

**Advance Care Planning for older people: The influence of ethnicity, religiosity,
spirituality and health literacy**

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Abstract

Older people from cultural and ethnic minorities have low access to palliative or end-of-life care and there is poor uptake of Advance Care Planning by this group across a number of countries where Advance Care Planning is promoted. For many, religiosity, spirituality and health literacy are significant factors that influence how they make end-of-life decisions. Health literacy issues have been identified as one of the main reasons for a communication gaps between physicians and their patients in discussing end-of-life care, where poor health literacy, particularly specific difficulty with written and oral communication often limits their understanding of clinical terms such as diagnoses and prognoses. This then contributes to health inequalities given it impacts on their ability to use their moral agency to make appropriate decisions about end-of-life care and complete their Advance Care Plans. Currently, strategies to promote Advance Care Planning seem to overlook engagement with religious communities. Consequently, policy makers, nurses, medical professions, social workers and even educators continue to shape Advance Care Planning programmes within the context of a medical model. The ethical principle of justice is a useful approach to responding to inequities; and to promote older peoples' ability to enact moral agency in making such decisions.

Key words: Advance Care Planning; older people; religiosity; spirituality; health literacy; moral agency; social justice

Introduction

A substantial literature attests that older people from cultural and ethnic minorities have low access to palliative or end-of-life care services [1-10]. Consequentially, as a means of increasing access to these services, there has been an unprecedented drive to promote Advance Care Planning (ACP) across a number of countries whose populations are culturally diverse. It has, however, also been argued that the imperative to put in place documentation that determines the wishes and preferences of older people on care at the end of life has an undercurrent of protection, expediency and cost saving, disguised by rhetoric on improving the end-of-life care for older people generally [11]. This raises ethical concerns that cost considerations could disproportionately influence transparency and the sensitive communication process and jeopardise patient autonomy [12]. In the USA this rhetoric positions ACP as being encouraged to allow older patients to reject costly, intensive and futile medical treatments regardless of mental capacity [5, 6, 13]. The drive to protect older people from invasive treatment at end of life emerges from a consensus amongst the medical and legal professions as well as the general public that it is harmful to prolong the life of older people at all costs [14, 15]. Additionally, mounting research, particularly in the USA,

documents that end-of-life health care expenditures are notably higher for Blacks and Latinos relative to Whites [16-18].

There is significant evidence that amongst linguistically, ethnically and culturally diverse populations there are substantial inequalities to be found with regard to end-of-life decision-making and care practices when compared to populations from English speaking backgrounds [19]. Consideration of cross-cultural perspectives within public policies and legislative frameworks, such as ACP, that have been put in place to support and expedite end-of-life care decision-making have only recently been investigated [20]. Furthermore, attention of the above challenges, plus the influence of religiosity, spirituality and health literacy in relation to the position taken by older people of different cultures and ethnicities when faced with the decision-making involved in planning for end of life, is poorly addressed in the literature [20].

Low uptake of palliative and end-of-life care services among ethnic minorities often mean they die in inappropriate care settings with substandard care [4]. Our literature reviews identified lack of awareness about available choices at end of life, lack of culture-based multilingual information and family and socio-cultural factors that often make ethnic minorities ambivalent to engaging with end-of-life care services [10, 21]. The low uptake of palliative and end-of-life care services for this population poses moral and ethical challenges for practitioners and service providers that could be difficult to overcome in end-of-life care situations. However, if ACP is applied it can ensure that patients' wishes and preferences, regarding their care at the end of life, are known and respected by their carers.

The purpose of this paper was to consider the existing literature on preparation for end of life for underserved populations and to discuss these issues from the perspective of moral agency in the context of health literacy and engaging in a conversation about ACP.

Advance Care Planning

ACP has been defined as a process of discussing and recording of wishes, values, and preferences for future care and treatment held between individuals, family members and their care provider(s) [22, 23, 24]. ACP is not only about completion of written documents, such as a Power of Attorney or Do Not Attempt Resuscitation order, but is also a process of

communication between patients, family members and their healthcare providers [25, 26, 27] and typically centres on the completion of a collection of written documents.

Advance Care Planning and older people from diverse cultural and ethnic backgrounds

It has been shown that Hispanic and African Americans are less likely than Euro-Americans to know about ACPs or to complete them [28-37]. Hispanic and African American's tend to trust their family to promote their end-of-life care and they more readily disclose to them their end-of-life wishes rather than complete formal documentation [28, 35, 38, 39]. In countries other than the USA there is also clear evidence of poor uptake of ACP by older people from diverse cultural and ethnic background, viz.: in the UK by people of Black, Asian and Minority Ethnic (BAME) groups [4]; in Australia there is low uptake by Aboriginal people [2]; and in New Zealand by Maori and Pacific populations [1]. There is scarce knowledge about perspectives of Indigenous American Indians' and First Nation Peoples (Canada) regarding end-of-life treatments, which has resulted in health care providers functioning at less than optimum levels. In one of the few studies on experiences of American Indians Colclough and Brown [40] found differing conclusions about how treatment decisions were made. The American Indians identified that the physician made treatment decisions for them, whilst health care providers in the study believed that this patient group participated in informed autonomous treatment decision making about end-of-life care.

