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# Expanding the Time Frame for Advance Care Planning: Policy Considerations and Implications for Research

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## 1. Introduction

This paper addresses the policy challenge of comprehensive advance care planning in late life. It envisions end-of-life decision making as promoting meaningful living, even for individuals with end stage diseases. We first review the current state of end-of-life decisions based on a personal autonomy model. This is followed by a summary of our prior research about attitudes of community dwelling aged toward end-of-life decision making. Based on this data we developed a proactive and collaborative approach to end-of-life planning. This is built upon patient preferences, physician and family partnerships, and best practices regarding advance care. Expanding the time frame from advance care to future care planning (FCP) empowers patients to be better advocates for their own care. It also supports a dynamic planning orientation that focuses on living as well as possible, while providing direction for immediate end-of-life needs.

The recent literature on end-of-life care emphasizes advance directives as the central feature of end-of-life care (De Boer et al., 2010; Perkins, 2007). These studies have also raised concerns about the current state of end-of-life care. They show that advance directives may not reflect the patient's desires near the end of life, and don't guarantee that directives will be implemented by family and/or health care providers (Lynch et al., 2008; Perkins, 2007). There is concern, too, about the appropriateness of hospitals as the settings where many individuals die, and the limited access of patients to different end-of-life care locations (Detering et al., 2010; Hallenbeck, 2008; Miller & Han, 2008). This literature also recognizes that options for end-of-life care are enhanced where there is coordination between patients, health care providers and family members (Cartwright et al., 2009; Engelberg et al., 2010).

The emphasis on the final days that patients live is consistent with the current policy focus on advance directives for end-of-life care. However, this tends to draw attention away from the period that precedes the immediate end-of-life. Our paper seeks to emphasize this time frame that is between the individual's knowledge that he/she has life-limiting illness, recognition of the nearness of the end of life, and the actual death. We believe that end-of-life decision making should encompass health care planning for this more extended time frame - which is so critical to ensuring that the individual can live as well as possible

(Berzoff & Silverman, 2004). Such planning is entirely consistent with promoting the goals of personal autonomy that animates end-of-life public policy (Tauber, 2005).

## 2. The law and end-of-life decision making

In the United States, federal law cedes authority to states and every state has statutory provisions for preparation of advance directives (Pollack et al., 2010). Generally these laws call for naming a single person as a proxy decision maker, should the patient no longer be competent to make decisions in his or her own behalf. The Patient Self-Determination Act of 1990 requires all hospitals in the U.S. to inform adult patients, on admission, about their rights regarding advance directives (Yates & Glick, 1997).

The principle of personal autonomy has guided end-of-life legal policy. Based on the broad concept of a "right to privacy," American courts have presumed that individuals – and not the state or medical professionals – are the ultimate decision-makers with respect to their own lives. This solicitude for personal autonomy applies whether the decisions being made are beneficial or injurious. Indeed, in case after case, the law has sustained decisions by competent individuals to end medical treatments, notwithstanding the impact on the patient.

While the principle of autonomy has deep roots in Anglo-American law, practical considerations also support this principle as applied to end-of-life legal policy. The organizational needs of hospitals, long-term care facilities and the physicians, who operate within them, are advanced when patients have clearly stated plans for when they would like treatments to end. Without patient direction – made when the individual was competent – these difficult choices must be made by others, and may cause conflict with family members. The lack of direction can lead to greater financial costs involved in prolonging life with extraordinary treatments. It can generate fears of lawsuits by health care organizations and providers, and can result in unnecessary suffering and undignified deaths.

For these reasons, the use of advanced directives for end-of-life decisions are necessary and should be encouraged as a matter of public policy. By statute, living wills are recognized as the basic model for providing advance directives – and seek to avoid issues presented when a patient is no longer competent to make decisions. These statutes make provision for relieving physicians or health care organizations from liability if they follow the patient's wishes as stated in the living will.

