

# Older Adults Newly Diagnosed With Symptomatic Myeloma and Treatment Decision Making

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**T**reatment decision-making (TDM) studies have focused on decisional control preferences, with most studies conducted in breast and prostate cancer populations. A systematic review of decisional role preferences among patients with cancer has shown an increasing trend of patients being interested in more participation during TDM (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). To meet and facilitate the patient's preferred level of participation during TDM, interventional studies geared toward increasing a patient's decisional satisfaction, reducing decisional conflict, and preventing anxiety and depression related to TDM have been steadily increasing in numbers (Allen et al., 2010; Caldon et al., 2010; Evans et al., 2010), with some studies targeting the older adult with cancer population (Lewis et al., 2010; van Tol-Geerdink et al., 2008).

Interest is growing in the direct assessment of patient preferences, in terms of control of decision making and the changing landscape of the priorities of patients' information needs (Beaver & Booth, 2007; Denberg, Melhado, & Steiner, 2006; Flynn, Smith, & Vanness, 2006; Mancini et al., 2007; Sabo, St-Jacques, & Rayson, 2007), as well as a predicted shift away from paternalistic decision as baby boomers age (Pipe, Conner, Dansky, Schraeder, & Caruso, 2005). This presents substantial opportunities for improving patient care and clinical outcomes in the area of TDM, particularly in the older adult patient with cancer population.

Increased patient participation in TDM has been associated with positive clinical outcomes such as a greater level of satisfaction with decisions and better psychological adjustment (i.e., less post-decision anxiety and depression) (Gaston & Mitchell, 2005; Gattellari, Butow, & Tattersall, 2001). However, the preferred level of participation in TDM for older patients newly diagnosed with symptomatic myeloma has not been previously studied. In addition, the influence of sociodemographic

**Purpose/Objectives:** To describe the preferences for participation in decision making of older adult patients newly diagnosed with symptomatic myeloma and to explore the association between sociodemographic variables and decisional role preferences.

**Design:** Descriptive, cross-sectional design.

**Setting:** Participants' homes and two large academic cancer centers in Seattle, WA, and Chicago, IL.

**Sample:** A convenience sample of 20 older adults (60 years of age and older) with symptomatic myeloma diagnosed within the past six months.

**Methods:** The Control Preferences Scale was administered followed by an in-person, one-time, semistructured interview.

**Main Research Variables:** Role preferences for participation in treatment decision making, age, gender, race, work status, personal relationship status, education, and income.

**Findings:** Fifty-five percent of the participants preferred a shared role with the physician and 40% preferred to make the decisions after seriously considering the opinion of their physicians. Only one participant preferred to leave the decision to the doctor, as long as the doctor considered the patient's treatment preferences.

**Conclusions:** The study findings indicate that older adults newly diagnosed with myeloma want to participate in treatment decision making. Oncology nurses must respect the patient's desired role preference and oncology clinicians must listen to the patient and allow him or her to be autonomous in making treatment decisions.

**Implications for Nursing:** Nurses and other oncology clinicians can elicit a patient's preferred level of participation in treatment decision making. Oncology nurses can make sure patients receive disease- and treatment-related information, encourage them to express their decisional role preference to the physician, develop a culture of mutual respect and value their desire for autonomy for treatment decision making, acknowledge that the right to make a treatment choice belongs to the patient, and provide support during treatment decision making throughout the care continuum.

**Key Words:** decision making; decisional role preferences; patient education; multiple myeloma

ONF, 41(4), 411–419. doi: 10.1188/14.ONF.411-419

factors in older myeloma patients' levels of participation during TDM also is unknown.

Very few nursing research studies involve patients with multiple myeloma. With the rapidly growing number of treatment options for that patient population, this TDM study is timely. Research findings from the current study will help nurses in guiding their myeloma care practice.

