Young adults' perspectives on advance care planning: Evaluating the Death over Dinner initiative

Article *in* Death Studies · February 2020

DOI: 10.1080/07481187.2020.1731015

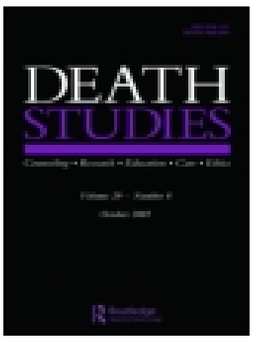
3 authors, including:

Emily Mroz
University of Florida
9 PUBLICATIONS **16** CITATIONS

SEE PROFILE

Susan Bluck
University of Florida
220 PUBLICATIONS **6,081** CITATIONS

SEE PROFILE



Death Studies

ISSN: 0748-1187 (Print) 1091-7683 (Online) Journal homepage: https://www.tandfonline.com/loi/udst20

Young adults' perspectives on advance care planning: Evaluating the Death over Dinner initiative

Emily Mroz, Susan Bluck & Krista Smith

To cite this article: Emily Mroz, Susan Bluck & Krista Smith (2020): Young adults' perspectives on advance care planning: Evaluating the Death over Dinner initiative, Death Studies, DOI: 10.1080/07481187.2020.1731015

To link to this article: https://doi.org/10.1080/07481187.2020.1731015

Published online: 25 Feb 2020.

DEATH STUDIES
https://doi.org/10.1080/07481187.2020.1731015

Routledge
Taylor & Francis Group

Young adults' perspectives on advance care planning: Evaluating the Death over Dinner initiative

Emily Mroz, Susan Bluck, and Krista Smith

Department of Psychology, Life Story Lab, University of Florida, Gainesville, Florida, USA

ABSTRACT

We investigated how death attitudes and experience relate to perspectives on advance care planning (ACP) in young adulthood, and whether attending a Death over Dinner event affects perspectives on ACP. Participants ($N = 109$) were assigned to a Death over Dinner or waitlist control condition, completing pretest and post-test measures. Higher Death Rejection and having more Experience with Death predicted Reservations about ACP. Participation in a Death over Dinner decreased Reservations toward ACP compared to the control group. Death over Dinner appears to be useful in ameliorating reservations toward ACP without shortening individuals' sense of their time left to live.

Despite an upsurge in death education in the United States over the past half century, thinking and talking about death has been considered irrelevant or even morbid, especially for young people (Gerard, 2017). This situation may be due in part to the assumption that thinking about death prompts psychological discomfort for young adults, as it reminds them that their lifetime is limited. Some individuals may find it particularly difficult, or anxiety-provoking, to reflect on past losses or consider their own mortality. Recent work, however, suggests that, generally, thinking and talking about death can be valuable across the adult lifespan (e.g. Mroz, Bluck, Sharma, & Liao, 2019). Thinking about death has been linked to enhanced end-of-life communication for the terminally ill (e.g. Emanuel, Fairclough, Wolfe, & Emanuel, 2004; Mori et al., 2017) and to the clarification of life values and reduction of anxiety in healthy adults (e.g. Llewellyn et al., 2016; Yuan et al., 2019), including young adults (Gerard, 2017). Not thinking about death, in contrast, has drawbacks: avoiding the topic affects the likelihood of preparing for death, including participation in advance care planning (ACP).

There is currently a critical communication gap regarding ACP, particularly for young adults (Tripken & Elrod, 2018). Ensuring that end-of-life values are known by medical providers and loved ones rely on early conversations about ACP, requiring willingness to think and talk about death far in advance of illness or injury (Mack et al., 2012). Factors affecting young adults' perspectives on ACP are not well known, and ACP education initiatives for younger persons have been understudied (Fletcher, Hughes, Pickstock, & Auret, 2018). The current research investigates whether existing attitudes toward death and experiencing loss, affect young adults' perspectives on ACP. It also experimentally evaluates a national death education initiative, Death over Dinner, in terms of its effects on young adults' perspectives on ACP.

Engagement in advance care planning

ACP is relatively new in historical terms (e.g. Detering, Hancock, Reade, & Silvester, 2010). It is the practice of refining one's personal values (Fried et al., 2012) and documenting preferences for future medical care (e.g. end-of-life care; Von Gunten, Ferris, & Emanuel, 2000). Best practices for incorporating ACP into medical care are still being debated, with some recent critics concerned about the lack of education, resources, and support available to individuals as they consider (e.g. Zivkovic, 2018) and document (e.g. Duffy, 2019) their values pertaining to this complex topic. Despite these critiques, ACP appears to have clear benefits for older adults, including decreased use of futile medical treatment, increased patient satisfaction, and reduced family stress (Brinkman-Stoppelenburg, Rietjens, & Van der Heide, 2014; Detering et al., 2010). Some similar benefits for younger patients have also been documented

CONTACT Emily Mroz elmroz@ufl.edu Department of Psychology, University of Florida, P.O. Box 115911, Gainesville, FL 32611, USA.

(e.g., Hammes, Klevan, Kempf, & Williams, 2005), demonstrating that ACP is likely helpful for individuals of all ages. Introducing ACP earlier in adulthood (e.g. beginning with young adults) may help to ensure that the process of ACP includes ongoing contemplation and discussion of care goals. Ideally, ACP is not something that is ever finished, but a process that should be addressed and re-addressed across the adult lifespan. Despite this, ACP with healthy young adults rarely occurs.

