Predicting Young Adults’ Engagement in Advance Care Planning

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Abstract

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Predicting Young Adults’ Engagement in Advance Care Planning

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Advance care planning (i.e., the process by which individuals identify life-sustaining treatment preferences; ACP) is frequently targeted to older adult and terminally ill populations. This is a shortcoming because young adults are also at risk for sudden illness and traumatic injury, and making advance care plans prior to becoming ill may make decision-making easier for both individuals and their families. As such, this dissertation views ACP as a life-long process that should begin when individuals are young adults. Because ACP is often perceived as a difficult conversation and individuals are reluctant to engage in it, it is important to understand the individual and relational factors that affect young adults’ intent to have ACP conversations. This dissertation advances health communication research by developing the difficult conversation model (DCM) that bridges components of the theory of planned behavior, the health belief model, and the disclosure decision-making model.

The following dissertation reports three studies that build upon one another to finally assess the proposed DCM model. The first step in building and evaluating this model was formative research. Formative research allowed for both the exploration of anticipated individual motivating factors as well as the discovery of unanticipated individual and relational factors. Results of the focus groups showed that relational
factors do play a part in individuals’ intent to communicate about ACP. In Study 1, I applied the findings of the focus groups by testing several of the individual and relational factors for the model. Study 2 was an extension of Study 1, in which I added the remaining individual and relational factors, and the DCM was developed and assessed. The results of Study 2 indicated that barriers, severity, anticipated response, attitude, perceived behavioral control, and cues to action affect young adults’ intent to have ACP conversations. Several interesting mediations were also revealed.
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Chapter One: Introduction

Advance care planning (ACP) is the process by which individuals identify the type of care they would want to receive in the event that they are unable to communicate due to a severe illness or injury (Dobbs, Emmett, Hammarth, & Daaleman, 2012). ACP is enacted through completion of advance directives (ADs) and conversations with loved ones (Dobbs et al., 2012). ADs are legal health care documents that specify a plan of action (Durbin, Fish, Bachman, & Smith, 2010). The two most common ADs are (a) living wills, which detail a patient’s specific life-sustaining treatment desires (e.g., mechanical ventilation) under a variety of circumstances and situations, and (b) healthcare powers of attorney, which designate a healthcare proxy to make medical decisions (Janssen, Engelberg, Wouters, & Curtis, 2012). Other types of AD documents include value statements that address emotional and spiritual well-being in addition to medical care preferences (e.g., the Five Wishes® document), and do not resuscitate (DNR) orders that direct physicians not to perform cardiopulmonary resuscitation.

In addition to executing ADs, medical professionals also encourage individuals to enact ACP by communicating proxy and life-sustaining treatment preferences to friends and family (Moorman, 2011). It is important that individuals have conversations in addition to completing ADs so that proxies have a full understanding of patients’ wishes (Moorman, 2011). It has been suggested that ADs should be completed “through open and honest communication within the family about the issues addressed in the advance directive” (Kapp, 2000, p. 45). Thus, conversations provide a starting point for individuals to make advance care plans (Lange, 2012).
In the literature and in praxis, ACP is frequently conceptualized as an issue only important for those nearing end-of-life, namely the elderly and terminally ill populations (Rauscher & Nacinovich, 2012). This is a shortcoming because ACP is beneficial and relevant to adults of all ages (Rauscher & Nacinovich, 2012). Moreover, engaging in ACP before becoming ill may make the medical treatment decision-making process easier for patients and their family (Rauscher & Nacinovich, 2012). For these reasons, this dissertation answers calls for research that envisions ACP as a life-long and intergenerational process that begins before an individual is ill (see Kapp, 2000; Rauscher & Nacinovich, 2012; Resnick & Andrews, 2002). ACP engagement should begin through conversations with family when individuals turn 18 and have the legal authority to make treatment decisions.

As part of reimagining ACP as a process that young adults engage in, it is important to recognize that individuals of different ages have different goals, attitudes, and experiences that lead them to manage communicative events in different ways (Nussbaum, 2007). Thus, current ACP literature on elderly and terminally ill individuals may not translate to the healthy, young adult population. For example, in a cross-generational study of African Americans, there were differences in perceived barriers to ACP among age groups, such that several barriers held by the elderly population did not exist in the young adult population and vice versa (West & Hollis, 2012). Because the young adults have different needs and priorities than that of the elderly population (Nussbaum, 2007), more research is needed to determine the factors that predict their intent to have ACP conversations about their own preferences.
To understand factors that predict ACP conversations among young adults, we need models that encompass both individual and relational factors of behavior. Theories from the field of psychology—such as the health belief model (HBM; Becker, 1974) and the theory of planned behavior (TPB; Ajzen, 1991) that have long and consistently captured the individual-centered elements of behavioral intention—provide a starting place from which to understand ACP engagement. At the same time, however, relational factors should be taken into account because ACP conversations inherently involve interaction, particularly with family members with whom they are close, about a topic that is often difficult to navigate. As stated by the disclosure decision-making model (DD-MM; Greene, Magsamen-Conrad, Venetis, Checton, Bagdasarov, Banerjee, 2012), individuals consider relational factors (e.g., a partner’s anticipated response) when deciding to disclose information. As such, this dissertation proposes the difficult conversation model (DCM), which incorporates various individual factors from the TPB and HBM, as well as relational factors from the DD-MM.

In sum, this dissertation advances health communication research by identifying factors that affect young adults’ intention to have ACP conversations and by developing a model that incorporates individual and relational predictors of communicative behavior. The results of this research will help scholars and practitioners motivate young adults to have ACP conversations, ultimately improving young adults’ ACP engagement rates. Additionally, the DCM is theoretically driven, and its orientation towards communication as both individual- and relationship-dependent may make it translatable to other types of
conversations in health contexts. For example, this model may also predict individuals’ intent to talk with a partner about safe sex.

To these ends, the following dissertation unfolds in six chapters. I review relevant literature in the second chapter of this dissertation. Specifically, I begin by discussing the importance of ACP and why young adults should engage it, followed by a review of the individual and relational factors that motivate behavior. I conclude this chapter with an outline of the components of the DCM.

I describe my formative research in the third chapter. I conducted focus groups to identify young adults’ salient attitudes and beliefs about ACP conversations. I asked participants about their knowledge, personal experience, willingness, self-efficacy, perceived severity, perceived susceptibility, perceived barriers, and perceived benefits related to ACP conversations. The results of the formative research informed the second component of this dissertation, Study 1.

Study 1, as I describe in chapter four, was a preliminary study that had two goals. First, I piloted several measures for inclusion in Study 2. Second, I tested the appropriateness of the HBM variables—the most commonly used variables in ACP research—and one relational variable for inclusion in the DCM. A hierarchical multiple regression analysis determined the most significant predictors. The results of Study 1 furthered the development of the DCM, as tested in Study 2.

I describe Study 2 in chapter five. I built on the results of Study 1 in Study 2 by including additional concepts related to the TPB and the DD-MM. I used path analysis to
develop and assess the DCM. I removed three non-significant paths, ultimately arriving at desirable model fit indices.

In chapter six, the final chapter in this dissertation, I discuss the cross-study findings presented in this dissertation. I review the differences and similarities between elderly and young adults in relation to ACP and ways in which the DCM might be applicable in other contexts. In these sections I offer practical and theoretical implication before discussing limitations.
Chapter Two: Literature Review

ACP is important for several reasons. One reason why ACP is important is because it has the potential to preserve individuals’ autonomy. ACP preserves autonomy by allowing patients to remain in control of their medical treatment in situations where they cannot communicate their preferences for life-sustaining treatment (Tremethick, Johnson, & Carter, 2011). Patients who do not engage in ACP and consequently leave medical treatment decision-making to their family members may not receive the same care they would have chosen for themselves. This discrepancy is a result of proxies’ frequent inability to accurately guess patients’ wishes (Shalowitz, Garrett-Mayer, Wendler, 2006). Proxies are only able to correctly predict their loved ones’ medical preferences 68% of the time (Shalowitz et al., 2006). Incorrectly guessing a loved one’s life-sustaining treatment preferences results in either (a) the patient not receiving desired medical treatment, causing his or her life to end prematurely or (b) the patient receiving undesired medical treatment (Tremethick et al., 2011). In the latter case, the patient may be forced to live a life that he or she perceives to be of low quality (e.g., being permanently attached to a ventilator; Lee, 2009; Tremethick et al., 2011). Thus, ACP helps preserve patient autonomy in medical treatment decision-making.

The second reason ACP is important is because it mitigates family members’ stressful decision-making. Acting as a proxy for a loved one is a stressful position due to the emotional and serious nature of the consequences (Rauscher & Nacinovich, 2012). The stress is especially heightened, however, when proxies are unaware of the patients’ life-sustaining treatment preferences (Rauscher & Nacinovich, 2012). Proxies who must
make medical decisions without knowledge of the patients’ wishes have an increased burden because of the difficulty of making weighty decisions during an already tumultuous time (Rauscher & Nacinovich, 2012). However, when patients engage in ACP, the decision-making “process becomes more straightforward and this predetermined direction can provide comfort by clarifying the intentions of the patient[s]” (Rauscher & Nacinovich, 2012, p. 1). Although being a proxy may always involve a degree of stress, knowledge of a patient’s life-sustaining treatment preferences can comfort the proxy with the reassurance that he or she is following the loved one’s wishes (Rauscher & Nacinovich, 2012). As outlined above, there are several reasons why it is important for individuals to engage in ACP. However, these reasons are frequently promoted only for the elderly and terminally ill. This is a shortcoming because it is also important for young adults to engage in ACP.

**Advance Care Planning Among Young Adults**

There are two primary reasons why young adults should be encouraged to have ACP conversations. First, healthy, non-elderly adults are at risk for being in situations where they are unable to communicate their medical treatment wishes and thus can benefit from having ACP conversations (Rauscher & Nacinovich, 2012; Kapp, 2000). In fact, young adults may be at an increased risk of accidental injury because of their tendency to feel invincible and to engage in riskier behavior (Kapp, 2000). Individuals aged 25 to 44-years-old make more visits to the emergency room than any other age group (CDC, 2010), indicating that they may be at the greatest risk for experiencing sudden situations that would necessitate making life-sustaining treatment choices.
Second, ACP conversations are commonly only conducted when a person is seriously ill or nearing the end-of-life (Rauscher & Nacinovich, 2012). Although ACP becomes particularly salient under these circumstances, waiting to engage in ACP may create more difficult situations for the patient. Just as it is difficult for proxies to make medical decisions in a high-stress situation, it is difficult for patients to make medical decisions when facing their own end-of-life. Levi and Green (2010) note that “medical decision-making under such circumstances can be difficult, especially when the outcomes are uncertain and the stakes high” (W1). To avoid the difficulty that comes with decision-making when individuals are under pressure, and to be prepared for potential situations where medical treatment decisions are necessary, ACP should begin when individuals are young adults (Rauscher & Nacinovich, 2012). Despite ACP’s benefits and importance for people of all ages, the emotions and uncertainties that arise during ACP discussions make them difficult conversations.

Communicating about Advance Care Planning

Difficult conversations are discussions in which the topic is steeped in emotion and uncertainty (Keating, Russell, Cornacchione, & Smith, 2013). ACP and other end-of-life discussions are considered to be difficult conversations because they involve both the emotionally-challenging task of considering the death of others and of one’s self, as well as uncertainties about various aspects of ACP and end-of-life (Hines, 2011; Keating et al., 2013). Given the uncomfortable nature of ACP conversations, it is unsurprising that individuals are reluctant to engage in them (Kapp, 2000). This reluctance underscores the need to explore the factors that affect intention to have ACP conversations. Theories such
as the theory of planned behavior (TPB) and the health belief model (HBM) provide insight into the individual factors that affect individuals’ behavior.

**Individual motivating factors.** According to the TPB and the HBM, individual factors consist of cognitions that individuals form about themselves in relation to a behavior, as well as states and traits that play a role in behavioral intention (Ajzen, 1991; Becker, 1974). For example, individuals consider whether they have the ability to perform the behavior, and whether they will experience positive or negative outcomes as a result of the behavior (Ajzen, 1991). Although many constructs of the TPB and HBM have rarely been applied to ACP research, they may be useful in the DCM. In what follows, I review the tenets of and current literature on the models. My hypotheses pertaining to the DCM are reserved for a separate section at the end of the chapter. This chapter is organized in this manner to allow me to build a clear argument in support of my model-related conclusions.

**Theory of planned behavior.** The TPB suggests that behavior can be predicted by intent, and that intent is determined by three factors—attitude, perceived behavioral control, and subjective norm (Ajzen, 1991). The TPB also occasionally recognizes background variables (Ajzen, 1991; Ajzen, 2002). See Figure 1 for a visual of the model.

Attitude, the first main construct of the TPB, is the evaluation of the behavior (Ajzen, 1991). Individuals are more likely to perform a behavior if they have a more positive evaluation of it (Ajzen, 1991). Of all the TPB variables, attitude commonly emerges as the strongest predictor of behavioral intent (Freberg, 2013). For example, attitude was the greatest predictor of individuals’ intent to comply with a food recall...
message (Freberg, 2013) and to discuss smoking-related behaviors (Brann & Sutton, 2009). However, it is accepted among the TPB community that the relevance of each of the TPB’s primary variables—attitude, subjective norm, and perceived behavioral control—may vary depending on the population and topic at hand (Fishbein & Ajzen, 2010).

![Diagram of the Theory of Planned Behavior (TPB)](image)

*Figure 1. The Theory of Planned Behavior (Ajzen, 1991).*

Perceived behavioral control is the second main construct of the TPB (Ajzen, 2002). Perceived behavioral control refers to the degree to which individuals perceive themselves to be capable of performing a behavior and the amount of control he or she believes to have over performing the behavior (Ajzen, 2002). The greater the perceived behavioral control an individual has, the greater the likelihood is of him or her performing the behavior (Ajzen, 2002). Research has shown mixed results in terms of the significance of perceived behavioral control for predicting behavioral intent. It should be
noted that intent to comply with a food message (Freberg, 2013) and intent to discuss smoking-related behaviors (Brann & Sutton, 2009) were not predicted by perceived behavioral control. However, perceived behavioral control was a significant predictor of young adults’ intent to stop smoking (Murnaghan et al., 2009). Whereas complying with a food recall message and discussing smoking-related behaviors may be construed as relatively easy behaviors, smoking cessation is extremely difficult for those addicted to nicotine (Murnaghan et al., 2009). Therefore, perceived behavioral control may be more important for difficult behaviors. This makes sense theoretically, as difficulty would decrease an individuals’ perception of his or her ability to perform the behavior.

In the typical TPB model, perceived behavioral control has a direct path to intent and it is co-varied with the other two primary TPB constructs. Research suggests, however, that the model may be improved by also creating a path from perceived behavioral control to attitude (Mou & Lin, 2015). Perceived behavioral control was a significant predictor of young adults’ attitude towards podcast-adoption (Mou & Lin, 2015). Young adults who felt more confident about adopting new technologies had a more favorable attitude towards adopting podcasts (Mou & Lin, 2015). Therefore, it may not be enough to simply co-vary the constructs in the model. Perceived behavioral control and attitude may be related on a deeper level than just correlation.

Subjective norm, the third main construct of the TPB, is comprised of injunctive and descriptive norms (Ajzen, 2002). Injunctive normative beliefs are individuals’ perceptions of what is expected of them by others (Ajzen, 2002). These beliefs can be formed through either inference or explicit instructions (Ajzen, 2002). On the other hand,
descriptive normative beliefs are perceptions of how others behave (Ajzen, 2002).

Individuals are often motivated to act similarly to others (Ajzen, 2002). Individuals with greater subjective norms are more likely to perform a behavior (Ajzen, 2002).

Like perceived behavioral control, the traditional TPB model has a direct path from subjective norm to intent, and co-variances between subjective norm and the two other primary TPB variables. However, research suggests that subjective norm may be more appropriate elsewhere in the model (Armitage & Conner, 2011; Hagger, Chatizisarantis, & Biddle, 2002; Mou & Lin, 2015). Subjective norm was a significant predictor of perceived behavioral control in a study of podcast-adoption intent, such that individuals who believed their peers to be adopting podcasts had more self-efficacy towards their own ability to adopt podcasts (Mou & Lin, 2015). Additionally, meta-analyses have shown that when compared to attitude and perceived behavioral control, subjective norm typically has the weakest effect on—and sometimes zero shared variance with—intent (Armitage & Conner, 2011; Hagger et al., 2002). Given these conclusions, it is possible that subjective norms may have a mediated relationship with intent. It may be that subjective norms are related to intent through perceived behavioral control. In other words, individuals who perceive others to exhibit and/or support a behavior are more likely to perform the behavior because they have more confidence in their ability. This makes sense in the context of the spiral of silence theory, which states that individuals are less likely to voice their opinion if they believe that it is inconsistent with the majority opinion because they have decreased confidence (Noelle-Neumann, 1984). Therefore,
perceived behavioral control may mediate the relationship between subjective norm and intent.

In addition to the three main constructs, literature on the TPB also occasionally mentions background variables. Background variables are factors such as demographic characteristics, personality traits, and personal experience that are believed to affect behavioral intent when they are directly related to either attitude, subjective norms, or perceived behavioral control. Research has identified many background influence variables that affect elderly adults’ willingness to complete ADs. Individuals are more likely to complete an AD if they are older (Rosnick & Reynolds, 2003), have a college degree (Wagner, Riopelle, Steckart, Lorenz, & Rosenfield, 2010), have a higher income (Rosnick & Reynolds, 2003), are married (Morrison, Zaya, Mulvihill, Baskin, & Meier et al., 1998), and have poor health (Morrison et al., 1998). Although ethnicity has been identified as a factor affecting AD execution (Landry, Kroenke, Lucas, & Reeder, 1997; Reynolds, Hanson, Henderson, Steinhauser, 2008), ethnicity does not significantly predict AD completion when other factors are controlled for (Morrison et al., 1998).

The TPB model provides a good foundation from which to build the DCM. However, the HBM addresses several unique variables that may be relevant for predicting young adults’ intent to have ACP conversations. Ajzen (1991) suggested that additional variables may improve the predictability of the model, given a strong theoretical rational for adding them. To these ends, the DCM will incorporate not only TPB variables, but many variables from the HBM, as well.
**Health belief model.** According to the HBM, the likelihood of an individual adopting a health-related behavior can be predicted by the presence of cues to action and four perceived constructs: threat (a combination of perceived severity and perceived susceptibility), barriers, benefits, and self-efficacy (Becker, 1974). See Figure 2 for a visual depiction of the model.

![Diagram of the Health Belief Model](image)

*Figure 2. The Health Belief Model (Becker, 1974).*

The first construct of the HBM is cues to action. Cues to action are messages that remind individuals about a behavior (Becker, 1974). These messages can be external (e.g., a public service announcement) or internal (i.e., a bodily event that serves as a reminder; Becker, 1974). The more reminders individuals receive, the more likely they are to complete the behavior (Becker, 1974). Cues to action is the least frequently studied
variable in the HBM, although the reason for this is unclear (Carpenter, 2010). In fact, there was not enough data on this variable to include it in a meta-analysis of the HBM variables because so few studies incorporate it (Carpenter, 2010). Despite its low popularity, some studies have demonstrated the significance of cues to action. For example, cues to action was a significant predictor of air-conditioning use among older adults with heart disease (Richard, Kosatsky, & Renouf, 2011).

The second construct of the HBM is perceived severity (Becker, 1974). Perceived severity is the degree to which individuals believe a situation to be harmful. It is suggested that an individual is more likely to take action if they perceive the situation to be severe (Becker, 1974). However, a large number of studies show severity to be the weakest HBM variable in predicting intent (Carpenter, 2010). This could be due a lack of variance, as people commonly agree on the severity of certain situations, such as getting cancer (Carpenter, 2010). Despite this trend, perceived severity significantly predicted parents’ intent to purchase helmets for their children (Witte, Stokols, Ituarte, Schneider, 1993). This significance could be attributed to differences in anticipated consequences of falling off a bike while not wearing a helmet; some parents might be concerned about the long-term effects of head injuries, whereas others might only expect the child to suffer a scrape.

