



Published in final edited form as:

*Cancer Treat Commun.* 2014 ; 2(2-3): 34–47. doi:10.1016/j.ctrc.2014.08.003.

## 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 ( > 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.

**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

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Authors' contribution: The first author wrote most of the first draft of this manuscript, created the interview protocol, performed the statistical analysis, conducted data collection and implemented most of the manuscript's revisions. The second and third authors co-designed the study with the first author and critique the entire manuscript. The fourth author contributed by helping in participants recruitment and the fifth author supervised the conduct of research and served as chair of the dissertation committee of the first author. All authors read and approved the final manuscript.

opportunity to choose the best possible treatment within the limits of the patient's personal, social and medical contexts.

### Keywords

Multiple Myeloma; Older adults; Treatment decision making; Decision making factors; Patient education

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### 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 1973-2005, 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.

### 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]. QOL, comorbidities, treatment tolerance and life expectancy have been proposed as important considerations in the TDM of older adults with cancer [32-34]. In fact, older adults have ranked QOL as a top priority in life [35]. When asked about the importance between QOL and quantity of life in relation to their treatment decisions, 97% (N=42) of older adults (age range 60-85 years, median 71 years) with acute myeloid leukemia or advanced myelodysplastic syndrome shared that QOL, rather than *length* of life, was an important factor in their choice of therapy [36].

In summary, there is strong evidence that older patients with various types of cancer do have personal preferences and values and contextual factors influencing their treatment decisions. There is also considerable evidence that patients want to be informed and consulted with regard to the impact of treatment on QOL as well as overall survival. However, no data exist regarding influential factors that older adults diagnosed with symptomatic MM consider during TDM. Moreover, physician factors influencing treatment decision have not been previously studied in older adults newly diagnosed with symptomatic MM. It is uncertain how physician factors affect the decision of older adults with symptomatic myeloma during TDM.

## **Purpose**

The purpose of this study was to explore patient- and physician-related factors influencing treatment decisions in older adults newly diagnosed with symptomatic MM (myeloma patients who have end organ damage manifested as hypercalcemia, renal insufficiency, anemia, bony lytic lesions, neuropathy or neutropenic sepsis). The first objective of the study was to examine the patients' perspectives on TDM, including their personal and contextual factors relevant to TDM. The second objective was to describe physicians' perspectives on the TDM in older adults ( ≥ 60 years of age) newly diagnosed with symptomatic MM.

## **Methods**

### **Design**

The study employed a descriptive, cross-sectional design using semi-structured interviews. Since TDM is a complex health care phenomenon that has not been elaborated in patients with MM, a qualitative approach was used to explore the perspectives of patients and physicians during TDM and to examine the factors influencing treatment decisions from both perspectives.

### **Sample**

The patient sample consisted of older who were newly diagnosed with symptomatic MM and had been referred to Seattle Cancer Care Alliance or the Northwestern University Myeloma Program by hematologists/oncologists in the greater Seattle or Chicago areas, respectively. To be eligible for study, patients were (a) older adults (60 years of age and above); (b) newly diagnosed (6 months from diagnosis) with symptomatic MM; (c) able to read and write English; (d) able and willing to give informed consent. The physician sample consisted of physicians from Seattle Cancer Care Alliance and University of Washington-affiliated clinics and from Northwestern University Myeloma Program who were directly providing care to MM patient participants.

### **Patient and Physician Recruitment**

Approvals from the University of Washington and Northwestern University Human Subjects Divisions to recruit older adults newly diagnosed with symptomatic MM to participate in the study were obtained. The researchers made every attempt to recruit from both university-and community-based practices to enhance the diversity of study participants. Eligible

participants were recruited by mail using a recruitment flyer (University of Washington) or a direct approach (Northwestern University) in the recruitment of study participants. Physicians from both universities were recruited via e-mail and by direct approach.

## Procedure

A semi-structured interview was conducted in a designated research-related conference room at University of Washington and Northwestern University outpatient cancer clinics. These rooms were assigned for research use only and met the standard for patient privacy. Similarly, the physician interview was conducted in a place where privacy was secured, such as the physician's or researcher's office.

Patient participants were asked about the treatment options discussed by their physicians including risks and benefits, their preferred role during decision making and how they make the best treatment decisions for themselves. Physician participants were asked to recall their experiences of how they usually presented treatment options to patients. They were then asked specifically about which factors they consider when making a treatment decision, their preferences and perceptions of patient participation during the decision-making process and how they make the best treatment decision for their patients.

