

# Marginal Competence, Risk Assessment, and Care Decisions: A Comparison of Values of Health Care Professionals and Older Adults

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## RÉSUMÉ

Par l'utilisation d'un scénario impliquant une femme âgée vivant seule compétent marginalement à risque, nous avons évalué les décisions liées aux soins réalisés par les adultes plus âgés ( $n = 82$ ) et les professionnels de la santé (professionnels de la santé,  $n = 87$ ), et les différences identifiées dans les valeurs qui sous-tendent les décisions relatives aux soins. Dans l'ensemble, les participants n'ont pas placé une grande valeur à l'indépendance quand on a évalué les risques pour le client comme plus élevé et la sécurité comme aussi bas. Dans ces conditions, les répondants âgés tendaient à être plus paternaliste dans leurs décisions concernant les soins, tandis que les professionnels de la santé ont tendance à être plus salubre. Si les valeurs des professionnels de la santé diffèrent de ceux des personnes âgées, quelle est la probabilité que les soins dispensés aux personnes âgées peu compétentes seront conformes à leurs désirs? Les soins donnés par les professionnels de la santé pourrait être améliorés en y incorporant la connaissance des valeurs et des perspectives des autres adultes âgés.

## ABSTRACT

Using a case scenario involving a marginally competent elderly woman living alone at risk, we assessed the care decisions made by older adults ( $n = 82$ ) and health care professionals (HCPs,  $n = 87$ ), and identified differences in the values underlying the care decisions. Overall, participants did not place a high value on independence when they appraised the risk to the client as high and safety as low. Under these conditions, elderly respondents tended to be more paternalistic in their decisions about care, while HCPs tended to be more beneficent. If the values of HCPs differ from those of elderly people, how likely is it that the care provided to marginally competent elderly people will be congruent with their wishes? The care provided by HCPs might be improved by incorporating knowledge of the values and perspectives of other older adults.

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## Introduction

Within the framework of client-centred care, clients are assumed to be competent, autonomous beings with values that provide standards against which they will weigh information and make decisions. Clients are in the best position to make health care decisions on their own behalf because they are the experts on what is

important to them. The role of the professional is to provide technical knowledge to clients so that decisions can be made on the basis of accurate information. It is accepted that competent clients might make, in the eyes of others, bad or foolish choices, but that it is their right to do so without interference (Kluge, 2005). If a client is incompetent, then there are legal and clinical

practices in place that allow others to make the necessary decisions and that delineate the role of the health care professional in such a situation. Problems arise, however, when the client falls into a grey area of marginal competence. Legally, this client is still deemed competent, yet his or her ability to make rational decisions might be compromised. In this situation, health care professionals (HCPs) generally lack guidelines about how to proceed with decision making.

This issue – the ability to make rational decisions – has particular salience for the growing population of marginally competent elderly people living alone in the community. The Canadian Study of Health and Aging found that an estimated 37,800 (31.4%) elderly persons with dementia live alone in the community and are potentially at risk (Alzheimer Society, n.d.). Dementia is a behavioural diagnosis that identifies people with cognitive impairment. This cognitive impairment is assumed to be related to underlying brain pathology. However, a period of marginal competence can occur whereby an individual is deemed neither competent nor incompetent. Frequently, elderly individuals with a dementia and living alone come to the attention of HCPs when it appears they are “at risk” or unsafe, but adamant about remaining at home (Tuokko, MacCourt, & Heath, 1999). Both the ratings of risk and safety, and the resulting action that HCPs believe to be required, are value laden (Silberfeld & Fish, 1994). Risk is a subjective notion and can be assessed differently by each observer on the basis of personal values and tolerance for ambiguity (Clemens, Wetle, Feltes, Crabtree, & Dubitzky, 1994). It is often assumed that marginally competent elderly persons are unable to articulate their values and/or defend them. This belief has led to others imposing their values and decisions upon these individuals. If marginally competent clients are not assumed to be autonomous decision makers whose decisions are based on information filtered through personal values, then whose values should underlie decisions made about them or their circumstances?