## Theoretical Framework

Degner and Beaton's (1987) Patterns of Decision Making Model provided the theoretical framework for this study. These patterns encompass the various levels of patient participation in decision making and are patient-centered, directly eliciting decisional role preferences from the patient's perspective. According to the model, four decision-making patterns may occur: A *provider-controlled* decision-making pattern emerges when patients decline to become involved in selecting their own treatment, even when urged to do so by the physician. In this case, the patient is essentially saying, "It's up to you, doctor. You're the expert." On the other

hand, a *patient-controlled* decision-making pattern occurs when patients make it clear that they are the ones who will make the decisions (Degner & Beaton, 1987). When patients want to discuss the options with their physician and think about the options prior to making the final decision with their physician, a *jointly controlled* decision-making pattern occurs. Finally, when patients are incapable of making treatment decisions and the family makes decisions for them, a *family-controlled* decision-making pattern emerges (Degner & Beaton, 1987). No cases of family-controlled decision-making were evaluated in the current study because the sample criteria excluded anyone in this category.

Figure 1 illustrates the various roles patients can play during TDM. This framework of decisional role patterns was developed based on a four-year qualitative study into decision-making roles in life-threatening situations such as cancer (Degner & Beaton, 1987). The Control Preferences Scale (CPS) is a measure of decision-making preferences developed from a qualitative study by Degner, Sloan, and Venkatesh (1997).

The purpose of the current study is to describe the preferences for participation in decision making of patients newly diagnosed with multiple myeloma and to explore the association between sociodemographic variables and decisional role preferences.

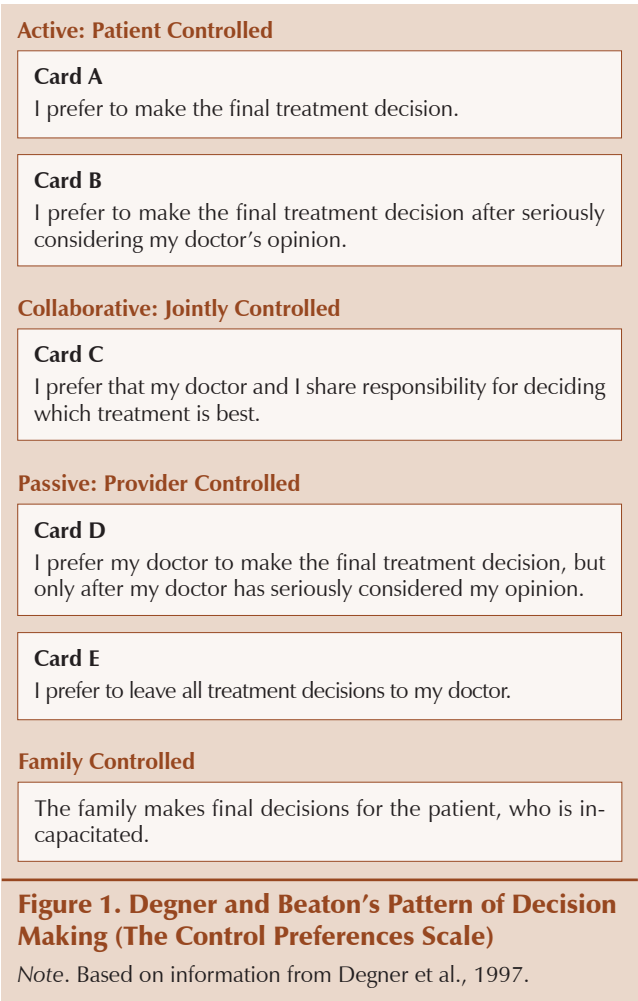
## Methods

### Design and Sample

A descriptive, cross-sectional study was conducted involving administration of the CPS followed by a semistructured interview. The convenience sample consisted of 20 older adults referred to the Seattle Cancer Care Alliance (SCCA) or the Northwestern University Myeloma Program (NUP) by several hematologists/oncologists in the greater Seattle, WA, or Chicago, IL, areas, respectively. Eligibility criteria included adults who were (a) 60 years of age and older, (b) diagnosed with symptomatic myeloma within the past six months, (c) able to read and write English, and (d) able to give informed consent.