The third construct, perceived susceptibility, is the degree to which an individual considers his or herself at risk of experiencing the situation (Becker, 1974). A greater perception of susceptibility is thought to lead to a greater likelihood of performing the behavior (Becker, 1974). Like perceived severity, perceived susceptibility is also
considered a weak HBM variable (Carpenter, 2010). This could be due to the optimism bias, which leads individuals to believe that they will not experience negative events (Lange, 2012). However, many of the studies that found perceived susceptibility to be weak were applying the HBM to predict treatment behavior (e.g., complying with drug regimens) as opposed to predicting prevention behavior (e.g., eating healthily). This is an important difference, given that perceived susceptibility is more likely to be significant when predicting prevention behavior than it is when predicting treatment behavior (Janz & Becker, 1984). For example, perceived susceptibility did predict parents’ intent to purchase helmets for their children—a preventative behavior (Witte et al., 1993). Susceptibility may have a stronger relationship with prevention than treatment behavior because the former situation involves more uncertainty—more of the unknown. Fear is sometimes a powerful motivator, leading individuals to perform (preventative) behaviors in attempt to thwart the danger (Nabi, 2002). When individuals are complying with treatment behavior, however, they likely have already experienced—and adjusted to—the “danger,” making fear less of a motivator. Thus, it could be the presence of uncertainty that allows susceptibility to be a predictor of preventative behavioral intent.

The fourth and fifth constructs of the HBM are perceived barriers and perceived benefits. Perceived barriers are obstacles that prevent an individual from performing the behavior (Becker, 1974). Individuals who perceive fewer barriers are more likely to take action than individuals who perceive more barriers (Becker, 1974). Conversely, perceived benefits are the positive outcomes that individuals expect from performing the behavior (Becker, 1974). Barriers and benefits are typically stronger predictors of
behavioral intent than the other HBM variables (Carpenter, 2010). Occasionally, these two constructs are represented as one construct in the model. A total score for barriers and benefits is obtained by subtracting the perceived barriers score by the perceived benefits score (Becker, 1974). This results in a score akin to cost versus reward; individuals who perceive more cost than rewards will be less likely to complete the behavior than individuals who perceive more rewards than costs (Becker, 1974).

However, barriers and benefits are also occasionally represented and tested separately in the model. One study found that when compared in a single study, barriers—but not benefits—were a significant factor affecting the elderly’s intent to engage in ACP (Hamel, Guse, Hawranik, & Bond, 2002). This relationship suggests that for the elderly, barriers to ACP are so great that the benefits cannot overcome them (Hamel et al., 2002).

Of all the HBM variables, perceived barriers and benefits are the only variables that are measured with any frequency in ACP research. The most commonly reported barriers to AD completion among older adults include the fear of upsetting family members (Crain, 1996), the fear of physicians acting independently of their desires (Ko & Berkman, 2003), the fear that medical treatment preferences will change over time (Ditto, Jacobson, Smucker, Danks, & Fagerlin, 2006), the desire to leave the decision-making to family members (Bowman & Singer, 2001), the uncertainty about medical treatment preferences (Ko, 2008), and the low perceived susceptibility to being in situation that would make advance care plans go into effect (Ko & Berkman, 2003). Although research has not focused on healthy, young adults or ACP conversations, it is
possible that some of the barriers about ADs may be applicable to ACP conversations, and that young adults may share some of the barriers with older adults.

Commonly reported benefits of AD completion among older adults include avoiding a low quality of life (Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000), experiencing a death with minimal pain and suffering (Mezey et al., 2000), preserving autonomy (Singer, Martin, & Kelner, 1999), reducing family burden (Moore & Sherman, 1999), and obtaining peace of mind from knowing that the future is planned (Mezey et al., 2000). Similar to perceived barriers, perceived benefits research on the elderly population may also be relevant to the young adult population.

Self-efficacy, the fifth construct of the HBM, overlaps with the TPB. Self-efficacy is similar to the TPB’s perceived behavioral control; greater self-efficacy leads to a greater likelihood of the individual performing the health-related behavior (Becker, 1974). For example, efficacy beliefs were positively related to tooth brushing frequency (Anagnostopoulos, Buchanan, Frousiounioti, Niakas, Potamianos, 2011).

Together, the TPB and the HBM cover a wide range of factors that may affect ACP engagement. Although the majority of the TPB and HBM variables have not been tested in ACP research, their potential relevance is underscored by the theoretical and statistical support in contexts similar to ACP engagement. However, because conversations occur between two people, it is necessary to consider relational variables that may influence engagement in ACP.

**Relational motivating factors.** When an individual decides to communicate with another person, he or she considers relational factors that are evaluations of the other
person and of their relationship as a whole (Greene et al., 2012). For example, individuals consider whether their partner will react poorly to a disclosure (Greene et al., 2012). The disclosure decision-making model (DD-MM) addresses the relational factors that affect intent to communicate. Similar to the TPB and the HBM, the DD-MM has rarely been applied to ACP research. However, many of its components may be useful in the DCM because illness and ACP disclosures are both information-sharing processes.

**Disclosure decision-making model.** The DD-MM offers a way to assess the likelihood that someone will disclose an illness to another party (Greene et al., 2012). Although ACP is not an illness, the act of disclosing treatment preferences shares a similarity to that of disclosing a diagnosis; they both involve assessing uncertainty (e.g., speculating about how the other person will react) and disclosing important information not previously known to the receiver. See Figure 3 for a visual representation of the model.

The first component of the DD-MM is information assessment. Individuals are believed to assess five aspects of information related to illness disclosure: stigma, prognosis, symptoms, preparedness to disclose, and relevance (Greene et al., 2012). Individuals are more likely to disclose an illness if there is less perceived stigma, a more positive prognosis, more visible symptoms, more preparation to disclose, and if the diagnosis is relevant to others (Greene et al., 2012). This type of information assessment was present in HPV+ individuals’ decision to disclose (Smith, Hernandez, & Catona, 2014). Specifically, HPV+ individuals considered the stigma that surrounds HPV and their ability to hide an HPV diagnosis because of invisible symptoms (Smith et al., 2014).
Likewise, stigma was associated with married partners’ intent to disclose fertility issues with friends and family (Steuber & Solomon, 2011). It is noted, however, that the importance of the various types of information assessments may vary depending on the type of illness (Greene, 2009). For example, stigma and relevance to others may weigh the most in individuals’ decision to disclose a sexually transmitted disease diagnosis (Greene, 2009).

![Diagram of the Disclosure Decision-Making Model](image)

*Figure 3. The Disclosure Decision-Making Model (Greene et al., 2012).*

In addition to information assessment, individuals also assess their disclosure-efficacy (Greene et al., 2012). Disclosure-efficacy, much like the HBM’s self-efficacy and the TPB’s perceived behavioral control, pertains to how confident an individual feels...
in his or her ability to perform a behavior. The more disclosure efficacy an individual has, the more likely he or she is to complete the behavior (Greene et al., 2012).

Disclosure-efficacy was related to married couples’ intent to discuss fertility problems (Steuber & Solomon, 2011). Per the DD-MM, several factors contribute to disclosure-efficacy, including relationship quality (i.e., relational closeness), the anticipated initial response, the anticipated overall outcome, and their confidence in the response.

Relational quality (measured in the DD-MM as relational closeness) is believed to increase individuals’ efficacy beliefs (Greene et al., 2012). The DD-MM has not been widely studied, but the concept of closeness has been identified as an important factor in a variety of interpersonal interactions that involve disclosure. Specifically, closeness increased the likelihood and depth of disclosure in same-sex male friendships (Bowman, 2008), the frequency of verbal communication about sex among married couples (Hess & Coffelt, 2012), and the likelihood of married couples to disclose infertility to friends and family (Steuber & Solomon, 2011). One possible explanation for the relationship between relational closeness and disclosure is that relational closeness creates a more comforting and open atmosphere, thus making it easier to disclose (Bowman, 2008).

Anticipated response also affects disclosure intent (Greene et al., 2012). Anticipated response is the immediate reaction that individuals expect the other person to exhibit (Greene et al., 2012). Individuals feel more efficacious and are therefore more likely to disclose an illness if they have a more positive anticipated response (Greene et al., 2012). Again, although the DD-MM is not well studied, anticipated response has also been linked to disclosure in a number of other cases. For example, individuals are more
likely to reveal family secrets (Vangelisti, Caughlin, & Timmerman, 2001), personal
secrets (Caughlin, Afifi, Carpenter-Theune, & Miller, 2005), and HIV+ statuses (Greene
& Faulkner, 2002) if they expect the other people’s immediate reaction to be favorable.

Anticipated overall outcome is another construct that affects disclosure intent
(Greene et al., 2012). Individuals are more likely to disclose an illness if they have a
more positive anticipated overall outcome (Greene et al., 2012). Anticipated outcome has
been linked to individuals’ decisions to disclose an HPV+ status (Greene, 2009).
Specifically, individuals with HPV are concerned about disclosure resulting in social
rejection and dissolution of personal relationships (Greene, 2009). Conceptually,
anticipated overall outcome construct is similar to the benefits and barriers constructs of
the HBM. Many of the barriers and benefits that individuals form about a behavior
pertain to the overall outcome (e.g., “My doctor will give me poor care” or “I will receive
the type of medical care I want”).

Finally, confidence in response also affects intent to disclose (Greene et al.,
2012). Individuals are more likely to disclose an illness if they have greater confidence
in the other person acting in the manner that is anticipated (Greene et al., 2012). A review
of the literature shows that this construct is rarely studied outside of the original paper
that proposed the DD-MM.

**The Difficult Conversation Model**

Both behavioral change and disclosure models are necessary to understanding the
likelihood of individuals engaging in ACP conversations. Whereas behavioral change
theories—such as the TPB and HBM—center on individual-focused predictors of
behavior, communication theories—such as the DD-MM—incorporate relational factors that affect intent to communicate. Because ACP is an individual health behavior that requires interacting with a partner, elements from both behavioral change and relational communication theories are needed to understand individuals’ intent to engage in ACP conversations. Each variable and path to be included—or excluded—in the DCM is reviewed below. Hypotheses are stated in-text at the end of each argument and synthesized in Table 1. Figure 4 provides a visual representation of the DCM.

**TPB variables.** Although research utilizing the TPB to study ACP is scarce, the TPB has had immense success in predicting a variety of health behaviors (Ajzen, 2002). As such, the attitude, perceived behavioral control, and subjective norm variables provide a solid theoretical base from which to build the DCM. This is especially true of attitude. As previously mentioned, attitude was the greatest predictor of individuals’ intent to comply with a food recall message (Freberg, 2013) and to discuss smoking-related behaviors (Brann & Sutton, 2009). Although complying with a food recall message and discussing advance care planning are somewhat different, they are both preventative behaviors, and studies show that constructs tend to share the ability to predict across contexts when the behaviors are either both preventative or both treatment related (Janz & Becker, 1984). ACP is a preventative behavior in the sense that engaging in ACP prior to becoming ill may reduce the chances of the patient not receiving desired medical treatment—or received undesired medical treatment—as explained earlier in the chapter. Given the role of attitude in predicting these behaviors, it is suggestible that young adults’ attitude towards ACP affects their intent.
Perceived behavioral control may be another important factor in predicting intent. Although research on ACP has not identified whether efficacy beliefs are a significant factor of intent, the importance of efficacy in predicting behavior is illustrated by its presence in all three models discussed in this dissertation. Further, as previously discussed, the significance of perceived behavioral control is likely dependent on the difficulty associated with the behavior and, as previously mentioned, ACP is believed to be a difficult conversation (Keating et al., 2013). Thus, it is possible that perceived behavioral control affects young adults’ intent to have ACP conversations.

According to Ajzen (2002), the perceived behavioral control construct of the TPB and the self-efficacy construct of the HBM are conceptually similar because they all tap into individuals’ perceptions of confidence, capability, and control. The same can be said for the disclosure-efficacy construct of the DD-MM. As such, it is not necessary to include all three in the DCM. Due to the conceptual similarity, theoretical justifications cannot support choosing one variable over the other. As a result, I diverted to the proven statistical success of the TPB’s perceived behavioral control (see Ajzen, 2002) as a deciding factor to include perceived behavioral control instead of self-efficacy or disclosure-efficacy.

Subjective norm may also affect young adults’ intent to have ACP conversations. Studies have shown that older adults’ decision to execute an AD is influenced by their family, friends, and health care providers (Tremethick et al., 2011). Older adults are more likely to execute ADS when they believe that their friends, family and health care providers support the decision (Tremethick et al., 2011). Given the common
understanding that ACP is only for the elderly and terminally ill, it is possible that young adults do not believe their peers, family, or doctor to be supportive of them having ACP conversations and are therefore less likely to perform the behavior.

As mentioned earlier, the TPB also occasionally theorizes about the importance of background beliefs. This construct is not included in the DCM. Background variables are not included because of the sample in the three studies. The samples within this dissertation are made up of undergraduates and are therefore unlikely to vary on demographic factors that affect AD intent such as education, income, marriage, and age. Consequently, background variables would be unlikely to co-vary with any of the other variables.

**HBM variables.** In addition to the constructs provided by the TPB, perceived severity, perceived susceptibility, perceived barriers, perceived benefits, and cues to action are components of the HBM that may be useful for the DCM. In the context of ACP, perceived severity refers to individuals’ perceptions of the seriousness of forgoing ACP but later experiencing illness or injury and being unable to communicate treatment preferences. As discussed above, perceived severity is often a weak predictor of intent. However, this could be attributed to a lack of variability in the construct, given that people commonly agree on the severity of situations (e.g., many people agree that getting cancer is a severe situation; Carpenter, 2010). However, some older adults do not view not having ACP plans as a severe situation because they believe family members are able to make the decisions for them (Ko, 2008). If young adults feel similarly, their lack of perceived severity may be related to their intent to have ACP conversations.
Perceived susceptibility may also be an important variable for the DCM. In the context of ACP, perceived susceptibility refers to individuals’ perceptions of their risk of being in a situation where they are unable to communicate their medical treatment wishes. As mentioned earlier, perceived susceptibility is another weak predictor. This is most common, however, in studies that predict treatment, as opposed to preventative, behavior—a relationship that I suggest is related to the diminished presence of fear (Janz & Becker, 1984). Because ACP is a preventative behavior, perceived susceptibility may be significant in predicting intent. Given that the present study focuses specifically on young adults engaging in a behavior that is commonly done only by older adults, and because young adults perceive death to be very far in the future (Lange, 2012), it is likely that perceived susceptibility will be low. Therefore, it is possible that the less perceived susceptibility a young adult has, the less likely they are to have ACP conversations. As displayed in Figure 2, perceived severity and perceived susceptibility are commonly entered into the HBM model as observed variables for the latent variable, perceived threat. I chose to keep them separate in case only one of the two variables is a predictor of ACP intent.

Perceived barriers and benefits are important to include because they have been identified in previous ACP research as significant predictors of intent (see, for example, Ko & Berkman, 2003 & Mezey et al., 2000). As previously mentioned, there are two ways to incorporate barriers and benefits data in a model. I chose to include barriers and benefits separately, instead of subtracting them to create a single score. This was done in case either one of the constructs are not relevant for the young adult population. As
mentioned earlier, research on older adults suggest that the presence of barriers may
diminish the significance of benefits to ACP (Hamel et al., 2002). However, it is unclear
is this relationship exists in the young adult population. Therefore, the constructs will be
entered into the model separately, but I hypothesize that each are important in predicting
intent.

Finally, cues to action is an important concept to include because repeated
messages often increase the likelihood of individuals performing health behaviors, as
exemplified by the increase in air-conditioning use among older adults with heart and
lung disease (Richard et al., 2011). Even though air-conditioning use and ACP
discussions are very different, they are both preventative behaviors. This suggests that
cues to action may predict young adults’ intent to have ACP conversations. And, as
previously mentioned, cues to action can be external or internal. For this dissertation, I
chose to construe cues to action as external and not internal because it is unlikely that the
average young adult experiences bodily events (e.g., near death experiences or terminal
illness symptoms) that remind them of the need to engage in ACP.

**DD-MM variables.** Also important to the DCM are two relational constructs of
the DD-MM. First, relational closeness may be a factor in individuals’ decisions to have
ACP conversations. Individuals who feel more comfortable with each other are more
likely to engage in difficult conversations because they are comforted when they
experience negative emotions (Keating et al., 2013). Relational closeness may lend itself
to creating a comfortable space to talk about ACP, such that individuals are more likely
to discuss ACP plans with a family member if they perceive closeness in the relationship.
Second, individuals’ anticipated response might also affect their intent to have ACP conversations, such that individuals are more likely to discuss ACP plans with a family member if they expect that person to react favorably. Anticipated response is an important factor because individuals often do not engage in ACP for fear of upsetting family members (Crain, 1996). Therefore, individuals who fear they might upset their family members may indicate a negative anticipated response and be less likely to have ACP conversations.

The remaining components of the DD-MM are not necessary to include in the DCM, either due to relevancy or redundancy. First, anticipated outcome is captured by the barriers and benefits constructs. As discussed above, benefits are the positive outcomes that an individual expects. Several of the items on the barriers index are also outcome-oriented (the rest of the items are pre-behavior obstacles). Thus, while I agree that anticipated outcome is an important concept, young adults’ anticipated outcome of ACP is already captured by the HBM variables. I chose to exclude anticipated outcome in favor of barriers and benefits because the latter is the dominant theoretical framework in ACP research (see Ko & Berkman, 2003 & Mezey et al., 2000).

Confidence in response is also not relevant to the DCM because the strength of confidence in individuals’ anticipated response is measured by the variation in the Likert-scale. Adding variables to a model is done so at a tension with Occam’s razor, which suggests that the best answer is the simplest answer. This is why some of the model fit values for path analysis are very sensitive to parsimony. Thus, adding variables to a model should only be done through strong theoretical justification. However,
conceptually speaking, at least some degree of confidence in response is captured by the Likert-scale for the anticipated response measure, which gives participants the option to select “neutral” or “neither agree nor disagree.” I am not convinced that the additional information that confidence in response contributes—above and beyond that of “neutral option”—is worth the costs to parsimony. Further, unlike other DD-MM variables such as relational closeness and anticipated response, confidence in response is rarely measured in DD-MM research.

Information assessment is another variable that is not relevant for the DCM due to redundancy. In the context of ACP, information assessment is likely to be relevant only insofar as ACP’s association to death makes it a hard topic to discuss, causing individuals to fear that their family will react poorly (Crain, 1996). However, young adults’ expectations of others’ responses is accounted for in the anticipated response construct. Therefore, it is not necessary to include information assessment in the DCM.

**Paths.** The DCM consists of 12 paths. Some of the paths are consistent with those proposed in the TPB, HBM, and DD-MM. However, I modified some of the TPB’s, HBM’s, and DD-MM’s original paths when such modification had theoretical support.

**Attitude mediation.** Like the TPB, I proposed a path from attitude to intent in the DCM. Unlike the TPB, however, I hypothesized attitude to mediate five relationships in the DCM. My justification for proposing all five of these mediated relationships is essentially the same: although attitude is an important and useful concept, we are often left wondering, what is shaping this population’s attitude? This is where the HBM and DD-MM variables are especially valuable. Because many of the HBM and DD-MM
variables are much less abstract and broad than those of the TPB, they may help explain some of the TPB variables. Therefore, the five relationships that I expected to be mediated by attitude are proposed in an attempt to increase the explanatory ability of the attitude construct.

The first and second mediated relationships that I expected are barriers and benefits to affect intent through attitude (H9 & H10). This is consistent with expectancy value theory which states that the more positive—and fewer negative—expectations individuals have about a behavior, the more positive attitude individuals will have towards the behavior (Fishbein, 1967). And, of course, attitude has a strong relationship with intent (Azjen, 2002). Therefore, young adults with greater benefits and fewer barriers may be more likely to have ACP conversations because they have a more positive attitude towards the behavior.

Third, I hypothesized that anticipated response affects intent through attitude (H13). Based on conjecture, young adults may have a more positive evaluation of the behavior if they expect positive reactions to come from their partner. Therefore, I hypothesized that young adults who anticipate a more positive response from their partner may be more likely to have ACP conversations because they have a more positive attitude towards the behavior.

The fourth and fifth relationships that I expected to be mediated by attitude are severity and susceptibility to intent, such that greater severity and greater susceptibility increase intent because of a more positive attitude. Findings on research about fear (Nabi, 2002) suggest that ACP offers individuals a way to feel better about their fear that arises
from the combined risk and seriousness of being unable to make medical decisions. Thus, young adults who have greater perceived susceptibility and perceived severity may be more likely to have ACP conversations because they have a more positive attitude towards the behavior.

The first several paths that I proposed were justified primarily by the broadness of the attitude construct. Like attitude, a significant perceived behavioral control finding may also leave us wondering, what is contributing to individuals’ control beliefs? I attempted to explain some of the contribution to young adults’ control beliefs in respect to ACP by proposing four relationships that I believe are mediated by perceived behavioral control.

**Perceived behavioral control mediation.** First, I hypothesized that perceived behavioral control mediates the relationship between anticipated response and intent (H12). This is consistent with the DD-MM, which suggests that a positive anticipated response increases efficacy beliefs (Greene et al., 2012). Therefore, it is likely that young adults are more inclined to have ACP conversations when they expect a positive reaction because they feel more efficacious.