All study interviews were audio-recorded and then transcribed verbatim. Identifying names or proper nouns were not included in the transcription. All transcripts were checked against the original audio recording by the researchers.

## Analysis

Directed content analysis procedures [37] were used to develop major themes from the patient and physician participant interviews. Initial categories and their definitions were developed based on a literature review of physician and patient factors influencing treatment decisions in cancer [38]. Interview text was read line by line by the lead researcher (JDT) and then imported to NVivo 8 (QSR International, Victoria, Australia), [39] a qualitative data software analytic program. Initial categories and definitions were also imported to NVivo. The minimum unit of analysis was typically one sentence, but sometimes the unit was an entire paragraph, depending on whether the patient shifted the topic in a different direction other than what was asked in the interview schedule or in follow-up probes. Probes included statements such as, "Tell me more about the role you have selected," or "What else are the influential factors in your treatment decisions?" If the interview text matched the definition of a pre-established category, that code was assigned to the text. Text that could not be coded within the initial categories was given a new category and definition. Some categories were grouped together to create major themes. Interview transcripts were re-coded based on the subsequent identification and definition of these new themes or other new categories.

Full agreement between researchers A and B in terms of coding scheme and their definitions was reached utilizing the process of consensual validation [40]. Initial and emerging categories were reviewed and discussed among three members of the research team (researchers A, B and C). Ongoing in-depth discussions and agreement about the wording of

final themes, factors encompassed by major themes and definitions were carried out by the researchers A and B.

## Results and Discussion

### Results

A total of 79 potential participants at Seattle Cancer Care Alliance and University of Washington-affiliated clinics were sent recruitment letters from October 2009 through July 2010. Of these 79 potential participants, 14 responded to the mailer (17.7 % response rate) and all agreed to participate in the study. At Northwestern University clinic all six potential participants who were approached by the researcher agreed to participate.

A total of 16 physicians were approached from Seattle Cancer Care Alliance, University of Washington-affiliated community clinics and Northwestern University cancer clinic. Three physicians from Seattle Cancer Care Alliance, two physicians from University of Washington-affiliated community clinics and five physicians from Northwestern University cancer clinic agreed to participate (62.5% recruitment rate). Informed consent was obtained from all study participants. Eleven matched patients from Seattle Cancer Care Alliance physicians, 3 matched patients with two University of Washington-affiliated physicians and 6 matched patients with 5 Northwestern University physicians comprised the total patient and physician study subjects.

The patient participants sample mean age was 64.7 years ( $SD=7.6$ ); mostly Caucasian men and women participated, with only one Asian and one Native American. The sample of ten physician participants consisted mainly of women ( $n=7$ ) between 30-39 years of age ( $n=8$ ), but with varying race/ethnicity and title or position in the institution. Tables 3 and 4 list all demographic information collected for the patient and physician participants, respectively.

The percent agreement for the coding of patient interview themes and factors were 86.66% and 81.43%, respectively. For physician interview themes and factors, the percents of agreement were 91.66% and 86.08%, respectively. Given the exploratory nature of this study, the degree of agreement for coding that was achieved between researchers A and B was considered acceptable [41]. Nine major themes were identified from the patient interviews and seven major themes were identified from the physician interviews. The major themes with definitions and frequencies of occurrences for both patient and physician interviews are shown in Tables 1 and 2.

**Major Themes for Patient Interviews**—Trust in the physician, the health care team and the institution

Decisional role preferences vary

Patients have many sources of information related to MM

Patient-specific and contextual factors influence treatment decisions (Please see tables 5 and 6 for exemplars, respectively).

Negative perceptions of the TDM process

Treatment decisions are driven by the *benefits* of being cancer-free, the desire to be in remission, and the desire to live a longer life

State of shock at the time of diagnosis

Hope for advances in science

**Major Themes for Physician Interviews**—Physicians consider QOL or OS alone or simultaneously considers treatment effectiveness, QOL, and OS

Physician-specific factors influenced decision making (Please refer to table 7 for exemplars).

Strong considerations of eligibility for Autologous HSCT

Limited time is a major barrier to effective TDM

Physicians use various ways of assessing patient decisional role preferences

The patient ultimately makes the final treatment decision

When needed, physicians attempt to persuade patients to take their recommended treatment option

## Discussion

The findings from this study document many themes and factors considered by physicians and patients with symptomatic MM during TDM. There are some similarities between the physician and patient results regarding influential factors for treatment selection such as QOL, convenience, insurance, cost, family opinion, age, patient's medical and clinical factors and social support considerations. These multidimensional factors are simultaneously weighted by patients and physicians to make the “best decision” in the setting of clinical uncertainty. Berry and colleagues [42] have previously reported similar personal factors that were influential in the treatment choices of men diagnosed with localized prostate cancer, including: age, cancer in the family, family responsibilities and desire for longevity, as well as physician factors that included consideration of the patient's comorbidity and pathology.