Another mechanism for advanced planning is the durable power of attorney. This allows the patient to transfer authority to an agent who becomes a health care decision maker. This authority is considered "durable" in that the incapacity of the patient does not extinguish the authority of the agent. This represents a modification to the common law "powers of attorney" that would end with the incapacity of the principal, and was provided by statutes (e.g., Uniform Probate Code) beginning in the 1970s to accommodate the needs of the aged. It should be noted that these powers can be withdrawn by the principal, amended, and cannot be utilized where the patient has the competence to provide informed consent.

The responsibility for following patient wishes is not vitiated if the patient lacks a living will or durable power of attorney. An effort must be made by the physicians and health care organization to ascertain what the wishes of the patient would have been if he were

competent. Thus it is recommended that those treating the patient consult with family members. Nevertheless, under the law the ultimate decision must be in alignment with the wishes of the patient – which at times may not be consistent with those of the family.

The utility and need for formalized end-of-life directives cannot be minimized, even as complementary models, like those advocated in this paper, are explored. These serve a crucial purpose at the very last stage of life. But the role of social support, caring interventions, and community based involvement are not central features of the current legal model of end-of-life decision making. Indeed, the model at present puts little emphasis on planning for living, and the husbanding of family and community resources. These can greatly enhance quality of life during a prolonged period of life that many individuals experience when dealing with a terminal illness.

Putting aside criticisms pertaining to the existing advance directive orientation (George & Harlow, 2011; Fried & Drickamer, 2010), the following sections explore the enhanced quality of life framework we are proposing. We do not weigh in on the questions related to percentages of adults who in fact prepare advance directives, or the controversy surrounding cost savings by patients who forego end-of-life treatments. Rather, we explore the attitudes of the aged population toward advance planning, and consider the possibilities for them to build capacity to enhance the remaining period of their life. To do so, we also recognize that health care professionals, social workers, and families are critical to improving care during the prolonged end-of-life period (Stein & Sherman, 2005).

### **3. Expanding the time frame for future care planning**

We aim to expand advance care planning by focusing on the multiple care needs that emerge in the final years of life (Penrod et al., 2011). Few people face death in the absence of disabling health conditions. Individuals of advanced age, who have experienced some form of chronic illness and disability, make up the vast majority of those facing end-of-life decisions. Nevertheless, these individuals strive for, and often experience, a good quality of life during extended periods prior to death. The information obtained from these older individuals – which will be discussed in the section below – provides a useful template for understanding the challenges faced by people of all ages near the end of life (Thomas, 2007).

Understanding of the maintenance of good quality of life, in the time frame prior to the end of life, has been limited by lack of systematic theoretical attention (Conway, 2011). In order to improve care, and promote policies that further caring, we must synthesize orientations from the fields of gerontology, nursing, social work, psychology, and sociology. Approaches we find useful include recent developments from the palliative care movement (Lorenz et al., 2008), as well as long standing frameworks relating to stress models (Pearlin, 1989).

The palliative care movement has called for systemic changes in health care delivery to decrease the suffering of seriously ill and dying patients. These changes are advocated across care settings ranging from hospitals to nursing homes (Abbey et al., 2006; Chochinov et al., 2007). This movement endorses caring for patients in the period leading up to death. During this time-frame careful judgments must be made to ensure that life of the impaired is valued and respected (Kastenbaum, 2004). The social stress model captures the normative nature of health related stressors and social losses (Folkman, 2010). Individuals, under this

model, must adapt proactively to ensure that they can maintain a good quality of life even as they face disability due to chronic illness, encounter acute health events, and deal with a shrinking social network (E. Kahana & B. Kahana, 2002; Kelley-Moore et al., 2006).

Drawing on ideas from the palliative care movement and social stress models – in addition to our empirical work in the field of aging – leads us to conclude that enhancing capacity for “care-getting” is crucial to end-of-life planning. This entails marshaling informal and formal support to help individuals maintain comfort, experience psychological well-being and feel that others are caring for them (E. Kahana et al., 2010; Nolan & Mock, 2004).

