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Published in:
Seminars in Oncology Nursing

DOI:
10.1016/j.soncn.2021.151231

Published: 03/12/2021

Document Version
Peer reviewed version

Exploring the dilemma of ethical issues using the lens of Seedhouse can help oncology nurses to gain a different perspective on caring for older adults with cancer

Seminars in Oncology nursing

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Word count: 3452 including references

Abstract

Objective: To explore ethical issues associated with older adults with cancer and the people who matter to them.

The article uses the lens of the Seedhouse ethical grid to enable a practical exploration of ethical issues with older adults with cancer and their families with global relevance.

Implications for nursing practice: the article is of particular relevance to practising oncology globally nurses as the framework can be easily used in clinical practice.

Keywords:

Ageism, older adults, ethics, cancer, ethical grid, moral philosophy

Introduction

This article explores the dilemma of ethical issues impacting older adults with cancer. We use the lens of the Seedhouse ethical grid to enable a practical exploration of ethical issues with older adults with cancer and their families with global relevance. The use of this practical ethical framework means that this article is of particular relevance to practising oncology nurses as the framework can be easily used in clinical practice.

Background

The global population of those over 65 is expected to rise by 16% by 2050. [1] This poses a global public health challenge as the number of older adults with chronic, debilitating illnesses will also rise. [2] This is specifically true in cancer, a common disease of older adults [3], where annual diagnosis in older adults is expected to almost treble by 2035. [4]

A range of age-related physiological changes [5,6] coupled with co-morbidities and polypharmacy [7] in older cancer patients spawn heterogeneity which complicates diagnosis and shapes decisions around treatment goals and outcomes. [3,4,6] Best practice in the treatment of older people with cancer is further hampered as they are under-represented in clinical trials [8] which can lead to over and under treatment which may be detrimental to survival rates [3, 9] Older cancer patients are not only diverse biologically but also in their functional ability [5], socio-economic status [10] and their life philosophy which is based on their culture, values and belief systems. [11] Each variable can determine how an older adult responds to life events [12] , including a cancer diagnosis and its sequelae. [13, 14] Consequently, running in parallel with the need to accurately diagnose and provide optimal cancer treatment in this population, it is imperative to provide high quality, person-centred

supportive care throughout their cancer journey [15] to sustain and nurture health and wellbeing. [9]

The parallel increase in both dependence and cancer in an older population, therefore, leads to ethical debates on how to balance the benefits of specific cancer treatment as well as their potential harms. For example, clinicians, people with cancer and their families need to consider the excessive toxicity of treatment. [6] This may also lead to questions about how to validate treatment decisions in cognitively impaired people and how to collect consent from the person and his/her family. [16-18] A recent scoping review [19] found many factors interfering with the decision to investigate and treat, leading to late or unstaged disease, palliative-oriented care instead of curative, and a higher risk of unjustified transfers to acute care settings.

There is evidence that for the majority of older adults the most important reason to undergo treatment is preservation or improvement of quality of life. [20] Yet, physicians often find it challenging to select the best cancer treatment when older adults have co-morbid illness in addition to cancer, impacting life expectancy, quality of life and treatment tolerability. [21] The more complex the needs, the higher the risk of poor outcomes that stem from processes and decisions that only focus on the cancer pathology and do not take account of factors such as frailty, comorbidity or social situation. [21]

Specific challenges relate to the just distribution of resources (resource allocation), balancing health care professional judgment (medical paternalism) with respect for patient autonomy.[22] As well as, reducing the social inequalities that contribute to disparities in cancer diagnosis and outcomes. Nevertheless, balancing resources with treatment decisions is also an issue in both resource poor and high income countries.

Ageism is a "social construct of old age that portrays ageing and older people in a stereotypical, often negative, way" [23] Discrimination and prejudice stemming from negative representations of old age are well recognised in cancer care [24] and adds further complexity to the treatment and care of older adults with cancer. [25] For instance, being constantly faced with frail and sick older adults perpetuates negative stereotyping and ageism and remind professionals of their own mortality. [26] Such thoughts trigger death anxiety which means that professionals withdraw contact from older people with cancer to protect their wellbeing which leads to isolation and leads to reduced quality and quality of care. [25] Consequently, ageism and death anxiety, coupled with the uncertainties of how to best to treat cancer in older adults leads to reduced quality and quality of care. As such professionals need to find a path through these uncertainties.

Ethics

Although ethics can be complex – *ethical* and *moral* are wording whose significance and meaning permeate all areas of human thought and action and are essential in the world of health care. [27] A simple definition of ethics is that it is concerned with 'how men and women ought to live their lives". [28]

Using an ethical lens the following review of the supportive care of older adults with cancer will employ the Seedhouse (2009) [28] ethical framework to explore key areas in a practically applicable way across the cancer journey.

Seedhouse ethical grid

The ethical grid devised by Seedhouse [28] is designed to be used as framework to help guide the health professional to make ethical decisions.

(Add figure 1 ethical grid)

There are four different layers to the grid usually indicated by different colours: blue, red, green and black. Each layer is independent and detachable. The grid is designed to be applied to practical cases to enable practitioners to solve and elucidate the main issues in everyday ethical dilemmas. [28]

Autonomy

The **blue or middle** layer is at the centre of the grid as it provides the core rationale. The four boxes that make up the middle layer represent the central conditions necessary for health. The boxes are create autonomy, respect autonomy, respect persons equally and act to serve needs before wants (Seedhouse, 2009). [28]

Creating and Respecting Autonomy

Personal autonomy is the ability to self-rule, make free choices and to control one's life plans. [29] However, autonomy is also relational and is intertwined with the autonomy of

others. [30] In the older adult with cancer this means that the autonomy of professionals, patients and families come together, thus creating and respecting autonomy become complex to achieve. For example, professionals are often seen in a position of power and may override the wishes of patients which results in paternalistic decision making. [31] Alternatively, family members autonomy may be allowed to take precedence by the patient as do not want to feel like a burden on others, especially when their illness becomes advanced. [32] So rather than creating and respecting autonomy which are essential for the creation of full personhood and shared decision making [33] decisions may be based on the wishes of others.

