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# Coping With Client Death: How Prepared Are Home Health Aides and What Characterized Preparedness?

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## Abstract

This study explored the experiences of 80 home health aides (HHAs) whose client died within the last two months. Data collection involved comprehensive semi-structured in-person interviews to try to better understand characteristics of HHAs and their clients associated with preparedness for death. Among those, personal end-of-life (EOL) care preferences of HHAs and having knowledge of preferences and decisions regarding client's EOL care showed significant links to preparedness. Findings suggest that HHAs' preparedness for client death could be enhanced both by addressing their personal views on EOL care and by providing more information about the client's EOL care plans.

### Keywords

client death; direct care staff; end-of-life care; grief; home care workers; preparedness

### INTRODUCTION

Home care is one of the fastest growing healthcare sectors and the number of home health aides (HHAs) is estimated to reach almost 1.3 million in the US by the year 2018 (Bureau of Labor Statistics, 2014). As many elders indicate a wish to be cared for at home, it is likely that the demand for homecare services will exceed the capacity of the workforce (Higginson & Sen-Gupta, 2000) in the future. HHAs also play an increasingly important role in providing palliative and end-of-life (EOL) care in the community. In this care context, HHAs are often confronted with the death and dying of their clients. However, to date, little attention has been paid to HHAs' experiences around a client's death.

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By providing the bulk of the day-to-day care and sometimes being the only regular social contact a client has, HHAs often develop close and strong ties to their clients. In their own voice, HHAs have described relationships with clients as friendships or even family-like (Piercy, 2000). In a similar vein, Herber & Johnston (2013) highlighted that HHAs spend a great deal of their time providing emotional and other support to both clients and clients' families, and the main work-related challenges in this profession include the emotional attachment to the client. This issue is also reflected in HHAs' grief reactions after client death that have recently been shown to reflect many of the core grief symptoms reported by bereaved family caregivers (Boerner, Burack, Jopp & Mock, 2015). This study also found that feeling not at all prepared for client death is rather common among HHAs, and identified low preparedness for death as one of the main predictors of more intense grief among direct care staff.

These findings are consistent with prior research on preparedness for death among family caregivers that have shown significant associations between low levels of preparedness for death and higher separation and traumatic distress, more symptoms of complicated grief and depression, as well as higher anxiety and low quality of life (McCarthy et al., 2010; Hebert, Dang & Schulz, 2006a; Valdimarsdottir, Kreicbergs & Hauksdottir, 2007; Hauksdottir, Steineck, Furst & Valdimarsdottir, 2010a). Only one of these studies identified patient and caregiver factors as predictors of preparedness (Hauksdottir, Valdimarsdottir, Furst, Onelov & Steineck, 2010b). These included patient age and disease progression, health care-related information, and awareness of and willingness to talk about impending death, or efforts to avoid thinking and talking about the topic.

The issue of preparedness for death may be especially important for HHAs because of their unique work environment. HHAs care for their clients in the clients' homes. Families and clients often wish for an HHA to behave as if they were part of the family, while at the same time paying for this service, which is what Hochschild (2003, p.203) referred to as a "marketized private life." Similarly, Herber & Johnston (2013) highlight role ambiguity as a major challenge for HHAs. An example often times described in this context is that of families expecting the HHA to go beyond the job description (e.g., performing household tasks such as cleaning or staying with the client beyond the paid shift). The role ambiguity is also likely related to the close relationship HHAs have to their clients, which may cause them to feel obligated to adhere to the family's or the client's wishes even if they are not part of their job description. This closeness between HHA and client/client's family amplifies a blurring of boundaries. Due to this easy blurring of boundaries and the perception of the HHA-client relationship as friendship or family-like (Piercy, 2000), it may sometimes become unclear to the HHAs which expectations apply, those of the work life or those of the private life. Denton, Zeytinogly & Davies (2002) were able to show an positive association between HHAs' job stress and having to deal with difficult, demanding clients. Even though support from peers was associated with less job stress, it is important to note that the work environment of HHAs entails only infrequent contact with coworkers or supervisors. Instead, HHAs are often times solely responsible not only to provide care but also to notify other health care professions about changes they observe in a client (Piercy, 2000). This responsibility makes it all the more important for HHAs to be knowledgeable

about and prepared for a client's death and dying in order to appropriately monitor changes in client status and provide appropriate care.