Maintaining QOL during therapy was very important, not only from the patient's perspective but also from the physician's point of view. Among the contextual factors described by patient participants, the convenience of oral chemotherapy has been described as influential in the treatment decisions. Since a pill can be conveniently taken at home, a decision for oral chemotherapy translates to fewer visits to the clinic, ultimately impacting patient's QOL. This option is very attractive to older adults above the age of 70 years, because it offered them more independence and required less family burden to complete the therapy since they don't need to ask family members to drive them to the clinic.

QOL and independence are values that are consistently ranked by older adults as their top priorities in life [35, 36]. Husain and colleagues [43] have also reported QOL and independence as influential factors in the treatment choices by older women (>70 years of age) with breast cancer. For physician participants in this study, oral chemotherapy is appealing as long as the patients can adhere to the prescribed therapy and treatment efficacy is not compromised. Kreling and colleagues [44] have reported some similarities in what they called patient's contextual factors influencing treatment decision in older women (65 years of age) with breast cancer, including the patient's age, functional status, comorbidities and perceptions of the benefits and side effects of chemotherapy.

The patient participants were making treatment choices based on contexts in their lives. For example, the availability of support from family and friends influenced the patients' choice of HDT because it requires a significant time commitment and caregiver support during the acute phase of therapy (typically days 1-30 post-transplant). From the physician's perspective, the participants were cognizant of patient preferences and contextual factors and offered treatment recommendations with strong consideration of the patient's personal factors and social contexts. The physician participants talked about the importance of assessing a patient's financial, logistical and social support status and how these factors influenced their treatment recommendations to their patients. One study [45] has reported family burden, cost and travel requirements as important factors influencing the physician's decision to use adjuvant chemotherapy among older adults (65 years of age) diagnosed with stage III colon cancer, but these contextual factors were not ranked as important as patients' comorbidities and medical evidence for treatment. There are some similarities in the patient-specific factors (i.e., age, past health-related experience, insurance, social support, family burden, geographic barrier) influencing treatment decisions when compared to patient-specific factors of other older patients diagnosed with cancer. However, some personal and social contexts (i.e., actual experience, some aspects of personal beliefs and values, opinion of others, significant events in the family, convenience of oral pills and faith in high power) varies from the personal and social contexts in patients with breast, prostate, colorectal and ovarian cancer.

At a certain point, age becomes influential in the treatment choice; in general, physician participants consider 70 as the cut-off age for HDT. In this study, patient participants also consider their own particular age as influential in their treatment choice. For example, patient participants who were under 65 years (n=14) considered themselves as strong candidates for HDT, while those who were 70 years and above (n=6) did not consider HDT. The older patient's preference for HDT or non-intensive therapy could have been influenced by their physician's recommendation, as this study has documented. Kutner and colleagues [45] have reported similar patient-reported considerations of the physician's decisional factors. Notwithstanding this, some physician participants in this study would still consider HDT for patients above the age of 70, provided that the patient has good performance status and no comorbidities. Physician participants strongly considered treatment effectiveness and OS, albeit while keeping an eye on the patient's QOL. The patient's age has been reported as influential by both patient and physician as a factor in their treatment decisions in patients with breast and prostate cancers [42, 45].



It was not surprising that both the patient ( 65 years of age) and physician participants were considering HDT. HDT using high-dose intravenous melphalan followed by autologous HSCT is considered an important treatment option for MM patients under the age of 65. More studies are needed to develop innovative methods to help both patients and physicians reach a consensus on which treatment approach (i.e., HDT versus non-intensive) is best to take in a given context. Furthermore, more studies are needed to help physicians develop clinical decision pathways or treatment decision algorithms with regard to screening patients for eligibility for HDT followed by APBSC in order to have some general guidelines for non-myeloma specialists.

