

Original Article

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Attitudes and completion of advance care planning: Assessing the contribution of health beliefs about Alzheimer's disease among Israeli laypersons

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Abstract

Objectives. The purpose of this study was to assess laypersons' attitudes and completion of advance care planning (ACP) and to examine associations with sociodemographic characteristics and health beliefs on Alzheimer's disease.

Methods. A cross-sectional telephone survey was conducted during April and May 2017, with a sample of 514 Israeli adults, aged 18 years and above. A structured, pretested questionnaire assessing participants' awareness, attitudes, and completion of ACP, as well as health beliefs on Alzheimer's disease (subjective knowledge, susceptibility, and worry), and sociodemographic factors, was used.

Results. Two-fifths of the participants had heard of at least one of the terms: advance directives or durable power of attorney. Overall, participants expressed positive attitudes toward ACP. Results of regression models showed that gender, religiosity, and subjective knowledge of Alzheimer's disease were statistically significant correlates of attitudes toward ACP. Adding health beliefs on Alzheimer's disease doubled the amount of the variance explained, from 3% to 6%.

Significance of results. Our results support the use of cognitive models of health behavior by assessing intra-personal beliefs and knowledge to understand ACP attitudes and completion. Specifically, we demonstrated the importance of knowledge of Alzheimer's disease for ACP attitudes, suggesting the importance of including a module on the topic to ACP interventions.

Introduction

Advance care planning – definition and benefits

Promoting autonomy and improving end-of-life care are core public health issues (Rao et al., 2002). Advance care planning (ACP) is recognized as a mechanism to attain these goals (Institute of Medicine, 2014). ACP is broadly defined as a process by which adult persons understand and share their personal values, life goals, and preferences for future medical care (Sudore et al., 2017a). While originally focused on the completion of written, legal documents such as advance directives and durable power of attorney, today, ACP is conceptualized as a social process including formal and informal communication of end-of-life treatment wishes and values (Ryan et al., 2017).

An increasing body of knowledge shows that ACP is associated with positive outcomes for both patients and family members, such as better end-of-life quality, increased satisfaction with regard to treatment and care, reduced family members' burden and anxiety, and reduced hospitalization (Brinkman-Stoppelenburg et al., 2014). Yet, its implementation, in general, remains a challenging and complex task (Dixon et al., 2018)

Factors associated with the completion of ACP

Surveys assessing ACP among the general population have identified several individual-level factors as barriers for the completion of ACP. These included sociodemographic characteristics such as younger age, lower educational level, and belonging to a minority group (Lovell & Yates, 2014; van der Steen et al., 2014; Lund et al., 2015; Ng et al., 2017; Clark, et al., 2018; Howard et al., 2018), as well as negative attitudes and poor knowledge of ACP (Ng et al., 2017). However, these factors had only a limited contribution to the understanding of ACP completion (Khosla et al., 2016). Obviously, additional factors have to be explored to understand this complex behavior better. In the present study, we examined the contribution of health beliefs on Alzheimer's disease as one of these factors.

ACP and Alzheimer's disease

Alzheimer's disease is characterized by the development of progressive cognitive impairments that ultimately interfere with the performance of daily social and occupational activities. Alzheimer's disease is the most common type of dementia and dominates public perceptions (Rizzi et al., 2014). ACP is of special importance in the area of Alzheimer's disease, as persons with the disease will ultimately not have the capacity to express their care preferences and values. Therefore, initiating ACP is strongly recommended in the case of Alzheimer's disease, as a means for supporting autonomy and expressing care preferences and values, as well as for improving end-of-life outcomes (Cotter et al., 2018; Dixon et al., 2018). Laypersons' beliefs on Alzheimer's disease may be one of the factors involved in attaining this goal.

Health beliefs regarding Alzheimer's disease and the completion of ACP

Perceived susceptibility (defined as the perception of the likelihood of developing a disease), worry (defined as the subjective concerns and fear about developing a disease), and subjective knowledge of a disease are central components of cognitive models for encouraging involvement in health behaviors (Conner & Norman, 2005). As ACP could be conceptualized as health behavior (Fried et al., 2009; Ernecoff et al., 2016; Ng et al., 2017), we hypothesized that health beliefs regarding Alzheimer's disease would significantly contribute to the understanding of laypersons' attitudes toward ACP.