HCPs can lay no claim to special expertise in making appropriate decisions for marginally competent people. HCPs are trained to base their decisions on knowledge, technical criteria, and objective data, and to avoid personal biases and subjectivity. In the absence of clear roles and responsibilities in situations involving marginally competent individuals, the decisions that are made are nevertheless likely to reflect an HCP’s personal and professional values (Clemens & Hayes, 1997; Kaufman, 1995). While elderly persons and HCPs may share some similar personal values, they come from different age cohorts, and their values are quite likely to differ on this basis alone (Bradley, Zia, & Hamilton, 1996; Egri & Ralston, 2004; Keating, Fast, Connidis, Penning, & Keefe, 1997; ; Lawton, Moss, Hoffman,

Grant, Have, & Kleban, 1999; Shidler, 1998). By definition, HCPs’ practices are guided by values, which few older adults share, inculcated through their professional socialization (Clark, 1997; Clouder, 2003; Kane, Bershady, & Bershady, 2006). Indeed, using scenarios presented to 211 HCPs regarding recommendations for care, Kane et al. (2006) concluded that “Each discipline appears to have its own set of experiences and beliefs that may influence recommendations” (p. 474). Furthermore, HCPs’ practice decisions are also influenced by the values and goals of the health care system for which they work (Clark, 1997).

Given this situation, there is reason to believe that HCPs and elderly people may have different perceptions about the circumstances under which intervention in the lives of marginally competent older adults is warranted (Kane, Rockwood, Finch, & Philp, 1997). Some of these differences can be accounted for by differences in each group’s beliefs about what makes a life worth living. Indeed, some research has found that HCPs consistently underestimate the quality of life their elderly clients experience (Fitzsimmons, George, Payne, & Johnson, 1999; Otto, Dobie, Lawrence, & Sakai, 1997), and the level of treatment they desire (Ouslander, Tymchuk, & Rahbar, 1989). As these HCPs are often in the position of making judgements and decisions about marginally competent elderly people, such an attitude has the potential to be problematic.

In fact, the values of elderly people are more likely to reflect the values, life experiences, goals, and perspectives of other elderly people than those of HCPs. While it is acknowledged that elderly people are by no means a homogeneous group, they do share cohort experiences different from those of younger persons. These shared experiences can produce a unique outlook in terms of worldviews, development, and values. Also, if asked, elderly individuals are willing and able to articulate and prioritize the values they consider important in making health care decisions (Degenholtz, Kane, & Kivnick, 1997; Feinberg & Whitlatch, 2001; Mack, Salmoni, Viverais-Dressler, Porter, & Garg, 1997). Indeed, Degenholtz et al. (1997) found that elderly consumers of community long-term care attached the greatest importance to privacy and family involvement, as well as freedom and safety. However, they were ambivalent when asked to choose between the two, because they wanted both. Similarly, Raymond and Wentworth (1993) found that older clients did not view autonomy and safety as contradictory. Values such as these are thus likely to influence the decisions made by elderly persons (Arber & Evandrou, 1993; Aronson, 1990; Kaufman, 1994; King, Collin, & Liken, 1995).

In summary, different values lead to differences in health care decision making. These, in turn, have the

potential to influence individuals, policy, professional practice, and ultimately, client care. Older, marginally competent adults are highly vulnerable to having their quality of life underestimated by HCPs who use their own values to judge the quality of these individuals' lives (Miller & Bolla, 1998). Such under-valuation can shape the decisions made about, and the care provided to, marginally competent elderly people. Given that the values of HCPs are likely different from those of elderly people (Kane et al., 1997; McCullough, Wilson, Teasdale, Kolpakchi, & Skelly, 1993), how likely is it that the care provided to marginally competent elderly people will be what they want? This issue is particularly salient when a marginally competent adult is deemed to be "living at risk". Silberfeld (1992) stated that there is no formula for drawing a line between acceptable and unacceptable levels of risk, and that risk assessments themselves are highly value laden.

There has been a lack of research on how the values of elderly people and HCPs influence health care decisions for those living at risk. This study addressed this gap by examining the underlying values of a sample of elderly people and HCPs who have been asked to make health care decisions on behalf of a hypothetical marginally competent elderly individual living at risk. Using a vignette-based approach, we compared elderly people and HCPs in relation to (a) perceived safety and risk of harm; (b) recommended care (e.g., home, or institutional); and (c) the relationship between recommended care and both safety and risk of harm.

## Method

### *Participants*

The study employed two convenience samples: elderly people and HCPs. Although it is acknowledged that convenience samples may not be representative of the larger populations in question, a mail survey allowed for many questionnaires to be distributed broadly in a short period of time. Furthermore, this method ensured that there was no direct contact between participants and the researcher, thereby eliminating the possibility that the researcher unintentionally influenced participants to participate or respond in a particular manner. This process also ensured anonymity and confidentiality of participants in both groups.