There was evidence of discordance between the physician and patient's perspectives with regard to who the decision maker actually should have been. The majority of the patient participants perceived that the physicians made the decision for them. This belief ran somewhat contrary to many physicians' statements that it was ultimately the patients who made the treatment decision. This is an interesting finding, and one that requires further investigation. In patients who were in shock at the time of diagnosis, it is conceivable that the physicians presented several options to patients, who were unable to recall the options that were offered due to difficulty processing all information. It is also possible that when physicians made a strong recommendation for a particular option, the patients may have perceived that they didn't have enough knowledge about the different options and therefore they would leave the decision to their physician, who ultimately made the decision for them. In other qualitative studies in men diagnosed with prostate cancer [49] and women with ovarian cancer, [44] the treatment decision also seemed to be driven mostly by the physicians, with some patients perceiving themselves as passive recipients of care. Future research should seek to uncover whether physicians can present treatment options with more equipoise and whether patients who desire a more shared or active decisional role can be given the opportunity by their physicians to participate more fully in the actual decision making.

Limited time has been reported as one of the barriers to effective treatment decision-making [50]. The study findings described above have confirmed that this negative aspect of TDM was pervasive. Both patient and physician participants acknowledged that the time allotted for TDM discussion was limited and not sufficient to fostering the kind of discussion of options needed to reach a tailored or "best" treatment decision. The onus is with the physician to provide patients ample time to process the treatment options that they are offering to their patients. Poor quality patient-physician communication has been identified as one of the challenges in TDM [51] and is also an area that requires further investigation. Studies that can guide administrative policies on adequate time allocation in terms of treatment decision encounters would be very beneficial not only for the patients but also for the physicians.

Past health experiences and actual experience with MM therapy have been found to be influential in the treatment considerations by older MM patients in this study. These findings have been previously reported in studies conducted in older women ( 70 years of age) with breast cancer. For example, Husain and colleagues [43] reported that two women in their study strongly preferred a specific treatment based on their previous health care experience.

The researchers found that these women did not consider the treatment information provided by their clinicians; instead they simply requested a specific treatment based on their personal experience with breast cancer therapy. Kreling and colleagues [52] have found that women who underwent chemotherapy experienced side effects that were more uncomfortable than what they have expected with one subject who eventually requested a change on her chemotherapy regimen due to the devastating effect of alopecia on her mental health.

In this study, family opinions and opinions of others including a second physician opinion have been considered by older MM patients as having an influence in their treatment decisions. Other TDM studies in patients with prostate, [13] ovarian, [44] breast, [43, 52] and colorectal cancer [45] have also found these factors as having an influence on treatment decisions.

The issue of therapy cost and its eventual impact on personal finances has been described previously as influential factors in TDM [45, 53]. In this study, some patient participants related how they made sure that their insurance covers the treatment that they were going to have so as to avoid any negative impact on their personal finances. Some of them take into account the actual co-pays and out-of-pocket cost when they made their treatment decisions.

The physician's expertise and practice type have been previously reported as having an influence in treatment selection. For example, one study [54] found that Hodgkin disease experts are more likely to individualize patient's therapy than non-Hodgkin expert physicians and academic physicians are more likely to choose combined modality therapy (CMT) over radiation therapy or chemotherapy alone. Similarly, in patients with localized prostate cancers (LPC), a survey showed that urologists tend to favor surgery while radiation oncologists tend to favor radiation therapy over surgery [55]. In an international survey, gastroenterologists tend to favor surgery for the management of gastric lymphoma, while hematologists and oncologists are more inclined to favor conservative therapy [56]. In this study, the majority of physician participants (N=8) work in a MM practice with a strong HSCT program. This would have a clear influence in TDM as far as screening patients for autologous HSCT eligibility. This study showed that 9 out of 10 physician participants screened their patients for autologous HSCT eligibility. There was only one physician participant who did not mention screening for autologous HSCT.

## Limitations

This study was limited by the exploratory nature of the design, limiting generalizability beyond the setting of a comprehensive cancer center. Also, the sample was not diverse with respect to race and ethnicity; African Americans and Hispanic patients with myeloma were not represented in this study. Moreover, the participants in the study were mostly with high level of education, achieving at least 2 year college level education. Lastly, since this is a cross-sectional study, the findings may not be applicable to symptomatic myeloma patients who are beyond 6 months of diagnosis. Further study using a longitudinal approach is needed to better describe the changes in study participants' influential factors during TDM over time, especially in older adults diagnosed with cancer.