ACP in Israel

In Israel, there are 2 ways of formally undertaking ACP for end-of-life care: advance directives and power of attorney. The Ministry of Health established these forms within the framework of the "Dying Patient Law," enacted in 2005. According to this law, a patient is defined as *terminally ill* if s/he is suffering from an incurable disease and has a life expectancy of up to 6 months. While attention to palliative care, in general, and ACP, in particular, has developed over the last years in Israel (Bar-Sela et al., 2017; Bentur & Sternberg, 2017; Feder et al., 2018), still less than 1% of the adult population has formally completed advance directives or signed a durable power of attorney (Shvartzman et al., 2015).

Thus, the current study aimed to assess attitudes and completion of ACP and their association with sociodemographic and Alzheimer's disease health beliefs among a sample of the adult population in Israel.

Methods

Design and participants

This cross-sectional study was based on a national sample of the adult (18 years or older) non-institutionalized population in Israel. Phone calls were conducted during April and May 2017, using random digit dialing, with the adult having the most recent birthday designated as the respondent from all available respondents in each household. If that person was absent, then the next eligible adult was selected as the respondent. Of the 1,044 phone numbers called, 459 refused to participate (69 had problems understanding the topic, and the rest did not have time), rendering a response rate of 56%. Additionally, 71 participants

who did not complete all parts of the questionnaire were not included in the statistical analyses. Thus, a total of 514 adults participated in the study. The sample size was estimated based on previous studies examining knowledge and attitudes regarding Alzheimer's disease (Werner et al., 2013).

Survey questionnaire and measures

The survey questionnaire was pretested on 20 potential participants. Small modifications were made in 2 of the questions for increasing clarity. The questionnaire assessed awareness, attitudes, and completion of ACP, as well as health beliefs on Alzheimer's disease and sociodemographic variables. Items assessing attitudes and the completion of ACP were asked after a short definition of advance directives and durable power of attorney was read to the participants.

Awareness of ACP

Similar to Teixeira et al. (2015), participants were asked whether they had ever heard of the terms, *advance directives* and *durable power of attorney*. A negative answer was rated as 0, and a positive answer was 1. An overall index of subjective knowledge of ACP was calculated by summing both items.

Attitudes toward ACP

Were assessed using an adapted version of Nolan and Bruder's (1997) Attitudes toward Advance Directives Scale (ADAS), containing 10 items rated on a 4-point Likert-type scale, ranging from 1, strongly disagree, to 4, strongly agree. Good internal reliability scores were reported for the English version of the scale (Douglas & Brown, 2002; Lee & Park, 2014; Marshall et al., 2017). For this study, the scale was translated back and forth into Hebrew, and an overall index was calculated by summing the items. The internal reliability of the index was adequate (Cronbach's alpha = 0.71).

Completion of ACP

Similar to Teixeira et al. (2015), 4 items were used to assess the completion of ACP. The first 2 assessed the formal completion of advanced directives and durable power of attorney. The other 2 assessed the informal aspects of ACP: conducting conversations on the topic with family members or friends and with the family physician. All items were rated 0 if the participant answered "no" and 1 if s/he answered "yes." Two indices indicating the formal and informal completion of ACP were calculated by summing the items.

Health beliefs on Alzheimer's disease

Similar to previous studies (Werner et al., 2013), these included: subjective knowledge of Alzheimer's disease; perceived susceptibility, and worry about developing it; and familiarity with the disease.

Subjective knowledge of Alzheimer's disease was assessed with a single question: "How much do you know about Alzheimer's disease?" Answers were rated on a 5-point Likert-type scale, ranging from 1, not much at all, to 5, very much.

Perceived susceptibility was assessed with a single question: "How likely do you think it is that you will develop Alzheimer's disease?" Answers were rated on a 5-point Likert-type scale, ranging from 1, not at all likely, to 5, very likely.

Worry about developing Alzheimer's disease was assessed by a single question: "How much do you worry that you will develop Alzheimer's disease?" Answers were rated on a 5-point

Likert-type scale, ranging from 1, not at all worried, to 5, very worried.

