

Preferred communication with adolescent and young adult patients receiving bad news about cancer

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Abstract

Purpose: Several studies have investigated good communication practices with adult patients receiving bad news about cancer. However, communication preferences differ between adult and adolescent and young adult (AYA) patients. These preferences have not been determined for AYA patients. The primary endpoint of this study was to describe the communication preferred by AYA patients with cancer.

Methods: The study cohort consisted of 15 patients who received a cancer diagnosis at the age of 15–29 years. Semistructured interviews were conducted, and content analysis was performed to analyze the data.

Results: For the preferred communication of AYA patients, 80 attributes were extracted in the following five domains: 1) “Supportive setting,” 2) “Method of disclosure of bad news,” 3) “Information given,” 4) “Emotional support,” and 5) “Support for the patient’s decision-making.” Although more than half of the attributes extracted were identical to the preferred communication of adult patients, some attributes specific to AYA patients were identified that physicians should consider. Preferences specific to AYA patients included mentioning generation-specific social factors, not showing excessive empathy, and communicating in a manner considering their age and cognitive development that supports their decision-making.

Conclusion: Although physicians should be mindful of the specific preferences of AYA patients, the basic attitude and communication preferences are similar to those of patients of other generations.

1 Background

Communication and engagement with adolescent and young adult (AYA) patients with cancer have not garnered extensive attention as they represent fewer patients than children and older adults. However, the particularity of AYA patients and the lack of age-appropriate support have been highlighted more recently.

During normal adolescent development, individuals gain independence from their parents, formulate self-identity, strengthen peer and romantic relationships, and define their future role in life [1]. A fatal illness like cancer during this time has a major impact on their psychological and physical development. For example, cancer makes them compromise independence from parents, interferes with school and social interactions, and potentially causes physical and emotional changes, thereby arresting further development [2, 3]. Regardless of how independent they are of their parents before the diagnosis, many AYA patients need the support of family members [4]. In particular, the role of parents is important in decision-making regarding the treatment plan [5]. In fact, even when patients are mature enough to decide by themselves, parents may still have the right to make decisions [6].

The American Academy of Pediatrics and the World Health Organization recommend that patients join the process of decision-making if they are developmentally and emotionally capable. [7, 8]. In addition, AYA patients have demonstrated sufficient ability to join the discussion on the treatment plan and

expressed the desire to be a part of the discussion [9]. However, a previous survey that explored medical communication between pediatricians and adolescents in Japan showed that pediatricians informed patients of diagnosis and recurrence 95% and 83% of the time, respectively, but only 36% of the time for incurability [10]. In fact, previous studies regarding communication with younger patients pointed out that physicians are not being trained to communicate; therefore, they lack the knowledge and skills needed to communicate with AYA patients [11] and do not have sufficient time to prepare for communication and care for patients after disclosure [12]. Additional challenges include the ambiguous right for decision-making and the preference of the parents for physicians not to communicate with patients [13].

The preferences and values of AYA patients are not inherently the same as their parents or physicians. In fact, to improve patient autonomy and well-being, it is important that the patient's values and preferences are taken into consideration [14]. Many studies have investigated how to ensure good communication with adult patients receiving bad news about cancer. [15–17]. However, communication preferences can differ between adults and AYA patients, and preferences for disclosing bad news about cancer to AYA patients have received little research attention.

The primary endpoint of this study was to identify and describe the preferred communication of AYA patients with cancer.

2 Methods

2.1 Participants

Study participants were 15 patients who met the following inclusion criteria: 1) diagnosed with cancer; 2) received a diagnosis between 15 and 29 years of age; 3) over 20 years old at the time of survey; 4) no recent bad news in the previous 3 months, including news related to diagnosis, recurrence, or treatment failure; and 5) no active anticancer treatment. In addition, we used the following exclusion criteria: 1) difficult to be interviewed because of psychiatric symptoms, 2) difficulty in Japanese communication, and 3) critical cognitive disabilities. As the definition of AYA varied among previous surveys, we defined an AYA patient as an individual between the age of 15 and 29 years undergoing cancer diagnosis according to the United States National Cancer Institute's Surveillance, Epidemiology, and End Results Program and the Children's Oncology Group [18]. This definition was used because medical communication can be sufficiently conveyed to and understood by individuals of around 20 years of age, which is the legal age for decision-making in Japan.