## Conclusion

Older MM patients ( > 60 years of age) with symptomatic MM consider personal, social and contextual factors during TDM. These factors include actual experience with MM therapy, physician's opinion, personal beliefs and values, family opinion, family burden, social support, insurance and convenience of therapy as influential factors in their treatment decisions while physicians treating older patients with symptomatic MM consider the patient's comorbidities, performance status, supportive care requirements, their own personal beliefs and values, patient's medical and clinical factors, patient's context, family opinion and patient's treatment preference as having an influence on their treatment decisions. Though there are similarities in both patient-and physician-specific influential factors, some differences exist and must be seriously considered in actual TDM to improve decisional satisfaction. Therefore, it is critical that patients are given the opportunity to choose the best possible treatment for their MM within the limits of the patient's personal, social and medical contexts. In the future, it would be easier to guide MM patients with symptomatic disease make treatment decisions using probabilistic model if RCTs clearly show which therapy provides better QOL and OS outcomes for the patients.

## Acknowledgments

This work is made possible by the excellent mentorship of Donna L. Berry (Supervisory Committee Chair) and Barbara B. Cochrane (co-sponsor of my NRSA grant). Special thanks to Helene Starks for serving as my Graduate School Representative. Sincere appreciation also goes out to Jerald R. Herting, Kevin Cain, and Jeff Sloan for their statistical support and for the recruitment assistance provided by Aimee Kohn, Lynley Fow, Elaine Zedella, Judy Petersen, Kenda Burg, Jose Velasquez and Tom Blackney.

This work was supported by the National Institutes of Health-National Institute of Nursing Research Biobehavioral Training Grant (T32NR07106) and the National Research Service Award Grant (F31NR011124), the Achievement Rewards for College Scientists (ARCS) Fellowship, Seattle chapter, The John Behnke Foundation and the Hester McLaw's Nursing Scholarship Fund.

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## Abbreviations

<b>TDM</b>	Treatment Decision Making
<b>MM</b>	Multiple Myeloma
<b>QOL</b>	Quality of Life
<b>HSCT</b>	Hematopoietic Stem Cell Transplantation
<b>RCT</b>	Randomized Controlled Trials
<b>HDT</b>	High Dose Therapy

**Table 1**  
**Major Themes from Patient Participant Interviews on TDM**

Themes	Definitions	N (%)
<b>Trust in the physician, healthcare team, and/or institution</b>	Participants verbally expressed their trust in the physician, the health care team, and/or the institution as influential in treatment decisions. This definition also includes implicit trust to the physician by going along with physician's treatment recommendations or decisions.	20 (100)
<b>Participants have many sources of information related to myeloma</b>	Participants described the different sources of myeloma-related information such the Internet, physicians, family and friends who help do the research and obtain myeloma-related materials, physician visit companions, books, pamphlets, nurses, myeloma patients, other cancer patients, and support group such as the multiple myeloma fighters and myeloma or lymphoma society. This is distinct from "other's opinions" in which the information or opinion was identified as actually influencing the treatment decision	20 (100)
<b>Participants have various decisional role preferences</b>	Patients described their role preferences or any changes in role preferences as being active (patient making his or own treatment decision with or without consideration of the physician's opinion), shared (patient and physician share responsibilities in making the treatment decision), or passive (patient delegating the treatment decision to the physician) or changes in their role preferences outside of the context of being in a state of shock.	20 (100)
<b>Patient-specific factors influence treatment decisions</b>	Patient-specific factors refer to patient's actual experience with myeloma-related therapy, age, beliefs and values, faith in a higher power, opinions of family, opinions of others, past health-related experience not related to myeloma, and self description of "What I'm like" influencing treatment decisions. This theme will be coded along with the patient-specific factor.	19 (95)
<b>Negative perceptions of treatment decision making</b>	Patients described negative perceptions of treatment decision-making such as lack of discussion of treatment options, long periods of waiting during the encounter, inability to reach a health care team member, and wanting to have more information related to disease, prognosis, treatment, and side effects or having questions left unanswered, not achieving the desired level of participation	17 (85)
<b>Treatment decisions are driven by the <i>benefits</i> of being cancer-free, the desire to be in remission, and the desire to live a longer life</b>	Patients described the <i>benefits</i> of their therapy such as being cancer-free, killing the cancer cells (patients also describe their myeloma marker at 0 level), being in remission, and living a long life	15 (75)
<b>Contextual factors influence treatment decisions</b>	Patients' contextual factors refer to issues of health insurance, financial status, availability of free medication regardless of insurance, geographical barriers, treatment costs, social support, housing/ lodging, retirement planning, recent significant events in the family, and transportation/ convenience of oral therapy at home influencing treatment decisions. This theme will be coded along with the specific contextual factor.	14 (70)
<b>Some participants were in a state of shock at the time of diagnosis</b>	Participants described being in a state of shock, feeling very overwhelmed and not at the right frame of mind, unable to process what was heard from the physicians during the visit, feeling pretty much out of it or kind of in a fog, and feeling paralyzed from participating in treatment decision making	6 (30)
<b>Advances in science provide hope for future treatment options</b>	Participants described advances in science provide hope for future treatment options but not influencing their current treatment decision	4 (20)