Historically, young adults have seldom been encouraged to consider death and dying (Gerard, 2017) partly because of the societal notion that exposure to death is not normative in this life phase (e.g. that fewer deaths occur for young adults than middle-aged or older adults; Balk, 1996). Recent work, however, suggests that young adults have thought extensively about death and dying and are willing to engage in further exploration (Tripken & Elrod, 2018). They may value ACP because they are seeking to take on autonomous adult decision-making activities (Arnett, 2000), including decisions concerning their health and healthcare (Wray-Lake, Crouter, & McHale, 2010). Most medical networks, however, target middle-aged and older adults when distributing resources about end-of-life options (Yingling & Keeley, 2007), leaving young adults under-informed. ACP education initiatives that do include young adults are typically targeted to those who are ill (e.g. Fletcher et al., 2018). Thus, the majority of young adult deaths, those that occur from sudden or unexpected injury, are medically managed without ACP in place.

Evidence suggests young adults hope to have opportunities to be involved in ACP (Kavalieratos, Ernecoff, Keim-Malpass, & Degenholtz, 2015). The completion of ACP, however, relies on more than having a generally positive attitude. Getting ready to engage in ACP involves multiple steps (e.g. Emanuel & Emanuel, 1998) including moving from pre-contemplation to action through reflecting on preferences for end-of-life care, communicating with others, and documenting wishes in medical records (Sudore et al., 2008). The Decisional Balance model (Fried et al., 2012) highlights understanding perceived ACP benefits and overcoming reservations (Sudore et al., 2017) as necessary to meaningfully engage with ACP.

Despite a lack of formal knowledge about ACP (Tripken & Elrod, 2018), young adults have often developed preferences for end-of-life (e.g. prioritizing autonomy when ill; Kavalieratos et al., 2015). We suggest young adults' perspectives on ACP may be at least partially related to their existing attitudes toward death and to the number of previous losses experienced. Our focus on these two factors is based on past literature. For example, research suggests death attitudes influence issues such as reactions to loss (Neimeyer, Wittkowski, & Moser, 2004), memorializing (Bluck & Mroz, 2018), and also ACP in later adulthood (Carr & Khodyakov, 2007). Regarding previous experiences with loss, young adults who have prior exposure to the threat of death report more interest in ACP as well as higher comfort with conversations about ACP (Kavalieratos et al., 2015; Tripken & Elrod, 2018). As such, experiencing more deaths in this life phase is likely linked to more positive perspectives on ACP.

Though we investigate whether these preexisting factors lead to some young adults having relatively positive perspectives on ACP, we recognize that most young adults still do not seek opportunities to engage in ACP (Kavalieratos et al., 2015). Taking the first step is often the most difficult part of the process (Emanuel & Emanuel, 1998), but individuals report being willing to discuss ACP if someone else initiates the conversation (Schrader, Nelson, & Eidsness, 2010).

Death over dinner

A variety of death education initiatives occur in both community (i.e. Death Café, www.deathcafe.com; Before I Die Walls (Chang, n.d), www.beforeidieproject.com) and classroom settings. Many initiatives focus on changing attitudes toward death (e.g. McClatchey & King, 2015; Wallace, Cohen, & Jenkins, 2019). One novel initiative, Death over Dinner, more directly targets perspectives on ACP and seems particularly suited to young adults.

Created by Michael Hebb in 2012, Death over Dinner has initiated a national conversation about death, dying, and end-of-life care among friends, families, and strangers. Though it is not a formal intervention set on changing perspectives, since 2013 more than 100,000 Dinners have been held in 30 countries to encourage open discussion about this topic (Harris, 2016). Hebb's original inspiration for Death over Dinner occurred when he realized that individuals "haven't talked to their families about their preferences, and no one has asked" (Hebb, 2018, p. 7), resulting in end-of-life wishes going uncommunicated. Death over Dinner scaffolds discussion on ACP: guests engage in conversation about end-of-life and information on Advance Directives is provided. Preliminary research suggests Death over Dinner is an

appropriate format for community discussions of ACP (Glover et al., 2018) among all ages (South & Elton, 2017).

Although this initiative has been popular, including among young adults, it has not been empirically tested. One concern about discussing death with young adults is that they may be distressed by thinking about their future time in life as limited or being cut short (e.g. Kastenbaum, 2015). Classically, consideration of time left to live has been conceptualized and measured as one's future time perspective (Liao & Carstensen, 2018). Young adults typically report a long, open future time perspective (i.e. compared to older persons) reflecting their perception that they have a relatively unlimited amount of time left to live (Rohr, John, Fung, & Lang, 2017). Death over Dinner promotes discussing death but does so in the context of living one's life, focusing partly on how death can clarify one's life values. As such, Death over Dinner may be particularly suited for the young in that it allows conversations about ACP without accentuating that future time left to live is ultimately limited, thereby without triggering distress.

We first aimed to identify the extent to which death attitudes and experience with death predict perspectives on ACP (i.e. benefits and reservations). We hypothesized that higher acceptance of death and having experienced more deaths in one's life would relate to reporting greater perceived benefits of ACP (Hypothesis 1a) and relate to reporting lower reservations toward ACP (Hypothesis 1b). Second, we aimed to test the efficacy of participating in a Death over Dinner for enhancing perceived benefits of, and decreasing reservations toward, ACP. We hypothesized that, from pretest to post-test and compared to a waitlist control condition, young adults who participate in a Death over Dinner will perceive greater benefits of ACP (Hypothesis 2a) and will report fewer reservations toward ACP. Third, we aimed to explore whether participating in a Death over Dinner influenced young adults' future time perspective. No hypothesis was generated for this exploratory aim.