Second, I expected perceived behavioral control to mediate the relationship from anticipated response to attitude (H17). As mentioned above, perceived behavioral control likely leads to greater attitude because young adults who believe they are able to have ACP conversations may be more likely to have a positive attitude towards the behavior (Mou & Lin, 2015). Thus, I hypothesize that young adults that expect a more positive
anticipated response will have better attitude about ACP conversations because of greater perceived behavioral control.

The third relationship that I expected perceived behavioral control to mediate is the relationship between subjective norms and intent (H14). A discussion of this mediation necessitates a discussion of the paths I excluded from the model. As argued previously, subjective norms are frequently unrelated to intent (Armitage & Conner, 2011; Hagger, Chatizisarantis, & Biddle, 2002). However, subjective norms did predict individuals’ perceived behavioral control of podcast-adoption intent (Mou & Lin, 2015). This suggests that subjective norms may affect intentions indirectly through perceived behavioral control. As such, I did not include a path directly from subjective norm to intent, but instead I included a path that is mediated by perceived behavioral control. Thus, in the context of ACP, I hypothesized that young adults who see others supporting and performing the behavior will be more likely to have ACP conversations because they will have more confidence in their own ability to act similarly.

The fourth and final relationship that I expected perceived behavioral control to mediate is the relationship between subjective norms and attitude (H17). Again, I argue that having greater subjective norms gives individuals greater perceived behavioral control (Mou & Lin, 2015). And as mentioned above, perceived behavioral control likely leads to greater attitude (Mou & Lin, 2015). Thus, I hypothesized that young adults with greater subjective norms to have a better attitude about ACP conversations because they have greater perceived behavioral control.
**Anticipated response mediation.** I also hypothesized anticipated response to mediate two relationships. First, I expect relational closeness to affect perceived behavioral control through anticipated response. Second, I expect relational closeness to affect attitude through anticipated response. The direct path from relational closeness to anticipated response is consistent with the DD-MM. Individuals who are more close with their partners are more likely to anticipate a more positive response from them (Greene et al., 2012). And, as discussed above, I hypothesized that anticipated response predicts both behavioral control and attitude. Therefore, it is possible that young adults with greater relational closeness are more likely to have greater perceived behavioral control and a more positive attitude because they expect a more positive response.

**Direct path.** Finally, I hypothesized a direct relationship from cues to action to intent. This is consistent with the HBM (Becker, 1974). As mentioned earlier, cues to action was a significant predictor in air-conditioning use (Richard et al., 2011). Because both ACP and air-conditioning use are preventative behaviors, frequent reminders may also positively affect individuals’ intent to have ACP conversations.

**Conclusion**

In sum, ACP benefits both the patient and the patient’s health care proxy and is not only important for the elderly, but for young adults, as well. However, death is often perceived as an uncomfortable topic with many uncertainties, leading ACP to be considered a difficult conversation. Because it is a difficult conversation, it is important to understand what motivates individuals to enact ACP. The TPB provides a theoretical
foundation from which to build the DCM. However, components of the HBM and the DD-MM are also important to include.

The first step in building and evaluating a model is formative research. Through formative research, I explored the relevance of several individual motivating factors, and also allowed other individual and relational factors to emerge as important. Results of the focus groups suggested that relational factors do play a part in young adults’ intent to communicate about ACP. In Study 1, I applied the findings of the focus groups by testing the HBM variables and one additional relational variable. In Study 2, I added the remaining individual and relational developed the DCM.
Table 1.

*Research Questions and Hypotheses*

<table>
<thead>
<tr>
<th>Hypothesis/Research Question</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>H1: Greater perceived susceptibility will predict intent to have ACP conversations.</td>
<td>X</td>
</tr>
<tr>
<td>H2: Greater perceived severity will predict intent to have ACP conversations.</td>
<td>X</td>
</tr>
<tr>
<td>H3: Greater self-efficacy will predict intent to have ACP conversations.</td>
<td>X</td>
</tr>
<tr>
<td>H4: Fewer perceived barriers will predict intent to have ACP conversations.</td>
<td>X</td>
</tr>
<tr>
<td>H5: Greater perceived benefits will predict intent to have ACP conversations.</td>
<td>X</td>
</tr>
<tr>
<td>H6: Greater relational closeness will predict intent to have ACP conversations.</td>
<td>X</td>
</tr>
<tr>
<td>H7: Greater perceived susceptibility will predict intent to have ACP conversations through a more positive attitude.</td>
<td>X</td>
</tr>
</tbody>
</table>

RQ1: What experiences do young adults have with ACP?

RQ2: Are young adults willing to have ACP conversations?

RQ3: What are young adults’ perceptions of their self-efficacy with respect to ACP conversations?

RQ4: What are young adults’ perceptions of the severity of being unable to make medical decisions but failing to complete ACP ahead of time?

RQ5: Do young adults think they are at risk for being in a situation where they are unable to make medical decisions due to a serious illness or injury?

RQ6: What are young adults’ perceived barriers to having ACP conversations?

RQ7: What are young adults’ perceived benefits to having ACP conversations?
| H8: Greater perceived severity will predict intent to have ACP conversations through a more positive attitude. | X |
| H9: Greater benefits will predict intent to have ACP conversations through a more positive attitude. | X |
| H10: Greater barriers will predict intent to have ACP conversations through a more negative attitude. | X |
| H11: Greater relational closeness will predict a more positive attitude through a more positive anticipated response. | X |
| H12: A more positive anticipated response will predict intent to have ACP conversations through greater perceived behavioral control. | X |
| H13: A more positive anticipated response will predict intent to have ACP conversations through a more positive attitude. | X |
| H14: Greater subjective norm will predict intent to have ACP conversations through perceived behavioral control. | X |
| H15: More frequent cues will predict intent to have ACP conversations. | X |
| H16: A more positive anticipated response will predict attitude through perceived behavioral control. | X |
| H17: Greater subjective norms will predict attitude through perceived behavioral control. | X |
| H18: Greater relational closeness will predict greater perceived behavioral control through more positive anticipated response | X |
Figure 4. The Hypothesized Difficult Conversation Model.
Chapter Three: Formative Research

I conducted formative research in the form of focus groups as a starting point from which to build the DCM. The purpose of the formative research was to identify factors that may be relevant for inclusion in the model. The research was guided by the overarching question, what are young adults’ attitudes towards and beliefs about ACP conversations? More specific research questions are detailed in Table 1. To be consistent with past ACP research, the focus group questions were theoretically guided by the constructs of the HBM. This allowed me to get a sense of whether the individual motivating factors suggested by this theory are relevant for the context of ACP in the young adult population. However, the open-ended nature of the focus group discussions also allowed for potentially relevant individual and relational factors to emerge organically. In what follows, I outline the methods of the focus groups, followed by the results and a discussion of the findings.

Methods

Participants. I recruited a convenience sample of college students from a subject pool at a Mid-western university (N = 38). Students earned course credit for participating in the study. Participants were able to opt out of the study and complete an alternative assignment for the same course credit. The only inclusion criterion was that participants needed to be 18 years of age or older at the time of the study. I set the inclusion criterion at 18 because that is the age an individual can legally determine medical treatment plans for his or herself. I obtained IRB approval before collecting data.
The participants’ ages ranged from 19-24, with a mean age of 21.3 years old. The majority of participants were juniors (42.1%; n = 16) and seniors (42.1%; n = 16), although a small percentage (15.8%; n = 6) were sophomores. There were slightly more males (57.9%; n = 22) than females (42.1%; n = 16). Half (50%; n = 19) of the participants were Asian/Pacific Islander, 44.7% (n = 17) were Caucasian, 2.6% (n = 1) were Middle Eastern and 2.6% (n = 1) were African American.

There were no married, divorced or separated participants. Although the majority (89.4%; n = 34) indicated that they were not parents, 5.3% (n = 2) of participants indicated they did have children and another 5.3% (n = 2) declined to answer. Most of the participants rated their overall physical health as “good” (50%; n = 19) or “very good” (31.5%; n = 17), but several participants indicated that they were in “fair” (8%; n = 3) or “excellent” (10.5%; n = 4) health.

Although the majority of participants also indicated that they did not have a living will or medical proxy (74%; n = 28), 13% (n = 5) indicated they had a living will and another 13% (n = 5) indicated they had a medical proxy. All of the participants who said they had an AD were of Asian/Pacific Islander ethnicity; 70% (n = 7) were male, 30% were female (n = 3), none were parents, and their self-reported health status ranged from “fair” to “excellent.”

**Data Collection.** I collected data through six focus groups. Two focus groups were made up only of males, two focus groups were only females, and the final two focus groups were mixed sex. Controlling for sex within the focus groups makes it possible for males and females to voice opinions that they may be hesitant to do in mixed company.
Prior to the start of the focus groups, I notified participants that the discussion would be audio recorded with their permission. Participants then agreed to an informed consent and filled out demographic (Appendix A) and course credit information on two separate papers.

I conducted the focus groups by following a semi-structured discussion guide (Appendix B). This semi-structured nature of the guide allowed me to remain consistent with the questions among groups, but also allowed for follow-up questions as necessary. The guide consisted of open-ended questions aimed at encouraging dialogue between the participants. To assess the participants’ current relationship to ACP, I asked them questions about their knowledge of, experience with, and willingness to participate in ACP. The discussion then moved to components of the HBM: perceived barriers, benefits, susceptibility and severity. Finally, participants were asked future-oriented questions about potential motivators, facilitators, and information seeking. The focus groups lasted an average of 45 minutes each. All participants received a debriefing message identifying the purpose of the study at the end of the focus group.

**Data Analysis.** I transcribed and analyzed each focus group after it was conducted. After transcription, I coded the data according to guidelines suggested by Lofland and Lofland (1995). The first step was open-coding data for initial themes. In doing so, I assigned codes to each idea or sentence from the focus groups. I chose initial codes directly from the participants’ narratives to ensure that the themes were grounded in the data and not influenced by my knowledge of previous research. Examples of initial codes included *trust [my parents]* and *parents are capable.* These were drawn from the
statements, “Realistically, I would trust [my parents] to do whatever they want” and “My parents are capable of making the decisions,” respectively. The next step was focused coding. Focused coding is used to rename, collapse, subcategorize, or eliminate less useful categories (Lofland & Lofland, 1995). In continuing the above example, I collapsed the two initial codes into the focused code, *diverting onus*. I re-coded all transcripts with the focused codes in mind. After assigning the final focus codes, I reread the coded data in order to answer my research questions.

**Results**

In response to the research questions, I found that the majority of the groups reported being unaware of ACP. However, the majority opinion among groups was that they were willing to have ACP conversations, and that they felt capable of having the conversations and susceptible to being in a situation that would require advance care plans. Six perceived barriers and three perceived benefits of ACP were identified.

**Knowledge and Experience.** The first research question asked about young adults’ previous experiences with ACP. Most groups agreed that they had not heard of ACP and have not previously considered what life-sustaining treatment they would want. In some instances, where participants indicated that they have heard of living wills, they referred to it as a document that identifies ownership of estates. The participants who referred to ADs as documents that identify life-sustaining treatment preferences were either exposed to ACP through (a) a class taken at the university or (b) a relevant experience in their family. The few participants who heard about it at school took classes in personal finance and health services administration. Of the participants who had
personal experience with ACP, one female stated that she “always thinks about the choices [her dad] makes to prolong his life” (Focus group, 6/12/14, females). For this participant, watching her dad make ACP choices made her question her own wishes. Another female participant became aware of ACP because she recently was named on her grandfather’s power of attorney for healthcare. A third female participant had knowledge of ACP because her family had to make uninformed decisions about her grandfather’s medical treatment.

Of the participants who had heard about ACP, the majority had given some thought as to what kind of life-sustaining treatment they would want. One male participant stated, “From the videos and stuff that I watched in class I know what I want now” (Focus group, 6/11/14, mixed sex). Although several participants did spend time thinking about their life-sustaining treatment preferences, only two had communicated their wishes to their family. One female was inspired to do so after learning about it in class. When I asked participants why they had thought about their preferences but have not brought it up to their family, they agreed that they were unsure of what treatment they would prefer. One female participant said, “I’m not fully sure exactly what I would want to have happen if I was in this situation” (Focus group, 6/12/14, females).

In some cases, however, even though participants had been exposed to the topic through personal experience, they had not considered what treatment options they would prefer. When asked why not, a majority opinion in the groups was that ACP was not relevant to them. The female participant whose family had to make difficult medical decisions for the grandfather said, “We talk about other situations like my grandpa, but
we don’t talk about it ourselves because I think we think it’s far away” (Focus group, 6/12/14, females). Many groups agreed that they were not currently susceptible to being in a situation that would require life-sustaining treatment decisions. Overall, a majority opinion among groups was that uncertainty and susceptibility prevented them from thinking about or communicating the life-sustaining treatment preferences.

**Willingness.** The second research question asked if young adults are willing to have ACP conversations. The majority opinion among most groups was that they were willing to have ACP conversations, citing that the topic pertains to decisions about “[their] life so [they are] willing to say whatever [they] want” (Focus group, 6/10/14, males). Another common opinion among groups was that they were willing to discuss ACP, “if the conversation came up” (Focus group, 6/12/14, females). A minority stance among groups was complete unwillingness. When asked why, one male participant said, “I would just rather not know. I would rather have [my parents] decide” (Focus group, 6/14/14, males). The majority of groups agreed that they would be most likely to have these conversations with parents and family.

Although most participants agreed that they would be willing to have these conversations, when I subsequently asked if they will leave this focus group and call their family to express their medical wishes, the response was a unanimous “no” across all groups. When asked why, one male participant responded, “It’s scary to talk about and I’m afraid of what my parents might say if I do say that” (Focus group, 6/11/14, mixed sex). The majority of the group agreed that those are “the two biggest” reasons for not immediately engaging in ACP (Focus group, 6/11/14, mixed sex). The majority of a
different focus group agreed that the topic is not relevant enough to them. One male participant stated, “Nothing’s happened. That’s why. My health is fine right now. Nothing is going on” (Focus group, 6/11/14, mixed sex).

**Self-Efficacy.** The third research question asked how young adults rate their self-efficacy in relation to ACP conversations. The first component of self-efficacy that was discussed was the ease of conversation. The majority opinion among groups was that the conversations would be “pretty easy” and “not too hard” (Focus group, 6/11/14, mixed sex; 6/13/14, males). When I asked participants why the conversations would be easy, a common answer referred to the openness of the family. One female participant responded, “I think necessarily in our house it wouldn’t be that difficult because our family is pretty open” (Focus group, 6/12/14, females). Participants who felt the conversation would be difficult to have frequently noted the topic of death as being the source of difficulty.

The second part of self-efficacy that was discussed was confidence in ability. In some groups, the majority opinion was that participants did not feel confident in their ability to have ACP conversations because they did not have enough knowledge about the topic. One female participant said, “[I do not feel] very confident. I don’t know anything of that sort so if something were to happen tomorrow I don’t know what I would do. I’m not prepared for that. I’m unsure of the options” (Focus group, 6/12/14, females). On the same token, the majority opinion in other groups was that participants felt confident because they were knowledgeable. One female participant said, “I’m pretty confident because I’ve learned a lot of the different options so I know there are options”
Participants that said they were knowledgeable of the topic also indicated a belief in self-efficacy.

Despite the majority of many groups agreeing that they would be confident in their ability to have ACP conversations, the same groups also agreed that initiating the conversation would be difficult. One male participant noted, “It might be awkward to just randomly bring it up. There would have to be a reason to have the conversation I feel like to make it normal” (Focus group, 6/11/14, mixed sex). The majority opinion in some groups was that it would be easier for the child to initiate the conversation, because the parents may not want to scare the children by initiating it. Others groups, however, agreed that they do not think initiating the conversation would be perceived well by their parents. One male participant noted, “My mom would probably be freaked out if I just randomly brought it up” (Focus group, 6/11/14, mixed sex).

Severity. The fourth research question asked about young adults’ perceived severity of being in a situation where they could not communicate their wishes but had not engaged in ACP ahead of time. The majority opinion among groups was that this was a serious concern. Some participants, however, said that they do not think it would be a serious situation. The few that indicated low perceived severity cited trust in their parents as the reason: “I would trust my parents to handle the situation” (Focus group, 6/10/14, males). Another participant added, “If I didn’t have parents it would be a very serious situation” (Focus group, 6/10/14, males).

Susceptibility. The fifth research question asked how young adults perceive their susceptibility to being in a situation that would require life-sustaining treatment
decisions. The majority opinion in some groups was that it is important for young adults to have ACP conversations. One male participant said, “I think it’s pretty important for anyone of any kind of age. As soon as you’re 18 and actually have a choice of what happens to your body” (Focus group, 6/10/14, males). However, the majority opinion in other groups was that ACP is not important for them until they are in serious relationships or have a family. A male participant stated, “I don’t think I’m going to be worried about it until I have a significant other” (Focus group, 6/10/14, males).

Although many groups agreed that it is important for young adults to enact ACP, the majority of those groups also agreed that they were not concerned with making their health care preferences known: “I feel like I shouldn’t worry too much at this point” (Focus group, 6/10/14, males). Another male participant agreed, “Ya, I don’t plan on that for at least another 40 years” (Focus group, 6/10/14, males).

The groups also agreed that they were not concerned because they want the onus to be on their parents. One male participant stated, “I kind of assumed my parents would make the best judgment decision” (Focus group, 6/11/14, mixed sex). Although they were not previously concerned, some groups indicated they are “more concerned about it now that we’re having this conversation” (Focus group, 6/12/14, females).

**Barriers.** The sixth research question asked about barriers to young adults’ willingness to have ACP conversations. Many of the salient barriers have already been discussed above in relation to other questions, but will be summarized here for clarity. The first perceived barrier is family reaction. The majority of groups indicated fear that their parents would react badly to the discussion being brought up either because of the
topic of death or because a difference in opinion. One participant perceived her dad and mom to be of two different opinions about life-sustaining treatment—resulting from the father’s favoring attitude towards religion and the mother’s favoring attitude towards science—and did not want to cause rifts in the family. The second and third perceived barriers are awareness and knowledge. The majority of groups noted that they were not aware of the topic, or that they did not have enough knowledge to feel capable of having the conversations. The fourth barrier is indecision. Most groups indicated that “knowledge of knowing exactly what you want” is an obstacle for ACP conversations (Focus group, 6/11/14, mixed sex). The fifth barrier is unimportance. The majority of groups indicated that it was not important to them because they are young, healthy, and not at risk for being in a situation that would necessitate advance care plans. The groups also indicated a desire to divert onus by leaving the medical treatment decision-making to their parents. The sixth and final barrier is difficult topic. The majority of groups perceived talking about death and dying as difficult.

**Benefits.** The seventh research question asked what benefits young adults perceive to be associated with ACP. The majority of groups struggled with listing potential benefits to ACP. Several groups mentioned that ACP would allow their wishes to be respected, decrease familial burden, and prevent conflict.

**Discussion**

ACP is important for individuals of all ages but it is frequently only completed by older adults. In order to increase ACP engagement among the young adult population, it is necessary to determine the factors that affect intent. Thus, the purpose of this formative
research was to identify variables that are relevant to the young adult population. Several HBM constructs were supported by the focus groups, including cues to action, self-efficacy, barriers, susceptibility, and severity. It was unclear, however, whether benefits are important to young adults’ willingness to have ACP conversations. Finally, two unanticipated relational variables were identified: relational closeness and anticipated response. Each construct is reviewed below, followed by a discussion of the overall theoretical and practical implications. A discussion of the limitations is reserved for chapter six to avoid repetition across the three studies that make up this dissertation.

**Cues to Action and Self-efficacy.** The first relevant HBM construct was cue to action. This is consistent with HBM research that suggests more frequent messages about the behavior will positively affect intent (Becker, 1974). Cues to action was supported both directly and indirectly. It was supported directly because some groups explicitly stated that they were motivated to have ACP conversations after learning about ACP in class. In this manner, classes are the external cues that motivate young adults to engage in ACP. Cues to action was also supported indirectly in discussions about the association between knowledge, self-efficacy, and willingness to engage in ACP (RQ1-RQ3). Groups who indicated that they were willing to have ACP conversations cited personal experience and knowledge about ACP as reasons. Conversely, groups who indicated that they were not willing to and did not feel efficacious about having ACP conversations indicated that they did not have enough information about it and, consequently, were uncertain about their treatment preferences.
The connection between lack of knowledge and low intent also suggests that young adults are likely in the pre-contemplative stage of the transtheoretical model (TTM). The TTM states that when individuals are uninformed or under informed of the consequences of a behavior, they are likely to avoid thinking about ceasing said behavior (Prochaska, DiClemente, & Norcross, 1992). For example, if individuals are not aware of the serious risks of smoking, it is not likely that they will consider smoking cessation. These individuals are considered to be in the pre-contemplation stage. Although the TTM is frequently used to study the cessation of high-risk behavior, the principles of the theory are still applicable here. It is likely that young adults who are unaware of the consequences of not having ACP conversations are not yet motivated to perform the behavior.

