

Review Article

Helping Family Make Decision for Cancer Treatment

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Abstract

Older adults' cancer diagnosis and decision making for its treatment can be shocking and burdensome to the whole family, especially to their designated caregivers. The decision making process for cancer treatment is complicated and sometimes changeable in complex ways, giving the unique structure of each family. While formal community based long-term care is designed to deliver the needed care to older adults in reducing their institutional or hospital admissions and facilitating aging in place, the formal care may be hard to involve in decision making process for cancer treatment that encompasses more than logical rationales within the family infrastructure. Thus, family members play an important role in making decision for cancer treatment when the older adults are physically and emotionally overwhelmed. In this article, we provide an overview on various responses in decision making for cancer treatment, critique what aspects of health services could be improved, and make suggestions to better inform patients, families, and health professionals who serve the aged population undergoing cancer treatment.

INTRODUCTION

An estimated 1.7 million new cases of cancer would be diagnosed and 600,000 would die from cancer in the USA during 2016 [1]. Advancing age is related to high incidence of cancer, with persons over 65 accounting for 60% of newly diagnosed cancer and 70% of all cancer mortality [2]. However, with greying of 78 million of baby boomers, the growing care gap becomes a serious concern at future declines in the availability of family caregivers [3] because older adults often rely on their family members for care to age in place, instead of being placed in an institute [4]. The demand and supply imbalance unavoidably creates a phenomenon of increasing older adults suffering from cancer with less available family members to provide care. Regardless, making decision for cancer treatment will activate the entire family. Although the formal community based long-term care has been developed since 1970s [5] to provide older adults with health services in their accustomed surroundings [6], decision making for cancer treatment is a complex family matter requiring continuous interactions due to the dynamic nature of changing conditions of older adults with cancer. Patients and families face excessive challenges in making decisions for treatment because the life is at stake, and the unease may lead to regret the decision they made [7] or refuse the treatment [8]. In this article, we attempt to present a wide range of decision making for cancer treatment, critique the room for improvement, and make suggestions to help health professionals understand

patients and families who are involved in the decision making process, and thus, we can provide them with empathetic care and obtain informed decision.

Decision making for cancer treatment

After reviewing literature, we categorize the findings into four major types: decision making process, decision preference, using complementary and alternative medicine (CAM), and refusing treatment. We also offer critique for current healthcare services and make suggestions in the end of each section.

Decision making process

The process is complex, difficult, distressing and challenging for patients and families even though the issue of clinical decision making has greatly evolved in the past 25 years [9]. Shared decision making is increasingly advocated as a tenet of contemporary medicine and oncology practice [10]. The pros of shared decision making is associated with better quality of care, greater satisfaction with treatment, and better communication [11,12]. However, conflicting findings are also found because not every patient prefers to play the same role in the decision making process, especially when the patient is newly diagnosed, or faces mismatch between the information needed and obtained [10].

Regarding shared decision making, several issues need to be addressed. First is about its pros and cons. In a survey of 604 Australian physicians who treat various types of cancer, the

barriers in implementing shared decision-making included time constraints, lack of applicability due to patient characteristics, and lack of applicability due to clinical situation [13]. The facilitators included providers' motivation, positive impacts on the clinical process, and positive impacts on patient outcomes [13]. Next is about the quality of decision aids, which have been developed and introduced to support patients' decision-making during the past two decades. A large-scale study revealed a considerable diversity in both format and available evidence; while strong evidence showed that cancer-related decision aids increase knowledge without adverse impact on decisional conflict or anxiety, only moderate- or low-strength evidence were found that patients using decision aids are more likely to make informed decisions, have accurate risk perceptions, make choices that best agree with their values, and not remain undecided [14]. Some researcher suggest that the readability and cultural sensitivity issues need to be considered because most decision aids include difficult texts and do not focus on specific cultural groups [15]. Others recommend new format using a user centered approach to producing decision aids through iterative observation of discussions between physicians and patients [16]. This approach resulted in succinct, easy to use tools that provide graphic displays of the benefits and harms of different options organized around concerns that are important to patients and families [16].

In sum, while the intention of shared decision making is legitimate, health professionals need to first assess if patients and families are prepared to participate the conversation at this stage with various physical or emotional issues. Then, we need to carefully choose or design decision aids that fit patients' and families' cultural, educational, and technical background to help them better understand and accept the information given. Those steps can help patients and families involve in the decision making process without unnecessary struggles to grope in the dark.