### Instrument

The CPS is a measure of decisional role preferences using a card-sort technique that has two sets of five cards each. Each card describes a different role in decision making and is illustrated with a sketch of characters (physician or patient) representing their different roles in decision making. The first set of five cards illustrates possible roles that the patient could assume, ranging from the patient selecting his or her own treatment (cards A and B), through a collaborative role model (card C), to a scenario where the physician makes the decision (cards D and E). The process of



administering the card sort was described extensively by Degner et al. (1997).

The CPS offers a simple and fast method to elicit a patient's decisional role preference (Degner et al., 1997). This scale has been found to be a valid tool in the measurement of decisional role preferences in patients newly diagnosed with various types of cancer (Degner & Sloan, 1992).

## Recruitment Procedures

After the researchers obtained approval from the University of Washington and Northwestern University human subjects divisions, older adults recently diagnosed with symptomatic myeloma were recruited to participate in the study. The researcher made every effort to recruit from both university- and community-based practices to best include a diversity of study participants. Adults aged 60 and older who had an appointment at the hematology or transplantation service of SCCA or NUMP and were found to be eligible for the study were recruited by mail using a recruitment flyer. Older patients diagnosed with asymptomatic myeloma disease not requiring therapy were not recruited in the study because treatment decisions are not needed at the time of diagnosis. At NUMP, one of the researchers personally approached potential participants and introduced the study to gauge patient interest based on institutional review board-approved protocol. A review of clinic schedules at SCCA and NUMP was conducted weekly to identify potential study participants. One other UW-affiliated community clinic was checked weekly for potential study participants.

The CPS was administered and an interview conducted in either the patients' homes or designated research-related conference rooms at SCCA and NUMP. These rooms were strictly assigned for research use only and met the human subjects division's standard for patient privacy. If a patient wanted the interview to be conducted at a later time, a one-week period following the clinic appointment was allowed for rescheduling. In addition, if a patient wanted the interview to be conducted at his or her home, the researcher conducted the interview at the home as requested. Patients also were asked to describe the decisional role that they preferred from the CPS card. Interviews were audio recorded and transcribed verbatim by professional transcriptionists and verified by the principal investigator against the actual recording. The study participants received a \$5 gift certificate after completing the interview schedule.

## Analysis

### Coombs' Unfolding Analysis

Data from the CPS scale were analyzed using SPSS®, version 18. This analysis was based on a scaling model

**Table 1. Sample Characteristics (N = 20)**

| Characteristic                      | $\bar{x}$ |
|-------------------------------------|-----------|
| Age (years)                         | 67.45     |
| Characteristic                      | n         |
| <b>Age (years)</b>                  |           |
| 60–70                               | 14        |
| 71–82                               | 6         |
| <b>Gender</b>                       |           |
| Male                                | 8         |
| Female                              | 12        |
| <b>Race</b>                         |           |
| Caucasian                           | 18        |
| Asian                               | 1         |
| Native American                     | 1         |
| <b>Work status</b>                  |           |
| Full-time                           | 2         |
| Working on medical leave            | 2         |
| Not working                         | 2         |
| Retired                             | 13        |
| Student                             | 1         |
| <b>Personal relationship status</b> |           |
| Single                              | 2         |
| Married or partner                  | 12        |
| Divorced                            | 5         |
| Widowed                             | 1         |
| <b>Highest level of education</b>   |           |
| 9th–12th grade                      | 5         |
| Two years of college                | 2         |
| Four years of college               | 10        |
| Graduate degree                     | 3         |
| <b>Annual household income (\$)</b> |           |
| 18,000 or less                      | 3         |
| 18,001–35,000                       | 2         |
| 35,001–55,000                       | 5         |
| 55,001–85,000                       | 5         |
| 85,001 and greater                  | 5         |

developed by Coombs (1964) called the unfolding theory. According to Degner et al. (1997), this psychological scaling model is based on the assumption that “an individual's preference corresponds to an ideal point on a continuum, and that this ideal point can be derived by presenting successive paired comparisons of stimuli that fall along the continuum” (p. 25).