Method

Participants

Participants were aged 18–28 years ($M = 19.79$, $SD = 2.10$); with 58 women, 49 men, and 2 identifying as gender non-binary. In terms of race, 64% identified as Caucasian, 14.1% as Asian, 8.5% as biracial, 4.2% as African American, 3.5% as Middle Eastern, 2% as American Indian and Pacific Islander, and 3% as other. Recruitment occurred in the southeastern United States was through university student organizations, listservs, websites, and flyers. Participants were compensated USD$30. Originally, 147 young adults were recruited. Foils were included in both the pre- and post-test questionnaires to ensure participants were paying attention (e.g. Answer "Mostly agree" for this item). Five participants were dropped as they answered more than two of five foil items incorrectly. Thus, 142 participants completed the pretest measures. A total of 109 young adults attended their scheduled dinner and completed both pretest and post-test in the Death over Dinner ($n = 56$; 30 women, 26 men) or control ($n = 53$; 30 women, 23 men) conditions.

Measures

Demographic characteristics, death attitudes, and death experiences were measured at pretest only. ACP and Future Time Perspective were completed at pretest and post-test. Items pertaining to reflection on death during study participation and to completion of the "homework" component of the study were also given at post-test.

Demographics

A standard set of demographic items was administered regarding personal characteristics including age, sex, and race.

Death experiences

On the Death Experiences Questionnaire (Bluck, Dirk, Mackay, & Hux, 2008), participants reported close others lost in past by responding to a list (e.g. mother and grandfather) with the ability to write in others (e.g. great-uncle and cousin). On average, participants had experienced 2.02 deaths ($SD = 1.37$). Participants reported having lost no (13.4%), one (25.4%), two (28.2%), three (16.9%), four (11.3%), or five (4.9%) people important to them.

Death attitudes

Participants completed two subscales of the Multidimensional Orientation toward Death and Dying Inventory (MODDI; Wittkowski, 2001): Death Acceptance (six items; e.g. The fact that I will die someday is something absolutely natural for me) and Death Rejection (five items; e.g. Inwardly, I resist the thought of my own death). Ratings were made on

Likert-type scales from 1 (do not agree at all) to 5 (agree completely). Subscales in our sample had good reliability (acceptance Cronbach's $\alpha = 0.82$; rejection, $\alpha = 0.83$).

Advance care planning

Using the ACP Decisional Balance (Fried et al., 2012) questionnaire, participants rated agreement with Perceived Benefits (six items; e.g. Doing ACP would give me peace of mind.) and Reservations (6 items; e.g. it would be hard to do ACP because I do not like thinking about being very ill) on Likert-type scales ranging from 1 (not at all) to 5 (completely agree). Subscales had good reliability at pretest (Benefits, $\alpha = 0.84$; Reservations, $\alpha = 0.70$) and post-test (Benefits, $\alpha = 0.90$; Reservations, $\alpha = 0.75$).

Future time perspective

The 10-item Future Time Perspective Scale (Carstensen & Lang, 1996) was used (e.g. Most of my life lies ahead of me). Items were rated using Likert-type scales from 1 (very untrue) to 7 (very true). Pretest Cronbach's $\alpha = 0.51$; post-test $\alpha = 0.64$.

Reflection on death

To get a sense of reflection on death during the week of the study period, participants rated at post-test: "During the past week, how often have you *thought about* themes related to death, dying, and end-of-life?" and "During the past week, how often have you *talked about* themes related to death, dying, and end-of-life?". They responded using Likert-type scales from 1 (never) to 5 (very frequently).

Completion of death over dinner homework

One standard component of Death over Dinner is exposure to materials that help individuals think about death prior to attending the dinner. Two to three days before attending their Death over Dinner, experimental condition participants were given "homework" to complete. This included watching a video about the founder of Before I Die walls, reading an article about a man who has cared for over 12,000 people as they die, and considering how their own life experiences have affected their views of death. At post-test, participants saw this survey item, "before the dinner, we provided some information to open your mind to conversations regarding death and dying … on a scale from 0 to 100%, how much of this 'homework' did you do?" Participants responded by marking the amount they completed with a slider.

Design and procedure

This study was approved by the institutional review board at the University of Florida, and participants gave informed consent. They were randomly assigned to either attend a Death over Dinner or be on a waitlist control. All participants received the same measures, through an online survey. Death over Dinner participants completed the pretest approximately one week prior to attending their dinner. All participants completed the post-test 7–10 days after the pretest. Participants in the waitlist condition were invited to participate in a Death over Dinner following collection of the post-test data.

Death over Dinner events was modeled based on the official website, www.deathoverdinner.org. Eleven Dinners, each with five to seven participants, were held over a 4-month period in a private area of the same local restaurant. Facilitators were three young adult women. They were selected to facilitate based on their experience and interest in research on death and dying and received formal training from individuals who had led Death over Dinner in the surrounding community. These peer-facilitators led discussions, guiding attendees through the conversation topics using an informal script modeled after the instructions on the Death over Dinner website. For example, prompts included having participants reflect on those they have already lost (i.e. To start the meal, let us … acknowledge a loved one you have lost), who they would want to speak for them in health care settings (i.e. who might you choose to be your Healthcare Surrogate?), exploration of how to live one's life given it will one day end (If you were told today that you had 30 d before you died, what would you do with that time?), and appreciation of life (… Let us go around the table and share something that we appreciate about our lives today). Dinners lasted between 90 and 105 min ($M = 93.33$; $SD = 6.61$).