This finding has important implications for the DCM, as it suggests that cues to action and efficacy beliefs likely have a positive relationship with intent and should be included in the DCM as such. Additionally, the association between cues to action, knowledge, and the TTM is an important finding for practitioners (e.g., medical professionals and campaign specialists) who wish to change ACP behavior among young adults. The results suggest that in order for cues to action to be effective among the young adult population, the messages must not simply serve as a reminder but must be informative in nature so that they are increasing young adults’ knowledge about ACP. Future research should conduct experimental studies with pre- and post-tests to determine the effect of knowledge-based cues to action on intent.
Barriers. Results of the focus groups also indicated that the HBM construct, perceived barriers, might influence ACP conversations (RQ6). Most of the barriers that emerged in the focus groups overlap with other constructs that have already been or will be discussed. However, indecision and diverting onus were two barriers that are unique from other concepts. These barriers to ACP are also common among elderly adults. Elderly adults indicate uncertainty about life-sustaining treatment preference and a desire to leave decision making to others as reasons for not having ACP conversations (Bowman & Singer, 2001; Ko, 2008). One explanation for this finding could be the weightiness of this life-and-death decision that contributes to the uncertainty and desire to divert onus. The decisions made during ACP are weighty because they have life-changing consequences. Thus, individuals may be apprehensive to make such decisions for fear of making the wrong choice. Alternatively, individuals may wish to divert onus because they feel uniformed about ACP. In sum, the results of the focus groups strongly suggest that barriers should be included in the DCM. However, the implications for practitioners is not as clear. This is because more research is needed to determine why individuals are motivated to divert onus. Additional research is needed because the two explanations that I suggested lend themselves to two very different approaches to reducing this barrier due to differences in ontological and epistemological uncertainty.

As its names implies, ontological uncertainty questions the nature of the world (Babrow, 2001). This can take two forms: analogous—the inability to categorize something—and causal—the inability to determine the cause of something (Babrow, 2001). If individuals are diverting onus due to the weightiness of the decision, they could
be struggling with analogous ontological uncertainty. Individuals may be unsure about whether to categorize life-sustaining treatment as good or bad, for example.

Uncertainty can also be epistemological. Epistemological uncertainty refers to difficulties in understanding (Babrow, 2001). This uncertainty could stem from the quality, adequacy, accuracy, or difficulty in ranking the information (Babrow, 2001). If young adults’ desire to divert onus is not a result of an inability to categorize something but instead a result of information inadequacy, then their uncertainty is epistemologically based.

Prior to Babrow’s (2001) distinction between the two forms of uncertainty, the common approach to reducing uncertainty was to give large amounts of information to the person. This is problematic, however, because an increase in information only helps individuals when their uncertainty is rooted in epistemology, and when the epistemological issue is a lack of information (Babrow, 2001). Such would be the case for the second explanation I provided above. However, giving more information to someone who is ontologically uncertain would not reduce his or her uncertainty, and could quite possibly worsen it (Babrow, 2001). Therefore, it is important for scholars and professionals to further define the reasons why individuals divert medical treatment decision-making.

Benefits. It is unclear whether the sixth HBM construct, perceived benefits, influences young adults’ intent to engage in ACP (RQ7). The majority of the focus groups struggled to name the advantages of ACP. Still, the benefits that were discussed—such as getting desired medical treatment and saving money—are consistent with
previous research on the elderly (Ko, 2008). One possible explanation for their difficulty in naming benefits is that events and consequences that are perceived to be far away typically seem less important in the present (Kapp, 2000). Thus, a consequence like “I will get the treatment I want” may be less important to someone who does not expect to be in that situation for several decades. Alternatively, young adults’ struggle to name benefits of ACP may be related to their self-professed lack of knowledge about the behavior. The latter explanation seems more likely because the participants verbally expressed that they do not know what benefits might come of ACP. This construct should be tested in the DCM, although it is not clear if it will be significant. This finding is important for practitioners because it identifies an area ripe for intervention. Campaigns meant to increase ACP intent could promote the benefits of the behavior. Future research should explore what, if any, benefits resonate the most with the young adult population.

**Susceptibility and Severity.** The next HBM construct that was supported by the focus groups was perceived susceptibility (RQ5). Many groups stated that they have not had, and did not plan to have, ACP conversations because they did not expect to need them in the near future. This suggests that the focus groups shared an indifferent attitude towards ACP because they did not perceive it to be of immediate relevance. This is consistent with research on African American young adults, which found that susceptibility had an important role in intent to have ACP conversations (West & Hollis, 2012). One explanation for this finding is the feeling of invincibility that is common among young adults (Kapp, 2000). However, this could also be a result of the general
societal perspective that ACP is only important to the elderly or terminally ill population (Rauscher & Nacinovich, 2012). The support from the focus groups and previous ACP research suggests that this construct should be included in the DCM. It is likely that there will be a negative relationship between perceived susceptibility and intent to have ACP conversations among young adults, and that this relationship is mediated by attitude.

Perceived severity had mixed support. Most groups agreed that needing but having forgone ACP would be a severe situation (RQ4). A small percentage of groups, however, did not believe it to be a severe situation, mostly due to a reliance on parent’s decision-making capabilities. This finding suggests that, as predicted by the HBM, perceived severity may play a role in young adults’ behavioral intent and the construct should be included in the DCM. Whereas young adults who find the situation to be severe will be more likely to have ACP conversations, young adults who do not find the situation to be severe will be less likely to have ACP conversations. Again, future research needs to determine what is motivating individuals to leave the decision making to others.

These findings are also important for practitioners who wish to increase ACP intent among young adults. Practitioners should craft messages that increase young adults perceived threat. Specifically, the messages should point to the risk and severity of being in a situation where they are unable to communicate medical treatment wishes. One possible way in which they could convey threat is by including real-life stories of young adults who were in situations that necessitated life-sustaining treatment decisions. Although studies that used fear appeals to increase elderly adults’ completion of ADs
were not successful (Cugliarli, Sobal & Miller, 1999; Payne, Prentice-Dunn & Allen, 2010), the presence of fear appeals in real-life stories might motivate young adults to have ACP conversations (Nabi, 2002). The difference might lie in the way in which age affects orientation to information; older adults tend to focus on more positive than negative information (Payne et al., 2010). Future research should explore the effect of fear appeals on ACP intent among young adults.

**Anticipated Response.** One relational variable to emerge as relevant was anticipated response (RQ8). Results of the focus groups indicated that anticipated response might affect intent to have ACP conversations. Groups agreed that they were not willing to have ACP conversations because talking about death might scare their parents. This is consistent with previous research on elderly adults that found fear of upsetting family members to be a barrier to AD completion (Crain, 1996). One explanation for this finding is that the young adults infer from their parents’ behaviors and comments that their parents would be too devastated at the thought of their child’s death to discuss ACP. However, an alternative cause is that the stigma that surrounds the topic of death causes individuals to assume that others would be upset by ACP conversations (Keating et al., 2013). It is unclear which explanation is more probable. However, it can be suggested that young adults who perceive a more negative response from their parent will be less likely to have ACP conversations. The results of my focus groups and previous research provide clear support for this construct to be included in the DCM. Additionally, this finding has implications for parent-child interactions about ACP. Parents should initiate the conversations about ACP, perhaps just by mentioning
that they would be open to a discussion about life-sustaining treatment preferences. This would reduce young adults’ fear of upsetting their parents by talking about ACP.

**Relational Closeness.** In addition to anticipated response, closeness also emerged as a potentially important relational factor that may affect intent (RQ8). Several participants who were willing to have ACP conversations indicated that they felt comfortable having the discussion because they are close with their parent(s). One explanation for this finding is that individuals in close relationships already have a high rate of disclosure (Greene et al., 2012; Hess & Coffelt, 2012), and ACP is viewed as just another piece of information to disclose. An alternative, but somewhat related, explanation is that closeness creates a more open, comforting atmosphere (Keating et al., 2013) that makes disclosure more likely because individuals expect a positive response. This is consistent with the path from closeness to anticipated response in the DD-MM (Greene et al., 2012). Thus, individuals from families with greater relational closeness may be more likely to have ACP conversations because they have a more positive anticipated response. The data from the focus groups and disclosure research suggests that this variable should be included in the DCM.

**Theoretical Implications and Future Research.** The most prominent theoretical implication is the finding that relational constructs were discussed in the focus groups, despite any items on my focus group guide specifically asking about them. This provides support for my argument that relational variables are important to predicting health communication behavior. Any study that attempts to predict or change health communication behavior should address both individual and relational factors. However,
more research is needed to determine what specific individual and relational factors are the strongest predictors, and whether they are the strongest predictors across a number of health-related and non-health-related contexts. For example, this dissertation attempts to explain intent to have ACP conversations. Although it seems as if many of the constructs that predict ACP conversations would also predict intent to have other health-related conversations (e.g., perceived susceptibility and anticipated response are probably important to safe-sex conversations), it is unclear if the factors that affect ACP intent also affect non-health-related conversations, such as disclosing family secrets. Constructs like perceived severity and susceptibility would likely not be relevant in the sense that—in most scenarios—perceived threat may not motivate young adults to disclose family secrets. However, constructs like perceived susceptibility and perceived severity may be relevant in a different way. For example, individuals may evaluate the likelihood of them getting caught telling the secret (perceived susceptibility). They may also evaluate the severity of the punishment if they get caught. Future research should explore this further.

**Practical Implications and Future Research.** Overall, these findings indicate that there are numerous factors that decrease young adults’ intent to have ACP conversations. This is not surprising, given that ACP is not encouraged among the young adult population. Several steps could be taken in order to shift the cultural trend. First, physicians could include this as talking point during wellness visits. Just as physicians ask individuals about their sugar intake and exercise habits, they could also ask if any ACP conversations have taken place. Additionally, parents could introduce the topic to their teenagers. This on-going conversation might begin with the parents discussing their
own treatment preferences. Undergirding these policy recommendations, however, are
values and ethical dilemmas that should be considered before the policies are
implemented. Guttman (2000) called for a type of intervention scholarship and practice
whereby the values that undergird the intervention are made transparent. For example, an
ethical dilemma that is presented by my suggestions is the creation of anxiety in
individuals. For many people, death is an unpleasant topic (Keating et al., 2013). Even
though ACP is an attempt to reduce uncertainty, as Babrow (2001) noted, any attempt at
uncertainty reduction in one area may create uncertainty in another. It is possible that
thinking about ACP may boost anxiety in individuals. More research is needed to fully
identify the values and ethical issues that are inherent in policy decisions about ACP.

Conclusion. In sum, the results of this formative research reinforced the proposed
relevance of the HBM and identified two relevant relational variables to be included in
the DCM. It is likely that individuals with greater perceived susceptibility, greater
perceived severity, more frequent cues to action, greater self-efficacy, fewer perceived
barriers, a more positive anticipated response, and greater relational closeness will be
more likely to have ACP conversations. It is unclear if perceived benefits affect intent.
The results of this study provided a starting place for variables to be statistically tested in
Study 1.
Chapter Four: Study 1

Study 1 was the second step in building the DCM. The purpose of this study was to act as a preliminary test for factors to include in the model. I tested several HBM constructs—perceived self-efficacy, severity, susceptibility, barrier, and benefits—and one relational factor—relational closeness. I chose these constructs as a starting point for identifying variables to be included in the DCM because they are the most commonly studied variables in ACP and disclosure research. I also used this first study as an opportunity to pilot measures for inclusion in Study 2. In what follows, I review the methods, results and discussion of the findings.

Methods

Participants and Procedures. I recruited 534 college students, aged 18-50 ($M = 19.12$, $SD = 2.66$) from a subject pool at a Mid-western university. Students earned 1.5% course credit for participating in the study. Participants were able to opt out of the study and complete the alternative assignment for the same course credit. The only inclusion criterion was that participants needed to be 18 years of age or older at the time of the study. However, because some individuals may find the topic of death upsetting, participants with sensitivity to the topic of death were encouraged to complete the alternative assignment. I obtained IRB approval before collecting data. Participants began the online questionnaire after providing informed consent. To earn course credit, participants entered their name and student ID in a separate online survey. All participants received a debrief message identifying the purpose of the study after completing the survey.
I first removed cases that were missing the entirety of data ($n = 42$). I then removed an additional 118 cases for failing to pass an attention check. The attention check was one item that said, “Please answer strongly disagree to this question.” Any participants who did not answer strongly disagree were removed. These attention checks ensure that participants are reading the questions carefully (Mason & Suri, 2012; Oppenheimer, Meyvis, & Davidenko, 2009). Excluding cases due to missing data and the attention check resulted in a final sample size of 374.

Of the participants who provided demographics ($n = 359$), 35.3% were males and 64.7% were females. Slightly more than half (59.9%) of the participants were freshman, 21.1% were sophomores, 13% were juniors, 5% were seniors, and 1% indicated “other.” The majority of participants were Caucasian (85.8%), 5.8% were African American, 2.9% were Asian or Pacific Islander, 1.9% were Hispanic or Latino/a, 3.6% were multi-racial or multi-ethnic.

**Measures.** The measures used in this study include perceived severity, perceived self-efficacy, perceived susceptibility, perceived barriers, perceived benefits, relational closeness, and communication intent. At the beginning of the study, participants were asked to select a referent (mother, father, male guardian, or female guardian) as the person they are most likely to talk with about an important health-related issue. A quarter (25.4%) of participants chose their father as a referent, 70.9% chose mother, .03% chose male guardian, 1.9% chose female, and the remaining 1.6% did not respond. Their answer choice then appeared in the relational closeness items as the person that the
individual should refer to when responding to the items. All items were on a five-point Likert scale (1 = Strongly Disagree; 5 = Strongly Agree) unless otherwise indicated.

**Missing data.** I assessed both the items and the individual cases for missing data. Frequencies and the missing data analysis patterns showed that items pertaining to personal experience had a substantial amount of missing cases. This is due to recoding the “not applicable” values as “system missing.” All other variables had 10 or less missing cases, which I deemed unproblematic. There were no clear patterns to the places in which various cases were missing data. Several of the cases were missing a substantial portion of the data. However, any cases that had answers to at least one item were permitted to remain in the data set. To address the missing values, all analyses were conducted by excluding cases pairwise.

**Item-level analysis.** I analyzed the items for normality prior to forming scales. I began item-level analysis by checking the histograms for bimodality. Next, I examined skewness and kurtosis by dividing the skew and kurtosis statistic by their respective standard errors to determine the skew and kurtosis t-values. A criterion of $p < .01$ ($t > 2.58$) was applied because of the large sample size (Tabachnick & Fidell, 2007). Finally, I assessed the standard deviations to check for adequate variance as determined by a standard deviation greater than or equal to 0.80.

**Scale development and analysis.** Although I tried to use pre-existing measures when possible, in some instances it was necessary to create scales specifically for this study. To ensure measurement reliability and validity for scales that were both pre-existing and developed for this study, I took several steps. First, I assessed the items for
face validity. Next, I checked the items for internal consistency via approximately equal means, standard deviations, and inter-item correlations. I then conducted exploratory factor analyses by first verifying that the Kaiser, Meyer, Olkin (KMO) value was greater than .50—which indicates that the factor analysis is appropriate (Kaiser, 1974)—before ensuring that the unidimensional scales were only loading onto one factor. Finally, I calculated Cronbach’s alpha to determine the reliability. Items that failed one or more of the aforementioned tests were marked for removal or removed entirely. Scales that I removed items from are detailed below, in the scale descriptions.

**Perceived severity.** Perceived severity refers to how serious participants rate a situation where they are unable to communicate their medical treatment wishes, but did not make advance care plans a head of time. This measure is adapted from McCornack and Levin (1990) and begins with the prompt, “How serious of a situation would it be if you were unable to communicate your medical treatment wishes but had not done any advance care planning ahead of time?” The scale presents the participants with four, five-point visual analog items (e.g., 1 = minor, 5 = major). I modified this measure by adding two additional items and decreasing the scale points from seven to five, in order to be consistent with the other measures used in this stud. The two additional items, drawn from De Paoli, Manongi, Klepp (2004), were “1 = not a serious situation at all, 5 = a very serious situation” and “1 = not a big deal at all, 5 = a very big deal.”

There were no issues with face validity, internal consistency, inter-item correlations, standard deviation, or kurtosis. The scale was negatively skewed, as the calculated skew statistic was -6.73. I determined that this was not problematic, however,
because even small deviations from normality are significant with large sample sizes (Osborne, 2013). It is generally recommended that variables should only be a candidate for transformation if the actual skew statistic is greater than the absolute value of one (Osborne, 2013). In this case, the skew statistic was -.86, so no transformation was performed. An EFA (KMO = .91) showed that the items loaded onto one factor. I averaged the scores to create a unidimensional scale, with a greater score indicating greater perceived severity. The scale had high reliability, $a = .97 (M = 3.96, SD = 1.00)$.

**Perceived self-efficacy.** I assessed participants’ perception of their ability to successfully engage in ACP conversations with three items. The items asked participants to agree or disagree with statements such as, “I feel confident in my ability to have advance care planning conversations with my family.” This measure was adapted from Chadwick (2010); I modified this measure by changing the topic to that of ACP conversations.

There were no issues with face validity, internal consistency, inter-item correlation, standard deviation, or kurtosis. This scale was also negatively skewed, with a calculated skew statistic of -3.86. Again, the actual skew statistic (-.49) was less than the absolute value of one, so I deemed this non-problematic. An EFA (KMO = .74) indicated that the items loaded onto one factor. The scores were averaged to create a unidimensional scale, with a higher score equally greater self-efficacy. The scale had high reliability, $a = .85 (M = 3.56, SD = 0.81)$.

**Perceived susceptibility.** I measured the degree to which participants perceive themselves as susceptible to being in a situation that would require life-sustaining
treatment decisions using a modified version of Chadwick’s (2010) five-item scale. I modified the topic to be applicable to the present study. Participants agreed or disagreed with statements such as, “At this point in my life, it is likely that I will personally experience a situation where I won’t be able to communicate my medical treatment wishes.”

There were no issues with face validity, internal consistency, inter-item correlation standard deviation, skewness, or kurtosis. An EFA (KMO = .84) showed that the items were loading on to two factors. The item that was loading poorly was a reverse coded item. The results of the Cronbach’s alpha also suggested that this reverse coded item was problematic. I dropped this item in response to these indicators. This improved the EFA and Cronbach’s alpha values. I averaged the scores to create a unidimensional scale, with a higher score equaling greater perceived susceptibility. The scale had high reliability, $a = .89$ ($M = 2.14$, $SD = 0.73$).

**Perceived barriers.** I measured participants’ perceived barriers to ACP using Ko’s (2008) nine-item modified version of Vandecreek and Frankowski’s (1996) original index. Ko (2008) modified the scale by including several barriers and changing the wording to be more accessible. I modified the measure for this study by including items that were identified as relevant in the literature and in my focus group research for a total of 18 items. The nine additional barriers that I included were fear of substandard treatment, religious or spiritual beliefs, availability of a family member to talk discuss advance care plans, access to AD forms, fear of upsetting family, trust in parents, unawareness, lack of information, and embarrassment. Participants agreed or disagreed
with statements such as, “It is hard for me to know now what I might want when I am faced with the threat of death.” Again the calculated skew statistic of -3.5 was significant, however, the actual skew statistic (-.44) was less than one. Therefore, no transformation was performed. I averaged the scores to create an index, with a greater score indicating more perceived barriers ($M = 2.78$, $SD = 0.42$).

**Perceived benefits.** I measured participants’ perceived benefits of ACP using Ko’s (2008) eight-item modified version of Vandecreek and Frankowski’s (1996) original index. Ko (2008) modified the wording of the original scale and included two additional items pertaining to peace of mind and receiving desired medical treatment. I separated one of the items that Ko (2008) added into two items for this study because it was double-barreled. Participants agreed or disagreed with statements such as, “Making advance care plans will help those around me to know what my wishes are for medical treatment.” There were no issues with skewness or kurtosis. I averaged the scores to create an index, with a greater score indicating more perceived benefits ($M = 3.89$, $SD = 0.60$).

**Communicative intent.** I used the first of Chadwick’s and Szalai’s (2014) two-part communicative intent measure to determine if participants intended to have ACP conversations in the next 30 days. The measure asks participants about their intent to communicate with individuals about their life-sustaining treatment wishes. For example, participants agree or disagree with, “I am likely to talk with a family member about my wishes.” There were no issues with standard deviations, skewness, or kurtosis. However, a review of face validity and inter-item correlations indicated the items might be
measuring two different things: intent to talk with loved ones and intent to talk with professionals. This was verified with an EFA (KMO = .80) that showed that the items loaded onto two factors. I dropped the two items about talking to professionals because they were not relevant for this study. I averaged the scores to create a unidimensional scale. The scale had high reliability, $a = .90 (M = 2.52, SD = 1.14)$.