**Table 2**  
**Major Themes from Physician Participant Interviews on TDM**

Themes	Definitions	N (%)
<b>Physicians consider QOL or survival alone or simultaneously consider QOL, treatment effectiveness, and survival</b>	Some physicians describe QOL or survival consideration and some physicians simultaneously consider multiple factors including efficacy, QOL, and survival in their treatment decisions. This theme is also coded when the physician mentions morbidity, mortality, and life expectancy considerations when making treatment decisions.	10 (100)
<b>Physician-specific factors influence treatment decisions</b>	These are aspects of the physician's life that influence treatment decisions. These factors include patient's context, patient's family opinion, patient's co-morbidities, functional status, and supportive care requirement, patient's treatment preference, patient's age, patient's medical and clinical factors, physician's beliefs and values, and physician's expertise and type of practice. This theme is coded in conjunction with the specific physician factors.	10 (100)
<b>Eligibility for autologous HSCT is an important treatment consideration</b>	Physicians evaluate their patients' overall medical condition for eligibility for autologous stem cell transplantation	9 (90)
<b>Physicians use various ways of assessing patient decisional role preferences</b>	Physicians share that they have no systematic tool to assess preference; sometimes they ask or sometimes they indicate they just have a feeling for the patient's role preference. This theme does not include the physician's own description of the decisional role of patients.	9 (90)
<b>Barriers to effective decision making</b>	Physicians describe limited time and lack of long term outcome data as barriers to effective decision making; physicians share that there is a need to spend more time talking with patient	7 (70)
<b>The patient ultimately makes the treatment decision</b>	Physicians describe providing different treatment options to patients, explaining risk and benefits, <i>and</i> specifically state that patient ultimately makes the final decision. This does not include physician's belief on patient participation or non-participation with decision making	5 (50)
<b>When needed, physicians attempt to persuade patients to take the physician's recommended treatment option</b>	Physicians describe presenting strong treatment recommendations to patients when patients make illogical decisions	2 (20)

Abbreviations: QOL = quality of life; TDM = treatment decision making; HSCT = hematopoietic stem cell transplantation



**Table 3**  
**Sociodemographic Characteristics of the Patient Sample**

<b>Variable</b>	<b>N</b>	<b>%</b>
<b>Age (mean, 67.45 years)</b>		
60-70	14	70
71-82	6	30
<b>Gender</b>		
Male	8	40
Female	12	60
<b>Race</b>		
Caucasian	18	90
Asian	1	5
American Indian/Native	1	5
Alaskan Native		
<b>Work Status</b>		
Full time	2	10
Working on medical leave	2	10
Not working	2	10
Retired	13	65
Student	1	5
<b>Personal Relationship Status</b>		
Single	2	10
Married or partnered	12	60
Divorced	5	25
Widowed	1	5
<b>Highest Level of Education</b>		
9 <sup>th</sup> – 12 <sup>th</sup> grade	5	25
2 years of college	2	10
4 years of college	10	50
Graduate degree	3	15
<b>Annual Household Income</b>		
\$18,000 or less	3	15
\$18,000 to \$35,000	2	10
\$35,001 to \$55,000	5	25
\$55,001 to \$85,000	5	25
\$85,001 and above	5	25

**Table 4**  
**Sociodemographic Characteristics of the Physician Sample**

<b>Variable</b>	<b>N</b>	<b>%</b>
<b>Age group</b>		
30-39	8	80
40-59	2	20
<b>Gender</b>		
Male	3	30
Female	7	70
<b>Race</b>		
White	5	50
Asian	3	30
African American	2	20
<b>Title or Position</b>		
Fellow	5	50
Attending Physician	3	30
Private Practice Physician	2	20
<b>Personal Relationship Status</b>		
Single	1	10
Married or partnered	9	90