The death of a client has unique pragmatic consequences for HHAs, in particular the loss of income until reassignment to a new client has occurred. After a client's death, HHAs leave their familiar work environment and must wait for their agency to reassign them. This adds even more strain to their situation after a client's death. A quick reassignment is vital for HHAs for continuity of income. However, given the finding of more intense grief reactions associated with low levels of preparedness (Boerner et al., 2015), one can imagine that it might be difficult for a HHA, who had close ties with a client who passed and felt not at all prepared for his/her death, to quickly connect with a new client.

But what exactly does preparedness for death entail? As the available empirical evidence suggests that being told a prognosis does not necessarily translate into an overall sense of preparedness, it has been noted that preparedness might be better understood if knowledge or information about an imminent death and the emotional or mental aspect of preparedness are differentiated and explored separately (Hebert, Prigerson, Schulz & Arnold, 2006b). Subsequently, Hebert, Schulz, Copeland & Arnold (2009) argued that preparedness for death can be conceptualized as a multidimensional construct, and suggested that caregiver preparedness could be enhanced by targeting both cognitive/informational as well as emotional preparation. Hebert et al. (2009) noted a third, behavioral dimension to preparedness referring to activities such as estate planning and funeral arrangements. Since these activities are often exclusively taken care of by family members, we decided to focus on informational and emotional preparedness as they are applicable to professional caregivers. When we speak about informational preparedness we refer to a clear understanding of the clients' condition, care needs and goals of care for the client, whereas emotional preparedness focuses on feeling mentally/emotionally prepared through finding closure or reaching at state of being at peace with the impending loss. The finding of a significant positive correlation but not complete overlap between emotional and informational preparedness for death among direct care staff (Boerner et al., 2015) supports the notion of an emotion- versus information-based facet of preparedness.

Hence, building on previous research related to grief and preparedness for death among family and staff caregivers (e.g., Rickerson et al., 2005, Boerner et al., 2015, Hebert et al., 2006a), we had two aims for this study. Our first was to identify characteristics of the HHA and the client (as per HHA's knowledge and perceptions) that may influence the HHA's emotional and informational preparedness for the client's death. Our second aim was to determine which of the associated characteristics relative to one another may be most important in explaining variation in preparedness among HHAs, and if predictive patterns differ for emotional versus informational preparedness for client death.

#### METHODS

#### **Recruitment and eligibility**

This study is part of a larger mixed-method study that looked at bereavement in direct care staff in nursing homes and in homecare. For the homecare sample, we recruited actively

employed HHAs from the community service division of an elder care system in Greater New York, and other agencies subcontracted by this long-term care organization. HHAs had to have experienced the death of a client for whom they were the permanent HHA within approximately two months to be eligible. The two-month time frame was chosen to ensure that interviews with participating HHAs are close enough to the event of the death that reports can be meaningfully tied to it. The participating agencies' administrative staff informed us when client deaths occurred and asked the primary HHA of the deceased client if it was permissible for study personnel to contact them. If the HHA agreed, study staff followed up with a phone call to explain the study and schedule an interview. Since English language proficiency was not a job requirement for HHAs and the pool of potential participants included individuals whose primary language was Spanish, HHAs could choose to complete the interview in Spanish. Of a total of 122 HHAs we attempted to reach, 38 could not be reached within two months of the client's death due to HHAs' schedules (e.g. sick time or vacation) and limitation in research staffing. 80 out of the 84 we were able to reach agreed to participate and the other four refused. Thus, the overall response rate was 95%. The participating HHAs were representative of the larger pool of HHAs serving the organization's clients with regard to age, gender and tenure. However, when compared by race and ethnicity, we found a difference in the proportion of Black and Hispanic HHAs. Our study sample was 67% Black and 29% Hispanic, whereas the larger pool of HHAs was 33% Black and 64% Hispanic.

#### **Data Collection and Measures**

One-to-one interviews were conducted in-person by four trained interviewers with a Bachelor's or Master's degree. Interviews lasted on average 83 minutes (ranging from 37 to 196) at a place and time that was convenient to the participant. Prior to all interviews written informed consent was obtained and participants received \$30 for their time. Interviews were never conducted during the HHAs' work hours.