Following ethical approval, participants were recruited through seniors' centres, recreational centres, and organizations where health care professionals were providing care to older adults. The seniors and recreational centres were located in a large urban area on Vancouver Island, British Columbia. The organizations targeted for the recruitment of HCPs were distributed throughout British Columbia. Survey packages containing an information letter about the study, a community

and facility care information sheet, and the questionnaire were mailed to these organizations. The respective organizations were asked to make the survey packages available to the seniors and HCPs. Two hundred survey packages were mailed to seniors' associations and recreational centres, of which 86 (response rate of 43%) were completed and returned by elderly respondents. Similarly, 200 survey packages were distributed to professional associations, medical clinics, health units, and hospitals, of which 88 (response rate of 44%) were completed and returned by HCPs. The inclusion criteria for elderly participants included being over the age of 65 and living in the community. The inclusion criteria for HCPs included being employed in health care and being aged 65 years or less. Participants were asked to complete the questionnaire and return it by mail in the self-addressed, stamped envelope. Four incomplete questionnaires from the elderly sample and one from the HCP sample were discarded, leaving a total sample size of 82 elderly and 87 HCP participants.

To determine whether or not the sample size was adequate, a power calculation was done based on the mean difference ( $-0.003$ ,  $s = .006$ ) between 87 elderly persons and 82 HCPs in their safety rating of mentally incompetent persons. For a two-tail test, the resulting power calculation is 90.13 per cent suggesting that the sample of 169 elderly persons and HCPs is sufficient for the proposed analyses.

### *Elderly Participants*

The mean age of elderly participants was 73 years, and 73.2 per cent of respondents were female. The majority of participants were married (54.9%), while 54.3 per cent lived with a spouse and 1.4 per cent lived with another family member. Over three quarters of the elderly participants (78.9%) rated their health as good or better. Very few of the participants had not completed high school (15.6%), with 48.8 per cent having gone on to college or university. Close to half (45%) of the participants received the British Columbia guaranteed annual income supplement (GAIN), which is used as an indicator of low-income status. Over one third of participants (35%) had at one time been employed in the health care sector, primarily as professionals. Almost one quarter of all participants had worked with older people prior to their retirement.

### *Health Care Professional Participants*

The mean age of HCPs was 47 years, ranging from 26 to 64 years old. One quarter of the HCPs were age 40 or under. The vast majority of respondents were female (85.1%) and married (84.9%). The primary professions represented by the HCPs included nurses (58.8%), physicians (18.9%), and social workers (9.4%). The

largest group of HCPs (39%) described their current practice as community-based (versus facility- or acute-based) and, on average, had practised in their professions for 20 years.

### *Materials*

#### *Information Sheets*

To ensure that participants based their decisions on current and accurate information about community support services and institutional care, an information sheet<sup>1</sup> about cost, eligibility, living accommodations, and available services was developed and provided to each participant. To ensure content validity, one administrator and two long-term-care case managers were asked to rate the clarity of presentation, accuracy of information, and objectivity of presentation using a five-point scale. When ratings of five were achieved for each dimension from all three respondents (the administrator and case managers), the information sheets were deemed valid.

#### *Questionnaires*

Separate questionnaires were developed for the elderly and HCP groups. The questionnaires were designed to be self-administered. The first section of the questionnaire was used to collect demographic information such as age, sex, marital status, and education. Elderly participants were also asked about living situation, health status, income, and past employment. Information concerning discipline, years of experience with elderly persons, and primary place of employment, (e.g., community or institution) was asked of HCPs. The second part of the questionnaire assessed respondents' personal experience in caring for elderly family members with dementia and their experience with community and facility care. The final section presented the scenario whereby respondents were asked to assess the situation of a hypothetical elderly person and to make decisions related to the care of this individual.

#### *Scenario*

Methods developed by Kelly, Knox, and Gekoski (1998) were modified for use in this study. Kelly et al. surveyed 434 women between the ages of 18 and 92 years about the long-term care choice (community or facility) they felt appropriate for a hypothetical elderly woman. One of the six scenarios developed by this group formed the basis for the scenario used in our study. As the focus of this study involved a marginally competent person, the chosen scenario was based on someone with moderate cognitive impairment (called Mrs. Smith). A modification was made to the scenario for this study that added descriptors of functioning associated with moderate cognitive impairment based on the Global

Deterioration Scale developed by Reisberg, Ferris, de Leon, and Crook (1982). To maximize value-laden decision making, the scenario was further modified to depict Mrs. Smith as living alone without informal support from nearby family members. A copy of the final scenario is found in Appendix 1.

