Summer 2016

Narrative Processes and Well-being in the Context of Chronic Illness

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Narrative Processes and Well-being in the Context of Chronic Illness

By

Hannah Shucard

Accepted in Partial Completion
Of the Requirements for the Degree
Master of Science

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Hannah Shucard
July 11, 2016
Narrative Processes and Well-being in the Context of Chronic Illness

A Thesis
Presented to
The Faculty of
Western Washington University

In Partial Fulfillment
Of the Requirements for the Degree
Master of Science

By
Hannah Shucard
July 2016
Abstract

The purpose of the current study was to broaden research on how narrative processes relate to well-being by examining narratives of an ongoing challenge in a novel context - living with a chronic health problem - as narrative researchers have focused primarily on discrete past events. By studying self-defining illness memories of a sample of midlife adults living with chronic health problems, I was able to examine the relation between narrative processes and well-being in the context of an ongoing event. Results indicate, as hypothesized, that both positive resolution and agency were associated with well-being. However, in contrast to my hypothesis, the narrative processes did not mediate the relation between physical health and well-being. These findings have implications both for the study of narrative processes as well as for individuals living with chronic health problems.
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Narrative Processes and Well-being in the Context of Chronic Illness

The ways in which people narrate their past experiences have implications for their identities (McLean, Pasupathi, & Pals, 2007; McLean, Syed, Yoder, & Greenhoot, 2014), their well-being (Adler, Lodi-Smith, Philipe, & Houle, 2015), and their health (Pennebaker & Seagal, 1999). In particular, narrative characteristics such as coherence, expressions of personal growth, and positive endings have consistently been associated with well-being (Lilgendahl & McAdams, 2011; Pals, 2006). This research gives us clear empirical knowledge of what constitutes a ‘healthy story’ about the past, which is important for applied contexts such as therapy (Adler, 2012; Singer, Blagov, Berry, & Oost, 2013). However, the extant empirical work has been oriented towards challenging past events, overlooking the role that ongoing challenges may play in well-being, despite the fact that many people may experience ongoing challenges. Additionally, recent findings have shown that it is important to consider not only how narratives are told, but also the content of those narratives, to understand how narrative processes relate to well-being (Greenhoot & McLean, in preparation; McLean, Syed, & Shucard, 2016).

The purpose of this study was to broaden research on what makes a story “healthy” by examining how individuals narrate a challenge that is still occurring at the time of narration. One ongoing challenge that can greatly affect the lives of midlife adults is living with a chronic illness. The diagnosis of a chronic illness represents a non-normative, disruptive life event that causes ongoing physical and psychological distress (e.g. Kralik, 2002; Sidell, 1997). In addition to representing an ongoing challenge, health problems also represent a specific narrative content, thus addressing the call for more attention to what stories are actually about (Syed & McLean, 2014).
Storying Challenging Life Events

People experience a variety of challenging life events, such as the death of a loved one, divorce, or job loss, which they narrate in a variety of ways. Of particular interest here are patterns of narrating these events that are associated with well-being. Broadly speaking, researchers have found that narrators who report growth from and resolution to past challenges also experience better psychological and physical health. For example, in one study about narrating difficult past events (Pals, 2006), individuals who described themselves as experiencing positive change(s) as a result of a challenging past event experienced higher life satisfaction and better physical health nine years later. Additionally, individuals with narratives that were resolved coherently and positively also had higher life satisfaction nine years later. Similarly, in a study of narratives about learning that one’s child had Down Syndrome, researchers found that narratives with a happy ending predicted increased well-being - in this case, life satisfaction, a sense of coherence, optimism, and self-esteem - two years later (King, Scollon, Ramsey, & Williams, 2000). Taken together, these findings suggest that narrating past challenges so that they end on a positive note is predictive of future well-being. One question I raise however, is whether or not one can find closure if a challenge is still ongoing.

Narrative identity and ongoing events

According to the theory of narrative identity, we come to understand who we are through an internalized, evolving, and integrative story about our lives (McAdams, 2001). This life story, which is composed of autobiographical memories and life scripts (Singer, Blagov, Berry, & Oost, 2012), gives structure to the events that people
experience, and creates a sense of coherence and continuity across the lifespan (Bluck & Habermas, 2000; McAdams, 2001).

Empirically, narrative research has focused almost exclusively on memories of discrete past events. Although, at first this may appear to be an oversight because it neglects the importance of current life events, it accurately reflects the life story model of identity established by McAdams (2001). According to McAdams, the stories that an individual tells about his/her life come together to form one’s identity through a subjective reinterpretation of one’s past. This reinterpretation reflects how an individual perceives his/her present experience as well as the anticipation that one has for the future.

Narrative researchers have also limited their focus to the past due to the underlying assumption that it is necessary to have time between when events occur and the present in order to make meaning of them and understand their impact on identity (Conway, Singer, & Tagini, 2004), an assumption that has received some empirical support. For example, Habermas and Berger (2011) tested the effect of temporal distance on narrative style by examining narratives of emotional events one week after they occurred and then three months later. They found that attempts to problem solve in the narrative and evaluations of the event changed over the three months. Negative events, in particular, were more resolved three months later suggesting that as distance from an event increases interpretations of the event also change. Fivush and Sales (2006) also addressed the issue of temporal distance by examining mother-child conversations about two different types of events related to the child’s asthma - a discrete challenge and an ongoing challenge. They found that the use of emotional language and explanations were higher when discussing an acute asthma attack versus the ongoing challenge of having
asthma. These studies highlight the effect that temporal distance can have on narrative processes. It is for this reason that memories must be more than a year old to be considered as self-defining and is why many narrative processes, such as autobiographical reasoning and self-event connections, rest on temporal distance between the event and when it is being narrated (Lilgendahl & McAdams, 2011).

Although some researchers (e.g. Adler, 2012; Fivush & Sales, 2006; Habermas & Berger, 2011) have begun to examine the role of temporal distance, by focusing on narratives of past events, most researchers have failed to fully examine the issue of time as they have not taken into account the present. Some researchers have even purposefully removed any narratives from their analyses in which a challenging event was still ongoing at the time of the study (e.g., Pals, 2006) (and in many studies this aspect of time is either not evaluated or not a part of analyses). Pals’ (2006) decision to remove these ongoing events indicates a recognition that ongoing events may be processed differently than past events. Thus, although the life story theory has been useful in capturing processes important to narrating past events, little research has actually examined how people narrate the present and/or future; therefore the full scope of the theory remains relatively untested (Syed & McLean, in press).

The Importance of Narrative Content

Broadly, the majority of narrative research has focused on narrative processes, such as growth and resolution (Syed & McLean, 2014), which are central to understanding the relation between narrative construction and well-being. This means, however, that little attention has been given to the content of narratives, or what the narratives were about. Attention is beginning to shift to content, with a recent and
growing body of empirical evidence that shows that taking content into account matters for both identity development (McLean, Syed, & Shucard, 2016) and well-being (Greenhoot & McLean, in preparation). For example, in a study of narratives about different identity domains (e.g. family, dating, values), McLean and colleagues (2016) found that participants made more meaning in their narratives when writing about certain domains, such as religion, compared to other identity domains. This suggests that narrative processes differ depending on the content of the narrative. Narrative content might be especially relevant in the context of challenging events, because what one person considers challenging, another may deem manageable. To attempt some control over this variability, I chose to examine a life event that is both challenging and ongoing, but that concerns one content domain: chronic illness.

**Chronic Illness as Biographical Disruption**

Chronic illnesses are defined by three key features: duration, impact on daily functioning, and the need for ongoing medical care (Goodman, Posner, Huang, Parekh, & Koh, 2013). Such illnesses represent a long-term burden, requiring adjustment in all domains of one’s life. Even after initially adjusting to diagnosis, individuals must continuously re-adjust as physical limitations, and symptoms change and develop over the course of the lifespan.

One of the important functions of constructing a life story, or narrative identity, is to provide a sense of continuity across time (McAdams et al, 2006; Pasupathi, Mansour, & Brubaker, 2007). That is, a healthy life story allows individuals to see connections between who they were in the past with who they currently are. Continuity can stem from the way that people construct their life story (Linde, 1993; Pasupathi, Mansour, &
Brubaker, 2007); it can also come from following cultural scripts for how a life should be lived (Habermas, 2007), and from experiencing life events in culturally or societally appropriate order (Elder, 1998; Habermas, 2007). That is, when life events occur out of order, or the normal life course is disrupted, people often experience distress.

One example of a distressing biographical disruption is the diagnosis of a chronic illness in midlife. Older adults and the elderly anticipate living with health problems (Wethington, Kessler, & Pixley, 2004), but relatively good health is expected earlier in the lifespan. For midlife adults who are living with a chronic illness then, the typical distress resulting from their illness is compounded by the fact that their illness also represents a non-normative event. Thus, when a midlife adult experiences a chronic illness, it represents a mistimed event (Elder, 1998) that heightens one’s awareness of death (Sidell, 1997), and disrupts the normal life course expectations (Erikson, 1963; Habermas, 2007).

**Health and Well-being in the Context of Chronic Illnesses**

In addition to being a biographical disruption, chronic illnesses are also distressing due to physical limitations and other bodily issues that they cause. The amount of distress that individuals experience as a result of their illness is often a function of their health status. Although chronic illnesses are broadly experienced as distressing events, health status can vary quite broadly both between and within types of illnesses. That is, individuals with arthritis may experience more physical limitations than those with cancer; however, one individual with cancer may also experience more physical limitations than another. Thus, measuring health status is important, as it is an
indicator of how well an individual is adjusting to their illness, as well as of their well-being (Stewart et al, 1989).

In the current study, participants reported a myriad of chronic illnesses, each of which may have a very different impact on an individual’s life; therefore, it was important to measure physical health status in a variety of ways. One objective indicator of health status is participants’ ability to perform instrumental activities of daily living (IADLs). IADLs are a good indicator of an individual’s functional status or level of independence and tend to be without subjective bias (Graf, 2013). Subjective indicators also provide important information about how an individual experiences his/her illness. One of the most commonly used subjective indicators is health-related quality of life (HRQoL; Stewart et al, 1989). HRQoL is different than physical functioning as measured by the IADL scale because it focuses on quality of life (as opposed to just functional ability) and often includes well-being subscales, in addition to physical functioning. Illness perceptions are also commonly examined as a subjective indicator of health status for individuals living with chronic health problems. The perceptions that individuals hold about their illness create a framework in which they can make sense of their illness by providing individuals with cognitive models of their illness’ cause, timeline, and consequences (Weinman, Petrie, Moss-Morris, & Horne, 1996).

**Linking Physical Health to Narrative Processes**

A strong line of research on written emotional expression has shown that writing about emotional events in one’s life can have positive physical health benefits (Smyth, 1998). For example, Pennebaker (1997) has found that participants who write narratives about emotional experiences go to the doctor less often and have better immune function
(among other health benefits) than those asked to write about superficial topics. Despite these findings that narration can influence physical health, narrative researchers have given little attention to the influence of physical health, instead focusing on understanding how narrative processes relate to psychological health. Recently, however, researchers have begun to look at associations between physical health and narrative processes with mixed findings.

In Pals’ (2006) longitudinal study of midlife women narrating challenging events, she found that individuals who had positive self-transformations in their narratives had better physical health nine years later than those who did not. Adler and colleagues (2006; 2015) however, found no associations across three different samples between physical health and several different narrative processes - contamination sequences (narrative arc from good to bad), redemption (narrative arc from bad to good), agency (the amount of control the protagonist displays), or communion (coming together in caring relationships). These results are somewhat surprising given the number of narrative processes they examined and the fact that they looked at individuals both with and without chronic illnesses. It is important to note that the narratives collected from their chronic illness sample were collected prior to diagnosis, meaning that the narrative processes they used may not be the same as those that they may use post-diagnosis. Additionally, they only measured one indicator of health status, HRQoL, which may not have captured a complete picture of physical health. This is one reason that the current study involves multiple indicators of health status.

Current Study
The primary goal of this study was to test whether the narrative processes that have been found to be associated with well-being when narrating a single event also predict well-being in the context of an ongoing event. To this end, participants were asked to write a narrative about an ongoing challenge—living with a chronic illness—which were then coded for the narrative processes of positive resolution and agency.

Researchers have found that the way that stories end is important for well-being outcomes (Adler, Lodi-Smith, Phlippe, & Houle, 2015). Specifically, ending stories in a positive and resolved manner has been shown to be important in the context of challenging events, as evidenced by Pals’ (2006) research on difficult past events of midlife women and King and colleagues’ (2000) study on parents of children with Down Syndrome. As previously discussed, living with a chronic illness is challenging for many reasons – thus given the importance of positive resolution in previous research on challenging events I anticipated that positive resolution would be similarly implicated in this novel context- living with a chronic health problem.

In terms of examining events that are distinctly in the past versus ongoing, one of the few studies to examine the narrative construction of a present experience is a longitudinal study of psychotherapy by Alder (2012). This study followed clients over the course of 12 therapy sessions and asked them to write a narrative about their experience in therapy and how it affected their sense of self following each session. These narratives were not coded for their level of resolution, but were coded for the narrative theme of agency. Alder found that there was a change in narrative processes over time such that the theme of agency increased over the course of therapy, and was associated with improvements in mental health over time. Further, changes in agency preceded changes
in mental health. These results suggest that agency is another narrative process that may be important for well-being when facing an ongoing challenge. Further, not only has agency been implicated in narrative research, but research in other areas has shown that agency, or psychological control, is important for adjusting to chronic illness (e.g. Taylor & Brown, 1994); thus, I hypothesized that narrative agency would also be an important indicator of well-being in this context.