**Relational closeness.** I used Buchanan, Maccoby, and Dornbusch’s (1991) Parent-Child Closeness scale to measure individuals’ perceptions of relational closeness. Nine semantic differential items ask questions such as, “How close do you feel to your [referent]?” There were no problems with face validity, internal consistency, inter-item correlation or standard deviations, and an EFA showed that the items loaded onto one factor (KMO = .89). However, there were significant issues with skewness and kurtosis.

The scale was negatively skewed, as indicated by the calculated skew statistic of -12.83. The actual skew statistic (-1.64) was greater than the absolute value of one. The scale was also leptokurtoic. The calculated kurtosis statistic was 13.23. Leptokurtosis is problematic because the lack of variance may result in an inability to detect significant relationships. However, I chose not to transform the variable because it is an established scale. Transforming established scales is sometimes not recommended because it makes it difficult to compare results across studies when the results are transformed (Osborne, 2013). I averaged the scores to create a scale, with a higher score equaling greater relational closeness. The scale had high reliability, $a = .92 (M = 4.30, SD = 0.75)$.

**Analysis.** The goal of this study was to determine which factors are the most significant predictors of young adults’ intent to have ACP conversations. A two-step
Hierarchical multiple regression was conducted. HBM variables were entered in the first step, and relational closeness was entered in the second step. This two-step approach allowed me to see if relational closeness added any explanatory power to the model above and beyond that of the HBM variables. Prior to analyzing the data, I tested the assumptions of linear regression. The Mahalanobis distance was calculated to check for multivariate normality. Five cases were identified as outliers. Because their scores were not too extreme, (exceeding the critical value by less than or equal to .92) and because the sample size was large, the cases were permitted to remain in the data. The Shapiro Wilk’s score, another indicator of normality, was significant (p < .001) for each variable in the study, including ones that were not skewed or kurtotic. This may be explained by the test’s sensitivity to large sample sizes (Tabachnick & Fidell, 2007). The limitation of this will be addressed in chapter 6. There were no violations of the assumptions of linearity, multicollinearity, or homoscedasticity, however.

**Results**

A two-step hierarchical multiple regression was used to test several hypotheses about factors that affect young adults’ intent to communicate about ACP with their family. The correlations among variables are provided in Table 2. Table 3 shows the values for each step. The first step of the model answered five hypotheses. Specifically, I proposed that susceptibility (H1), severity (H2), self-efficacy (H3), perceived barriers (H4) and perceived benefits (H5) predict young adults’ intent to have ACP conversations. The first step of the model, in which HBM variables were entered, was significant: $F =$
9.633 (5, 34), \( p < .001 \). Self-efficacy \( (\beta = .20, t = 2.83, p = .005) \), susceptibility \( (\beta = .36, t = 4.69, p < .001) \), and benefits \( (\beta = .26, t = 2.62, p = .009) \) were significant predictors in this step. The model was statistically significant with an adjusted \( R^2 \) value of .12.

<table>
<thead>
<tr>
<th>Table 2. Hierarchical Regression Correlations</th>
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<tr>
<td>1. Intent</td>
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<tr>
<td>2. Severity</td>
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<td>3. Self-efficacy</td>
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<td>4. Barriers</td>
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<td>5. Benefits</td>
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<td>6. Susceptibility</td>
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<td>7. Closeness</td>
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Note: * = \( p < .01 \); ** = \( p < .001 \)

The second step of the model answered an additional hypothesis about relational closeness. Specifically, I proposed that relational closeness predicts intent to have ACP conversations (H6). In the second step, relational closeness was added to the model. The addition of relational closeness was insignificant: \( \Delta F = .51 \) (1, 353), \( p = .477 \). In sum, the size and direction of the relationships suggests that intent to communicate is greater among people who perceive themselves to be more capable of having ACP conversations.
conversations, more susceptible to being in a situation that would necessitate life-
sustaining treatment decisions, and who perceive more benefits to ACP conversations.

<table>
<thead>
<tr>
<th>Table 3.</th>
<th>Hierarchical Regression Steps</th>
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<tbody>
<tr>
<td>Variable</td>
<td>ΔR2</td>
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<tr>
<td>Step 1:</td>
<td>.12</td>
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<tr>
<td>Severity</td>
<td>.07</td>
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<tr>
<td>Self-efficacy</td>
<td>.20</td>
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<td>Susceptibility</td>
<td>.36</td>
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<tr>
<td>Benefits</td>
<td>.26</td>
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<tr>
<td>Barriers</td>
<td>-.24</td>
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<tr>
<td>Step 2:</td>
<td>.00</td>
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<tr>
<td>Relational Closeness</td>
<td>.05</td>
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Discussion

Research on the factors that motivate young adults to engage in ACP is lacking. Therefore, this study attempted to identify factors. The HBM—specifically the barriers and benefits constructs—is the most commonly used theoretical framework in ACP research on older adults. For this reason, I used the HBM as a starting point to determine if those factors predict intent to have ACP conversations. Susceptibility, self-efficacy, and benefits were found to affect intent. This study also included one relational variable that was prominent in the literature and focus groups to see if it was relevant to young
adults’ intent to have ACP conversations. An additional goal of this study was to determine if the variance accounted for may be improved upon by adding the TPB variables in future studies. The adjusted $r^2$ value suggests that it may be beneficial to apply the TPB. The third and final goal of this study was to pilot several measures for the DCM. I review the findings of the study below, before discussing the theoretical and practical implications. I review the limitations in chapter six, to reduce repetition across studies.

As suggested by the results of my focus groups, susceptibility was a predictor of intent in the regression model (H1). This is consistent with research on African American young adults that found susceptibility to be an important factor in young adults’ decisions to have ACP conversations (West & Hollis, 2012). It is inconsistent, however, with a meta-analysis of the HBM, which suggested that susceptibility is one of the weakest variables (Carpenter, 2010). As I hypothesized earlier, this could be because susceptibility is a stronger predictor of preventative, as opposed to treatment, behavior—a relationship that I attribute to the decreased presence of fear (Janz & Becker, 1984).

Susceptibility could play a significant role in young adults intent because of the general societal perspective that ACP is only important to the elderly or terminally ill population (Rauscher & Nacinovich, 2012). However, it is more likely that young adults do not perceive themselves to be susceptible to being in a situation that would necessitate advance care plans due to the aforementioned feelings of invincibility (Kapp, 2000). This is more likely because research has shown that this optimism bias increases risky
behavior (Kapp, 2000). This finding underscores the importance of susceptibility to be included in the DCM.

This finding also has implications for practitioners that aim to increase ACP intent among young adults. As mentioned earlier, practitioners should craft messages that increase young adults’ perceived susceptibility. Specifically, the messages should point to the risk of being in a situation where they are unable to communicate medical treatment wishes. Fear appeals that are couched in a real-life story about a young adult who was unable to communicate treatment preferences may be an effective way to increase susceptibility (Nabi, 2002). Although research suggests that fear appeals are not effective when aimed at increasing AD completion among elderly adults (Cugliarli et al., 1999; Payne et al., 2010), they may be effective for increasing ACP conversations among young adults. The difference might lie in they way in which age affects orientation to information; older adults tend to focus on more positive than negative information (Payne et al., 2010). Future research should explore the effect of fear appeals on ACP intent among young adults.

However, severity—the other component of perceived threat—was not a significant predictor in the regression (H2). This is consistent with the meta-analysis finding that severity is a weak predictor (Carpenter, 2010). It has been proposed that severity often does not predict intent because of a lack of variance (Carpenter, 2010). However, in the present study, the severity construct had a standard deviation of 1.00, which indicates that it had adequate variance. Another possible reason for the non-significance in the present study could be the role of mediators. I hypothesized in the
DCM that severity affects intent through attitude. It is possible that the relationship is fully mediated and therefore not significant without the presence of attitude. Severity should still be included in the DCM, but with attitude as a mediator, to determine if this is the case.

Inconsistent with the results of my focus groups is the present study’s finding that benefits, but not barriers, significantly predicted intent (H4 & H5). This is also inconsistent with research on the elderly. One study found barriers, but not benefits, to be a significant factor affecting the elderly’s intent to engage in ACP (Hamel et al., 2002). This is likely because, for older adults, barriers to ACP outweighed the benefits (Hamel et al., 2002). It is surprising that the opposite is true for young adults. It is possible that benefits predicted intent in the present study because of participants’ potential fear of death. Young adults typically have a greater fear of death than elderly adults (Cicirelli, 2002). If young adults are fearful, benefits to ACP may offer them some comfort in knowing that their future is planned.

Conversely, barriers could be unimportant because young adults have not yet thought through the steps it takes to engage in ACP and thus are less aware and concerned about the barriers. The latter explanation may be the most accurate, as indicated by the low mean for the barriers (2.78). A mean of 2.78 indicates that many of the young adults did not rate the barriers as obstacles to having ACP conversations. This may have been improved by including only barriers that have been tested among the young adult population. Although some of the barriers in the index that I used were added from the results of my focus groups—and are therefore likely relevant for the young adult
population—the majority of the barriers were from the original scale that was created for research on older adults. Future research should identify the specific barriers that are important to the young adult population. For the DCM, it is clear that benefits should be included as a factor that affects intent. And, as previously discussed in regard to severity, barriers should still be tested in the DCM, but with attitude as the mediating variable as originally hypothesized.

Another significant finding was the relationship between self-efficacy and intent (H3). Consistent with HBM research and the results of my focus groups, efficacy was an important factor in determining individuals’ behavioral intentions. This is not surprising, as individuals are more likely to perform behaviors if they feel efficacious (Ajzen, 2001; Becker, 1974; Greene et al., 2012). Future research should identify why some young adults do not feel efficacious in regard to ACP. Practitioners can then use that information to boost the population’s intent to have ACP conversations by increasing their efficacy beliefs.

This finding underscores the need for an efficacy construct in the DCM. However, I am choosing to replace self-efficacy with perceived behavioral control in the final study. As mentioned earlier, because these two variables are conceptually similarly, and theoretical justifications cannot support choosing one variable over the over, I diverted to the proven statistical success of the TPB’s perceived behavioral control as a deciding factor to include perceived behavioral control instead of self-efficacy.

Closeness was not a significant predictor of intent (H6). This is inconsistent with a number of previous studies that suggest closeness is strongly related to disclosure intent.
(Greene et al., 2012; Hess & Coffelt, 2012; Steuber & Solomon, 2011). There are two potential causes for this non-significant result. First, mediators may be important to this relationship. In the DCM, I hypothesized that relational closeness affects attitude through anticipated response, and that anticipated response affects intent through attitude. It is possible that relational closeness only has a relationship with ACP intent when it is mediated by anticipated response and attitude. An alternative, and seemingly more likely explanation is the normality issues with the relational closeness measure. It had a lot of problems with skewness, kurtosis, and standard deviation. The lack of variance within this variable could have resulted in a non-significant finding because it is unable to covary with other variables (Osborne, 2013). These normality problems likely arose from the format of the survey, where I asked individuals to select a parent or guardian that they would talk to about ACP, and then rate their closeness with that person. As a result, there was little variance, likely because individuals may tend to talk about ACP with someone whom they perceive as relationally close. It was not possible to change this measure for study 2, as this realization came too late. Consequently, relational closeness will be excluded from the DCM for the remainder of this dissertation. Future research should explore a way to measure closeness in a different manner. One suggestion is to use openness as a proxy. Openness is often a characteristic of dyads that have high relational closeness (Koerner & Fitzpatrick, 2002).

The second goal of the study—to determine if the TPB variables may explain additional variance—was answered by examining the adjusted $r^2$ value. The HBM constructs accounted for 12% of the expected variance in intent to have ACP
conversations among the young adult population. This effect size is categorized as a small effect (Cohen, 1988). Although I did not use the TPB in this study, it is useful to compare the effect size seen here and the typical effect size of the TPB, as the HBM is typically used in ACP research and the TPB is recognized as a stronger model. A meta-analysis of studies that predicted intent using the TPB indicated $R$ values that ranged from .55 to .94 (Ajzen, 1991). Given this high success rate, it is possible, then, that the TPB may be a more theoretically sound model and, consequently, may account for more variance in ACP intent than what was accounted for by the HBM variables. This provides tentative support for the inclusion of the TPB variables in the DCM.

The third and final goal in this study was to pilot several variables for inclusion in Study 2. This provided information about three measures. First, perceived susceptibility had one reverse-coded item that presented problems with the EFA and the Cronbach’s alpha. It was removed for this study, but for Study 2 the item was reworded so that it did not need to be reverse-coded. The second measure that had issues was the dependent variable, intent. Two of the four items were removed, resulting in a two-item measure. This is not ideal, as a scale with only two items leaves more room for measurement error (Tabachnick & Fidell, 2007). The third measure that was problematic was relational closeness. This variable was non-normal, likely due to the way in which I constructed the survey. Changing the format of the survey, however, was not an option because it necessary to ask the participants to rate their closeness with the person they are most likely to talk to about ACP. As mentioned earlier, using openness as a proxy for closeness in future research may solve this issue.
Theoretical Implications and Future Research. This study has two theoretical implications. First, the results suggest that the factors that affect ACP intent among young adults may be very different than the factors that affect ACP intent among older adults. For example, perceived susceptibility was a significant predictor in this study. This is unlikely to be a predictor in the elderly population because ACP is encouraged for their age group. And, as previously discussed, this study found benefits, but not barriers to be significant. This is contrary to research on the elderly (Hamel et al., 2002). Therefore, the present study’s findings underscore Nussbaum’s (2007) argument that individuals in different life stages approach communicative events in different ways because they have unique values and goals. These findings also support the need for more research on ACP across all life stages including young adult, middle-aged, and older adult.

The second implication is the use of the HBM in ACP research. As previously mentioned, ACP research primarily relies on the HBM as a theoretical framework. However, the present study’s findings suggest that research may be better served by applying the TPB, rather than the HBM. The effect size in this study is small—especially compared to the effect size of other non-ACP studies that have used the TPB. The small effect size supports arguments the TPB is a stronger model than the HBM. However, using the TPB as opposed to the HBM based purely from a methods perspective comes at a cost. As I argued at the beginning of this dissertation, I do not find the TPB to have as much theoretical explanatory ability as the HBM. A middle ground solution may be to
apply a model that incorporates both aspects of the TPB and HBM—such as the one proposed in this dissertation.

**Practical Implications and Future Research.** Like with the results of the focus groups, the present study’s findings suggest that the cultural trend of not encouraging ACP among the young adult population is negatively impacting their intent. This is illustrated by the significance of perceived susceptibility and by the significance of barriers, which I argued could be a result of young adults’ lack of awareness about ACP. There are two steps that I suggest in order to shift this cultural trend. First, physicians could include ACP as a talking point during wellness visits, similar to the way they routinely ask about sugar intake and exercise habits. Second, parents could introduce this on-going conversation by discussing their own life-sustaining treatment preferences with their teenagers. This might prompt an open dialogue and also encourage the teenagers to begin thinking about their own preferences. Of course, this necessitates a discussion of the values and ethical dilemmas that undergird these recommendations (Guttman, 2000). For example, these recommendations may cause individuals to experience anxiety brought on by thinking about death (Keating et al., 2013). Future research should explore these possible consequences more fully.

**Conclusion.** In sum, Study 1 tested the HBM factors and one relational factor for its ability to predict intent to have ACP conversations among young adults. The results showed that individuals with greater perceived susceptibility, greater perceived self-efficacy, and greater perceived benefits are more likely to have ACP conversations. The effect size, however, was small. This suggests that the inclusion of cues to action,
anticipated response, and the TPB variables may contribute substantially in predicting intent.
Chapter Five: Study 2

Study 2 contributes to the construction of the DCM by building on Study 1. Study 1 determined how accurately the most commonly used model in ACP research—the HBM—and relational closeness predicted intent. Although most variables were significant, they only accounted for 12% of the variance, leaving room for additional variables to contribute to the model. As such, Study 2 includes the TPB, the anticipated response, and cues to action variables not tested in Study 1. Together, these variables account for both the individual and relational factors at play in individual health communication behaviors. Furthermore, Study 2 incorporates changes in measurement as suggested by the results of Study 1. I used path analysis to build and assess the DCM. Figure 4 shows the hypothesized paths for the model.

Methods

Participants and Procedures. I recruited 361 college students, aged 18-40 ($M = 19.67$, $SD = 1.90$) from a subject pool at a Mid-western university. Students earned 1.5% course credit for participating in the study. Participants were able to opt out of the study and complete the alternative assignment for the same course credit. The only inclusion criterion was that participants needed to be 18 years of age or older at the time of the study. I obtained IRB approval prior to collecting data. Participants began the online questionnaire after providing informed consent. At the end of the questionnaire, participants entered their name and student ID in a separate online survey in order to receive course credit. This information was recorded separately from the questionnaire.
answers. All participants received a debrief message identifying the purpose of the study after completing the survey.

I first removed cases that were missing data (n = 16) and cases that had the same answer for all items (n = 6). I then removed an additional 39 cases for failing to pass the attention checks. The attention checks were two items that said, “I am having a heart attack right now” and “Most of the time, the sky is green.” I removed any cases that had a response of agree or strongly agree to either of these questions. These attention checks ensure that participants are reading the questions carefully (Mason & Suri, 2012; Oppenheimer et al., 2009). Excluding cases due to missing data and the attention check resulted in a final sample size of 300.

Of the participants who provided demographics (n = 300), 42.3% were males and 57.7% were females. Almost half (46.3%) of the participants were freshman, 31% were sophomores, 12.3% were juniors, 9.7% were seniors, and .07% indicated “other.” The majority of participants were Caucasian (86.3%), 4% were African American, 3.7% were Asian or Pacific Islander, 1.7% were Hispanic or Latino/a, .07% were multi-racial or multi-ethnic.

Measures. The measures used in this study include attitude, subjective norms, perceived behavioral control, cues to action, perceived barriers, perceived benefits, anticipated response, ACP conversation intent, relational quality, perceived severity, and perceived susceptibility. At the beginning of the study, participants were asked to select a referent (mother, father, male guardian, or female guardian) as the person they are most likely to talk with about an important health-related issue. The majority of participants
indicated mother (70.3%), 27.7% indicated father, 1.3% indicated male guardian, and 
.07% indicated female guardian. All measures are on a five-point Likert scale unless 
otherwise noted. Additionally, I chose to measure all TPB variables directly—as opposed 
to indirectly—as suggested by Ajzen (2002). Direct measures typically have a stronger 
association with outcomes than indirect measures (Glanz, Rimer & Viswanath, 2002).

**Item-level analysis.** I analyzed the items for normality prior to forming scales. I 
began the item-level analysis by checking the histograms for bimodality. Next, I 
examined skewness and kurtosis by dividing the skew and kurtosis statistic by their 
respective standard errors to determine the skew and kurtosis t-values. A criterion of \( p < .01 \) \((t > 2.58)\) was applied because of the large sample size (Tabachnick & Fidell, 2007). 
Finally, I assessed the standard deviations for adequate variance as determined by a 
standard deviation greater than or equal to 0.80. Items that failed one or more of the 
aforementioned tests were marked for removal or removed entirely. Scales that I removed 
items from are detailed below, in the scale descriptions.

**Scale development and analysis.** I tried to use pre-existing measures when 
possible, however, in two instances it was necessary to create scales specifically for this 
study. To ensure measurement reliability and validity for scales that were both pre-
existing and developed for this study, I took several steps. Prior to scale formation, I 
analyzed the potential scales for reliability and validity. First, I assessed the items for face 
validity. Next, I checked the items for internal consistency via approximately equal 
means, standard deviations, and intercorrelations. I then conducted exploratory factor 
analyses by first verifying that the Kaiser, Meyer, Olkin (KMO) value was greater than
.50—which indicates that the factor analysis is appropriate (Kaiser, 1974)—before ensuring that the unidimensional scales were only loading onto one factor. Finally, I calculated Cronbach’s alpha to determine the reliability. Again, items that failed one or more of the aforementioned tests were marked for removal or removed entirely and any removal is detailed below, in the scale descriptions.

**Attitude toward the behavior.** I assessed participants’ attitude towards engaging in ACP conversations with a modified version of Chadwick and Szalai’s (2014) five-item semantic differential scale. This scale was developed based on previously established TPB scales. I changed the wording from “advance directives” to “advance care planning conversations,” and the Likert-scale range from seven points to five points in order to remain consistent with other measures in this study. Participants indicated whether having an ACP conversation in the 30 days would be *very bad/*very good, *very valuable/*very worthless, and *very undesirable/*very desirable. There were no issues with face validity, skewness, kurtosis, internal consistency, inter-item correlation, or standard deviation. An EFA (KMO = .76) showed that the items loaded onto one factor. I averaged the items to create a scale, with a higher score equaling a more positive attitude. The scale had acceptable reliability, \( a = .73 \) (\( M = 3.07, \ SD = 0.06 \)).