The unfolding theory holds that, for any given hypothesized scale, only 11 subsets of the 120 possible permutations of the five decisional role cards will be transitive. These 11 transitive responses include ABCDE, BACDE, BCADE, BCDAE, CBDAE, CDBAE, CDBEA, CDEBA, DCEBA, DECBA, and EDCBA. *Transitivity* means that a participant's response falls within the 11 possible valid permutations and the preference for each of the paired comparisons of stimuli is consistent with the hypothesized A to E psychological continuum. The reliability of the scale is established when 50% plus one of the experimental participant's preferences fall along the hypothesized scale (i.e., the

## Knowledge Translation

Contrary to findings from meta-analysis where older patients preferred a more passive role in treatment decision making (TDM) than younger patients, the current study showed only 5% of participants preferred a passive role.

The emergence of active and shared dichotomous roles found in this study require additional investigation.

Oncology nurses and other oncology practitioners must elicit a patient's decisional role preference and respect the patient's desire for autonomy during TDM.

ABCDE metric). One could easily see that a patient's logic on taking control of the decision-making process falls off the hypothesized scale when the order presentation of the card that the patient chooses is BCDEA or BCEDA. In other words, card B represents active decision role as well as card A, and when these two card options are at extreme ends of the card sort arrangement, the respondents did not understand the logic of taking control of the decision-making process.

## Association Analyses

The differences in decisional role preferences were examined using dichotomous categories of gender (male versus female), age (younger than age 70 years versus age 70 years and older), education (less than four years of college versus four years of college or more), marital status (single versus married), income (\$55,000 or less versus more than \$55,000), and work status (retired versus not retired). The comparisons were made using simple analysis of variance (ANOVA). As often as possible, the cut off for each category was based on equal distribution of the number of participants on each category. Spearman rank-order correlations were used to determine the relationship between ordinal CPS score and the respondent's age, education, and income variables. Given the results of the bivariate analysis and the small sample size, multivariable analyses were deemed unwarranted.

## Triangulation of Qualitative and Quantitative Data

Across-method triangulation (Waltz, Strickland, & Lenz, 2005), a form of methods triangulation, was employed for cross validation of the data obtained pertaining to patient's decisional role preferences. The patients' verbal descriptions of their desired level of participation, as elicited using the interview and the patients' preferences for participation, and as measured by the CPS card sort, are compared. This approach collected rich detailed information from the partici-

pants regarding their perspectives on decisional role preferences, which were then compared to the original description of the CPS cards.

## Results

Seventy-nine potential participants were contacted by mail at SCCA from October 2009 to July 2010. Of these, 14 (18%) responded and all participated in the study. At NUMP, the researcher identified six potential participants and one of the investigators approached them in person about participation. All six agreed to participate. Informed consent was obtained from all study participants. Fourteen of the 20 interviews were conducted in participants' homes. Table 1 presents sociodemographic characteristics.

## Coomb's Unfolding Analysis for Reliability Criterion

As illustrated in Table 2, the hypothesized ABCDE decision-making scale comprised 70% ( $n = 14$ ) of the respondents' answers. This means that the data show support for an underlying dominant dimension of control, ranging from keeping control (active: cards A and B) through collaboration (sharing: card C) to giving away control (passive: cards D and E). In addition, these results show that the 50% plus one criterion of reliability had been met. Of note, the DCBAE metric also had 70% ( $n = 14$ ) of the respondents' answers. This means that a second, competing model of dichotomous preference (shared, card C; and active, cards B and A) is seen in this group of older adults newly diagnosed with symptomatic myeloma. All other competing scales had 9 or fewer participants out of 20 possible and, therefore, did not meet the eligibility criterion for validity of underlying theory of varying degree of control preferences. Figure 2 shows the distribution of respondents' preferences on and off the hypothesized decision-making control scale.