Results

A correlation matrix of relevant pretest study variables for the entire sample was inspected (see Table 1). Death Acceptance, Death Rejection, and the Total Number of Deaths Experienced relate to Reservations about ACP ($p < .05$). Perceived Benefits of and Reservations toward ACP were negatively correlated ($r = -0.41$; $p < .01$), as was Death Acceptance and Death Rejection ($r = -0.61$; $p < .01$). Age and gender were not related to major study variables so were not included in subsequent analyses. In addition, prior to

Table 1. Zero-order correlations ($N = 142$) between death attitudes, death experience, and perceived benefits of and reservations toward ACP (Pretest).

	Variable	1	2	3	4	5	6	7
1	Death acceptance	–	–	–	–	–	–	–
2	Death rejection	−0.61**	–	–	–	–	–	–
3	Number of deaths Experienced	−0.14	−0.01	–	–	–	–	–
4	Perceived benefits of ACP	0.13	−0.08	−0.11	–	–	–	–
5	Reservations toward ACP	−0.30**	0.45**	0.20*	−0.41**	–	–	–
6	Age	−0.07	0.10	0.21*	0.04	0.02	–	–
7	Gender	0.03	−0.11	0.07	−0.01	0.01	−0.09	–

Note: *$p < .05$, **$p < .01$. Pearson's correlations shown for continuous variables; Spearman's rank-order correlations for gender (male = 1, female = 2).

Table 2. Summary of regressions predicting perceived benefits of and reservations toward ACP ($N = 142$).

Variable	*B*	*SE B*	*β*	*t*
Criterion: perceived benefits of ACP				
Death acceptance	0.11	0.11	0.11	0.99
Death rejection	−0.01	0.10	−0.01	−0.08
Number of deaths experienced	−0.05	0.06	−0.08	−0.98
Criterion: perceived reservations toward ACP				
Death acceptance	0.01	0.08	0.01	0.08
Death rejection	0.36	0.07	0.49	4.97**
Number of deaths experienced	0.10	0.04	0.17	2.35*

Note: *$p < .05$. **$p < .001$.

major analyses, participants' reflections on death during the course of the study, as well as homework completion in the Death over Dinner condition, were assessed. On average, participants thought ($M = 3.28$; $SD = 1.02$) and talked ($M = 2.31$; $SD = 1.06$) about these death and dying occasionally during their participation in this study, with no differences across study conditions (thought, $t = 1.02$, $p < .10$; talked, $t = 1.04$, $p < .10$). Death over Dinner participants reported, on average, completing at least one component of the "homework" prior to the dinner ($M = 44.89\%$; $SD = 37.15$).

Predicting young adults' perspectives on ACP

We tested hypotheses 1a and 1b using pretest data. Two linear regressions were conducted (see Table 2). The first explained Perceived Benefits of ACP. Death Acceptance, Death Rejection, and Total Number of Deaths Experienced were entered into the model, $F(3,135) = 1.05$, $p > .1$, $r = 0.02$. None was related to Perceived Benefits of ACP. The second linear regression explained Reservations toward ACP. Death Acceptance, Death Rejection, and Total Number of Deaths Experienced were entered into the model, $F(3,135) = 16.48$, $p > 0.001$, $r^2 = 0.27$. Greater Death Rejection ($\beta = 0.49$, $p < .001$) and higher Number of Deaths Experienced ($\beta = 0.17$, $p < .05$) both explained greater Reservations toward ACP.

Table 3. Means and standard deviations for ACP benefits and reservations by condition and time.

	Perceived benefits of ACP				Reservations toward ACP			
	Pretest		Post-test		Pretest		Post-test	
Condition	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Death over Dinner	3.58	0.90	3.98	0.72	2.23	0.77	1.77	0.56
Waitlist control	3.65	0.88	3.81	0.98	2.02	0.74	2.04	0.77

Changing ACP perspectives through Death over Dinner

We tested hypotheses 2a and 2b with a doubly multivariate MANOVA. Dependent variables were Perceived Benefits of ACP and Reservations toward ACP. Each was entered as within-participants repeated measures (i.e. at pre- and post-test). Condition was the between-participants factor (experimental: Death over Dinner; control: Waitlist). No main effect was expected or found for condition at pretest ($p > .10$). A time by condition interaction emerged, $F(2, 102) = 4.21$, $p < .05$, $\eta_p^2 = 0.02$. See Table 3 for mean and standard deviation values. Contrary to Hypothesis 2a, Perceived Benefits of ACP did not change from pretest to post-test in either condition, $F(1, 102) = 0.60$, $p > .10$, $\eta_p^2 = 0.01$. In support of hypothesis 2b, however, Reservations toward ACP changed from pretest to post-test by condition, $F(1, 102) = 8.49$, $p < .01$, $\eta_p^2 = 0.08$. Participants who attended a Death over Dinner reported lower Reservations toward ACP after participating as compared to at pretest ($t = 3.43$; $p < .01$) whereas control participants showed no change from pretest to post-test ($p > .10$). Figure 1 shows this interaction.