In the UK the Care Quality Commission review [41] found that existing evidence suggest that BAME groups may have more unmet end-of-life care needs than people from white backgrounds, and that they experience barriers to accessing good and personalised care. The barriers were due a lack of understanding, knowledge and information about end-of-life care, lack of religious and cultural sensitivity, language barriers, and poor communication.

Influence of religiosity and spirituality on advance care planning for older people from diverse ethnicities

Religiosity, regular attendance at religious service, and positive religious and spiritual coping are negatively associated with the probability of completing an ACP [42, 43, 44]. Research in this field has predominantly focused on African American populations. This research demonstrates that African Americans' attitudes with regard to preparation and planning for end-of-life care vary considerably based on individual history, religiosity and socioeconomic

status [45, 46]. Spirituality is an important part of African-American culture and is often cited as an explanation for the more aggressive treatment preferences of some African Americans at the end of life [28, 30]. Older African Americans are known to be a particularly religious group [46, 47, 48] and their religiosity and spirituality is expressed in reverence and a deep faith in God and their faith community through active congregational involvement [28, 46]. Many African Americans [28, 45, 49], Hispanics [13] and older UK BAME people [50] hold a strong belief in God as a controller of physical and spiritual well-being and life and death; often, in the absence of family, the faith community acts as a surrogate. Religion and spirituality also dictate how African Americans make end-of-life decisions and influences how they cope with adversity [30, 31, 32]. A tradition of employing a family-centred decision making process during family crisis is common [5, 6, 13, 27, 51]. Furthermore, for older African Americans invasive medical care may be pursued to buy time for God to manifest healing [28]. Factors that influence decisions about end-of-life care and completion of an ACP for this group also included concerns about institutionalised care and health insurance coverage [30, 31, 32], as well as wanting to avoid burdening caregivers and remain in control of personal health care [49]. Additionally, African Americans prefer to be agents of their own lives through their decisions and actions about health and functional status, but not necessarily of their dying or death, which could explain a lack of interest in ACP [52, 53].

Having strong religious affiliation and a family decision making style were also significantly negatively correlated for completion of Advanced Directives by 45 community dwelling Asian Indian Hindus [54]. Fifteen older Malaysians, with ages ranging from 65 to 83 years, felt that the future should be left to fate or God, and none had made any contingency plan for coping with severe future illnesses, citing religion as the reason for this view [55].

In a study in the UK that examined the influence of spiritual beliefs on African Caribbean Black families' experiences of health and well-being, the participants argued that good health and well-being was not possible without a spiritual relationship with a higher being or God [56]. Their religious and spiritual beliefs gave them inner peace and contentment and contributed toward a healthy mental outlook and social well-being. Furthermore, they argued that their health and well-being was a matter for God and not them.

Influence of health literacy on end-of-life care decision-making

The concept of health literacy has broadened since its emergence in the 1970's [57]. The concept includes a number of factors that may impact upon an individual's ability and capacity to gain access to, comprehend, and make use of health information from numerous sources [57]. Researchers have noted that individuals' literacy in terms of decisions related to ACP needs attention [58, 59, 60]. Substantial literature exists on risks for adverse health outcomes such as low socioeconomic status, race and low health literacy [52], which contribute to health inequities [61]. Poor health outcomes originating from limited health literacy are implicitly a fundamental injustice of the healthcare system [62]. A high level of health literacy is associated with higher social benefits and capital; low literacy is associated with individuals' poor understanding of disease and treatment options such as ACP and choice of end-of-life care [52].

Links between health and literacy have received substantial attention over the past decade, establishing this as an essential field of inquiry [63]. Health literacy is defined as "the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course" Rootman and Gordon-El-Bihbety [64] page11). Early definitions of health literacy focused on individuals' skills, motivation and abilities to obtain, use and understand information [63]; increasing attention has focused on abilities and assumptions of professionals who develop and provide information about health and on health services [63]. This broader focus includes individuals' abilities and characteristics of professionals and services that "may support or inhibit individual action" Rudd et al., [63] page14). Attention beyond that of individuals' abilities includes texts, health professionals' skills and assumptions within health care settings [63]. This broadens the concept beyond functional health literacy or access to information and use of reading skills to include personal agency and the "need to consider the patient/individual as an active participant in the creation of health" Rudd et al., [63] page 24).

Within the context of ACP, health care providers [65] need to attend to "multiple components of communication and interaction" Rudd et al., [63] page 23) (such as ease of exchange, pauses, posing questions) and engage in authentic discourse about the values, beliefs, and preferences patients have in preparation for dying [52]. Health care providers need to explain things clearly and provide information that is appropriate for patients [65, 66] and use communication strategies that elicit the values of patients and their families rather than focusing on explicit treatment choices [67]. Unfortunately, health care providers frequently

avoid ACP discussions despite patients' satisfaction with engaging in such discussions [68] or patients' desire to have such conversations [69]. Thus, health literacy is multidimensional, involving the intersection of patient skills and physician skills, and literacy demands imposed by the clinical environment [70].

