FACING OUR FEELINGS IN FUTURE PLANNING:

EFFECT OF EMOTION ON EPISODIC SIMULATION OF FUTURE HEALTH EVENTS

by

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ABSTRACT OF THE THESIS

Facing our Feelings in Future Planning:

Effect of Emotion on Episodic Simulation of Future Health Events

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Efforts to address inadequacies in end of life care and reduce negative outcomes for surviving relatives has led to enhancements in advanced care planning, encouraging adults to develop detailed, action-driven and individualized plans. The current exploratory study investigated the influence of age and threat level on affective activation during the planning process by analyzing affective activation in three ways: measuring affective content of each narrative using the Linguistic Inquiry and Word Count program (Pennebaker et al., 2007), measuring a phonemic indicator (average fundamental frequency) of affective activation using the Praat system (Boersman, 2001; Scherer, 2003), and finally through a self-report, Likert scale rating of affect used previously (Addis, Wong & Schacter, 2008). 25 undergraduate students (18-22) and 23 "older" adults (65+) responded to 6 scenarios: three non-health related and three health-related. The three health-related scenarios varied in threat level; a) Low Threat: having a "flu", b) Medium Threat: living with a chronic illness, and c) High Threat: having 2-6 months to live. Contrary to expectations, analysis identified a significant effect of threat level on the negative affective content of the narratives, with higher affective content appearing in the low-threat scenario, than in the medium and high threat scenarios. There was no significant effect of

threat level on affective activation measured through fundamental frequency. Results were significant in the expected direction for self-reported affect which increased as threat level increased. Age moderated the effects of threat level on self-reported affect with older adults self-reporting higher levels of negative affect than younger adults for each of the health scenarios. Results for both self-reported affect and fundamental frequency are inconsistent with Reed & Carstensen's (2012) assumption that differences in affective responding with age reveal a *positivity effect* - a trend in which older adults express more positive than negative affective reactions to life situations. The data suggest that a *positivity effect*, if it exists, is context specific, appearing in many everyday events but not in response to health threats. Future analysis, should investigate the effects of affective activation on the specificity of plans which vary from relatively non-life-threatening to highly life-threatening.

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Introduction

Planning requires that an individual, living in the present, engages the past to imagine and anticipate both immediate and remote future experiences. The past establishes priors, or expectations for the present and the future (Klein, 2013; Schacter, Addis & Buckner, 2007). Although activities of daily living take place in the present, investigators often overlook the universal fact that the present is embedded in the future as well as the past. This embeddedness is evident in the simplest of daily acts, such as walking, as each step is shaped automatically by the prior step, expectations as to the subsequent steps, as well as the changing shape of the environment. More complex acts, such as taking a lunch break, are responses to prior signals from clocks, one's coworkers, and the body (e.g., feelings of hunger for specific foods), all generating expectations of oncoming performance. As the time between present and future expands (e.g., planning a summer vacation in January), perceptual, behavioral and cognitive processes involved in imagining positive and negative experiences in specific environments come into play, along with the specific costs and benefits of these future events (e.g., specific issues involved in seeking accommodations and travel). The extent of conscious engagement and search for information will be minimal for trivial, relatively short-lived events, and increasingly conscious and deliberative for important events such as taking a vacation trip, selecting an Undergraduate major, or searching for a place to live (Addis & Schacter, 2008).

Anticipating and planning to manage life threatening illnesses and death, a more dramatic and emotionally evocative future event, poses a complex set of problems for the vast majority of individuals. Anticipating and planning is compounded by a host of moderators ranging from personal history (e.g. the status of the physical and psychological self that varies by age and medical history), and experience gained by observing and managing events during severe illness

and death of close others. As planning for life threatening illness and death involves the core of oneself (i.e. one's existence), it creates a special opportunity for understanding the planning process when emotionally provocative events are ahead. There is both practical and scientific value to examining how people plan to manage future, severe threats to life, as severe illness and death is intrinsic to the human condition.

In addition to increasing our understanding of the planning process from a scientific perspective, there is a clear practical value in doing so. This is particularly true given that the 1990 Patient Self-Determination Act, requires all federally-funded health care facilities to provide patients with an opportunity to complete an *advanced directive* which included a *living will* and a durable power of attorney for health care (DPAHC) (PSDA, 1990). A *living will* is a legal document that specifies which medical treatments a person would like to receive if rendered incapacitated (Van Leuven, 2012); the DPAHC allows designation of a surrogate to make health care decisions in the event the patient is incapable of doing so (Van Leuven, 2012). Patients are also encouraged to informally discuss their treatment preferences with their family members and care providers to ensure the surrogate is aware of their preferences (Doukas & Hardwig, 2003). Despite the legal requirements, only 33-50% of adults in the United States have an advanced directive (AD) (Moorman, 2011; U.S. Department of Health and human Services, 2008).

Consider the following Clinical Case Vignette presented in the New England Journal of Medicine (Slutsky, et al., 2009).

A 56-year-old homeless man was found having a seizure and was transported to the hospital. He was found to have a subarachnoid hemorrhage, acute hydrocephalus and a ruptured aneurysm. He underwent intubation, and mechanical ventilation was started.

Both the neurologist and the neurosurgeon agreed that he had an 80-90% chance of being in a long-term persistent vegetative state and his prognosis was, at best, to have a severe disability that would leave him dependent on care by others.

The patient had not been in contact with his family. He had a son who, by state law, was the legal next of kin for making medical decisions if the patient was unable to do so himself. When contacted, the [other] relatives agreed that the patient would not want to live in a state in which he would be largely dependent on others for daily care and would have severely impaired cognition.

However, the son described the patient as "a fighter" who would want aggressive care until the prognosis was much more certain. Further complicating the matter, it was later discovered that the patient had a very close relationship with a counselor at a homeless shelter who related that the patient had told him that he wished to avoid hospitals and that "when his time came" he wanted no aggressive medical care.

If this man had completed an AD, conflicts between the opinions of medical professionals, family members and close others would not be at issue. There would be little risk that the patient's son or family members would feel burdened financially or psychologically by the need to make this decision. Furthermore, the hospital would have a legal document dictating who should be the final decision maker, removing some of the liability that the hospital could face if they were to follow their own clinical judgment as well as that of the patient's recent confidant. An AD that was specific and detailed as to the patient's wishes would serve to memorialize such wishes and allow him to advocate on his own behalf.

The above is just one of many examples motivating the recent advocacy, both by major medical organizations and individuals, for improved advanced care planning. The importance of

advance care planning on improving end-of-life care and reducing negative outcomes for surviving relatives has been heavily supported (American Medical Association, 1998; Institute of Medicine, 2015; Lambert, et al., 2005; Wright, et al., 2008). For example, in a multi-site, prospective, longitudinal cohort study of 332 patients with advanced cancer, Wright and colleagues (2008) found that patients who reported having end-of-life discussions with their physicians were less likely to have aggressive medical treatments including mechanical ventilation (1.6% vs. 11.0%; $P = .02$), resuscitation (0.8% vs. 6.7%; $P = .02$), and admission into intensive care unit (4.1% vs. 12.4%; $P = .02$). These aggressive medical procedures were associated with poorer quality of life scores, as reported by caregivers during the last week of their loved one's life ($F = 3.61_3$; $P = .01$). Given that the primary purpose of these plans is to clarify a patient's wishes, needs and preferences in the event they are unable to communicate them, a detailed plan may result in various medical, psychological and practical benefits. It is important to note that, even when prepared, relatively few advance directives are sufficiently detailed to permit decision making by family members and/or medical staff, when the individual is unable to do so on his or her own (Emanuel et al., 1991; Teno et al., 1997). For example, in a study of 4804 patients with serious illnesses, admitted to five U.S. teaching hospitals during the two years following the implementation of the Patient Self- Determination Act, Teno and colleagues (1997) found that only 90 had advanced directives which gave specific instruction and only 36 of those addressed life-sustaining care. Researchers concluded that the directives, as they were written, did not provide sufficient detail to "direct" medical care (Teno et al., 1997). However, little research has yet to address how to improve the quality of advanced care planning. The current exploratory study will focus on the potential effects of affective processes on future planning. Although a number of factors create difficulties in addressing these issues,

this preliminary investigation focuses on the relationship of emotional reactions to planning for future, possibly painful, and disabling medical decisions. The current study investigated the influence of affective activation on the planning process by analyzing the potential effect of age on affective activation in three ways: measuring emotional content of each narrative (using the LIWC program described below), measuring average fundamental frequency (using the Praat system described below), and finally through a self-report item used in the previous works.

