Qualitative analysis of the roles of physicians and nurses in providing decision support to patients with relapsed or refractory leukemia and malignant lymphoma

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Research Article

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Abstract

Purpose

This study clarified the roles of hematologists and expected roles of other professionals in providing decision support to patients with relapsed or refractory leukemia and malignant lymphoma.

Methods

Semi-structured interviews were conducted with 11 hematologists regarding the role of physicians in providing decision support and the expected roles of other professionals. Interview data were then subjected to a content analysis.

Results

Hematologists were tasked with gathering information about the patient prior to discussions; specifically, they would select required information, communicate issues in a way that patients and their families could easily understand, respect the wishes of the patients and their families, and pay attention to any emotional needs. They were also expected to alter the way information was conveyed in cases of particular severity, while explaining the options they believed were best. Regarding multidisciplinary collaboration, roles included valuing communication, managing entire teams, and encouraging active participation among other professionals. On the other hand, hematologists expected other professionals to actively participate in discussions, express opinions, share information about the patient's situation and related discussions, and provide emotional support.

Conclusions

During interviews, hematologists conveyed information that physicians keep in mind when providing decision support to patients and explained how they prioritized treatment options. Information must be organized not only in terms of the patient's image and hematologist's perspective, but also in terms of the patient's priorities and values. As such, a multidisciplinary professional team is needed to share patient information and provide multifaceted support.

Introduction

Patients with leukemia and malignant lymphoma have experienced better remission rates and extended survival through enhanced chemotherapy regimens, hematopoietic cell transplantations, and therapeutic agents targeted at various adverse events. On the other hand, some types of leukemia and malignant lymphoma can become treatment resistant, and are thus incurable [1]. Even in cases of relapse, however, these patients may have the option to receive high-dose chemotherapy treatments or hematopoietic cell

transplantations aimed at long-term survival, but there is also a certain rate of therapy-related mortality and situations in which remission is not achieved. There are also life-related side effects, such as myelosuppression, which increases the risk of treatment. In this context, it is important to ensure that patients fully understand information related to their illness when making decisions about future treatments, including how to spend their time and whether the recuperation conditions reflect their own values. Indeed, research has shown that patients and their families may find it difficult to understand the complex pathophysiology and treatment approaches for leukemia and malignant lymphoma [2, 3].

A random controlled trial (RCT) among patients with acute myeloid leukemia showed that those who received integrated palliative and oncology care were more likely to discuss their end-of-life (EOL) preferences, and also reported reduced psychological anxiety and improved quality-of-life (QOL) at week two; these effects were sustained thereafter [4]. However, research has also shown that patients with hematologic malignancy tend to receive much less palliative or hospice care when compared to those with other cancers (risk ratio 0.46, [95% confidence intervals 0.42–0.50]) [5]. Further, hematologists have difficulty timing referrals to palliative care from specialists because patients with leukemia and malignant lymphoma require aggressive treatment until the EOL [6]. This makes it difficult to believe that these patients are able to make informed decisions.

The American Society of Clinical Oncology (ASCO) has published consensus guidelines for clinician-patient communication, specifically recommending that clinicians provide information that is congruent with their patients' interests and intentions while jointly considering their goals for treatment [7]. Physicians should also collaborate with other professionals when providing support for patients who must make these difficult medical decisions, which requires a further clarification of the treatment goals [8]. To establish this type of collaboration, it is important for each professional to understand their own roles as well as those expected of other professionals.

Based on the above, this study clarified how hematologists perceive the roles of doctors in providing decision-making support to patients with relapsed and refractory leukemia and malignant lymphoma, including their own roles in supporting decision-making via multidisciplinary collaboration and the roles they expect other healthcare providers to fill.

Methods

Participants and Recruitment

We used the opportunistic sampling technique to recruit hematologists who were board-certified in their specialty and worked for hospitals that provided hematology medicine services. All potential participants were required to have worked in their areas of expertise for a minimum of five years.

Data Collection

We conducted in-depth interviews to identify the attributes and roles of doctors as well as the expected roles of nurses in the context of providing decision-making support to patients with relapsed or refractory leukemia and malignant lymphoma. Specifically, we scheduled face-to-face semi-structured interviews in private rooms between August and December of 2011. All interviews were conducted, audio recorded, and fully transcribed by one researcher (MM, a research nurse), who also took detailed field notes during each. We asked all participants about their roles in treating patients with relapsed or refractory leukemia and malignant lymphoma. They were also asked for demographic details, including information on age, the type of facility where they worked, and the number of years they had worked in their area of specialization.

