The illness trajectory of elderly cancer patients across cultures: SIOG position paper

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Background: Due to the aging of the population, cancer has become a health priority worldwide. While the number of elderly cancer patients is rapidly increasing, many barriers still exist to their effective management. Compared with their younger counterparts, the elderly are less likely to receive optimal medical, psychological and spiritual treatment provided in a culturally competent manner.

Design: The scanty literature on cultural competence in elderly cancer patients has been reviewed. Additional material has been selected based on the authors' clinical research in medical oncology and psycho-oncology, and on their scholarly work in anthropology and bioethics.

Results: The aging process is a synergistic product of biological, behavioral and social issues within a cultural context. Knowledge about how older people understand, perceive and experience their illness trajectory and make choices is essential to the planning and delivering of effective cancer care.

Conclusion: This position paper of the SIOG Task Force on Cultural Competence in the Elderly creates awareness of the influence of culture in geriatric oncology. Negotiating cross-cultural issues in geriatric oncology helps managing possible conflicts between patients, families and physicians over differing health care values, beliefs, or practices. Possible areas of future scholarly investigation and clinical research are identified.

Key words: cultural competence, geriatric oncology, psycho-oncology

‘The meaning we attribute to old age shapes the very meaning of our entire cycle of human life.’ Simone de Beauvoir, The Coming of Age, 1970.

introduction

Cancer is primarily a disease of adults, with approximately 60% of all cancers occurring in people older than age 65 [1, 2]. The World Health Organization recently declared the fight against cancer a health priority. In fact, due to the aging of the population worldwide, cancer mortality is increasing also in developing countries, yet many barriers still exist to effective management of cancer in the elderly. Society and healthcare providers continue to view the older population through a skewed ‘ageist’ prism, acting on assumptions of uniform frailty, treatment intolerance, and cognitive impairment. This distorted appraisal continues to limit the adequacy of research, appropriateness of care, and currency of unbiased education in oncology. The older adult population, however, is physiologically, psychologically, socially and culturally heterogeneous. Old age and culture are interdependent variables, which encompass different aspects, including anthropological, philosophical, medical, psychological and political dimensions. Negotiating cross-cultural issues will be increasingly required in geriatric oncology, where cultural competence needs to be combined with a special level of sensitivity and of respect for the reality of each individual patient within particular health care systems. Compared with their younger counterparts, the elderly are less likely to receive optimal medical, psychological and spiritual treatment provided in a culturally competent manner. Thus, this paper aims to create awareness of cultural issues in geriatric oncology and to foster cultural competence in the elderly.

definition(s) and measure(s) of old age

The aging process is a synergistic product of biological, behavioral and social issues within a cultural context of time and place. The terms ‘older persons,’ ‘the elderly,’ and ‘the aged’ are used virtually synonymously. Age 65 and over frequently is adopted as an arbitrary point for defining people as elderly.
Researchers and clinicians, however, must attend to different needs within the elderly patients [3]. It has been suggested that those over 65 should be divided into younger-old (age 65–74 years), mid-old (age 75–84 years), and old-old (age exceeding 85 years), with 75 years and older set as the cut-off point for more vigilant attention, because the incidence of age-related physiologic changes increases sharply between 70 and 75 years. The cutoff of 75 years thus seems to better reflect the complexity of cancer, comorbidity, and old age [4].

Most of the confusion regarding optimal care of older adults arises from our inability to measure aging directly. We can measure numerous age-related outcomes (e.g., loss of occupation, diminished cognitive alertness and physical vigor, and manifestations of physical disabilities), but each of these and all other indirect indices of aging are also influenced by genetics, environmental factors and economic policies in addition to aging per se. Moreover, all the biologic and health policy changes caused by illness are embedded in a social macrocosm of culture, ethics and historical values. Old age cannot be understood apart from its context in the life cycle and from a cross-cultural and historical perspective.

Older people have typically retired from paid employment, their friends and close relatives may pass away, their physical health declines, and they have reduced opportunities to be involved in society. Socio-economic factors create fundamentally different outcomes in the aging population and for many ethnic minorities around the world the common factor of low socioeconomic and minority status among the elderly has a major negative influence on health status and resources.