In addition to narrative styles, the well-being of individuals living with chronic health problems is also influenced by the severity of their illness (e.g. Stewart et al, 1989). Although chronic illnesses can often be managed, many of the physical limitations that individuals experience as a result of their illness cannot be changed. As such, well-being must be improved through other means. One way to potentially ameliorate individuals’ experiences is by changing the way in which they tell stories about their lives, a hypothesis that I took the first step towards addressing by examining whether positive resolution and agency acted as mediators between an individual’s health status and his/her well-being.

The current study was designed to investigate the following hypotheses about the relationship between narrative processes and well-being in the context of chronic health problems:

1. Positive resolution and agency will be associated with well-being, above and beyond demographics typically associated with well-being (e.g., Adler, Lodi-Smith, Phlippe, & Houle, 2015).

2. Positive resolution will mediate the relationships between health status and well-being.
3. Agency will mediate the relationships between health status and well-being.

**Method**

**Participants and Procedure**

Participants were recruited from Amazon’s MTurk under the restriction that they were 40-60 years old, U.S. residents, and had at least 90% approval rate for their previous tasks. Since workers on MTurk are from all over the world, these restrictions allowed me to control for language ability and other demographics, as well as to ensure that the participants provided high quality data.

Table 1 shows the measures used in the current study based upon their timing. Table 2 gives a breakdown of participant’s demographic information by wave. Table 3 shows the breakdown of education level across waves, and Table 4 shows their employment status.

**Wave 1.** An initial sample of 1,274 participants completed a pre-screening survey that included demographic questions as well as a brief health history (Sirois & Glick, 2002). Completing these measures took less than ten minutes. The brief health history was used to screen for people who have a chronic illness. Because this is a study of ongoing events, I was also concerned with obtaining a sample that showed variability the current impact of the chronic illness on their daily functioning. That is, I wanted to have participants whose day to day lives are currently impacted by their chronic illness as well as those who have been diagnosed with a chronic illness but are less impacted by it on a daily basis. Thus, I used participants’ ratings of illness severity (as elicited by the brief health history) to attempt to obtain an equal breakdown of severity level. Table 5 shows participant invitation and completion rates based on the illness severity.
All questions for this wave can be found in Appendix C. In line with the average rate of pay (Shapio, Chandler, & Meuller, 2013) participants were paid $0.05 for completing this survey. Four hundred and sixty-four participants were invited to participate in the second wave of the study, based on the fact that they met the screening criteria in Wave 1 and reported having a chronic illness.

**Wave 2.** The second wave involved completing a number of well-validated measures of health, well-being, and personality. This part of the study took participants approximately 30 minutes to complete. Participants completed this wave of data collection approximately one week after they completed Wave 1. The measures that they were given are as follows (in the order that they were given): Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985), Wellness Behaviors Index (Sirois, 2001), Instrumental Activities of Daily Living Scale (Graf, 2013), Medical Outcomes Short-form (Ware & Shelbourne, 1992), Illness Perceptions Questionnaire (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Bluck, 2002) Neuroticism subscale of the Neuroticism, Extraversion, and Openness Scale (NEO; Costa & McRae, 1985), Perceived Stress Scale (Cohen, Kamarack, & Mermelstein, 1983), and the Center for Epidemiological Studies Depression Scale (Radloff, 1977). The Satisfaction with Life Scale was given first so that responses to this scale were not influenced by participants’ thoughts about their illness. The health measures started with the most general and end with questions specifically about the chronic illness. The survey ends with the perceived stress and depression scales so that health status information was not contaminated by
thinking about levels of stress and depression. Placing these scales after health status questionnaires is common in chronic illness research.¹

All measures for this wave can be found in Appendix D. Participants who answered at least 75% of the items on each scale and did choose the same response option for an entire survey, were paid $0.80 for their participation, and were invited to complete the third wave during which they were asked to write several narratives as well as give a rating of their current mood. Of the 309 participants who completed Wave 2, 290 of them met these criteria and were invited to participate in Wave 3.

**Wave 3.** In the third wave, participants were asked to write four narratives: the chapters of their lives, a self-defining memory (Singer & Blagov, 2002), the chapters of their illnesses (McAdams, 1995), and a memory about their illness (adapted from Singer & Blagov, 2002). For the purposes of this thesis, only the illness memory was of interest; the other prompts are to be used in future analyses. Participants completed this wave of data collection approximately one week after completing Wave 2. After writing the self-defining memory and illness memory, they were asked to respond to several questions about sharing each of the memories (Pasupathi, McLean, & Weeks, 2009) and how central the memories are to their identity (Berntsen & Rubin, 2006), which are not part of the present analyses. Finally, they provided a rating of their current mood (Watson, Clark, & Tellegen, 1988). Although individual completion times varied, this part of the study took approximately one hour to complete.

¹ I had planned to use neuroticism and negative affect as covariates as they are known to influence both narration (e.g. Bauer, McAdams, & Sakaeda, 2005; Lilgendahl, McLean, & Mansfield, 2013), symptomology, (Affleck, Tennen, Urrows, & Higgins, 1992), and illness perceptions (Watson & Pennebaker, 1989). I was unable to use neuroticism due to a clerical error and unable to use negative affect due to a skewed distribution. These issues are discussed in further detail in Appendix A.
The narrative prompts can be found in Appendix E. Participants were paid $1.50 for completing the narratives. Participants had to complete all narratives in line with their associated instructions (i.e. at least one paragraph for the memories and at least 3 sentences for the chapters) in order to be paid for their participation. Of the 197 participants who completed Wave 3, 191 of them were included in the final sample. Three participants were excluded because they did not write complete narratives; three were excluded because they reported having no chronic health problem (despite reporting at least one in Wave 1).

The final sample of participants included in the subsequent analyses (75.5% female, 90.4% white; $M_{\text{age}} = 49.27, SD = 5.88$) reported a variety of different health problems. The most commonly reported health problems were chronic back problems (14%), diabetes (9%), and arthritis (8%). The average length of primary chronic illness that participants reported was 16 years ($SD = 11.84$). Many participants also reported having multiple chronic health problems, with approximately 40% of participants reporting a more than two chronic health problems. Additionally, participants varied in their ratings of their overall health; 4% rated their health as excellent, 24% rated their health as very good, 34% rated their health as good, 27% rated their health as fair, and 5% rated it as poor.

**Measures**

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2 Other reported health problems (in descending order): chronic pain (16%), mental health problems (13%), high blood pressure (6%), asthma (6%), (5%), neurological problems (4%), other chronic health problems, chronic migraines (3%), heart disease (3%), fibromyalgia (3%), inflammatory bowel disease or irritable bowel syndrome (2%), multiple sclerosis (2%), chronic fatigue (1%), cancer (1%), liver disease (1%), kidney stones (1%).
All measures can be found in the Appendices (C-E) in the order in which they were given; this order is also represented in the order in which the measures are described below. Recruitment, consent, and debriefing information can be found in Appendices F and G.

Wave 1.

Demographics and screening questions. Participants answered the following demographic questions during the first wave of the study: age, gender, marital status, education, socio-economic status (SES; measured using the The MacArthur Scale of Subjective Social Status; Adler & Stewart, 2007), mental health problems, chronic illnesses screening (measured using the Brief Health History; Sirois & Glick, 2002), health insurance, religion, and ethnicity. The two scales used are described below; the rest of the measures were all single items.

Socio-economic status. The MacArthur Scale of Subjective Social Status was used to measure SES (Adler & Stewart, 2007). This is a single item scale that asks participants to indicate where they are on a ladder, relative to other people in the United States. The top of the ladder represents people who are the best off in the country and the bottom of the ladder represents those who are the worst off; thus, higher scores reflect higher SES. Scores range from 1-7, with higher scores representing higher SES. The average SES for the final sample was 3.87 (SD = 1.40).

Chronic illness screening. The Brief Health History questionnaire (Sirois & Glick, 2002) was used as a screening questionnaire to establish whether participants had chronic health problems as well as the severity of those health problems. Participants were asked to indicate whether or not they have had the acute or chronic physical health
problems in the past 3 months as well as the severity of the chronic health problems (from not bothered to extremely bothered). This scale includes 13 acute physical health problems (e.g., colds, headaches, digestive problems) and 10 chronic physical health problems (e.g., asthma, diabetes, arthritis). For participants who reported multiple chronic health problems, I measured their severity level as the highest one indicated. Table 4 shows a breakdown of completion rates for each wave of data collection based on illness severity reported in the Brief Health History.

Wave 2.

Positive well-being. Positive well-being was measured using Diener’s Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985). This scale includes five items (e.g. I am satisfied with life) which are rated on a seven-point Likert scale (1 = strongly disagree, 7 = strongly agree). A mean score is calculated, with higher scores equalling greater satisfaction with one’s life (α = .92). The average score for the final sample was 4.16 (SD = 1.51).

Health-related quality of life. To assess subjective health, health-related quality of life (HRQoL) was measured using the Medical Outcomes Study Short-Form 36 (SF-36; Ware & Shelbourne, 1992). This is a generic HRQoL measure, meaning it is not disease specific. It covers eight health domains: physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. The scale includes 36 items such as, “During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?” The items have a mixture of response options (e.g. yes/no, Likert Scales). Subscales are scored by summing responses across subscale items,
with higher scores indicating better physical HRQoL. For the purpose of this study only the physical health composite (composed of the first four domains) was examined ($\alpha = .95$). Scores were adjusted to be on a 1 to 5 scale so as to be on the same metric as the narrative processes and well-being measures, which were all on five-point scales. The average (adjusted) score for the final sample was 3.42 ($SD = 1.25$)

**Objective health.** A number of questions regarding participant’s objective health were designed for the purpose of this study. Three items from this questionnaire (“How many doctors do you have? How many times have you gone to a doctor in the past month? and Please list any medications you are currently taking”) were collapsed to form a composite indicator of objective health status ($\alpha = .74, M = -0.01, SD = 0.81$).

**Perceived Stress.** Perceived stress was measured using the Perceived Stress Scale (PSS; Cohen, Kamarck & Mermelstein, 1983). The PSS is a widely used 10-item scale with questions such as “In the last month, how often have you felt nervous and "stressed"?” Questions are rated on a 5-point Likert scale from never to very often. After reverse scoring four items, a mean score was calculated, with higher scores representing higher levels of stress ($\alpha = .93, M = 2.77, SD = 0.78$).

**Depression.** Depression symptomology was measured using the Center for Epidemiology’s Studies Depression Scale (CES-D; Radloff, 1977). The CES-D contains 20 items on a 4-point Likert scale, from rarely or none of the time, to most or all of the time. Items include statements such as “I felt fearful,” or “I had crying spells” and refer to the past week. The CES-D is a widely used measure in studies of stress and coping and psychological well-being (Lewinsohn, Seeley, Roberts, & Allen, 1997). After reverse-
scoring two items, a mean score was calculated. Higher scores represent higher levels of depression symptomology \((\alpha = .91, M = 0.95, SD = 0.70)\).

**Negative well-being.** As anticipated, perceived stress and depression were strongly positively correlated with one another \((r = .80, p < .01)\), suggesting a high degree of overlap between scales. Thus, I created a composite variable to capture negative well-being \((\alpha = .89)\). The average negative well-being score for the final sample was -0.01 \((SD = 0.94)\). Life satisfaction was negatively correlated with both perceived stress \((r = -.47, p < .01)\) and depression \((r = -.44, p < .01)\), though there was less empirical and conceptual overlap between these assessments; thus I elected to preserve life satisfaction as an assessment of positive well-being. These two indicators of well-being are analyzed separately in the following analyses.

**Wave 3.**

**Narrative Prompts.** For the purpose of this thesis, the narrative of interest is the illness memory, which allowed me to consider the question of whether the narrative processes that are “healthy” when narrating discrete past events are the same when narrating an ongoing event. In addition to the illness memory, participants were also asked to respond to three other narrative prompts: the chapters of their life story, a self-defining memory, and the chapters of their illness; these narratives will be used in future analyses.

Participants began by describing the chapters of their life story. This prompt comes from the Life Story Interview (McAdams, 1995), which is commonly used in narrative research. It acts as an opener that helps people to begin thinking about their life story. Next, participants were asked to write a self-defining memory. The self-defining
memory prompt is taken from Singer and Blagov (2002) and is also widely used in narrative research. It asks a number of specific questions in order to get participants to think of a memory that is self-defining which participants are then asked to write down. After writing a self-defining memory, participants were asked a number of questions regarding whether or not the memory has been shared (Pasupathi, McLean, & Weeks, 2009) as well as the Centrality of Events Scale (Berntsen & Rubin, 2006). Following this, participants were asked to describe the chapters of their illness, similar to the chapters of their life story. Finally, they were asked to provide an illness memory. The prompt for the illness memory was created for this study and is based on the self-defining memory questionnaire but the wording of the prompt was changed to ask specifically for a memory that represents their illness experience. After writing this narrative, participants were again asked to respond to several memory telling questions (Pasupathi, McLean, & Weeks, 2009) and the Centrality of Events Scale (Berntsen & Rubin, 2006) which were not used in the current analyses.

