A consolidated evaluation of resources on treatment decision aids (DAs) for multiple myeloma (MM) is lacking in the literature. This review identified 29 published DAs. Further analysis of these DAs revealed that the personal values and preferences of patients with MM are not well integrated into the development of these DAs, indicating the need for a more explicit shared decision-making model of MM care delivery. The development and testing of a web-based and individualized treatment DA will likely promote a shared decision-making process in clinical practice, improve patient satisfaction with treatment decisions, and decrease decisional regrets in patients newly diagnosed with MM.

AT A GLANCE

- Future DAs for patients with MM must be web-based and incorporate patients' values and preferences for treatment.
- The shared decision-making model for MM treatment should be built in as an interactive feature of the DA.
- Future DAs must be based on high-level evidence, such as data from systematic reviews or randomized, controlled trials.

KEYWORDS

multiple myeloma; decision aids; shared decision making; decision support techniques

DIGITAL OBJECT IDENTIFIER

10.1188/17.CJON.660-664

Decision Aids

Assisting patients with multiple myeloma and caregivers with treatment decision making

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A 52-year-old named S.C., a chief financial officer at a law firm, was referred to a multiple myeloma (MM) specialist at a large academic medical center in the Midwest. He visited his primary care provider because of progressive bone pain in the left hip area for more than two months, and x-rays of the left posterior iliac crest and left femur showed osteolytic lesions concerning for malignancy. Additional diagnostic workup completed by the MM specialist revealed anemia with a hemoglobin of 9.8 mg/dl, normal kidney function with a creatinine of 1.1 mg/dl, no hypercalcemia with serum total calcium level at 9.2 mg/dl, a high immunoglobulin G (IgG) level of 6,520 mg/dl with a monoclonal spike of 5.9 g/dl on serum protein electrophoresis, immunofixation positive for IgG kappa monoclonal protein, and a high beta-2 microglobulin level of 5.8 mcg/ml. A bone marrow biopsy showed 60% monoclonal, kappa-restricted plasmacytosis with intermediate cytogenetic risk profile consisting of t(4;14), 1q gain, and high plasma cell S-phase based on the updated Mayo Clinic mSMART guidelines (Mikhael et al., 2013). Magnetic resonance imaging of the skull, spine, and pelvis revealed multiple focal lesions on the frontal bone, lumbar spine, left posterior iliac, and left femoral bones. S.C. was diagnosed with symptomatic MM requiring therapy. S.C. asked his nurse for available resources on treatments for newly diagnosed MM so he could make an informed treatment decision.

Research studies involving individuals newly diagnosed with MM reveal an in-

creasing patient need for information regarding treatment and disease knowledge (Tariman, Doorenbos, Schepp, Singhal, & Berry, 2015), particularly for those who are diagnosed with MM at a younger age (Rood et al., 2015) like S.C. In another study, 19 of 20 older adults newly diagnosed with symptomatic MM wanted to participate in the treatment decision-making process (Tariman, Doorenbos, Schepp, Singhal, & Berry, 2014). With the growing evidence of patient needs for disease- and treatment-related information and patient willingness to participate in cancer treatment decision making (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010), providing patients with relevant and meaningful information on MM treatments can empower them to become active participants in shared treatment decision making (Kane, Halpern, Squiers, Treiman, & McCormack, 2014).

A Cochrane systematic review of decision aids (DAs) involving 86 studies revealed that the use of DAs can increase patients' participation in making decisions, increase knowledge of available treatment choices, enhance clarity in prioritizing what is important to them, and improve their communication with the healthcare team (Stacey et al., 2014).

Review Objectives

The objectives of this integrative literature review are to examine all accessible MM treatment DAs for patients and clinicians and to appraise the strength of evidence supporting these DAs using Melnyk and Fineout-Overholt's (2011) hierarchy of evidence.

Conceptual Framework

Knowles's (1984) theory of adult learning guided this review. According to this theory, adults who are diagnosed with cancer will seek treatment information when they are ready and motivated to learn about their cancer treatments. Self-directed learning is the pillar of Knowles's theory. Adults with MM will be intrinsically motivated to learn about their treatment options because of the availability of multiple treatments and because of healthcare consumerism, fueling an increased desire to participate in the treatment decision. The theory of adult learning also posits that adults are more engaged in the learning process when they are learning content that is relevant and practical to their lives; as a result, the integration of patients' personal values and preferences into DAs was also examined.

