indicated that the higher-PTG group answered questions in the most socially desirable way, the non-significant correlation between the higher-PTG group's M-C SDS and PTGI indicated that the PTGI score was not related to the M-C SDS score.

This study also investigated how, if at all, the individual participant's interviews appeared to be influenced by social desirability. To address *Question 5B* and *Question 5C*, the individual participants' MC-SDS scores were compared with the memos taken during the interview and coding process. This comparison was made to see if social desirability influenced the presentation of personal growth during the interview process. The data revealed that, in the lower-PTG group, participants who seemed to present during the interview as if they were members of the higher-PTG group produced social

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desirability scores nearly 1 standard deviation above the mean for that group. In one memo the researcher wrote, "She discussed themes of seeing life differently after being on her death bed, increased spirituality, and living for her children. If I had to guess which group she was in, I would guess the high-PTG group." The participant who reported this quote was in the lower-PTG group; however, her presentation seemed like a higher-PTG participant. All of the participants in the lower-PTG group whose scores on the social desirability measure scored near or below the mean presented as if they were in the lower-PTG group.

The converse did not hold up for the higher-PTG group. In other words, participants from the higher-PTG group, who presented as if they were from the lower-PTG group, did not consistently produce significantly lower social desirability scores. Only about half of the participants in the higher-PTG group who presented as if they were in the lower-PTG group scored nearly 1 standard deviation below the mean on the social desirability measure. In one memo the researcher wrote,

It seemed like she was straightforward with her responses and I did not sense that she was omitting anything. I suspect that she was in the low-PTG group, but I am not sure. She did report some changes but stated that overall her life did not change. (Participant was in the higher-PTG group.)

The participants in the higher-PTG group whose scores on the social desirability measure were near or above the mean had no predictable pattern of presenting in the higher-PTG or lower-PTG group. Therefore, it appears that social desirability obscured the group membership in only the lower-PTG group, where high social desirability coincided with the presentation of personal growth during the interview process. This qualitative finding is consistent with the quantitative finding of a significant correlation between the PTGI total score and the MC-SDS (r = 0.78; p < 0.05) in the lower-PTG group only (see Table 11). Therefore, social desirability was significantly related to the quantitative report of growth.

#### Conclusion of Results

This chapter reviewed the research questions, reported the results of the quantitative screening, and explained the content that emerged during the qualitative analysis. Because the data did not converge into a core category informed by the Posttraumatic Growth (Tedeschi & Calhoun, 2003) theoretical model, this chapter provided additional clarification in answering the research questions by reviewing the content of the transcripts and integrating information across the quantitative and qualitative data. In the next chapter, the major findings of this study will be discussed within the context of taking the next step in the literature exploring the process of Posttraumatic Growth within people living with HIV/AIDS. In addition, the next chapter reviews the limitations of this study and recommends future directions in this line of research.

# CHAPTER V

## DISCUSSION

This chapter reviews the major findings of this study and integrates the findings with the past literature. Then it discusses the implications of the findings, reviews the limitations of this study, and recommends future directions in this line of research. The purpose of the current study was to further explore Posttraumatic Growth (PTG) in people living with HIV/AIDS (PLWHA). To date, the extant literature has been able to establish that some PLWHA report positive changes in their lives as a result of living with their disease. The current study attempted to address the gaps in the literature by exploring positive changes in PLWHA using a discernable theoretical framework (PTG; Tedeschi & Calhoun, 1996), a standardized assessment of growth (Posttraumatic Growth Inventory [PTGI]; Tedeschi & Calhoun, 1996), and a theoretically based qualitative methodology (grounded theory; Strauss & Corbin, 1998). The current study also explored the process for developing PTG in PLWHA by comparing the differences in coping, quality of life, and meaning-making in PLWHA who report higher or lower levels of PTG. Specifically, this study examined the extent to which the theoretical precursors to PTG (Tedeschi & Calhoun, 2003) appeared to exist across the groups of PLWHA who report higher or lower levels of PTG.

The central purpose of this study was to compare PLWHA with higher- and lower- self-reported levels of PTG as measured by the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). Interviews were used to investigate various aspects of theory regarding PTG in these two samples. Based on the similarity of interview responses between higher- and lower-PTG groups, it is uncertain whether the PTGI functioned effectively to screen participants for interviews who were qualitatively different from one another on the factors of PTG. Alternatively, these results call into question some of the assumptions underlying experiences of PTG in this population. The findings of this study are first reviewed and processed in reference to the presence or absence of PTG in PLWHA, assuming that the PTGI did accurately screen participants, then the utility of the PTGI is discussed in further detail, and finally the findings are discussed in reference to differences based on the mixed methodology used to collect and analyze data.

## Major Findings of the Present Study

The major findings of this study are reviewed related to the presence of the precursors for Posttraumatic Growth, participants' perceptions of traumatic experiences, changes within the 5 factors of Posttraumatic Growth, quality of life, and social desirability. Implications for theory are also discussed.

#### Precursor for Posttraumatic Growth (PTG)

One of the central purposes of this study was to examine the extent to which the theoretical precursors to PTG proposed by Tedeschi and Calhoun (2003) existed among the groups of people living with HIV/AIDS (PLWHA) who reported higher or lower levels of PTG on a standardized instrument. Tedeschi and Calhoun (2003) identified five

theoretical precursors for PTG including having a traumatic experience that is severe enough to challenge previously held assumptions about the world, being able to manage distress, disengaging from previously held goals, the distress persisting for some time, and creating new personal narratives to accommodate the new traumatic information. Having a lower level of PTG theoretically suggests that these conditions for PTG were not met (Tedeschi & Calhoun, 2003). In this study, the components of *Research Question 1*, asking participants what their lives were like when they first found out they were HIVpositive, were used to examine the extent to which the precursors of PTG were present within the interview sample.

To address the first precursor, having a traumatic experience that is severe enough to challenge previously held assumptions about the world, the participants were asked if finding out they were HIV-positive challenged their previously held beliefs about life, the self, or others. Theoretically, in order to develop PTG, the experience should be traumatic enough to shatter previously held beliefs so that the person reframes information related to the event and personal beliefs (Tedeschi & Calhoun, 2003). More than half of the participants reported that their beliefs were challenged (11 participants; 5 higher-PTG, 6 lower-PTG). Reasons for the challenges were stated as becoming aware of stigma, questioning God, questioning authority figures, and having people turn against them. Some of the participants reacted to this challenging of beliefs by developing a negative outlook, becoming more spiritual, becoming less materialistic, or becoming more selective about disclosing one's HIV status. Similar to the theoretical prediction, these participants seemed to have their worldview shattered by negative events that were linked to HIV. Most of the remaining participants who reported that their beliefs were not challenged after becoming HIV-positive reported that their life did not change much because they would either not let it change or that it did not really "hit" them yet (that they were HIV-positive) because they remained relatively healthy. In other words, finding out they were HIV-positive did not disrupt their lives enough to conflict with previously held beliefs. Theoretically, it would make sense that these participants might not develop PTG because HIV was not disruptive to their lives and this precursor was not met. However, the results from the current study revealed that a similar number of higher- and lower-PTG participants reported that there was no change or no challenge to their beliefs (5 participants; 3 higher-PTG, 2 lower-PTG).

To address the second precursor, being able to manage distress, the participants were asked how they were able to cope with any distress related to becoming HIV positive. Theoretically, in order to develop PTG, the person must be able to adequately manage his or her distressing emotions in order to allow the cognitive process of reframing to occur (Tedeschi & Calhoun, 2003). Most of the participants (10, with an equal number from the higher- and lower-PTG groups) reported trying at least one coping strategy, while the remaining participants (6) reported that they did not cope. In addition, an equal number of higher-PTG and lower-PTG participants reported that they did not cope because they did not know what to do. The coping strategies that were reported covered a range from adaptive to maladaptive coping including planning what to do, seeking social services or social support, engaging in activities, turning to spirituality, yelling at others, using illicit drugs, and isolating themselves.

When examining the results in reference to PTG theory, it is important to note that more of the higher-PTG participants reported maladaptive coping strategies than lower-PTG participants. Theoretically, this could be explained in terms of the number of barriers the participants would have to overcome in order to begin to feel positive emotions again. For example, it may take more effort to cope with drug addiction in addition to being HIV-positive and therefore it would take more work to reframe the situation in a positive way and produce growth. In other words, these participants needed a big shock or "wake up call" in order to promote PTG. This same finding, relating to the higher-PTG participants engaging in more maladaptive coping, could also be seen as going contrary to theory. Specifically, the maladaptive coping strategies might not have been alleviating enough stress to allow for the reflection about current life circumstances and the reframing of HIV in a more positive way. In addition, an equal number of higher-PTG and lower-PTG participants said they simply did not cope with their distressing emotions. This runs contrary to theoretical predictions, in which one would expect the higher-PTG participants to engage in some form of coping in order to begin the cognitive reframing process of PTG.