In order to better understand the multidimensional effects of emotion on future planning, it is integral to use a multi-method approach to assess affect that uses both subjective and objective data. Subconscious emotional activation can be measured using acoustic software to perform a prosodic analysis of emotional activation during the generation of a future plan (Boersman, 2001; Scherer, 2003). This method may provide a measure of emotion which may not be accessible subjectively as a participant may seek to sensor their levels of emotional activation or may not be able to adequately report their state of affective arousal. It is expected that the content and speech indicators can provide an objective measure of affective arousal. Studies of affective speech prosody have demonstrated that acoustic features such as frequency and amplitude vary strongly across various emotional states (Sherer, 2003; Banse & Sherer, 1996). Furthermore, research suggests that either frequency or amplitude on its own can discriminate between prosody at above-chance levels (Belyk & Brown, 2014). Acoustic analysis of affective prosody allows for the measurement of subconscious emotion. Previous studies have demonstrated the utility of prosodic analysis of emotion to generate a fuller understanding of the multiple dimensions of emotional activation and expression. For example, in a study investigating methods of measuring emotional expression from natural speech, Cohen and colleagues (2009) found that, content and prosodic analyses of emotion did not significantly

correlate with each other suggesting that these analyses reflect different channels of emotional expression (Cohen et al., 2009). The current study analyzed affective activation in three ways: measuring emotional content of each narrative (using the LIWC program described below), measuring average fundamental frequency (using the Praat system described below), and finally through a self-report item used in the previous works of Addis, Wong and Schacter (2008). Future analysis will investigate the effects of affective activation on the specificity of plans generated for future events that vary from relatively non-threatening to highly life-threatening.

The evolution of the current study can be traced to a series of studies on the relationship of future memory (i.e. the use of memory when building an imagined future event) to advanced care planning. Each of these previous studies have observed age-related differences in the way in which individuals plan for the future. For example, researchers at the University of Toronto utilized the Autobiographical Interview measure to investigate age-related reduction in specificity of autobiographical memory (Levine, et al., 2002). In their investigation, Levine and colleagues studied 30 adults (15 adults aged 19-34; 15 adults aged 66-89) who were asked to recall events from five distinct life periods (early childhood, adolescent-teenage years, early adulthood, middle age, and the previous year), using a list of 100 typical life events to assist in memory retrieval. The results of the study suggest that younger adults are more likely to provide specific, episodic details in comparison with older adults who provide more generalized statements or details which are not specific – i.e. not connected to a particular time and place (Levine, et al., 2002).

Later research highlighted the fact that many of the cognitive and neural mechanisms involved in remembering past events, are also utilized to imagine future events. Harvard psychologist, Daniel Schacter, and colleagues utilized an adapted Autobiographical Interview

measure to extend the previous findings of reduced episodic specificity in the retelling of past events by older adults (Levine, et al., 2002), to imagined future events (Addis, Wong & Schacter, 2008). In their study, Addis, Wong and Schacter (2008) presented 34 individuals (17 younger adults and 17 older adults) with eight randomly presented noun cues in each of four time conditions (past few weeks, past few years, next few weeks, and next few years). This study also investigated the association of self-rated emotion on the difference in specificity; participants rated the intensity of their emotional reactions (from 1 = non-emotional to 5 = highly emotional) to each narrative (Addis, Wong, & Schacter, 2008). While Levine and colleagues differentiated details as "episodic" (i.e. reflecting actions, thoughts, locations all related to the prompt) and "semantic" (i.e. not connected to a particular time or place), Addis and colleagues distinguished between *internal / specific details* (descriptions of the event as well as details relating to the sensory or mental state of the event), and *external details* (semantic or factual statements and details not related to the event). Within the planning arena, **specific details** can be categorized as those which utilize **specific details** to describe future actions / behaviors (i.e. the who, what, when and where of an event). Conversely, **external details** can be categorized as those which refer to tangential facts or references to tangential events (i.e. those that do not provide specific actions or behaviors and instead convey more general details (Madore, Gaesser & Schacter, 2014). These details are, undoubtedly, not mutually exclusive as an individual will likely include both types of details in their planning. Plans may, however, be categorized by the predominance of specific or external details. In their study, Addis, Wong and Schacter (2008) replicated findings from Levine and colleague (2002) and found that when compared to younger adults, the older participants present significantly fewer specific (internal) details $F(1,30) = 14.49$, $P_{rep} = .99$, $\eta^2 = .326$. Furthermore, Mann-Whitney U tests suggest that older adults produced more

emotionally intense narratives, based on self-report ratings, than did younger adults ($U = 73.00$, $P_{rep} = .89$). As this result conflicted with the authors hypotheses, i.e. that specificity would be related to greater emotionality, they concluded that emotionality did not play a role in specificity of narratives.

The above referenced study lead to further investigations into the age-related differences in specificity along with its potential implications for planning for health events. In a following unpublished study, Korovikov (2008) sought to replicate the reduced specificity findings of Addis, Wong, and Schacter (2008) using health-related cues. In his study, Korovikov provided 36 participants (24 adults aged 18-23 and 12 adults aged 77-92) with eight health related and four non-health related cues from which participants would generate narratives of prior and anticipated experiences / events. Replicating previous studies, results suggest that younger adults provided more internal / specific and fewer external details than elderly adults when responding to non-health related cues ($t(34) = 5.587$, $p < .001$). However, Korovikov also found that age-related differences were not significant in narratives from health-related cues ($t(34) = 1.461$, p =NS). The current exploratory study is aimed at identifying possible explanations for these previous results. Are the age-related changes in specificity that are associated with differences in affective processing and activation by age (theories of which will be discussed in detail below), cognitive changes or a combination of the two? Furthermore, how does the inclusion of potentially threatening, health related cues change relationship between affective response and specificity? The current study will focus primarily on the effects of affective activation across health planning episodes varying in threat levels.

The current exploratory study focuses on affective responses and age (e.g. positivity preference in older adults, which will be further detailed in the discussion), threat level and

proximity to the proposed threat (e.g. an older individual is considered closer to end of life scenarios). Future analysis will examine the moderating effects of affective response in high-threat scenarios (e.g. end of life decision making) while investigating the association between varying indices of affective arousal and the specificity of future plans for scenarios with differing levels of threat (i.e. low, mild and high threat).

Specifically, our current aims are to determine the following: (1) The nature of the relationship between affective response and age: specifically, (a) do older adults demonstrate significantly less negative emotion than younger adults, a "positivity effect, as hypothesized by Carstensen and colleagues (Reed & Carstensen, 2012; see discussion for further details) or (b) is affective response moderated by proximity to threating activity (i.e. firsthand experience with chronic illness or end of life issues). (2) Whether increasingly threatening health-related cues are related to elevations in one or more of the three affective indicators, i.e. do self-report ratings of emotionality, negative affective content or vocal frequency, increase more with scenarios describing impending death than those describing chronic illness or a transient health threat, the flu. (3). In summary, the current study is designed to examine the effects of age and threat level on affective activation – measured through self-report, content analysis, and speech analysis, in response to cues about how one would respond to health events that vary from relatively non-life-threatening to highly life-threatening (See Table 1). The study also examines the association between affective activation and age, across the various threat levels. Experience / Proximity is expected to moderate the association between affective activation and threat level.

Methods

Participants

   Data were analyzed for 48 of 93 participants, 25 undergraduate students at Rutgers

University (aged 18-22, mean = 19.1) and 23 "older adults" (aged 60-91, mean = 72.7) who

volunteered to participate in a *Future Planning Study* (Age and Context-Related Changes in

Episodic Simulation of Future Events; IRB# 13-221M). The *Future Planning Study,* was

designed to compare the level of specificity of narratives produced by three age groups: younger

adults (18-22), middle-aged adults (30-59), and older adults (60+). The current analysis focused

on the oldest and youngest groups, reducing the number of participants to 78 of the original 93

participant volunteers. The *Future Planning Study* sought to distinguish between level of

specificity in narratives provided under two different frames of reference, spiritual and social

frameworks, and alternated between presenting narratives in a social / spiritual and spiritual /

social framework. For the current analysis, only responses provided under the social frame were

considered. However, review of transcripts revealed that five of the older adult participants failed

to distinguish between the differing frames, noting the repetition of questions when asked to

respond under the second frame. Given this finding, participants who indicated that they had

"already answered this question" when provided prompts with a social frame were excluded

from the current analysis (reducing the number of older adult participants from 28 to 23). This

resulted in 15 older adult participants responding in the first half of the interview and 8

participants responding in the second half, all younger adult participants responded within the

first portion of the interview. Further information regarding sample selection can be found in the

appendix. Undergraduate participants were compensated with course extra credit or $10. Older

adult participants were compensated $10 for their participation. Previous research examining

specificity in the simulation of health versus non-health events found that samples of 25 or fewer

participants per condition, were sufficient to compute significant group differences (Korovikov, 2008).