Decision preference

After experiencing initial decision making process, the preference of treatment options begin to show; however, they may be inconsistent among patients, families, and physicians [13]. In the following section, studies related to motives, factors and willingness affecting the decision preference are discussed. The motives of the decision preference are related to control: (1) desire to control disease; (2) desire to control suffering; (3) desire to control death; and combinations of the three as Knops and colleagues claimed control is the main consideration in patients' treatment preference [17]. Cancer patients and families often need to make decisions while they are emotionally overwhelmed, after reviewing related studies Newman and colleagues summarized that factors influencing their treatment preferences were age at the time of making decision, having a partner, having children, inability to work due to side-effects of the treatment, the nature of the side-effects, disease-related life expectancy, and the baseline of quality of life, which were influenced by their age and education [9]. Nevertheless, another study in advanced cancer patients found significant inter-individual variability in the willingness to accept chemotherapy with age, experiences of adverse effects, and self-assessed quality

of life being significant predictors [18]. Before the therapy, only 72.1% patients were given information about adverse effects of treatment and 39.5% were told of alternative treatments [18]. Likewise, another study in 192 cancer patients showed that only half of patients thought that they were offered treatment choices [19]. Those aforementioned findings reveals room for more informed decision for cancer treatment be provided.

In sum, regardless the motives, factors and willingness in initial treatment preference, patients' decision preference might change during the disease process. A study in 135 breast cancer patients found that almost half of patients changed their preference of treatment [20] and another study in 70 early-stage prostate cancer patients also revealed the dynamic decision process because what is important to them may vary over time [21]. Unpleasant side effects of treatment often lead to the change; therefore, updated tools used to assess the adverse effects of cancer treatment was developed to apply in adults and children under cancer treatment to objectively assess its side effects [22,23]. Those assessment tools could serve as one of the predictors of changing treatment in future studies and should be routinely applied in oncology. Health professionals may need to pay more attention in future studies about factors leading to change of decision preference in order to provide patients and families with better care, and even predict the possible changes before they have occurred. Thus, we can be an active communicator to discuss advantages and disadvantages of the possible changes of treatment preference with them in advance.

Using complementary and alternative medicine

Some patients and families may choose to change their decision preference to CAM. Although much discrepancy exists over the definition of CAM, the use of CAM is increasingly common among cancer patients [24]. In the following section, prevalence, reasons, factors and who using CAM are presented. About prevalence, in a systematic review of 26 articles showed that the ranges of using CAM among adult cancer patients were 7 to 64% [25]. Another systematic review revealed five major reasons for CAM use: (1) perceived as beneficial, (2) wanting control, (3) a strong belief in CAM, (4) treating CAM as a last resort, and (5) disappointment with conventional treatment or disappointment with a conventional practitioner [26]. This study also found that women and younger patients were more likely to use CAM than men and older persons [26]. Many cancer patients fear pain more than death. In a systematic review in using CAM for pain management (such as acupuncture, massage, reflexology, yoga, Tai-Chi, hypnotherapy), the authors claimed that quality of life in cancer patients can be effectively improved with the combination of pharmacological and non-pharmacological therapies [27]. Patients using CAM to control pain were associated with attending support groups and disease characteristics, but no associations with their education, income, or geographic locations were found [27].

In a study using focus groups to investigate 31 cancer patients who decided to forgo conventional cancer treatments in favor of CAM, researchers revealed predisposing and direct factors of using CAM [28]. Predisposing factors included (1) negative experiences with mainstream medicine; (2) having close

relatives or friends who have died from cancer when receiving conventional treatment; (3) experiences around their diagnosis; and (4) a belief in healing rather than curing. Direct factors of using CAM were: (1) the communication with health providers about treatments, (2) perceived side effects of conventional treatment, (3) personal beliefs, and (4) the need for control [28].

In sum, many cancer patients choose to use CAM in spite of its high cost, limited access, lengthy time required to complete the therapy, little scientific evidence, and possible harm induced by CAM. While some may use CAM to replace conventional treatment totally, others may use CAM as a supplement of conventional treatment. Patients and families either could no longer to grind and bear the previous treatment, or treat CAM as the last resort, they want to feel 'hope.' However, the lack of scientific evidence often lead to physicians' skeptical responses or express their opposite position to patients leading to poor relationships with them. On one hand, further research is needed to bridge the gap in the effectiveness of CAM. On the other hand, physicians need to hold a more neutral attitude to better communicate with their patients and families to detect or avoid further harm. Do not close the communication route with them to further push them away as negative with a conventional practitioner are one major reason for them to choose CAM.