Familiarity was assessed by asking participants if they knew someone with Alzheimer's disease among their relatives or acquaintances.

Sociodemographic variables included gender (female or male), age, years of education, religion (Jewish or non-Jewish), religiosity (secular or religious), marital status (not married or married), perceived health status (excellent, good, fair, bad, and very bad), and perceived economic status (excellent, good, fair, bad, and very bad).

Statistical analysis

The data were coded, cleaned, and analyzed using SPSS version 22.0. Descriptive statistics were used to describe the sample and main variables. Pearson correlations were calculated to assess the relationships among the dependent and independent variables. The determinants of attitudes were assessed using ordinary least squares (OLS) hierarchical regression. We tested for multicollinearity, and the results indicated that it was not a concern in our model. The variance inflation factor (VIF) did not exceed 2.3. Only variables that were found to be significantly correlated with attitudes toward ACP were included in the regression analyses. In the first step of the regression, we included sociodemographic factors, and in the second step, we included health beliefs on Alzheimer's disease.

Ethical considerations

The study was approved by the Ethics Committee of the University of Haifa.

Results

Characteristics of the participants

As shown in **Table 1**, the majority of the participants were female and Jewish, with a mean age of 53 years (range 18–94) and an average education of 14 years (range 0–30). Most were married and reported their income and health status as excellent or good. Regarding Alzheimer's disease measures (**Table 2**), slightly over one-half of the participants reported knowing someone with the disease, and the reported levels of knowledge, susceptibility, and worry were moderate to low.

Awareness of ACP

Only 13.8% of the participants reported having heard the term *advance directives*, and 39.5% reported having heard the term *durable power of attorney*. Overall, 43% reported hearing at least one of the terms. The percentage of participants who reported having heard at least one of the items was higher among Jewish than non-Jewish participants (49.6% and 19.4%, respectively, $X^2_{(1)} = 30.4$, $p < 0.001$), and among those who knew a person with Alzheimer's disease than among those without such familiarity (49.1% and 36.5%, respectively, $X^2_{(1)} = 8.2$, $p < 0.01$).

Attitudes toward ACP

Overall, attitudes toward ACP were positive, with the participants scoring above the median in all the items assessing attitudes. The least positive attitude was reported for the item relating to physicians respecting the participant's concerns for end-of-life treatment decisions (**Table 2**).

Table 1. Distribution of participants by sociodemographic characteristics ($n = 514$)

Characteristic	Percentage or mean (SD)
Gender (%)	
Female	60.9
Male	39.1
Mean (SD, range) age	53.4 (17.6, 18–94)
Mean (SD, range) number of years of education	14.3 (3.6, 0–30)
Marital status (%)	
Married	72.6
Not married	27.4
Religion (%)	
Jewish	79.5
Non-Jewish (Muslim, Christian, Druze, Other)	20.5
Religiosity (%)	
Secular	48.1
Religious (Traditional, Religious, Ultra-Orthodox)	41.9
Perceived health status (%)	
Excellent or good	67.8
Fair, bad, or very bad	32.2
Perceived economic status (%)	
Excellent or good	50.2
Fair, bad, or very bad	49.8

Factors associated with attitudes about ACP

The correlation matrix (**Table 3**) reveals that attitudes toward ACP were significantly correlated with 4 sociodemographic variables (gender, education, religion, and religiosity), with higher levels of education and lower levels of religiosity being associated with more positive attitudes toward ACP. Additionally, female and Jewish participants reported more positive attitudes toward ACP than male and non-Jewish ones. As for the associations with health beliefs on Alzheimer's disease, our results showed that higher levels of subjective knowledge of the disease, as well as higher perceptions of susceptibility, were significantly correlated with more positive attitudes.

Table 4 presents the results of the 2-step hierarchical regression analysis. Our results showed that in the first equation depicting sociodemographic variables, only gender and religiosity were significantly and negatively associated with attitudes. In the second equation, which included health beliefs on Alzheimer's disease, we found that gender, religiosity, and subjective knowledge of Alzheimer's disease were significantly associated with the dependent variable. Although, overall, a very small share of the variance was explained by the variables examined, adding health beliefs on Alzheimer's disease increased the amount of the variance explained from 3% to 6%.