Patients were recruited in two ways. First, we recruited patients at the Department of Breast and Medical Oncology of the National Cancer Center Hospital, Japan. When a patient who met all eligibility criteria was identified, their physician contacted the investigator (S.Y.). The investigator then informed the prospective participant of the purpose of the study, and written consent was obtained from all seven participants recruited in this manner. Second, participants were recruited through an association of AYA patients with cancer named "STAND UP!!" One of the study's collaborators (M.M.), who is a pediatrician

and representative of the association, identified eight prospective participants who met the eligibility criteria. Informed consent from all eight patients was obtained.

2.2 Procedure

We conducted one-on-one interviews with patients between February and August 2016. All interviews were semistructured and face-to-face. A study author with specialization in medical psychology (S.Y.) conducted all interviews in a room where the privacy of participants was ensured. The interviews followed an interview guide developed by the authors for this study, which was based on a previous report [15]. The interview contained the following five predetermined open-ended questions: 1) "How were you told about your cancer diagnosis and treatment from the time you were first diagnosed to now?" 2) "If you received bad news from your physician again, how would you want to be told?" 3) "How would you not want to be told?" 4) "What is the essential skill that a physician must have to communicate well with you?" and 5) "How should your physician take care of you?"

Participants were encouraged to respond freely to the questions. When necessary, the interviewer asked further questions to clarify the reply. Each interview took approximately 40–100 min. As no new content was obtained from the fifteenth interview, we deemed that we had reached saturation.

2.3 Analysis

All interviews were audiotaped and transcribed. Two trained nurses then independently labeled the transcribed data containing the same meaning as an attribute. When judgments differed, they discussed their views until an agreement was reached. Next, three focus groups were established. Two nurses who with specialization in AYA cancer care took part in the first group. A pediatrician, oncologist, and psychologist comprised the second group, whereas two AYA cancer survivors took part in the third group. In each group, attributes were classified into broad domains through discussion. Finally, three psychologists and a psychiatrist who had specialized in AYA cancer care discussed the domains based on the results of the three focus groups. In the final analysis, a conceptual model derived in a previous study [15] was used as a reference, and the analysis was conducted deductively.

3 Results

3.1 Participant backgrounds

All 15 patients participated in interviews between February and August 2016. No one refused to participate. The backgrounds of the participants are listed in Table 1.

3.2 Preferred style of communication

For the preferred style of communication with AYA patients, five domains with 80 attributes were extracted: 1) "Supportive setting," 2) "Method of disclosure of bad news," 3) "Information given," 4) "Emotional support," and 5) "Support for the patient's decision-making" (Table 2).

Of the 80 extracted attributes, 6 of 13 classified into “Supportive setting,” 18 of 26 into “Method of disclosure of bad news,” 14 of 23 into “Information given,” 7 of 14 into “Emotional support,” and 1 of 4 into “Support for the patient’s decision-making” were identical to those of a previous study that examined preferred communication with adult patients [15]. Further, seven new attributes were extracted and classified into “Supportive setting” (e.g., “Not dealing with them as a child,” “Asking them whether they want someone to be with them at the time of bad news”) and eight new attributes into “Method of disclosure of bad news” (e.g., “Using words considering the patient’s developmental stage,” “Not acting high and mighty”). We also found that nine new attributes were extracted and classified into “Information given” (e.g., “Describing the risk of not receiving anticancer treatment,” “Discussing fertility preservation,” “Discussing peer support”) as well as seven new attributes into “Emotional support” (e.g., “Not showing empathy excessively,” “Not forcing exploration of the patient’s feelings”). “Support for the patient’s decision-making” was the new domain, and three of the four attributes were newly extracted (e.g. “Allowing the patient to decide their treatment,” “Providing enough time to decide”).