Literature on end-of-life decisions and health literacy is scarce; this relationship was explored with an African American population and the study concluded that health literacy was associated with communication barriers between practitioners and patients [59]. Low health literacy is a significant barrier to clear communication and can “confound the relationship between race and informed decision-making” Volandes, et al., [59] page 755). Barriers such as cultural differences, different beliefs, and advance age can contribute to individuals' lower functional health literacy [71]. In a multi-ethnic, multilingual study of perceived barriers to quality end-of-life care it was found that health literacy issues were identified as one of the main reasons for a communication gaps between physicians and their patients [68]. The authors found that limited health literacy affects older Americans disproportionately, along with visual and hearing deficits. For example, older dialysis patients were found to have limited understanding of end-of-life language (functional), lacked opportunities for meaningful end-of-life discussion with providers and family (interactive literacy), resulting in uncertainty about future care (critical literacy) [66]. Even though this population has a high mortality rate only 13% of patients had end-of-life care discussions with their physicians (interactive literacy) and found it difficult to raise the topic due in part to their lack of understanding of end-of-life terminology [66]. Low health literacy disproportionately affects African Americans and Hispanics, persons of lower socioeconomic status, and older adults, partly explaining high use of aggressive end-of-life treatment in these populations [52, 59, 60]. It is of concern that advocates of ACP, and related policies and programmes developed to improve end-of-life care, continue to diminish and disregard the important differences in the way in which people of diverse cultural backgrounds identify, experience, interpret and describe illness and how this influences their experiences of these processes [19]. This suggests that poor health outcomes originating from limited health literacy is a basic “injustice of the health care system” [62] page 5).

Linguistic barriers between nurses and patients can perpetuate discrimination and compromise nursing care. There are significant organisational and relational challenges involved in ensuring adequate use of interpreters by nurses [72]. However, communication

practices vary when the backgrounds between clinicians and patients differ, leading to difficult decisions about care [73]. In general, misunderstanding and misinterpretation of information occur because of different beliefs, language barriers, sensory and cognitive changes, advanced age, and chronic illness adding to functional health literacy [52, 71].

In the UK, the poor level of accessible information regarding the nature of illnesses and likely prognoses; lack of knowledge about the terms ‘palliative care’ or ‘end-of-life care’; lack of information about available services; lack of cultural competency among health professionals; and refusal to acknowledge terminal illness, all contributed to not accessing end-of-life services has been identified [74].

Improving literacy and communication and for people from diverse ethnicities

Numerous methods have been proposed to enhance communication of information to patients and contribute to patients’ informed decision-making [59]. For example, visual images have been used effectively to improve communication of information to patients [75]. Also access to information through the use of the internet may encourage adults’ adoption of ACP, these could be tailored to their wishes closer to end of life [29]. Health care providers, including nurses, can reduce health literacy demands on patients by tailoring their teaching approach to align with patients’ needs and removing clinical environmental barriers [66] and through patient-centered communication and processes [76]. In end-of-life care, clear communication that reduces literacy demands needs to occur so that “patients of all functional literacy levels can fully engage in care” Ladin et al., [66] page 7). Communication can be enhanced when providers anticipate emotional responses to end-of-life discussions and can address patient misunderstandings [66]. Further, Garrido et al. [42] propose that ACP discussions could be held within religious congregations as this is a nonclinical setting in which individuals who have similar attitudes, values and beliefs about the end of life could discuss their treatment preferences with others who share their views. These ACP discussions can help to nurture individuals’ moral agency in terms of their “capability and freedom to exercise choice and opportunity” [77] page 1654) in making such decisions.

Conclusion

Ethnicity, religiosity and culture are significant influencing factors when people are facing the end of life. All patients need to exercise moral agency in their end-of-life care since ACP

can influence treatment options. Giving voice and autonomy to all older people of all cultures will help to dispel ethical concerns about transparency and any undercurrent of protection, expediency and cost saving when offering end-of-life care options to this patient group.

There is a growing recognition of the complexity associated with end of life decision-making for individuals with poor health literacy. People with poor health literacy have specific difficulty with written and oral communication that may limit their understanding of terms such as diagnoses and prognoses that then has an impact on their ability to make decisions about end-of-life care and complete ACPs. Given the importance of spirituality and religion in the lives of many people from diverse populations, there is a need to integrate ACP across professional fields and for specific training in inter-professional teamwork to include spiritual leaders in end of life decision-making process. Currently, strategies to develop ACPs are framed within the context of a medical model and appear to overlook and make little or no use of religious communities. Policy makers, nurses, medical professions, social workers and even educators continue to shape ACP programmes devoid of any or very little spiritual leadership. Inequities such as poor health literacy need to be addressed at both at the clinical and policy levels. Responding to such inequities using the ethical principle of justice is important in order to promote older peoples' ability to enact moral agency in making such decisions.

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