Despite recognition in the social sciences that the meaning of chronological age is social, contextual and cultural, biomedicine tends to focus on disability and loss at this stage of life rather than on what is gained in the aging trajectory. Philosophy, sociology and anthropology would be useful in geriatrics to address the difficulties in defining aging biomedically. Conflicting cultural assumptions about the social value of the older population collide with medical ‘facts’ of senescence. The words used to describe this life stage in developed and highly industrial countries tend to be pejorative and stereotypical and to equate aging with a negative or inferior state of being. By contrast, many non-western cultures revere their elderly members, value them for their life history and wisdom and attribute to them an important societal role. For example, Native Americans in the United States have traditionally based their decision making process in a tribe within the circle of elders, whose wisdom is treasured. Far Eastern and Muslim cultures also revere the elderly, though communities within an ethnic group may vary according to the degree of modernization and nuclearization of the family that has occurred. In these cultures, the elders recognize that they are going through a less economically productive and more physically limited phase of their life, when they are likely to face many personal losses. However, they also recognize they are still morally productive and that they can give contribution and support to the community and be vital and valued members of their social network. They have a purpose in life, and thus a reason for living.

Perhaps, most cultures honor their elders. This value, however, is challenged when the economic pressure mitigate the ability or will of a society to support its members who are no longer ‘productive’. If we only define productivity in economic terms, then the elderly have less ‘value’. Much of the discussion in oncology regarding the approach to elderly cancer patients reflects the beliefs held by society with respect to the meaning of aging and the value attributed to elderly members of different communities, but the aging demographics are forcing a re-evaluation of aging and societies’ ability to economically and socially support this shift in the world’s population.

cancer and the elderly

world demographics

Today, one of every 10 persons is 60 years old or over, totalling 629 million people worldwide. By 2050, one of every five persons will be 60 or older, and by 2150 this ratio will decrease to one of every three persons. By 2050, the actual number of people over the age of 60 will be almost 2 billion, at which point the population of older persons will outnumber children up to 14 years old [5].

The older population is itself aging. The United Nations Statistics on Population Aging in 2000 notes that the average life span increased by 26 years since 1950 and the proportion of people over 65 years old increased from 1 in 30 to about 1 in 6. Currently, the oldest old, aged 80 years and older, make up 12% of the population over 60 and this segment is the fastest growing of the older population. By 2050, 21% of the older population is expected to be 80 years or older [5].

The majority of elderly are women. Worldwide, there are 81 men aged 60 or older for every 100 women, and among the oldest old, 53 men for every 100 women. The ratio of men to women in older age groups is lower in the more developed regions than in the less developed regions. While 78% of older men are currently married, the corresponding figure for older women is 44% [5].

cancer in the elderly

Cancer is the leading cause of death among women aged 40 to 79 and among men aged 60 to 79 and one of the three leading causes of death over 80 years of age [5]. As the world population continues to see rapid demographic shifts, the number of older adults receiving cancer care worldwide will be unprecedented.

Many older adults with cancer tend to be underserved. Compared with their younger counterparts, people aged 65 years or older are less likely to receive optimal or standard cancer care [6]. Studies show that cancer screening is less likely proposed to the elderly and, when a diagnosis of cancer is made, curative therapies or participation in clinical trials are less likely offered [7–9]. In addition, appropriate and tailored palliation is less frequently provided, and elderly patients with advanced cancer often experience avoidable loss of quality of life and increased psychological and physical stress. Older adults may also receive less aggressive therapy, often based on erroneous assumptions that they neither want nor would tolerate such therapies [10, 11].

Current practice of care for elderly cancer patients is based more on stereotypes than evidence. Empirical evidence that describes the unique needs of older adults with cancer is strikingly limited in proportion to the demographics of cancer.
in our aging society. Historically, patients older than 65 were—and still are—excluded from clinical trials, resulting in a paucity of data relevant to this particular age group. Behavioral and social research has also focused largely on younger adults; leading to a void in understanding the complex psychosocial needs of older adults facing cancer. By contrast, the recognition of distinctions among chronologic, biologic and functional age, along with unique features of aging such as concomitant illnesses, achievement of age-appropriate social roles, and thinning social support are necessary to foster a new, more effective paradigm of care and research in geriatric oncology.