To address the third precursor, the distress persisting for enough time to engage in PTG, participants were asked about the length of time they felt distressed after finding out they were HIV-positive. Theoretically, in order to develop PTG, the person must feel distressed for a long enough period of time in order to go through the process of challenging previous beliefs and reframing the events (Tedeschi & Calhoun, 2003). Because there is no published or predetermined amount of time that would be considered appropriate for this process, the length of time reported by each of the PTG groups was simply compared. Both of the PTG groups had participants who reported experiencing acute stress for each time frame after diagnosis: less than one year, five years or less, over

10 years, and continual distress. Differences in the PTG groups revealed that more participants in the higher-PTG group experienced stress for a shorter period of time (less than 1 year), and more of the participants in the lower-PTG experienced stress for a moderate period of time (5 years or less). This finding seems to be contrary to theoretical predictions, which expect a positive correlation between the duration of the distress and the level of PTG, because some of the higher-PTG participants were more likely to experience stress for a shorter period of time. In addition, the higher-PTG group had been living with HIV for a longer period of time (M = 14.25 years) than the lower-PTG group (M = 10.29 years). Therefore, it is unclear if this is an accurate measure of time, if looking back the higher-PTG group minimized the length of time, or if the higher-PTG group began making positive changes in meaning sooner and that alleviated their subjective level of stress. Also, there were some higher-PTG participants who did report experiencing stress for more than five years, so there was some variability within the higher-PTG group regarding duration of distress. What can be seen regarding theory is that the third precursor, duration of distress, did not predict higher levels of PTG within the current sample.

To address the fourth precursor, disengaging from previously held goals, participants were asked whether finding out they were HIV-positive affected their goals in life. Theoretically, in order to develop PTG, the person will disengage from goals they had before the traumatic event because those goals might no longer apply to their current life situation. Then, through the process of PTG, the person would make new goals that fit in with his or her current understanding of the world and life circumstance (Tedeschi & Calhoun, 2003). Most of the participants reported a change in their goals after finding out they were HIV-positive, with equal numbers from the higher-PTG and lower-PTG groups. The remaining participants from each group reported that their goals had remained the same since finding out they were HIV-positive. What can be seen regarding theory here is that the fourth precursor, disengaging from previously held goals, did not predict higher levels of PTG within the current sample. Because the number of participants from each group that meet the goal precursor is the same, it is possible that the way in which the person recreates new goals could help determine PTG. Whether the participants were able to make new goals is reviewed later in this chapter in the section that discusses currently living with HIV.

To address the fifth precursor, creating new personal narratives to accommodate the new traumatic information, the participants were asked to talk about whether their lives changed after they found out they were HIV-positive and in what way they were personally different. Theoretically, in order to develop PTG, the person would begin to craft a new narrative about his or her life, incorporating the new HIV-related information (Tedeschi & Calhoun, 2003). Most of the participants reported changes in their personal narrative after being HIV-positive, with similar numbers from both higher-PTG and lower-PTG groups. Theoretically, it makes sense that the higher-PTG participants were able to form new personal narratives incorporating new HIV-related information; however, it seems contrary to theory that a similar number of lower-PTG participants also reported creating new narratives. In addition, across both of the groups the narratives included a mixture of positive and negative events such as becoming more spiritual, slowing down, becoming more aware of other people's needs, spending more time with their children, becoming ill, losing a job, experiencing negative emotions, and losing relationships. The mix of positive and negative events within the narratives is consistent with theoretical predictions because PTG occurs along with negative events, so many individuals experiencing PTG acknowledge going through difficult times in addition to growth (Tedeschi & Calhoun, 2004).

To summarize the discussion from *Research Question 1*, participants from both higher- and lower-PTG groups met criteria for the precursors of PTG. In addition, the number of lower-PTG participants who met the criteria for each precursor either exceeded or was equal to the number of higher-PTG participants endorsing that particular precursor. Therefore, the presence or absence of theoretical precursors to PTG in the participant's self-reported history did not predict higher levels of PTG as measured by the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996).

Regarding the categories generated by grounded theory analysis, many of the themes and categories generated were reported to a similar degree by higher- and lower-PTG participants with a few exceptions. First, the higher-PTG participants reported more destructive or maladaptive coping strategies, such as drug use, than the lower-PTG participants. As stated previously, this was a surprising finding because such coping strategies might not have been sufficient to allow for the reflection about current life circumstances and the reframing of HIV in a more positive way, but maybe these findings also represent a "shock" to the system that promoted PTG in these participants. Second, the lower-PTG participants reported more vocational or socioeconomic concerns than the higher-PTG participants. Finally, the lower-PTG group. The differences in the endorsement of these categories, with lower-PTG participants reporting more vocational
and medical concerns, seems to indicate that the lower-PTG participants were experiencing more urgent needs that made HIV more salient to them. These participants spontaneously reported the loss of work or income, and the deterioration of health more often than the higher-PTG group reported. It could be that these losses were linked to HIV more in the minds of the lower-PTG participants than in the minds of the higher-PTG participates.

#### Perception of Traumatic Experiences

One important component of PTG is whether the individual perceived the event as stressful enough to engage in the process of reframing the event in a positive way (Tedeschi & Calhoun, 2004). For example, if the participant did not perceive becoming HIV-positive as a threatening or traumatic event, then it would follow that they would not begin the PTG process. In this study, the components of *Research Question 2* were used to examine the extent to which the participants perceived being diagnosed with HIV and living with HIV as traumatic events. In addition, the participants were asked about other traumatic events that occurred in their lives to examine whether the participants had experiences in coping with significant trauma, and whether those experiences informed how they cope with HIV.

Regarding the level of perceived stress after diagnosis, most of the participants reported that finding out they were HIV-positive was a stressful experience and rated it near the top, or a 7/10 or above, on the scale of intensity. This finding was similar for higher- and lower-PTG participants. Most of the participants reported that the stress from finding out they were HIV-positive lasted for less than five years, which did not include

current stress. More of the lower-PTG participants reported experiencing acute stress for longer periods of time, specifically for five years or less. On the other hand, while there was variability within the higher-PTG group, more of the higher-PTG participants reported the stress lasting for less than one year. Similar numbers of higher- and lower-PTG participants reported the stress lasting for greater than 10 years or continual. These results indicate that although both higher- and lower-PTG participants found being diagnosed as HIV-positive highly stressful, more of the lower-PTG participants seemed to experience the stress for a longer period of time. Specifically, this finding seems to be in the opposite direction of theoretical predictions, which expects a positive correlation between the duration of the distress and the level of PTG. It is possible that the higher-PTG participants were able to derive positive meaning from their circumstances, or reframe their experiences in such a way that alleviated their stress sooner than the lower-PTG participants. In addition, it is also possible that because more of the higher-PTG participants endorsed maladaptive coping strategies, such as drug use, these participants might not have perceived stress as intensely after self-medicating.

Regarding the level of perceived stress in currently living with HIV, many of the participants reported that living with HIV is still stressful, with slightly more lower-PTG participants reporting current stress. The intensity of the stress, however, was lower than after first diagnosis. Most of the participants rated their current stress at a moderate level of 4-6/10, with lower-PTG participants reporting a higher intensity of stress than higher-PTG participants indicated. Some of the participants reported a low level of current stress (0-2/10), with representation from both higher- and lower-PTG group. These findings make theoretical sense, because if the lower-PTG participants are reporting more current

distress they could be more focused on their current stressors and less likely to find positive changes in their lives related to HIV. However, because members from each PTG group also reported low stress, there appears to be great variability in the perception of current stress across the PTG groups.

Regarding the duration of stress, some of the participants reported that they are still in a high level of distress that has persisted since they were diagnosed as HIVpositive, other participants reported that their stress gradually diminished as they adapted to HIV and their medication began controlling their symptoms, and some participants were unsure about how the stress has changed or did not directly answer the question. There were similar numbers of higher-PTG and lower-PTG participants reporting each level of duration of stress. Some of the lower-PTG participants reported that living with HIV has not been stressful at all. Although this finding seems to be inconsistent with the previous finding that more lower-PTG participants reported higher levels of distress than higher-PTG participants, it again illustrates the variability of the perception of stress within the members of the lower-PTG group.

The participants also explained how they attempted to cope with distressing emotions related to living with HIV. Similar numbers of participants from both the higher- and lower-PTG groups reported coping by paying close attention to their health, following their doctor's instructions, helping other people, and getting family or social support. More of the higher-PTG participants reported coping by maintaining a positive attitude and prioritizing stressors. More of the lower-PTG participants reported coping by keeping busy with other tasks, turning to spirituality, getting more education about HIV, and isolating themselves.

The participants also identified other stressors in their lives that were not related to HIV. Most of the participants identified a non-HIV stressor; only 2 participants, one from each PTG group, denied any additional stressor. Members of both PTG groups reported events related to grief/loss, divorce, and personal illness. Most of the participants who reported personal illness as their additional stressor explained that their other illness was more stressful than HIV because those illnesses were more acute and had immediate potential for lethality. One notable difference was that members of the higher-PTG group reported grief/loss more frequently than lower-PTG participants. It is possible that coping with issues related to grief/loss is more similar to coping with HIV, because it may be a life-threatening disease, and therefore provided a chance to practice coping and reframing skills. The lower-PTG group reported additional types of traumatic events including surviving assault and a busy schedule. These types of events illustrate the variability in the lower-PTG group. Coping with a busy schedule, which may not even be considered a traumatic event, does not seem to employ the same types of coping skills as learning to live with HIV. Surviving an assault, if not processed or reframed, could become a disempowering event that could be similar to the same schema that produces lower levels of growth. On the other hand, surviving an assault could be such an empowering experience that living with HIV could seem less severe in comparison, and so no change or growth would be reported after living with HIV.