Measures of Interest

  Emotion-Related Measures. Emotional reaction to the scenarios were recorded in three ways: 1) self-reported emotionality at the completion of each narrative; 2) an analysis of the of emotional content of the narrative assessed with the Linguistic, Inquiry and Word count (LIWC) program (Pennebaker et al., 2007); 3) an acoustic analysis of speech generating a score for emotional reactivity (Boersman, 2001). Self-reports of emotionality were made on 5-point scale after completing each scenario (1 = Not at all, to 5 = Extremely). The Linguistic Inquiry and Word Count (LIWC) program (Pennebaker et al., 2007) generated a score for the affective narrative's affective content by comparing its content to a dictionary of over 2,200 word stems and dividing the number of target words by total words to correct for variation in response length. The LIWC has been validated for analysis of both positive and negative emotional responses and is associated with subjective emotion-ratings (Kahn et al., 2007). The Praat system (Boersman, 2001) generated the third measure by analyzing and scoring acoustic features of the participant's speech indicative of emotional arousal: specifically, the mean Fundamental Frequency, perceived by the human ear as the mean pitch of speech (F_0, measured in hertz units, or Hz) (Scherer, 2003). The three measures differ therefore, in the degree to which the participant is directly aware of and in control of reporting or conveying her/his emotional state; self-report most aware, followed by content, and finally speech analysis as furthest from ones' own control.

  Specificity-Related Measures. Similar to previous studies (Korovikov, 2008; Addis, Wong & Schacter, 2008), audio recordings of interviews were transcribed and coded for

Specificity of Thought Units. First, individual thought units were tallied and labelled as internal and situation specific or external and tangential in nature. The ratio of internal /situation specific units to total units was calculated for each narrative to assesses the degree to which a participant "rambled," (i.e. "filled" the allotted time with irrelevant speech). These data will be presented in a follow-up report examining the relationship of specificity to the affective measures used in the current study.

Procedure

All study procedures were approved by the Rutgers University Institutional Review Board. Participants responded to 6 scenarios following the procedures adapted from the? Autobiographical Interview system (Levine, et al., 2002); three non-health related and 3 health related. The current study focuses on three health-related scenarios which varied in threat level; a) Low Threat: have a flu, b) Medium-level Threat: living with a chronic illness, and c) High Threat: Having 2-6 months to live. The three scenarios were responded to in the following order: **I.** Health-related, medium-threat: "Imagine you have developed a serious illness such as diabetes or a serious heart condition that will last your life time. And while imagining this, consider how your relationships with family, friends and/or community would help you to go about living your daily life. Imagine and tell what you would think, feel, see and do on a typical day if you were living with this illness."

II. Health-related, high-threat: "Imagine you have only 2 – 6 months to live. And while imagining this, consider how your relationships with family, friends and/or community would help you to go about living your daily life. Imagine and tell what you would think, feel, see and do on a typical day if you were nearing the end of your life."

III. Health-related, low-threat: "Imagine you have a bad case of the flu, you are infectious, have to stay home and will miss two days of an important social get-together with family and friends. Imagine and tell what you would think, feel, see, and do, as if you were there."

After reading each scenario participants were instructed to: "Say what comes to mind; there is no right or wrong answer. You do not have to use all 3 minutes." Following each response, they completed a brief questionnaire which asked for the participant's rating (on a scale of 1-5) for the following: (1) the level of detail in his/her response, (2) its personal significance, and (3) the strength of his/her emotional reaction when responding, the latter the self-report measure of subjective emotion. All narratives were recorded and transcribed.

Following completion of the narratives, participants completed a Demographic and Health Questionnaire the assessed the following: age, gender, marital status, ethnicity, employment status, level of education and income, and health factors including: overall ratings of health at the present time, ratings of health compared to other men or women of the same age group, and health status regarding chronic illnesses (e.g. diabetes, heart disease, cancer, etc.). The questionnaire also asked participants if they had "witnessed a family member/friend experience a health threat" as well as familiarity with and preparation of a living will, and an advanced directive. Procedures for coding will be reported in a later document.

Statistical Analysis

A combination of t tests repeated measures Analysis of Variance and general linear regression analyses were used to examine the association between age and each of the three measures of affective activation (explicit (LIWC), implicit (acoustic analysis) as well as Self-reported), across the three threat levels. Potential covariates included experience with serious or chronic illness. First, descriptive statistics were inspected to determine whether or not

assumptions for the general linear model are met. Specifically, normality, skew, kurtosis, and homoscedascity was evaluated.

Hypothesis 1a. Affect (implicit/speech, explicit/content and self-report) will increase as threat level increases with the lowest levels of affective activation occurring in the Flu scenario and the highest level of affective activation in the End of Life scenario. 1b: This relationship, between affect and threat, will be evident across both age groups. To test this hypothesis, a repeated measures ANOVA will be run with each affective measure to determine if affect is significantly different across threat levels.

Hypothesis 2a. Older Adults will have significantly greater affective activation (measured through Speech) than Younger Adults in the End of Life scenario. To test this hypothesis, independent samples t-tests will compare mean F_0 within the high threat scenario between the two age groups. If an analysis of variance reveals an effect, separate t-tests will compare mean F_0 within the low and medium threat scenarios between age groups to detect where these effects occur. It would be expected that there will be non-significant differences between age groups within the low threat scenario as well as reduced significance on the medium threat scenario as compared to the high-threat scenario. To investigate the possible effect of experience, an ANCOVA will be performed with implicit Affect (Dependent Variable), Threat group (fixed factor) and Experience (as a dichotomized covariate).

Hypothesis 2b. Prior experience with serious personal loss (e.g., death of parent, sibling, close friend, etc.) will moderate the association between age cohort and differences in implicit affective responses to the highly threatening scenarios. Specifically, undergraduate respondents who have experienced a serious loss (e.g., death of parent, sibling, close friend, etc.) will generate narratives with significantly higher mean F_0 as compared to undergraduates who do not

have such experience. To test this hypothesis, a multiple regression will be performed where implicit affect is the Dependent Variable (DV) and Age / Cohort, Experience with significant loss (both dichotomized) and the Cohort X Experience interaction as Independent Variables (IV) (step 2).

Hypothesis 3. Older adults will have less self-reported negative affect than younger adults in each threatening scenario. This will help to determine if the positivity effect (Reed & Carstensen, 2012) is supported in the current study. We will also investigate this relationship in the other affective measures.

Results

The final dataset for the current study contained responses to 144 narratives, three health narratives (low, medium and high threat) for each of 48 participants; 25 young adults aged 18-22 and 23 elder adults aged 65-92. Means for each of the three affect measures – affective activation as measured through fundamental frequency; negative affective content; as well as self-reported affect – are listed in Table 1. Prior to conducting repeated measures ANOVAs each of the variables were tested for sphericity using Mauchly's Test of Sphericity (Mauchly, 1940); the tests indicated that the variances of the differences between all combinations of threat level were sufficiently alike to conduct repeated measures analysis of variance. The analysis identified a significant effect of threat level on the negative affective content ($F(2, 92) = 15.2$, $p < .01$) of the narratives for both older and younger adults, the highest negative affective content appearing in the low-threat, flu scenario than in the chronic illness or the end of life scenario, an effect opposite to expectations (difference = 1.171, $p < .01$; difference = 1.527, $p < .01$ respectively). Results were also statistically significant for self-reported Affect ($F(2, 92) = 16.9$, $p < .01$), in the opposite direction however, as self-reported affect increased as threat level increased (see Table 2 for full list of pairwise comparisons). There was no significant effect of threat level on affective activation as measured through fundamental frequency, $F(2, 92) = 0.805$, $p = .450$. Further analysis of the repeated measures ANOVA found that age moderated the effects of threat level self-reported affect, $F(2, 92) = 5.844$, $p < .01$, with older adults reporting greater affect across all threat levels.

Further analysis was conducted to determine correlations between affective indicators at the various threat levels. To account for age-related differences, scores were transformed into z-scores within each age group and analysis of correlations was conducted based on these

transformed scores. Among the older adult population, affective activation, as measured through fundamental frequency, was significantly correlated to self-reported affect across low-threat scenario, was approaching significance in the mid-threat scenario, and was nonsignificant in the high threat scenario ($r(21) = .448$, $p = .032$; $r(21) = .405$, $p = .055$; and $r(21) = .348$, $p = $ ns, respectively). Within the younger adult population, none of the three affective variables were significantly correlated within any of the three threat levels.