**existential, social and ethical issues**

The existential meaning of aging has been the subject of passionate literary essays and of philosophical inquiry since ancient times. Philosophy of medicine has also dealt with aging in different forms. Whether or not senectus ipsa morbus est (old age itself is a disease), the boundaries between aging and illness—especially chronic illness—are fuzzy. Cancer poses additional formidable challenges at the physical level and it raises profound emotional issues for the elderly patient. This, in turn, may have deep repercussion on individual patient–doctor relationships in geriatric oncology.

Generally, older people become less and less actively involved in society due to factors beyond the control of the individual, such as compulsory retirement, dysfunctional illnesses and death of relatives and friends, distancing of the nuclear family in industrialized societies, and diminished financial resources. Furthermore, older people tend to occupy fewer social roles and have fewer social interactions. They may choose to reduce the scope of their social lives, spending increasing time home alone and gradually narrowing their life-space [12]. Elderly patients may be more likely to adhere to certain religious or cultural attitudes toward health issues, including the relationship to individual physicians, health-care workers and institutions. They may wish to rely on their own family and community up to the point of delegating to them major medical decisions, and they may be more suspicious of technology in its different forms and may have great difficulties navigating through modern health-care systems, necessitating additional educational, emotional, and structural support.

Cancer in the elderly raises many ethical and social quandaries for health-care providers and policy makers. In modern societies focused on competitiveness and economic productivity, the elderly often suffer from isolation and poverty. Health care resources are limited and major issues of fairness and justice in their distribution arise with respect to elderly patients. Access to cancer care and research may be extremely limited.

**aging, gender and support**

Aging affects and influences men and women in divergent ways. As they perform different roles throughout their lives, men and women encounter dissimilar experiences and needs. Many of these differences relate to inequalities in relationships, unequal social positions and unequal distribution of wealth. Gender has enormous implications for economic security, access to resources, and survival. Social roles become proxies for obligations, mores and norms, which have consequences for careers and available resources in the post-retirement years. With respect to overall health issues, illness-related mortality is higher for men, while women tend to have increased comorbidity and lower self-rated health, resulting in overall compromised life quality as they age [13]. Older women’s psychological and physical health may also be especially affected by a lifetime of gender-based inequalities.

Until current times, men generally played a ‘productive’ role while women played a ‘reproductive’ role [14]. Much of men’s work has been public, acknowledged and valued while women’s work has been generally undervalued. The manner in which culture and society consider people according to gender is bound to promote and perpetuate inequality. Gender differences in the culture of interpersonal interactions encourage men to use such interactions to compete for hierarchical status, while women tend to focus on creating emotional rapport and social affiliation [15].

Gender differences in patterns of social support are well-recognized and suggest that the demands and rewards of social network participation have a distinct psychological meaning and value for older men and women that impact their ability to manage illness. Gender differences in friendship and emotional support are particularly marked. Studies have increasingly pointed to the value of special relationships in adjusting to the stresses and strains of later life, and have shown that women tend to look beyond their family to other women for psychological support. Men, by contrast, name their wives as their main source of such support and, often, as their only confidant.

Women’s friendships reflect a person-oriented paradigm characterized by emotional support, intimacy, verbal interaction, self-disclosure and mutual assistance. On the other hand, men’s friendships tend to be activity-oriented and to be based on shared pragmatic experiences of ‘doing’ and ‘accomplishing’ [16]. Research has confirmed that women are more likely to assume primary care giving responsibilities toward their family, but also their friends, and devote long hours to the tasks associated with informal care giving [17, 18].