Participants also discussed their coping strategies for the non-HIV stressors. Members of both PTG groups reported similar strategies including using social or family support, not knowing what to do or doing nothing, focusing on other responsibilities, and trusting the medical care providers. Some members of the higher-PTG group reported coping by using spirituality, minimizing the problem, and keeping a fighting attitude. Some members from the lower-PTG group reported coping by using illicit drugs and withdrawing from activities.

Participants were asked how similar their coping strategy for the other stressor was to how they coped with HIV-related stress. Of the participants who identified non-HIV related stressors, half of the participants reported strategies comparable to coping with HIV, some participants reported strategies different than coping with HIV, and other participants reported an unclear relationship between coping strategies. There were equivalent numbers of participants from each PTG group reporting in the various levels of correspondence in coping strategies.

To summarize the conclusions from *Research Question 2*, which focused on the extent to which the participants perceived being diagnosed with HIV and living with HIV as traumatic events, most of the participants reported that finding out they were HIV-positive was a stressful experience and rated it as a high intensity stressor. In general, more of the lower-PTG participants reported experiencing acute stress related to their initial diagnosis for longer periods of time than the higher-PTG participants. Similar numbers of higher- and lower-PTG participants reported the stress from their initial diagnosis as lasting for greater than 10 years or continually. In addition, many of the participants reported that living with HIV is still stressful, with slightly more lower-PTG participants reporting current stress. The intensity of current stress was lower than after first diagnosis, with lower-PTG participants reporting a higher intensity of current stress than higher-PTG participants indicated. Conversely, some of the participants reported a low level of current stress (0-2/10), with representation from both higher- and lower-PTG

groups. The duration of stress from living with HIV varied from distress that has persisted since participants were diagnosed as HIV-positive, to stress levels that gradually diminished as participants adapted to living with HIV. Taken collectively, these findings seem to be contrary to theoretical expectations, which predict a positive correlation between the duration of the distress and the level of PTG.

Most of the participants identified a non-HIV related stressor. Members of both PTG groups reported similar strategies for coping with the non-HIV stressor. Half of the participants, with similar numbers of participants from each PTG group, reported that the strategies for coping with the additional stressor were similar to strategies for coping with HIV. These findings taken collectively also seem to be contrary to theoretical expectations because there were no significant differences between higher- and lower-PTG groups in the identification of, or strategies to cope with, non-HIV-related stressors. Theory would predict that participants who had experiences coping with other significant life stressors would be more likely to develop PTG because these participants would have more practice at coping with challenging experiences. When looking at these results in reference to theory, it appears that having experience with other significant life stressors did not predict higher levels of PTG within the current sample.

Regarding the categories generated by grounded theory analysis, many of the themes and categories generated about the non-HIV stressor were reported by similar numbers of higher- and lower-PTG participants with a few small exceptions. First, the higher-PTG participants reported using more resources and outside support in coping. Second, the higher-PTG participants reported experiencing more negative feelings or reactions to the non-HIV stressor. Third, the lower-PTG group reported using more spirituality in coping. Fourth, the lower-PTG group reported more positive and negative reactions to the non-HIV stressor from other people in their lives. Finally, the lower-PTG group discussed more medical conditions, symptoms, and interventions related to the non-HIV stressor. Contrary to theory, which would predict that coping with a stressor similar to HIV would produce more PTG, the lower-PTG group reported more medically related non-HIV stressors than the higher-PTG group. In addition, there appeared to be variability within the lower-PTG group regarding the types of events that were considered severe stressors, how they coped with events, and how other people in their lives reacted to the events. To summarize these results in relation to theory, because there were similar themes and categories reported by both PTG groups, experience in coping with a non-HIV stressor did not predict higher levels of PTG within the current sample.

# Personal Changes Within the Five Factors of Posttraumatic Growth Since Becoming HIV-Positive

This study also examined the types of changes that occurred in the participants' lives since being diagnosed as HIV-positive, using the PTG model (Tedeschi & Calhoun, 1996, 2004) as a framework. The areas of potential change were Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation for Life. Although it is possible to experience growth within some areas of life and not others (Tedeschi & Calhoun, 1996), it would be logical that the lower-PTG participants would not report as many changes across the factors of PTG as higher-PTG participants. The components of *Research Question 3*, asking participants what their lives are like today as they are currently living with HIV, were used to examine the extent to which the factors of PTG were present within the interview sample.

The participants were first asked a general question about changes that occurred in their lives since they have been living with HIV to see what types of changes the participants would spontaneously report. Participants from both higher- and lower-PTG groups reported negative global changes, a more positive attitude, and sobriety. The higher-PTG group reported changes related to increased spirituality, increased community involvement, increased openness to new things, and decreased materialism. Two of the higher-PTG participants reported no change in their life since they have been living with HIV. The lower-PTG group reported changes related to a decrease in employment or financial stability, a decrease in overall quality of health, a decrease in social interactions, and a decrease in anger. In general, it appears that participants with higher-PTG spontaneously reported more current positive life changes related to PTG, and participants with lower-PTG spontaneously reported more current negative life changes.

To explore potential changes in views about life, participants were asked about any personal meaning that they have discovered since they have been living with HIV. Some participants from both the higher-PTG and lower-PTG groups reported no change or no discovery of meaning. Participants from both PTG groups reported finding positive meaning in HIV as part of God's plan for them, helping others, leaving a positive legacy for their children, and that anything is possible with a positive attitude. In addition, participants from both groups identified negative meaning including HIV as a punishment from God, and that HIV has made their life much worse.

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To address the first factor of PTG, Appreciation for Life (Tedeschi & Calhoun, 1996), participants were asked whether their appreciation for life had changed. Most of the participants reported that their appreciation for life had changed since they have been living with HIV, with similar reports from both PTG groups. In addition, participants were asked how their priorities in life had been affected by living with HIV. Participants from both higher- and lower-PTG groups reported that their priorities had changed. The results indicated that there was no consistent difference seen in the higher- or lower-PTG groups. These results are inconsistent with theory, because the higher- and lower-PTG groups both reported positive changes in the PTG factor Appreciation for Life.

To address the second factor of PTG, Relating to Others (Tedeschi & Calhoun, 1996), participants were asked about changes in their interpersonal relationships and relationships with the community (Tedeschi & Calhoun, 1996). Participants from both higher- and lower-PTG groups reported varying levels of changes in interpersonal relationships including having some people in their lives reject them while other relationships grew stronger, developing a closer bond with only family, and having no change in relationships. In addition, participants with lower-PTG reported interpersonal changes including not trusting others after being rejected by those who were close to them, and having only friendships become closer but not family relationships. Participants from both higher- and lower-PTG groups also reported varying levels of change relating to their interactions with the community. Half of the participants reported that they are more involved with the community including HIV-service organizations, other participants reported no change in community involvement, and some participants reported being less involved with the community and more withdrawn. The results indicated that there were few constant differences seen in the higher- and lower-PTG groups. Consistent with theory, some of the lower-PTG participants reported a negative change in their interpersonal relationships; however, these changes were reported in addition to the reported positive changes. These results are conflicting with theory, because the higher- and lower-PTG groups both reported positive changes in the PTG factor Relating to Others.

To address the third factor of PTG, Personal Strength (Tedeschi & Calhoun, 1996), participants were asked to discuss whether they are personally different since they have been living with HIV. More participants from the lower-PTG group reported no personal changes since living with HIV, compared to the higher PTG-group. In addition, participants from both groups reported several similar positive personal changes including being more compassionate toward others, more altruistic, more mature, feeling stronger, and liking their current life more than before.

To further address the third factor of PTG, Personal Strength, participants were asked to discuss what, if anything, they have discovered about themselves since they have been living with HIV (Tedeschi & Calhoun, 1996). Some participants from both higher- and lower-PTG groups reported no personal discoveries since living with HIV. In addition, participants from both higher- and lower-PTG groups reported positive personal changes and discoveries. Consistent with theory, participants with lower-PTG were more likely to report negative health changes or negative self-assessments such as being "neurotic" or "stupid." The results indicated that there were few predictable differences seen in the higher- or lower-PTG groups. These results conflict with theory, because both the higher- and lower-PTG groups reported positive changes in the PTG factor Personal Strength.

To address the fourth factor of PTG, New Possibilities (Tedeschi & Calhoun, 1996), participants were asked about how living with HIV has affected their goals in life. Most of the participants from both higher-PTG and lower-PTG reported that their goals have been affected. There were similar numbers from each PTG group reporting the different types of changes including positive change or adding new goals, negative changes or giving up goals, and no change in goals. The results indicated that there was no consistent difference seen in the higher- or lower-PTG groups related to making or giving up goals. These results are inconsistent with theory, because both the higher- and lower-PTG groups reported changes in the PTG factor New Possibilities.