The ability of an individual near the end of life to draw on a variety of social resources and to secure advocates who can represent their values is a crucial component of planning. This will assist individuals in obtaining responsive home care, if this is possible, as well as ensure that their medical and longer term care needs are considered fully. For many individuals, and especially seniors, this also entails mobilizing community resources within the broader aging network (Force et al., 2010; Gelfand, 2006).

In the United States, Area Agencies on Aging (AAAs) can serve important roles in offering transportation, caregiver support and health promotion resources for frail elders (J. Kahana & Force, 2008, Force et al., 2010). This broader vision of services is consistent with emerging approaches to health promoting palliative care delivered in a community context that is becoming prevalent in Australia (Rosenberg & Yates, 2011). Indeed, for seniors, planning that includes “care getting” can be vital to aging in place and completing one’s final years living independently. Nevertheless, a growing number of elders live out their final years in nursing homes (E. Kahana, et al., 2011). These facilities are not well equipped to address the care needs of seriously ill and of dying patients (Wetle, et al., 2005). The current set-up of long term care facilities – and reimbursement patterns – creates obstacles to offering individualized and dignity-conserving care to patients.

Ethical dilemmas are presented “inside the world of the nursing home” that impinge on patient autonomy (Moody, 1992, p. 109). Paternalistic policies on the one hand, and lack of adherence to informed consent principles on the other, leave patients with little control over the final period of their lives. Patient autonomy is further compromised by the assumption that those with cognitive deficits are lacking in the capacity for self-determination (Small et al., 2008). Public policies that support caring for seniors within long term care facilities – especially in the period leading up to death – are needed to protect the welfare of these individuals. Utilizing the existing resources of long-term care ombudsmen can help achieve these objectives (J. Kahana, 1994).

#### **4. Attitudes of the aged toward end-of-life care and planning**

Gerontologists have paid relatively little attention to end-of-life issues. The emphasis on productivity in aging, health in advanced years, and continuing to make social contributions has made “successful aging” the dominant model (Rowe & Kahn, 1998). The medical literature addresses end-of-life issues in the context of chronic illness. It does so based on illness categories such as cancer, dementia and heart disease (Keating et al., 2007; Selman et al., 2007; Van der Steen & Deliëns, 2009). The nursing community has shown a greater interest in the subject of care for older individuals at the end of life (Hansen et al., 2009).



Watson's notion of being "cared for" is particularly relevant to the service needs of those at the end stage of life (Watson, 1996).

The Elderly Care Research Center has conducted several funded studies to inform our approaches to end-of-life care (E. Kahana & B. Kahana, 2002; E. Kahana, 2010). These studies include *Adaptation to Frailty among Dispersed Elders*, a National Institutes of Health 20-year study of healthy older adults. More recently, the National Institute of Nursing Research funded a study about attitudes and behaviors of diverse community dwelling elders regarding planning for advance care (E. Kahana & B. Kahana, 2010).

Our interest in end-of-life research has been a natural outgrowth of the aging of our original research sample. As respondents in our longitudinal study were increasingly lost to mortality, we became interested in perspectives on the end of life among representative samples of older adults. Our review of the literature on end-of-life issues revealed that knowledge about the end of life is based on the health care literature focusing on terminally ill patients (Thomas & Lobo, 2011). We realized that much could be learned about the end of life by considering perspectives of older adults who confront varying trajectories as they approach this period of life.

These studies have shown that, as older adults get closer to the end of life, they do not seem to fear death. They do, however, fear suffering close to the end of life (E. Kahana & B. Kahana, 2010). Thus, 85.6% of our respondents are in favor of obtaining effective medications that relieve pain close to the end of life. Attitudes of respondents regarding death and dying may be characterized by the adage "hope for the best and prepare for the worst" (E. Kahana, et al., in press).