Several surveys were administered but were not used in analyses for various reasons, an explanation of which can be found in Appendix A.

**Narrative coding**

All narratives were coded by the author according to the subsequent coding systems. A subset of the narratives (20%) were be coded for reliability purposes by a trained undergraduate research assistant. We reached acceptable reliability for both positive resolution (ICC = .75) and agency (ICC= .86).

**Positive resolution.** The extent to which individual’s narratives end on a coherent and positive note was coded using Lilgendahl’s coherent positive resolution coding
below (adapted from Pals, 2006). Narratives were rated on a 1 to 5 scale \( M = 3.10, SD = 1.40 \). A score of 1 was given to narratives that were very unresolved, a score of 2 was given to narratives that were somewhat unresolved, a score of 3 was given to narratives that were mixed in their level of resolution or were neutral, a 4 was given to narratives that were somewhat resolved and 5 was given to narratives that were very resolved. An example of a statement that was scored as having low positive resolution is, “I am worried that I will be useless and a drain on my family.” An example of high positive resolution is, “I am so much happier now because of this decision.”

**Agency.** The amount of control or agency an individual expressed in their narratives was coded using a four-point scale based on Adler’s well-established coding system (e.g. Adler, 2012). The average score for the final sample was 2.74 \( (SD = 1.55) \). A low score on this scale (i.e. 1) was given to narratives in which the protagonist is completely at the mercy of their circumstances. A score of 2 was given to narratives in which the protagonist is somewhat at the mercy of circumstances. Narratives that contained a mixture of both agentic and non-agentic elements were given a scores of 3. A score of 4 was given to narratives in which the protagonist was minimally at the mercy of circumstances and a score of 5 was given to narratives in which the protagonist was agentic and has control over their own experiences. An example of a statement that was scored as having low agency is, “The, GOD decided that we needed to have another baby.” An example of high agency is, “I was 59 and knew it was time to finally have a knee replacement. I made all the arrangements and went to the hospital for the surgery.”

Appendix B shows the full coding instructions for both positive resolution and agency.
**Narrative content.** After reading the narratives, it became apparent that not all narratives were about a chronic health problem. Thus, each narrative was coded (by the author) for whether it was about an individual’s own experience of living with a physical health problem or something else. This type of analyses allowed me to examine whether participants followed our instructions. I found that 14% of the narratives were not about a physical health problem. While coding for content, the type of chronic health problem mentioned in the narrative was also noted so that it could be compared to other reports of health problems in this study to see if there was consistency across time points.

**Results**

**Preliminary Analyses**

I first examined relations between demographic factors and the main variables of interest – narrative processes, health, and well-being. Neither age, education level, nor SES was correlated with positive resolution (all $r’s < .02$, all $p’s > .17$) or with agency (all $r’s < .02$, all $p’s > .06$). An examination of the relations between demographic variables and well-being however, showed that greater education was significantly correlated with less negative well-being ($r = -.21, p < .01$), and higher SES was significantly associated with both greater positive and lower negative well-being ($r = .45, p < .01$, and $r = -.38, p < .01$, respectively). A series of $t$-tests revealed that there were no gender differences in narrative processes, well-being, or health outcomes (all $p’s > .06$), thus gender was not further examined in the analyses below. Ethnicity was not included in these analyses due to range limitations (sample was 90.4% white). As a result, only education and SES were included in the analyses below.
As can be seen in Table 6, the correlations between narrative processes, health, and well-being indicated that both positive resolution and agency were statistically significantly associated with negative well-being such that individuals with more positive resolution or agency in their narratives reported lower levels of negative well-being. However, only positive resolution was statistically significantly associated with positive well-being such that participants reporting greater positive resolution tended to report greater positive well-being. In terms of health status, both positive and negative well-being and positive resolution were statistically significantly associated with health-related quality of life (HRQoL). Positive resolution, negative well-being, and HRQoL were statistically significantly associated with objective health such that individuals with better objective health (i.e. those who scored lower) were higher in positive narrative resolution and reported better HRQoL, while those with poorer objective health had greater negative well-being and reported poorer HRQoL.

**Hypothesis 1: Relations between Narrative Processes and Well-being**

I hypothesized that positive resolution and agency would each predict positive and negative well-being above and beyond demographics. Partial correlations between narrative processes and well-being, statistically considering the relevant demographics (i.e., education and SES), indicated that positive resolution was associated with both positive well-being ($r = .20, p < .01$) and negative well-being ($r = -.21, p < .01$).

The relationship between agency and well-being was only significant for negative well-being (not positive well-being), indicating that individuals who demonstrated greater agency reported less negative well-being. Similar to positive resolution, when education
and SES were statistically considered, partial correlations between agency and negative well-being were significant \((r = -.16, p = .03)\).

**Hypothesis 2: Positive Resolution Mediates the Relation between Health and Well-being**

Hypothesis 2 was that positive resolution would mediate the relationships between health status and well-being. Meeting the first step of requirements, positive resolution was correlated with objective physical health \((r = -.16, p = .03)\), HRQoL \((r = .34, p < .01)\), positive well-being \((r = .21, p < .01)\) and negative well-being \((r = -.21, p < .01)\).

I tested mediation models using SPSS and PROCESS (Hayes, 2013), with HRQoL as a predictor of well-being in two separate models- one for positive and one negative well-being- with positive resolution as the mediator between the link between HRQoL and the well-being outcomes (Model 4, Hayes, 2013). Results indicated that positive resolution did not mediate the relationship between HRQoL and positive or negative well-being. The path coefficients are shown in Table 7.

I was unable to conduct the second proposed mediation model in which objective health was used to predict well-being, because the correlation between objective health and well-being was non-significant \((p > .05)\).

**Hypothesis 3: Agency Mediates the Relation between Health and Well-being**

Hypothesis 3 was that agency in the illness specific memory would mediate the relationship between health status and well-being. Because agency was not correlated with positive or negative well-being, objective health status, or HRQoL, this hypothesis could not be tested.
**Post-hoc Analyses**

While coding the narratives, it was noted that 25% of participants were not consistent in what they reported as their primary chronic health problem throughout the various sections of the study. Given this, in a post-hoc fashion, I examined whether there were differences between the participants who were consistent in how they reported their chronic health problem and those who were not. The results indicated that the significant associations between positive resolution and the well-being outcomes found for the entire sample only held when considering those who were inconsistent in their illness reporting. When considering agency and well-being, the association between agency and negative well-being that was significant for the entire sample became non-significant for both the inconsistent group and the consistent group, however agency was significantly associated with positive well-being for the inconsistent group. Additionally, the associations between narrative processes and well-being are stronger for the inconsistent group. These results suggest that there is something different about the group of participants who were inconsistent in their reports of their illness. Table 8 shows all correlations for both groups. Interestingly, the lack of consistency was not related to age ($r = .03, p = .66$), sex ($r = -.07, p = .33$), SES ($r = .05, p = .50$), the number of chronic health problems ($r = .04, p = .57$), or the number of mental health problems reported ($r = .11, p = .60$).

**Discussion**

The purpose of the current study was to examine whether the narrative processes associated with well-being when narrating a single event also predict well-being in the context of an ongoing event: living with chronic health problems. As hypothesized, positive resolution and agency were associated with well-being, beyond demographics.
However, positive resolution did not mediate the relation between HRQoL and well-being. Additionally, I was unable to test the mediation model involving agency as it was not related to either of the health status measures.

**Positive Resolution and Well-being**

In line with my first hypothesis, positive resolution was associated both positive and negative well-being above and beyond relevant demographics. This finding is in line with prior research showing that ending narratives on a positive, resolved note is associated with better well-being (e.g. Pals, 2006). This finding extends that prior research by showing that individuals can resolve their narratives, even in the context of an ongoing challenge (living with chronic health problem), as in the following narrative:

*This event happened on October 13, 2000 and has never ended. I'm tired of them, sick of them, but live one moment, one day at a time. I choose joy and will someday be free from these headaches. No one has any idea why they occur 24/7 and how to get rid of them. The only positive is I have an excuse for getting out of things I don't want to do!* :)

Narrative resolution has been defined as a *subjective* process that is separate from the *objective* resolution of events (Pals, 2006). The results of the current study- as exemplified above- support this conceptualization by demonstrating that individuals can have a positive, somewhat resolved interpretation of their illness (this narrative has a resolution score of 2) even if it is not a positive experience and even if it has no end in sight. This finding is important, as the current study is the first to examine positive resolution in narratives about an ongoing event. These results also add to the growing literature by showing that the way in which individuals end their narratives may be one of
the more important components of narrative construction with regard to well-being (see Adler et al., 2015). Additionally, the mean levels of positive resolution found in the current study are similar to those found in Pals’ (2006) study of discrete past events. These results suggest that narrating ongoing challenges may not differ from narrating past challenges, at least in terms of positive resolution.

It is important to note, however, that although the context of the current study was an ongoing challenge, participants were asked to provide narratives of events that were at least a year old, per the self-defining memory prompt. By asking for memories that were at least a year old, there should have been some distance from the event, which may have made the event easier to resolve. As Habermas and Berger (2011) demonstrated, greater distance from the time of event is associated with more closure or resolution in narratives. Although participants were asked for a past event however, some narratives still reflected a past event that was part of an ongoing set of experiences, as is evidenced in the example above. An important next step will be to code the narratives for the degree to which past events are connected to the present, to see if there is an influence on the relation between positive resolution and well-being. In line with Habermas and Berger’s (2011) findings, it is anticipated that events that are firmly in the past would have more positive resolution and stronger relations between positive resolution and well-being compared to those that are about ongoing events.

**Agency and Well-being**

The hypothesis that agency would be associated with well-being is in line with other studies that have shown that individuals who narrate stories in an agentic manner (i.e., they have a sense of choice and control over their lives) have higher well-being than
individuals who narrate stories in a less agentic manner (e.g. Adler, 2015; Adler, Skalina, & McAdams, 2008). The results of the current study partially supported this hypothesis, such that agency was associated with negative—but not positive—well-being above and beyond relevant demographics.

Much of the extant empirical data showing that narrative agency is important for well-being have been collected in a particular context—psychotherapy (e.g. Adler, 2012; Adler, Skalina, & McAdams, 2008). Writing about psychotherapy is quite different than writing about living with a chronic health problem. The finding that individuals in the current study who demonstrated greater agency in their narratives reported lower negative well-being not only replicates previous findings but also extends the study of agency and well-being to a novel context. As previously mentioned, recent evidence shows that associations between narrative processes and well-being rest in part on the content of narratives (Greenhoot & McLean, in preparation; McLean et al., in press). Given the differing content of narratives between the current study (chronic illness) and previous research (experiences while being in or recalling past psychotherapy), the addition of the current study’s results suggest that agency has implications for well-being in a variety of contexts. As with positive resolution, this finding is in line with previous research on agency and well-being that has found that motivational themes (e.g. agency) are important for well-being (Adler et al., 2015). Considering that previous research has focused on discrete past events, these findings also suggest that the narrative processes healthy for ongoing challenges are the same as those for discrete past events.

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3 It should be noted that prior to Adler’s work researchers did examine the relation between agency and well-being in contexts other than psychotherapy (e.g. Bauer & McAdams, 2004) however their coding system for agency varies greatly from what was used in the current study and thus the findings are irrelevant.
Positive Resolution and Agency do not Mediate Physical Health and Well-being

My last hypotheses were that positive resolution and agency would mediate the relation between physical health and well-being. These hypotheses stemmed from research that has shown that there is a well-established relation between physical health and symptom severity and well-being (e.g. Bener, Ghuloum, Al-Hamaq, & Dafeeah, 2012), and the idea that one way to ameliorate well-being may be through the way that one constructs the story about their illness, or their narrative processes. The results of the mediation analysis however showed that neither positive resolution nor agency mediated the relation between physical health and well-being, though for differing reasons.

Positive Resolution. The mediation analysis of positive resolution as a mediator of HRQoL and well-being showed that positive resolution did not mediate either of these relations, meaning that the relation between positive resolution and well-being did not hold when physical health was taken into account. Prior research has shown that there is a strong relation between physical health and well-being (e.g. Bener, Ghuloum, Al-Hamaq, & Dafeeah, 2012; Stewart et al., 1989), therefore in order to mediate this relation the mediator would need to be highly influential. In the current study positive resolution was only measured in a single narrative. One possibility is that in order explain the relation between physical health and well-being one would need to measure positive resolution in a number of narratives (e.g. across the life story interview) and aggregate them in order to capture an individual’s narrative “style”, if he or she has one (see McLean et al., in press).

Agency. I was unable to test whether agency mediated the relation between physical health and well-being as agency was not associated with either measure of
physical health (objective health or HRQoL). This finding replicates previous research (Adler et al., 2015) that found that agency was not associated with HRQoL. Considering the measurement limitations in previous research examining agency and physical health that may have obscured the relationship between the two variables, the current study measured physical health in more ways than in previous research. In the end however, I ended up using the same physical health measure for HRQoL that Adler et al did, thus it is not surprising that their results were replicated.