Review of the dataset revealed that all older adults (n=23) reported prior close experience with a serious health threat, rendering the planned statistical analysis of potential moderating effects of experience on any of the affective measures invalid.

Discussion

The current exploratory study had two aims: the primary aim was to better understand the relationship between affective responses and threat level across different age groups.

Effects of threat on affect

It was hypothesized that all measures of affect (implicit, explicit and self-report) would be associated with threat level, each of the three increasing from the low (flu) to high threat (end of life in months) scenarios. The self-report data was consistent with expectations, participants giving higher ratings to their emotional state for end of life than for chronic illness and flu scenarios. Post-hoc pairwise comparisons showed significantly higher levels of self-reported emotion after the end of life scenario than for the chronic illness scenario and self-reported emotion was also significantly higher following the chronic illness scenario than the flu scenario.

Surprisingly however, both affective activation as measured by negative affective content and fundamental frequency responded opposite to expectations, though the difference in fundamental frequency was not significant; each decreased as scenarios became more threatening. The low threat (flu) scenario produced the largest number of words reflecting negative affect and highest fundamental frequency, while the high-threat (end of life) scenario was lowest on both indicators. Pairwise comparison between scenarios showed significantly more negative affective content in responses to the flu scenario, than either the chronic illness or the end of life scenario; the chronic illness and end of life scenarios did not differ in speech content. Based on the unexpected and varied findings regarding the effect of threat level on affective activation, the correlations between the three affective measures were calculated to see if the associations among the three indicators would clarify the findings. The correlations showed affective activation, assessed by the average fundamental frequency, was positively correlated to

self-reported affect, in older adults, under the low threat, flu scenario. Despite their significance, these correlations were moderate ($0.3 < r < 0.4$) and did not clarify the mean differences of the indicators across the scenarios. Overall, these results seem to suggest that the self-reporting of affect may be more closely linked to the "representation" of a health threat than either of the objective measures as it follows the pattern suggested by the severity of these threats.

Effects of age on the affect – threat relationship

Participant age moderated the effects of threat level on self-reported affect with older adults self-reporting higher levels of negative affect than younger adults for each of the three, health scenarios. Although the pattern for the analysis of vocal tone of speech was similar to that for self-report, the index was not significantly higher overall for older than younger adults. There were however, no significant age differences for negative content. Although the findings are mixed, the results for both the self-report and fundamental frequency are inconsistent with Reed and Carstensen's (2012) suggestion that differences in affective responding with age, reveal a *positivity effect*, a trend in which older adults express more positive than negative affective reactions to life situations. The data suggest that a "positivity effect", if it exists, is context specific, appearing in many everyday events but not in response to health threats.

Affect Threat relationship and the Common Sense Model. When viewed within our current conceptual framework, a possible explanation of disparate findings begins to emerge. Consider the following model of cognitive affective processing of illness representations (Figure 1):
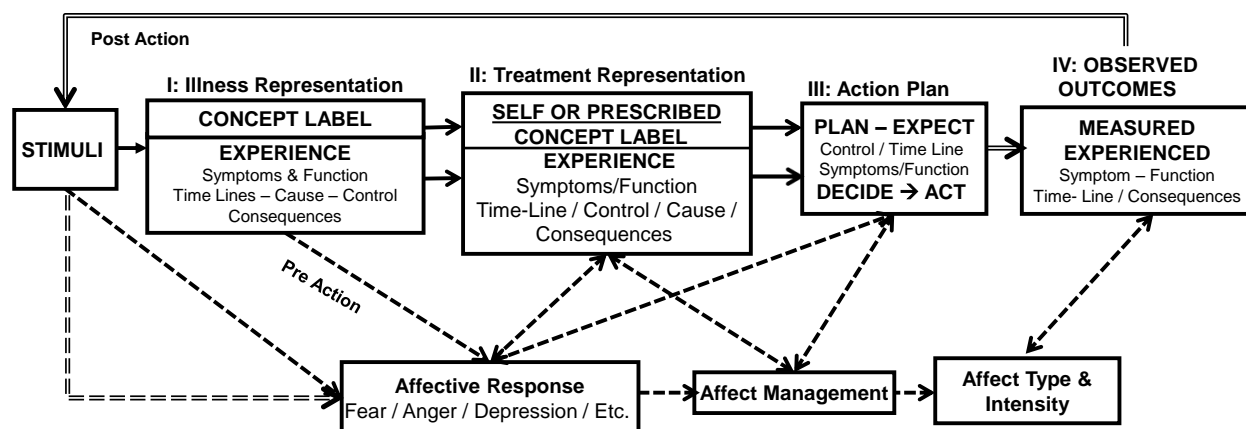
Figure 1: Common Sense Model of cognitive affective processing (Leventhal, et al., 2015).

Based on the above model, it is hypothesized that representations of both illness (health threat) and treatment representation, are developed at both conceptual and experiential levels. It is likely that the future planning paradigm did not adequately engage individuals at the experiential level. A more elaborate and detailed prompt, perhaps to imagine oneself laying in a hospital bed, surrounded by the concerned faces of your loved ones, with sharp sensations of pain running through particular parts of your body, might better engage individuals on an experiential level than a prompt to imagine an unspecified fatal illness.

The possibility, that age differences in cognitive affective arousal described by Carstensen (Reed & Carstensen, 2012) may affect the cognitive or emotional processing components of the decision making model, remains. However, this may only arise under conditions in which the experiential component is fully engaged. For example, older adults might experience stronger emotional activation when considering end-of-life scenarios, which may promote activation of emotional heuristics to quickly engage coping / management strategies which can affect the cognitive appraisal / re-appraisal stages of the process (see Fig. 2).

Post Action

I: Illness Representation

II: Treatment Representation

III: Action Plan

IV: OBSERVED OUTCOMES

STIMULI

CONCEPT LABEL

EXPERIENCE
Symptoms & Function
Time Lines – Cause – Control
Consequences

SELF OR PRESCRIBED CONCEPT LABEL
EXPERIENCE
Symptoms/Function
Time-Line / Control / Cause / Consequences

PLAN – EXPECT
Control / Time Line
Symptoms/Function
DECIDE → ACT

MEASURED EXPERIENCED
Symptom – Function
Time- Line / Consequences

Pre Action

Affective Response
Fear / Anger / Depression / Etc.

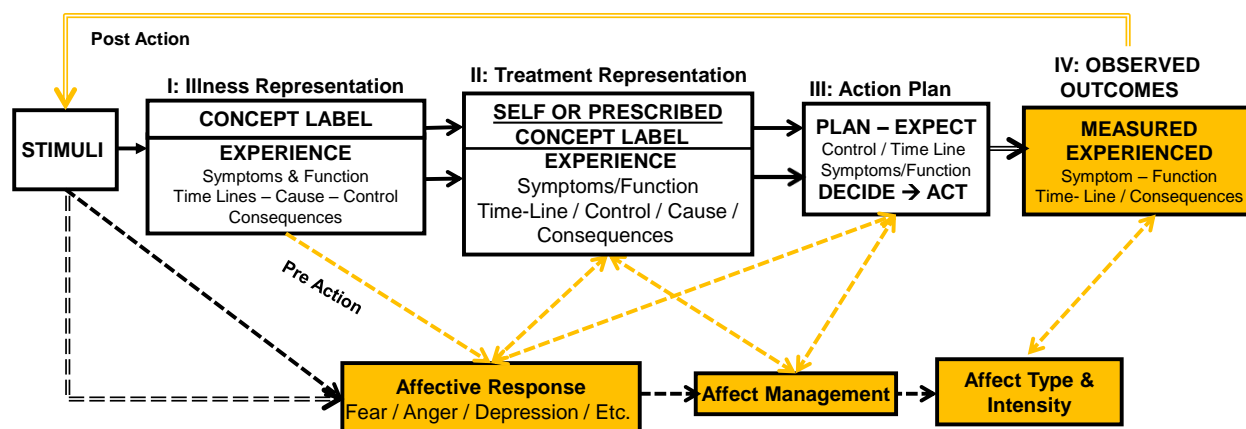**Affect Management**

Affect Type & Intensity

Figure 2: Modified Common Sense model of cognitive affective processing with expedited emotional component

By examining the manner in which people generate future health-related plans, the study hoped to contribute to existing literature on how to optimize patient's treatment decisions and end of life care planning. It is possible that more elaborate prompting is needed to emulate the medical decision-making process. Wilson and Gilbert (2003) noted that adults consistently have difficulty with anticipating the intensity and duration of the emotion they will experience in specific, future situations, though they are able to accurately predict its valence. These difficulties may hinder medical decision making as one might struggle to anticipate future treatment preferences.