Completion of ACP

Regarding ACP completion, only 11.4% ($n = 8$) of the participants who heard about advance directives reported completing it, and 8.9% ($n = 18$) of those who heard of a durable power of attorney has designated a decision maker. Regarding informal measures of

Table 2. Percentages and means for study ($n = 514$)

Variables	Percentage or mean (SD)
ACP measures	
<i>Awareness of ACP (%)</i>	
Heard about advance directives	13.8
Heard about a durable power of attorney	39.5
Heard at least one of the terms	43.2
<i>Attitudes of ACP (mean and SD)</i>	
I have choices in the treatment I would receive at the end of my life.	3.2 (0.9)
My doctor would include my concerns in decisions on my treatment at the end of my life	2.6 (1.0)
If I could not make decisions, my family would be given choices on the treatment I would receive	3.3 (0.9)
I think my family would want me to have an advance directive	3.3 (0.9)
Making my end-of-life treatment wishes clear with advance directives would keep my family from disagreeing over what to do if I were very sick and unable to decide for myself	3.2 (0.9)
Having an advanced directive would make my family feel left out of caring for me. [^]	2.8(1.0)
Making my end-of-life treatment wishes clear with an advance directive would help to prevent guilt in my family	3.3 (0.9)
Having an advanced directive would make sure that my family knows my treatment wishes	3.5 (0.7)
Having an advanced directive would make sure that I get the treatment at the end of my life that I want	3.3 (0.8)
It is better to make an advance directive when you are healthy	3.4 (0.9)
<i>Completion of ACP (%)</i>	
Completed an advanced care plan	11.4 ^a
Designated a person to be their health care decision maker	8.9 ^a
Had discussions with family or friends regarding health care treatment preferences	23.0 ^b
Had discussions with a family physician regarding health care treatment preferences	7.8 ^b
Health beliefs on Alzheimer's disease	
Mean (SD) subjective knowledge	3.0 (1.2)
Mean (SD) perceived susceptibility	2.3 (0.9)
Mean (SD) perceived worry	2.3 (1.4)
Knows a person with Alzheimer's disease (%)	54.3

[^]Reversed item

^aPercentage of those who heard the term ^bPercentage of the entire sample

ACP, 23% ($n = 116$) of all participants reported having conversations with family or friends about treatment preferences, and 8% ($n = 40$) reported having these conversations with their family physician. Attitudes toward ACP were significantly higher among participants who engaged in conversations than among those who did not.

Discussion

This study aimed to assess attitudes and completion of ACP in a national sample of the general public in Israel. Though there have been several previous studies examining ACP in national samples, they concentrated mostly on examining completion of ACP (Raijmakers et al., 2013; de Vemlick et al., 2014; Rao et al., 2014; Huang et al., 2016; Clark et al., 2018) and did not assess associations with health beliefs associated with Alzheimer's disease. This is an important contribution for several reasons. First, as already stated, given the characteristics of the disease,

persons with Alzheimer's disease will not be able at some stage of the disease to express their values and preferences for end-of-life treatment. Second, as the number of persons with Alzheimer's disease increases worldwide (Alzheimer's Disease International, 2018), an increased number of laypersons will become exposed to persons with the disease, some of them as caregivers.

Our findings showed that approximately two-fifths of the participants were familiar with at least one of the terms examined: advance directives and durable power of attorney. This percentage is higher than the one reported in previous surveys conducted on the general population in Canada (Teixeira et al., 2015) and Singapore (Ng et al., 2017), as well as with older persons in China (Zhang et al., 2015). However, it should be noted that in these survey participants were asked, in general, about ACP. Indeed, awareness rates were very similar in the 4 countries while comparing this identical item, suggesting that despite the priority given worldwide to the topic, laypersons are still quite

Table 3. Correlations between attitudes and study variables ($n = 514$)