Many elderly people have been married for a long time, leading to deep attachments and to entrenchment of family roles and daily schema. Cross-cultural data describe considerable stability in long-standing social relationships that prevail until very late in life [19]. In response to cancer, patients may seek increased relatedness and closeness to other family members [20, 21]. Elderly patients tend to successfully incorporate in their scripts and expectations the unexpected changes due to the chronic evolution of the illness and its treatment and others comorbidities. However, cancer may adversely affect couples’ closeness and satisfaction, especially when open communication and emotional support are impaired, exacerbating the emotional distress within the family. Social relationships contribute significantly to the health and well-being of the elderly person through their influence on the care-giving role, as well as through their potential to influence successful aging. Couples who have reduced access to meaningful memories, or are isolated from social support and unable to share problems with a sense of perspective, may benefit from professional assistance to acknowledge their fears about the illness and the...
uncertain future [22]. In the past, historical misconceptions and old wives’ tales distorted the older generation’s perception of mental health care, leading to embarrassment or shame about ‘sharing’ or ‘receiving help’. Today’s cohort of older people may find it very relevant and beneficial to engage in reminiscing about past abilities, successes and accomplishments. The goal will be to assist them in reckoning more fully with the many threads of their own course of adult development to achieve a better quality of life and sustain the emotional resiliency needed to cope with the present illness and to pursue a meaningful tomorrow.

**aging and the path to wisdom: mastering cancer**

The way people respond to a cancer diagnosis generally is determined by their personal experiences, history, and system of belief, social relationships, cultural meanings and clinical features of the disease itself. Knowledge about how older people understand, perceive and experience their illness, however, is scant concerning people 75 years of age and older [23]. While existing research focuses on losses, paradoxically, elderly people may adjust and adapt to stressful events better than younger people by using passive and emotional-focused coping strategies such as distancing, acceptance of responsibility, and positive reappraisal [24]. Greater life experience may also lead to an increased ability to confront and endure the hardships and the vicissitudes of the cancer and the dying process [25, 26].

One consistent theme that emerges from a review of the literature on psychosocial factors in aging is the importance of perceived control over circumstances—mastery—and beliefs about one’s ability to successfully accomplish tasks or meet age-appropriate goals—self-efficacy. Both concepts are grounded in a social cognition framework whereby an individual’s perception of control over events is partially a function of the feedback they receive from the social environment [17]. Understanding the illness and having the power to maintain an internal sense of control make daily life meaningful and easier. Awareness of the diagnosis and of treatment options is important in developing effective coping strategies, such as controlling, disassociating, adapting and comparing the cancer experience with former life challenges and outcomes. These strategies reflect the balance between what the person chooses to accept or confront and ignore or postpone [23, 27]. Irrespective of the strategy used, a positive outcome is dependent on the older person’s power and freedom to choose.

**cultural competence in geriatric oncology**

The ability to successfully negotiate cross-cultural issues in the clinical setting plays an important role in today’s practice of oncology. Such ability is based on cultural competence, which entails the recognition and understanding of the role that culture plays in the patient–doctor relationship as well as the acquisition of specific skills and attitudes. Cultural competence seems especially salient in the field of geriatric oncology, where generational differences may intersect and compound with cultural differences, with significant repercussions also on individual patient–doctor relationships.

Each person’s identity, view of the world and value system depends on her culture. Culture provides each person with a reference framework to interpret the external world and to relate to it. Each person relies on her culture when trying to make sense of what is happening to her, especially at difficult or traumatic times in life, such as during the course of a serious illness [28]. Thus, culture plays a significant role in the patient’s experience of cancer, which often encompasses great physical and psychological distress, suffering, losses and uncertainties. Culture also defines the meaning of old. Culture equally shapes the identity, world view and value system of the clinician as well as the patient. In our rapidly demographically and politically changing world, dissonance between the culture of the patient and that of the physician is extremely likely [29]. Notably, the patient and the doctor may share a common ethnic culture, but medicine is itself a culture and socializes its members to think and act in particular ways [30].

In contemporary societies, cross-cultural encounters between patients and physicians occur with increasing frequency not only in highly multiethnic and multicultural society, such as the United States, but also in more homogeneous societies. Generational gaps often contribute to cultural differences in patients’ and physicians’ attitudes toward disease, illness and health-care strategies. Truth-telling to cancer patients and end-of-life decisions are examples of common sources of misunderstandings and of possible conflicts. Internationally, cultures differ significantly in their assumptions about the ethical standards against which clinical practice should be measured that range from full disclosure to total deception depending upon the age, sex, gender and site of the cancer [31, 32]. Cultural factors also play a role in the existing major disparities in access to health care and research for minority and/or underprivileged cancer patients [33].