Death over dinner: effects on future time perspective

ANCOVA determined whether Future Time Perspective varied by condition at post-test, with pretest Future Time Perspective as a covariate to equate

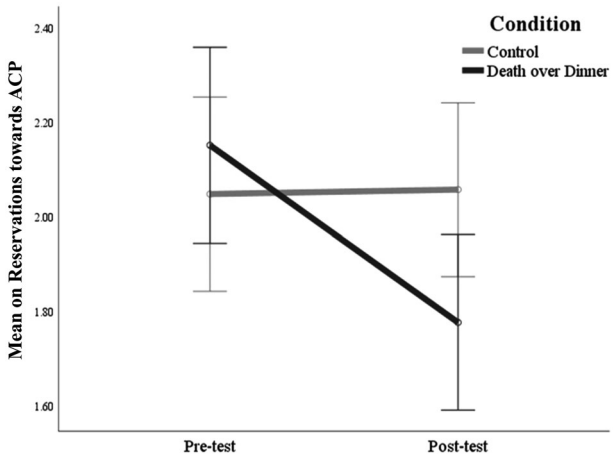


Figure 1. Reservations toward ACP from pre- to post-test by condition. *Note*: Y-axis does not represent all possible scale values.

conditions. Post-test Future Time Perspective differed by condition, $F(2, 89) = 4.93$, $p < .05$, $\eta_p^2 = 0.05$. Control participants reported a more limited sense of future time at post-test ($M = 4.65$; $SD = 0.77$) compared to pretest ($M = 4.83$; $SD = 0.55$; $t = 2.26$; $p < .05$) whereas Death over Dinner participants did not change at post-test ($M = 4.90$; $SD = 0.60$; $p > .05$) from pretest ($M = 4.81$; $SD = 0.66$).

Discussion

There is a substantial need to promote communication about ACP, particularly for young adults (Tripken & Elrod, 2018). Our findings suggest that education initiatives that recognize preexisting personal factors, including level of death rejection and participants' own past history with loss, may be particularly useful. Death over Dinner appears to show promise for decreasing reservations toward ACP, thereby potentially moving young adults to contemplate ACP (Sudore et al., 2008). It appears to do so without negative effects on perception of time left in life. The current findings elucidate young adults' reservations toward ACP, but no effects were found regarding changing perceived benefits of ACP.

We hypothesized that death attitudes, as well as having experience with death, should relate to perceived benefits of, and reservations toward, ACP in young adulthood. No such relations were found for perceived benefits of ACP. This may be because perceived benefits are relatively obvious to people of all ages, so are disconnected from personal factors. Encouraging young adults toward ACP engagement may rely on them having relatively low reservations toward participation. Our findings do show that higher levels of rejection of death and having more personal experiences with death predict greater reservations about ACP.

Young adults who more strongly reject the concept of death reported greater reservations toward ACP. Reservations include such things as not wanting to think about being very ill, and not wanting to talk about dying with family. Individuals who strongly reject death avoid thinking or talking about death in any capacity, likely including as part of ACP, in an effort to minimize anxiety (e.g., Kastenbaum, 2015). Death anxiety in young adults has been related to the type of issues often addressed during ACP such as pain, helplessness, and breakdown of the body (Thorson & Powell, 1994). It thus makes good sense that those who have an attitude of rejecting death are not interested in pursuing, and have high reservations toward, ACP.

Young adults who had experienced more personal losses also reported greater reservations toward ACP. Prior research on the relation between death experiences and ACP (Kavalieratos et al. 2015; Tripken & Elrod, 2018) has, in contrast, found positive relations between exposure to the threat of death and engagement in ACP. Based on those results, we had expected more experience with death to relate to fewer reservations toward ACP. Previous studies, however, assessed death experience using dichotomous-response questions (e.g. Kavalieratos et al. 2015) regarding whether the participant themselves or anyone close to them, ever had a life-threatening illness. Such questions do not assess loss but threat of loss, including both personal illness and illness of others, and do not assess the extent to which individuals have faced loss (i.e. one time in their lives versus multiple times). The measure used in the current study assessed death experience in quite a different way, which may explain the contrary findings. We focusing on the number of losses experienced thus far in life and found that, for young adults, the loss of many close persons early in life is related to greater reservations toward ACP. We speculate that young adults who have lost multiple persons so early in life may have a lack of confidence that ACP will help them maintain control over end-of-life outcomes. Patients have historically reported lack of control at end-of-life (e.g. Redding, 2000), including inability to control their care (e.g. Meier et al., 2016) which also affects their loved ones (Redding, 2000). Young adults who have experienced multiple deaths may have vicariously witnessed this lack of control and have, therefore, reservations about

the worth of thinking about being very ill in the future by engaging ACP.

Illness, injury, and the breakdown of the human body are inevitable aspects of life. Though uncomfortable to contemplate, facing the reality of one's mortality is a necessary first step to avoiding unwanted care at end-of-life (e.g. Brinkman-Stoppelenburg et al., 2014). Those individuals most adverse to ACP, who are highly rejecting of death or who have multiple experiences with loss, may benefit most from guided exploration of ACP, to clarify the value of ACP. Thus, though individuals who have built up strongly adverse attitudes toward death, or experienced several losses early in life, endorse more reservations about ACP, they may also benefit highly from education which dispels uncertainties about the efficacy of ACP and feel empowered to participate in ACP in the future.