Attesting to valuation of social relations close to the end of life, 90.3% want to be surrounded by friends and family, and 91.8% want to have others pray for them as they near the end of life. The vast majority of respondents prefer to die at home (92.3%). Our findings thus reveal that social connections remain salient to older adults as they contemplate the end of life. These concerns can best be addressed by meaningful dialogue between patients, their family members and their health care providers. Such dialogue can result in anticipating responsive care (E. Kahana et al., 2010).

Important themes that emerged from elders' narratives include lack of fear by the very old about impending death, and a strong desire to remain connected to significant others in their lives. In discussing preparations for the end of life, the focus was not as much on their preferences, fulfillment or comfort, but on their desire to care for the people they felt close to or responsible for. Respondents reported making plans for end-of-life care so that their families would not be burdened. They also made funeral arrangements to leave their loved ones with minimal worry of financial responsibility (Casarett, 2010).

## **5. The role of providers, community, and family in advance care planning**

The role of doctors, patients and family in care of the aged close to the end of life has been the subject of our research. We sought to understand the health care partnerships that emerge as older adults encounter the cascade of disability reflected in increasing chronic illnesses, physical impairments, and functional limitations (Verbrugge & Jette, 1994). We

conducted interviews with older adults, their primary care physicians and family members who played a major role in their health maintenance. We inquired about advance directives based on questions posed to elders, their primary care doctors and family members.

A majority of 231 respondents, whose physicians and family participated in this study, prepared advance directives (60%). Those who discussed end-of-life issues most often did so with family, and particularly, spouses. Among different types of advance directives, the most common was a living will (84%), followed by durable power of attorney (32%). It is notable that about one-quarter (24%) of the sample made no end-of-life care plans

Few respondents (15%) discussed their advance directives with their physicians. Primary care physicians whom we interviewed confirmed this pattern, as they were generally unaware of advance directives prepared by their patients. Only 28% of physicians whose patients reported having made advance directives were informed about their patient's wishes. Furthermore, about a third of physicians whose patients did not provide advance directives, were under the mistaken impression that such plans existed. In contrast, family caregivers were far more likely to be well informed about their relative's advance directives.

Findings suggest insufficient communication between elders and health care professionals. There is little evidence of effective health care partnerships close to the end of life (B. Kahana et al., 2004). It is also important to recognize that different factors may be salient to patients, family and health care providers near the end of life (Steinhauser et al., 2000).

Our research has investigated health communication relevant to the very old, including those close to the end of life. In our ongoing study we explored respondents advance care planning in terms of traditional indices of living wills, power of attorney of health care, and conversations with family and with health care providers about end-of-life issues. Based on data from 514 community-dwelling respondents, less than one third of our sample reported having had conversations with family members (28%). An even smaller proportion reported conversations about advance care plans with physicians (14.7%). Elderly respondents indicated that discussions were generally initiated by the patient, rather than the doctor.

The subject of physician initiated discussion generally focused on preparation of documents such as living wills. Our findings indicate that advance care plans were typically undertaken to protect family members from being burdened. In response to the question, "Is there anything that you would like your health care providers and family to know about your wishes for end of life care?" there was a notable lack of specificity. Only 21% stated specific wishes. Among those expressing wishes the most frequently noted were the desire to avoid extreme measures (20%), such as life support. These data raise provocative questions about the absence of motivation and/or opportunities for meaningful end of life conversations for elderly persons who are nearing the end of life (B. Kahana et al., 2004).

Our findings based on relatively healthy older adults who are able to live in the community in spite of multiple chronic illnesses, have helped us take a broader view of older adults' attitudes and preferences regarding planning for the end of life. Nevertheless, we recognize that, with aging and the cascade of disability (Verbrugge & Jette, 1994), there may be greater interest in end-of-life planning focused on maintenance of personal comfort and management of the dying process.

## 6. Practice implications

What are the implications of these research findings for consideration of the needs of elders close to the end of life? Educational interventions may benefit such elders to enhance their competence and confidence in communication with families and health care providers (E. Kahana et al., in press). It is particularly important as part of an expanded end-of-life planning program to enhance communication skills among seniors, and especially minority, underserved, and disabled older adults (Elder et al., 2009).