The larger study was designed as a mixed method study with a data collection involving semi-structures interviews. The interviews included both standardized measures (e.g. HHAs' personal EOL care preferences) and sections with open-ended questions about the staff members' experiences after client death (e.g. knowledge of client's EOL care preferences and decisions). While these sections had preset questions, we allowed for narrative development within the sections. (Responses were written down verbatim, entered into a word file after the interview and then uploaded into Atlas/ti, a qualitative analysis software). However, the indicators from the open sections that we selected for the present paper based on previous literature were most adequately captured with dummy coding (yes/no) due to the nature of the participant responses to these questions (see description of Knowledge of client's and/or family's EOL care preferences and decisions below).

*Preparedness for death* was assessed with two questions based on prior work examining preparedness for death among family caregivers (Hebert et al., 2006a): To what extent were you prepared for the client's death mentally or emotionally?; To what extent were you prepared for the client's death in terms of the information you had about his/her state/your

understanding of the situation? Participants scored each of the two items on a 4-point Likert scale ranging from (1) not at all to (4) very.

*Socio-demographic* characteristics assessed included age, gender, education, marital status, and race/ethnicity. Length of time care was provided to the deceased client was addressed with the question: For how many months/years did you provide care to this client?

**Prior experiences with client death**—HHAs were asked whether or not they ever experienced the death of a client before.

**HHAs' personal EOL care preferences**—Participants were asked to indicate their agreement with a selection of personal EOL care preferences commonly reported and sensitive to ethnic/cultural differences (e.g., Duffy, Jackson, Schim, Ronis & Fowler, 2006; Steinhauser et al., 2000). Items were assessed on a 5-point Likert scale ranging from (1) Disagree a lot to (5) Agree a lot. For the present analysis we selected the four items most relevant as indicators of the HHA's palliative care orientation ("I want to use all possible treatment options no matter what the chance of recovery", "Using pain medication is very important to me", "I prefer not to be told bad news", "I'm in favor of alternative medicine").

**Perception of client at end-of-life**—HHA's perception of the client as being "in pain" and "aware of dying" during the last weeks of were each rated on a scale from (1) not at all to (4) very much.

Knowledge of client's and/or family's EOL care preferences and decisions— HHAs' knowledge of the client's and/or families' wishes concerning EOL care and treatment was addressed with the following three open-ended questions: Were you aware of the preferences for EOL care that (client) might have had? Were you aware of the preferences for EOL care that (client's) family might have had? How did you feel about care-related decisions that (primary contact) made? Since almost half of HHAs reported not knowing about client/family EOL care preferences or family care-related decisions, responses were coded based on whether or not a HHA indicated having knowledge of either aspect. Thus, we formed two variables, one reflecting whether (1) or not (0) the HHA had knowledge of the client's and/or client family's care preferences, and the other reflecting whether (1) or not (0) the HHA was aware of care decisions made by the client's family.

#### **Statistical Analysis**

Associations of preparedness outcomes and continuous variables were evaluated with bivariate correlations and associations with categorical variables were examined with ANOVAs. Multiple regression analysis was used to assess the relative role of associated characteristics for emotional and informational preparedness. Due to the limited sample size, we were parsimonious in our selection of correlates, focusing on those characteristics that had shown marginal or significant bivariate associations with at least one of the two preparedness outcomes.

# FINDINGS

Descriptives of sample characteristics and major study variables are displayed in Table 1. Reflective of the larger population of HHAs, participating HHAs were mostly women. Regarding ethnicity, about one third identified as Hispanic, and nearly all those endorsed either white or other for race two thirds of the sample identified as Black for race and endorsed "not-Hispanic" for ethnicity. Most HHAs were High School graduates or had at least some college. Almost one third indicated being married or living as married, another third being divorced or separated, and a little more than a third reported having never been married. About half of HHAs reported never having experienced a client death before. On average the HHAs had been working in the profession for 6 to 7 years and cared for their deceased client for 18 months. Over 40% of the HHAs reported not having any knowledge of the client's or client's family's EOL care preferences or care-related decisions.