In addition to measurement issues, another problem with the hypothesized mediations is the lack of temporal framing for the model. Previous longitudinal research has shown that changes in agency occur prior to improvements in mental health (Adler, 2012), thus supporting the direction in the relationship between agency and well-being. However, in my more recent review of the literature it became evident that there was no precedent for having the measurement of physical health precede narrative processes. Indeed, previous studies examining narration and physical health have all been designed for the measurement of narrative processes to occur prior to measuring physical health (e.g. Adler et al., 2015; Pennebaker, 1997). For example, Adler’s study of individuals with the diagnosis of a chronic illness examined narrative processes prior to diagnosis and then considered physical and mental health. Similarly, Pennebaker (1997) asked individuals to write emotional memories and then physical health was assessed at a subsequent time point. Although it is possible that individuals adjust how they narrate following health problems, as I hypothesized, longitudinal research examining this process is necessary in order to truly test the hypothesized mediations.

**Limitations**
**Measuring Health**

In the current study I tried to measure health both subjectively (using HRQoL) and objectively. I did this because the way that an individual subjectively views their health may be closely related to the way that they narrate, thus making it difficult to untangle whether narrative processes actually mediate the relation between physical health and well-being. Obtaining a good measure of objective health however was quite complicated and my measure of objective health did not appear to be as strong of a measure of physical health as the HRQoL measure. One explanation for this difficulty is that participants in the current study did not all have the same health problems. Given this, I used generic or non-disease specific measures of health. It may be that measures of objective health status need to be tailored specifically to each illness type because different illnesses are differentially associated with different types of impairments.

Another problem that I encountered when trying to measure health in this study was the lack of consistency in illness reporting across time. Participants were asked to report their primary chronic health problem two times - once in Wave 2 and once in Wave 3. There was also the assumption (and explicit request) that their narrative would be about the same primary health problem. Thus, there were three different opportunities for participants to report their primary chronic illness. In looking at the data however, it quickly became evident that this was not the case. An analysis of the three different illness reports highlighted this; approximately 75% of participants reported the same health problem at all three opportunities and 25% of participants did not. Fifteen percent of those participants wrote about the same health problem that they reported during Wave 3 but this health problem differed from what was reported one week earlier in Wave 2.
The rest of the participants either reported the same health problem at Wave 2 and Wave 3 but wrote about something else in their narratives, or had no consistency between reports.

The lack of consistency in illness reporting highlights the fact that individuals living with multiple chronic illnesses may be differentially affected by their illnesses depending on the day. Because I asked participants to list the health problem that bothered them the most as their primary chronic illness I am likely responsible for eliciting this variability. This variability is quite influential though, as post-hoc analyses showed that, in general, the relations between narrative processes and well-being outcomes were stronger for participants who were inconsistent in their reporting.

Untangling what these results mean is difficult, given the fact that this inconsistency was not associated with any of the variables of interest in this study. Studies of individuals living with multiple chronic health problems have consistently shown that the more chronic health problems individuals have, the more burdened they are by their diseases (see Fortin, Soubhi, Hudon, Bayliss, & van den Akker, 2007 for a review). Importantly, it is not simply the number of chronic health problems that an individual has but the cumulative severity of those illnesses that influences outcomes such as psychological distress (Fortin, Bravo, Hudon, Lapointe, Dubois, & Almirall, 2006) and quality of life (Fortin, Bravo, Hudon, Lapointe, Dubois, Almirall, et al., 2006). Based on the fact that participants in the current study were asked to report their primary chronic illness as the one that bothered them the most, it is possible that the inconsistent participants were experiencing greater cumulative severity and that narrative processes are more beneficial in ameliorating the burden experienced by individuals with greater cumulative severity.
In order to test this, future studies should include a better measure of disease burden such as the Cumulative Illness Rating Scale (Linn, Linn, & Gurel, 1968) that measures the level of impairment individuals experience as a result of their illnesses.

The Timing of Measurements

In addition to using different measures of disease burden, another way of resolving the consistency issue would be to measure everything at a single time point. In this study, data was collected from participants at three different time points; this was done so that participants with chronic illnesses could be recruited without being explicitly told that the study was about living with chronic health problems and also so as to reduce the burden of participation by breaking the study up into several shorter sections rather than one long one. Several participants noted that writing the narratives took a long time, thus it is important that the study was broken up the way that it was. However, as previously noted, conducting the study in three waves also introduced more variability in the data. In addition to contributing to the lack of consistency in illness reporting, having multiple waves of data collection may have also been problematic for measuring agency. Perceived control, or agency, has been shown to have important implications for coping with and adjusting to chronic illnesses (Endler, Kocovski, & Macrodimitris, 2000). Additionally, illness severity has been found to be both a moderator and a mediator for the relation between perceived control and adjustment, indicating that the severity of one’s illness is critically linked to their perceptions of control. As discussed above, the data from the current study suggest that many individuals in this study were differentially affected by different illnesses throughout the study. That means that the severity of each of their illnesses may have been changing over the course of the study, thereby
potentially influencing their level of perceived control or agency. This would not be problematic if agency, health, and well-being were all measured concurrently, however agency was measured one week after the physical health and well-being measures were given. Therefore, the data may reflect mismatched reports of health status and agency which would not have occurred if they had been measured at the same time.

**Future directions**

This study originally stemmed from a desire to understand what a healthy story looks like for individuals living with chronic health problems. As previously discussed, researchers have established the characteristics of a healthy story in a variety of contexts, such as challenging life events, but narratives about living with a chronic illness have not been examined prior to the current study. Although the results of this study begin to address what a healthy story looks like in this context, questions surrounding narration and chronic illness still exist. Several potential future directions for this data are discussed below.

**Narrative Processes in Non-illness Narratives**

In the current study I examined narratives about a self-defining illness memory. In addition to this illness memory, participants also wrote a domain-free self-defining memory; that is, a self-defining memory about content of their choosing. One of the next steps in understanding the association between narrative processes and well-being in this context is to code the domain free self-defining memories for positive resolution and agency and comparing these results to the results of the current study. Doing this will allow me to see whether the relations between narrative processes and well-being differ depending on whether the narrative is about chronic health problems or another non-
illness topic (most of the domain-free self-defining memories are not about chronic health problems).

Another important argument for examining non-illness narratives is that researchers have found that there is intra-individual variability in narrative processes, meaning that narrative processes differ depending on narrative content or type that participants are asked for (McLean, Syed, & Shucard, 2016; McLean et al., in press). Given this, it is important to examine the narrative processes in the other self-defining memory as the way that individuals narrate may differ depending on the content domain that is asked for and may differentially relate to well-being. For example, previous research on agency and well-being has found stronger associations between agency and well-being than what I found in the current study (Adler, 2012; Adler, Skalina, & McAdams, 2008) which indicates that there may be something different about writing about one’s health. By studying both the domain specific illness memory and the domain-free self-defining memory I will be able to compare the two different types of memories in order to more closely examine health as a narrative content.

**Illness Characteristics and Narrative Processes**

In addition to examining positive resolution and agency in the domain-free self-defining memories another important next step is to consider how illness characteristics may influence the narrative processes in the self-defining illness memory. For example, the length of time an individual has been living with their chronic health problem may influence how resolved their narratives about their illness are. Individuals with longer illness duration will have had more opportunities to construct a story about what it is like
to live with their illness thus it may be easier for them to narrate a story that is more resolved.

In addition to the illness length, the severity of one’s illness should also be taken into consideration. In the current study, I examined the relation between narrative processes and well-being for all participants however, as previously mentioned, the participants in this study reported being bothered by their illness(es) to varying degrees. Therefore, it is possible that the strength of the relation between narrative processes and well-being differs depending on the severity of one’s illness. The first step in addressing this question will be to see if the level of positive resolution and agency differs depending on how much participants are bothered by their illness. I would expect that individuals who are not bothered by their illness should show levels of positive resolution and agency similar to what is found in other, non-illness studies whereas individuals who are more bothered by their illness may show lower levels of positive resolution and/or agency. If there is a difference, then severity could be examined as a potential moderator for the relation between narrative processes and well-being.

In addition to length and severity, type of illness is also an important consideration. Participants in the current study reported more than a dozen different types of chronic health problems. Another way of examining illness characteristics and narrative processes could be to group these chronic health problems so as to reduce some of the variability that stems from different illnesses. Given that agency is a central part of this study, one way of grouping them could be by the how medically controllable the illness is. This would allow me to investigate whether levels of agency are similar across all participants or whether it differs depending on how controllable their illness is.
Agency is a form of psychological control but each illness also has a different type of control, or in other words, how well it can be managed via medical interventions such as medication or surgery. This type of control is referred to as treatment control (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Bluck, 2002). The best way to group participants in this study would be to group participants based on their scores on the treatment control subscale of the Illness Perceptions Questionnaire (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Bluck, 2002) as there are too many differing illnesses in this study to easily objectively group them. This will allow me to examine whether the relations between agency and well-being differ depending on individuals’ perceived treatment control. It is anticipated that participants high in treatment control will show similar associations to the overall results of the study. For those low in treatment control, however, agency may be more strongly associated with the well-being outcomes, because having agency or psychological control may act as a buffer to the lack of treatment control associated with their illness(es).

**Memory Telling and Well-being**

In the current study, I examined one aspect of narration, narrative processes or how individuals tell their stories through writing. In addition to narrative processes, disclosure, or the sharing of memories, is another aspect of narration that may have implications for well-being (e.g. Beals, Peplau, & Gable, 2009). Researchers have found that listeners and disclosure context play a role in what stories individuals tell and how they tell them (McLean & Jennings, 2012; McLean, Pasupathi, & Pals, 2007) and that writing about emotional events is associated with positive outcomes such as better well-being (e.g. Smyth, 1998). However, little attention has been given to the influence that
perceived listener responses have on well-being. Examining listener responses is important, especially in the context of living with a chronic illness, as individuals with chronic health problems are often reluctant to share illness information with others (Charmaz, 2002). It is possible that one reason that individuals do not want to share illness information is due to the ways that listeners may respond, which may in turn influence their well-being.

In the current study participants were asked to answer several memory-telling questions after writing their self-defining memories (both domain-free and illness). These questions focused on the last time that they shared this memory with someone else. Of particular interest are the questions about how listeners responded to the narrator after they shared that memory (e.g. how supportive the narrator perceived the listener to be). Examining whether people shared their self-defining illness memories to the same degree as other memories, as well as whether there is an association between listener responses and well-being, will allow me to study another potential influence on well-being for individuals living with chronic health problems. Such results can also lay the groundwork for future studies on the influence of listener responses on well-being.

**Chronic Illness and Identity Integration**

There is a strong body of research on how identity is impacted by living with a chronic illness (e.g., Bury, 1982; Charmaz, 1983, 1995; Hubbard, Kidd, & Kearney, 2010; Whittemore & Dixon, 2008). Bury (1982) was the first to suggest that chronic illnesses act as a biographical disruption, something that has been echoed throughout the literature ever since (e.g., Hubbard, Kidd, & Kearney, 2010). Conceptualizing chronic illness in this way has led to a particular interest in how individuals integrate their illness
into their identity after this disruption has occurred. This has been studied from a number of different perspectives, including sociology and nursing, however little research in this area has been conducted from a narrative identity perspective. Unexamined data from the current study has the potential to address this in two ways, firstly by examining the centrality of events and secondly by examining life chapters.

In the current study, participants were asked to answer several questions regarding how central the memory that they wrote about is to their identity. In addition to how individuals compose their memories, the extent to which they see them as central defining feature of who they are also has important implications for well-being as perceiving a negative event as a defining feature of who you are can negatively affect well-being (e.g., Bernsten & Rubin, 2006). Participants in the current study were asked to write about a self-defining memory regarding their illness. Self-defining memories are, by definition, important to how individuals view themselves, however it is unknown whether events related to living with a chronic health problem are actually a defining feature of an individual’s identity. By examining participants’ responses to the Centrality of Events Scale (Berntsen & Rubin, 2006), I will be able to expand the understanding of how identity may be influenced by one’s illness. Similarly, an examination of the life story chapters (i.e., key sections of an individual’s life) will also give insight to how individuals contextualize their illness in the larger framework of their identity. If events surrounding one’s illness, such as the diagnosis, are not included in the chapters, that may suggest that the individual has integrated the illness into his or her life and it is no longer seen as a separate aspect of identity. It is also possible that excluding one’s illness from the life story chapters is actually a negative compartmentalization and represents a lack of
identity integration. Examination of both the life chapters and the centrality of the illness memory may help elucidate the relationship between illness and identity. If an illness memory is seen as a central aspect of one’s identity but their chapters do not include anything about the illness, it may suggest a lack of integration. Similarly, it will be important to examine whether there are differences between those who report their illness(es) as a chapter and those who do not in terms of the well-being outcomes in order to understand if one form of identity organization is healthier than the other, especially given that the life story chapters have not been examined in this way in previous research.