**Subjective norms.** I measured participants’ perceptions of injunctive and descriptive norms using a modified version of Chadwick and Szalai’s (2014) Likert scales. This scale was also developed based on previously established TPB scales. Similar to the modifications made of the attitude measure, these scales were also changed by replacing “advance directive” with “advance care planning conversations,” and by
using a five points instead of a seven points. The first five items asked participants to disagree or agree with the statements such as, “My parent[s] thinks that I should have an advance care planning conversation in the next 30 days.” The next four items asked participants to disagree or agree with the statements such as, “Most people my age have had advance care planning conversations.” There were no issues with face validity, skewness, kurtosis, internal consistency, inter-item correlation, or standard deviation. An EFA (KMO = .84) showed that the items were loading onto one factor. I averaged the scores to create a scale, with a greater score equaling greater subjective norms. The scale had high reliability, \( a = .89 \) (\( M = 2.47, SD = 0.62 \)).

**Perceived behavioral control.** I measured the degree to which participants feel capable of having an ACP conversation using a modified version of Chadwick and Szalai’s (2014) scale. This scale was also developed based on previously established TPB scales. Again, the wording was changed from “advance directives” to “advance care planning,” and the Likert-scale was changed from seven points to five points. Participants disagreed or agreed with statements such as, “I am confident that if I wanted to, I could have an ACP conversation in the next 30 days.” There were no issues with face validity, skewness, kurtosis, internal consistency, inter-item correlation, or standard deviation. An EFA (KMO = .82) indicated that the items were loading onto one factor. I averaged the scores to create a scale, with a greater score equaling greater perceived behavioral control. The scale had high reliability, \( a = .89 \) (\( M = 2.53, SD = 0.78 \)).

**Cues to action.** I measured the frequency of which participants are confronted with messages of ACP using a scale created for this study. Five items asked participants
to disagree or agree with statements such as, “I often hear about advance care planning in my daily life.” There were no issues with face validity, skewness, kurtosis, internal consistency, inter-item correlation, or standard deviation. An EFA (KMO = .74) indicated that the items loaded onto one factor. I averaged the scores to create a scale, with a greater score equaling more frequent cues to action. The scale had high reliability, \( a = .92 \) (\( M = 1.81, SD = 0.75 \)).

**Perceived barriers.** I measured participants’ perceived barriers to ACP using Ko’s (2008) modified version of Vandecreek and Frankowski’s (1996) original index. Ko (2008) modified the scale by including several barriers and changing the wording to be more accessible. I modified the measure slightly for this study by including items that were identified as relevant in the literature and in my focus group research (see the description in Study 1). Participants agreed or disagreed with statements such as, “It is hard for me to know now what I might want when I am faced with the threat of death.” Although there were no issues with kurtosis, the index was negatively skewed. The calculated skew statistic of -3.3 was significant, however, the actual skew statistic (-.40) was less than the absolute value of one. Therefore, no transformations were performed. I averaged the scores to create an index, with a greater score indicating more perceived barriers (\( M = 2.98, SD = 0.35 \)).

**Anticipated response.** I measured the degree to which participants believe their parent will have a positive response to an ACP conversation using a scale created for this study. Five items asked participants to disagree or agree with statements such as, “My [referent] will respond positively to me bringing up my life-sustaining treatment wishes.”
There were no issues with face validity, skewness, kurtosis, internal consistency, inter-item correlation, or standard deviation. An EFA (KMO = .76) indicated that the items were loading onto one factor. I averaged the scores to create a scale, with a greater score equaling a more positive anticipated response. The scale had high reliability, $a = .93$ ($M = 3.69, SD = 0.80$).

**ACP conversation intent.** I measured the degree to which participants intend to have an ACP conversation in the next 30 days using a modified version of Chadwick and Szalai’s (2014) intent scale. This scale was also developed based on previously established TPB scales. I changed the wording from “advance directives” to “advance care planning,” and the Likert-scale from seven points to five points. Three items asked participants to disagree or agree with statements such as, “In the next 30 days, I intend to have an advance care planning conversation.” There were no issues with face validity, skewness, kurtosis, internal consistency, inter-item correlation standard, or standard deviation. An EFA (KMO = .76) showed that the items loaded onto one factor. I averaged the scores to create a scale, with a greater score indicating greater intent. The scale had high reliability, $a = .92$ ($M = 2.39, SD = 0.93$).

**Perceived severity.** I measured how serious participants rate a situation where they are unable to communicate their medical treatment wishes, but did not make advance care plans ahead of time. This measure was adapted from McCornack and Levin (1990) and begins with the prompt, “How serious of a situation would it be if you were unable to communicate your medical treatment wishes but had not done any advance care planning ahead of time?” I modified this measure by adding two additional items and
decreasing the scale from seven points to a five points, in order to be consistent with the rest of the measures. This scale presents the participants with six visual analog items (e.g., 1 = *no big deal*, 5 = *a very serious concern*). There were no issues with face validity, kurtosis, internal consistency, inter-item correlation, or standard deviation. The scale was negatively skewed, with a calculated skew statistic of -6.70. However, the actual skew statistic (-.83) was less than one so I deemed this non-problematic. An EFA (KMO = .92) confirmed that the items loaded onto one factor. I averaged the scores to create a scale, with a greater score indicating greater perceived severity. The scale had high reliability, $a = .97$ ($M = 3.92, SD = 0.99$).

*Perceived susceptibility.* I measured the degree to which participants perceive themselves susceptible to being in a situation that would require life-sustaining treatment decisions using a modified version of Chadwick’s (2010) five-item scale. I modified the topic to be applicable to the present study. Additionally, I dropped one item due to problems with the Cronbach’s alpha and the EFA, as suggested by the results of Study 1. Participants rated the extent to which they disagreed or agreed with statements such as, “At this point in my life it is likely that I will personally experience a situation where I won’t be able to communicate my medical treatment wishes.” There were no issues with face validity, skewness, kurtosis, internal consistency, inter-item correlation, or standard deviation. An EFA (KMO = .82) confirmed that the items were loading onto one factor. I averaged the scores to create a scale, with a greater score indicating greater perceived susceptibility. The scale had high reliability, $a = .90$ ($M = 2.16, SD = 0.79$).
Perceived benefits. Participants’ perceived benefits of ACP was measured using Ko’s (2008) eight-item modified version of Vandecreek and Frankowski’s (1996) original index. Ko (2008) modified the wording of the original scale and included two additional items pertaining to peace of mind and receiving desired medical treatment. I separated one of the items that Ko (2008) added into two items for this study because it was double-barreled. Participants agreed or disagreed with statements such as, “Making advance care plans will help those around me to know what my wishes are for medical treatment.” I averaged the scores to create an index, with a greater score indicating more perceived benefits ($M = 4.00, SD = 0.65$).

Analysis. The goal of this study was to develop and assess a model that predicts young adults’ intent to have ACP conversations. I conducted path analysis using the AMOS 22.0 program. Similar to multiple regression, path analysis identifies path coefficients (Kline, 2011). Unlike multiple regression, however, path analysis can be conducted for multiple dependent variables simultaneously. I used the maximum likelihood estimation method, as this is the most traditional approach in path analysis (Kline, 2011). The hypothesized model was recursive, meaning that the causal flow of the model was in a single direction (Kline, 2011). The hypothesized model was identified because it met the basic criteria that the number of observations in the model exceeded the number of parameters (Kline, 2011). There were no violations of the assumptions of normality, linearity, multicollinearity, or homoscedasticity.

Model fit. I used several fit indices to assess the model. It is important to look at a variety of tests in order to get a clear picture of the model fit (Hooper, Coughlan, &
Mullen, 2008). The first test that I used to assess the model is the chi-square test (Kline, 2011). The chi-square value should be non-significant, as indicated by a $p$ value of .05 or greater (Kline, 2011). However, it should be noted that the chi-square is not always a good model fit indicator due to its sensitivity to sample size. Larger sample sizes tend to result in a significant chi-square value. Thus, it is important to also look at other model fit values.

The second test that I used to assess the model was the comparative fit index (CFI). The CFI compares the hypothesized and baseline models (Kline, 2011). The baseline model—also referred to as the null model—assumes that there are zero correlations among the variables in the population. The CFI, then, determines how much improvement in fit that the proposed model delivers above the baseline model. CFI scores greater than .95 are acceptable (Hu & Bentler, 1999).

The third test that I used to assess the model was the root-mean-square-error of approximation (RMSEA). The RMSEA measures the hypothesized model in relation to the population’s covariance matrix (Hu & Bentler, 1999). RMSEA is sensitive to parsimony, in that it favors models with the least number of parameters (Hu & Bentler, 1999). It is generally accepted that the RMSEA value, and its associated confidence intervals, should be no greater than .08 (Hu & Bentler, 1999).

The fourth test that I used was the goodness of fit index (GFI). Like the normed chi-square value, the GFI is an alternative to the chi-square test (Hooper et al., 2008). The GFI assesses the covariance matrix in comparison to the population (Hooper et al., 2008).
A less stringent minimum value for the GFI is .90, however, a stricter minimum value of .95 has also been proposed (Hooper et al., 2008).

Finally, the fifth test that I used was the root mean square residual (RMR). The RMR assesses the residuals between the covariance matrixes (Hooper et al., 2008). The standardized RMR is often used when the ranges within the measures are inconsistent (e.g., a mix between five-point and seven-point scales; Hooper et al., 2008). However, all measures in this study were on a single scale, so the standardized RMR was not necessary. Acceptable values for the RMR should be less than .08 (Hooper et al., 2008).

Results

**Hypothesized Model.** Table 4 lists the correlations among variables. Figure 5 presents the hypothesized model with path coefficients. Of the 12 hypothesized paths, six were significant, four were not significant, and two were not tested. H18 and H11, which hypothesized about the relationship between intent and closeness, were not tested due to aforementioned issues in the study design. Only one of the hypothesized paths was direct. H15 proposed a positive relationship from cues to action to intent. This hypothesis was supported by the data ($\beta = .29, p < .001$). In addition to this direct path, five mediated hypotheses were supported, whereas four were not. Table 5 summarized the direct and indirect beta values.
Table 4.

*Path Analysis Correlations*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>1.</td>
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<td>2.</td>
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<td></td>
<td>.11</td>
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<td>3.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-.15* .18**</td>
</tr>
<tr>
<td>4.</td>
<td>-.03</td>
<td>-.02</td>
<td></td>
<td>.22**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>-.05</td>
<td>-.13</td>
<td>.04</td>
<td>.49**</td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>6.</td>
<td>-.08</td>
<td>.35**</td>
<td>.44**</td>
<td>.16**</td>
<td>-.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>-.02</td>
<td>.30**</td>
<td>.40**</td>
<td>.17**</td>
<td>.00</td>
<td>.48**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>.05</td>
<td>.25**</td>
<td>.24**</td>
<td>.07</td>
<td>.01</td>
<td>.19**</td>
<td>.17**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>.06</td>
<td>-.08</td>
<td>.00</td>
<td>.37**</td>
<td>.33**</td>
<td>.02</td>
<td>-.04</td>
<td>-.01</td>
<td></td>
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<tr>
<td>10.</td>
<td>-.10</td>
<td>.05</td>
<td>.38**</td>
<td>.34**</td>
<td>.30**</td>
<td>.26**</td>
<td>.22**</td>
<td>.15*</td>
<td>.18**</td>
</tr>
</tbody>
</table>

Note: * = $p < .01$; ** = $p < .001$
Figure 5. The Hypothesized Difficult Conversation Model with Path Coefficients. All paths are significant at the $p < .05$ level, except for those marked with an asterisk.
<table>
<thead>
<tr>
<th>Path</th>
<th>Direct Effect $\beta$</th>
<th>Indirect Effect $\beta$ Via Attitude</th>
<th>Indirect Effect $\beta$ Via Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude $\rightarrow$ intent</td>
<td>.30**</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Susceptibility $\rightarrow$ attitude</td>
<td>.01</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Susceptibility $\rightarrow$ intent</td>
<td>--</td>
<td>.00</td>
<td>--</td>
</tr>
<tr>
<td>Severity $\rightarrow$ attitude</td>
<td>.16*</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Severity $\rightarrow$ intent</td>
<td>--</td>
<td>.05*</td>
<td>--</td>
</tr>
<tr>
<td>Benefits $\rightarrow$ attitude</td>
<td>.02</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Benefits $\rightarrow$ intent</td>
<td>--</td>
<td>.00</td>
<td>--</td>
</tr>
<tr>
<td>Barriers $\rightarrow$ attitude</td>
<td>-.13*</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Barriers $\rightarrow$ intent</td>
<td>--</td>
<td>-.04*</td>
<td>--</td>
</tr>
<tr>
<td>Response $\rightarrow$ attitude</td>
<td>.25**</td>
<td>--</td>
<td>.14*</td>
</tr>
<tr>
<td>Response $\rightarrow$ intent</td>
<td>--</td>
<td>.18*</td>
<td>.21**</td>
</tr>
<tr>
<td>Response $\rightarrow$ control</td>
<td>.47**</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Control $\rightarrow$ intent</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Control $\rightarrow$ attitude</td>
<td>.29**</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Norm $\rightarrow$ intent</td>
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<td>--</td>
<td>.02</td>
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<tr>
<td>Norm $\rightarrow$ attitude</td>
<td>--</td>
<td>--</td>
<td>.00</td>
</tr>
<tr>
<td>Norm $\rightarrow$ control</td>
<td>.08</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Cues $\rightarrow$ intent</td>
<td>.29**</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

Note: ** = $p < .001$, * = $p < .05$
**Attitude mediation.** H7 suggested that attitudes mediate the relationship between susceptibility and intent. This hypothesis was not supported. Although attitudes significantly predict intent ($\beta = .30, p < .001$), susceptibility was not directly related to attitudes ($\beta = .01, p = .84$), and the indirect effect from susceptibility to intent though attitude was also non-significant (.00, 95% CI = -.04 to .04, $p = .97$). H8 suggested that severity mediates the relationship between attitudes and intent. This hypothesis was supported. Severity has a direct relationship with attitudes ($\beta = .16, p = .002$), as well as an indirect relationship with intent through attitudes (.05, 95% CI = .01 to .09, $p = .01$).

H9, which proposed that attitudes mediate the relationship from benefits to barriers, was not supported. Benefits was not directly related to attitude ($\beta = .02, p = .72$), nor was the indirect effect of benefits on intent through attitude significant (.01, 95% CI = .00 to .08, $p = .74$). Conversely, H10, which suggested that attitudes mediate the relationship between barriers and intent, was significant. Barriers were directly related to attitudes ($\beta = -.13, p = .01$) and the indirect effect of barriers on intent though attitude was also significant (-.04, 95% CI = -.22 to -.01, $p = .02$). H13 proposed that attitudes mediate the relationship between anticipated response and intent. This hypothesis was supported. Anticipated response was directly related to attitude ($\beta = .25, p < .001$), and the indirect effect of response on intent through attitude was significant (.18, 95% CI = .12 to .31, $p = .005$).

**Perceived behavioral control mediation.** H12 suggested that perceived behavioral control mediates the relationship between anticipated response and intent. This hypothesis was supported. Anticipated response is directly related to perceived
behavioral control ($\beta = .45, p < .001$) and the indirect effect from response to intent though control was significant (.21, 95% CI = .15 to .25, p = .005). H14, which suggested that perceived behavioral control mediates the relationship between subjective norm and intent, was not supported. Subjective norm was not directly related to perceived behavioral control ($\beta = .08, p = .11$), nor was the indirect effect from norm to intent though control significant (.02, 95% CI = -.01 to .08, p = .115). H15 proposed that perceived behavioral control mediated the relationship between anticipated response and attitude. This hypothesis was supported. The indirect effect from response to attitude through control was significant (.14, 95% CI = .05 to .15, p = .007). Finally, H17 proposed a relationship from subjective norm to attitude through control. The indirect effect from norm to attitude through control was not significant (.00, 95% CI = .00 to .60, p = .11).

Despite the majority of hypotheses being supported, the model did not fit the data well. The chi-square value ($\chi^2 = 104.40, df = 30, p < .001$) indicated poor fit. Although the GFI (.94) and the RMR (.05) were acceptable, the CFI (.84) and the RMSEA (.09, 90% CI = .07 to .11) were unfavorable. Several modification steps were taken to improve the model fit.

**Model Modification.** Because the initial model fit was not ideal, I used exploratory measures to modify the hypothesized model. The modification indices did not suggest any additional paths, so the next step was to remove non-significant paths. I modified the hypothesized model iteratively by removing non-significant paths via model trimming, beginning with the most non-significant path (Kline, 2011). Path significance
was determined by the critical ratio value exceeding the absolute value of two (Kline, 2011). Each time a path was added or removed, the model was re-estimated. This resulted in three iterations. Table 6 indicates the model fit values by step.

<table>
<thead>
<tr>
<th>Step</th>
<th>$\chi^2$ (df)</th>
<th>CFI</th>
<th>RMSEA(CI)</th>
<th>RMR</th>
<th>GFI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothesized</td>
<td>104.40(30)*</td>
<td>.84</td>
<td>.09(.07; .11)</td>
<td>.05</td>
<td>.94</td>
</tr>
<tr>
<td>Without susceptibility</td>
<td>96.93(24)*</td>
<td>.83</td>
<td>.10(.08; .12)</td>
<td>.05</td>
<td>.94</td>
</tr>
<tr>
<td>Without benefits</td>
<td>46.16(18)*</td>
<td>.92</td>
<td>.07(.05; 1.00)</td>
<td>.04</td>
<td>.96</td>
</tr>
<tr>
<td>Without subjective norm</td>
<td>11.94(12)</td>
<td>1.00</td>
<td>.00(.00; .06)</td>
<td>.02</td>
<td>.99</td>
</tr>
</tbody>
</table>

Note: * = p < .001

The first path to be deleted was susceptibility to attitude. This was the least significant path. Because that path was the only one connecting susceptibility to the rest of the model, the entire variable was removed. A review of the model fit indices showed an improvement. This makes sense theoretically, as low perceived susceptibility would likely not affect attitude towards ACP. The second non-significant path was benefits to attitude. Again, because no more paths were going to or from benefits, the entire variable was removed. This also makes sense theoretically, from a cost benefits analysis, given that barriers are significant in the same model. This further improved the fit values. The third, and final, non-significant path was subjective norm to perceived behavioral control. This variable was also removed because no more paths to or from it remained. After
removing this variable, the model fit values indicated that the model was a good fit. This is justified theoretically, as the TPB’s basic tenets include a direct—not mediated relationship—from subjective norm to intent. Figure 6 illustrates the final model.

![Figure 6. The Final Difficult Communication Model with Path Coefficients](image)

The final model fit the data well. The chi-square value ($\chi^2 = 11.95$, $df = 12$, $p = .45$) was non-significant, the GFI (.99) surpassed the most stringent value of .95, the CFI (1.00) exceed the acceptable value of .95, and both the RMR (.03) and RMSEA (.00, 90% CI = .00 to .06) were well below the cut-off values of .08. Nearly all of the significant path coefficients remained static throughout the model modifications.
Anticipated response’s effect on attitude did drop by .01 ($\beta = .24$, $p < .001$), and anticipated response’s effect on control increased by .01 ($\beta = .48$, $p < .001$). Overall, the variables accounted for 25% of variance in anticipated response, 23% of the variance in attitude, and 23% of the variance in intent, per the squared multiple correlations.

**Discussion**

Like many health behaviors, ACP requires interacting with a partner in order to accomplish its goals. However, research has not yet provided a model that incorporates both individual and relational factors that are needed to predict disclosure behavior. This study attempted to fill this gap in health communication research. Specifically, the goal of this study was to develop and assess a model that predicted young adults’ intent to engage in ACP. Specific findings are discussed below, followed by implications and future directions. Limitations are discussed in chapter six.

**Severity, Cues to Action, and Susceptibility.** I predicted that greater perceived severity would affect intent to have ACP conversations through a more positive attitude (H8). This hypothesis was supported, such young adults who perceived the situation as severe were more likely to have ACP conversations because they had a more positive attitude towards the behavior. The TPB recognizes the relationship from attitude to intent; however, it does not note severity’s relationship with attitude. One possible explanation for this finding is that individuals, who are concerned about the inability to communicate their medical wishes, view ACP as potential relief from some of the negative outcomes of that situation. The mediating role of attitude may also explain why severity is frequently non-significant in HBM applications (see Carpenter, 2010).
I also hypothesized that cues to action is a significant predictor of intent (H14). This hypothesis was supported, such that the more frequent messages that young adults encounter, the more likely they are to have ACP conversations. This is consistent with the HBM principles, which posits that more messages increase an individuals’ likelihood to perform a behavior (Becker, 1974). The combined importance of severity and cues to action in predicting intent is an important finding for practitioners who want to increase ACP intent among young adults. Practitioners should create messages that will act as cues to action. The data suggest that these messages should attempt to increase young adults’ perceived severity of being unable to communicate medical treatment preferences, but not having completed ACP ahead of time. Specifically, the messages could explicitly state (a) the possibly of not receiving desired medical treatment/receiving undesired medical treatment, (b) the difficulty patients have when making ACP decisions during times or illness, and (c) the difficulty and emotional burden proxies endure when making ACP decisions without knowing the patients’ wishes. More research is needed to determine which of the three consequences young adults find the most troublesome.