To address the fifth factor of PTG, Spiritual Change (Tedeschi & Calhoun, 1996), participants were asked about how living with HIV has affected their spirituality. Participants in both the higher and lower-PTG groups reported becoming more spiritual, having no change in spirituality, and having the same spiritual beliefs but no longer attending religious services. Some participants from the lower-PTG group did report incidents of moving away from previous religious beliefs or even abandoning spirituality. The results indicated that there was no consistent difference seen in the higher- or lower-PTG groups for positive changes in spirituality. This is inconsistent with theory, because participants from both the higher- and lower-PTG groups reported positive changes in the PTG factor Spiritual Change. One finding that was consistent with PTG theory was that some of the lower-PTG participants reported negative changes with spirituality, such as the abandonment of religious beliefs. This finding makes theoretical sense because these participants were unable to make meaning of living with HIV using their pre-HIV spiritual worldview and rather than assimilating the new information they abandoned their old spirituality schema.

To summarize the conclusions regarding the five factors of PTG proposed by Tedeschi and Calhoun (1996), participants from both higher- and lower-PTG groups reported positive changes in those five factors. In general, the number of lower-PTG participants who reported each factor was similar to the number of higher-PTG participants endorsing that particular factor. Therefore, the participants' self-reports of the factors of PTG in their lives were not predicted by the levels of PTG as measured by the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). Theoretically, the participants' scores on the PTGI should have predicted the degree of positive changes they reported during the interviews; however, the results of this study revealed no consistent differences between the higher- and lower-PTG groups in the amount of positive change reported. In other words, PTG theory would have predicted that the lower-PTG group would report significantly fewer positive changes than the higher-PTG group during the interview process, which did not occur during this study.

Regarding the categories generated by grounded theory analysis, many of the themes and categories were reported by similar numbers of higher- and lower-PTG participants. The higher-PTG participants seemed to report "no change" in life since living with HIV more often than lower-PTG participants. In addition, higher-PTG participants reported developing a positive new attitude more frequently than the lower-PTG participants. In contrast, it appeared that the lower-PTG group reported currently experiencing more negative events, in addition to positive events, than the higher-PTG

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group. These tendencies between groups support the PTG theory in a very superficial way because the higher-PTG group reported developing a new positive attitude and the lower-PTG group reported experiencing more negative events; however, these superficial differences only seem to reflect general growth and do not reveal any additional information about the specific factors of PTG.

The lower-PTG participants identified a variety of negative events and challenges related to currently living with HIV. First, the lower-PTG participants discussed using more coping strategies than the higher-PTG participants. Second, the lower-PTG participants reported more vocational or socioeconomic concerns than the higher-PTG participants, specifically loss of employment or income. Third, lower-PTG participants discussed the negative aspects of interpersonal relationships, such as friendships, more often than higher-PTG participants. Fourth, the lower-PTG participants reported more medical and health-related problems than higher-PTG participants. Finally, lower-PTG participants reported more categories within the theme of Negative Life Experiences than the higher-PTG group including Stress, Negative Feelings/Reactions, and Negative Societal Reaction.

These findings, taken collectively, suggest that both PTG groups report experiencing the factors of PTG at a similar rate; however, the lower-PTG group reported more negative content within the factors. Although Tedeschi and Calhoun (2004) explained that individuals reporting PTG may also report simultaneous negative changes, this finding seems contrary to theoretical expectations because the lower-PTG group reported both positive and negative changes, rather than only negative changes. Therefore, the presence or absence of the factors of PTG in the participant's self-reported current life narratives were not predicted by the levels of PTG measured by the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996).

# Perceptions of Quality of Life

This study also examined the extent to which living with HIV affected quality of life, as measured by the World Health Organization's Quality of Life- HIV- Brief (WHOQOL-HIV BREF) instrument (World Health Organization, 2003a, 2003b, 2004). The components of *Research Question 4* were used to examine the extent to which perceived quality of life (QOL) was related to levels of PTG within the entire survey sample, the top and bottom quartiles of the sample, and the interview sample. Regarding the general level of QOL the higher-PTG group scored the highest, the entire survey sample was in the middle, and the lower-PTG group scored the lowest. In addition, QOL was found to be positively correlated with PTG for the survey sample, but not for either of the interview samples. This suggests that, in general, the higher the QOL score the participant reported, the more likely he or she was to report PTG. It is unclear why this relationship did not extend to either of the interview samples, but could be related to the small sample size (n = 16). This general finding makes theoretical sense because developing PTG is thought to enhance the individual's ability to find meaning and make positive changes in life, which could correlate to QOL. Also, the fact that both the WHOQOL-HIV BREF and PTGI are self-report instruments may help explain the positive correlation between these measures. Participants who perceive more positive emotions in one part of their life could experience a self-report halo effect, and be more likely to report both positive changes and a higher QOL.

## Social Desirability and Reports of Posttraumatic Growth

This study also examined the extent to which reports of PTG are related to social desirability, as measured by the Marlowe-Crowne Social Desirability Scale (M-C SDS; Crowne & Marlowe, 1960). Theoretically, PTG should be independent from measures of social desirability (Tedeschi & Calhoun, 1996). The components of *Research Question 5* were used to examine the extent to which social desirability was related to levels of PTG within the entire survey sample and the interview sample. Results from the questionnaires indicated that the higher-PTG group reported the most social desirability compared to the other groups, which makes logical sense because the higher-PTG group could be reporting positive changes because that is the socially desirable thing to do. The level of social desirability was not found to be statistically related to the PTG scores within the higher-PTG group. This null finding is consistent with theoretical predictions, which expects that PTG should not be related to social desirability; however, the null finding could also be related to the small sample size within the higher-PTG group (n = 8).

The level of social desirability was related to quantitative measures of PTG within the other groups, which is contrary to theoretical expectations. The entire survey sample reported in the middle range of social desirability and the level of social desirability was related to the PTG scores. The lower-PTG group reported the lowest level of social desirability within this study, yet the relationship between social desirability and the PTG score in the lower-PTG group was the most statistically significant relationship in this study. In other words, even though the lower-PTG group reported the lowest levels of PTG and social desirability, the level of social desirability reported by the lower-PTG group predicted the amount of PTG reported. This suggests that, overall, the more social desirability the participants reported, the more PTG they also reported. The strength of this relationship within the lower-PTG group may be explained by the variability of PTGI scores within this group. Specifically, the range of PTGI total scores within the lower-PTG group indicated that those participants varied widely as to whether they reported any PTG at all, and the variability of scores was larger than that of the higher-PTG group. Therefore, it seems that the wide range of scores within the lower-PTG group might have magnified the relationship between PTG and social desirability because some participants reported low social desirability and absolute minimal growth, while others within the lower-PTG group reported some nominal growth as well as social desirability in their responding.

The participant's tendency toward social desirability appeared to influence his or her presentation during the interview process for the lower-PTG group only. It was discovered that in the lower-PTG group, participants who seemed to present during the interview as if they were members of the higher-PTG group produced social desirability scores nearly 1 standard deviation above the mean for that group. All of the participants in the lower-PTG group whose scores on the social desirability measure scored near or below the mean presented as if they were in the lower-PTG or the group in which their scores on the PTGI placed them. The converse did not hold up for the higher-PTG group and the social desirability scores had no predictable pattern of presenting as if the participant belonged in the lower- or higher-PTG group. Therefore, it appears that social desirability could have affected how some participants from the lower-PTG group behaved during the interview process, possibly acting as if they were members of the higher-PTG group.

#### Summary of Major Findings Related to Differences in PTG Between Groups

The results of this study seem to indicate that there were few discernible differences in personal narratives between the higher- and lower-PTG groups. The participants from both higher- and lower-PTG groups met criteria for the precursors of PTG. During the interviews, participants from both higher- and lower-PTG groups reported factors of PTG in their daily lives and the number of lower-PTG participants who reported each factor was similar to the number of higher-PTG participants endorsing that particular factor. Therefore, the presence or absence of theoretical precursors to PTG, and the factors of PTG, in the participants' self-reported narratives were not predicted by their scores on the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996).

There are a few possibilities as to the reason why the quantitative results (Posttraumatic Growth Inventory, PTGI) and qualitative results (interview data) did not converge. One possibility is that the PTGI did not function effectively at screening participants for interviews who were qualitatively different from one another on the factors of PTG. If that was the case, then it is possible that the PTGI was not measuring the amount of change that participants experienced regarding each PTG factor, but rather some other variable that differentiated these groups of participants. It is possible that the PTGI could have been measuring the emotional state of the participants at the time they completed the instrument rather than internal growth, which would explain the variability among the higher- and lower-PTG groups' interviews. Although the qualitative data across the higher- and lower-PTG groups overlapped considerably, the lower-PTG participants did report more negative events such as more vocational or socioeconomic concerns, more medical and health-related problems, and more negative consequences in interpersonal relationships. In addition, the relationship between social desirability and the lower-PTG group's qualitative life narrative appears to further support the idea that the PTGI is looking at emotional states, because the participants who scored higher on social desirability also presented in a euthymic manner and reported experiencing many changes during the interviews, which obscured their actual group membership.