## Decisional Role Preferences

An examination of the distribution of preferences based on the first card in the preference order indicated that 55% ( $n = 11$ ) of the participants preferred a shared role with the physician, and that 40% ( $n = 8$ ) preferred to make the decisions after seriously considering the opinion of their physician (see Table 3). Only one participant preferred to leave the decision to the doctor as long as the doctor considered the participant's treatment preference. No individual chose card A or E, the extremes of decision-making preference choices. Overall, the percentage of participants wanting to have some kind of control over the treatment decision was very high (95%,  $n = 19$ ).



## Sociodemographic Variables and Decisional Role Preferences

No statistically significant differences were noted in decisional role preferences across dichotomous categories of gender, age, education, marital status, income, and work status using ANOVA. Also, no statistically significant correlations were found between CPS score and the age, education, and income variables.

## Quantitative and Qualitative Decisional Role Preference

Table 4 illustrates the study participants' decisional role preferences using the CPS card, the decisional category, and the participant's own description of preferred role. The majority of descriptions (85%,  $n = 17$ ) on preferred roles have similar or exact description with the decision categories originally described in the CPS card by Degner and Beaton (1987). Only three participants (15%) had a different personal meaning or interpretation of preferred role when compared to the original CPS description of the three decision categories.

## Discussion

In this study of decisional control preferences in older adults newly diagnosed with symptomatic myeloma, 19 of 20 participants indicated a preference for some control or full control of the treatment decisions, with only one expressing a preferred passive role. This finding is contrary to previous reports that older adults with various types of cancers, such as breast, prostate, and colorectal cancers, are passive recipients of medical care (Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Elkin, Kim, Casper, Kissane, & Schrag, 2007; Singh et al., 2010). Perhaps the impact of advanced age on relinquishing decisional control to physicians is moderated by higher education and higher income profile of the study participants; these are variables previously reported as having strong correlation with more decisional control preference (Degner & Sloan, 1992; Janz et al., 2004; Ryan & Sysko, 2007; Wallberg et al., 2000). Alternatively, researchers could theorize that older adults newly diagnosed with symptomatic myeloma may have a different profile of decisional role preferences because of their extensive previous and varied life experiences with the healthcare system, as most older adults could be expected to have at least one or more comorbidities. Whether the number of comorbidities and multiple exposures

to the healthcare system could increase or decrease decision making control preferences is unknown. This could be an area of future research on TDM experience. Anecdotally, one participant in the study shared that, when she experienced adverse effects of her first chemotherapy, it made her more involved in the decision-making process; she asked more questions to her oncologist prior to agreeing to the next line of chemotherapy for her myeloma.

The authors of the current article have documented that the participants demonstrated a strong desire to take part in the decision-making process, although they may not have a full understanding of myeloma because of the complexity of the disease. During the interview, the participants reported seeking information from various sources (as reported on in Tariman, Doorenbos, Schepp, Singhal, and Berry [In press]), and some identified their physicians as the primary source to explain the different treatment options available to them. These findings have strong implications for physicians to provide the information that the study participants want and need during TDM clinic encounters.