**Table 5**  
**Patient-specific Factors that Influenced Treatment Decisions**

Factors	Definitions	Exemplar Quote	N (%)
<b>Actual experience with therapy</b>	Participant's actual experience with therapy <i>specific</i> for their myeloma such as reaction, side effects, response or non-response to therapy influence subsequent decisions. This definition does not include experiences with therapies not related to myeloma (included in the definition of past health-related experiences)	"I had unfavorable reactions to the medication I was taking. I started developing neuropathy in my hands and feet. My doctor consulted a myeloma specialist and my treatment was changed."	16 (80)
<b>Beliefs and values</b>	Participants' personal belief about the necessity of completing a therapy or belief in the outcomes of a specific therapy and the participants' valuation of: QOL, independence, and not being a burden to family as influences on their treatment decisions. Beliefs and values are different from the perceived benefits of treatment	"I just think this cancer is very tricky and that we have to out-trick it. So I think novel treatments are where I see the greatest potential of a longer life for people like me. That's why I chose the clinical trial involving novel agents."	16 (80)
<b>Opinions of family</b>	Participants' solicitation and consideration of the opinions of family influenced treatment decisions; a specific <i>link</i> between family opinions and treatment choice was identified	"My children very much wanted me to fight this to the bitter end and regain my life back, because I think it was very hard for them to see me in an invalid kind of stage where they had to care for me at the beginning, and I'm always the one caring for them."	9 (45)
<b>Age</b>	Participants who described themselves as being at a particular age category and feeling healthy or being in a particular age, regardless of health status, had influenced their treatment decision	"Well, the option that was not seriously considered was stem cell transplantation; because of my age [80 years] that was ruled out."	9 (45)
<b>Opinions of others</b>	Participant's solicitation and consideration of the opinions of non-family members influenced treatment decision; a specific <i>link</i> between opinions of others and treatment choice was identified	"The thing that did influence me a lot was I talked to a gentleman during chemo that had gone through the stem cell and he was telling me how he had eight absolutely wonderful years where he traveled and he was free of cancer and he got his life back."	8 (40)
<b>Past health-related experience</b>	Participant's own past health-related (e.g., overall good health, past illness experience) and therapy-related experiences (not relating to myeloma) influenced participants' treatment choice	"I had 21 operations in my life. I've come through all that. This is just another step in my life and I'll come out the other end smiling. So that is why I decided to take the decision of having an auto stem cell transplant."	6 (30)
<b>"What I'm like"</b>	Participants who identified what they were like as a person—their job, their personality--influenced treatment decisions	"I didn't see any reason to question there was an alternative to this cutting edge treatment [auto stem cell transplant]. It seemed to me I'm a cutting edge guy so it appealed to me."	5 (25)
<b>Faith in a Higher power</b>	Participants described praying to a higher power and faith in a higher power as an influence in their treatment decision	"I prayed to God to give me the best treatment and the best doctor."	5 (25)

**Table 6**  
**Contextual Factors that Influence Treatment Decisions**

Factor	Definition	Exemplar Quote	N (%)
<b>Social support</b>	Availability of family and/or friends to provide caregiver support during therapy-- including attendance at the physician or clinic visits or availability of family members to take some household responsibilities, being single, family, and caregiver burden--influenced treatment decision.	"My wife is an absolute jewel. She insists on taking care of my every need and she invents some needs I probably don't think about. My concern is if she will wear down. She's 83 and she has a lot of energy and she's a wonderful caregiver, but I worry that I may wear her down."	9 (45)
<b>Insurance</b>	The type of insurance coverage for a particular therapy influenced participants' treatment choice.	"We were glad that we have very good insurance coverage. For two transplants, I was adamant that any procedure I do, it has to be certified and pre-approved [by the insurance company]."	5 (25)
<b>Transportation issues/Convenience of pills</b>	Travel issues from home to clinic to home-- such as availability of a driver or the ability of the participant to drive a car, or the convenience of taking oral chemotherapy at home--influenced treatment decisions.	"Basically my doctor offered either the IV or the Revlimid by pill. I felt that well, I guess the pill was more appropriate for quality of life from my standpoint. It's easier to do, it gives me more flexibility, and I don't have to keep going in to the clinic every day."	5 (25)
<b>Geographic barrier</b>	Participants described the actual distance and amount of time to travel to get the therapy influenced treatment decision and the need for housing or lodging during therapy due to distance of medical institution for the participant's residence.	"I considered Mayo. I have a relationship with them from many years ago, but I wanted to be in town [Chicago]. I'm impressed with the team in Northwestern facility and it also has the advantages of it being near my three daughters and my wife so that I didn't see any reason to go anywhere else."	5 (25)
<b>Finances</b>	The participant verbally expressed that the amount of money the participant has to pay out of his own pocket to get the therapy and costs of retirement influenced treatment decision. This factor includes participants getting <i>free medication</i> instead of paying several thousands of dollars for their chemotherapy	"I'm running on empty [finances] now. So I do take that into account."	5 (25)
<b>Significant events in the family</b>	Participants described how significant events or conditions in the family such as another sick member of the family or recent family death influenced treatment decision.	"My mother is ailing and she's very old, and we don't know what our family needs are in taking care of her needs. But I have wanted to avoid having a transplant, if possible."	3 (15)