Another possibility for the lack of convergence in the data is the differences in the types of information obtained from quantitative versus qualitative data. The current study, which is a mixed method design, illustrates some of the challenges of trying to integrate data from different methodologies. Some scholars within the Quantitative/Qualitative Debate (QQD) argue that the meta-theoretical paradigms associated with the methodologies are too different from one another, and that the underlying assumptions of each method would be violated if they are combined in a single study, so that reconciliation between these designs is not possible (Gelo, Braakmann, & Benetka, 2008). Specifically related to the current study, the quantitative methodology was measuring a single, tangible, and objective reality, which the PTGI was supposed to calculate and verify. In contrast, the qualitative methodology was investigating the multiple subjective realities of the participants that were socially and psychologically constructed by the participants, which were explored during the interview process. The differing results of the current study would then be both valid, yet parallel. Future research and refining of the research questions could help explore the lack of convergence seen in this study.

In summary, the results of this study indicated a high level of overlap in the responses to the interview questions between the higher- and lower-PTG groups. In

addition, there was a high level of variability of responses within the higher- and lower-PTG groups. The current study also revealed little apparent support for the precursors of PTG existing at different levels among the higher- and lower-PTG participants. The participants in both the higher- and lower-PTG groups reported experiencing positive changes consistent with the factors of PTG. Reasons why there were no discernible differences between the higher- and lower-PTG groups include the possibility that PTG is a poorly defined theory, that PTG is not applicable to this population, that the PTGI was not accurately measuring PTG, that there were too few participants in the interview sample to reveal the larger pattern of PTG, that PTG is cyclical and participants go through various stages of change at various times, and that the mixed methodology of the current study was actually assessing different phenomena. Additional data are necessary to fully support or refute these potential hypotheses.

#### Current Findings Related to the Literature

Comparing the current results to the extant literature reveals contrasting information because the qualitative reports from the higher- and lower-PTG groups appeared so similar, while the scores on the PTGI would suggest that they should be quite different (PTGI: higher-PTG M = 97.25; lower-PTG M = 32.62). There were no comparable studies found in the literature because many of the studies were examining the correlates of PTG, while this study was investigating the process for developing PTG by examining the precursors of PTG in participants who reported higher- and lower-PTG levels. Therefore, the findings of the current study are discussed within the context of filling the gaps in the literature.

The meta-analysis conducted by Helgeson, Reynolds, and Tomich (2006) identified limitations within the line of research on benefit finding after trauma that the current study tried to address. First, Helgeson and colleagues pointed out that benefit finding after a traumatic event clearly does exist and has been found to be related to decreased depression, increased positive affect, and increased avoidant/intrusive thoughts. The current study found that many of the participants within the survey sample did report some growth, with a mean PTGI total growth score of 67.7. This score was similar to PTGI total growth means for cancer patients in other published studies (Cordova, Cunningham, Carlson, & Andrykowski, 2001, M = 64.1; Widows, Jacobsen, Booth-Jones, & Fields, 2005 M = 65.7). In addition, many of the participants who were interviewed from both the higher- and lower-PTG groups reported a decrease in the amount of stress they have experienced since they have been living with HIV. Some of the participants from both higher- and lower-PTG groups reported an increase in positive emotions or positive ways of thinking since they have been living with HIV. The current study, however, did not note a difference in thought rumination or avoidant/intrusive thoughts in either the survey or interview samples.

Helgeson and colleagues (2006) also called for researchers to make a distinction as to whether benefit finding is being studied as a process or outcome. The current study attempted to examine the construct of benefit finding through the theoretical model of Posttraumatic Growth (PTG; Tedeschi & Calhoun, 1996) as both an outcome and a process. PTG was regarded as an outcome variable during the quantitative phase of the study, for the screening purposes of dividing the survey sample into groups of participants who reported higher or lower levels of PTG. The PTG model was then regarded as a process during the qualitative phase of the study. The results of the current study call into question PTG as either an outcome or a process variable because the higher- and lower-PTG groups paradoxically ended up being quantitatively different yet qualitatively similar. The reason for this finding is currently unknown; however, it is possible that the PTGI was measuring the emotional state that the participants were in at the time they completed the instrument and not PTG as a process. It is unclear whether the outcome variable of PTG, as measured by the PTGI, was not present or if the process for developing PTG was not supported in this study. It is suspected that the PTGI did not screen appropriately to divide the participants into groups for further analysis because of the qualitative similarities among the higher- and lower-PTG groups, based on the grounded theory analysis.

Helgeson and colleagues' (2006) meta-analysis also revealed that better results for the measurement and effects of benefit finding were found with well-established instruments. The current study attempted to address this recommendation by using the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), which is the most widely used instrument in the current literature. However, the results of the current study call into question the validity of the PTGI for measuring actual change in the population examined here. In addition, the studies that have used interview data (e.g., Siegel & Schrimshaw, 2000; Updegraff et al., 2002) did not report using a theoretically based qualitative methodology. The current study attempted to address this concern by using qualitative methodology based on grounded theory (Strauss & Corbin, 1998). Finally, Helgeson and colleagues explained that there needs to be a distinction between actual and perceived changes made when participants report finding benefits after trauma. In order to address this concern, the current study included a measure of social desirability. The results of the current study indicated that social desirability did appear to influence the qualitative presentation of some of the participants in the lower-PTG group, which could have contributed to these participants presenting as if they were members of the higher-PTG group.

Milam (2006b) identified variables that were related to Posttraumatic Growth in people living with HIV/AIDS. First, Milam concluded that PTG can occur within PLWHA and many report positive changes including increases in meaning in life, spirituality, sense of community, relationships with others, and altruistic behaviors. The current study found that similar numbers of participants in both the higher- and lower-PTG groups reported changes in those variables. Second, there are several correlates that have been found to contribute to PTG in PLWHA: being on antiretroviral treatment, increasing healthy behaviors, having a sense of religiosity/spirituality, being optimistic, and having lower levels of depressive symptoms. The current study revealed that all of the participants who were interviewed were currently on antiretroviral treatment and attempting to increase their healthy behaviors. Many of the participants in both the higher- and lower-PTG groups reported having a sense of spirituality and attempting to be more optimistic. In addition, some of the participants from both the higher- and lower-PTG groups reported past and current depressive symptoms.

Several demographic variables were found across studies to be related to increased PTG in PLWHA including being younger and female (Milam, 2004; Siegel & Schrimshaw, 2000); other studies presented mixed evidence for socioeconomic status and ethnicity being related to PTG (Milam, 2004; Updegraff et al., 2002). In the current study, the demographics in the higher- and lower-PTG groups were similar in age, gender, religion, and ethnicity. The lower-PTG group, however, reported more financial concerns than the higher-PTG group. Finally, some early evidence suggested that PTG may be related to disease progression (Milam, 2004). The current study had similar findings regarding years since diagnosis, with participants from the higher-PTG group being HIV-positive longer (M = 14.25 years) than the lower-PTG group (M = 10.29 years). There were, however, variations across PTG groups in the current health of the participants. The higher-PTG group had more participants who had converted to AIDS; but the lower-PTG group reported more health concerns and lower health-related quality of life scores on the WHOQOL-HIV-BREF.

The current study intended to take the next step in the line of research by exploring the extent to which the theoretical precursors to PTG (Tedeschi & Calhoun, 2003) exist across groups of PLWHA who report higher or lower levels of PTG. However, the results of this study seem to indicate that there were few, if any, predictable qualitative differences between the higher- and lower-PTG groups, while the participants' scores on the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) predicted that there should have been differences. The discrepancy in the current results could be viewed as an artifact of using quantitative (objective) compared to qualitative (subjective) assessments. Differences in ratings on similar scales between assessment method (objective vs. subjective) could be due to several reasons including that the scales are actually measuring different constructs, disparity between characteristics that are consciously recognized compared to unconsciously indicated, and variability in response styles across the assessment methods (Meyer, 1997). The results could also be viewed within the context of the Quantitative/Qualitative Debate (QQD) in that the quantitative and qualitative results were actually measuring different phenomena and are equally valid (Gelo et al.,, 2008).

The results of the current study coincide with a growing controversy within the literature over the validity of the constructs of PTG and the PTGI. Some researchers argue that using any self-report questionnaire to retroactively measure changes in personal attributes is a weak predictor of actual change because of inaccuracies in the participants' current perceptions of change (Nolen-Hoeksema & Davis, 2004; Robins, Noftle, Trzesniewski, & Roberts, 2005). Specifically related to PTG, some researchers question whether reports of PTG are reflecting actual changes (Frazier et al., 2009) or are ways in which participants are reframing their experiences to assist in coping (McMillen & Cook, 2003; Taylor, 1983). A few empirical articles have presented evidence that reports in growth are related to changes in perception rather than actual change. McFarland and Alvaro (2000) found that individuals who reported growth after a traumatic experience were actually degrading their pre-trauma self, so that current functioning appeared to be enhanced. Davis and McKearney (2003) found that bereaved participants who were primed about the traumatic event reported more positive changes than participants who were not primed. Frazier and Kaler (2006) found few differences in perceptions of growth between groups of participants who had experienced a stressor and participants who had not experienced any stressor. Ransom, Sheldon, and Jacobsen (2008) assessed cancer patients before and after radiotherapy and found that reports of PTG were related to both actual changes in goal orientation and perceived changes in self-assessed personal attributes. Frazier, Tennen, Gavian, Park, Tomich, and Tashiro

(2009) found that although participants perceived experiencing growth, their PTGI scores were not related to measures of actual growth based on pre- and post-trauma assessments and the PTGI scores were specifically not related to measures of actual growth in PTG factors. Taken together, the results of these studies seem to indicate that reports of growth are related to changes in perception rather than actual changes.