Conclusions

The results of the current study suggest that it is possible to have narrative positive resolution, even in the context of an ongoing event. This finding is important as it highlights the fact that narrative resolution and event resolution are two distinct processes. Additionally, the finding that agency was associated with well-being in this context suggests that agency may be protective in a variety of contexts. These findings extend the narrative literature to a novel context, and broaden our understanding of what it is like to living with a chronic health problem by taking the first steps towards examining what a healthy story looks like in this context. There is ample space for future studies to build upon the current findings by further extending temporal distance (e.g. to narratives about the present) and by examining specific health problems as well as more narrative processes.
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<td>Center for Epidemiology’s Studies Depression Scale</td>
</tr>
<tr>
<td><strong>Wave 3 (week 3)</strong></td>
<td>Narrative Processes</td>
<td>Positive Resolution</td>
<td>Pals, 2006</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Agency</td>
<td>Adler, 2012</td>
</tr>
</tbody>
</table>
Table 2. 
*Participant demographic characteristics across all waves of data collection*

<table>
<thead>
<tr>
<th>Wave</th>
<th>N</th>
<th>% female</th>
<th>Mean age (SD)</th>
<th>% white</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completed W1</td>
<td>1274</td>
<td>62.80</td>
<td>47.91 (6.01)</td>
<td>82.70</td>
</tr>
<tr>
<td>Invited to W2</td>
<td>464</td>
<td>71.10</td>
<td>48.29 (5.91)</td>
<td>88.60</td>
</tr>
<tr>
<td>Completed W2</td>
<td>309</td>
<td>75.70</td>
<td>48.77 (5.95)</td>
<td>88.30</td>
</tr>
<tr>
<td>Invited to W3</td>
<td>290</td>
<td>74.50</td>
<td>48.79 (5.94)</td>
<td>88.30</td>
</tr>
<tr>
<td>Completed W3</td>
<td>197</td>
<td>75.60</td>
<td>49.23 (5.84)</td>
<td>90.20</td>
</tr>
<tr>
<td>Final sample</td>
<td>191</td>
<td>75.50</td>
<td>49.27 (5.88)</td>
<td>90.40</td>
</tr>
<tr>
<td>Education Level</td>
<td>Completed Wave 1 Invited to Wave 2</td>
<td>Completed Wave 2 Invited to Wave 3</td>
<td>Completed Wave 3</td>
<td>In Final Sample</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-----------------------------------</td>
<td>-----------------------------------</td>
<td>------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Some high school</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>High school graduate</td>
<td>121</td>
<td>48</td>
<td>32</td>
<td>29</td>
</tr>
<tr>
<td>Some college or university</td>
<td>411</td>
<td>163</td>
<td>103</td>
<td>98</td>
</tr>
<tr>
<td>College/university</td>
<td>487</td>
<td>172</td>
<td>118</td>
<td>109</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>239</td>
<td>74</td>
<td>51</td>
<td>50</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 3. Participant education level across all waves of data collection
Table 4.  
*Participant employment status across all waves of data collection.*

<table>
<thead>
<tr>
<th>Status</th>
<th>Completed wave 1</th>
<th>Invited to wave 2</th>
<th>Completed wave 2</th>
<th>Invited to wave 3</th>
<th>Completed wave 3</th>
<th>In final sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time</td>
<td>705</td>
<td>222</td>
<td>138</td>
<td>132</td>
<td>84</td>
<td>81</td>
</tr>
<tr>
<td>Part-time</td>
<td>241</td>
<td>93</td>
<td>59</td>
<td>54</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Not at all</td>
<td>121</td>
<td>46</td>
<td>34</td>
<td>32</td>
<td>23</td>
<td>21</td>
</tr>
<tr>
<td>Retired</td>
<td>54</td>
<td>23</td>
<td>17</td>
<td>16</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Disabled/sickness leave</td>
<td>67</td>
<td>45</td>
<td>38</td>
<td>35</td>
<td>26</td>
<td>26</td>
</tr>
<tr>
<td>Other</td>
<td>84</td>
<td>34</td>
<td>24</td>
<td>21</td>
<td>12</td>
<td>12</td>
</tr>
</tbody>
</table>
Table 5.  
*Participant invitation and completion rates across all waves of data collection, based on illness severity as measured by the Brief Health History*

<table>
<thead>
<tr>
<th>Illness severity</th>
<th>Completed wave 1</th>
<th>Invited to wave 2</th>
<th>Completed wave 2</th>
<th>Invited to wave 3</th>
<th>Completed wave 3</th>
<th>In final sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>No illness</td>
<td>766</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Bothered level missing</td>
<td>-</td>
<td>49</td>
<td>41</td>
<td>39</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Not bothered</td>
<td>81</td>
<td>80</td>
<td>51</td>
<td>50</td>
<td>31</td>
<td>30</td>
</tr>
<tr>
<td>Mildly bothered</td>
<td>109</td>
<td>80</td>
<td>47</td>
<td>44</td>
<td>41</td>
<td>39</td>
</tr>
<tr>
<td>Moderately bothered</td>
<td>125</td>
<td>97</td>
<td>62</td>
<td>57</td>
<td>48</td>
<td>48</td>
</tr>
<tr>
<td>Very much bothered</td>
<td>106</td>
<td>83</td>
<td>54</td>
<td>50</td>
<td>39</td>
<td>37</td>
</tr>
<tr>
<td>Extremely bothered</td>
<td>87</td>
<td>75</td>
<td>54</td>
<td>50</td>
<td>38</td>
<td>37</td>
</tr>
<tr>
<td><strong>Total N</strong></td>
<td><strong>1,274</strong></td>
<td><strong>464</strong></td>
<td><strong>309</strong></td>
<td><strong>290</strong></td>
<td><strong>197</strong></td>
<td><strong>191</strong></td>
</tr>
</tbody>
</table>
Table 6. 
*Correlations between narrative processes, health, and well-being*

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Positive resolution</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Agency</td>
<td>.50**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Positive well-being</td>
<td>.21**</td>
<td>.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Negative well-being</td>
<td>-.21**</td>
<td>-.17*</td>
<td>-.48**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Objective health</td>
<td>-.16*</td>
<td>.12</td>
<td>-.03</td>
<td>.16*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. HRQoL</td>
<td>.34**</td>
<td>.14</td>
<td>.37**</td>
<td>-.52**</td>
<td>-.35**</td>
<td></td>
</tr>
<tr>
<td>7. SES</td>
<td>.08</td>
<td>.09</td>
<td>.45**</td>
<td>-.38**</td>
<td>-.02</td>
<td>.38**</td>
</tr>
</tbody>
</table>

*Notes:* *p < .05, **p < .01; N = 191. Higher scores on objective health indicate poorer health status (i.e. more doctors and medications) while higher scores on HRQoL indicate better health status.
Table 7. *Tests of Mediation*

<table>
<thead>
<tr>
<th>Mediation models</th>
<th>Coefficient pathways</th>
<th>Test of mediated effects</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Diagram" /></td>
<td>a coefficient (SE)</td>
<td>b coefficient (SE)</td>
</tr>
<tr>
<td>HRQoL→ positive resolution → positive well-being</td>
<td>.38 (.08)*</td>
<td>.10 (.08)</td>
</tr>
<tr>
<td>HRQoL→ positive resolution → negative well-being</td>
<td>38 (.08)*</td>
<td>-.03 (.05)</td>
</tr>
</tbody>
</table>

*Notes: Mediation models are shown with the independent variable (X) on the left, the mediator (M) in the middle, and the outcome (Y) on the right. Model variables and pathways are labeled using the nomenclature of Bauer, Preacher, and Gil (2006); the a coefficient summarizes the effect of X on M, b summarizes M on Y, and c' is used to identify the remaining effect of X on Y, after M is considered. *p < .001*
Table 8. Correlations between narrative processes, health, and well-being based on consistency in illness reporting.

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Positive resolution</td>
<td>-</td>
<td>.52**</td>
<td>.12</td>
<td>-.16</td>
<td>-.14</td>
<td>.33**</td>
</tr>
<tr>
<td>3. Positive well-being</td>
<td>.49**</td>
<td>.31*</td>
<td>-</td>
<td>-.45**</td>
<td>-.06</td>
<td>.36**</td>
</tr>
<tr>
<td>4. Negative well-being</td>
<td>-.38*</td>
<td>-.25</td>
<td>-.55**</td>
<td>-</td>
<td>.13</td>
<td>-.49**</td>
</tr>
<tr>
<td>5. Objective health</td>
<td>-.22</td>
<td>.13</td>
<td>.06</td>
<td>.20</td>
<td>-</td>
<td>-.36**</td>
</tr>
<tr>
<td>6. HRQoL</td>
<td>.43**</td>
<td>.22</td>
<td>-.31</td>
<td>-.60**</td>
<td>-.31</td>
<td>-</td>
</tr>
</tbody>
</table>

Notes: Values given above the diagonal are for participants who were consistent in reporting their primary chronic health problem, \( n = 145 \); values given below the diagonal are for those who were inconsistent in reporting their primary chronic health problem, \( n = 42 \). * \( p < .05 \), ** \( p < .01 \). Higher scores on objective health indicate poorer health status (i.e. more doctors and medications) while higher scores on HRQoL indicate better health status.
Figure 1. Mediation model (Hypotheses 2 and 3) whereby the narrative processes mediate the relation between health status and well-being.
Appendix A

The following is an explanation of several measures that were included in the study but were unable to be used in any analyses.

**IADL scale**

The IADL scale (Instrumental Activities of Daily Living; Graf, 2013) is supposed to measure an individual’s functional status via eight items that assess an individual’s ability to complete activities of daily living, such as housekeeping. However, the scale was positively skewed, with very few individuals scoring above 1 (being completely able to complete the task) for any item. Thus, I decided to dichotomize the items, such that 1 indicated being able to complete the task, and 0 being any indication that individuals are unable to complete the task. A sum of the items was calculated with higher scores representing the ability to complete more activities of daily living. More than half of the participants scored perfectly on the scale, meaning that they were able to complete all activities of daily living, despite living with one or more chronic illnesses. This suggests that this measure did not capture variability in objective health in this sample and thus could not be used.

**Wellness Behaviors Index**

The Wellness Behaviors Index (WBI; Sirois, 2001) was used to measure engagement in health-promoting behaviors. Originally I had intended to use this as part of the objective health composite, however reliability of the scale was poor ($\alpha = .60$). Upon examination of the questions I also realized it was not adequately capturing the phenomenon I was interested in. For example, items included statements such as “I eat at least 3 meals a day” and “I take time to relax”, things that are important to health but are
not relevant when trying to capture objective health specific to living with a chronic health problem.

**Neuroticism**

I had planned to use the neuroticism subscale of the NEO personality inventory (John & McRae, 1985). However, due to a clerical error the items included in this study were incorrect and thus the scale could not be used in any analyses.

**Negative Affect**

Participant’s negative affect was measured using the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988) which asks individuals to report how they are currently feeling by rating how much a number of emotion words (e.g. interested, stressed) represent to their current state. Half of the items on the PANAS represent positive affect, and half represent negative affect. A mean score for each subscale was calculated, with higher scores representing higher negative/positive affect. For the purpose of this study only the negative affect subscale was used (α = .91).

I had originally planned to include negative affect as a covariate in the examination of narrative processes and well-being. This was included so that I could account for whether I induced a negative mood by asking participants to write about their chronic health problems. Upon examination of the scores however, I found that the majority of participants reported feeling the negative emotions associated with negative affect very little or not at all. Although I did not take a baseline measure of negative affect prior to when participants were asked to write their narratives, based on the lack of negative affect reported it seems that writing the narratives did not induce a negative mood and thus it was not necessary to include negative affect as a covariate.
Other measures

The following measures were included in the study but not used in the present analyses due to lack of relevance. These measures were included for future analyses.

Wave 1

Wellness Behaviors.

The Wellness Behaviors Index (WBI; Sirois, 2001) will be used to measure engagement in health-promoting behaviors. The WBI includes 10-items that measure how often individuals engage in common health behaviours (e.g., healthy eating, exercising). Responses are given on a 5-point scale (1 = less than once a week or never, 5 = every day of the week), with higher scores representing engagement in more health-promoting behaviors.

Wave 2

Illness Perceptions.

Illness perceptions will be measured using the Illness Perceptions Questionnaire (IPQ; Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002). The IPQ is a thirty-eight item measure that assesses five dimensions of cognitive representations of illness: identity, consequences, cause, timeline, and cure or control. Items are rated on a one to five Likert scale (1 = strongly disagree, 5 = strongly agree) and include questions such as, “How much control do you feel you have over your illness?” After reverse scoring the appropriate items, a mean score for each subscale is calculated. On the identity, timeline, and consequences subscales, higher scores indicate strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness, and the cyclical nature of the
condition. On the control subscale, higher scores represent positive beliefs about the controllability of the illness and a personal understanding of the condition.

**Coping.**

How well individuals are currently coping with their chronic health problem was measured using the Coping Efficacy Scale (Gignac, Cott, & Badley, 2000). This scale includes three-items (i.e. “I am successfully coping with the symptoms of my chronic illness”) which are rated on a 5-point scale from *strongly disagree* to *strongly agree*.

**Wave 3**

**Centrality of Events Scale.**

How central the self-defining memory and illness memory are to an individual’s identity will be measured using the short-form of the Centrality of Events Scale (Berntsen & Rubin, 2006). The scale includes 7 items, each of which is rated on a five-point Likert scale (1 = *totally disagree*, 5 = *totally agree*). Items include statements such as “*I feel that this event has become part of my identity.*” A mean score is calculated with higher scores representing higher event centrality.