4 Discussion

To the best of our knowledge, this study is the first to qualitatively investigate the content of preferred communication with AYA patients regarding bad news about cancer. We identified 80 attributes that we classified into five domains: “Supportive setting,” “Method of disclosure of bad news,” “Information given,” “Emotional support,” and “Support for the patient’s decision-making.”

The most important discovery in this study was the identification of attributes that were not previously identified as the preferred communication with adult patients with cancer. Some of the new attributes classified into “Supportive setting” and “Method of disclosure of bad news” were related to patient age, such as “Not dealing with them as a child,” “Not making them feel there is a distance or wall between the physician and the patient,” and “Using words considering the patient’s developmental stage.” It was interesting that there was no obvious difference in the trends between adolescent (A) and young adult (YA) participants; there were adolescent patients who preferred “Not dealing with them as a child” and patients over 25 years of age who preferred “Not making them feel there is a distance or wall between the physician and the patient” and vice versa. Young adults often see themselves as “in-between,” moving toward independence but still closely tied to their parents [19]. As the extent of independence varies widely among persons approximately 20 years old, decisions on how to behave and interact with patients should not be exclusively based on their age; instead, there is a need to individually assess each patient’s preference.

We also extracted new age-specific attributes classified into “Information given,” including “Discussing fertility preservation,” “Discussing the late effect of treatment,” and “Discussing factors related to school.” There are many physical and social impacts related to treatment on a patient’s life that are specific to AYA patients. [20, 21]. It is important to explain these influences in addition to the treatment itself. Further, it is notable that the new attribute “Describing the risk of not receiving anticancer treatment” was extracted. One participant remarked that “Physicians must emphasize the risk of not receiving anticancer

treatment. If not, I may have refused the difficult treatment." This attribute is important because adult patients' cognitive development is innate when it comes to assessing short-term pros versus serious future cons. However, an adolescent's ability to judge long-term harm, as opposed to short-term harm, may not be fully developed [22]. Physicians should understand this cognitive trend of AYA patients, especially adolescents, and explain not only treatment necessity and risk but also the long-term risks or consequences of not receiving the treatment.

Moreover, among attributes of the "Emotional support" domain, the new attributes "Not showing empathy excessively" and "Not forcing exploration of the patient's feelings" were noteworthy and differ from those found in previous studies. For adult patients with cancer, the importance of empathy and compassion has been emphasized. [23, 24]. In contrast, many participants in our cohort remarked "I don't expect physicians to show compassion to me because they cannot understand my distress. The physicians should concentrate on explaining the disease and treatment. Instead, I'd like to share my distress with other AYA patients." In previous studies, similar [25] or higher [26] rates of depression were reported in AYA patients than in older adults. It was also reported that more than 40% of AYA patients have high distress at the time of diagnosis [27], indicating that the psychological distress of AYA patients does not decrease after the disclosure of bad news. Nevertheless, this study showed a preference among AYA patients not to seek excessive empathy from physicians. AYAs tend to compare themselves and others to seek their identity, and importantly, to find their identity, they use social comparisons more than other generations [28]. Previous studies have reported that upward comparisons (i.e., comparison with a superior person) trigger the deterioration of self-esteem and mental health. [29, 30]. Similarly, social comparisons with healthy people including physicians can bring negative emotions to AYA patients, with such emotions possibly resulting in the refusal or rejection of a physician's empathy. The experience of AYA patients is highly specific. Therefore, physicians should be careful when they show an empathic reaction and explore the patient's emotions. However, this context does not mean an avoidance of these actions or a recommendation not to show empathy to AYA patients.