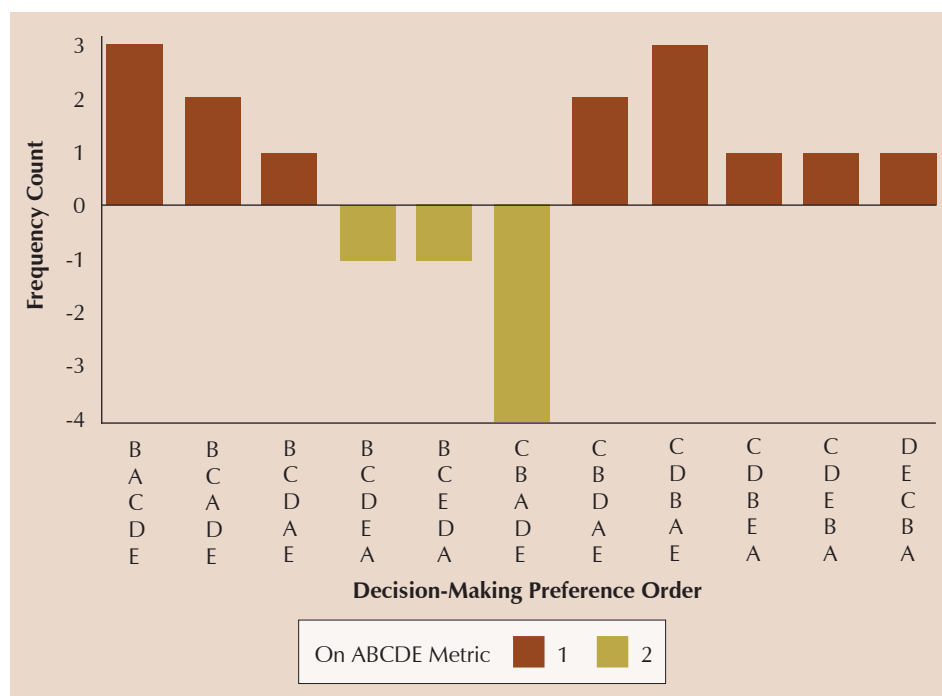
The findings of the study are consistent with findings reported in studies from the United Kingdom (Caldon, Walters, & Reed, 2008) and Canada, where research showed increasing numbers of patients with cancer wanting to have some control of treatment decisions—as high as 92%–93% in some studies (Davison, Goldenberg, Gleave, & Degner, 2003; Davison, Goldenberg, Wiens, & Gleave, 2007; Singh et al., 2010).

**Table 2. Rank Ordering of the Two Competing Scale Models, Control Preference Scaling, and Summary for Scoring**

| Scale Name   | Valid | Valper | Invalid | Invalper | Cell | Reversal |
|--------------|-------|--------|---------|----------|------|----------|
| <b>ABCDE</b> | 14    | 70     | 6       | 30       | 3    | No       |
| <b>DCBAE</b> | 14    | 70     | 6       | 30       | 6    | No       |
| CBADE        | 9     | 45     | 11      | 55       | 8    | No       |
| ACBDE        | 7     | 35     | 13      | 65       | 8    | No       |
| DBCAE        | 7     | 35     | 13      | 65       | 8    | No       |
| ADCBE        | 6     | 30     | 14      | 70       | 8    | No       |
| BCADE        | 6     | 30     | 14      | 70       | 9    | No       |
| BCDAE        | 6     | 30     | 14      | 70       | 8    | No       |
| DABCE        | 5     | 25     | 15      | 75       | 9    | No       |
| DACBE        | 4     | 20     | 16      | 80       | 10   | No       |

Invalper—invalid permutations; Valper—valid permutations

Note. The table shows the top two competing treatment decision-making scale models (in bold) that meet Coombs' reliability criterion of 50% plus one (valid permutation greater than 11).



tended to fall into either the active or passive categories (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Cassileth, Zupkis, Sutton-Smith, & March, 1980), particularly in older adult patients with cancer (Singh et al., 2010). The current article shows that those preferences are now shared or active.

## Limitations

Limitations of this study are primarily related to sample size and demographics. The small sample primarily consisted of Caucasians who were college educated with relatively high incomes. In addition, the majority of participants were receiving care at the same university-based comprehensive cancer center.

The small sample size and lack

of diversity limit the generalizability of study findings. The authors were unable to make more meaningful comparisons of differences in decisional role preferences by subgroups and also were unable to examine associations of decisional role preferences with multiple sociodemographic variables. In addition, because the current study is cross-sectional, the findings may not be applicable to symptomatic patients with myeloma who are beyond six months since diagnosis. These limitations should be addressed in future research.