Refusing Treatment

Even with various treatment options, patients may totally or partially refuse the suggested conventional treatments or the mainstream medicine at a rate of 7.5 per 1,000 [29]. The process behind the decision are complex and might take patients and families' thoughtful deliberation, weighing all the pros and cons, considering personal circumstances based on the one's attitudes toward living, suffering and dying as well as their family and friends' opinions [30]. The reasons of declined treatments in eight patients with prostate cancer were that they wanted control over their treatment process, including controlling over the timing of treatment, controlling for information about conventional treatment and risk assessment, designing alternative treatment plans, coordinating cancer care, and monitoring and evaluating disease progression [31]. The reasons in 14 cancer patients who declined the conventional treatments were (1) to avoid damage or harm to the body, (2) feeling that conventional treatment would not improve their disease, (3) having unsatisfactory relationship with healthcare providers that stopped them from using conventional treatments, and (4) discoveries of CAM [32]. Another interview with nine patients who refused the recommended diagnosis or treatment were that: (1) patients wanted to deal with their health problems on their own; (2) patients do not think their problems were as serious as the assessment of their physicians; (3) they believed that a power is larger than themselves, which would decide their ultimate destiny; (4) they did not trust the medical authority; (5) the explanations from health professionals were often multidimensional; (6) they preferred to live without knowing their diagnosis; (7) they refused because they did not receive sufficient information; (8) they wanted to avoid the possible physical discomfort accompanying medical procedures; and (9) they wanted to have the power of self-determination [33].

In sum, health professionals tend to deem refusing treatment

leading to a poor quality of life as the cancer progresses without treatment. Interestingly, that might not be the case, especially for individuals with advanced stage cancer [30]. Researchers have found that when patients refused the suggested treatment, the physicians had mixed feelings and concerns and often feel uncomfortable when facing patients who against their medical advice with strained communication [34]. Physicians' constructions of their experience focus on uncertainty and concern, and may even encounter ethical challenge when those patients return for follow-up [35]. With regard to treatment refusal, patients and families felt that the communication became difficult while their physician perceived their refusals as irrational, and they did not get a chance to talk about their values, emotions and the reasons for refusal with their physicians [36]. The aforementioned results appeared to show both sides of care providers and recipients are not happy with each other so the communication may be severely blocked. Researchers suggest investigating the outcomes of treatment refusal that may help more cancer victims and families [28]. It is our sincere wish that health professionals should not physically or mentally abandon those who chose refusing treatment as irrational without even listening to them. Listening is very therapeutic to patients and their family even refusing treatment is not the best way we think they should choose.

DISCUSSION

Cancer is a family affair and family should be treated as a care unit to participate all conversations in cancer treatment decision with health professionals when the patient is an older adult. The growing body of literature regarding older cancer patients' treatment decision indicates the importance and demands in this area. For example, older women with breast cancer wanted information and decision support from their clinicians along with a specific tailored information booklet to support this treatment process [37]; or when evaluate the impact of the geriatric oncology consultation on the final therapeutic management of cancer in elderly patients, it showed that concordance between the cancer treatments proposed after the consultation was excellent except for chemotherapy and surgery because both were often replaced by a less aggressive treatment [38]. The treatment decision making process and preferences is complex and influenced by many factors and often involved the whole family. While many decision aids have been developed to facilitate shared decision making, further study should address the practical implementation and outcome evaluation with patients' need for control the decision in mind. Among other options, CAM has been popularly used to replace or supplement the conventional treatment. In spite of remaining doubts, the multiple resources of CAM need to be examined for their accuracy and scientific base by health professionals. Meanwhile, health professionals need to avoid blocking the route of communication with patients and families who choose to use CAM or refuse the recommended treatments. While we respect their decision, the process and outcomes of patients' treatment changes should receive more concerns in future research for the greater good of the increasing sizable patient population. Thus, possible predictors of treatment changes can be assessed and located for us to implement early detection and intervention. When life is at stake, health professionals may need to bear in mind of bioethical

concerns of the rights to life and health, respect, dignity, and empathy to patients and families.

CONCLUSION

Decision making for cancer treatment is dynamic and highly individualized process, especially when the patient is an older adult without advance directive, including living will, medical durable power of attorney. Each person and family's context will influence their decision. Not all families experience the same level of apprehension while making decision for cancer treatment. However, their families may be in agony of watching the older adult suffer without an advance directive, and thus making family members in an even more difficult, emotional process of disagreement. When an older adult is diagnosed with cancer, health professionals should urge the patient and family to discuss an advance directive if they have yet done so. In addition to patients' profiles, their family primary caregivers' gender, age, education, relationship to and dependency of the older adult with cancer, and other demands on the family caregivers' energy at work and/or home may all become influential. Therefore, it is important to regularly assess patients with their families before conditions lead to more serious strain and possible confusions and adverse effects.

Interdisciplinary teams in acute care and home-based care settings can complete periodic assessments of family members with influential role in decision making for cancer treatment during patient visits. This can prevent myths, miscommunications, and lack of knowledge that lead to serious stress, and strain and eventually detour from suitable cancer treatment. Obtaining baseline data and monitoring family primary caregivers regularly allows health teams to gauge the intensity of strain caused by difficult decision for cancer treatment as well as understand and manage what specific aspects of the decision are the most difficult for patients and families. Respecting the decision of patients and families even it is not our best recommendation and maintaining an open-minded manner are anticipated from health professionals. Further studies are suggested to explore and predict the decision changes in order to provide appropriate care needed.

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