Theorizing about maintenance of the self in late life underscores the abiding desire of human beings to maintain their long established identity, retain autonomy, and garner respect from their social environment for their values, preferences, and cultural diversity (George, 1999). Throughout much of adult life and well into healthy old age, this identity can be autonomously maintained. The final years of life pose a challenge to this self-reliant, autonomous identity, as aged persons facing frailty and social losses must increasingly be cared for by others (Wykle et al., 2005). This developmental challenge and its successful resolution present the basis for a care-getting model we developed (E. Kahana et al., 2010).

The final stage of life is often characterized by severe symptoms, and dependence on others (Twycross & Lichter, 1996). It is at this point that sensitivity and responsiveness of health care providers to patient preferences and needs becomes most challenging and important. While advance directives may reflect personal patient preferences, health care providers must also remain sensitive to the cultural values of patients and their families and to subtle communications about changing needs (Nolan & Mock, 2004).

During the final stage of life, care is focused on comfort, while 'cure' remains primarily the focus of medical therapy. For older adults suffering from many co-morbidities, treatment may have to be continued even while comfort needs increase in priority. Care in the final stage focuses on understanding psychological needs and providing optimal comfort to the patients. Supportive care emphasizes the individual's wishes and needs. At the same time, for some older adults, life extension can remain an enduring desire (Singer et al., 1999).

In this paper we argued for expanding the temporal context of end-of-life care. It is important to note that decisions relevant to the end of life may be legitimately made long before the final days or months of living. A second important point relates to the paradigm shift away from leaving the responsibility for advocacy and communication near the end of life to physicians and other health care professionals. Given the failures of the current health care system, it is important for patients and their family advocates to be informed, and to take initiatives toward ensuring responsive health care close to the end of life. We propose that formal health care advocates and agencies support both patient education and provider education efforts, to improve care close to the end of life. Empowerment, involvement and participation by patients, families and communities are increasingly called for in public health and public policy approaches to improve end-of-life care (Kumar, 2011).

We support recommendations for expanding the definition and time frame for palliative care. This can result in removing unnecessary stigma and expanding substantive benefits to patients regarding comfort and a more hospitable health care environment. To make progress in improving lives of elders close to the end of life we must think outside the box



regarding empowerment of patients during the final period of their lives. This involves risk-taking by presenting patients with real choices in areas that are meaningful to them.

We must also re-examine our orientation to diversity in order to ensure that patients can define culturally meaningful practices related to the final period of their lives (Elder et al., 2009). We must acknowledge potential differences in desires and value orientations of those facing long term, sudden or gradual disability in late life. The concept of "inherent dignity" (Robinson et al., 2006) is useful for achieving a synthesis between concerns of disability advocates and perspectives of older adults who are latecomers to the disability community and may not identify themselves as persons with disabilities, even close to the end of life.

## **7. Lived experience: A challenge to prevailing practices**

We distilled these perspectives from up-close observations of the final years of "Sari", a close relative of the two senior authors. Sari died at the age of 85 in a high quality, not-for-profit nursing home. Her struggles and experiences are quite typical of the challenges faced by many older adults as they approach the end of life. They also call into question many of our current practices in caring for patients close to the end of life. Her reactions to prevailing treatment practices illustrate the need for a paradigm shift in offering "caring," rather than just medical care, close to the end of life (Watson, 1996).

Our initial anecdote aims to emphasize the complexities of advance directives. It is generally agreed upon that advance directives are a necessary and desirable way to influence and possibly curtail medical care close to the end of life. Recent literature has demonstrated that in spite of mandated efforts to obtain advance directives, especially from patients in long-term care facilities, such directives are not regularly implemented (Lynch et al., 2008; Perkins, 2007). It is only very recently that more fundamental questions have been raised about the value and meaning of advance directives.