Shared decision making is seen as a cornerstone to person-centred cancer care and wherever possible this should be promoted. [34] There are many models and frameworks of communication that would promote the therapeutic relationship required for person-centred cancer care. [35] Taking a routine approach to information giving where the patients and their families are given all the salient information about an illness and its treatments will help patients make an informed choice and give informed consent. [27] Older adults' ability to make informed choices and give informed consent may be compromised by cognitive impairment. To ensure they get the highest quality of care that meets their needs an assessment of capacity may be required and subsequently the use of incapacity legislation and other decision-making processes put into place. [36] In some cases this means that the patient has a legally identified healthcare proxy who will make decisions on their behalf to support their best interests. [37] It is incumbent that the professional team be fully aware of who has the right to make decisions on behalf of the patient and what decisions

have been made this should be supported by high quality documentation which further acknowledges respect for autonomy and shared decision making. [38]

Respect persons equally and act to serve needs before wants

It has already been acknowledged that ageism has a negative impact on equity of cancer care. [24] Society and health providers need to move away from the notion that older adults are a burden on society and promote effective ageing. The authors urge nurses to remember that as nurses we need to treat and care for people based on need rather than age or even diagnosis.

Beneficence and Non-Maleficence

The **second or red layer** includes; promise keeping, truth telling, intention to enable (beneficence) and minimise harm. In this layer the focus is on duties and motive. The notion the health professional is asking here is ' how do I enable the enhancing potentials of people? This layer corresponds with the main deontological theory of moral philosophy. In this layer nurses and other health professionals consider the aforementioned important during moral deliberation.

Promise Keeping and Truth Telling

Tenets of the therapeutic relationship in cancer care are trustworthiness and honesty which relate to the ethical principle of beneficence. [39] Consequently, professionals who break promises and withhold the truth from patients and families may lose their trust which in

turn leads to distress, anxiety, anger and fear as well as poorer patient and bereavement outcomes. [40, 41]

There is a long-held understanding that telling patients and their families the truth about serious illness and its sequalae enables them to be partners in their care which reduces the anxieties related to uncertainty [42] and supports psychological wellbeing and treatment concordance. [43] Much in keeping with shared decision making the key to ethical truth telling is a person-centred approach which ensures information giving is in the best interest of the person/people receiving it. [35] The decision to share, what may be classed as 'bad news', should be taken by the care team as a whole and there are a number of models of delivering bad news such as SPIKES [44] which can help with the practicalities of information giving in a compassionate way that supports the therapeutic relationship and does not impact on hope. [45]

Duty of Care

Although it is recognised that current best practice in the care and support of older cancer patients is scant [3] professionals have a duty of care to ensure they weigh up the harms and benefits of all interventions and the consequences of these. [29] One way of achieving care that promotes holistic wellbeing and minimises harm in older adults with cancer is the use of evidence-based assessment tools, care guidance and frameworks. [6] For example, recent work on the Comprehensive Geriatric Assessment suggests this may be an effective way of identifying unknown health conditions which may affect cancer treatments [6] and enable supportive care that maintains health and wellbeing in older adults across their cancer

journey. [15] Another example is that of advance care planning which enables the patient, in conjunction with their family to deliberate on what having a potentially life limiting illness may have on their future and to document what they would like to happen to them should they become unable to make their own decisions. [46, 47]

The **next or green** layer includes aspects of the theory of consequentialism and contains the concept; increase of individual good, increase of social good, increase of the good of a particular group and increase of self-good.

In terms of the green area – it encourages us as nurses to focus attention on the consequences of a particular situation not just for this person but for society as a whole. For instance if I give this expensive treatment or this toxic treatment- what are consequences for other similar people with this illness. Are the consequences justified?

The final outside layer is the **black layer.** Although, this layer is of great importance – Seedhouse (2009) [28] postulates that it includes facts that are often not given sufficient attention by moral philosophers. Although, all the layers need to be used to come to an ethical decision in health care, the black layer is of particular importance and significance for nurses and health care practitioners wherever they are in the world and wherever they practice. The issues in this layer are: disputed facts, the degree of certainty of the evidence on which an action is taken. Codes of practice (for nurses in UK the NMC code [48] and US [49])

The risks; effectiveness and efficiency of action; the responsibility to justify all actions in terms of external evidence; wishes of others; legal rights of others (the law).
The black box should be used in all occasions. There is an abiding responsibility for anyone who intervenes in the life of another person to be able to justify their actions in terms of the extremal evidence. Any health care professional who has responded morally in an appropriate fashion will be an excellent position to do this.

There is a lack of an evidence base in training older adults with cancer but using the grid teases out the best evidence available to support practice. It is incumbent for nurses and other health care professionals to work within the laws and codes of conduct of their country and jurisdiction. What may be legal in one country is not in another.

Conclusions

Older adults with cancer experience ageism, which stems from a range of uncertainties on best practice in care and treatment. By employing an ethical lens professional decision making can be aided by creating and promoting autonomy through impeccable communication. Best interests can also be served by working in a way that serves needs first and acts in the best interests of the patient. It is important that even with scarcity of resources that individual older adults with cancer are treated equally and receive the best care possible. We also need to always remember the needs of those people important to the individual older adult with cancer. Finally we owe it to older adults to ensure the nurse and other health care professionals are properly equipped with training to care appropriately.

Declaration of Competing Interest

None.

Funding

None

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