In addition, "Support for the patient's decision-making" was extracted as a new domain for AYA patients. Importantly, this result shows that decision-making is a high-interest topic for AYA patients with cancer; furthermore, physicians must consider the decisions that will be made based on the content of bad news about cancer when they communicate it. In the present study, we also found that there were different opinions about the presence of family members at the time of disclosure of bad news. In a study that clarified the preference of Japanese adult patients for bad news [15], they found that many wanted their family members to be present when given bad news. In contrast, our findings indicated that younger patients do not necessarily desire family-centered decision-making, which is considered an inherent characteristic of decision-making in Japan. Decision-making of AYA patients, especially adolescents, remains controversial in Japan because of legal limitations and family relations to authority in Japan [10]. However, according to the results of this study, Japanese physicians should be more proactive in considering AYA patient-centered decision-making when giving bad news. Furthermore, among the participants in this survey, both "Making the patient decide the treatment by his/herself" and "Showing the physician's recommendation" were extracted. These attributes demonstrate the importance of asking

the patient regarding their preferred decision-making style. In addition, many patients expressed the preference that physicians should be sensitive to the feelings of family members during and after giving bad news. This finding is similar to the national characteristic of Japanese patients reported previously [15] and further shows the importance of family care in Japan being important not only for older adults but also AYA patients. In this study, most patients mentioned concern for their parents, but for married patients, partners and children may also be included. This point needs clarification in future research.

Finally, it is important to highlight that more than half of the attributes extracted in this study were identical to those in a previous study on the preferred style of communication with adult patients [16]. Although some results specific to AYA patients were identified that should be considered by physicians, the basic attitude and communication are common among different generations. This result means that physicians do not have to be excessively anxious with AYA patients, but they should be mindful.

4.1 Study limitations

This study has a few limitations. First, the number of participants was modest and half of them were recruited using convenience sampling. The study was conducted to extract the preferred style of communication of AYA patients considering various factors such as the hospital they were treated at and their age. These different backgrounds contributed to the variety of the categories extracted. However, the sample size and recruiting method may have introduced bias as the literature on adult oncology has shown that the value of medical communication differs widely among individuals [16]. To clarify the preferences of most AYA patients, further quantitative research with larger sample sizes based not only on the result of this survey but also on previous studies among adult settings is necessary. Second, most of the participants in our cohort had sarcoma, so they did not reflect all types of cancer, and some patients had partners or children. Family status affects a patient's communication preferences. Therefore, a survey assessing patients' wider background and examining how their background affects their communication preferences is warranted. Third, this study was based on a qualitative analysis of information obtained from in-depth interviews. Although careful attention was given to the trustworthiness and integrity of those involved, there can be errors in coding and analysis. To ensure reliability and objectivity, we implemented a three-step analysis and incorporated multiple viewpoints, including those of survivors. However, we cannot eliminate the possibility that the analysis was arbitrary. To address this limitation, a quantitative study should be conducted and multivariate analysis performed to statistically assess the appropriateness of the domains.

4.2 Clinical implications

The results of this study suggest that physicians should keep the following in mind when communicating any bad news to AYA patients: 1) understand the preferences of each patient regardless of their age, 2) discuss the physical and social effects unique to the AYA generation, 3) explain the long-term risks involved in treatment choices so that they are fully aware, 4) avoid excessive empathy, and 5) support decision-making based on bad news.

5 Conclusions

Preferences specific to giving AYA patients bad news related to cancer included communicating in a way that considers their age and cognitive development, mentioning generation-specific social factors, not showing excessive empathy, and communicating in a way that supports their decision-making. Although physicians should take these points into account, the basic attitude and communication are common across generations.

Statements And Declarations

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Ethics Approval

This research conforms to the Declaration of Helsinki. Ethics approval was obtained from the Institutional Review Board of the National Cancer Center (number 2015-264). This research conforms to the Declaration of Helsinki.

Consent to participate

Informed consent was obtained from all participants prior to their participation in the study.

Consent to publish

Informed consent was obtained from all participants for publishing their data.

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Competing interests

The authors have no competing interests to declare that are relevant to the content of this article.

Author contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Saran Yoshida, Ken Shimizu and Motohiro Matsui, under the supervision of Maiko Fujimori and Yosuke Uchitomi. The funding was provided by Keizo Horibe and Saran Yoshida. The first draft of the manuscript was written by Saran Yoshida and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Data Availability Statement

Data supporting the results of this study are available from the corresponding author upon reasonable request. However, the data are in Japanese language only.

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Tables

Tables 1 to 2 are available in the Supplementary Files section

Supplementary Files

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