#### *Measure of Values*

Rather than directly asking participants which values led to a particular decision, questions about health care decisions were asked that reflected the values of safety, rights, and obligations. As Clark (1991) pointed out, many people do not consciously make health care decisions on the basis of their values, and even if asked, cannot articulate the values that underlie their decisions. Furthermore, Horowitz, Silverstone, and Reinhardt (1991), in a scenario-based study of autonomy, noted that people did not explain their choices in terms of concepts like autonomy, beneficence or paternalism, but rather in terms of safety, rights, and obligations.

The scenario used in this study represented, as much as possible, the circumstance under which HCPs might make decisions on behalf of marginally competent individuals. Specifically, Mrs. Smith was portrayed as an elderly woman, unable to provide clear competent directions, but with a strong preference for remaining at home alone without services, despite a number of obvious potential risks to her. Note that the information provided in the scenario did not include Mrs. Smith's reasoning for wanting to remain living independently in the community. We felt that the introduction of this more subjective information might bias responses.

A series of questions (see Appendix 2) were developed to elicit the values underlying the health care decisions made by the participants. These questions were based on information derived from the literature describing five elements: (a) values held by elderly persons, their families, and HCPs concerning long-term care decisions (King et al., 1995; McCullough et al., 1993); (b) values held by elderly persons and their families concerning conflicts between the autonomy of elderly people versus their health and safety needs (Horowitz et al., 1991); (c) the value that elderly community-dwelling persons place on the trade-off between freedom and safety (Degenholtz et al., 1997; Raymond & Wentworth, 1993); (d) the experience of risk to independent living as perceived by community-dwelling elderly persons (Mack et al., 1997; Porter, 1994); and (e) how HCPs balance safety and autonomy for elderly clients at risk (Clemens & Hayes, 1997; Kaufman, 1995). Perceptions of risk and safety, as they affected the decisions made, were also explored.

After reading the scenario, participants were asked to rate: (a) Mrs. Smith's safety, and (b) the degree to which



they thought specific risk factors (e.g., self-injury, crime, isolation, not eating properly, poor hygiene, or not getting help quickly) jeopardized Mrs. Smith's ability to remain living independently. The scale used to rate safety ranged from extremely unsafe (1) to completely safe (5), while the scale used to rate risk factors ranged from no risk (1) to major risk (5). Participants were next asked to identify the kind of care they would recommend for Mrs. Smith. If risks were rated high and/or safety was rated low, the participants might act in a protective manner and choose facility care for the individual. If, instead, the participants chose community care or no care for the individual, this might imply that the highest value was placed on autonomy.

The entire survey package was pilot tested with a convenience sample of four older adults. Using a five-point scale, these individuals were asked to rate each question on the basis of clarity. In the case of ambiguity, a discussion was held between the older adult and the researcher to refine the question as needed. Once a perfect score was reached on all questions by each participant in the pilot study, the entire package was administered to three Home Support Supervisors and four psychogeriatric clinicians, and a similar procedure was followed.

## Analyses

A between-groups design was used to compare the care decisions made by the HCPs and the elderly participants on behalf of Mrs. Smith. To address the first issue of perceived safety and risk of harm, t-tests were used to examine the relationship between group membership and (a) the appraisal of how safe Mrs. Smith was perceived to be, and (b) the overall risk score derived by summing the individual risk factors. The relationship between group membership and each of the individual risk factor ratings was then examined using a multivariate analysis of variance (MANOVA). The MANOVA allows for the testing of multiple dependent variables simultaneously. Next, the issue of recommended care between groups (elderly persons and HSPs) for Mrs. Smith was examined using the  $\chi^2$  test of independence. The final question examining the relationship between recommended care and both safety and risk of harm was addressed in two parts. First, correlations were used to examine the relationship between risk factors, overall risk, and safety ratings (by all participants). Second, MANOVAs were used to examine the relationship between care choice and risk/safety within each group, and between groups. All analyses used an alpha level of less than 0.05 to determine significance.