**Memory telling questions.**

The memory telling questions are a series of single item questions related to the last time they shared a memory with someone (e.g. “Who did you share it with?” “What kind of response did they give”) (Pasupathi, McLean, & Weeks, 2009). Most items are rated on a 7-point Likert scale.
Appendix B
Full coding instructions for resolution and agency

Resolution

This dimension captures the extent to which the person has constructed a coherent and positive conclusion to the narrative that conveys a sense of emotional resolution in the present. People high on coherent positive resolution have clearly resolved the event and moved past it so that it no longer exerts a negative influence on one’s emotional state and outlook on life. Additionally, the ending of the narrative is coherent and positive in emphasis (or at least not negative). For these people, the narrative is complete and provides emotional distance from the event. In contrast, people low on coherent positive resolution clearly continue to be troubled and emotionally affected by the event in a negative way, so that the event does not seem over in terms of the person’s internal experience of it. For these people, the life narrative seems “stuck” in the negative event and unable to fully move on. The narrative ends on a more negative, uncertain, or unresolved note, as if a positive ending has not yet been developed. People in the middle of this scale either a) do not clearly communicate one way or another about their current state of resolution and have a more neutral ending, or b) display a mix of thoughts and feelings that suggest that the event is partly resolve and partly unresolved – a work in progress that does not clearly lean in either direction (i.e., more resolved or unresolved) yet. (adapted from Pals, 2006)

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very</td>
<td>Somewhat</td>
<td>Neutral/ Mixed</td>
<td>Somewhat</td>
<td>Very</td>
</tr>
<tr>
<td></td>
<td>Unresolved</td>
<td>Unresolved</td>
<td>Resolved</td>
<td>Resolved</td>
<td></td>
</tr>
</tbody>
</table>
Agency

Narratives high in agency are fundamentally concerned with the autonomy of the protagonist. Highly agentic narratives describe protagonists who can affect their own lives (Lysaker), initiate changes on their own (Adler, Skalina, & McAdams), and who achieve some degree of control over the course of their experiences (McAdams’ status/victory). This theme is related to the degree to which people internalize their actions, reflect on them, and engage in them with a full sense of choice (Deci & Ryan’s Self-Determination Theory). This achievement may come through self-insight, gaining a sense of control, or a feeling of increased power (McAdams’ self-mastery). The theme of agency bears some relationship to internal locus of control (Rotter), but it is not identical; for example, if someone feels that they are responsible for everything in their life, but they are failing at all of them, they might be rated as high in internal locus of control, but low in agency. This theme should be coded only as it pertains to the protagonist of the narrative, not other characters.

- Code 1-5, where 5 = highest agency

1. Protagonist is completely powerless, at mercy of circumstances; all action is motivated by external powers; or narrative is not written in first person (rare).

2. Protagonist is somewhat at the mercy of circumstances, with primary control of the plot at the hands of external powers.

3. Recorded where there is no code-able language pertaining to the theme of agency (quite rare), or when narrative displays both agentic and non-agentic elements.

4. Protagonist is minimally at the mercy of circumstances, with the majority of the control of the plot in the hands of the protagonist.

5. Protagonist is agentic, able to affect their own lives, initiate changes on their own, and achieves some degree of control over the course of their experiences; may or may not include description of some struggle to achieve agentic status.
Appendix C
Demographic questions for pre-screening survey (Wave 1).

Age: ___________________
Sex: ____________________
Female _______ Male _______ Other _______

In what country/continent do you currently live?
- Canada
- USA
- Australia
- South America
- United Kingdom
- Europe
- Other (please list) ____________________

What is your highest level of education?
- some high school
- high school graduate
- some college or university
- college/university graduate
- Graduate degree
- Other _______

Are you currently employed (please check all that apply):
- full-time
- part-time
- not at all
- retired
- Disabled/Sickness leave
- Other ____________________

What is your first language?
________________________________________________________________

What ethnic/cultural background do you most identify with? (check all that apply)
(1) Asian or Asian American, including Chinese, Japanese, and others
(2) Black or African American
(3) Hispanic or Latino, including Mexican American, Central American, and others
(4) White, Caucasian, Anglo, European American; not Hispanic
(5) American Indian/Native American
(6) Mixed; Parents are from two different groups
(7) Other (write in): ________________________________

What is your religious background?
[ ] Protestant  [ ] Catholic
[ ] Jewish  [ ] Muslim
[ ] Hindu  [ ] Buddhist
[ ] Agnostic  Other: ____________________

Are you:
[ ] single
[ ] dating
[ ] in a committed romantic relationship
[ ] married
other ____________________

Financially, would you say that you are:

| Comfortable, don't worry too much about money |
|____________________________________________|
| Making ends meet, getting by |
| Struggling a lot, have some immediate financial concerns |

What category best describes your annual household income?
[ ] Less than $24,999
[ ] $25,000 to $49,999
[ ] $50,000 to 99,999
[ ] $100,000 or more
McArthur Scale of Subjective Social Status

Think of this ladder as representing where people stand in the United States.
At the top of the ladder are the people who are the best off – those who have the most money, the most education and the most respected jobs. At the bottom are the people who are the worst off – who have the least money, least education, and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

Where would you place yourself on this ladder?
Please place a large “X” on the rung where you think you stand at this time in your life, relative to other people in the United States.
Have you been diagnosed with any psychiatric or mental health conditions?

NO [ ] YES [ ]
(e.g., clinical depression, anxiety, panic attacks, etc.)

If yes, please list all
________________________________________  ___________________________________

Please rate your overall health (check one most appropriate box):

Excellent □ Very good □ Good □ Fair □ Poor □

Do you have health insurance?
[ ] yes
[ ] no

What is the source of your health insurance?
[ ] job
[ ] private
[ ] federal/state program
Other _________________________________

What is your annual deductible?
____________________________________
**Brief Health History**

This section deals with health issues you have experienced that are either temporary or over a short period of time (acute), or that can repeatedly occur over a longer period of time (chronic).

---

**ACUTE OR TRANSITORY HEALTH PROBLEMS:**

Please indicate which ones you are currently experiencing, or can remember experiencing within the past 3 months, and the number of times you have experienced each. – please click all that apply

<table>
<thead>
<tr>
<th>Back problems</th>
<th>Insomnia</th>
<th>Allergies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sprains or muscle strains</td>
<td>Infections</td>
<td>Skin problems/rashes</td>
</tr>
<tr>
<td>Headache</td>
<td>Flu, cold or fever</td>
<td>Reproductive/menstrual problems</td>
</tr>
<tr>
<td>Acute digestive problems (constipation, heartburn, etc.)</td>
<td>Dental problems</td>
<td>Other acute problems: please specify e.g., bone fractures, etc.</td>
</tr>
</tbody>
</table>
CHRONIC OR RECURRING HEALTH PROBLEMS:
Please indicate which of the following health issues you have been diagnosed with – check all that apply under "YES". For those problems you do have please indicate how much this problem or its symptoms has bothered you in the past 3 months by clicking the appropriate box.

<table>
<thead>
<tr>
<th>YES</th>
<th>not bothered</th>
<th>mildly bothered</th>
<th>moderately bothered</th>
<th>very much bothered</th>
<th>extremely bothered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic migraines or headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart disease (cardiovascular disease)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High blood pressure (hypertension)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
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<td>Arthritis</td>
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<tr>
<td>Fibromyalgia</td>
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<tr>
<td>Inflammatory Bowel Disease (Crohn’s, colitis)</td>
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<tr>
<td>Multiple Sclerosis</td>
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<td>Chronic Fatigue syndrome</td>
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<td>Irritable Bowel Syndrome (IBS)</td>
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<tr>
<td>Liver disease</td>
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<td>Lung disease</td>
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<td>Kidney disease</td>
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<tr>
<td>Chronic back problems</td>
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<tr>
<td>Other chronic condition:</td>
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<tr>
<td>Please specify – e.g., sickle cell disease, psoriasis, etc.</td>
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</tbody>
</table>
Appendix D
Survey measures included in Wave 2 of data collection on Mturk.

Satisfaction with Life Scale

**DIRECTIONS:** Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number in the line preceding that item. Please be open and honest in your responding.

1 = Strongly Disagree
2 = Disagree
3 = Slightly Disagree
4 = Neither Agree or Disagree
5 = Slightly Agree
6 = Agree
7 = Strongly Agree

_____ 1. In most ways my life is close to my ideal.

_____ 2. The conditions of my life are excellent.

_____ 3. I am satisfied with life.

_____ 4. So far I have gotten the important things I want in life.

_____ 5. If I could live my life over, I would change almost nothing
**Wellness Behaviors Index**

Please indicate approximately how often you currently perform the behaviours listed below by checking the appropriate box for each item. Think about how often you do these things in general, that is over the **past month**.

<table>
<thead>
<tr>
<th></th>
<th>less than once a week or never</th>
<th>one day a week</th>
<th>2–3 days a week</th>
<th>4–5 days a week</th>
<th>every day of the week</th>
</tr>
</thead>
<tbody>
<tr>
<td>a)</td>
<td>I eat breakfast.</td>
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<tr>
<td>b)</td>
<td>I get a good night’s sleep, for example, uninterrupted, restful sleep.</td>
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<td>c)</td>
<td>I drink 2 or more caffeinated beverages, such as coffee, tea or colas.</td>
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<td>d)</td>
<td>I exercise for 20 continuous minutes or more, to the point of perspiration.</td>
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<tr>
<td>e)</td>
<td>I eat at least 3 meals a day.</td>
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<td>f)</td>
<td>I take time to relax.</td>
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<tr>
<td>g)</td>
<td>I eat fresh fruits and/or vegetables.</td>
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<td>h)</td>
<td>I walk as much as possible, for example, I take the stairs not the elevator, etc.</td>
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<tr>
<td>i)</td>
<td>I take vitamins.</td>
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<tr>
<td>j)</td>
<td>I eat junk foods, such as chips, candy/candy bars, French fries, etc.</td>
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<tr>
<td>k)</td>
<td>I eat healthy, well-balanced meals.</td>
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<tr>
<td>l)</td>
<td>I take natural supplements, such as garlic pills, Echinacea, herbals, etc.</td>
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</tr>
</tbody>
</table>
Instrumental Activities of Daily Living Scale

Please circle the number that corresponds to your current ability to perform the task listed.

A. Ability to use telephone
   1. I operate a telephone on my own; look up and dial numbers
   2. I dial a few well-known numbers
   3. I answer the telephone but do not dial
   4. I do not use telephone at all

B. Shopping
   1. I take care of all my shopping needs independently
   2. I shop independently for small purchases
   3. I need to be accompanied on any shopping trip
   4. I am completely unable to shop

C. Food preparation
   1. I plan, prepare, and serve adequate meals independently
   2. I prepare adequate meals if I am supplied with ingredients
   3. I heats and serve prepared meals or I prepare meals but do not maintain adequate diet
   4. I need to have meals prepared and served

D. Housekeeping
   1. I maintain the house alone with occasional assistance (heavy work)
   2. I perform light daily tasks such as dishwashing, bed making
   3. I perform light daily tasks, but cannot maintain acceptable level of cleanliness
   4. I need help with all home maintenance tasks
   5. I do not participate in any housekeeping tasks

E. Laundry
   1. I do my personal laundry completely
   2. I launder small items, rinses socks, stockings, etc
   3. All laundry must be done by others

F. Mode of transportation
   1. I travel independently on public transportation or drive my own car
   2. I arrange my own travel via taxi, but do not otherwise use public transportation
   3. I travel on public transportation when assisted or accompanied by another
   4. My travel is limited to taxi or automobile with assistance of another
5. I do not travel at all

G. Responsibility for own medications
   1. I am responsible for taking medication in correct dosages at correct time
   2. I take responsibility if medication is prepared in advance in separate dosages
   3. I am not capable of dispensing my own medication

H. Ability to handle finances
   1. I manage financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); I collect and keep track of my income
   2. I manage my day-to-day purchases but need help with banking, major purchases, etc
   3. I am incapable of handling money
Health-related Quality of Life
Medical Outcomes Study Short-Form 36

Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

1. In general, would you say your health is:
   □ Excellent
   □ Very good
   □ Good
   □ Fair
   □ Poor

2. Compared to one year ago, how would you rate your health in general now?
   □ Much better now than a year ago
   □ Somewhat better now than a year ago
   □ About the same as one year ago
   □ Somewhat worse now than one year ago
   □ Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
   
   A. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.
      □ Yes, limited a lot.
      □ Yes, limited a little.
      □ No, not limited at all.

   B. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?
      □ Yes, limited a lot.
      □ Yes, limited a little.
      □ No, not limited at all.

   C. Lifting or carrying groceries.
      □ Yes, limited a lot.
      □ Yes, limited a little.
      □ No, not limited at all.

   D. Climbing several flights of stairs.
      □ Yes, limited a lot.
      □ Yes, limited a little.
      □ No, not limited at all.
E. Climbing one flight of stairs.
   - Yes, limited a lot.
   - Yes, limited a little.
   - No, not limited at all.