Sari was diagnosed as a diabetic at age 75. She developed circulatory problems and required amputation of her leg at age 80. She refused to give permission for the amputation, arguing that her life would not be worth living as an amputee. She made it clear that she was ready to die. At the time, she was a distraught, cognitively intact, bright and opinionated woman. Her family concluded that her wishes expressed both verbally and in writing should be honored. We do not know what transpired in the operating room, but after many frantic phone calls and psychiatric consults Sari's leg was amputated below the knee. The physician who had known her for a number of years indicated that he was convinced that she really wanted to live but could not accept the specter of becoming a disabled amputee.

After her amputation, Sari was in a good frame of mind and thanked profusely everyone who did not listen to her. She felt she survived in spite of herself and that she had much to live for. While still in the hospital, she decided that she did not want the home health services offered that were predicated on her being homebound. Instead, in the spirit of the Americans with Disabilities Act, she called the Hungarian church and asked to find a personal aide who could take her shopping and help her cook for her family from her wheelchair. In many subsequent conversations, Sari explained that prior to being faced with the prospect of amputation and permanent disability, she could not know that life could be

worth living in the aftermath. She was convinced that she was at the end of life. Of course it is important to realize the distinction between prospects of living as an amputee, where a meaningful life is still possible, from the prospects of living in a vegetative state. Nevertheless, the question is still unanswered regarding the knowledge of what we would want in a future situation that we cannot fully comprehend in advance of its occurrence.

Our next relevant encounter involved advance directives regarding end-of-life issues. Sari lived a very meaningful life sharing a home with her family for three years after her initial amputation. She did suffer a number of mini strokes during this time and exhibited relatively mild signs of dementia. Her circulatory problems continued and she required a second amputation that resulted in her placement in a nursing home. Sari was given about three months to live at the time of her admission. To everyone's amazement she lived for two more years. Once again, estimates of when the end of life would occur were inaccurate.

Close to the end of her life, Sari left us with one more lesson to ponder. Her condition was generally deteriorating as her dementia progressed. One day, when her daughter came to visit, she was in bed and running a fever. The daughter was told that the doctor wanted to talk with her. The doctor, a kindly older geriatrician, came by and standing at Sari's bedside, noted that Sari had a severe urinary tract infection and that he was hesitant to transfer her to the hospital. He felt that based on her poor quality of life this might be a good time to "let go" and protect her from further, ultimately futile interventions. The doctor was persuasive and the family agreed. At this point, totally unexpectedly, Sari opened her eyes and announced in a clear voice "I want to get better, take me to the hospital".

How does this incident inform our understanding of the recent literature on end of life? One of the clear recommendations in this literature relates to not transferring demented elders from nursing homes to acute care hospital settings (Van der Steen & Deliens, 2009). This is framed as diminishing the suffering at the end of life and seldom referred to as a cost-saving measure. Sari's story points to the complexity of this picture. The three days that Sari spent at the hospital treating her infection became the highlight in her life near the end of her life. She enjoyed the attention of the nurses, the dignity with which she was treated and the fact that they did not treat her as an incontinent patient as they did in the nursing home. During this hospital visit we discovered that, in fact, she was not incontinent, but required a great deal of effort to be toileted. The hospital made the accommodations to provide her access to the toilet. Her infection cleared up and she did not want to go back to the nursing home. She lived three more months after this end-of-life hospitalization.

Looking at the situation in an unimpassioned way, a reasonable argument could be made that funds would have been saved by the health care system had she been allowed to die three months earlier without this final hospitalization. But it would be hard to argue that she would have been better off. Sari's lived experience reflects on current controversies in the end-of-life literature. It raises important questions regarding individuals' ability to predict at earlier points in their lives what would be in their best interest during critical periods when decisions about their end of life are being made. It also calls into question whether the effort to limit hospital placements for elderly disabled and demented patients at the end of life always benefit the patient. These are just some of the questions that illustrate the complexity involved in bureaucratizing end-of-life care and decision making.