I also predicted that attitude mediates the relationship from susceptibility to intent (H7). This hypothesis was not supported. This indicates that young adults’ perception of susceptibility does not affect their attitude about ACP. This could be because young adults do not feel susceptible, and therefore it does not affect their attitude towards ACP. Alternatively, it is possible that susceptibility needs a direct path to intent, not a mediated one through attitude. This explanation is especially likely given (a) the direct relationship was significant in Study 1 and (b) susceptibility and intent are correlated in the present
study, where as susceptibility and attitude are not correlated. Future research should explore the significance of susceptibility with a direct path to intent.

**Anticipated Response.** I hypothesized that anticipated response affects intent through attitude (H13). This hypothesis was supported, such that the more positive response an individual anticipates, the more likely they are to have ACP conversations because of the more favorable attitude they have towards ACP. This finding is consistent with research that has found individuals to perceive potential health conversations as favorable if they believe the experience will be positive (Greene et al., 2012). As with perceived severity, this finding has theoretical importance for behavioral and disclosure intent research because it points to a previously unknown relationship between anticipated response, attitude, and intent.

I also predicted that anticipated response also affects intent through perceived behavioral control (H12). This hypothesis was supported, such that young adults who expect a positive reaction from their partner are more likely to have ACP conversations because they feel more capable. This path is consistent with DD-MM research whereby anticipated response increases the likelihood of disclosure through greater efficacy beliefs (Greene et al., 2012).

Finally, I predicted that the relationship between anticipated response and attitude is mediated by perceived behavioral control (H15). This prediction was supported, such that young adults who expect a more positive response have a more positive attitude towards ACP because they feel more confident in the behavior. This finding is logical, as individuals often have a more positive attitude about behaviors that they view as easy.
and/or are confident in (Mou & Lin, 2015). The finding that perceived behavioral control is related to attitude on more than just a correlation level is supported by research on podcast adoption (Mou & Lin, 2015), but is otherwise a relatively new development in TPB research.

From these three findings it is clear that anticipated response plays an important role in ACP intent. Not only does anticipated response affect intent indirectly through both attitude and perceived behavioral control, but it also affects attitude indirectly by increasing perceived behavioral control. For those hoping to inspire young adults to have ACP conversations, this finding illustrates the importance of addressing anticipated response. This could be done in parent-child interactions about ACP, for example. The data suggest that because young adults are concerned about their parents reacting negatively, it may be beneficial for parents to initiate the conversations about ACP. One way in which they could do this is by mentioning that they would be open to a discussion about life-sustaining treatment preferences. This would reduce young adults’ fear of upsetting their parents by talking about ACP and improve (a) their attitude towards the behavior, (b) their perceived behavioral control of the behavior, and (c) their intent to engage in the behavior.

**Barriers and Benefits.** In addition to severity and anticipated response, I also predicted that attitude mediates the relationship between barriers and intent (H10). This hypothesis was supported. Young adults who perceive fewer barriers are more likely to have ACP conversations because they have a more positive attitude about ACP. This finding is in line with expectancy value theory, which asserts that the more positive—and
fewer negative—expectations individuals have about a behavior, the more positive attitude individuals will have towards the behavior (Fishbein, 1967).

This finding is especially interesting in comparison with the lack of support for my prediction that attitude mediates the relationship between benefits and intent (H9). There are three possible explanations for why barriers, but not benefits, were significant. One explanation is that, like the elderly population, the barriers to ACP are so great that they overcome any possible benefits of the behavior (Hamel et al., 2012). Another possible explanation is that the benefits in the measure are not relevant to young adults, and therefore the benefits did not have an effect on young adults’ attitude towards ACP. The third possible explanation is that benefits was misplaced in the model. It is possible that benefits would be significant with a direct path to intent—although it is unclear as to why a direct relationship is more appropriate than a mediated relationship for this construct. The latter explanation seems more likely, as benefits was a significant predictor in Study 1.

These findings have important implications for practitioners who wish to increase ACP intent among young adults. The data suggest that physicians and campaign specialists might specifically address barriers to ACP in their efforts to increase intent. For example, physicians might explain to patients that having ACP will not decrease quality of care, which is a concern among older adults (Ko, 2008). However, future research should explore barriers to ACP more fully because it is not clear which barriers are relevant for the young adult population and which are not relevant. As suggested by the data, it is not clear if emphasizing benefits would be an effective strategy to increase
intent. Future research should explore the significance of benefits if it is placed elsewhere in the model.

**Subjective Norm.** My final two predictions were that perceived behavioral control mediates the relationship between subjective norms and intent (H14) and between subjective norms and attitude (H17). The data did not support either prediction. This indicates that young adults’ perception of what their peers are doing does not affect their efficacy beliefs of or attitude towards ACP. This non-significant relationship could be because young adults do not see their peers engaging in ACP and it therefore has no affect on their feelings about the behavior. Alternatively, subjective norm may be better suited as a direct predictor of intent, per the TPB. Future research should explore whether subjective norm belongs elsewhere in the model, as this has important implications for practitioners.

**Theoretical Implications and Future Research.** This study has two important theoretical implications for behavioral change research. First, this study adds to the explanatory power of the attitude and perceived behavioral control TPB constructs. The data suggest that the HBM and DD-MM variables may be a valuable addition to the solid theoretical foundation of the TPB. Specifically, perceived severity, barriers, and anticipated response are constructs that predict attitude and/or perceived behavioral control. To include these variables in other TPB applications might reveal more specific information about what motivates individuals to act. However, it is not clear if these same relationships are generalizable to contexts other than ACP, or with age groups other than young adults. Future research should explore this further.
The second important theoretical implication is the inclusion of both relational and individual variables in models that attempt to predict communicative behavior. Although the subjective norm construct of the TPB refers to other people, it is still mainly an individual-focused construct because it is centered on individuals’ common concern, “Am I like other people?” This is in stark contrast to relational-focused constructs, which are entirely related to interactions with other people. For example, the core question at the heart of anticipated response is, “Is she going to react badly? The results of this study suggest that ACP research that focuses on conversations—as opposed to ADs—should begin adding relational variables to their studies.

**Practical Implications and Future Research.** This study has important practical implications. Generally, individuals are reluctant to engage in ACP (Kapp, 2000). This is commonly attributed to the fact that ACP is considered a difficult conversation (Keating et al., 2012). The difficulty stems from the uncertainty and emotion that surround ACP (Keating et al., 2012). However, ACP conversations are important to have because they decrease familial burden and stressful decision-making (Hines, 2011). Therefore, it is important to identify what contributes to individuals’ reluctance so that practitioners can overcome these obstacles. The two biggest obstacles that this study revealed were perceived anticipated response and perceived barriers. Parents and physicians could overcome these two obstacles separately, with parents addressing young adults’ concern about anticipated response at home, and with physicians addressing the barriers during wellness checks. Parents could address the anticipated response issue by approaching their children and letting them know they are open to a discussion about this topic. These
findings may also be relevant to the middle and older adult population. More research is needed to fully understand both the individual and relational factors that affect intent to engage in ACP among all age groups.

Physicians could negate the barriers by distributing pamphlets and then verbally reinforcing the information stated in the text. Because the physician is available to answer questions about information contained in the pamphlet, this intervention would then be both interactive—as opposed to didactic—and multimedia. On the whole, individuals respond more favorably to interactive than to didactic interventions, and to multimedia interventions that include both written and verbal information (Durbin et al., 2010; Jezewski, Meeker, Sessanna & Finnell, 2007). An example of a barrier that could be de-escalated in this manner is individuals’ concern that their treatment preferences will change over time. Through the pamphlet and interpersonal discussion, physicians could inform patients that they can notify their family and physicians of their change in treatment preferences at any time—and that this change will go into effect immediately. Other barriers, such as “It’s hard to know now what I’d want later,” require more research until specific suggestions can be made. As mentioned earlier, practitioners should first know where the uncertainty stems from before attempting to change it (Babrow, 2001).

**Conclusion.** In sum, six of the 12 hypothesized paths were supported and the revised model fit the data well. Path coefficients in this model suggest that, in the context of ACP conversations among young adults, intent can be predicted by a combination of
variables from the HBM, TPB, and DD-MM. These findings provide support for the inclusion of relational factors in a model for predicting ACP intent.
Chapter Six: Discussion

The purpose of this dissertation was to build and assess a model that predicts young adults’ intent to engage in ACP conversations. This dissertation advances health communication research in at least two ways. First, it identified factors that affect young adults’ intent to have ACP conversations. The second way in which this dissertation advances health communication is by building a behavioral model that includes both relational and individual elements. Each contribution is discussed in more detail below, followed by a discussion of the limitations.

Young Adults and ACP

One goal of this dissertation was to identify factors that predict ACP intent because, despite ACP’s importance to all individuals aged 18 and older, it is frequently only promoted among the elderly and terminally ill. ACP is important for all adults because it can help preserve autonomy, and engaging in ACP before becoming ill may make the medical treatment decision-making process easier for patients and their family (Rauscher & Nacinovich, 2012). However, many people are reluctant to have ACP conversations, most notably because the uncertainty and emotion that surround death make ACP a difficult conversation (Keating et al., 2013). Therefore, it is important to understand what factors affect intent so that practitioners can shape their messages to be more effective in increasing ACP behavior. The results of this dissertation, when compared with the current ACP literature on older adults, suggest that there are both similarities and differences in the factors that affect intent across generations.
Similarities. One similarity between the results of my studies on young adults and the current research on older adults was the reluctance to engage in ACP. Just as older adults often do not want to have ACP conversations (Keating et al., 2013), the results of my focus groups suggest that young adults are equally as reluctant. This was also partially supported by the low mean score of intent (~2.50) across both Study 1 and Study 2. The lack of intent to have ACP conversations could be due to the common perception that ACP is a difficult topic (Keating et al., 2013). Alternatively, there could be a multi-generational lack of awareness about the benefits of ACP. This finding underscores the need for future research and practitioner efforts to continue their focus on ACP engagement for all adults.

Also consistent with previous research on older adults (Bowman & Singer, 2001) was the finding from the focus groups that suggested that young adults would rather leave the medical decision-making to their family members. One possible reason for this could be an anticipated negative response. This finding could also be due to indecisiveness as a result of the weightiness of the issue or a lack of information. The latter explanation is supported by comments in my focus groups, where the majority opinion was that the participants would not have ACP conversations because they were not sure about their life-sustaining treatment preferences.

On a related note, the mean scores for self-efficacy in Study 1 (3.56) and for perceived behavioral control in Study 2 (2.56) are notably different. This could be due to sampling error, or it could be that, contrary to Ajzen’s (2002) suggestion, these constructs are measuring different beliefs. A comparative look at the face validity across the two
measures suggests that although both measures refer to confidence in having ACP conversations, only the perceived behavioral control measure refers to ease and possibility. Therefore, it could be the addition of these two items that is pulling the mean downward. If such is the case, it is important to know what is causing young adults to have a poor outlook on the ease and possibility of ACP. Addressing these obstacles could result in an increase in ACP intent among young adults. This finding also suggests that future research should compare these constructs and determine which is more conceptually important to ACP research. In other words, should we use self-efficacy or perceived behavioral control in future ACP studies?

Another commonality across the young adults in the present study and older adults in previous ACP is the concept of anticipated response. Older adults often do not engage in ACP for fear of upsetting family members (Crain, 1996). Concern for parent’s reaction was discussed in my focus groups and was also significantly related to intent in Study 2. This finding has important implications: family members should begin the dialogue by expressing to each other that they are open to talking about ACP. This “incremental disclosure” approach allows family members to “test the waters” in an effort to see if the other will be receptive to the conversation (Greene et al., 2012, p. 366). For young adults, it may be best for the parents to bring up the topic first, as they are often viewed as the authority figures and have the ability to set communication climate (McLeod & Chaffee, 1972).

The final similarity across young adults in this study and older adults in previous studies is the presence of low perceived susceptibility. This was a sentiment shared
among my focus groups; many groups stated that they have not had, and did not plan to have, ACP conversations because they did not expect to need them in the near future. The low mean scores of the measure in Study 1 (2.15) and Study 2 (2.16) also illustrated the presence of low perceived susceptibility. This suggests that both older (Ko & Berkman, 2003) and young adults have low perceived susceptibility to being in situations that would make advance care plans go into effect. However, perceived susceptibility was not significant in the final model. As suggested earlier, one explanation for this finding is that susceptibility affects intent directly, not indirectly through attitude. For example, although some young adults may perceive themselves to be at-risk for needing ACP, their attitude may not be affected because the negatives (e.g., barriers) outweigh the positives. Still, they may be driven to have ACP conversations because they feel susceptible. In other words, it may still feel necessary to them, even if they have an overall unfavorable evaluation of the behavior. This explanation is supported by the results of Study 1, which showed a significant and direct relationship between susceptibility and intent. However, an additional, equally supported explanation is that perceived susceptibility does not affect attitude towards ACP because the perceived susceptibility is so low that they are indifferent to the behavior. The low mean scores for susceptibility support this explanation. Future research is needed to determine which explanation holds more weight among the young adult population.

**Differences.** The results of my studies, when compared with previous ACP research on older adults, suggests that although there are similarities in factors affecting intention across generations, there also appears to be several differences. First, in Study
2, subjective norm was not found to significantly affect young adults’ attitude towards ACP. This is inconsistent with research that has shown that family, friends, and health care providers influence older adults’ assessment of ADs (Tremethick et al., 2011). One explanation for this could be because, unlike older adults, young adults’ friends, family, and health care providers are not commonly discussing ACP, nor are these individuals likely encouraging them to have ACP conversations. This is supported subjective norm’s low mean score (2.47). Alternatively this could have been because subjective norm was misplaced in the model. A more appropriate place for this construct may be with a direct path to intent, as the TPB suggests. If subjective norms scores among young adults were high, it would be logical that norms positively affect attitude. However, it is illogical to suggest that that the lack of encouragement by role models and engagement in the activity by peers would lead to a negative attitude towards the behavior—it seems more likely that low subjective norms would have no effect on attitude. Conversely, as the TPB suggests, it is logical that that the lack of encouragement by role models and engagement in the activity by peers would have a negative affect on intent. Future research is needed to determine if subjective norm has a role in predicting intent.

Another difference between the young adults in my studies and the older adults in previous ACP research is the type of barriers that are prominent for each age group. Barriers among older adults include the fear of physicians acting independently of their desires and the fear that medical treatment preferences will change over time (Ditto et al., 2006; Ko & Berkman, 2003). These are different from some of the barriers that emerged during the focus groups (e.g., lack of awareness or knowledge about ACP).
differences suggest that, on the whole, barriers for the young adult population fall within the pre-contemplation stage of ACP, whereas barriers for the elderly population fall within the contemplation stage. This is likely because the non-elderly population has not been encouraged to seriously consider engaging in ACP, and because concerns about health and death are often more salient with age. This finding is important for practitioners who wish to change ACP intent by addressing barriers that prevent individuals from acting. As mentioned earlier, physicians could address the barriers via verbally and in writing through educational interventions that occur during wellness checks.

This type of intervention would be especially effective for two reasons. First, the presence of the physician and his or her ability to answer questions makes this intervention interactive, as opposed to didactic. Second, the combination of both verbal and written messages makes this a multimedia intervention. Both interactive and multimedia interventions are more effective at changing behavior than interventions that are didactic and occur through only one medium (Durbin et al., 2010; Jezewski et al., 2007). An example of a barrier that the physician could negate is individuals’ concern that their treatment preferences will change over time. As part of information presented in the pamphlet and reinforced verbally, physicians could inform patients that they can notify their family and physicians of their change in treatment preferences at any time. Other barriers, such as indecisiveness and the desire to divert onus, require more research until specific suggestions can be made. As mentioned earlier, practitioners should first know where the uncertainty stems from before attempting to change it (Babrow, 2001).
Additionally, although the focus groups results suggested the saliency of certain barriers, this information has not been verified statistically. Future research should explore this in a quantitative manner by analyzing the barriers that are relevant for each group. This could be done in three ways. First, the saliency of each barrier could be assessed by determine the mean score, with a greater mean equaling more saliency. Second, examining its correlations with intent, with a greater correlation indicating more saliency, could assess the saliency of each barrier. Finally, conducting a regression in with each barrier is entered individually could assess the saliency of each barrier.

Related, it was interesting to find that in Study 1, benefits, but not barriers, significantly predicted intent. This differed from findings on older adults where barriers were significant and benefits were not (Hamel et al., 2002). This relationship could be a result of young adults’ potential fear of death, whereby benefits to ACP may offer them relief from their fear (Cicerelli, 2002). Another explanation is that barriers could be unimportant to young adults who have not yet thought through the steps it takes to engage in ACP, and thus are less aware and concerned about the barriers. However, in Study 2, it was barriers, not benefits that were significant. The only difference across these two studies was the dependent variable change from intent to attitude. Consequently, future research may find that benefits, with an unmediated path to intent, may be significant in predicting ACP engagement among young adults. This could be because the barriers outweigh the benefits in individuals’ assessment of ACP, resulting in an unfavorable attitude towards the behavior. Still, young adults may ignore their
unfavorable view of ACP and have the conversation regardless because they recognize its benefits.

The final difference between the generations is perceived severity. Older adults have low perceptions of severity, in part because they know that they have someone to rely on in case they are unable to communicate (Ko, 2008). The results of this dissertation suggest the opposite for young adults. Severity had a mean score of about 4.00 for both Study 1 and Study 2. This suggests that young adults find needing, and not having, ACP to be a severe situation.

**The Difficult Conversation Model and ACP**

The second way in which this dissertation contributed to health communication research is through the development of a model that includes both individual- and relational-focused elements. Prior to this dissertation, the literature pointed to two types of models that predicted intent: those based on behavioral change theories with an emphasis on the individual, and disclosure models with an emphasis on interpersonal interactions. The DD-MM does have some overlap—it includes disclosure efficacy, for example—on the whole, however, it does not include a number of other important individual constructs such as those in the TPB and HBM. The results of this dissertation suggest that ACP research that focuses on conversations should begin adding relational variables to their studies. This may bring them greater success in developing interventions aimed at increasing ACP intent. It could, of course, be argued that the present model is primarily individual-focused and more similar to behavioral change models because there is only one relational variable. However, I recognize that future
research is needed to determine other relational variables that may be important for predicting intent. It is the approach I have taken to developing this model—one in which both individual and relational variable are equal players in predicting communication about health—that differentiates my dissertation from belonging distinctly to either of the two model types. Further, the relational variable that I included—anticipated response—was a central antecedent to much of the other variables so it could also be argued that quality of effect on variables is more important than the quantity of relational variables present.

The heuristic value of this model can be seen in its relevance for physician-patient communication. The model can be translated into a template for physicians to use when engaging in clinical conversation with their patients. This template would address three things: the barriers to ACP, the anticipated response that patients expect from their parents, and perceived severity. Specifically, the template negate young adults’ perceived barriers to ACP, assure young adults that an adult in their life would react favorably to an ACP conversations, and increase young adults’ perceptions of severity. Addressing these three things would increase young adults’ perceived behavioral control and attitude towards ACP engagement, which, in turn, would increase ACP intent among young adults. Medical students can be trained to use this scripted algorithm.

However, this recommendation for praxis makes an assumption about young adults’ perceptions of susceptibility and difficulty in regard to ACP conversations. It is possible that some young adults do not perceive ACP as a difficult conversation because they do not perceive themselves as susceptible to being in a situation that would require
ACP plans to go into effect. This, of course, begs several questions. First, given young adults’ feelings of invincibility, are middle-aged adults a better target audience? Research suggests that behavioral change is easier to encourage among young adults than middle-aged and older adults (Ridder & Wit, 2006). However, it is possible that a life cycle adjusted model may be needed to address ACP behavioral change in middle-aged and older adults who did not adopt the behavior as a young adult. Second, does a separate model need to be developed for young adults who do not feel susceptible? As I discussed in chapter five, I expect future research to show susceptibility to be an important factor in predicting ACP intent among young adults. If this is the case, an additional model for young adults with low susceptibility is not needed—susceptibility would become one of the elements addressed in the physician algorithm that I detailed above. However, if research shows that susceptibility does not belong in the DCM, a separate model may be needed.