F. Bending, kneeling or stooping.
   - Yes, limited a lot.
   - Yes, limited a little.
   - No, not limited at all.

G. Walking more than one mile.
   - Yes, limited a lot.
   - Yes, limited a little.
   - No, not limited at all.

H. Walking several blocks.
   - Yes, limited a lot.
   - Yes, limited a little.
   - No, not limited at all.

I. Walking one block.
   - Yes, limited a lot.
   - Yes, limited a little.
   - No, not limited at all.

J. Bathing or dressing yourself.
   - Yes, limited a lot.
   - Yes, limited a little.
   - No, not limited at all.

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

   A. Cut down the amount of time you spent on work or other activities?
      - Yes   - No

   B. Accomplished less than you would like?
      - Yes   - No

   C. Were limited in the kind of work or other activities
      - Yes   - No

   D. Had difficulty performing the work or other activities (for example, it took extra time)
5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

   A. Cut down the amount of time you spent on work or other activities?
      ☐ Yes ☐ No

   B. Accomplished less than you would like?
      ☐ Yes ☐ No

   C. Didn't do work or other activities as carefully as usual?
      ☐ Yes ☐ No

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
   ☐ Not at all
   ☐ Slightly
   ☐ Moderately
   ☐ Quite a bit
   ☐ Extremely

7. How much bodily pain have you had during the past 4 weeks?
   ☐ Not at all
   ☐ Slightly
   ☐ Moderately
   ☐ Quite a bit
   ☐ Extremely

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
   ☐ Not at all
   ☐ Slightly
   ☐ Moderately
   ☐ Quite a bit
   ☐ Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks:

   A. did you feel full of pep?
      ☐ All of the time
Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

B. Have you been a very nervous person?
☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

C. Have you felt so down in the dumps nothing could cheer you up?
☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

D. Have you felt calm and peaceful?
☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

E. Did you have a lot of energy?
☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

F. Have you felt downhearted and blue?
☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
G. did you feel worn out?
- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

H. have you been a happy person?
- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

I. did you feel tired?
- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?
- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

11. How TRUE or FALSE is each of the following statements for you?

A. I seem to get sick a little easier than other people
- Definitely true
- Mostly true
- Don't know
- Mostly false
- Definitely false

B. I am as healthy as anybody I know
☐ Definitely true
☐ Mostly true
☐ Don't know
☐ Mostly false
☐ Definitely false

C. I expect my health to get worse
☐ Definitely true
☐ Mostly true
☐ Don't know
☐ Mostly false
☐ Definitely false

D. My health is excellent
☐ Definitely true
☐ Mostly true
☐ Don't know
☐ Mostly false
☐ Definitely false
The following questions are about your experience of living with a chronic illness. If you have more than one chronic illness, please choose the illness that you feel is most problematic or difficult. This will hereafter be referred to as your “primary chronic illness.” Please keep this illness in mind as you answer the following questions.

**General Health**

Please state your primary chronic illness below:

________________________________________________________________________

At what age did you first start experiencing symptoms?

________________________________________________________________________

At what age were you diagnosed?

________________________________________________________________________

Have you been diagnosed with any other physical health problems? If yes, please list below:

________________________________________________________________________

How many doctors do you have?

________________________________________________________________________

How many times have you gone to a doctor in the past month?

________________________________________________________________________

Please list any medication you are currently taking (including natural supplements) as well as the reason you are taking them.

________________________________________________________________________
Coping with your Chronic Health Condition

Please indicate how well you feel you have been dealing with the different aspects of your condition in general by checking a box for each question.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>m) I am successfully coping with the symptoms of my condition</td>
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<tr>
<td>b) I am successfully coping with the day to day problems that living with my condition creates</td>
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<tr>
<td>c) I am successfully coping with the emotional aspects of my condition</td>
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</table>
**Illness Perceptions Questionnaire**

We are interested in your own personal views of how you now see your primary chronic illness. Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

<table>
<thead>
<tr>
<th>VIEWS ABOUT YOUR ILLNESS</th>
<th>Strongly Disease</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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<tbody>
<tr>
<td>My illness will last a short time</td>
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<td>My illness is likely to be permanent rather than temporary</td>
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<tr>
<td>My illness will last for a long time</td>
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<tr>
<td>This illness will pass quickly</td>
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<tr>
<td>I expect to have this illness for the rest of my life</td>
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<tr>
<td>My illness is a serious condition</td>
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<tr>
<td>My illness has major consequences on my life</td>
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<tr>
<td>My illness does not have much effect on my life</td>
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<tr>
<td>My illness strongly affects the way others see me</td>
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<tr>
<td>My illness has serious financial consequences</td>
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<tr>
<td>My illness causes difficulties for those who are close to me</td>
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<tr>
<td>There is a lot which I can do to control my symptoms</td>
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<tr>
<td>What I do can determine whether my illness gets better or worse</td>
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<tr>
<td>The course of my illness depends on me</td>
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<tr>
<td>Nothing I do will affect my illness</td>
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<tr>
<td>I have the power to influence my illness</td>
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<tr>
<td>My actions will have no effect on the outcome of my illness</td>
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<tr>
<td>My illness will improve in time</td>
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<tr>
<td>There is very little that can be done to improve my illness</td>
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<td>My treatment will be effective in curing my illness</td>
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<td>The negative effects of my illness can be prevented (avoided) by my treatment</td>
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<tr>
<td>My treatment can control my illness</td>
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<tr>
<td>There is nothing which can help my condition</td>
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<tr>
<td>The symptoms of my condition are puzzling to me</td>
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<tr>
<td>My illness is a mystery to me</td>
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<tr>
<td>I don't understand my illness</td>
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<tr>
<td>My illness doesn't make any sense to me</td>
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<tr>
<td>I have a clear picture or understanding of my condition</td>
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<tr>
<td>The symptoms of my illness change a great deal from day to day</td>
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<tr>
<td>My illness is very unpredictable</td>
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<tr>
<td>I go through cycles in which my illness gets better and worse</td>
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<tr>
<td>I get depressed about my illness</td>
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<tr>
<td>When I think about my illness I get upset</td>
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<tr>
<td>My illness makes me feel angry</td>
<td></td>
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<td></td>
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<tr>
<td>My illness does not worry me</td>
<td></td>
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<td></td>
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<tr>
<td>Having this illness makes me feel anxious</td>
<td></td>
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<tr>
<td>My illness makes me feel afraid</td>
<td></td>
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</table>
Neuroticism Subscale of the NEO-FFI

Carefully read all of the instructions before beginning. Read each statement carefully. For each statement, fill in the appropriate oval under the numbers 1 to 5 that best represents your opinion. Fill in only one response for each statement. Please respond to each.

<table>
<thead>
<tr>
<th>Statement</th>
<th>O</th>
<th>O</th>
<th>O</th>
<th>O</th>
<th>O</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am not a worrier.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>2. I often feel inferior to others.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
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<tr>
<td>3. Some people think I’m selfish and egotistical.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
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<tr>
<td>4. I really enjoy talking to people.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>5. My life is fast paced.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
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<tr>
<td>6. I believe we should look to our religious authorities for decisions on moral issues.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>7. I have a lot of intellectual curiosity.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>8. I often feel as if I’m bursting with energy.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>9. I am not a very methodical person.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>10. I often feel tense or jittery.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>11. I often get into arguments with my family and co-workers.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>12. When I am under a great deal of stress, sometimes I feel like I’m going to pieces.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the past month. In each case, please circle the number that represents how often you felt or thought a certain way.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td>almost never</td>
<td>sometimes</td>
<td>fairly often</td>
<td>very often</td>
</tr>
</tbody>
</table>

1. In the last month, how often have you been upset because of something that happened unexpectedly? 0 1 2 3 4
2. In the last month, how often have you felt that you were unable to control the important things in your life? 0 1 2 3 4
3. In the last month, how often have you felt nervous and "stressed"? 0 1 2 3 4
4. In the last month, how often have you felt confident about your ability to handle your personal problems? 0 1 2 3 4
5. In the last month, how often have you felt that things were going your way? 0 1 2 3 4
6. In the last month, how often have you found that you could not cope with all the things that you had to do? 0 1 2 3 4
7. In the last month, how often have you been able to control irritations in your life? 0 1 2 3 4
8. In the last month, how often have you felt that you were on top of things? 0 1 2 3 4
9. In the last month, how often have you been angered because of things that were outside of your control? 0 1 2 3 4
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? 0 1 2 3 4
## Center for Epidemiology Studies Depression Scale

For each of the following statements, tell us how often you felt or behaved this way during the past **week**:

<table>
<thead>
<tr>
<th></th>
<th>Rarely or none of the time (less than 1 day)</th>
<th>Some or a little of the time (1 to 2 days)</th>
<th>Occasionally or a moderate amount of the time (3 to 4 days)</th>
<th>Most of or all of the time (5 to 7 days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was bothered by things that don’t usually bother me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I did not feel like eating; my appetite was poor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I felt that I could not shake off the blues, even with help from my family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I felt that I was just as good as other people.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I had trouble keeping my mind on what I was doing.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I felt depressed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I felt that everything I did was an effort.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I felt hopeful about the future.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I thought my life had been a failure.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I felt fearful.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. My sleep was restless.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I was happy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I talked less than normal.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. People were unfriendly.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I enjoyed life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I had crying spells.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
18. I felt sad.

19. I felt that people disliked me.

20. I could not “get going.”
Appendix E

Narrative prompts used in Wave 3 of Mturk data collection.

Life story chapters.

To begin, we would like you to think about your life as if it were a book or novel. Imagine the book has a table of contents, containing the titles of the main chapters in the story. Please give each chapter a title and describe very briefly what each chapter is about (with 1 – 3 sentences). You may also want to say a word or two about how we get from one chapter to the next. You may have as many chapters as you want, but we suggest having two to seven of them.
Self-defining memory.

This part of the study concerns the recall of a special kind of personal memory called a self-defining memory. A self-defining memory has the following attributes:

1. It is at least one year old.
2. It is a memory from your life that you remembered very clearly and that still feels important to you even as you think about it.
3. It is a memory about an important enduring theme, issue, or conflict from your life. It is a memory that helps explain who you are as an individual and might be the memory you would tell someone else if you wanted that person to understand you in a profound way.
4. It is a memory linked to other similar memories that share the same theme or concern.
5. It may be a memory that is positive or negative, or both, in how it makes you feel. The only important aspect is that it leads to strong feelings.
6. It is a memory that you have thought about many times. It should be familiar to you like a picture you have studied or a song (happy or sad) you have learned by heart.

To understand best what a self-defining memory is, imagine you have just met someone you like very much and are going for a walk together. Each of you is very committed to helping the other get to know the “Real You”. You are not trying to play a role or to strike a pose. While, inevitably, we say things that present a picture of ourselves that might not be completely accurate, imagine that you are making every effort to be honest. In the course of the conversation, you describe a memory that you feel conveys powerfully how you have come to be the person you currently are. It is precisely this memory, which you tell the other person and simultaneously repeat to yourself, that constitutes a self-defining memory.
Following the guidelines above, please write your self-defining memory below. We ask that you write a description of the memory that is **at least a paragraph or two in length**. Think about the event carefully and then include all of the following in your written description of the event:

1. When did the event occur? (How old were you?)
2. What exactly happened in the event?
3. Who was involved in the event?
4. What were you thinking, feeling, and wanting in the event?
5. Why do you think that this is an important event in your life story? What does this event say about who you are, who you were, who you might be, and how you have developed over time.

[After writing the narrative, participants will be asked to respond to the following questions]
The Centrality of Events Scale

Please think about the memory you just wrote and answer the following questions in an honest and sincere way, by circling a number from 1 to 5.

1. I feel that this event has become part of my identity.
   totally disagree 1 2 3 4 5 totally agree

2. This event has become a reference point for the way I understand myself and the world.
   totally disagree 1 2 3 4 5 totally agree

3. I feel that this event has become a central part of my life story.
   totally disagree 1 2 3 4 5 totally agree

4. This event has colored the way I think and feel about other experiences.
   totally disagree 1 2 3 4 5 totally agree

5. This event permanently changed my life.
   totally disagree 1 2 3 4 5 totally agree

6. I often think about the effects this event will have on my future.
   totally disagree 1 2 3 4 5 totally agree

7. This event was a turning point in my life.
   totally disagree 1 2 3 4 5 totally agree
Memory telling questions

1. How old were you when this event occurred? __________

2. How often have you shared this memory with others?

<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Frequently</th>
</tr>
</thead>
</table>

Next we would like you to think about the last time you shared this memory with someone.

1. Who did you share it with? (e.g. mom, friend, spouse) __________

2. How much do you think the listener enjoyed your telling of the experience?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Very Much</th>
</tr>
</thead>
</table>

3. How responsive was the listener while you were telling about the experience?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Responsive</th>
<th>Very Responsive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

4. What kind of response did they give?

<table>
<thead>
<tr>
<th>Negative/unsupportive</th>
<th>Positive/supportive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

5. Was your friend rude?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

6. Did your friend give any verbal feedback while you were telling about the experience?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

7. Did your friend ask questions?

<table>
<thead>
<tr>
<th>None</th>
<th>Many</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
The following prompts ask you to write about your experience of living with a chronic illness. If you have more than one chronic illness, please choose the illness that you feel is most problematic or difficult. This will hereafter be referred to as your “primary chronic illness.” This illness should be the same as the illness that you reported in part one of this study.

Please state your primary chronic illness below:
________________________________________________

Please keep this illness in mind as you respond to the following prompts.

**Illness chapters.**

Now we would like you to focus on your experience of living with a chronic illness. Thinking only about the time in your life during which you have had your chronic illness, we would like you to think about your illness as if it were a book or a novel, as you did in writing your general life chapters. Imagine the book has a table of contents, containing the titles of the main chapters in the story. Just like you did before, please give each chapter a title and describe very briefly what each chapter is about (in 1 – 3 sentences). You may also want to say a word or two about how we get from one chapter to the next. You may have as many chapters as you want, but we suggest having three to seven of them.
Illness memory.