Reservations about ACP were reduced following Death over Dinner as compared to a waitlist control, while perceived benefits of ACP were unchanged. Death over Dinner offers a social platform for discussing thought-provoking topics regarding life and death, guided by a facilitator. Sharing experiences about life and death with same-age peers reveals similarities across individuals, promoting new perspectives and deepening reflection (South & Elton, 2017). The conversational format may allow young adults to feel comfortable with sharing thoughts on life, death, and personal wishes and learning from others' views. Death over Dinner thus prompts young adults to realize they are not alone in their attitudes and experiences with loss, likely helping them to address reservations about planning for their own end-of-life.

Common approaches to ACP education involve patients' independent review prepared informational materials (Ramsaroop, Reid, & Adelman, 2007). Such approaches have been criticized for lacking consideration of individuals' level of familiarity with, and readiness to engage in, ACP (Rosnick & Reynolds, 2003). If individuals have serious reservations about ACP, they may not seek out ACP resources. Indeed, as ACP is not incorporated into health care for young adults, those with any reservations at all may feel contented avoiding ACP conversations with loved ones or care providers entirely (e.g., Schrader et al., 2010). Death over Dinner may be effective in decreasing ACP reservations in young adults because Dinner conversations naturally evolve in relation to the level at which individuals are ready to engage. This may be particularly important for young adults, who are not likely contemplating ACP (Sudore et al., 2017). Beyond passive interaction with educational materials, participants in Death over Dinner are prompted to thinking about how they want to spend their time in life, and what they feel will be fitting for them at the end-of-life (Hebb, 2018).

Death over Dinner did not increase perceived benefits of ACP. Participants reported similar, relatively high levels of perceived benefits across time and conditions. That is, before beginning in the study, participants already seemed to understand that ACP is useful. This is consistent with previous research: both older (e.g. Fried et al., 2009) and young adults (e.g. Kavalieratos et al., 2015) have reported general interest in ACP, including articulation of its benefits. If views of ACP are already positive, attending a Death over Dinner may not further change them. To promote engaging in ACP, however, it is necessary for individuals to not just agree that it is a good idea, but for their reservations to be addressed such that they are likely to take further steps to engage in ACP (Schwarzer, 2008). It may be that individuals already know that ACP is useful, but need their reservations dispelled in order to move toward taking action. As such, Death over Dinner is effective as it appears to target and reduce reservations.

Those who were exposed to thinking about death, dying, and end-of-life only through completion of study questionnaires (i.e. waitlist control), reported a more limited future time perspective by post-test, whereas those who attended a Death over Dinner showed no change in future time perspective. Regardless of condition, participants reported thinking and talking about death to the same extent over the study timeframe. Exposure to the death-related topics in the questionnaires only, however, prompted a reduced sense of time left to live. One speculative interpretation is that Death over Dinner allows for death education without provoking distress over having a limited future. Participating in the waitlist necessitated consideration of such topics independently, without guidance or exposure to perspectives from peers. Discussing death with others in the right context may allow young adults to see that death is not simply life "being cut short" but instead brings poignancy to the life lived (Bluck & Mroz, 2018). This type of candid discussion of personal experiences and opinions with peers may allow for positive exploration of what to do with the time one has left to live (South & Elton, 2017).

This study had two main limitations. Though effects were found for reservations toward ACP, no effects emerged in relation to perceived benefits of ACP. The perceived benefits measure may not have

had the necessary sensitivity, given that most individuals appear to generally recognize the benefits of planning. In future research, more fine-tuned measures, potentially including qualitative interview data, may be needed to fully examine the perceived benefits of ACP. That said, enhancing involvement in ACP may not rely on perceived benefits but instead largely depend on identifying barriers that prevent people from participating in ACP (Schickedanz et al., 2009). A second limitation is that young adults who decided to participate in the study may have already been more comfortable talking about death than other young adults who did not volunteer. As such, findings cannot be generalized to all young adults. Due to the critical need to provide ACP education opportunities to young adults, Death over Dinner is a promising initiative. We suggest, however, that researchers and educators continue to identify a variety of alternative options for death education that reaches out to different subgroups of young adults, including those unlikely to attend a Death over Dinner.

In conclusion, societal misconceptions suggest young adults are not interested in end-of-life planning (Gerard, 2017) partly due to the assumption they have limited experience with death. It appears, however, that young adults have relatively positive views toward ACP, and that what is needed is to understand and reduce their reservations toward engagement. Our findings provide guidance in that regard. Young adults' existing attitudes toward death and their extent of lived experience with loss are both related to their reservations about engaging in ACP. Dispelling those reservations may be partly accomplished through the Death over Dinner initiative that provides an intimate, constructive setting for exploring life and talking about death. Though our research focused on young adults, Death over Dinner instructions have now been developed for different groups (e.g. Healthcare professionals, https://deathoverdinnerhealthcare.org/; Jewish individuals, https://deathoverdinner-jewishedition.org/). We hope that future research will continue to test the efficacy of Death over Dinner as an educational initiative for younger adults, but also in a variety of groups. Creating a society in which individuals talk more freely about death, and meaningfully about life, will allow for better preparation for shaping each of our endings.

Acknowledgments

The authors would like to acknowledge the University of Florida Jacqueline Goldman Awards Program, which helped to fund this research.

References

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, *55*(5), 469–480. doi:10.1037/0003-066X.55.5.469.