Additional research using a longitudinal approach is needed to better describe the stability or change in study participants' decisional role preference over time in older adults diagnosed with cancer. Patients diagnosed with myeloma are an excellent study population for studies involving older adults since the incidence of myeloma peaks at the seventh decade of life (Kyle et al., 2004), but recruitment of a large number of participants remains a major challenge because myeloma remains a rare form of cancer, accounting for only 1% of all cancers diagnosed each year (National Cancer Institute, 2014). A direct approach in study recruitment is a very effective way of recruiting participants; far better than the mail approach. The direct approach should be used if the local institutional review board committee still allows this approach in study participant recruitment. Finally, myeloma affects a minority of younger patients (younger than age 60). Examining the treatment decision-making patterns of this younger patient subgroup should be done in future studies and

| Preferred Role | Frequency | %   | Valid % | Cumulative % |
|----------------|-----------|-----|---------|--------------|
| B              | 8         | 40  | 40      | 40           |
| C              | 11        | 55  | 55      | 95           |
| D              | 1         | 5   | 5       | 100          |
| Total          | 20        | 100 | 100     | —            |

**Table 4. Patient's Decisional Role Preference, Category, and Description**

| Patient         | First Card in CPS | Decisional Category | Patient's Description of Preferred Decisional Role  |
|-----------------|-------------------|---------------------|---|
| 1               | B                 | Active              | So, it was neutral at first, and then as some of the shock wore off and some of the reality came in, I started participating more in my treatment.  |
| 2               | C                 | Shared              | The fact that, before treatments are started, I know what it is going to be, and if there is, for some reason, a drug that I don't feel I could take, then I still have a right to say no to that.  |
| 3               | D                 | Passive             | I definitely want to be involved in the decision, but knowing that the doctor knows more than I do about the treatments that are available and which one I'm best suited for, I would go with the doctor's opinion after I've heard what the options are and discussed them.  |
| 4               | B                 | Active              | I would like to have full involvement. I will listen to what the doctor says or what he feels, because I feel he has that knowledge. And I probably would take his recommendation, but I would make the decision myself.  |
| 5               | C                 | Shared              | My oncologist seems to think that acupuncture and massage are all fine, but those are things that I've explored myself. So, I take his advice, and then I do my other kinds of things that are alternative sorts of things, too.  |
| 6               | C                 | Shared              | I take the input from what I've gotten back from the tests that my doctor sends me. But that wasn't good enough for me because I wanted a second opinion.   |
| 7               | C                 | Shared              | Now that I've kind of had a chance to step back and have a more sober view of it and more objective view, I feel that I'm in a better frame of mind, if you would, to maybe look at the options and discuss this in a more objective manner.  |
| 8               | C                 | Shared              | I want to know about things. I'm curious. I want to know as much as I can. And then, with the help of my husband and my kids, make a decision.  |
| 9               | B                 | Active              | Well, I will make my decision along with my husband at that point on which is best for us as a family, and we rely upon our doctor's medical advice to lead us to a conclusion.   |
| 10              | B                 | Active              | I ask her [my doctor] everything I can think of when we meet. I listen to what she has to tell me. If the decision is something clear enough that I can make it immediately or if I need to make it immediately, I do.  |
| 11 <sup>a</sup> | C                 | Shared              | I want her [my doctor] to see how I'm doing and see what condition I am and how I'm progressing, you know; worse or better, then, make her decision based on that.  |
| 12 <sup>a</sup> | C                 | Shared              | I want to know. I am very, very nosey that way. I want to know.   |
| 13              | B                 | Active              | My wife was heavily involved in making the decision, too. Since she was very much affected by it, so together we made the decision. I probably had a little more influence than her, but her opinion was considered, as well.   |
| 14              | C                 | Shared              | Well, my preference is, and it has been so far, is shared involvement with the doctor and, also, a key to it has been the ability to be able to get a second opinion so I can have two experts look at the situation.   |
| 15              | B                 | Active              | I write things down and I try to get as many opinions as possible. And, of course, I think the doctor's opinion about what to do is 90% of what it is. But I want to understand, if decisions are being made on my behalf, why they're being made.  |
| 16 <sup>a</sup> | B                 | Active              | I want to know, I like to understand, really, why something is being done. Not that I truly would understand it as a lay person, but I want to understand the logic for doing something and I do want to understand the potential for being successful and risk factors, you know, because I want to use that to gauge how fast I want to live my life. |
| 17              | C                 | Shared              | I would like to go over the pros and cons of therapy. I see them in my life for me and then make that decision with the doctor as far as what the doctor feels after the doctor heard where I was coming from. The doctor knows what would be the best for me in this situation because the doctor has the overall picture and I only have pieces.      |