## Results

### *Safety and risk of harm*

Elderly participants and HCPs did not differ in relation to their ratings of Mrs. Smith's overall safety ( $t = -.028$ ,  $p = .976$ ,  $df = 163$ ). In fact, both elderly participants ( $M = 2.256$ ,  $SD = 0.766$ ) and HCPs ( $M = 2.252$ ,  $SD = 0.702$ ) appraised Mrs. Smith's safety between "somewhat unsafe" and "very unsafe". MANOVA results, however, suggest that elderly participants and HCPs differ in relation to their ratings of specific risks, ( $F = 5.624$ ,  $p = .000$ ,  $df = 6,165$ ). HCPs rated the risk of not eating properly as a significantly higher risk to Mrs. Smith ( $M = 4.407$ ,  $SD = 0.772$ ) than did elderly participants ( $M = 4.025$ ,  $SD = 0.816$ ) ( $F = 9.519$ ,  $p = .002$ ,  $df = 1,165$ ). Elderly participants rated poor hygiene as a significantly higher risk to Mrs. Smith ( $M = 3.5823$ ,  $SD = 1.093$ ) than did HCPs ( $M = 3.1860$ ,  $SD = 1.297$ ) ( $F = 4.460$ ,  $p = .036$ ,  $df = 1,165$ ).

### *Recommended care*

The majority (76%) of participants chose community care for Mrs. Smith. When examining differences between elderly persons and HCPs in relation to recommended care, a significant relationship was found ( $\chi^2 = 16.973$ ,  $p = .001$ ,  $df = 1$ ), with 37.8 per cent of elderly respondents selecting facility care compared to 10.6 per cent of HCPs selecting facility care. None of the participants selected "no care" as the recommended level of care for Mrs. Smith.

### *Relationship between recommended care and safety and risk of harm*

When the relationship between each risk factor and safety ratings was examined, with the exception of crime, a significant negative correlation was found between safety and all individual risk factors. In other words, lower safety was related to higher risk. All correlations were significant at the .01 level except poor hygiene, which was significant at the .05 level. When the relationship between care choice and risk/safety was examined, no significant relationships between the care choice made by HCPs and how they rated safety and risk measures was evident ( $F = 1.478$ ,  $p = .180$ ,  $df = 7,84$ ). When individual risk factors were examined, however, a significant relationship was found between the care choice and not receiving help quickly ( $F = 5.324$ ,  $p = .024$ ,  $df = 1,84$ ), and between the care choice and risk from poor hygiene ( $F = 7.387$ ,  $p = .008$ ,  $df = 1,84$ ). Specifically, the higher these risks were rated, the more likely HCPs were to recommend facility care.

For elderly participants, no relationship between care choice and the risk and/or safety measures was found

( $F = 1.476, p = .190, df = 7,79$ ). However, similar to HCPs, when individual risks factors were examined, significant relationships were found between the care chosen by elderly participants and the risk of not eating properly ( $F = 6.082, p = .016, df = 1,79$ ); and the risk of poor hygiene ( $F = 6.804, p = .011, df = 1,79$ ). In other words, the higher these risks were rated, the more likely that facility care was recommended.

When both groups were combined, a significant association between risk/safety measures and care choice was seen ( $F = 3.011, p < .005, df = 7,163$ ). Significant relationships were also found between choosing facility care and several specific risks: risk from not receiving help quickly ( $F = 4.082, p = .045, df = 1,163$ ); risk from poor hygiene ( $F = 17.032, p = .000, df = 1,163$ ); and risk of self-injury ( $F = 5.741, p = .018, df = 1,163$ ). There was also a significant relationship found between the recommended care setting and safety ( $F = 4.732, p = .031, df = 1,163$ ).

## Discussion

This study has demonstrated that there were both similarities and differences found between elderly participants and HCPs in terms of decisions made about Mrs. Smith's care, as well as the factors that influenced these decisions. The appraisal of risk and safety were similar between groups; the appraisal made by each group could be explained in terms of each group's values. Overall, the study participants did not place a high value on independence when they had appraised the risk to Mrs. Smith as high and her safety as low. In these circumstances, a significant number of elderly participants made decisions based on a sense of obligation, while HCPs made decisions based on safety.