We would now like you to write another self-defining memory, this time specifically about your illness. That is, we would like you to write about a memory of your illness experience that represents what it is like to live with your illness and that has the following attributes:

1. It is at least one year old.
2. It is a memory from your experience of living with your illness that you remembered very clearly and that still feels important to you even as you think about it.
3. It is a memory about an important enduring theme, issue, or conflict from your illness experience. It is a memory that helps explain who you are as an individual and might be the memory you would tell someone else if you wanted that person to understand you in a profound way.
4. It is a memory linked to other similar memories that share the same theme or concern.
5. It may be a memory that is positive or negative, or both, in how it makes you feel. The only important aspect is that it leads to strong feelings.
6. It is a memory that you have thought about many times. It should be familiar to you like a picture you have studied or a song (happy or sad) you have learned by heart.

Following the guidelines above, please write your illness memory below. We ask that you write a description of the memory that is at least a paragraph or two in length. Think about the event carefully and then include all of the following in your written description of the event:

1. When did the event occur? (How old were you?)
2. What exactly happened in the event?
3. Who was involved in the event?
4. What were you thinking, feeling, and wanting in the event?
5. Why do you think that this is an important event in your life story? What does this event say about who you are, who you were, who you might be, and how you have developed over time.
[After writing the narrative, participants will be asked to respond to the following questions]

**The Centrality of Events Scale**

Please think about the memory you just wrote and answer the following questions in an honest and sincere way, by circling a number from 1 to 5.

1. I feel that this event has become part of my identity.
   - totally disagree 1 2 3 4 5 totally agree

2. This event has become a reference point for the way I understand myself and the world.
   - totally disagree 1 2 3 4 5 totally agree

3. I feel that this event has become a central part of my life story.
   - totally disagree 1 2 3 4 5 totally agree

4. This event has colored the way I think and feel about other experiences.
   - totally disagree 1 2 3 4 5 totally agree

5. This event permanently changed my life.
   - totally disagree 1 2 3 4 5 totally agree

6. I often think about the effects this event will have on my future.
   - totally disagree 1 2 3 4 5 totally agree

7. This event was a turning point in my life.
   - totally disagree 1 2 3 4 5 totally agree
NARRATING ONGOING EVENTS

Memory telling questions

1. How old were you when this event occurred? __________

2. How often have you shared this memory with others?
   Never 1 2 3 4 5 6 7
   Frequently

Next we would like you to think about the last time you shared this memory with someone.

1. Who did you share it with? (e.g. mom, friend, spouse) __________

2. How much do you think the listener enjoyed your telling of the experience?
   Not at all 1 2 3 4 5 6 7
   Very Much

3. How responsive was the listener while you were telling about the experience?
   Not at all Responsive 1 2 3 4 5 6 7
   Very Responsive

4. What kind of response did they give?
   Negative/unsupportive 1 2 3 4 5 6 7
   Positive/supportive

5. Was your friend rude?
   Not at all 1 2 3 4 5 6 7
   Very Much

6. Did your friend give any verbal feedback while you were telling about the experience?
   Not at all 1 2 3 4 5 6 7
   A great deal

7. Did your friend ask questions?
   None 1 2 3 4 5 6 7
   Many
PANAS

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you **feel this way right now**, that is, at the present moment. Use the following scale to record your answers.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>very slightly or not at all</td>
<td>a little</td>
<td>moderately</td>
<td>quite a bit</td>
<td>extremely</td>
</tr>
</tbody>
</table>

| interested | hostile | nervous |
| distressed | enthusiastic | determined |
| excited | proud | attentive |
| upset | irritable | jittery |
| strong | alert | active |
| guilty | ashamed | afraid |
| scared | inspired | |

Overall, how do you feel right now? (circle your response)

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely unhappy</td>
<td>Neither happy or unhappy</td>
<td>Extremely happy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Wave 1.

**Title:** Fill out a brief survey now for $0.05 and make $3.00 later as part of a longitudinal study

**Brief description:** Please answer a brief survey to see if you qualify for a two-part study. Must be 40-60 years old to participate.

**Full description:** We are conducting an academic study about self-perceptions in midlife. **THIS STUDY IS ONLY OPEN TO INDIVIDUALS WHO ARE 40-60 YEARS OF AGE.** This part of the study is a very brief demographic questionnaire (approximately 5 minutes) to see if you qualify for the study. Qualified participants have the opportunity to earn up to $3 for participating in the rest of the study, which includes questions about self-perceptions and personality as well as writing several memories about your life. Select the link below to complete the survey.

If you qualify for the study we will contact you within a week to invite you to the main study.

Please read everything carefully and answer truthfully. Responding to this survey should take approximately 5 minutes. We have allocated 1 hour for it simply to make sure you are not rushed and that you get paid for your work.

At the end of the survey, you will receive a code to paste into the box below to receive credit for taking this survey.

You will be paid if you follow the instructions in the survey, answer the questions thoughtfully AND enter the code below. Each person will only be paid for one survey completed, so please do not attempt to take the survey multiple times.
Wave 2.

Title: Self-perceptions in midlife study- part two (invited study)

Brief description: This is the second of three parts of the well-being in midlife study

Full description: This is the second short survey for those individuals who qualified for the study on how midlife adults perceive themselves and their lives. Only those individuals who have been invited to participate in this study and were sent a qualification code may participate. Make sure that you have your qualification code available as you will need to enter it in to the survey in order to participate.

There is one more part to the study after this, for which you will have the opportunity to earn $1.50

Please read everything carefully and answer truthfully. Responding to this survey should take approximately 30 minutes. We have allocated 2 hours for it simply to make sure you are not rushed and that you get paid for your work.

Select the link below to complete the survey.

At the end of the survey, you will receive a code to paste into the box below to receive credit for taking this survey.

You will be paid if you follow the instructions in the survey, answer the questions thoughtfully AND enter the code below. Each person will only be paid for one survey completed, so please do not attempt to take the survey multiple times.
Wave 3.

**Title:** Self-perceptions in midlife study-part three (invited study)

**Brief description:** This is the final part of the self-perceptions in midlife study

**Full description:** This is the final part of the self-perceptions in midlife study. Only those individuals who have been invited to participate in this study and were sent a qualification code may participate. Make sure that you have your qualification code available as you will need to enter it in to the survey in order to participate.

Please read everything carefully and answer truthfully. Writing the narratives should take approximately 1 hour. We have allocated 3 hours for it simply to make sure you are not rushed and that you get paid for your work.

Select the link below to complete the study.

At the end of the survey, you will receive a code to paste into the box below to receive credit for taking this survey.

You will be paid if you follow the instructions in the survey, answer the questions thoughtfully AND enter the code below. Each person will only be paid for one survey completed, so please do not attempt to take the survey multiple times.
Appendix G
Consent and Debriefing

Consent form- Part 1

**Purpose and Procedure:** the purpose of this study is to examine the self-perceptions of midlife adults (ages 40-60). In this part of the study you will be asked to respond to a brief demographic questionnaire that will take you approximately 5 minutes to complete. You are eligible to participate in this study if you are a US resident, between the ages of 40 and 60 years. Your responses to this questionnaire will determine if you are eligible to participate in the full study.

**Compensation:** You will receive $0.05 upon completion of this study for your participation. Please note that you must provide complete and thoughtful responses to the questions in order to receive compensation. If you are eligible for the full study then you will have the opportunity to earn up to $3.00 more.

**Risks:** Participating in this study will not expose you to major physical or psychological risks. It is possible, however, that some of the questions may make you feel uncomfortable. You may choose not to respond to any questions that you find distressing. You may also withdraw your consent to participate in this study at any time. It is important to note, however, that only those who complete the study in a thoughtful manner (i.e. 75% of the questions) will be compensated for their participation.

**Benefits:** Some potential benefits of this study to you include learning more about the process of psychological research. This study will also contribute to the research literature by providing information on the relations between self-perceptions, personality, and well-being in mid-life adults.

**Privacy and Confidentiality:** Your participation in this study is confidential and anonymous, only your worker ID will be used to link you to your responses. We may also use this ID to contact you regarding a follow-up study, but we do not have access to identifying information about you (e.g., name). Data from this study will be reported in the form of summaries about groups, not particular individuals.

If you have any questions regarding this project or this consent form before you participate, or afterwards, please contact Hannah Shucard or Kate McLean (360-650-3570) at shucard.research@gmail.com. This study has been approved by Western Washington University’s research ethics board. If you have any questions regarding your rights as a research subject, please contact Janai Symons (360-650-3220), who is the director of the protection of participants in research at Western Washington University.

**Consent:** I have read and understand the terms of the present consent form. I have made this decision based on the information I have received about it, and I accept its stipulations. I understand that by completing and submitting this electronic survey I am giving my consent to participate in this study according to the terms outlined above.
Please print a copy of this Letter of Consent for your records.

To acknowledge that you have read and understood this information and would like to continue with the survey, please click on “I agree” below.

Debriefing (for those who are not eligible for the full study)

Thank you for responding to this brief survey. Based upon your responses, you are not eligible to participate in the full study. We thank you for your interest in the study. Your time and thoughtful responses are greatly appreciated!

Hannah Shucard & Kate McLean

shucard.research@gmail.com
(360-650-3570)
Consent form - Part 2

Purpose and Procedure: the purpose of this study is to examine the self-perceptions of midlife adults (ages 40-60). In this part of the study you will be asked to respond to several surveys regarding your self-perceptions, personality, health, and psychological well-being. It will take you approximately 30 minutes to complete this study. You are eligible to participate in this study if you are a US resident, between the ages of 40 and 60 years.

Compensation: You will receive $0.80 upon completion of this study for your participation. Please note that you must provide complete and thoughtful responses to the questions in order to receive compensation.

Risks: Participating in this study will not expose you to major physical or psychological risks. It is possible, however, that some of the questions may make you feel uncomfortable. You may choose not to respond to any questions that you find distressing. You may also withdraw your consent to participate in this study at any time. It is important to note, however, that only those who complete the study in a thoughtful manner (i.e. 75% of the questions) will be compensated for their participation.

Benefits: Some potential benefits of this study to you include learning more about the process of psychological research. This study will also contribute to the research literature by providing information on the relations between self-perceptions, personality, and well-being in mid-life adults.

Privacy and Confidentiality: Your participation in this study is confidential and anonymous, only your worker ID will be used to link you to your responses. We may also use this ID to contact you regarding a follow-up study, but we do not have access to identifying information about you (e.g., name). Data from this study will be reported in the form of summaries about groups, not particular individuals.

If you have any questions regarding this project or this consent form before you participate, or afterwards, please contact Hannah Shucard or Kate McLean (360-650-3570) at shucard.research@gmail.com. This study has been approved by Western Washington University’s research ethics board. If you have any questions regarding your rights as a research subject, please contact Janai Symons (360-650-3220), who is the director of the protection of participants in research at Western Washington University.

Consent: I have read and understand the terms of the present consent form. I have made this decision based on the information I have received about it, and I accept its stipulations. I understand that by completing and submitting this electronic survey I am giving my consent to participate in this study according to the terms outlined above.

Please print a copy of this Letter of Consent for your records.

To acknowledge that you have read and understood this information and would like to continue with the survey, please click on “I agree” below.
Consent form- Part 3

Purpose and Procedure: the purpose of this study is to examine the self-perceptions of midlife adults (ages 40-60). In this part of the study you will be asked to write several memories about your life. It will take you approximately one hour to complete this study, though individual times may vary. You are eligible to participate in this study if you completed part 2 of the study, are a US resident, between the ages of 40 and 60 years.

Compensation: You will receive $1.50 upon completion of this study for your participation. Please note that you must provide complete and thoughtful responses to each narrative in order to receive compensation.

Risks: Participating in this study will not expose you to major physical risks. It is possible, however, that writing about past events may make you feel uncomfortable or cause you emotional distress. You may choose not to respond to narrative prompts that you find distressing. You may also withdraw your consent to participate in this study at any time. It is important to note, however, that only those who complete all narratives will be compensated for their participation.

Benefits: Some potential benefits of this study to you include learning more about the process of psychological research. This study will also contribute to the research literature by providing information on the relations between health, personality, and well-being in mid-life adults.

Privacy and Confidentiality: Your participation in this study is confidential and anonymous, only your worker ID will be used to link you to your responses. We may also use this ID to contact you regarding a follow-up study, but we do not have access to identifying information about you (e.g., name). Data from this study will be reported in the form of summaries about groups, not particular individuals. However, some narratives may be displayed for publication or presentation of this project. If this happens, all identifying information (e.g. names, specific geographic locations) will be changed or removed.

If you have any questions regarding this project or this consent form before you participate, or afterwards, please contact Hannah Shucard or Kate McLean (360-650-3570) at shucard.research@gmail.com. This study has been approved by Western Washington University’s research ethics board. If you have any questions regarding your rights as a research subject, please contact Janai Symons (360-650-3220), who is the director of the protection of participants in research at Western Washington University.

Consent: I have read and understand the terms of the present consent form. I have made this decision based on the information I have received about it, and I accept its stipulations. I understand that by completing and submitting this electronic survey I am giving my consent to participate in this study according to the terms outlined above.

Please print a copy of this Letter of Consent for your records.
To acknowledge that you have read and understood this information and would like to continue with the survey, please click on “I agree” below.
Debriefing Form

The purpose of this study is to investigate the relation between the way people narrate personal experiences and their psychological well-being. Specifically, we are interested how people living with chronic illnesses talk about their experiences of living with their illness. Previous research has shown that there are associations between how people talk about the past and their well-being but little research has investigated whether these associations are different in individuals living with a chronic illness. The results of this study have the potential, therefore, to help us better understand how individuals experience their chronic illness.

We would like to thank you for participating in this research. Your time and thoughtful responses are greatly appreciated!

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