The results of the current study seem to coincide with the studies finding differences in perception between actual and perceived growth. Unfortunately, the current study did not have any pre-HIV data for comparison; however, the similarity in the narratives in the higher- and lower-PTG groups seems to indicate that the PTGI could have been sensitive to the differences in perception about the current life circumstances between the groups. Specifically, the lower-PTG group reported more current stressors than the higher-PTG group, including financial concerns, a lower quality of life, and interpersonal issues. Although it is difficult to determine the accuracy of the participants' narratives, these differences in perceptions of current functioning could have influenced the scores for both groups on the PTGI. Therefore, it seems that in this study the PTGI could have been measuring participants' current perceptions about life at the time they completed the instrument.

#### Limitations and Implications for Future Research

There are several limitations of this research that should be addressed. First, this study used a cross-sectional design, and therefore causal relationships cannot be established. Even though there was a time delay of two to six months between collecting surveys and interviews, the research design was not intended to detect changes over time. However, the amount of time that passed between the survey and interview could have influenced the participants' outlook on life, or additional changes could have occurred, which could have affected the participants' self-report during the interview process. Repeating the survey measures at the time of the interview could have alerted the researcher to any potential changes and further informed the discussion. In addition, there were no pre-HIV data or collateral informants available to assess whether the changes reported by the participants were actual or merely perceived.

A second limitation is the generalizability of the results. This study used a diverse sample of people living with HIV/AIDS (PLWHA) that was recruited throughout Ohio from HIV-service organization. The findings of this study should be interpreted with caution in reference to other populations. Only PLWHA who were connected to the resources of the HIV-service organizations were invited to participate and therefore PLWHA who were not receiving services were not included. Importantly, the sample was self-selected at two different times: once for the survey and once for the interview. Some of the participants who completed a survey declined further participation by not returning phone calls when invited for interviews.

A third limitation is that the current study did not include measures of other variables that could be related to PTG including coping, personality, or other independent measures of the factors of PTG. It is possible that some of the reported differences in perceptions of living with HIV were related to the participants' natural personality or coping style, as opposed to actual growth. Independent measures of changes related to PTG could help establish whether change was actual or merely perceived. Fourth, there were some limitations related to the data collection. First, this study used a self-report paper and pencil questionnaire that relied on the recollection of the participants to report their perception of changes in their lives. This study used the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) to screen for participants reporting higher- and lower-PTG levels; however this method did not prove to be effective and did not produce groups that appeared qualitatively different. Second, this study used a semi-structured interview to further assess participants' past stress, coping, and current level of change. Some of the qualitative differences could have come from the stimulus demand of the interview or participants could have reported growth during the interview that they did not report on the questionnaire.

Finally, there were some limitations related to the analysis of the qualitative data. Grounded theory might not have been the appropriate methodology to answer the research questions of this study because of the structured nature of the research questions. Many of the statements from the participants were multi-layered and difficult to code into one mutually-exclusive category, even when considering that categories are able to have multiple dimensions. In addition, the themes that were generated from the grounded theory did not directly answer the research questions about the presence or absence of indicators of PTG, and so the content of the interviews had to be reviewed a second time by the research team to answer the research questions. The themes that were generated by the grounded theory did not permit the creation of a core category; however, this might not be unusual because there have been some studies in the literature that used grounded theory and did not generate a core category (e.g., Klunklin & Greenwood, 2006; Shakespeare-Finch & Copping, 2006). In addition, the themes that did emerge seemed to be artifacts of the research questions themselves. Specifically, in order to be able to adequately answer the research questions, any item that was not spontaneously brought up by a participant was later asked by the researcher. Therefore, themes related to coping and interactions with others emerged whether the participants spontaneously talked about them or not.

Although the current study did not address many of the gaps in the literature that it intended to, it still offers insight for improving future research. Primarily, the quantitative and qualitative results of this study did not converge and therefore future researchers are encouraged to continue to investigate alternative ways to measure actual versus perceived growth at various points in time. In addition, future researchers must reexamine the assumptions underlying the conceptual model of PTG. One possibility is to further explore whether growth is a cyclical or linear process. Another possibility is to determine whether growth entails behavioral changes or simply a reflection of positive reappraisal coping. Investigating this process would need access to pre-trauma data to see if the participants reporting changes are actually thinking and behaving differently than their pre-event selves, or if they are thinking about themselves in a more positive way. Future researchers are encouraged to cross-validate the present study's findings on other samples, including those who report higher- and lower- levels of growth or traumatic events. Future researchers should consider using alternative (e.g., longitudinal, qualitative) designs that can aid in determining the amount of actual growth and the process for developing growth.

The results of this study may also have implications for public policy regarding the availability of resources and quality of life for people living with HIV/AIDS. During

the interview process, participants who lived farther away from urban centers such as Akron, Cleveland, Columbus, and Youngstown, reported having less access to healthcare and social services. In addition, these participants reported a higher level of general discomfort due to encountering more HIV-related stigma within the community. This stigma extended into the healthcare system, with reports of healthcare professionals violating HIPAA laws regarding HIV-status, not being current about ways that HIV can and cannot be transmitted, and therefore treating HIV-positive patients as if they were highly infectious through casual contact. Participants who moved from rural areas to urban centers reported a decline in perceived stigma once they relocated, an increase in positive interactions with healthcare professionals, and an overall increase in their comfort within the community.

These reports demonstrate how community resources affect stigma and quality of life in people living with HIV/AIDS. People living with HIV/AIDS have different levels of access to healthcare and social service resources depending on where they live. Based on the qualitative reports of participants in this study, the amount of resources within the community seems to affect how the person living with HIV/AIDS perceives stigma, which influences her or his general comfort level and quality of life. More research is needed to further examine the relationship between geographic location, community resources, and HIV-related stigma within the community. Public policy advocates may want to examine these relationships to help reduce inequities in resources, reduce community stigma, and increase public education about living with HIV/AIDS.

In conclusion, the current study attempted to address the gaps in the literature by exploring positive changes in people living with HIV/AIDS (PLWHA) using a

discernable theoretical framework (PTG; Tedeschi & Calhoun, 1996), a standardized assessment of growth (Posttraumatic Growth Inventory [PTGI]; Tedeschi & Calhoun, 1996), and a theoretically based qualitative methodology (grounded theory; Strauss & Corbin, 1998). The current study also explored the process for developing PTG in PLWHA by comparing the differences in coping, quality of life, and meaning-making in PLWHA who report higher or lower levels of PTG on the PTGI. The results of this study indicate that there were few discernible differences in personal narratives between the higher- and lower-PTG groups. The participants from both higher- and lower-PTG groups met criteria for the precursors of PTG. During the interviews, participants from both higher- and lower-PTG groups reported factors of PTG in their daily lives and the number of lower-PTG participants who reported each factor was similar to the number of higher-PTG participants endorsing that particular factor. Therefore, the presence or absence of theoretical precursors to PTG, and the factors of PTG, in the participants' selfreported narratives were not predicted by their scores on the PTGI (Tedeschi & Calhoun, 1996).

The ability to compare higher- and lower-PTG groups relied on the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) to accurately sort participants into higher- and lower-PTG groups. Based on the similarity of responses between higher- and lower-PTG groups, it is possible that the PTGI was not measuring the amount of change that participants experienced regarding each PTG factor, but rather some other variable that differentiated these groups of participants. The PTGI might have been assessing the participant's emotional state at the time he or she completed the instrument, quality of life, social desirability, or some other unknown factor. Additional reasons why there were no discernible differences between the higherand lower-PTG groups include the possibility that PTG is a poorly defined theory, that PTG is not applicable to this population, that the PTGI was not accurately measuring PTG, that grounded theory did not detect response pattern differences that were present in these two groups, that there were too few participants in the interview sample to reveal the larger pattern of PTG, that PTG is cyclical and participants go through various stages of change at various times, and that the mixed methodology of the current study was actually assessing different phenomena.

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APPENDICES

## APPENDIX A

# HEALTH-RELATED QUALITY OF LIFE QUESTIONNAIRE: THE WHOQOL-HIV

## BREF

### WHOQOL HIV Group (2003a)

#### **ABOUT YOU**

Before you begin we would like to ask you to answer a few general questions about yourself: answer by circling the correct answer or by filling in the space provided.

What is your <b>gender</b> ?	Male / Female
How old are you?	(age in years)
What is the highest <b>education</b> you received?	None at all / High school / Some college / College graduate / Post-graduate degree
How is your <b>health</b> ?	Very Poor / Poor / Neither Poor nor Good / Good / Very Good
Do you consider yourself currently ill?	Yes / No
If there is something wrong with you (illness), wh	hat do you think it is?

Please respond to the following questions if they are applicable to you:							
What is your HIV serostatus?      Asymptomatic / Symptomatic / AIDS converted							
In what year did you first <b>test positive</b> for HIV?							
In what year do you think you were How do you believe you were <b>infect</b> Sex with a man / Sex with a woman Other (specify)	infected? ted with HIV? (circle one only): / Injecting drugs / Blood products /						

## **Instructions**

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

	Not at all	A little	A moderate	Very much	Extremely
			amount		
How well are you able to concentrate?	1	2	3	4	5

You should circle the number that best fits how well you are able to concentrate over the last two weeks. So you would circle the number 4 if you were able to concentrate very much. You would circle number 1 if you were not able to concentrate at all in the last two weeks.

# Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very	Poor	Neither poor nor	Good	Very
	poor		good		good
How would you rate your	1	2	3	4	5
quality of life?					

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	1	2	3	4	5

	Not	Α	А	Very	Extremely
	at all	little	moderate	much	
			amount		
To what extent do you feel that	1	2	3	4	5
physical pain prevents you from					
doing what you need to do?					
How much are you bothered by any	1	2	3	4	5
physical problems related to your					
HIV infection?					
How much do you need any medical	1	2	3	4	5
treatment to function in your daily					
life?					
How much do you enjoy life?	1	2	3	4	5
To what extent do you feel your life	1	2	3	4	5
to be meaningful?					
To what extent are you bothered by	1	2	3	4	5
people blaming you for your HIV					
status?					
How much do you fear the future?	1	2	3	4	5
How much do you worry about	1	2	3	4	5
death?					

The following questions ask about **how much** you have experienced certain things in the last two weeks.

	Not at	А	А	Very	Extremely
	all	little	moderate	much	
			amount		
How well are you able to	1	2	3	4	5
concentrate?					
How safe do you feel in your	1	2	3	4	5
daily life?					
How healthy is your physical	1	2	3	4	5
environment?					

	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	1	2	3	4	5
Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5
To what extent do you feel accepted by the people you know?	1	2	3	4	5
How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

	Very poor	Poor	Neither poor nor good	Good	Very good
How well are you able to get around?	1	2	3	4	5

The following questions ask you how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

	Very	Dissatisfied	Neither	Satisfied	Very
	dissatisfied		satisfied		satisfied
			nor		
			dissatisfied		
How satisfied are you	1	2	3	4	5
with your sleep?					
How satisfied are you	1	2	3	4	5
with your ability to					
perform your daily					
living activities?					
How satisfied are you	1	2	3	4	5
with your capacity for					
work?					
How satisfied are you	1	2	3	4	5
with yourself?					

How satisfied are you	1	2	3	4	5
with your personal					
relationships?					
How satisfied are you	1	2	3	4	5
with your sex life?					
How satisfied are you	1	2	3	4	5
with the support you get					
from your friends?					
How satisfied are you	1	2	3	4	5
with the conditions of					
your living place?					
How satisfied are you	1	2	3	4	5
with your access to					
health services?					
How satisfied are you	1	2	3	4	5
with your					
transportation?					

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite	Very	Always
			often	often	
How often do you have negative	1	2	3	4	5
feelings such as blue mood, despair,					
anxiety, depression?					

Did someone help you to fill out this form?

How long did it take to fill this form out?

Do you have any comments about the assessment?

## THANK YOU FOR YOUR HELP

\_\_\_\_\_

#### APPENDIX B

#### SUPPLEMENTAL DEMOGRAPHIC QUESTIONNAIRE

#### Please circle or fill in the blank with the most appropriate response.

1. In the past 12 months, have you had your viral load tested?

Yes No Don't know

2. If you had your viral load tested, what was your most recent viral load?

3. In the past 12 months, have you had a CD4 count?

Yes No Don't know

4. If you had a CD4 count, what was your most recent CD4 count?

5. In the past 12 months, have you been provided anti-retroviral therapy?

Yes No Don't know

6. Which of the following best describes your current living situation?

I live in my own house or apartment I live in another's house or apartment I live in a residential group setting (drug treatment facility, AIDS housing, etc.) I am homeless (no regular address, live in car, on streets, in shelter, etc.) I am in jail or prison

7. How many people live with you? \_\_\_\_\_

- 8. Which of the following people live with you (mark all that apply)?
  - Live alone Partner/spouse Roommate Friend Parents Children Brother/Sister Other relative (please list: \_\_\_\_\_) Group home residents

#### 9. What is your current relationship status?

Single, never married Married / Life partner Separated Divorced Widowed / Partner deceased Unknown Other (please describe) \_\_\_\_\_

10. How would you describe your sexual orientation?

11. With whom do you have / have you had sex?

Only men Only women Sometimes men, sometimes women Does not apply to me If you were to have sex, would it be with men, women, or both?

12. What is your current employment status (mark all that apply)?

Employed, full time Employed, part time Self-employed Retired Disabled Student Unemployed, looking for work Unemployed, not looking for work

13. What is your occupation or what was the last job that you held?

14. What is your religion, if any?

Christian	
Denomination (if any)	
Jewish	
Muslim/Islam	
Buddhist	
Hindu	
Unitarian Universalist	
No Religion/Atheist/Agnostic	
Other:	
15. Are you of Hispanic, Latino, or Spanish orig	gin?
Yes	
No	
Don't know	
16. What is your race (mark all that apply)?	
American Indian / Native Alaskan	
Black or African American	
Native Hawaiian or Other Pacific islande	er
White or European American	
Asian American	
Biracial	
Other (please describe)	

17. Before being diagnosed with HIV/AIDS, had you experienced other traumatic events in your life?

No Yes

If so, what were the events?

18. Do you have a history of abusing alcohol or drugs?

No	
Yes	
	If so, what?
	How much did you use?
	How often did you use?
	Are you still currently using?

 19. Have you ever been diagnosed with a mental illness or disability (such as but not limited to anxiety, depression, bipolar disorder, posttraumatic stress disorder, or schizophrenia)?

No Yes Don't know If so, what?

#### APPENDIX C

#### THE POSTTRAUMATIC GROWTH INVENTORY

#### Tedeschi & Calhoun (1996)

Indicate for each of the statements below the degree to which this change occurred in your life as a result of living with HIV/AIDS using the following scale.

0= I did not experience this change as a result of living with HIV/AIDS.

*l* = *I* experienced this change to a very small degree as a result of living with HIV/AIDS.

2= I experienced this change to a small degree as a result of living with HIV/AIDS.

*3*= *I* experienced this change to a moderate degree as a result of living with HIV/AIDS.

4= I experienced this change to a great degree as a result of living with HIV/AIDS.

5= I experienced this change to a very great degree as a result of living with HIV/AIDS.

		Degree of change				
	No	Very	Small	Moderate	Great	Very
	Change	Small				Great
1. I changed my priorities about	0	1	2	3	4	5
what is important in life.						
2. I have a greater appreciation for	0	1	2	3	4	5
the value of my own life.						
3. I developed new interests.	0	1	2	3	4	5
4. I have a greater feeling of self-	0	1	2	3	4	5
reliance.						
5. I have a better understanding of	0	1	2	3	4	5
spiritual matters.						
6. I more clearly see that I can count	0	1	2	3	4	5
on people in times of trouble.						

Degree of Change

	No	Very	Small	Moderate	Great	Very
	Change	Small				Great
7. I established a new path for my life.	0	1	2	3	4	5
8. I have a greater sense of closeness with others.	0	1	2	3	4	5
9. I am more willing to express my emotions.	0	1	2	3	4	5
10. I know better that I can handle difficulties.	0	1	2	3	4	5
11. I am able to do better things with my life.	0	1	2	3	4	5
12. I am better able to accept the way things work out.	0	1	2	3	4	5
13. I can better appreciate 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. I have more compassion for others.	0	1	2	3	4	5
16. I put more effort into my relationships.	0	1	2	3	4	5
17. I am 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 better accept needing others.	0	1	2	3	4	5

## APPENDIX D

## THE MARLOWE-CROWNE SOCIAL DESIRABILITY SCALE

## Crowne & Marlowe (1960)

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is *true* or *false* as it pertains to you personally.

1. Before voting I thoroughly investigate the qualifications of all the	True	False
candidates.		
2. I never hesitate to go out of my way to help someone in trouble.	True	False
3. It is sometimes hard for me to go on with my work if I am not	True	False
encouraged.		
4. I have never intensely disliked anyone.	True	False
5. On occasion I have had doubts about my ability to succeed in life.	True	False
6. I sometimes feel resentful when I don't get my way.	True	False
7. I am always careful about my manner of dress.	True	False
8. My table manners at home are as good as when I eat out in a restaurant.	True	False
9. If I could get into a movie without paying and be sure I was not seen I	True	False
would probably do it.		
10. On a few occasions, I have given up doing something because I	True	False
thought too little of my ability.		
11. I like to gossip at times.	True	False
12. There have been times when I felt like rebelling against people in	True	False
authority even though I knew they were right.		
13. No matter who I'm talking to, I'm always a good listener.	True	False
14. I can remember "playing sick" to get out of something.	True	False
15. There have been occasions when I took advantage of someone.	True	False
16. I'm always willing to admit it when I make a mistake.	True	False
17. I always try to practice what I preach.	True	False
18. I don't find it particularly difficult to get along with loud mouthed,	True	False
obnoxious people.		
19. I sometimes try to get even rather than forgive and forget.	True	False
20. When I don't know something I don't at all mind admitting it.	True	False

21. I am always courteous, even to people who are disagreeable.	True	False
22. At times I have really insisted on having things my own way.	True	False
23. There have been occasions when I felt like smashing things.	True	False
24. I would never think of letting someone else be punished for my	True	False
wrongdoings.		
25. I never resent being asked to return a favor.	True	False
26. I have never been irked when people expressed ideas very different	True	False
from my own.		
27. I never make a long trip without checking the safety of my car.	True	False
28. There have been times when I was quite jealous of the good fortune of	True	False
others.		
29. I have almost never felt the urge to tell someone off.	True	False
30. I am sometimes irritated by people who ask favors of me.	True	False
31. I have never felt that I was punished without cause.	True	False
32. I sometimes think when people have a misfortune they only got what	True	False
they deserved.		
33. I have never deliberately said something that hurt someone's feelings.	True	False

## APPENDIX E

## SEMI-STRUCTURED INTERVIEW QUESTIONS

I am going to ask you questions related to how you have coped with living with HIV/AIDS.