When participants were asked to rate the risk to Mrs. Smith's independence from six specific risk factors (self-injury, crime, isolation, not eating properly, poor hygiene, not getting help quickly), both groups rated all of the risks as between "medium" and "substantial", but HCPs and elderly participants ranked the risk factors differently. The differences in how the risks were ranked reveal differences in how important HCPs and elderly participants believe each of the risk factors are as threats to Mrs. Smith's ability to live independently. The different ranking of risks between HCPs and elderly participants, suggesting that they hold different values about what constitutes risk to independence, is consistent with research by McCullough et al. (1993). In their study of long-term care decisions, it was found that in dyads of elderly individuals and HCPs, each party identified different values that they had found most relevant to making a long-term care decision for the elderly. Additionally, when Kane et al. (1997) had asked HCPs and elderly individuals

(unknown to each other) to rate 12 items of activity of daily living or ADLs (e.g., bathing, toileting, transferring) and instrumental activities of daily living or IADLs (e.g., using telephone, meal preparation) in terms of the debility that could result to an older adult from deficits in the domains, the two groups rated the items differently.

The specific risks that differed between the elderly and HCPs groups were the risks that poor hygiene and not eating properly were believed to pose to Mrs. Smith's ability to live independently. Elderly participants rated poor hygiene as a higher risk to Mrs. Smith than did HCPs, while HCPs rated not eating properly as a higher risk to her than did the participants. In the study conducted by McCullough et al. (1993), HCPs identified care/supervision and health as the most important values in making a long-term care decision, while elderly people identified values concerning environment (privacy) and self-identity as most important. In our study, it is possible that poor hygiene was construed by elderly participants as evidence of failure by Mrs. Smith to maintain continuity of herself as an adult with dignity. Alternately, HCPs may have perceived not eating properly as a significant health risk for Mrs. Smith. However, this is just one of many possible interpretations, and further research is necessary to increase our understanding of the complexities of these findings.

Our findings – that only safety rating and specific risk factors (i.e., risk of not getting help quickly enough, poor hygiene, and self-injury) predicted care choice made by participants regardless of whether they were HCPs or elderly people – suggest tension between safety and supervision on the one hand, and between risk and independence on the other. As noted by Kaufman and Becker (1996), these values (i.e., safety and supervision versus risk and independence) compete in the delivery of health care and in how we conceptualize elderly people and how they should be treated. Healy (1999) has contended that the tension between respecting autonomy and beneficence is reflected in the concern for safety in home care situations, derived from the concept of beneficence.

The tension between safety and supervision versus risk and independence is further reflected in our observation that only 40 participants (largely elderly) of the total sample of 167 chose facility care for Mrs. Smith, despite rating risk high and safety low. This suggests that the majority of participants in this study placed a higher value on Mrs. Smith's right to risk and independence than on the need they saw for supervision and safety. Although Mrs. Smith's preference for remaining at home was respected, services to benefit her and to ameliorate some of the safety/risk concerns were recommended. None of the respondents, however,

chose either community or facility care for Mrs. Smith, which would have represented the highest regard for her autonomy, given that she was not depicted as wishing services. When another's protective conduct is not desired by an individual, it conflicts directly with that person's autonomy (Kapp, 1997).

Our observation that elderly participants would be more likely than HCPs to choose facility care for Mrs. Smith is consistent with the study by Horowitz et al. (1991) in which elderly individuals were quite prepared to make decisions that overrode the autonomous preferences of hypothetical older adults in vignettes. In our study, elderly participants may have judged that Mrs. Smith had made the wrong decision for herself, and they therefore made what, in their opinion, was a better decision for her. By recommending facility care, it could be suggested that they behaved in an authoritative manner. While this warrants further research, their choice was congruent with a study by Krothe (1997), in which the absence of family resources and declining mental functioning, both characteristics shared by Mrs. Smith in this study, were identified by community-dwelling older adults as primary reasons warranting facility care.

It was not surprising that few HCPs chose to contradict Mrs. Smith's preference to remain at home, despite concerns about her safety. Kapp (1997) observed that the imperative to "save elderly persons from themselves" is increasingly outweighed by a growing philosophical commitment among HCPs to protect and promote clients' autonomy including the right to live at risk. In a vignette-based study of case managers' support for the autonomy of frail elderly people, Healy (1999) found high levels of support for the autonomy of cognitively impaired elderly persons, even when safety risks were quite highly rated. Regarding the HCPs who behaved in a paternalistic manner, they may have been subject to what Moody (1987) described as the "logic of incarceration":

For the elderly "at risk" for nursing home placement, an ideology of professional control and interpretation of behaviour produces a logic of incarceration. The professional ideology amounts to a claim for superior knowledge in predicting the future course of chronic disease, especially the trajectory of decline in the patient's capacity to cope with activities of daily living. This appeal to superior professional knowledge is combined with an appeal to the principle of paternalistic beneficence toward the patient. (p. 17)