## 8. Policy considerations

This paper has considered expanding end-of-life decision making, beyond advanced directives, to include care planning for meaningful living even when individuals are confronting life-threatening illnesses. Public policies, and funding mechanisms within existing social programs (Medicare, Medicaid, Area Agencies on Aging), can support individuals and families who are facing chronic and disabling illnesses during the final years of life (Binstock & Post, 1991).

Our approach to planning as a distinctive policy goal for end-of-life decision making and care builds upon the palliative care movement and existing stress models. Research has shown that planning can minimize suffering and enhance opportunities for fulfilling social relationships (Jackson, 2002). Conflict between professionals, family members and those at the end of life can be reduced through planning efforts (Burck & Lapidus, 2002). It is also likely that substantial cost savings can be achieved when individuals remain in their communities longer and avoid expensive hospitalizations or admission to skilled nursing facilities. Even when more intensive care is needed, planning is an effective mechanism for limiting legal liability on the part of health organizations and providers.

The effectiveness of planning is dependent upon the partnerships and collaborations of all those interested in the well-being of the person nearing the end of life. Patients, family members, health care providers and institutions will make planning more effective when they are able to be proactive rather than responsive to upcoming medical events, including those psychological challenges facing individuals at the end of life (Steinhauser et al., 2000). Planning seeks solutions to upcoming challenges, and affords opportunities for joint discussion and decision making. In this respect it is an appropriate strategy for individuals who are in skilled nursing facilities and for their families (Kahana, 1994).

The growth of the aged population makes policy choices concerning planning especially timely. The "longevity revolution" is associated with more elderly also living and dying from chronic diseases (Roszak, 2001). Older individuals can expect to live with serious chronic illness during a period of several years prior to their ultimate death (Lynn & Adamson, 2003). Longer life spans and chronic illnesses for seniors increasingly occur in an environment where children and relatives live away from those in need of care. Thus, patterns of end-of-life care have also changed from being provided primarily by families in earlier times to being subsidized by Medicare/Medicaid and delivered by professional caregivers in long-term care facilities or in acute care hospitals (Wilner, 2000).

These demographic and social changes with respect to our senior population call for a public policy response that encourages planning. It must also be understood - as the research we presented earlier shows - that few individuals at present are comfortable with communicating ideas about planning, both within the family and between providers and patients. Without planning, especially for those with chronic illnesses such as cancer, stroke, diabetes and heart disease, medical events are likely to become crises, at which point too little time is available to properly consider all options relating to care (Pinquart et al., 2005).

The use of community resources, and policies that make these resources more accessible, are pivotal to enabling individuals to plan for likely medical events. Organizations like Area Agencies on Aging (AAAs) are a valuable resource for seniors and their families to find

information about community programs (J. Kahana & Force, 2008). These include home care services, opportunities for socialization, and nutrition programs through senior centers or home delivered meals (Grande et al., 1998). Those who qualify can also obtain support from case workers who can help with management of care. It is crucial, however, for family members to engage with such organizations prior to a medical crisis, as this affords the best chance for appropriate planning.

Health care providers and social workers within hospital settings must be encouraged through policy initiatives to help those at the end of life with planning (Stein & Sherman, 2005). Reimbursement protocols that fund such planning would achieve cost savings, as planning would emphasize utilizing community and family resources. When such information is provided by individuals perceived as medical authorities, older individuals will be more likely to marshal support from family and community service organizations.

## 9. Research implications

Future research on advance care planning will benefit from linking planning in late life in general to domain-specific planning relevant to health care and end-of-life care (Sorensen & Pinquart, 2001). The elderly patient's perspectives on health care options in times of serious illness must also be better understood. This is related to knowledge of diagnosis, prognosis and medical procedures. Additionally, we must have a better understanding of alternative orientations and needs of older adults, their family advocates, and of health care providers. There are many situations where conflicts of interest exist between older patients' desire for comfort and independence, and caregivers' concerns about patient safety (McCollough et al., 2002). Quantitative and qualitative studies that help us compare congruence and discordance in these stakeholders' perspectives, can offer guidelines for improving patient care during the final years of life. At present there is only very limited information about older adults' values and preferences about obtaining responsive care close to the end of life. Having a broad understanding of these processes before specific crises arise, positions elderly patients to make meaningful plans for future and advance care.