To address our first aim, which was to examine HHA and client characteristics, as described by HHAs, associated with emotional and informational preparedness, associations between the two facets of preparedness and continuous variables were evaluated with bivariate correlations and associations with categorical variables were examined with ANOVAs (Table 2). Endorsing the personal EOL care preference to prefer not to be told bad news was associated with less emotional preparedness, while endorsing the EOL care preference of favoring alternative medicine was related to greater emotional preparedness. Greater emotional preparedness was also found in HHAs who perceived their client as being aware of dying at the EOL and having some knowledge of the client's EOL care preferences.

Similar characteristics showed analogous significant associations with informational preparedness, in particular preferring not to be told bad news, perceiving the client as being aware of dying and having knowledge of client's EOL care preferences. Informational preparedness also yielded additional significant associations. Significantly greater informational preparedness was found in HHAs who perceived the client as being in pain at the EOL and who reported having some knowledge of care-related decisions.

Our second aim to determine the relative influence of associated characteristics on explaining variance in emotional and informational preparedness was examined with multiple regression analysis. Findings are displayed in Table 3.

The regression model for emotional preparedness explained 36% of the total variance, with endorsing a personal preference for not being told bad news and favoring alternative medicine, perceiving the client as aware of dying, and having knowledge of client's EOL care preferences as significant predictors. Preferring not to be told bad news predicted less emotional preparedness. Favoring alternative medicine, perceiving the client as aware of dying at the EOL and knowing about client's EOL care preferences were all predictive of greater emotional preparedness. Other predictors such as experienced death of client before, perceived client as being in pain at the EOL and knowledge of care-related decisions did not significantly add to explaining variance in preparedness outcomes, suggesting a relatively lesser role of these compared to the other characteristics in the equation.

The regression model for informational preparedness explained a similar proportion of the total variance (38%), and showed mostly similar individual effects as the model for emotional preparedness: preferring not to be told bad news was associated with less informational preparedness, whereas perceiving the client as aware of dying and the EOL and knowing about client's EOL care preferences were associated with greater informational preparedness. However, in contrast to the predictive pattern for emotional preparedness, favoring alternative medicine did not show a significant effect for informational preparedness, showed a marginal, positive effect for informational preparedness.

#### DISCUSSION

This study is a first step towards developing an understanding of what may characterize preparedness for client death among direct care staff working in the community. Consistent with prior research on factors related to preparedness among family caregivers (Hauksdottir et al., 2010b) study findings demonstrate significant associations for personal characteristics of the HHA (e.g. personal EOL care preferences) as well as attributes related to the client (e.g. client observed as being aware of dying). Furthermore, study findings supported the conceptual argument that preparedness for death is a multi-faceted construct (Hebert et al., 2009), encompassing emotional and information-related components, and that strategies to increase preparedness may need to target some similar but also some unique aspects to affect preparedness in both regards.

HHAs personal EOL care preferences were significantly related to the extent of preparedness for death. HHAs who endorsed the statement to prefer not to be told bad news were likely to report both less emotional and informational preparedness, perhaps implying a more avoidant attitude towards death and dying. Greater emotional preparedness was found in HHAs who expressed that they favor alternative medicine, possibly reflecting a personal perspective on health and health care in which health problems are seen as natural processes that may be supported with natural means. These findings suggest that addressing personal EOL care preferences in initial training and ongoing education might be beneficial not only for HHAs to be more prepared for a client death, but also for the client since a more avoidant attitude towards death and dying of might hinder the HHA's ability to adequately care for a client at the end-of-life. In particular the ability to provide emotional support during that time, one of the most frequently mentioned activities of HHAs (Herber & Johnston, 2013), might be limited when HHAs have a more avoidant attitude towards death and dying. The notion to address personal EOL care preferences in training is further supported by Leclerc et al. (2014) who showed that attitudes towards death, dying and EOL care did not differ depending on the time spend with clients but rather on the level of education. Those with higher levels of education (such as registered nurses, physicians, clinical managers and rehabilitation staff) reported more favorable attitudes towards death, dying and EOL care than hands-on caregivers (such as nursing assistants, patient assistants and volunteers).

HHAs who perceived that their client was aware of dying were likely to report both greater emotional and informational preparedness. Awareness of dying shows a significant negative

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correlation with the before mentioned EOL care preference to prefer not to be told bad news (r = -.31; p < .05). This could mean that HHAs endorsing such views are less likely to notice awareness of upcoming death in a client. In any case, the association between personal EOL care preferences and the perception of the client at the EOL underscores how important it is to address these personal views.