Methods

To provide a foundation for DAs in MM, the current authors used Whittemore and Knaff's (2005) integrative literature review framework. The current review included peer-reviewed articles, educational pamphlets, and online or web-based myeloma treatment DAs, which were critically appraised for strength of evidence using Melnyk and Fineout-Overholt's (2011) hierarchy of evidence.

Literature Search

A literature search was conducted using CINAHL® Complete, Cochrane, ProQuest Nursing and Allied Health Database, and PubMed. The following relevant Medical Subject Heading (MeSH) and common search terms were used during the search: *myeloma*, *multiple myeloma*, *decision aid*, and *decision support techniques*. In addition, a Google Scholar search was conducted using the search term *treatment decision aid for myeloma*. Table 1 illustrates the literature search process with corresponding yields from various computerized databases.

The literature search involved the following inclusion criteria: available full-text, peer-reviewed articles with a treatment DA component written in English

from January 2000 to January 2016. The titles and abstracts were examined, and duplicate articles were excluded from the total. Supportive treatment DAs for MM (e.g., growth factor use, bisphosphonates) were excluded. Twenty-nine articles met inclusion criteria in this review.

Data Synthesis and Analysis

To present the relevant findings in a cohesive manner, the current authors implemented Whittemore and Knaff's (2005) process of data reduction, display, and comparison using a matrix of data; this process helped categorize and summarize the variables of interest in this review. The variables of interest included the intended user of the DAs, format, level of evidence, and consideration of patient values and preferences. Table 2 shows the study DAs, the format of the DAs, the intended audience, and the strength of evidence (level I [lowest quality of evidence] to VII [highest quality of evidence]) for each respective DA based on Melnyk and Fineout-Overholt's (2011) hierarchy of evidence. The categorical data with respective numeric values were then imputed into SPSS®, version 21.0, for descriptive statistics analysis using frequencies and cumulative percentages (CPs).

Any inconsistencies on assignment of data category according to intended user and hierarchy of evidence were reviewed again by the two reviewers until mutual agreement was reached. Descriptive statistics using frequencies and percentages

provided summaries for intended users, the hierarchy of evidence, and the format for all 29 DAs.

Results

Twenty-nine DAs met inclusion criteria and were analyzed and appraised independently by two reviewers. Most DAs (N = 23, CP = 79%) were intended for clinician use only, and all were available electronically. Four DAs (CP = 93%) were developed as an online PDF intended for patients and their caregivers, and 2 DAs (CP = 100%) were intended for clinicians and patients and their caregivers. Further examination of these DAs revealed that they lacked explicit consideration of the patient values and preferences in the treatment decision-making process.

For DAs intended for clinicians, the overall strength of evidence was strong based on Melnyk and Fineout-Overholt's (2011) hierarchy of evidence considering the following results: 12 DAs were systematic reviews of randomized, controlled trials or clinical guidelines developed by MM experts (level I, CP = 41%); 1 DA for clinicians was based on a descriptive study (level VI, CP = 45%); 4 DAs were based on controlled, nonrandomized trials (level III, 55%); 4 DAs were based on systematic reviews of descriptive and qualitative studies (level V, CP = 79%); and 3 DAs were based on case control or cohort studies (level IV, 66%). The 5 DAs intended for patients were based on expert opinion (level VII, CP = 100%), which is the lowest level of evidence.

TABLE 1.
LITERATURE SEARCH PROCESS AND ARTICLE SELECTION

DATABASE	FOUND	SELECTED	EXCLUDED	USED
Google Scholar	5,760	33	25	8
ProQuest	233	19	10	9
PubMed	65	24	14	10
CINAHL® Complete	2	2	1	1
Cochrane	1	1	–	1
ProQuest—ProQuest Nursing and Allied Health Database				