The relatively few participants overall who chose facility care for Mrs. Smith in this study, however, stand in contrast to findings by Kelly et al. (1998). In their vignette-based study, women ages 18 to 92 were asked to make a long-term care choice for hypothetical

elderly women in a variety of living situations, and with varying degrees of cognitive and functional impairment. It was found that the overwhelming majority of respondents chose facility care as the most appropriate choice for older women living alone, regardless of their own age or the older women's level of functional and cognitive impairment (i.e., even when impairments were minimal). The fact that laywomen in the study by Kelly et al. (1998) chose facility care while HCPs in our study did not support the notion that HCPs considered Mrs. Smith from the perspective of their *professional* values, rather than from their personal ones.

### Limitations

A number of limitations are associated with the sample. First, 29 of the 83 elderly participants had a health care background, possibly confounding the results attributed to being elderly. Second, participants in both groups were generally healthy; both groups may have made decisions about Mrs. Smith from this perspective, which might have overridden differences between being elderly or an HCP. Third, there were few men in either the HCP or elderly sample, making it possible that many of the findings are a result of being female. Finally, nothing was known about the ethnicity, culture, or religion of either the elderly participants or the HCPs who participated in this study. Each of these factors could potentially account for value choices made by participants or a combination of each could play a more substantial role than being either elderly or a HCP.

In addition to the sample limitations, there are also several methodological limitations. First, as noted earlier, all older adults in this study were treated as a homogeneous group in terms of health. Yet, health differences existed and may have influenced decisions made around recommendations for care. A second limitation is the use of a convenience sample. Convenience samples are typically associated with higher levels of education, better health, and higher socio-economic status. Indeed, the elderly persons in this study were more highly educated (Lindsay, 2000) and had higher incomes than the elderly population generally. The effect of these factors on the decisions the respondents made about Mrs. Smith, and on their values, is unknown. Furthermore, convenience samples violate the assumption of randomness in that every person in the population does not have an equal chance of being selected. Because this study used statistical techniques that assume random selection, these statistical findings should be interpreted with caution and cannot be generalized to the population. This list of risks presented to respondents (see Appendix 2) is a further limitation of the study. The list of risks, initially generated from the literature, was reviewed and validated by a reference group of health care providers from different disciplines



that involve working with older adults. It is possible that respondents might have identified other risks had they been given the opportunity to do so.

A final methodological limitation is that the use of a scenario depicting a hypothetical person about whom respondents must make decisions also has some disadvantages. Although respondents were asked to imagine Mrs. Smith and her situation, we do not know how fully they were willing or able to do so. Kane (2000) suggested research that shows whether or not people make the same decisions in real life that they would make in scenario studies is equivocal. Additionally, although the findings from this study indicated that HCPs and elderly participants made different care decisions based on different values, we cannot know which group's decisions would have been more congruent with those Mrs. Smith would have made for herself while in her previously competent state.

#### *Implications for Policy, Practice, and Research*

The differences in the care decisions made by elderly participants for Mrs. Smith, compared to those made by HCPs, suggest that both practice and policy could better reflect the concerns, priorities, goals, and values of marginally competent elderly people if other competent older adults were able to provide input into these areas.

Elderly clients (perhaps all clients) should be encouraged by HCPs to document or share their values and beliefs with significant others in regard to long-term care planning in case of mental impairment. Representation agreements, currently being promoted in British Columbia, could be expanded to incorporate this type of information. We do not know, however, the extent to which individuals keep to their original decisions over time. Social workers could be charged with collecting information from older adults and their families when they first enter the long-term care system, in order to document the elderly person's advance directives (where possible) and social history (e.g., what the person believes, has valued, and coping mechanisms used throughout life). This information might provide some insight to HCPs about what might have been important to these clients if, in the future, like Mrs. Smith, they are later unable to make decisions on their own behalf.

Another way in which input from elderly persons could be used in decision making about marginally incompetent individuals is by involving them as consultants. Formal decision makers could recruit elderly persons of varying gender and background (e.g., educational, socio-economic, ethnic, cultural, and religious) to create a pool of consultants to match the diversity of the heterogeneous elderly population. When confronted with ethically challenging situations involving making care decisions on behalf of older

adults, HCPs could choose to explore relevant issues with a selected consultant (while protecting client confidentiality). This approach might be considered time-consuming, but perhaps should be weighed against the increased likelihood of making decisions on behalf of marginally competent persons that are more in keeping with their beliefs and values. The "Council of Elders" at Harvard University, to whom medical residents can present ethical dilemmas in caring for older patients, has provided some support and direction (Katz, Conant, Inui, Baron, & Bor, 2000). This innovation has proven successful in identifying novel ways to overcome health-related dilemmas and as an orientation for the residents to the lives and values of older adults.