*(Continued on the next page)*

<sup>a</sup> Description does not match with decisional category.  
CPS—Control Preference Scale

**Table 4. Patient's Decisional Role Preference, Category, and Description (Continued)**

| Patient | First Card in CPS | Decisional Category | Patient's Description of Preferred Decisional Role  |
|---------|-------------------|---------------------|---|
| 18      | C                 | Shared              | Well, I like to have the best possible treatment plans to cure my disease, and knowing my doctor, I was confident at that time to listen to her opinion, and we made a decision collectively to further my treatment.   |
| 19      | C                 | Shared              | I'd like to be well informed of my choices, on both the pros and cons of those choices, in language I can understand, so that I can help participate in making the choice.  |
| 20      | B                 | Active              | Well, we knew that it was incurable, and the medical community nationwide seemed to be taking the transplant approach to improve the possibilities of longevity. So, we were impressed with the facility and all of the staff and have decided to go ahead in that direction. |

<sup>a</sup> Description does not match with decisional category.

CPS—Control Preference Scale

the differences in role preferences and influential treatment decision factors also should be explored.

## Implications for Practice

The study findings suggest that study participants diagnosed with symptomatic myeloma do want to participate in the treatment decision-making process. Although myeloma is complex and not easy to understand for laypersons, these findings indicate that participants still want to learn as much as they reasonably can about the disease and treatment so as to understand the reason why certain treatment options might be better for them than others. The majority of participants also wanted to share the treatment decision with their physicians and/or want to make the decision themselves. Therefore, physicians, nurse practitioners, and physician assistants must practice full disclosure of treatment options to their patients so patients can make a truly informed decision. Because a patient's level of preference for participation is highly variable and could have personal meaning for each patient, physicians and oncology nurses also must elicit the patient's preference, explore what participation truly means for him or her, and facilitate the patient's decision process. Because more patients with cancer now want to participate in TDM, physicians, nurse practitioners, nurses, and policy makers must support more studies that can enhance patient involvement. Oncology nurses can do many things to help patients with cancer achieve the level of participation they desire, including (a) making sure patients receive disease and treatment-related information, (b) encouraging patients to express their decisional role preference to the physician, (c) developing a culture of mutual respect and value the patient's desire for autonomy for TDM, (d) acknowledging that the right to make a treatment choice belongs to the patient, and

(e) providing psychological support to the patient during TDM from the time of diagnosis to end-of-life care decision making.

## Conclusion

Older adults newly diagnosed with symptomatic myeloma want a role in the TDM process. More studies that focus on supporting and involving patients in the decision-making process are needed to influence clinical practice and policy in this direction. Oncology nurses must be cognizant of the differences in decisional role preferences in symptomatic patients with myeloma to best meet their individual decisional needs and preferences. Oncology clinicians must respect the patient's desired role preference and must listen to the patient and allow him or her to be autonomous in making treatment decisions if the patient desires such control. A culture of equipoise between the patient and the clinician during TDM must be cultivated to achieve the patient's desired level of participation.

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