TABLE 2.
DATA MATRIX ON STUDY TREATMENT AIDS, FORMAT, INTENDED AUDIENCE, AND STRENGTH OF EVIDENCE

STUDY	FORMAT	INTENDED AUDIENCE AND LEVEL OF EVIDENCE
Alberta Health Services, 2015	Online, web-based document	Clinicians; I
Engelhardt et al., 2014	Peer-reviewed journal article	Clinicians; I
Laubach et al., 2016	Peer-reviewed journal article	Clinicians; I
Ludwig et al., 2014	Peer-reviewed journal article	Clinicians; I
Medical Scientific Advisory Group, 2017	Online, web-based document	Clinicians; I
Moreau et al., 2017	Peer-reviewed article	Clinicians; I
mSMART, n.d.	Online, web-based document	Clinicians; I
Myeloma United Kingdom, 2017	Online, web-based document	Clinicians; I
National Comprehensive Cancer Network, 2016	Online, web-based document	Clinicians, patients, and caregivers; I
National Institute for Health and Care Excellence, 2016	Online, web-based document	Clinicians; I
National Myeloma Tumour Standards Working Group, 2013	Online, web-based document	Clinicians; I
Quill et al., 2015	Peer-reviewed journal article	Clinicians; I
Fleisher et al., 2014	Peer-reviewed journal article	Clinicians; III
Lee et al., 2008	Peer-reviewed journal article	Clinicians; III
Signal Genetics, 2014	Laboratory-based decision guide	Clinicians, patients, and caregivers; III
Waheed et al., 2011	Peer-reviewed journal article	Clinicians; III
Zhan et al., 2008	Peer-reviewed journal article	Clinicians; IV
Labonté et al., 2008	Peer-reviewed journal article	Clinicians; IV
Meissner et al., 2011	Peer-reviewed journal article	Clinicians; IV
Chng et al., 2016	Peer-reviewed journal article	Clinicians; V
Donfack Guefack et al., 2012	Peer-reviewed journal article	Clinicians; V
Ferrero et al., 2011	Peer-reviewed journal article	Clinicians; V
Rochau et al., 2015	Peer-reviewed journal article	Clinicians; V
Viala et al., 2007	Peer-reviewed journal article	Clinicians; VI
International Myeloma Foundation, 2017	Online, web-based document	Patients and caregivers; VII
Klepin et al., 2013	Peer-reviewed journal article	Clinicians; VII
Leukemia and Lymphoma Society, 2015	Online, web-based document	Patients and caregivers; VII
Multiple Myeloma Research Foundation, 2015	Online, web-based document	Patients and caregivers; VII
Myeloma Canada, 2014	Online, web-based document	Patients and caregivers; VII

Format of Decision Aids

Of the 29 compiled DAs, 17 DAs were available as peer-reviewed journal articles that can be accessed online (CP = 59%); 11 DAs were developed as an online, web-based document (CP = 97%); and only 1 DA was based on a commercially available laboratory genomic profile but could also be accessed online as a treatment decision guide (CP = 100%).

Discussion

This review presents a consolidated evaluation of the available DAs for patients and clinicians related to MM treatment

related to treatment decisions. Whether these DAs intended for patient use improve patient satisfaction with treatment decisions and decrease decisional regrets is unknown.

Limitations

One of the limitations of this review is the potential bias from the arbitrary creation of criteria for inclusion, which may have unintended selection bias effect. Although multiple computerized databases were used for the literature search, other relevant DAs may have been missed during the selection process.

Conclusion

This review provided a consolidated evaluation of resources on treatment DAs for MM, previously lacking in published literature. It suggests that DAs make shared decision making in clinical practice possible, improving patient satisfaction about treatment decisions and decreasing decisional regrets in patients newly diagnosed with MM. The findings of this review underscore the need for the development and testing of effective DAs that incorporate personal values and preferences of patients newly diagnosed with cancer and explicitly use the shared model of cancer care delivery.

"Decision aids make shared decision making in clinical practice possible, improving patient satisfaction and decreasing decisional regrets."

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The authors take full responsibility for this content and did not receive honoraria or disclose any relevant financial relationships.

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decision making. Most of these DAs are intended for clinician use only. The strength of evidence for the DAs intended for clinicians was strong, with most DAs developed using data from randomized, controlled trials. Only a few DAs were intended for patients and their caregivers and were developed by patient support group organizations, including the International Myeloma Foundation, Multiple Myeloma Research Foundation, Leukemia and Lymphoma Society, and Myeloma Canada. DAs intended for patients had the lowest level of evidence. Further examination of these DAs for patients revealed that they offer general information on myeloma disease processes and the multiple treatment options for MM. However, explicit consideration of patient values and preferences in the decision-making process, which is vital in the implementation of the shared model of cancer care (Kane et al., 2014), was lacking. A paucity of research shows how these DAs affect overall outcomes

Implications for Nursing

The identification and categorization of available DAs based on intended users and level of evidence should help oncology nurse clinicians meet the treatment information needs of patients newly diagnosed with MM. Oncology nurses should provide relevant and meaningful treatment information to patients and empower patients to voice their personal preferences for treatment during the shared treatment decision-making process. The information presented in this review could serve as a valuable resource for implementing evidence-based practice in the shared decision-making process for treatment with patients with MM. In addition, the results from this integrative review can serve as a foundation for moving future research toward the development and testing of computerized and individualized treatment DAs in MM that are designed to help patients make informed treatment decisions and improve outcomes.

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