In many cultures, illness and death may be considered with equanimity and acceptance as a natural course of life without disengagement and loneliness, but as the tendency in more industrialized countries is towards a societal devaluation of the elderly, they often feel ostracized and isolated from the main stream of life which adds further metaphorical meaning to their cancer. In all cultures, however, elders with cancer likely have deeply rooted convictions regarding their interpretation of the meaning of suffering in the context of their personal and cultural life-story. Older persons have faced mortality, pain, memories, and losses. Their life perspective and belief system will influence their attitudes toward enduring physical and emotional pain, and affect how they make practical decisions during the course of their illness.

To uncover and decipher potential cultural and generational differences, it is essential to understand that the purpose of every culture is to ensure physiologic health and emotional well-being [34]. This serves as premise to set the stage to negotiate with patients and their families among a wider set of options. A benefit to this perspective is also the self-reflective realization that many of the ‘vulnerabilities’ attributed to cultures other
than Western European and Northern American ones are often due to misinterpretations of these cultural values, beliefs and practices. Some of these practices may actually be more effective in adjusting to the diagnosis of cancer for elders than the Western European and North American based alternatives. This approach has been glossed as culturally competent medical practice, which describes a skill set that enables physicians engaged in culturally discordant encounters to respectfully and compassionately elicit the patient’s and family’s needs and perceptions and provide the necessary information in an appropriate manner to promote negotiation to establish mutually satisfactory goals for treatment.

While understanding the patient as an individual in the context of culture does not prevent conflicts over differing values, beliefs, or practices, the information gained from such an assessment serves to identify areas for negotiation of such conflicts. When physicians, patients and families have some understanding of each other’s perspective, such negotiations can take place in an atmosphere of mutual respect rather than frustration and misunderstanding and improve the likelihood that the all parties would be satisfied with the decisions made for treatment and the outcomes of care.

**Conclusion: SIOG Position on Cultural Competence in the Elderly**

Cancer in the elderly has become a health priority worldwide and health authorities are increasingly providing information worldwide to the aging population concerning cancer epidemiology and treatment options. However, clinicians usually underestimate the physical, mental abilities and willingness of elderly people to face such a chronic and potentially lethal condition. On the other hand, patients and their families may consider cancer like a disease untreatable in the aged and not understand the possibilities offered by treatment.

Biomedicine views most diseases as mechanistic errors that can ultimately be corrected, with disease as separate from moral status, and the spiritual implications of illness become secondary to the objectivity attributed to the biomedical approach. This dominant western model negates the belief structure of many cultural groups, including some European Americans, and restricts our ability to deliver optimal cancer care also to our elderly patients [35]. The pathophysiological condition may be universal, but the meaning of the disease, its symptoms, and the appropriate means to treat the disease are culturally framed.

Clinicians, then, must learn not only the physiological and psychological changes occurring with age, and with the pathophysiology of cancer in the elderly, but also the social and cultural aspects of aging, in order to provide culturally competent cancer care to their elderly patients. Numerous strategies have been outlined to teach and support the skill set known as cultural competence, but specific measures to evaluate the impact of teaching on health care outcomes and on patients’ satisfaction are still under investigation.

Clinicians, researchers, educators, legislators, and policy makers need to address the imminent demographic change and the consequent societal challenge by acquiring an innovative perspective on aging and cancer. This should rest on broader knowledge of the specificities of cancer in the elderly, on more sophisticated and redesigned systems of care, and on education and training of dedicated of geriatric oncology professionals skilled in cross-cultural, patient centered care.

Aging is an extremely complex, multidimensional process, which we have barely sketched in this position paper. While we tried to give an overview of the main psychological and cultural factors contributing to the illness trajectory of elderly cancer patients, we could only cover few limited aspects of the path to wisdom of elderly cancer patients. The SIOG Task Force on Cultural Competence in the Elderly recognizes that many other issues are of extreme importance in geriatric oncology. Among them are the inherent and culturally influenced limitations of autonomy in elderly cancer patients and the intricacies of balancing the beliefs and assumptions of patients, families and oncologists with respect to treatment and quality of life. We plan to publish additional scholarly work and to encourage the implementation of research in this field.

**References**