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Patient, physician and contextual factors are influential in the treatment decision making of older adults newly diagnosed with symptomatic myeloma

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Abstract
Aims: To examine patient perspectives on their personal and contextual factors relevant to TDM. The second aim was to describe physician perspectives on the TDM in older adults ($\geq$60 y.o.) diagnosed with symptomatic MM.
Study design: Descriptive, cross-sectional.
Methodology: A semi-structured interview schedule was administered. Directed content analysis procedures were used to develop major themes from the patient and physician participant interviews.
Results: Themes related to treatment decision making among patient participants include various decisional role preferences; several sources of information related to myeloma; contextual and patient-specific factors influence treatment decisions; negative perceptions related to the treatment decision-making process exist; strong desire to be in remission and to live a longer life; For physician participants, top themes related to decision making were: QOL or survival considerations or simultaneously considerations of treatment effectiveness, QOL and survival; screening patients for eligibility for autologous HSCT; time is a barrier to effective TDM; Various methods were used to assess patient decisional role preferences.

Abbreviations: TDM, treatment decision making; MM, multiple myeloma; QOL, quality of life; HSCT, hematopoietic stem cell transplantation; RCT, randomized controlled trials; HDT, high dose therapy

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Conclusions: Treatment decision making in older adults newly diagnosed with symptomatic myeloma is influenced by personal, social and contextual factors. Patients must be given the opportunity to choose the best possible treatment within the limits of the patient's personal, social and medical contexts.

1. Introduction

Multiple myeloma (MM) is a cancer of the plasma cells affecting primarily the elderly, with the highest incidence occurring at the sixth through the eighth decade of life [1]. In 2012, there were approximately 21,700 new cases diagnosed in the U.S., making MM the second most common hematologic malignancy after non-Hodgkin's lymphoma [2]. The overall annual incidence rate of MM in the U.S. from 1973 to 2005, age-adjusted to the 2009 population, was 11.0 and 4.3 per 100,000 person-years for blacks and whites, respectively [3]. Worldwide, MM has incidence rate from 0.4 to 5 persons per every 100,000 on a given year, with rates being higher in Western than in Asian countries [4,5]. MM is not curable; however, there are many effective treatments available that can extend patient overall survival with relatively good quality of life (QOL) [6].

The findings of randomized controlled trials (RCTs) comparing conventional versus high dose chemotherapy (HDT) followed by autologous hematopoietic stem cell transplantation (HSCT) show equivocal results in terms of overall survival, though they do show that the HDT offers longer *progression-free* survival [7,8]. Autologous HSCT is still widely accepted as a treatment option for MM patients $<$65 years of age, yet it is now being challenged through historical control studies and RCTs comparing outcomes from HDT versus non-intensive therapy using novel therapies such as thalidomide, bortezomib, lenalidomide and carfilzomib [9,10]. Currently, there is an ongoing RCTs comparing HDT followed by autologous HSCT with novel therapies [11].

Evidence-based treatment guidelines developed by the National Comprehensive Cancer Network, an organization of 21 leading comprehensive cancer centers in the US, do not identify one treatment as unequivocally superior to all alternatives for a given set of conditions [12]. MM treatments come in various forms, routes and intensities, including oral chemotherapies, IV chemotherapies and HDT or reduced intensity therapy followed by autologous HSCT. Other factors such as direct cost to the patient (co-pays and deductibles) and insurance coverage status may also influence treatment decisions. It is unclear how these variables ultimately influence actual treatment choices in older adults newly diagnosed with symptomatic MM.

Advances in MM genomics are beginning to shed some understanding on the role of genetic aberrations in the success rates of various MM therapies, adding still more complexity and uncertainty during treatment decision making (TDM) [18,19]. There is no doubt that the advent of novel therapies showing similar (or sometimes better) response rates when compared historically to the outcomes from traditional therapies (e.g., high dose dexamethasone) creates further clinical uncertainties in TDM [20-23].

Given the lack of one recognized "best" medical therapy, patients hear about the many available options and are in a position to select, along with the specialist, one or more treatments among others. With other cancer diagnoses in which adults have multiple treatment choices, there is evidence that personal factors and preferences are quite influential in determining how patients arrive at a final treatment decision [13,14]. Similarly, physician preferences and values have also been found to be influential in actual treatment decisions [15-17].

Research studies that examine not only the physician's perspectives, but also those of the patient, can inform both clinicians and policy makers on how to improve outcomes related to TDM. By exploring and understanding patient preferences and values, clinicians will be better prepared to engage in shared decision making with patients diagnosed with symptomatic MM. Information on TDM is particularly relevant for the elderly with MM, who may have a different set of values and preferences than younger patients. Conversely, by understanding physician perspectives, policy makers and medical practice administrators will have a broader view of the process and may be able to support innovative strategies that will enhance physician–patient TDM encounters.

1.1. Treatment considerations in older adults

There are specific treatment considerations in older adults with cancer. Age is likely to be an influential factor in TDM by both patients and clinicians. Berry and colleagues [24] found evidence of this in a study of 260 men with localized prostate cancer. A majority (70%) of the study participants reported that their age had influenced their treatment decision, with older men being more likely to eliminate a particular treatment option exclusively because of their advanced age. In addition, several studies have found that clinicians will either rule out particular treatments based on a patient's age or will give strong recommendations against particular treatments in patients with colorectal or breast cancer [25-29].

In a recent survey [30] of physicians who were involved in TDM with regard to chemotherapy in cancer patients aged 70 years and older, treatment side effects (24.4%), multiple illnesses (20.5%) and lack of support from family and friends (10.9%) were reported as challenges. The authors reported that in addition to the presence of comorbidities, functional status was among the principal factors physicians considered when they made such treatment decisions [30].

Older patients are at a higher risk for chemotherapy toxicities due to physiological changes associated with aging, potentially causing adverse QOL outcomes [31].