Balk, D. E. (1996). Models for understanding adolescent coping with bereavement. *Death Studies*, *20*(4), 367–387. doi:10.1080/07481189608252788.

Bluck, S., Dirk, J., Mackay, M. M., & Hux, A. (2008). Life experience with death: Relation to death attitudes and to the use of death-related memories. *Death Studies*, *32*(6), 524–549. doi:10.1080/07481180802138860.

Bluck, S., & Mroz, E. L. (2018). The end: Death as part of the life story. *The International Journal of Reminiscence and Life Review*, *5*, 6–14.

Brinkman-Stoppelenburg, A., Rietjens, J. A., & Van der Heide, A. (2014). The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*, *28*(8), 1000–1025. doi:10.1177/0269216314526272.

Carr, D., & Khodyakov, D. (2007). End-of-life health care planning among young-old adults: An assessment of psychosocial influences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *62*(2), S135–S141. doi:10.1093/geronb/62.2.S135.

Carstensen, L. L., & Lang, F. R. (1996). Future orientation scale (Unpublished manuscript). Stanford, CA: Stanford University.

Chang, C. (n.d.). *Before I Die*. Retrieved December 2019 from https://beforeidieproject.com/.

Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomized controlled trial. *BMJ*, *340*(1), c1345–c1345. doi:10.1136/bmj.c1345.

Duffy, F. (2019). A critical perspective on advance care planning for older people. *The British Journal of Social Work*, bcz092. doi:10.1093/bjsw/bcz092

Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *The Lancet*, *351*, SII21–I29. doi:10.1016/S0140-6736(98)90329-4.

Emanuel, E. J., Fairclough, D. L., Wolfe, P., & Emanuel, L. L. (2004). Talking with terminally ill patients and their caregivers about death, dying, and bereavement: Is it stressful? Is it helpful? *Archives of Internal Medicine*, *164*(18), 1999–2004. doi:10.1001/archinte.164.18.1999.

Fletcher, S., Hughes, R., Pickstock, S., & Auret, K. (2018). Advance care planning discussions with adolescent and young adult cancer patients admitted to a community palliative care service: A retrospective case-note audit. *Journal of Adolescent and Young Adult Oncology*, *7*(1), 112–119. doi:10.1089/jayao.2017.0032.

Fried, T. R., Bullock, K., Iannone, L., & O'Leary, J. R. (2009). Understanding advance care planning as a process of health behaviour change. *Journal of the American Geriatrics Society*, *57*(9), 1547–1555. doi:10.1111/j.1532-5415.2009.02396.x.

Fried, T. R., Redding, C. A., Robbins, M. L., Paiva, A., O'Leary, J. R., & Iannone, L. (2012). Promoting advance care planning as health behavior change: Development of scales to assess decisional balance, medical and religious beliefs, and processes of change. *Patient Education and Counseling*, *86*(1), 25–32. doi:10.1016/j.pec.2011.04.035.

Gerard, N. (2017). Can millennials talk about death? Young adults' perceptions of end-of-life care. *Journal of Health Administration Education*, *34*, 23–48.

Glover, T. L., Wolz, A., Meiring, A. M., Resnick, W., Clarizio, A. M., & Baron-Lee, J. (2018). Advance care planning: Senior center members' perceptions of a Death over Dinner event. *Journal of Palliative Medicine*, *21*(7), 892–892. doi:10.1089/jpm.2018.0080

Gunten, C. F. V., Ferris, F. D., & Emanuel, L. L. (2000). Ensuring competency in end-of-life care. *Archives of Family Medicine*, *9*, 1176–1180.

Hammes, B. J., Klevan, J., Kempf, M., & Williams, M. S. (2005). Pediatric advance care planning. *Journal of Palliative Medicine*, *8*(4), 766–773. doi:10.1089/jpm.2005.8.766

Harris, R. (2016, April 18). *Discussing death over dinner*. Retrieved from https://www.theatlantic.com/health/archive/2016/04/discussing-death-ovedinner/478452/

Hebb, M. (2018). *Let's talk about death (over dinner)*. Cambridge, MA: Da Capo Press.

Kastenbaum, R. (2015). *Death, society and human experience*. Boston, MA: Allyn & Bacon.

Kavalieratos, D., Ernecoff, N. C., Keim-Malpass, J., & Degenholtz, H. B. (2015). Knowledge, attitudes, and preferences of healthy young adults regarding advance care planning: A focus group study of university students in Pittsburgh, USA. *BMC Public Health*, *15*(1), 1–7. doi:10.1186/s12889-015-1575-y.

Liao, H. W., & Carstensen, L. L. (2018). Future time perspective. *GeroPsych*, *31*(3), 163–167. doi:10.1024/1662-9647/a000194

Llewellyn, R., Jaye, C., Egan, R., Cunningham, W., Young, J., & Radue, P. (2016). Cracking open death: Death conversations in primary care. *Journal of Primary Health Care*, *8*(4), 303–311. doi:doi:10.1071/HC15058

Mack, J. W., Cronin, A., Taback, N., Huskamp, H. A., Keating, N. L., Malin, J. L., … Weeks, J. C. (2012). End-of-life care discussions among patients with advanced cancer: A cohort study. *Annals of Internal Medicine*, *156*(3), 204–210. doi:10.7326/0003-4819-156-3-201202070-00008.