Questions related to the 5 precursors of PTG (Tedeschi & Calhoun, 2003):

- 1. When did you first find out that you are HIV-positive?
- 2. What was your life like before you found out you are HIV-positive?
- 3. How, if at all, did your life change when you found out you are HIV-positive?
- 4. How, if at all, were you different after you found out you are HIV-positive?
  - a. Possible follow up:
    - i. How, if at all, did finding out you are HIV-positive challenge your beliefs about the world and life?
- 5. On a scale of 1 to 10, with 1 being lowest and 10 being highest, how distressing was it for you when you first found out you were HIV-positive?
  - a. If not stressful, why not?
  - b. How did you cope with the stress?
  - c. How had you coped with stress in the past?
- 6. How long did this state of stress last?
  - a. How did it change over time?

Questions related to the perception of stress related to living with HIV/AIDS:

- 7. On a scale of 1 to 10, with 1 being lowest and 10 being highest, how distressing is it for you to be living with HIV/AIDS now?
  - a. If not stressful, why not?
  - b. How do you cope with this stress?
- 8. How long has this stress lasted?
  - a. How did it change over time?
  - b. What is the stress like today?
- 9. What other types of stressful events have occurred in your life, that are NOT HIV-related?
  - a. On a scale of 1 to 10, with 1 being lowest and 10 being highest, how distressing were those events?
  - b. How long did the stress last?
  - c. How did you cope with those events?

- d. How was your coping strategy, for those other events, similar to how you cope with HIV-related stress?
- e. How was your coping strategy, for those other events, different than how you cope with HIV-related stress?

Questions related to the 5 domains of Posttraumatic Growth (Tedeschi & Calhoun, 2006):

- 10. How, if at all, did your life change since you have been living with HIV/AIDS?
  - a. Possible follow up:
    - i. How, if at all, has living with HIV/AIDS affected your goals in life?
      - 1. What types of new goals have you developed, if any?
    - ii. Have your relationships with others changed since your diagnosis?1. If so, how?
    - iii. Has your relationship with your community changed?1. If so, how?
- 11. How, if at all, are you personally different since you have been living with HIV/AIDS?
  - a. Possible follow up:
    - i. What, if anything, have you discovered about yourself since the time of your diagnosis?
    - ii. Has your sense of spirituality or religious beliefs changed since you found out that you are HIV-positive?
      - 1. If so, how?
    - iii. Has your appreciation for life changed since your diagnosis?1. If so, how?
    - iv. Have your priorities in life changed since your diagnosis?1. If so, how?

Concluding questions:

- 12. Have you discovered any personal meaning in your HIV diagnosis?
  - a. If so, what?
  - b. How, if at all, has your meaning or purpose in life changed since you have been living with HIV/AIDS?
- 13. Is there anything else that you would like to tell me related to what we have been talking about today?

## APPENDIX F

## IRB APPROVAL LETTER AND INFORMED CONSENT

This appendix includes the IRB approval letter and informed consent document. The letter included is the IRB approval letter from the University of Akron. The letter indicates that this study qualified for an expedited review and presented minimal risk to the research subjects.



NOTICE OF APPROVAL

Date: March 26, 2009

To: Adrienne G. Bennett Psychology Department The University of Akron Akron, Onio 44325-4301

From: Sharon McWhorter, IRB Administrater The

Re: IRB Number 20080317-2 "An Examination of the Precursors of Post-Traumatic Growth In People Living with HIV/AIDS"

Thank you for submitting your Application for Continuing Review of Research involving Human Subjects for the referenced orbject. Your protocol represents minimal risk to subjects and has been approved under Expedited Category #7.

Approval Date: Expiration Date: Continuation Application Due: March 26, 2009 April 3, 2010 March 20, 2010

In addition, the following is/are approved:

- Waiver of documentation of consent
- Research involving children
- Research involving prisoners

Please adhere to the following IRB policies:

- IR3 approval is given for not more than 12 months. If your project will be active for longer than one year, it is your responsibility to submit a continuation application prior to the expiration date. We reduced submission two weeks prior to expiration to insure sufficient time for review.
- A copy of the approved consent form must be submitted with any continuation application.
- If you plan to make any changes to the approved protocol you must submit a continuation application for change and it must be approved by the IRB before being implemented.
- Any adverse reactions/incidents must be reported immediately to the IRB.
  If this research is being conducted for a make in them as destant discertation, and
- If this research is being conducted for a master's thesis or doctoral dissertation, you must file a copy of this letter with the thesis or dissertation.
- When your project terminates you must submit a Final Report Form in order to close your IRB file.

Additional information and all IRB forms can be accessed on the IRB web site al: http://www.uakron.edu/research/orsp/compliance/IRBIome.php

Co: Charles Waehler - Advisor Co: Stephanie Woods - IRB Chain M Approved consent form/s enclosed

Office of Research Services and Sponsored Programs Akron: OH 44325-2102 550 972 7666 • 320-972-6281 Hax

The University of Access is an Equal Feb outline and Employment it as for an

#### INFORMED CONSENT FORM An Examination of the Precursors of Posttraumatic Growth in People Living with HIV/AIDS

You are invited to participate in a study being conducted by Adriane Bennett, a Doctoral level student from the Department of Psychology, College of Arts and Sciences, University of Akron, Akron, OH,

The project focuses on how people living with HIV/AIDS cope with and find meaning in their disease. Specifically, the project will examine how people living with HIV/AIDS have coped with the positive and negative changes that have happened in their lives since they first found out they are HIV-positive. The researcher is particularly interested in coping styles that are related to positive and negative perceptions of living with HIV/AIDS and hopes to survey at least 80 people.

If you decide to participate you will be asked to complete a questionnaire, which should take only about 20-30 minutes. A smaller group of people who complete questionnaires will also be invited to participate in the second phase of this project, which is a face-to-face interview. If you are willing to be interviewed in order to provide more information, please provide your name and phone number on the form provided with the survey. This form will be separated from the survey upon collection, and will be stored in a separate locked cabinet from the surveys, so that no identifiable information will be in the surveys.

If you decide to participate in the second phase of the project, you will be asked to participate in a face-to-face interview at a convenient time and place for you. The interview should take 45 to 90 minutes and will be digitally recorded so that it can be transcribed into written form by the researcher. Only the researcher and her advisor will have access to the recordings and be able to link the audio recordings to the transcripts (until the recordings are crased). All identifying information will be omitted from the written transcript,

Participation in any part of the project is completely voluntary. If you agree to participate in the project, you may refuse to answer any questions and may withdraw from the study at any time without penalty. The risks and discomforts of participation will be minimal, but may include remembering negative experiences, depending on what your experiences have been. The benefits to you for participating in this study may include knowing that you are helping us have a better understanding of how people living with 111V/AIDS cope with changes that happen in their tives after diagnosis, which may help others who are learning to cope with HIV/AIDS in the future. However, you may receive no benefit from participating in this study.

> Department of Psychology Buchtel College of Arts and Sciences Akron, OH 44325-4301 330-972-7280

The University of Akcon

All participants who turn in a survey will receive \$10 in vouchers/gift certificates at the time they turn in the survey. All participants who are interviewed will receive another \$10 in vouchers/gift certificates for their time, at the end of the interview.

Your confidentiality will be protected throughout the study and only the researcher and her advisor will have access to the surveys and the audio recordings of the interviews (if you decide to participate in that part of the project). Any identifying information collected will be kept in a secure location (locked cabinet or storage area) and only the researcher and her advisor will have access to the data. The audio recordings will be crased at the completion of the project. Participants will not be individually identified in any publication or presentation of the research results. Only aggregate data will be used. Your signed consent form will be kept separate from your data, and nobody will he able to link your responses to you.

If you have any questions about the research project, you may contact Adriane at (330) 972-7280, or her faculty advisor Dr. Charles A. Waehler, Associate Professor in the Department of Psychology, at (330) 972-6701.

This project has been reviewed and approved by The University of Akron-Institutional Review Board. If you have any questions about your rights as a research participant, you may call the IRB at (330) 972-7666 or 1-888-232-8790.

Thank you for your participation!

Part 1:

I have read the information provided above and all of my questions have been answered. I voluntarily agree to participate in this study. I will receive a copy of this consent form for my information.

Participant Signature

Date

£,

#### Part 2:

I consent to participate in this project and further agree that my interview responses may be digitally recorded and transcribed;

Participant Signature

Date

APPS 1