The current exploratory study had several limitations. While previous studies were able to identify significant effects, there were multiple analyses which may not have identified real-world effects due to the small sample size. For example, correlations were noted to be "approaching significance" suggesting that with a larger sample size these measures may have been significantly correlated. Furthermore, analysis of the potential moderating effect of experience was not possible with the current sample as all members of the Older Adult group reported experience with serious health threats. Future studies might specify the type of experience with a health threat in order to measure which individuals may have had first-hand experience with a chronic or life-threatening illness. Another limitation of the current study

relates to the inability to distinguish between acoustic indicators of positive and negative emotion. While the fundamental frequency has been shown to be an accurate measure of overall emotional activation, it would be most insightful to pull out the specific indicators of negative affective.

Relating current findings to follow-up report on specificity

The current exploratory study utilized the Common Sense model of cognitive affective processing (Leventhal, et al., 2012; Leventhal, Phillips & Burns, 2016), which posits that increasing levels of affective reactivity will be associated with a greater number of internal / specific details considered during the planning process. End of life and / or advance care planning requires attention to imagined details of a future event, and one that is existential and threatening. For most, our own death and the death of loved ones is not a calm-inducing picture. Accordingly, the model suggests that the demand for detail will likely activate an affectively engaged response rather than a detached mental picture of the future health event.

Future planning draws upon the content and associated emotions of past experience, which may influence the construction of future events. For example, situations may lead to specific emotional states and be viewed "integral" to the situation under consideration (Lerner et al., 2015). Feelings and / or emotional reactions, which are integral to a situation can influence decisions both consciously and subconsciously (Green & Haidt, 2002). These influences can be disruptive (e.g., situationally elicited fear can promote avoidance if the individual lacks the resources to respond to the threat), or can activate coping strategies if specific resources for managing the threat are accessible (Loewenstein, et al, 2001; Bechara et al., 1999). In the context of end-of-life planning, feelings of fear elicited from the possibility of death may lead an individual to avoid all discussions of end-of-life decisions. Alternatively, fear activated by the

possibility of death might motivate the individual to act. Furthermore, worry elicited by the thought that family members would not be able to cope after one's death might motivate an individual to utilize available resources (e.g. psychological support or estate planning resources) or might cause an individual to avoid discussing these issues if resources are perceived as inaccessible or nonexistent. Models of end of life planning should consider both the potential positive and negative impact of emotion on planning.

It is also clear that the intensity of emotional upset associated with an image of a threatening future will be linked to the degree of detail in the image. For example, discussing ones death, and or that of a loved one, in the abstract is far less emotionally provocative than imagining or seeing death in detail; furthermore tears and emotional upset are far more likely when viewing a loved one's dead body than when discussing its antecedent causes and consequences. There is therefore, a conflict between the need for detailed imagery for effective planning (i.e., for imagining implementation of specific decisions and actions given the specific details of oneself severely / terminally ill and in pain), and the avoidance of affective arousal activated by such details. Although this conflict may be avoided by dealing with an end-of-life scenario, the adequacy of decisions generated by abstract reasoning depends upon the referents for the abstractions; (i.e., do the referents represent the specifics of the future event) (Leventhal, Phillips & Burns, 2016). In accordance with the Common Sense Model, as an individual gains experience with a particular threating event (e.g. living with a life-threatening condition, having close relationships with someone nearing the end of life), his or her expectations and representations of the threatening event is further updated. This model can lead to two distinct hypotheses regarding the relationship of affect and threat level: **First,** one can expect the situational accuracy of conceptual referents to improve with repeated attention to an event and

that repetition will be moderated by multiple factors, one of which will be age; older individuals are more likely to express and make "situationally" valid decisions for end of life planning as they are more likely to have visited the issues and done so on multiple occasions. Younger individuals (e.g., college-age students), are less likely to have considered end of life for themselves and therefore, less likely to access situationally relevant concepts to imagine and describe their responses when they are terminally ill. Realistic responding for the younger respondent will call for attention to details and the affective arousal associated with doing so. Younger individuals with experience dealing with potentially life threatening illnesses would serve as an exception to this theory.

Conclusion and future directions

Advanced directives have been promoted as a means of assistance in planning for life threatening health events while ensuring these wishes are respected in instances of incapacitation. The current exploratory study investigated the effect of age and threat level on affective activation. The current study has several potential implications for the field of behavioral health research as well as practical implications in the fields of medicine and psychology. First, it is hoped that this study will engage future research on differences in affective expression between age groups when developing future plans. Future studies may seek to develop interventions addressing the emotional disparity or the effect of emotion on other health-decisions, such as treatment planning.

Continued research within this field has practical implication within the field of medicine as well as the field of psychology. First, this study contributes to the existing body of knowledge on ways to improve the system for obtaining advanced directives; enhancing understanding of why advanced directives are not completed while also raising awareness for the inadequacy and /

or lack of detail of future planning and providing a potential avenue for intervention. Continued work in the area my help to reduce instances of unnecessary medical treatment or potential legal actions from surviving relatives unhappy with end of life care commonly associated with inadequacy or lacking of advanced directives. Finally, this study as well as studies informed by its findings may aid in the integration of research on the effects of emotion on cognitive processing with existing theories of age and context-related changes in cognitive processes. Results of future studies may indicate the need for psychological screenings / interventions for patients diagnosed with life-threatening illnesses before facing the task of advanced-care planning to address potential emotional 'roadblocks" to optimal planning.

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Table 1. Study Design

	Low Threat (Flu)	Mid-Threat (Chronic Illness)	High Threat (End of Life)
Self-Reported Affect	Older / Younger	Older / Younger Adults	Older / Younger Adults
Negative Affective Content	Older / Younger	Older / Younger Adults	Older / Younger Adults
Speech (Affective Activation)	Older / Younger	Older / Younger Adults	Older / Younger Adults

Table 2. Age-based means of affective measures across threat levels

	(Flu) Mean (SD)	(Chronic Illness) Mean (SD)	(End of Life) Mean (SD)
Self-Reported Affect			
Older Adult	3.61 (1.31)	3.70 (1.33)	4.04 (.928)
Younger Adult	2.32 (0.748)	3.32 (0.988)	3.72 (1.10)
Total Sample	2.94 (1.23)	3.50 (1.17)	3.88 (1.02)
Negative Affective Content			
Older Adult	2.94 (2.08)	1.27 (1.31)	1.11 (1.25)
Younger Adult	2.69 (1.28)	2.02 (0.811)	1.47 (1.37)
Total Sample	2.81 (1.70)	1.66 (1.14)	1.30 (1.31)
Speech (Affective Activation)			
Older Adult	148.46 (28.63)	147.51 (28.19)	147.42 (29.80)
Younger Adult	140.27 (36.89)	139.72 (35.44)	138.72 (38.06)
Total Sample	144.19 (33.10)	143.46 (32.08)	142.89 (34.28)

Table 3. Pairwise Comparisons between threat levels

	Mean Difference	Std. Error	Sig.
Self-reported Affect			
Flu vs. Chronic Illness	-0.543	.162	.002
Flu vs. End of Life	-0.917	.165	.000
Chronic Illness vs. End of Life	-0.374	.149	.016
Negative Affective Content			
Flu vs. Chronic Illness	1.171	.286	.000
Flu vs. End of Life	1.527	.328	.000
Chronic Illness vs. End of Life	0.356	.249	.161
Speech (Affective Activation)			
Flu vs. Chronic Illness	0.745	1.044	.479
Flu vs. End of Life	1.295	1.130	.258
Chronic Illness vs. End of Life	0.550	.885	.537

Table 4. Correlation between affective measures

	Older Adults		Younger Adults	
	Pearson Correlation	Sig.	Pearson Correlation	Sig.
Low Threat (Flu)				
Self-reported Affect *and* Negative Affective Content	0.223	.306	0.228	.273
Self-reported Affect *and* Speech (Affective Activation)	**0.448**	**.032**	0.134	.523
Negative Affective Content *and* Speech (affective Activation)	0.154	.482	-0.055	.228
Mid Threat (Chronic Illness)				
Self-reported Affect *and* Negative Affective Content	-0.202	.355	-0.229	.270
Self-reported Affect *and* Speech (Affective Activation)	0.405	.055	0.349	.087
Negative Affective Content *and* Speech (affective Activation)	0.055	.803	0.027	.898
High Threat (End of Life)				
Self-reported Affect *and* Negative Affective Content	0.014	.948	0.097	.646
Self-reported Affect *and* Speech (Affective Activation)	0.348	.104	0.381	.061
Negative Affective Content *and* Speech (affective Activation)	0.031	.889	-0.184	.379