Interview data were transcribed verbatim from the audio recordings. A content analysis was then conducted on all resulting data. First, MM extracted all statements related to the study topics from each transcript (e.g., the role of hematologists, role of hematologists in multidisciplinary collaboration, and expectations for other professional in the context of providing decision-making support). Under the supervision of an experienced hematology nurse (YS), we then carefully conceptualized and categorized the texts into content areas via content analysis following Klaus Krippendorff[9]. The text was divided into meaning units, which were then condensed, abstracted, and labeled with codes. The codes used for palliative care specialists and hematologists were then sorted into categories and subcategories based on similarities and differences in the abstracted and coded data. Next, another qualitative researcher (MT) was asked to review the categorizations (the rate of agreement between the researchers and coders was 91%). Finally, cases of discrepancy were reviewed based on a consultation involving the codes.

Results

Participant Characteristics

We conducted semi-structured interviews with a total of 11 hematologists. The average participant age was 44 years (35-54 years), while the average amount of specialization experience was 16 years (range of 7-26 years). Table 1 provides additional details.

The Role of Hematologists in Direct Decision Support

As shown in Table 2, we identified seven categories related to the roles of hematologists in providing direct decision support to patients, as follows: 1) preparing patients before informed consent, 2) selecting the information to convey, 3) choosing a method of conveying information, 4) respecting the intentions of patients and their families, 5) facilitating the direction of decision-making and considering fairness, 6) considering the emotional aspects of patients and their families, and 7) providing support after discussing treatments.

Preparing patients before informed consent (IC)

Several participants said they gathered information about their patients from family members and others before presenting any treatment options. They also encouraged family members to participate in decision-making discussions and worked to create an environment that allowed them to focus on IC. As such, physicians were expected to prepare patients before IC; for instance, they would provide them with information about the risk of relapse.

Selecting the information to convey

Many participants said they did not provide their patients with prognoses. Even further, more than half said they may not even tell their patients the truth depending on the severity of the illness, and were very selective about which information they were willing to provide in order to avoid the loss of hope. Many also said they communicated both the advantages and disadvantages of the presented treatment options, and provided information they believed would help patients and their families understand any such options before making their final decisions. A large number said they would inform family members about the possibility of sudden changes and specific prognoses, with more than half saying they would explain issues so that patients could visualize what may happen to them in the future. In sum, participants provided information to help patients and their families more thoroughly understand their current situations.

Choosing a method of conveying information

Nearly half of participants said they carefully considered both what they discussed and their manner of speaking, especially in consideration of the relatively long periods of association they had with their patients. In this regard, they conveyed information based on how patients reacted and their level of acceptance. They also provided explanations according to what they believed patients intended and thought, depending on their respective stages of readiness. Moreover, nearly half said they would explain issues without using jargon, thus ensuring that all relevant information was easy to understand. In sum, participants remained cognizant of the need to communicate both correctly and appropriately with patients and their families.

Respecting the intentions of patients and their families

More than half of participants said they helped patients and families make decisions by supporting and respecting their wishes and desired treatments. Several also said they helped patients and families set feasible goals after listening to their wishes.

Facilitating the direction of decision-making and considering fairness

More than half of participants said they made efforts to discuss and explain the treatment options they thought were most beneficial. Specifically, they would discuss the direction of these treatment options, thus facilitating the decision-making process. On the other hand, participants also said they were aware that the manner in which they spoke could affect how patients perceived the treatment options. In this regard, they attempted to remain impartial when conveying information.

Considering the emotional aspects of patients and their families

Nearly half of participants said they would attempt to instill hope among patients, and therefore considered the emotional aspects. Several also said they adopted a supportive stance as a way to assure patients that they were not abandoning them or their families.

Providing support after discussing treatments

Several participants said they informed patients about bad news and future treatments, then provided emotional support in consideration of any emotional fluctuations.

The Role of Hematologists in Multidisciplinary Collaboration and Decision Support

We identified the following five subcategories related to the roles of hematologists in multidisciplinary collaboration: 1) communicating with other professionals, 2) gathering information from other professionals, 3) providing information to other professionals, 4) managing entire medical teams, and 5) encouraging nurses to actively participate with patients during the decision-making process (Table 3). More than half of participants said they valued communication with other professionals and recognized their roles in obtaining information during those discussions. For example, they would ask nurses for information related to the patient's background and their ability to provide related support. On the other hand, they also provided information to other professionals. For instance, they would explain prognoses and future treatment plans. Nearly half of participants said they would make comprehensive decisions based on the information they obtained from other professionals, and recognized their roles in managing the medical team as a whole. Several also said they encouraged nurses to actively provide decision-making support and additional information to patients during discussions.