Observing the client as being in pain was associated with greater informational preparedness, but not with emotional preparedness. However, based on the available data, we do not know if such observations reflected actual pain experienced by the client, or if those HHAs who reported less informational preparedness and perception of their client as being in pain might have had clients who did not experience pain. Thus, our finding has to be taken with caution. How perceptions of client suffering, and client reported or otherwise evidenced signs of suffering might be related to staff preparedness is an interesting point for further study. If increased informational preparedness indeed led to improved pain recognition and management or vice versa, it seems that both would be worthwhile goals to pursue. Research has shown that even home care nurses, who receive considerably more training than HHAs, have less than optimal scores when tested on knowledge and perceived competence in pain management (Glajchen & Bookbinder, 2001). Considering that optimal pain management is a core goal of palliative care efforts, particular attention to HHAs' preparedness seems important, since they not only have daily contact with their clients, but also have the responsibility to alert other health care professions about significant changes or the presence of distressing symptoms, including pain, they might observe in the client (Devlin & McIlfatrick, 2010).

Both emotional and informational preparedness were greater in HHAs who reported some knowledge of client EOL care preferences, whereas knowledge of client care-related decisions was only linked to greater informational preparedness. That over 40% of the HHAs reported having no knowledge of either of these topics is important to note, considering their key role in managing a client's care on a daily basis (e.g. alerting other health care professions about changes, such as a nurse or emergency medical services). Findings suggest that having more information about a client's status, care preferences and care-related decisions might contribute to HHAs being better prepared for client death. Additionally, being more informed might also help to ensure that the care provided by the HHA is in line with the client's and/or family's wishes and with existing care plans. Difficulties in communication with other services and a need for increased support and supervision (Devlin & McIlfatrick, 2010) are problems frequently mentioned by HHAs which might be even more relevant when HHAs are not well informed about a client's EOL care preferences. If HHAs have to decide whether or not further intervention such as a hospitalization is needed and they are not provided with information on client preferences, they cannot factor in these preferences which might lead to unwanted medical interventions.

Several potential limitations of our research deserve mention. First, although we offered HHAs the choice to complete the interview in Spanish, the number of Hispanic HHAs was an underrepresentation of the population, as noted above. Future research might use an oversampling strategy to achieve a representative balance of ethnicity. Second, we only assessed HHAs' subjective perception of the client at the EOL and did not collect further

objective medical information about the client's status. This might provide a more detailed understanding of the client at the EOL in future studies. Third, we asked HHAs retrospectively to report their preparedness. Such retrospective assessments of preparedness for death can always be biased by the person's adjustment to the loss or other current events. Additionally we assessed each type of preparedness with a single item. Developing reliable multi-dimensional tools to measure preparedness in the future would enable an understanding of the relative importance of different domains of preparation and subsequently to develop targeted interventions for those aspects. Future research might also include an assessment of the work environment to get a better understanding of care context characteristics related to preparedness for death. Finally, the cross-sectional nature of the data did not allow us to discern the directionality of the identified association. Thus, we cannot determine if the characteristics associated with preparedness were aspects that influenced preparedness, if HHAs' levels of preparedness affected how they reported these characteristics, or if both was the case. However, regardless of which causes which, both enhancing HHAs' capacity for pain recognition and increasing their preparedness for client death are efforts that point in the same direction, which would be to strengthen the HHA's position and ability to provide the best possible EOL care. Similarly, having more information about a client's status and addressing personal EOL care preferences in educational sessions may help HHAs feel more prepared for client death, and increased preparedness may in turn lead to greater reflection among the HHAs on their personal EOL care preferences and how these views may impact their work life.