Appendix

Participants by Interviewer	
Interviewer	n
BN	3
CS	9
ER	1
JH	14
JY	4
KC	17
Total	48

Participants by Site	
Site Code	n
RU	29
PC	8
EB	6
CH	4
MT	1
Total	48

Interviewer / Site Matrix

<u>Interviewer - BN</u>
PC – 1 participant
RU – 2 participants

<u>Interviewer - CS</u>
CH – 4 participants
EB – 5 participants

<u>Interviewer - ER</u>
EB – 1 participant

<u>Interviewer - JH</u>
RU – 14 participants

<u>Interviewer - JY</u>
RU – 4 participants

<u>Interviewer - KC</u>
MT – 1 participant
PC – 7 participants
RU – 9 participants

Total Sample
(interviewed through the *Future Planning Study*)
93

Older Adults
(60+)
28

Middle-aged Adults
(30-59)
10

Younger Adults
(18-22)
55

Social Frame
(provided first)
15

Social Frame
(provided 2nd)
13-5 = 8*

Control Group
(not included in current sample)
10

Social Frame
(provided first)
25

Social Frame
(provided 2nd)
20
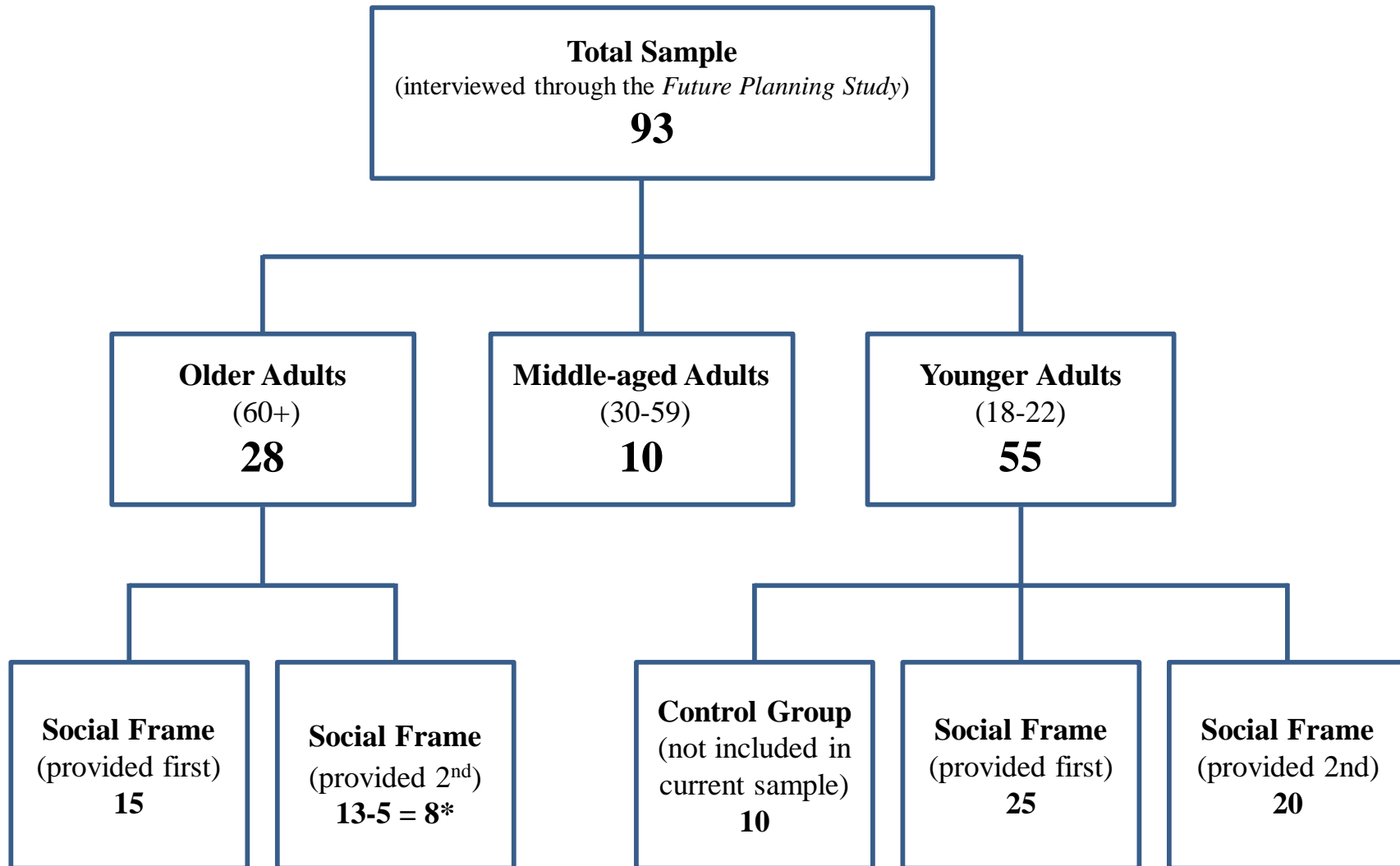
* 5 participants excluded as they did not distinguish from previous frame provided (i.e. "I've answered this already")

Title: Age and Context-Related Changes in Episodic Simulation of Future Events
PI: Howard Leventhal, Ph.D.

Attachment 4: CONSENT TO TAKE PART IN A RESEARCH STUDY

TITLE OF STUDY: Age and Context-Related Changes in Episodic Simulation of Future Events

Principal Investigator:	**Howard Leventhal, Ph.D.** **Institute for Health, Health Care Policy, and Aging Research** **Rutgers University** **112 Paterson Street** **New Brunswick, NJ 08901**
Co-Investigators:	**Emily Roman, BA** **Jenna Herold, BA**

This consent form is part of an informed consent process for a research study and it will give information that will help you to decide whether you wish to volunteer for this research study. It will help you to understand what the study is about and what will happen in the course of the study.

If you have questions at any time during the research study, you should feel free to ask them and should expect to be given answers that you completely understand by the research team.

After all of your questions have been answered, if you still wish to take part in the study, you will be asked to sign this informed consent form.

A member of the study team (an investigator) will also be asked to sign this informed consent. You will be given a copy of the signed consent form to keep.

You understand that you are not giving up any of your legal rights by volunteering for this research study or by signing this consent form.

Why is this study being done?
The purpose of this study is to learn how differences in age and differences in types of events may affect how people plan for future events. We believe that comparing and understanding the possible differences between age groups and event types will help us better understand how older and younger adults imagine their futures. This understanding may help us teach people how to make better decisions, plan more, increase their quality of life, and reduce unnecessary seeking of medical care.

Why have you been asked to take part in this study?
You have been invited to take part in the study because you are either: (1) a Rutgers University student between the ages of 18 and 25; or (2) a member of the community surrounding New Brunswick, NJ at or above the age of 50.

APPROVED

JUN 2 0 2016

EXPIRES

JUN 1 9 2017

Approved by the
Rutgers IRB

Approved by the
Rutgers IRB

Title: Age and Context-Related Changes in Episodic Simulation of Future Events
PI: Howard Leventhal, Ph.D.

Who may take part in this study? And who may not?
People MAY take part in this study if they: (1) are Rutgers University students between the ages of 18 and 25 OR members of the community surrounding New Brunswick, NJ at or above the age of 50; and (2) are able to read and speak English.

People MAY NOT take part in this study if they report any cognitive and/or speech impairment that prevent them from being able to complete the study interview or questionnaires.

How long will the study last and how many subjects will participate?
Approximately 100 participants (50 students and 50 community members) will take part in this study overall. Each participant will be involved in the study for one session that lasts 45-60 minutes.

What will you be asked to do if you take part in this research study?
If you choose to take part in this study, you will participate in one study appointment that includes the following:

1. Study Interview: Questions about how you might plan for the future.
2. Response Questionnaire: Questions regarding your responses about planning.
3. Demographic and Health Questionnaire: Questions regarding your age, gender, ethnicity, educational background, and general health.

Are there any benefits for you if you choose to take part in this research study?
You may benefit because you will be asked to consider and talk about scenarios you may not have considered previously. As a result, you may gain an increased awareness about your future as well as an increased ability to make informed decisions about medical situations.

What are your alternatives if you don't want to take part in this study?
You can choose not to participate in this study.

How will you know if new information is learned that may affect whether you are willing to stay in this research study?
During the course of the study, you will be updated about any new information that may affect whether you are willing to go on taking part in the study. If new information is learned that may affect you after the study is completed, you will be contacted.

Will there be any cost to you to take part in this study?
There will be no costs to you for participating in this study.