**Table 7**  
**Physician-specific Factors Influencing Treatment Decisions**

Factors	Definitions	Exemplar Quotes	N (%)
<b>Patient's co-morbidities, functional status, and supportive care requirements</b>	Physicians describe presence of comorbidities, poor or good functional status, and supportive care issues influencing choice of chemotherapy approach	"Other medical conditions, performance status, if they've had complications with the chemo before. Primarily comorbid conditions and their performance status would make me choose a less intensive approach."	10 (100)
<b>Physician's beliefs and values</b>	Physician's personal beliefs on patient-physician relationship dynamics; beliefs that the patient doesn't have much knowledge, need for oversimplification, need for slowly introducing myeloma concepts, and patient asking the physician to talk about what treatment physicians would choose if it were them; beliefs that patients should or should not participate in decision making; belief that myeloma decisions are becoming more technically difficult to understand for the patient influence treatment decisions	"I think that would still involve me being very active—because I believe in transplantation I think that I would be—try to be very convincing to—that would be wise. Because that's the approach I believe in."	10 (100)
<b>Patient's Context</b>	Physicians consider the patients' contextual factors such as health insurance, financial status, availability of free medication regardless of insurance, geographical barriers, treatment costs, social support, housing/lodging issue, transportation/ convenience of oral therapy at home, and treatment compliance issues as influential factors in treatment	"The patient's overall situation could alter my decision; their ability to come to the doctor, their ability to follow-up, could decide whether I would pick a non-transplant or transplant approach."	9 (90)
<b>Patient's medical and clinical factors</b>	Physicians consider <i>patient-specific medical and clinical factors</i> such as type of myeloma, high-risk disease features by cytogenetics, fluorescent in situ hybridization (FISH) test, or genomics, positive response or resistance to therapy, patient's actual experience with therapy, and any end-organ damage as influential factors in treatment selection	"The prognostic indicators of the cytogenetics of the bone marrow will also lead a little bit your decision making, and the treatment of multiple myeloma in the sense that if you have deletion 17, we know that myeloma won't be responsive to thalidomide or lenalidomide or the "-imides" in general. Therefore, you would start an induction treatment with bortezomib typically."	7 (70)
<b>Physician's expertise and type of practice</b>	The physician's expertise in stem cell transplantation and practice type (transplant center) influence treatment choice	"I think to some degree it's our own bias because we are a transplant center and I and most of my colleagues continue to believe that for the appropriate age and health condition, transplant is of value. And so I definitely approach a new patient with the idea of determining if they're a suitable patient for transplant."	6 (60)
<b>Patient's Age</b>	Consideration of patient's age (at 70 or older) regardless of other factors, influenced choice of a non-transplant option or very young myeloma patients aged 40-50 years old tending to have very aggressive treatment such as high dose chemotherapy. Age-related issues in the context of stem cell transplant discussion was coded under eligibility for HSCT	"I choose certain drugs for patients who are age 70 and over; certainly over this age we would consider non-transplant drugs."	6 (60)
<b>Patient's treatment preference</b>	Patient's expressed preference for a specific therapy influenced treatment choice	"If they[patients] say they just want pills and they understand all of the upsides and downsides, then sure."	5 (50)
<b>Family opinion</b>	Family member's opinion being weighed in by physicians as an influence in their treatment choice, but does not include physician's mention of the presence of a family member during patient-physician encounters	"The older the patient the more likely you are to have other family members involved. More than just the spouse. It might be the daughter, or the kids involved. It is important to get to the point where everyone is comfortable and	3 (30)

Factors	Definitions	Exemplar Quotes	N (%)
		understands what, and is in agreement with the goals of treatment.”	
<b>Clinical trials as an option</b>	Offering a clinical trial as a treatment option regardless of availability of free medication influenced treatment decisions	“For the patients over age 70 or certainly over age 75, we’d either be considering our clinical trial, which is lenalidomide/dexamethasone until progression, lenalidomide/dexamethasone for 18 months, or alkeran/predni-sone/thalidomide.”	2 (20)