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#### Table 1

#### Descriptive Information on Sample Characteristics and Study Variables (N=80)

	Mean (SD)	Range	N (%)
Gender (Female)			77 (96)
Age	43.2 (12.5)	24-69	
Ethnicity (Hispanic)			23 (29)
Race			
Black			52 (67)
White			8 (10)
Asian/Pacific Islander/Native			3 (4)
Other			15 (19)
Education			
Grades 7-9			8 (10)
Grades 10-11			8 (10)
General Educational Development (GED)			4 (5)
High School graduate			25 (31)
Some college/graduate			34 (42)
Marital status			
Married/living as married			23 (29)
Divorced/separated			24 (30)
Widowed			2 (3)
Never married			31 (39)
Years in profession	6.5 (6.6)	.16-29	
Months since client's death	1.08 (.98)	0-3	
Months cared for client	18 (29)	.03-168	
Experienced the death of a client before			39 (49)
Personal EOL preferences			
Prefer not to be told bad news	2.89 (1.65)	1-5	
In favor of alternative medicine	4.14 (1.30)	1-5	
Want to use all possible treatments	4.08 (1.37)	1-5	
Pain medication is very important	3.76 (1.44)	1-5	
HHA's perception of client at EOL			
HHA perceived client as aware of dying	2.86 (1.36)	1-4	
HHA perceived client as being in pain	2.73 (1.18)	1-4	
Knowledge of client EOL care preferences			42 (53)
Knowledge of care-related decisions			47 (59)
Preparedness			
Emotional	2.21 (1.22)	1-4	
Informational	2.23 (1.26)	1-4	

Note. SD= standard deviation.

# Table 2

Bivariate Associations of HHA Characteristics and Resident Status With Emotional and Informational Preparedness (N=80)

						acount index
	-	M (SD)	Significance	r	(QD)	Significance
HHA characteristics						
Age	.05		p = .68	.04		p = .70
Hispanic						
Yes		2.35 (1.11)	F(1,78) = .40		2.30 (1.22)	F(1,78) = .13
No		2.16 (1.27)	p = .53		2.19 (1.29)	p = .72
Black						
Yes		2.17 (1.26)	F(1,78) = .15		2.23 (1.34)	F(1,78) = .00
No		2.29 (1.15)	p = .70		2.21 (1.13)	<i>p</i> = .96
Years in profession	07		p = .54	02		p = .86
Months cared for client	18		p = .12	09		p = .44
Experienced death of a client before						
Yes		2.33 (1.28)	F(1,78) = .75		2.41 (1.28)	F(1,78) = 1.65
No		2.10 (1.6)	p = .39		2.05 (1.23)	p = .20
Personal EOL care preferences						
Prefer not to be told bad news	35		p = .00	30		p = .01
In favor of alternative medicine	.29		p = .01	.26		p = .26
Want to use all possible treatments	05		p = .68	04		p = .73
Pain medication is very important to me	.07		p = .57	.02		p = .84
Client status						
HHA's perception of client at EOL						
HHA perceived client as aware of dying	.43		p = .00	.46		p = .00
HHA perceived client as being in pain	.19		p = .11	.28		p = .01
Knowledge of client EOL care preferences						
Yes		2.64 (1.17)	F(1,78) = 12.65		2.64 (1.30)	F(1,78) = 10.90
No		1.74 (1.11)	p = .00		1.78 (1.06)	p = .00
Knowledge of care-related decisions						
Yes		2 34 (1 26)	F(1 78) = 1 27		2.49(1.35)	F(1 78) - 5 26

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*Note.* r = correlation coefficient; M = mean; SD = standard deviation.

# Table 3

Regression Analysis for Emotional and Informational Preparedness (N=80)

	Emotio	nal pre	Emotional preparedness	Informat	ional p	Informational preparedness
	B (SE)	β	Significance	B (SE)	β	Significance
HHA characteristics						
Experienced death of a client before	.00 (.26)	00.	66.	49 (.25)19	19	.05
Personal EOL care preferences						
Prefer not to be told bad news	18 (.08)	24	.03	16 (.08)	21	.05
In favor of alternative medicine	.22 (.10)	.23	.03	.14 (.10)	.14	.16
Client Status						
HHA's Perception of client at EOL						
HHA perceived client as aware of dying	.22 (.11)	.24	.05	.24 (.11)	.26	.03
HHA perceived client as being in pain	.09 (.11)	60.	.42	.21 (.11)	.20	.07
Knowledge of client EOL care preferences	.64 (.27)	.26	.02	.61 (.27)	.24	.03
Knowledge of care-related decisions	12 (.27)	05	.65	.11 (.27)	.04	.70
$R^2$	.36		00.	.38		00.