	Attitudes
Sociodemographic measures	
Gender	-0.12**
Age	0.07
Education	0.14**
Marital status	0.01
Religion	-0.12**
Religiosity	-0.14**
Perceived health status	0.03
Perceived economic status	-0.01
Health beliefs on Alzheimer's disease	
Subjective knowledge	0.20**
Susceptibility	0.13**
Worry	0.08
Familiarity	0.06

** $p < 0.01$ * $p < 0.05$

Table 4. Two-step hierarchical regression analyses for attitudes on ACP¹ ($n = 514$)

	Model 1	Model 2
Gender	-0.10	-0.09*
Education	0.07	0.03
Religion	-0.07	-0.06
Religiosity	-0.12*	-0.10*
Subjective knowledge on Alzheimer's disease		0.13**
Susceptibility		0.07
Adjusted R²	0.03	0.06

¹Numbers in the table are standardized betas.

* $p < 0.05$ ** $p < 0.01$

unfamiliar with the ACP concept. This is worrisome especially as a clear understanding of the concept by the general public was defined as central to the efforts to increase ACP (Conroy et al., 2009; Ke et al., 2015).

Similar to previous studies (Hong et al., 2018), laypersons pertaining to the minority group in Israel were less aware of the concepts of advance directives and durable power of attorney. This finding stresses the need to take culturally sensitive measures to increase the exposure of minorities to the meaning and importance of these concepts. A first step might be, similar to successful efforts described in the literature (Fischer et al., 2012; Sudore et al., 2016), to provide minority persons with accessible information in their mother tongue.

Despite the low levels of awareness found in our survey, if introduced to the definitions of advanced directives and durable power of attorney, participants reported moderately positive attitudes toward ACP. While similar findings were reported in a survey on ACP conducted among community-dwelling older adults in China (Zhang et al., 2015), we believe these findings rely on the characteristics of the Israeli society. Israeli society is characterized by strong values of familism and family solidarity (Katz et al.,

2015). The fact that 6 out of the 10 items in the scale used to assess attitudes related to the impact of ACP on family members might explain the overall positive attitudes toward ACP found in our study.

Examination of the factors associated with attitudes toward ACP reveals several interesting findings. First, the variables examined in this study explained only 6% of the variance in the dependent variable. This reflects the complexity and sensitivity of the topic (Sudore et al., 2010; Lovell and Yates, 2014; Jimenez et al., 2018) and the need to expand this line of research, qualitatively and quantitatively. Second, being female was significantly associated with more positive attitudes toward ACP. Previous studies examining gender differences in the process of ACP have also demonstrated that women reported higher levels of awareness of advanced directives (Dobbs, Park, Jang, & Meng, 2015) and were more likely to have an informal discussion on the topic than men (Carr & Khodyakov, 2007; Clark et al., 2018). Women's increased involvement in caring for family members along the life course (Silverstein et al., 2006) might explain these findings. Indeed, a recent study examining individual and health care factors associated with involvement in ACP in 11 developed countries found that greater informal caregiving was associated with higher involvement in ACP activities such as conversations with family and health care providers (Sable-Smith et al., 2017). Alternatively, the association between female gender and attitudes on ACP might be the result of a general tendency among women to plan for the future. Indeed, a study assessing older persons' advanced care planning showed that female gender was associated with greater planning behavior in a variety of areas (such as in the finance and socioenvironmental domains), not just in the health domain (Black et al., 2008).

Finally, similar to Garrido and colleagues (2012), multivariate analyses showed that religiosity, but not religion, emerged as an important sociodemographic characteristic associated with lower levels of positive attitudes toward ACP. While religion refers to an affiliation to a specific faith group, religiosity refers to the basic spiritual and existential beliefs of a person (Beit-Hallahmi, 2015). As the basic beliefs of the main monotheistic religions (Judaism, Islam, and Christianity) toward death, dying, and end-of-life issues are very similar (Puchalski & O'Donnell, 2005), our findings are not surprising, although they stress the need to examine the association between these beliefs and ACP further.