Another potential issue related to my recommendations for praxis is the ethical dilemmas that pervade every behavioral change intervention. First, my suggestion presents the distraction dilemma (Guttman, 2000). Physicians and patients have very limited time together and that time may be better spent discussing topics that are more immediately relevant to young adults than ACP (e.g., mental and sexual health issues). A second dilemma that my suggestion presents is the medicalization dilemma (Guttmann, 2000). Incorporating ACP into wellness checks may lead to a dependence on medical institutions and deemphasize cultural and spiritual health (Guttmann, 2000).
The Difficult Conversation Model and Other Contexts

Because the DCM is theoretically driven, its orientation towards communication as both individual- and relationship-dependent may make it translatable to other types of conversations in health contexts. This model was titled the DCM, or difficult communication model, because it was meant to embody the core factors at play in individuals’ decisions to engage in a variety of uncertain and uncomfortable discussions. These contexts can span from mundane, everyday conversations to conversations that are only prompted in specific situations.

One type of common—yet uncertain and uncomfortable—discussion that could be studied using the DCM is weight management communication. Parents are sometimes faced with the decision to address their children’s weight issues (Dailey, Thompson, & Romo, 2014). This is often an uncertain and uncomfortable conversation because parents must promote good health while also ensuring that their child does not perceive this conversation as an attack on their physical appearance (Dailey et al., 2014). For example, a single communicative act that may be predicted by the DCM is a parent’s decision to point out the amount of food that a child has eaten in any given day. The DCM, therefore, would be applicable to weight management conversations because it may predict parents’ intent to address weight issues with their children.

In addition to explaining intent to have common conversations, the DCM may also explain intent to have the uncertain and uncomfortable conversations that we are not presented with on a daily basis. For example, the DCM may also predict individuals’ intent to talk with a partner about safe sex. In the case of safe sex conversations,
individuals may evaluate the barriers (e.g., not knowing how to phrase the discussion) and, consequently, form a negative attitude towards safe sex talks. Their attitude may also be greatly affected by (a) the anticipated response of their partner and by (b) the perceived severity of consequences that come from not having safe sex talks. The anticipated response of their partner may also affect their perceived behavioral control, making them feel less confident in having the conversation if the anticipated response is negative. Their confidence, or lack thereof, may also positively affect their attitude towards safe sex talks. Finally, the increase in messages about safe sex conversations, their attitude, and their perceived behavioral control may predict their intent to talk with their partner about safe sex. Future research should explore DCM applications in other communication contexts.

**Limitations**

The first limitation of this dissertation is the convenience sample. As previously mentioned, the samples for Study 1 and Study 2 were primarily Caucasian females. Although AD research on elderly adults suggests that ethnicity and race do not play a role in intent to complete an AD, females are more likely to execute ADs (Morrison, 1998). Additionally, all participants in these studies were college students. Education is also known to positively affect intent (Morrison, 1998). Therefore, individuals with less education may have different factors that predict intent. The DCM also cannot be extrapolated to middle-aged and elderly adults. However, it is possible that relational factors are also important in a model that predicts middle-aged and older adults’ intent to have ACP conversations. More research is needed to explore the differences and
similarities between models developed for predicting ACP intent among a variety of ages and educational backgrounds.

The second limitation relates to measures. Although many of the measures in this study have been used in at least one study outside this dissertation, several of them were created for this dissertation. Ideally, all measures would be tested in a separate study. This decreases the chances of error due to reliability and validity issues. However, several steps were taken to decrease such error. First, I assessed the items for face validity. Next, I checked the items for internal consistency via approximately equal means, standard deviations, and inter-item correlations. I then conducted EFAs to verify that the unidimensional scales were only loading onto one factor. Finally, I calculated Cronbach’s alpha to determine the reliability. Items that failed one or more of the aforementioned tests were marked for removal or removed entirely. Future research should continue to verify the reliability and validity of these measures.

The third limitation pertains to the relational closeness variable. Individuals who feel more comfortable with each other are more likely to engage in difficult conversations because they are comforted when they experience negative emotions (Keating et al., 2013). The design of Study 1 and Study 2 asked individuals to choose someone they would be most likely to speak with about ACP. This answer then populated the scale that measured relational closeness. Because of this design, there was very little variance in relational closeness. It was excluded from Study 2 for this reason. This could have also accounted for its lack of significance in Study 1. However, DD-MM research and the results of my focus groups suggest that relational closeness could be an important factor
in individuals’ decision to disclose information such as medical treatment wishes. Future research should explore how to assess relational closeness in a way that shows more variance. One possible solution is adjusting the scale of the variable, to account for a wider range of answers. Alternatively, a proxy, such as openness, could be used to measure closeness. Openness is often a characteristic of dyads that have high relational closeness (Koerner & Fitzpatrick, 2002).

The fifth limitation is the exclusion of variables pertaining to gender, race, culture, religion, education, and age. Although some of these variables could not be included because of the sample demographics, other variables were excluded for parsimony. However, it is possible that these demographic characteristics act like moderators; in that they increase or decrease the effect that one variable has on another. For example, gender may moderate the relationship between severity and intent. Future research should explore the influence of these demographics on ACP intent among young adults.

**Conclusion**

In conclusion, this dissertation advanced health communication research by identifying factors that affect young adults’ intent to have ACP conversations and by developing a communicative behavior model that incorporates both relational and individual factors. The TPB, HBM, and DD-MM are important models and each provides a snapshot of the factors that affect intent. Taken together, however, they forge an even clearer picture of what an individual considers when deciding to have ACP conversations.
References


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Appendix A: Demographic Questionnaire

Please circle the answers that best describes you.

Age:
18  19  20  21  22  Other______

Year in school:
Freshman  Sophomore  Junior  Senior  Other______

Sex/Gender:
Male  Female  Transsexual

Race/Ethnicity:
Caucasian/White  African American  Asian/Pacific Islander  Native Hawaiian  Hispanic/Latino/a  Multi-racial/Multi-ethnic  Middle Eastern  Other______

Marital status:
Single  Married  Widowed  Divorced

Parental status:
I do have kids.  I do not have kids.

How would you rate your physical health?
Poor  Fair  Good  Very Good  Excellent

Do you have any of the following advance directives? (circle all that apply)
Living Will Healthcare proxy/medical power of attorney
Appendix B: Focus Group Guide

I. GREET AND THANK PARTICIPANTS; INTRODUCE SELF & TODAY’S GOALS (2 min.)
Welcome everyone! Thank you for coming in today. My name is Leah Cole and I am a doctoral student in the School of Communication Studies.

Today we are going to hold a group discussion about advance care planning. Advance care planning is the act of telling your family what kind of life-sustaining treatment you would want if you were to become very ill or suffered serious injury and could not communicate your wishes or make these decisions yourself. Life-sustaining treatment is things like CPR (Cardiopulmonary Resuscitation), ventilators/ respirators (for help breathing), and feeding tubes/ intravenous fluids (for nutrition and hydration).

I am interested in hearing what your thoughts and opinions are about this topic. My only role is to guide the discussion and make sure everyone has a chance to participate.

There are no right or wrong answers in anything we talk about today. Please just share your honest opinions. It is also okay to disagree with each other. Everyone’s opinion matters.

With your permission, I will audio record this conversation. The recordings will help me accurately remember what was said, and will also allow me to take less notes during our conversation. The recordings will be destroyed no later than August 29, 2014 and only I and my advisor Dr. Amy Chadwick will have access to them. The information we talk about today will help me write my dissertation and may also be presented at a conference or published in a journal. However, I will never use your real name when referring to what was said here.

Also, please be respectful of each other by not sharing what anyone says today with people outside of the group. And when someone is talking, please wait until they are finished before sharing your thoughts.

This discussion will take approximately one hour. If you feel uncomfortable or need to leave for any reason you may do so without fear of penalty. If you need me to repeat, rephrase or explain anything, please just ask.

II. INFORMED CONSENT (5 min.)
I am passing out a form that is called informed consent. This means that you are aware of what the research is about and that you are agreeing to participate. [Verbally discuss the form, ask for questions, collect the signed form.]

Does anyone have any questions before we begin?
III. DEMOGRAPHICS AND COURSE CREDIT (5 min.)
I am passing out a brief questionnaire. This information will be used to describe the people that participated in the focus groups. Your answers to this questionnaire will not be connected to what you say during the focus group. I am also passing out a form to make sure you get course credit for participating in the study. Please take a moment to fill these out. [Collect questionnaire and course credit forms and place them in separate envelopes.]

IV. INTRODUCTIONS (2 min.)
Let’s start our discussion by getting to know each other. Let’s briefly go around the room and say our names, our majors, and something fun we are doing this summer besides taking classes.

I’ll start. As I noted earlier, my name is Leah and I am doctoral student in Health Communication. This summer I got married and next month I am going on a vacation with my family to Colonial Williamsburg in Virginia.

V. ADVANCE CARE PLANNING DISCUSSION (45 min.)
To recap, advance care planning is the act of telling your family, friends or physician what kind of life-sustaining treatment you would want if you were to become very ill or suffered serious injury and could not communicate your wishes or make these decisions yourself. Life-sustaining treatment are things like CPR (Cardiopulmonary Resuscitation), ventilators/respirators (for help breathing), and feeding tubes/intravenous fluids (for nutrition and hydration).

1. What have you heard about advance care planning? This topic could have a number of names including advance directives, living wills, healthcare proxies, medical power of attorneys, or end-of-life conversations.
   a. Where have you heard it?

2. How much time have you spent thinking about whether you would want life-sustaining treatment?

3. How willing are you to talk with someone about your wishes or plans? Why?
   a. Who are you most likely to have these conversations with? Why?
   b. Least likely? Why?
   c. How easy or difficult would these conversations be? Why?

4. How confident are you in your ability to have these conversations?
   a. How confident are you in your ability to initiate, or bring up the conversation?

5. What do you think are some benefits to advance care planning? [List on sheet of paper. Have participant place dots next to advantages that are most and least
important to them.]
   a. Why are some of these more important to you than others?

6. How important is it for someone your age to have these types of conversations? Why?

7. How concerned are you, at this point in your life, with having conversations and making your healthcare preferences known? Why?

8. What do you think would prevent you, or someone your age, from having these types of conversations? [List on sheet of paper. Have participant place dots next to barriers that are most and least preventive.]
   a. Why are some of these bigger obstacles than others?

9. How serious a concern is it to be in a situation where you could not communicate your treatment wishes, but you did not do any advance care planning ahead of time?
   a. What do you think will happen?
   b. Who would it impact the most?
   c. How might it impact you?
   d. How does that make you feel? Why?
   e. How effective do you think advance care planning conversations would be in preventing negative outcomes in that situation?

10. What might motivate you to complete an advance directive form?

11. What might motivate you to have conversations about your healthcare wishes?

12. What help would you need to have these conversations?

13. When and where would you like to receive information about advance directives?

VI. CONCLUSION (2 min.)
I have asked all of my questions. Does anyone have any comments they would like to add to the discussion?

I want to thank everyone for being here today. You have given me a lot of good information to think about. I am passing out a description of the purpose of today’s focus group. [Distribute and briefly discuss informational debrief.]
Appendix C: The First Step in Model Modification
Without Susceptibility

Note: All paths are significant at the $p < .05$ level, except for those marked with an asterisk.
Note: All paths are significant at the $p < .05$ level, except for those marked with an asterisk.
Appendix E: Survey

[Identification of Referent]- Study 1 & 2

If you were to tell someone about your life-sustaining treatment preferences, which of the following people would you be most likely to talk to?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
<th>Female Guardian</th>
<th>Male Guardian</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
[Self-efficacy] Study 1

Please indicate how much you disagree or agree with each statement below.

<table>
<thead>
<tr>
<th>Statement</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>I feel confident in my ability to have advance care planning conversations with my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I would be successful in having advance care planning conversations with my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am not able to successfully have advance care planning conversations with my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
[Perceived Severity] Study 1 & 2

On the following scale, where one equals “no big deal” and five equals “a very serious situation,” please rate your answer to the following statement.

**How serious of a situation would it be if you were seriously ill or injured and unable to communicate your medical treatment wishes but had not done any advance care planning ahead of time?**

<table>
<thead>
<tr>
<th>Not a serious situation at all</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>A very serious situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not a big deal at all</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>A very big deal</td>
</tr>
<tr>
<td>Minor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>Major</td>
</tr>
<tr>
<td>Unimportant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>Important</td>
</tr>
<tr>
<td>Insignificant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>Significant</td>
</tr>
<tr>
<td>Irrelevant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>Relevant</td>
</tr>
</tbody>
</table>
### [Perceived Susceptibility] Study 1

Please indicate how much you disagree or agree with each statement below.

<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><strong>At this point in my life</strong> it is likely that I will personally experience a situation where I won’t be able to communicate my medical treatment wishes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>At this point in my life</strong> I am very much at risk for personally experiencing a situation where I won’t be able to communicate my medical treatment wishes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>At this point in my life</strong> I am very susceptible to the negative effects of being unable to communicate my medical treatment wishes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>At this point in my life</strong> I am very likely to experience the negative effects of being unable to communicate my medical treatment wishes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>At this point in my life</strong> I do not expect to experience personally the negative effects of being unable to communicate my medical treatment wishes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
**[Barriers] Study 1 & 2**

Please indicate how much you disagree or agree with each statement below.

<table>
<thead>
<tr>
<th>It is difficult for me to make advance care plans because…</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>It is hard for me to know now what I might want when I am faced with the threat of death.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I don’t think about my own death very much.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have many other more important concerns.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The doctors will not follow my wishes if I become seriously ill or injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I will probably change my plans if I become seriously ill or injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have a long life ahead of me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My doctor will not support me making advance care plans.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My family will not support me making advance care plans.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My family will not follow my wishes if I become seriously ill or injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am concerned that the doctors will give me poor medical care if I have advance care plans in place.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My religious or spiritual beliefs do not permit advance care planning.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>There is no one in my life that I feel I can talk to</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>-----------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>I do not have access to advance directive forms.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am afraid of upsetting my family by talking about a potential situation where I am seriously ill or injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I trust my parents to make the best choice if I was ever in that situation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was not aware of it before today.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I do not have enough information about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am embarrassed to talk about a potential situation where I am seriously ill or injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Please indicate how much you disagree or agree with each statement below.

<table>
<thead>
<tr>
<th>Statement</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>Making advance care plans will benefit my family by making it easier for them if I become seriously ill or injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Making advance care plans will help those around me to know what my wishes are for medical treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My “last days” will be more comfortable for me if I make advance care plans.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Making advance care plans will give my doctors guidelines on how to care for me if I become seriously ill or injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Making advance care plans will let my doctors know how I want to be cared for if I become seriously ill or injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Making advance care plans will prevent me from having to pay for medical treatment I do not want.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Making advance care plans would help me get the medical treatment I want for myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Making advance care plans would help me avoid medical treatment I do not want.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
**[Communicative Intent] Study 1**

Please indicate how much you disagree or agree with each statement below.

<table>
<thead>
<tr>
<th>In the next 30 days,</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>I am likely to talk with a family member about my wishes for life sustaining treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am likely to initiate a conversation with a family member about my wishes for life sustaining treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
[Relational Closeness] Study 1 & 2

Please use the following scale, where 1 = Not at all and 5 = Very, to respond to the questions.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>How openly do you talk with your parents?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How comfortable do you feel admitting fears and doubts to your parents?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How interested are your parents in talking when you want to talk?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How often do your parents express affection or liking you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How well do your parents know what you really like?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How close do you feel to your parents?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How confident are you that your parents would help you if you had a problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>If you needed money, how comfortable would you be in asking your parents for it?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How interested are your parents in the things you do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
[Demographics] Study 1 & 2

Please indicate your age: ______

Please choose your year in school:

<table>
<thead>
<tr>
<th>Freshman</th>
<th>Sophomore</th>
<th>Junior</th>
<th>Senior</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Please choose the sex that best describes you:

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
<th>Transgender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Please choose the race or ethnicity that best describes you:

<table>
<thead>
<tr>
<th>Caucasian / White</th>
<th>African American / Black</th>
<th>Asian/ Pacific Islander</th>
<th>Native Hawaiian or Alaskan</th>
<th>Hispanic / Latino/a</th>
<th>Multi-racial/ Multi-ethnic</th>
<th>Middle Eastern/ Arab American</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
</tbody>
</table>

Please choose the marital status that best describes you:

<table>
<thead>
<tr>
<th>Single/ Never married</th>
<th>Married</th>
<th>Divorced/Separated</th>
<th>Widowed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Please choose the parental status that best describes you:

<table>
<thead>
<tr>
<th>I do have a child/children</th>
<th>I do not have a child/children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
In general, how would you rate your physical health?

<table>
<thead>
<tr>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
**[Perceived Susceptibility] Study 2**

Please indicate how much you disagree or agree with each statement below.

<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><strong>At this point in my life it is likely that I will personally experience a situation where I won’t be able to communicate my medical treatment wishes.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>At this point in my life I am very much at risk for personally experiencing a situation where I won’t be able to communicate my medical treatment wishes.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>At this point in my life I am very susceptible to the negative effects of being unable to communicate my medical treatment wishes.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>At this point in my life I am very likely to experience the negative effects of being unable to communicate my medical treatment wishes.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
### [Communicative Intent] Study 2

Please indicate how much you disagree or agree with each statement below.

<table>
<thead>
<tr>
<th>Statement</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>I intend to talk with my [referent] about my life-sustaining treatment preferences in the next 30 days.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am likely to have an advance care planning conversation with my [referent] in the next 30 days.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I will make an effort to have an advance care planning conversation with my [referent] in the next 30 days.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
**[Perceived Behavioral Control] Study 2**

Please indicate how much you agree or disagree with each statement.

<table>
<thead>
<tr>
<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><strong>Having advance care planning conversations with my (referent) in the next 30 days is extremely easy.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>I am confident that if I wanted to, I could have an advance care planning conversation with my (referent) in the next 30 days.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Having advance care planning conversations with my (referent) in the next 30 days is possible for me.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>If I wanted to, I could successfully having an advance care planning conversation with my (referent) in the next 30 days.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
### [Cues to Action] Study 2

Please indicate how much you agree or disagree with each statement.

<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>I frequently encounter messages about advance care planning in my daily life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I often hear about advance care planning from the people around me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Advance care planning is something I frequently hear about.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
**[Attitude] Study 2**

My having an advance care planning conversation in the next 30 days would be:

<table>
<thead>
<tr>
<th>Very bad</th>
<th>Bad</th>
<th>Somewhat bad</th>
<th>Neither bad nor good</th>
<th>Somewhat good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very pleasant</td>
<td>Pleasant</td>
<td>Somewhat pleasant</td>
<td>Neither pleasant nor unpleasant</td>
<td>Somewhat unpleasant</td>
<td>Unpleasant</td>
<td>Very unpleasant</td>
</tr>
<tr>
<td>Very uncomfortable</td>
<td>Uncomfortable</td>
<td>Somewhat uncomfortable</td>
<td>Neither uncomfortable nor comfortable</td>
<td>Somewhat comfortable</td>
<td>Comfortable</td>
<td>Very comfortable</td>
</tr>
<tr>
<td>Very valuable</td>
<td>Valuable</td>
<td>Somewhat valuable</td>
<td>Neither valuable nor worthless</td>
<td>Somewhat worthless</td>
<td>Worthless</td>
<td>Very worthless</td>
</tr>
<tr>
<td>Very undesirable</td>
<td>Undesirable</td>
<td>Somewhat undesirable</td>
<td>Neither undesirable nor desirable</td>
<td>Somewhat desirable</td>
<td>Desirable</td>
<td>Very desirable</td>
</tr>
</tbody>
</table>
### [Anticipated Response] Study 2

<table>
<thead>
<tr>
<th>If I have an advance care planning conversation in the next 30 days my [referent] will…</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither Disagree nor Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be agreeable to me talking about my medical treatment preferences.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Respond positively to me talking about my medical treatment preferences.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Have a favorable response to me talking about my medical treatment preferences.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
**[Subjective Norm: Part 1] Study 2**

Please indicate how much you agree or disagree with each statement.

<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>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most people who are important to me approve of me having an advance care planning conversation in the next 30 days.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>My doctor thinks that I should have an advance care planning conversation in the next 30 days.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>My spouse, partner or significant other thinks that I should have an advance care planning conversation in the next 30 days.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Topic</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>My child or children would approve of me having an advance care planning conversation in the next 30 days.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>My parent or parents would approve of me having an advance care planning conversation in the next 30 days.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>I am having a heart attack right now.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>
[Subjective Norm: Part 2] Study 2

Please indicate how much you agree or disagree with each statement.

<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>Most people like me have had advance care planning conversations.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Most of my friends have had advance care planning conversations.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Most people my age have had advance care planning conversations.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Most people I know have had advance care planning conversations.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>