Will you be paid to take part in this study?
If you are an undergraduate student recruited via the Department of Psychology Subject Pool, you will not be paid for your participation in the study. You will be provided with 1 Research Participation Unit. If you are an undergraduate student recruited via other means (such as study flyers posted on campus bulletin boards), you will be paid $10 for your participation.

If you are an older adult, you will be paid $10 for your participation in the study.

APPROVED   EXPIRES

                                                JUN 1 9 2017

Consent Form, Version 5: 7/22/15   JUN 2 0 2016   Page 2 of 5

                        Approved by the   Approved by the
                        Rutgers IRB   Rutgers IRB

Title: Age and Context-Related Changes in Episodic Simulation of Future Events
PI: Howard Leventhal, Ph.D.

How will information about you be kept private or confidential?
This research is confidential. The research records will include some information about you and this information will be stored in such a manner that some linkage between your identity and the response in the research exists. Some of the information collected about you includes age, ethnicity, educational background, and general health. Please note that we will keep this information confidential by limiting individuals' access to the research data and keeping it in a secure location. In addition, you will be assigned a code number and your actual name will not be used. Only the principal investigator will be able to link the code number to your name and will keep this information for 3 years.

The research team and the Institutional Review Board (a committee that reviews research studies in order to protect research participants) at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, your identity will remain confidential and only group results will be stated. All study data will be kept for 3 years.

What will happen if you do not wish to take part in the study or if you later decide not to stay in the study?
You understand that you may choose not to be in the study. If you do choose to take part, it is voluntary. You may refuse to take part or may change your mind at any time.

You understand that you are not giving up any of your legal rights by signing this informed consent form or by taking part in this research study.

If you do not want to enter the study or decide to stop participating, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

You may also withdraw your consent for the use of data already collected about you, but you must do this in writing to Dr. Leventhal.

Who can you call if you have questions?
If you have any questions about taking part in this study, you may contact the Principal Investigator:

Howard Leventhal, Ph.D.
Institute for Health, Health Care Policy, and Aging Research
Rutgers University
112 Patterson Street
New Brunswick, NJ 08901
Phone: 848-932-7537
Email: hleventhal@ifh.rutgers.edu

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EXPIRES

JUN 1 9 2017

Title: Age and Context-Related Changes in Episodic Simulation of Future Events
PI: Howard Leventhal, Ph.D.

If you have any questions about your rights as a research subject, please contact an IRB Administrator at the Rutgers University, Arts and Sciences IRB:

Institutional Review Board
Rutgers, The State University of New Jersey
Liberty Plaza / Suite 3200
335 George Street, 3rd Floor
New Brunswick, NJ 08901
Email: humansubjects@orsp.rutgers.edu
Phone: (732)235-9806

AGREEMENT TO PARTICIPATE

I have read this entire form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form or this study have been answered.

I agree to take part in this research study.

Subject Name:_____

Subject Signature:_____ Date:_____

Signature of Investigator/Individual Obtaining Consent:

To the best of my ability, I have explained and discussed the full contents of the study including all of the information contained in this consent form. All questions of the research subject and those of his/her parent or legal guardian have been accurately answered.

Investigator/Person Obtaining Consent:_____

Signature:_____ Date: _____

APPROVED

JUN 2 0 2016

Approved by the
Rutgers IRB

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AUDIO ADDENDUM TO CONSENT FORM

You have already agreed to participate in a study entitled "Age and Context-Related Changes in Episodic Simulation of Future Events." We are asking for your permission to allow us to audiotape (sound) your interview.

The recording(s) will be used only for data analyses. The tape recordings will be transcribed; no personal identifiers will be transcribed from the recordings. You will be assigned a unique ID code number. Data coded and transcribed from tape recordings will have all identifiers, including names, removed and replaced by ID code numbers. The tape recordings will be kept in a secure password protected file at the Rutgers Institute for Health, Health Care Policy and Aging Research. Access to the recordings will be restricted to the senior investigators. The tape recordings will be kept for 1 year to ensure adequate time to accurately transcribe the data, after which time they will be destroyed. Transcriptions will be kept for 3 years.

Your signature on this form grants the investigator permission to record you as described above during participation in the above-referenced workshop. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written permission.

Subject (Print) _____

Subject Signature _____ Date _____

Investigator/Person Obtaining Consent Signature _____

Date _____

APPROVED

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Interviewer Instructions

<u>Materials:</u>
- Consent Form (TWO COPIES)
- Interview Script
- Interview Prompts
- Response Questionnaire
- Demographic and Health Questionnaire
- Audio Recorder
- Timer
- Compensation Receipt

<u>Procedure:</u>

Consent Process
1. Upon greeting the participant, provide TWO COPIES of the consent form. One copy is for the participant to sign and date; the second copy is for the participant to take home.
2. Carefully review the consent form with the participant.
    a. Summarize the study aims, inclusion and exclusion criteria, procedures, benefits, risks, and compensation.
    b. Emphasize that participation is completely voluntary and the research is kept confidential.
    c. Inform participants that they may contact Dr. Leventhal or the IRB Administrator with any questions or concerns.
3. Make sure the participant initials the bottom of each page and signs and dates pages 4 and 5.
4. Make sure you (the interviewer) sign and date pages 4 and 5.

Interview Process
1. Before beginning the interview, make sure you (the interviewer) have the correct script, prompts, and an audio recorder.
2. Turn on the audio recorder and record the following: "This is the end of life interview with participant number X. The interviewer is Y and the date is Z." Keep the recorder on for the duration of the interview.
3. Follow the interview script.
    a. For each scenario, present the participant with the appropriate printed prompt.
    b. Once you present each scenario, begin the timer and signal the participant to begin speaking.
    c. If the participant completes a story in less than 3 minutes, use the three follow-up questions: "Is that all?", "Do you have anything else to add?", "Are you done?".

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        d. If 3 minutes are up before the participant is done, say, "Time is up. Thank you." Proceed to Step 4.

4. At the completion of each scenario, provide the participant the Response Questionnaire. Please note that there is ONE Response Questionnaire per participant. Each participant will complete the 3 response items for each scenario on the same questionnaire.

5. Once the participant has completed all 6 scenarios, turn off the audio recorder and provide him/her the Demographic and Health Questionnaire. Please check that the participant answers all questions.

Compensation Process

1. Once the participant has completed the interview and the Demographic and Health Questionnaire, provide him/her with appropriate compensation.
   a. 2 RU credits for SONA students
   b. $10 for all other undergraduates
2. Have the participant initial and date the receipt.

Instructions to participants:

We are studying what people imagine they will see, feel, and do in specific situations in the future. We want to understand these images, as they affect how people plan for the future. We will present you with a total of 12 scenarios. You will have about 3 minutes, which is usually more than enough, to talk about each situation.

In those 3 minutes, we want you to see yourself in that situation and talk into the recorder and describe in as much detail as you can what you would think, how you might feel, and what you expect you might see and do; tell your story as if you were there. Remember, this is not a test so there is no right or wrong answer; just say what comes to mind. You do not have to use all 3 minutes for each story. After you have given your response, we may ask you "is that all" or "do you have anything else to add?" These prompts are to ensure that you have completed your story. When you finish a story, I will hand you a quick one page questionnaire.

Do you have any questions?

Pre- Question Cue:

Before you begin talking about these future events, it would help to "warm up" by talking about something that happened in the past. Think about breakfast this morning. Tell what you thought, felt, saw, and did as you had breakfast. Be as detailed and specific as possible. Say what comes to mind; there is no right or wrong answer. You do not have to use all 3 minutes.

Participant will provide story.

Good. Now that you have practiced and should feel comfortable with telling these brief stories, let's focus on the future. I will suggest five different types of events for you to talk about. The 5 events that you will plan and talk about are:

1. A weekend trip.

2. Taking care of a bad cold that keeps you out of action for a few days.

3. Planning to live with a serious illness for the rest of your life.

4. How you would live out your life if you lost most of your money.

5. Planning what you would do if you have only a few months to live.

Interviews with Family/Social Context:

Relationships with family, friends, and communities can play important roles in the plans and decisions a person makes about an upcoming, future event. As you talk about what you expect you will see, think and do, in these future events, keep these social relationships in mind. Many people's social relationships are based mainly on family, while others may include close friends. Some consider associations with work or community organizations as important. Whatever your specific or mix of social connections may be, keep them in mind and let them inform what you imagine and say about what you would think, feel and do in that situation.

You can take up to 3 minutes to talk about each event, but you do not have to use all of that time.

Ok are you ready? Good. Here is the first situation.

1. Imagine you are on a trip to a place you have never been to before, such as a national park, or a busy city with museums, theaters, and many different ethnic restaurants. Imagine and tell what you would think, feel, see, and do, as if you were there. Say what comes to mind; there is no right or wrong answer. You do not have to use all 3 minutes.