Expected Roles of Other Professionals in Decision Support

We extracted the following four categories related to the roles that hematologists expected other professionals to fill: 1) sharing patient information and care routines, 2) sharing information from treatment discussions, 3) providing emotional support for patients and their families, 4) assembling a medical team that understands hematological malignancies (Table 4). More than half of participants said they wanted patients to express their thoughts and intentions. They also expected other professionals to share information about their patients and how they cared for them. In addition, several said they wanted nurses and other professionals to attend discussions with patients, share their thoughts and opinions, participate in discussions, and provide patients and their families with emotional support. One participant also said he worked to assemble medical teams that understood hematological malignancy.

Discussion

In this study, we interviewed hematologists to assess their own roles and the roles they expected other professionals to fill in the context of providing decision-making support to patients with relapsed or

refractory leukemia and malignant lymphoma. In this regard, we found that hematologists were mindful and specific in their responses; for example, they would present treatment options while prioritizing factors such as the patient's goals, emotions, level of readiness, and severity of illness. Before discussing these options, they would also collaborate with other professionals to obtain specific information about the patients and their families, including background details, goals, and intentions. Following this, they would carefully determine which information should be communicated, making special efforts to explain all treatments and medical conditions without using jargon, thus ensuring that patients and their families could easily understand all related issues. Indeed, current guidelines recommend that doctors provide information in consideration of individual concerns and preferences expressed by patients [10], meaning that hematologists should engage accordingly.

Leukemia and malignant lymphoma may be treated with chemotherapy, even in cases of relapse and during the refractory phase. This makes it difficult to determine when to transition from curative treatments to those more focused on QOL [11, 12]. However, previous studies have reported that hematologists are reluctant to discuss EOL issues while primary disease treatments are still possible [6, 13]. In this study, more than half of participants said they would respect and support the patient's wishes and desired treatments. Research has also shown that patients tend to perceive information more positively and optimistically when their doctors emphasize the hopeful aspects [14], which may work as a barrier to more forthright communication. Discussions must therefore support hope while also broaching real future concerns. A previous study on decision-making support reported that palliative care professionals who assessed and supported patients with acute myeloid leukemia (AML) in understanding their conditions and expectations during hospitalization increased the rate of EOL discussions while decreasing the rate of chemotherapy in the weeks before death, which may severely diminish QOL [15]. To appropriately consider the future care goals of patients who have relapsed or are in the refractory phase, their decisions should be supported through discussions involving multidisciplinary collaboration between hematologists, their palliative care teams, and other professionals.

Many hematologists have unique ways of providing patients and their families with prognoses. For example, some may inform families about the possibility of sudden changes in prognoses, including specific numbers, while others do not provide patients with a prognosis at all, or may even withhold the full truth depending on the severity of the medical condition and stage of life. In this study, some participants said they did not directly state bad news, but instead explained issues to patients in order to help them visualize future occurrences. In addition, more than half said they would familiarize patients with treatment options they thought were most beneficial. In this regard, research has shown that patients with hematologic malignancy often prefer simple explanations that do not cause fear [16], and tend to desire passive decision-making roles due to the complexity of their diseases and treatment options [17-19]. As such, we assume that participants made efforts to recognize their patients' intentions and experiences through direct discussion and collaboration. On the other hand, research on decision-making satisfaction and regret among AML patients has shown that more than half prefer passive decision-making roles, but that more passive roles may also be less satisfying [19].

In sum, physicians should assist patients in thinking about their desired treatment and care options, as well as how to spend their time in the future while minimizing the potential for psychological invasion. For example, decision aids (e.g., lists featuring questions and prompts) can help doctors consistently ensure that their patients receive necessary information, understand any current or anticipated changes related to their condition, and know the risks and benefits of treatment [16]. The hematologists interviewed in this study also believed their roles consisted of obtaining information from other professionals regarding the social backgrounds and feelings of patients. In turn, they expected other professionals, including nurses, to actively participate in discussions, communicate the thoughts of patients and their families, and provide emotional support. A previous study similarly showed that oncologists (including hematologists) recognized the importance of having third parties present during treatment discussions, especially those who could help patients make decisions while reflecting and providing emotional support after meetings [20]. Patients must often make decisions while facing significant trade-offs, serious side effects, and risks associated with uncertain treatment options, making it necessary to organize information not only from the medical perspective, but also in terms the patient's priorities and values. This strongly emphasizes the need for multidisciplinary collaboration.

This study also had some limitations, including the use of opportunistic sampling, which makes it difficult to generalize findings. However, the purpose was to clarify the roles of hematologists in providing decision-making support and the roles they expected other professionals to fill. While we collected the opinions of hematologists from diverse hospitals in Japan, future research is needed to clarify the decision-making support roles of other professionals who care for patients with leukemia and malignant lymphoma, including nurses. This should facilitate the development of a shared decision-making support model for patients with hematologic tumors, as coordinated by multiple professionals.

Declarations

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