Another way to educate HCPs about older adults' experiences and worldviews could be through the collection of narratives that reflect the life course of elderly individuals (e.g., within the context of their particular times, culture, gender, and religious beliefs). These narratives or similar broader histories of specific groups might help care providers understand where their clients have come from, possibly providing insights into values that might be important to individuals.

Our study demonstrated that most health care professionals, despite discipline-specific values supporting autonomy and self-determination, primarily recommended some safety and supervision for Mrs. Smith. They took the middle ground between no services and facility placement. If there is disparity between the values HCPs subscribe to and the values reflected in their care management of elderly persons, the disparity should be made known. Conflict between the ethical principles that one believes in and those that one practices can lead to burn-out for professionals, with implications for themselves as well as their clients. Opportunities for education about ethical decision making when principles compete could be protective for HCPs. Additionally, opportunities to process difficult cases in the field, to make subjectivity and biases explicit and to share responsibility, could increase HCPs' accountability for their practice behaviours and decisions. While shared decision making could reduce the possibility of decisions being made on the basis of a single individual's biases, it is important that it occur only in the context of power-sharing, as opposed to hierarchical, teams.

## **Conclusion**

Our study suggests that, in general, elderly individuals make more congruent decisions with the values of older adults than those made by HCPs or younger adults. In further research, a study that compares the decisions made by older adults for other competent elderly individuals, with the decisions actually made by the target, would make a valuable contribution to



research. In addition, a comparison of HCPs and non-HCP adults under the age of 65 would be useful in exploring the effect of age alone on care decisions and values. To explore the effect of health on care decisions and values, a comparison of older adults in good health with those in poor health would also be useful. Similarly, the study reported here could be replicated, to explore the effects on decisions and values, with diverse samples of elderly people, HCPs, and non-HCPs under age 65 that include more men and people from a variety of ethnic, cultural, and religious backgrounds.

Given that safety and specific risk factors were significantly related to the care choice made by participants in this study, more knowledge about how these areas are evaluated would be useful. Qualitative research could be undertaken with both elderly people and with HCPs to ascertain how these factors are assessed. Little is known about the impact of risk factors on elderly, marginally competent individuals living alone in the community. A study could be undertaken to compare HCPs' pre-placement assessment of risk and safety of elderly persons to what actually happens to these individuals while in the community and to what prompts their relocation. Research in this area could provide knowledge about the probability of risks being potentiated and about contributory and protective factors.

## Note

1 A copy of the information sheet provided to each participant can be obtained from the corresponding author.

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## APPENDIX 1

### Scenario

Mrs. Smith is 84 years old and lives alone, with no children living nearby. She has become increasingly frail. She is mobile and physically able to carry out ordinary activities of daily living such as getting dressed and bathing. She often needs reminders to bathe or change her clothes. Mentally, Mrs. Smith is sometimes confused. Although she can remember things such as her name and address, she is quite forgetful. She often loses or misplaces things, and sometimes she has difficulty remembering recent events. She is able to make some simple decisions for herself, like what clothes to wear, but she is unable to manage major things such as banking and finances. She cannot make an adequate meal and has been known to burn pots. She does not feel she needs services and has refused them.

## APPENDIX 2

### Questionnaire

1. Overall, how safe do you feel Mrs. Smith is at this time?

- 1 – extremely unsafe
- 2 – very unsafe
- 3 – somewhat unsafe
- 4 – safe enough
- 5 – completely safe

2. Please rate each of the following in terms of how much risk you think each factor poses to Mrs. Smith's ability to live independently at the current time: Use 0 = no risk, 1 = insignificant risk; 2 = mild risk; 3 = medium risk; 4 = substantial risk; 5 = major risk.

- self-injury
- crime
- isolation/loneliness
- not eating properly
- poor hygiene
- not getting help quickly if sick or falls

3. Given her needs and limitations, and the information provided about each type of care, which type of care would you recommend for Mrs. Smith? (Please check.)

Institutional Care  Community Support   
Neither