The role of communication between older adults, family caregivers, and health care providers represents a fruitful area for future research (E. Kahana & B. Kahana, 2003). While prior work has documented the limited communication between older patients and physicians, particularly related to advance directives, the nature of barriers to communication is not well understood. Research is also needed on the relationship between patient initiatives and the influence of consumer behavior on care received (E. Kahana et al., 2010). Better understanding of care needs and opportunities for future care planning among low health literacy and disadvantaged elders will also illuminate health care needs of an increasingly diverse population of frail older adults (Institute of Medicine, 2004). There is also a need for qualitative research that moves beyond assessments of the preparation of legal documentation such as power of attorney for health care and withholding life-sustaining procedures at the very end of life. This research should focus on a broader array of concerns, wishes, values and preferences for how older patients wish to be cared for and live out their final period of life.

Future research can also benefit from exploring perspectives of diverse health care providers who may be involved in caring for patients in the final years of life. Direct care of elderly



patients has benefited, as well as suffered, from introduction of technology in health monitoring, home health care delivery and care provision in acute and long term health care settings (Thomas, 2003). More research is needed on the impact of electronic health care records, health communication and self-care close to the end of life.

Although the benefits of mixed methods research are increasingly recognized in the complex arena of health services research, our understandings for integrating perspectives based on alternative value orientations is limited. Finally, consistent with the focus of our discussion on policy perspectives, surveys of public attitudes regarding sponsorship, financing and delivery of high quality and responsive end-of-life care would be useful.

## 10. Conclusion

This paper helps articulate a vision of advance care that is consistent with emerging trends in palliative medicine. It seeks to enlarge the scope of caring for patients, and particularly for the elderly who are living with life-limiting illness. We thus advocate for educational interventions to help older patients marshal responsive care during the extended period of service needs during the final years. We discuss the role of responsible and creative policy initiatives that can help patients avail themselves of the best services their communities can provide. Recognizing the theoretical underpinnings of advance directives on the one hand, and of marshaling responsive care on the other, enables us to integrate perspectives of autonomy and stress. Accordingly, effective advocacy can be assumed by patients and families to make the final period of life more comfortable and livable. Health care providers can forge real partnerships with patients who have planned for future care and who can articulate their values and preferences early in their illness trajectory.

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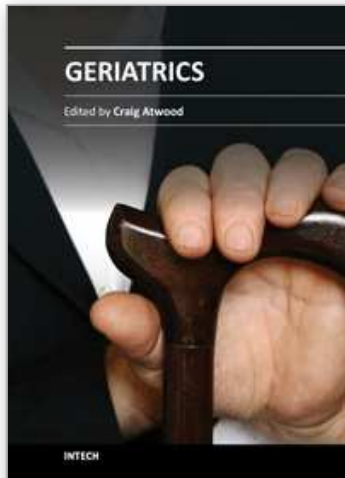
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With the baby boomer generation reaching 65 years of age, attention in the medical field is turning to how best to meet the needs of this rapidly approaching, large population of geriatric individuals. Geriatric healthcare by nature is multi-dimensional, involving medical, educational, social, cultural, religious and economic factors. The chapters in this book illustrate the complex interplay of these factors in the development, management and treatment of geriatric patients, and begin by examining sarcopenia, cognitive decline and dysphagia as important factors involved in frailty syndrome. This is followed by strategies to increase healthspan and lifespan, such as exercise, nutrition and immunization, as well as how physical, psychological and socio-cultural changes impact learning in the elderly. The final chapters of the book examine end of life issues for geriatric patients, including effective advocacy by patients and families for responsive care, attitudes toward autonomy and legal instruments, and the cost effectiveness of new health care technologies and services.

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