McClatchey, I. S., & King, S. (2015). The impact of death education on fear of death and death anxiety among human services students. *Omega—Journal of Death and Dying*, *71,* 343–361. doi:10.1177/0030222815572606

Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, *24*(4), 261–271. doi:10.1016/j.jagp.2016.01.135.

Mori, M., Yoshida, S., Shiozaki, M., Baba, M., Morita, T., Aoyama, M., … Miyashita, M. (2017). Talking about death with terminally-ill cancer patients: What contributes to the regret of bereaved family members? *Journal of Pain and Symptom Management*, *54*(6), 853–860. doi:10.1016/j.jpainsymman.2017.02.021.

Mroz, E. L., Bluck, S., Sharma, S., & Liao, H.W. (2019). Loss in the life story: Remembering death and illness across adulthood. *Psychological Reports*, *123,* 97–123. doi:10.1177/0033294119854175.

Neimeyer, R. A., Wittkowski, J., & Moser, R. P. (2004). Psychological research on death attitudes: An overview and evaluation. *Death Studies*, *28*(4), 309–340. doi:10.1080/07481180490432324.

Ramsaroop, S. D., Reid, M. C., & Adelman, R. D. (2007). Completing an advance directive in the primary care setting: What do we need for success? *Journal of the American Geriatrics Society*, *55*(2), 277–283. doi:10.1111/j.1532-5415.2007.01065.x.

Redding, S. (2000). Control theory in dying: What do we know? *American Journal of Hospice and Palliative Medicine®*, *17*(3), 204–208. doi:10.1177/104990910001700316.

Rohr, M. K., John, D. T., Fung, H. H., & Lang, F. R. (2017). A three-component model of future time perspective across adulthood. *Psychology and Aging*, *32*(7), 597–607. doi:10.1037/pag0000191.

Rosnick, C. B., & Reynolds, S. L. (2003). Thinking ahead: Factors associated with executing advance directives. *Journal of Aging and Health*, *15*(2), 409–429. doi:10.1177/0898264303015002005.

Schickedanz, A. D., Schillinger, D., Landefeld, C. S., Knight, S. J., Williams, B. A., & Sudore, R. L. (2009). A clinical framework for improving the advance care planning process: Start with patients' self-identified barriers. *Journal of the American Geriatrics Society*, *57*(1), 31–39. doi:10.1111/j.1532-5415.2008.02093.x.

Schrader, S.L., Nelson, M.L., & Eidsness, L.M. (2010). Dying to know: A community survey about dying and end-of-life care. *OMEGA – Journal of Death and Dying*, *60*(1), 33–50. doi:10.2190/OM.60.1.b.

Schwarzer, R. (2008). Modeling health behavior change: How to predict and modify the adoption and maintenance of health behaviors. *Applied Psychology*, *57*, 1–29. doi:10.1111/j.1464-0597.2007.00325.x.

South, A. L., & Elton, J. (2017). Contradictions and promise for end-of-life communication among family and friends: Death over dinner conversations. *Behavioral Sciences*, *7*, 24. doi:10.3390/bs7020024.

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., … Heyland, D. K. (2017). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management*, *53*(5), 821–832. doi:10.1016/j.jpainsymman.2016.12.331.

Sudore, R. L., Schickedanz, A. D., Landefeld, C. S., Williams, B. A., Lindquist, K., Pantilat, S. Z., & Schillinger, D. (2008). Engagement in multiple steps of the advance care planning process: A descriptive study of diverse older adults. *Journal of the American Geriatrics Society*, *56*(6), 1006–1013. doi:10.1111/j.1532-5415.2008.01701.x.

Thorson, J. A., & Powell, F. C. (1994). A revised death anxiety scale. In R. A. Neimeyer (Ed.), *Death anxiety handbook: Research, instrumentation, and application* (pp. 31–43). Washington, DC: Taylor & Francis.

Tripken, J. L., & Elrod, C. S. (2018). Young adults' perspectives on advance care planning survey. *American Journal of Hospice and Palliative Medicine®*, *35*(4), 627–634. doi:10.1177/1049909117727456.

Wallace, C. L., Cohen, H. L., & Jenkins, D. A. (2019). Transforming students' attitudes and anxieties toward death and loss. *OMEGA – Journal of Death and Dying*, *79*(1), 52–71. doi:10.1177/0030222817710140.

Wittkowski, J. (2001). The construction of the multidimensional orientation toward dying and death inventory (MODDI-F). *Death Studies*, *25*(6), 479–495. doi:10.1080/07481180126858.

Wray-Lake, L., Crouter, A. C., & Mchale, S. M. (2010). Developmental patterns in decision-making autonomy across middle childhood and adolescence: European American parents' perspectives. *Child Development*, *81*(2), 636–651. doi:10.1111/j.1467-8624.2009.01420.x.

Yingling, J., & Keeley, M. (2007). A failure to communicate: Let's get real about improving communication at the end of life. *American Journal of Hospice and Palliative Medicine®*, *24*(2), 95–97. doi:10.1177/1049909106297244.

Yuan, Z., Baranik, L. E., Sinclair, R. R., Sliter, M. T., Rand, K. L., & Salyers, M. P. (2019). Memento mori: The development and validation of the death reflection scale. *Journal of Organizational Behavior*, *40*(4), 417–433. doi:10.1002/job.2339.

Zivkovic, T. (2018). Forecasting and foreclosing futures: The temporal dissonance of advance care directives. *Social Science and Medicine*, *215*, 16–22. doi:10.1016/j.socscimed.2018.08.035.