   Provide the following 3 prompts to make sure participants have completed their story.
   1. Is that all?
   2. Do you have anything else to add?
   3. Are you done?

Okay, now I will ask you to fill in this one-minute questionnaire about your created story.

2. Imagine you have developed a serious illness such as diabetes or a serious heart condition that will last your life time. And while imagining this, consider how your relationships with family, friends, and/or community would help you to go about living your daily life. Imagine and tell what you would think, feel, see and do on a typical day if you were living with this illness. Say what comes to mind; there is no right or wrong answer. You do not have to use all 3 minutes.

   Provide the following 3 prompts to make sure participants have completed their story.
   1. Is that all?
   2. Do you have anything else to add?
   3. Are you done?

Okay, now I will ask you to fill in this one-minute questionnaire about your created story.

3. Imagine you have only 2 – 6 months to live. And while imagining this, consider how your relationships with family, friends, and/or community would help you to go about living your daily life. Imagine and tell what you would think, feel, see and do on a typical day if you were nearing the end of your life. Say what comes to mind; there is no right or wrong answer. You do not have to use all 3 minutes.

   Provide the following 3 prompts to make sure participants have completed their story.
   1. Is that all?
   2. Do you have anything else to add?
   3. Are you done?

Okay, now I will ask you to fill in this one-minute questionnaire about your created story.

4. Imagine you have a bad case of the flu, you are infectious, have to stay home and will miss two days of important social get-together with family and friends. Imagine and tell what you would think, feel, see, and do, as if you were there. Say what comes to mind; there is no right or wrong answer. You do not have to use all 3 minutes.

   Provide the following 3 prompts to make sure participants have completed their story.
   1. Is that all?
   2. Do you have anything else to add?
   3. Are you done?

Okay, now I will ask you to fill in this one-minute questionnaire about your created story.

5. Imagine you have lost your job or life-savings, and you only have enough money to account for your bare necessities. And while imagining this, consider how your relationships with family, friends, and/or community would help you to go about living your daily life. Imagine and tell what you would think, feel, see and do on a typical day if you were living with very little money. Say what comes to mind; there is no right or wrong answer. You do not have to use all 3 minutes.

> *Provide the following 3 prompts to make sure participants have completed their story.*
> 1. Is that all?
> 2. Do you have anything else to add?
> 3. Are you done?

Okay, now I will ask you to fill in this one-minute questionnaire about your created story.

6. Imagine you have a serious, fatal illness and must decide whether to engage in life-sustaining treatment. And while imagining this, consider how your relationships with family, friends, and/or community would help you to go about this decision. Imagine and tell what you would think, feel, see and do as you make this decision. Say what comes to mind; there is no right or wrong answer. You do not have to use all 3 minutes.

> *Provide the following 3 prompts to make sure participants have completed their story.*
> 1. Is that all?
> 2. Do you have anything else to add?
> 3. Are you done?

Okay, now I will ask you to fill in this one-minute questionnaire about your created story.

7. Imagine you are planning a celebration. And while imagining this, consider how your relationships with family and friends might influence how you go about making preparations for your party. Imagine and tell what you would think, feel, see and do as you begin your preparations.

> *Provide the following 3 prompts to make sure participants have completed their story.*
> 1. Is that all?
> 2. Do you have anything else to add?
> 3. Are you done?

Okay, now I will ask you to fill in this one-minute questionnaire about your created story.

Debrief:

I have a few questionnaires for you to complete at this time. When you have finished, I have a couple of things that I would like to tell you about the study.

Questionnaires completed

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Attachment 7-B: Response Questionnaire

Directions: Please answer the following questions in response to each verbal plan you provide. Place a check mark (√) in the appropriate box.

Plan 1

	1 Not at all	2	3	4	5 Extremely
How detailed was your verbal response?					
How personally significant was this scenario?					
How emotional was this scenario?					

Plan 2

	1 Not at all	2	3	4	5 Extremely
How detailed was your verbal response?					
How personally significant was this scenario?					
How emotional was this scenario?					

Plan 3

	1 Not at all	2	3	4	5 Extremely
How detailed was your verbal response?					
How personally significant was this scenario?					
How emotional was this scenario?					

Plan 4

	1 Not at all	2	3	4	5 Extremely
How detailed was your verbal response?					
How personally significant was this scenario?					
How emotional was this scenario?					

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Plan 5

	1 **Not at all**	2	3	4	5 **Extremely**
How detailed was your verbal response?					
How personally significant was this scenario?					
How emotional was this scenario?					

Plan 6

	1 **Not at all**	2	3	4	5 **Extremely**
How detailed was your verbal response?					
How personally significant was this scenario?					
How emotional was this scenario?					

If someone told you today that you had a serious chronic condition, had lost your life savings, or had no more than 6 months to live, would you immediately think of something specific to do, or would you prefer to wait and see how things develop?

I can think of several specific things to do right now. Yes   No

I would wait to see how things develop rather than do something right away. Yes   No

Response Questionnaire

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Attachment 7-C: Demographic and Health Questionnaire

Basic Information

ID: _____

Interview Date: _____

Gender:
- ☐ Male
- ☐ Female

Date of Birth: _____

Marital Status:
- ☐ Married
- ☐ Separated/Divorced
- ☐ Widowed
- ☐ Single

Race (Check all that apply):
- ☐ Caucasian/White/ European American
- ☐ Black/African American
- ☐ Asian/Pacific Islander
- ☐ Hispanic
- ☐ Native American
- ☐ Other _____

Highest education level:
- ☐ No degree/grade school only
- ☐ High school diploma
- ☐ GED
- ☐ Associate's Degree/2-year college
- ☐ Bachelor's Degree/4-year college
- ☐ Master's Degree
- ☐ Doctorate (MD, PhD)
- ☐ Other _____

Current work situation:
- ☐ Not working/retired
- ☐ Currently working full-time
- ☐ Currently working part-time
- ☐ Disabled/sick leave
- ☐ Homemaker
- ☐ Other _____

Combined family income:
- ☐ $150,000 or more
- ☐ $100,000 to $149,000
- ☐ $90,000 to $99,999
- ☐ $80,000 to $89,999
- ☐ $70,000 to $79,999
- ☐ $60,000 to $69,999
- ☐ $50,000 to $59,999
- ☐ $40,000 to $49,999
- ☐ $30,000 to $39,999
- ☐ $20,000 to $29,999
- ☐ $10,000 to $19,999
- ☐ Less than $10,000

Please continue to next page →

Demographic and Health Questionnaire

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Additional Information

What is your religious and/or spiritual affiliation? _____

How often do you attend religious and/or spiritual services?
- ☐ **At least once a week**
- ☐ **At least once a month**
- ☐ **Only during holidays and/or other celebrations**
- ☐ **Never**

How many close family members and/or friends would you say you have? _____

How often do you speak to or spend time with family and/or close friends?
- ☐ **At least once a week**
- ☐ **At least once a month**
- ☐ **Only during holidays and/or other celebrations**
- ☐ **Never**

Demographic and Health Questionnaire

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Your Health

How would you rate your health (please circle one)…

at the present time?	Poor	Fair	Good	Very Good	Excellent
Compared with other (men/women) your age?	Poor	Fair	Good	Very Good	Excellent

Has a doctor told you that you have any of the following conditions, or are you taking medication for any of the following conditions?
- ☐ Asthma
- ☐ Lung Problems
- ☐ Diabetes
- ☐ Cancer
- ☐ Ulcer(s)
- ☐ Heart Disease
- ☐ High Blood Pressure
- ☐ A Heart Attack
- ☐ Seizures
- ☐ Hepatitis
- ☐ Kidney Problems
- ☐ Tuberculosis (TB)
- ☐ Depression or Anxiety

Have you witnessed a family member/friend experience a health threat? If so, please describe:

Please continue to next page →

Demographic and Health Questionnaire

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Health Preparations

Have you discussed the types of medical treatment you want or don't want to receive if you become seriously ill in the future?
- ☐ Yes
- ☐ No

Do you have a living will or an advance directive? This is a set of written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate.
- ☐ Yes
- ☐ No

Have you made any legal arrangements for someone to make decisions for you about your medical care, if you become unable to make those decisions for yourself? This person is sometimes called a Durable Power of Attorney for Health Care.
- ☐ Yes
- ☐ No

Do you have a signed and witnessed will for your property or assets?
- ☐ Yes
- ☐ No

Have you ever had any long-term care insurance, not including government programs like Medicare or Medicaid?
- ☐ Yes
- ☐ No

Thank you for completing this questionnaire.

Demographic and Health Questionnaire