However, the principal finding of this study is the prominence of subjective knowledge on Alzheimer's disease as a correlate of attitudes toward ACP beyond the contribution of sociodemographic measures. While a couple of studies have examined the associations between ACP and patients' knowledge of their disease (see a systematic review on the topic by Ng et al., 2015), to our knowledge, our study is the first to establish the contribution of subjective knowledge on Alzheimer's disease to attitudes toward ACP. This is surprising especially because studies conducted with professional caregivers found that patients' knowledge on their disease plays a central role in their own end-of-life decision-making (Braun et al., 2010; Mousing et al., 2018). The association between knowledge of Alzheimer's disease and ACP attitudes is especially important in the area of Alzheimer's disease because of 2 reasons. First, as stated above, the disease is associated with a certainty of losing the capacity to express wishes and preferences as the disease progresses. Second, although initiating ACP as early as possible is strongly recommended in the case of Alzheimer's disease (Ryan et al., 2017) and is even included as a priority in national dementia

strategies in many countries (Fortinsky & Downs, 2014; Nakanishi et al., 2015) including Israel (Brodsky, Bentur, Laron & Ben-Israel, 2013; Bentur & Sternberg, 2017), studies show that in practice it is hardly applied (see Dixon et al., 2018). Our findings suggest that increasing laypersons' knowledge of the disease will improve their attitudes toward ACP and may, ultimately, increase its practice, as we showed that persons who reported being involved in informal ACP had more positive attitudes toward the process.

The lack of associations between attitudes toward ACP and beliefs of susceptibility, worry, and familiarity was surprising. Indeed, these are important factors in cognitive models of health behavior in general (Ferrer & Klein, 2015), as well as in a study assessing these beliefs in relation to ACP among persons aged 65 years and over and their caregivers (Fried et al., 2009). As it has been demonstrated that the importance of risk perceptions in health behavior models increases with the salience of the threat (Ferrer & Klein, 2015), the young age of our sample might explain the lack of association we found. The use of single questions to assess complex health beliefs might provide another explanation for our findings.

This study had a number of limitations. First, its cross-sectional design limits our capacity to demonstrate causal relationships. Second, we examined participants' awareness only in relation to advanced directives and durable power of attorney and did not ask whether they have heard of ACP. Future studies should also examine terms such as "choosing life-saving treatments," "choosing comfort measures," or, even, "advance care planning" itself as part of ACP awareness. Third, as stated, single questions were used to assess health beliefs on Alzheimer's disease. Fourth, the question used to assess knowledge reflected perceived knowledge (i.e., an individual's subjective assessment of general knowledge) rather than their actual knowledge (i.e., the extent to which an individual can recognize general factual information on a disease). The contribution of the present study would have been expanded if additional measures of Alzheimer's disease knowledge were included. Another limitation is that the examination of knowledge was focused only on Alzheimer's disease. Future research examining knowledge of other diseases is required to determine the relative importance of knowledge of Alzheimer's disease. Finally, similar to other public surveys, we relied on the participants' own reports, which might be affected by their honesty, their understanding of the questions, and social desirability bias. However, we hope the use of a pretested, anonymous questionnaire and the extensive experience of the interviewers minimized these biases.

Despite these limitations, our findings have substantial theoretical and practical significance. Theoretically, they contribute to the emerging conceptualization of ACP within the framework of public health and health promotion. This view calls for educating and informing the general public as early as possible, with special attention to younger persons (Seymour, 2018). Our study, however, found no age-related differences in laypersons' attitudes toward ACP, suggesting that interventions aimed at increasing awareness of the topic might use similar messages to younger and older persons.

Moreover, the present study encourages the use of cognitive models of health behavior by assessing intra-personal beliefs and knowledge (Galloway, 2003) to understand ACP attitudes. It also suggests that expanding knowledge about Alzheimer's disease, an aim that has been defined as a priority by national strategies worldwide to decrease stigma (Alzheimer Disease International, 2018), might be important in the case of ACP as well.

Practically, our study supports recent efforts to develop and implement effective and culturally sensitive website interventions to increase laypersons' understanding of ACP and facilitate their involvement in the process (Sudore et al., 2017b; Jimenez et al., 2018; Lum et al., 2018; Pereira-Salgado, et al., 2018). Moreover, it suggests including a module on knowledge of Alzheimer's disease as one of the components of these interventions.

Disclosures

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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