Communication Preferences in Young, Middle-Aged, and Elderly Cancer Patients

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\section*{Introduction}
Approximately 15,000 adolescents and young adults between 15 and 39 years of age are diagnosed with cancer each year in Germany [1]. The group of young adults in the age range of 18–39 years is characterized by specific physical and psychological challenges as well as personal developmental steps like education, starting a career, and family planning [2, 3].

Communication is an essential component of cancer care. Tailoring communication to the patient’s specific needs and preferences, particularly in delivering bad news, is crucial [4]. Buckman [5] defined bad news as ‘any information which adversely and seriously affects an individual’s view of his or her future’. There is a gap between the communication and information needs of young adult cancer patients and actual physician behavior, especially with regard to information on treatment side effects affecting sexual functioning and fertility [6, 7]. There are also discrepancies between patients’ needs and experiences during follow-up care of young adults [8]. It is important that doctors and other healthcare professionals deliver cancer and treatment-related information that is age-appropriate and considers the personal development status of the individual [9, 10].

Little research has focused on how much the communicative needs of young adults are in concordance with perceived physician behavior when delivering bad news. Existing studies show that patients’ needs were fulfilled only to a limited extent [11, 12], particularly with regard to long-term effects such as fertility risks, reproductive options, or parenthood [13, 14]. The way in which bad news are delivered can have an impact on psychological adjustment and patient satisfaction with healthcare services [15, 16]. Also, ineffective or inappropriate communication can cause long-lasting distress and might even influence treatment outcomes [17, 18].
Since limited data is available about young adult cancer patients’ communication preferences for delivering bad news to provide guidance for doctors initiating such conversations, we aimed to answer the following research questions:

What is the worst news received by patients?

Which communication preferences are most important to the patients?

Are there differences concerning communication preferences between younger and older cancer patients?

Does the proportion of unconsidered communication preferences and age have an impact on psychological distress?

### Patients and Methods

#### Patients and Procedures

We recruited adult cancer patients from 2 oncology wards of the University Cancer Center Hamburg over a period of 16 months. Patients were approached by a trained research assistant and fully informed about the study. Patients with insufficient German language skills and those with severe physical and/or mental symptom burden were excluded from our study. All participants provided written informed consent before study entry. Study approval was obtained from the ethics committee of the Medical Association of Hamburg.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Young cancer patients (n = 34), Mean age at survey, years (SD)</th>
<th>Middle-aged cancer patients (n = 148), Mean age at survey, years (SD)</th>
<th>Elderly cancer patients (n = 88), Mean age at survey, years (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic characteristics</td>
<td>30.8 (6.0) 18–39</td>
<td>54.4 (7.1) 40–65</td>
<td>71.0 (4.4) 66–88</td>
</tr>
<tr>
<td>Sex</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Female</td>
<td>11 (32.4)</td>
<td>82 (55.4)</td>
<td>33 (37.5)</td>
</tr>
<tr>
<td>Male</td>
<td>23 (67.6)</td>
<td>66 (44.6)</td>
<td>55 (62.5)</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>24 (70.6)</td>
<td>108 (73.0)</td>
<td>69 (78.4)</td>
</tr>
<tr>
<td>Children</td>
<td>Yes</td>
<td>11 (32.4)</td>
<td>108 (73.0)</td>
</tr>
<tr>
<td>Education</td>
<td>High school, university degree</td>
<td>22 (64.7)</td>
<td>38 (25.7)</td>
</tr>
<tr>
<td>Medical characteristics</td>
<td>12 (35.3)</td>
<td>46 (31.1)</td>
<td>18 (20.5)</td>
</tr>
<tr>
<td>Tumor site</td>
<td>8 (23.5)</td>
<td>7 (4.7)</td>
<td>3 (3.4)</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>5 (14.7)</td>
<td>13 (8.8)</td>
<td>27 (30.7)</td>
</tr>
<tr>
<td>Gastrointestinal cancer</td>
<td>1 (2.9)</td>
<td>7 (4.7)</td>
<td>9 (10.2)</td>
</tr>
<tr>
<td>Gynecological cancer</td>
<td>1 (2.9)</td>
<td>20 (13.5)</td>
<td>9 (10.2)</td>
</tr>
<tr>
<td>Head and neck cancer</td>
<td>–</td>
<td>3 (2.0)</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>–</td>
<td>7 (4.7)</td>
<td>2 (2.3)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (20.6)</td>
<td>11 (7.4)</td>
<td>2 (2.3)</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>&gt; 2 years</td>
<td>4 (11.8)</td>
<td>22 (14.9)</td>
</tr>
<tr>
<td>UICC staging</td>
<td>0–II</td>
<td>19 (55.9)</td>
<td>53 (35.8)</td>
</tr>
<tr>
<td>III–IV</td>
<td>15 (44.1)</td>
<td>95 (64.2)</td>
<td>45 (51.1)</td>
</tr>
</tbody>
</table>

SD = Standard deviation; UICC = Union for International Cancer Control.
Table 2. Highest and lowest ratings of patients’ communication preferences on item level (MPP-D)

<table>
<thead>
<tr>
<th>Item</th>
<th>Preference</th>
<th>Young cancer patients (n = 34) M (SD)</th>
<th>Middle-aged cancer patients (n = 148) M (SD)</th>
<th>Elderly cancer patients (n = 88) M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 most preferred physicians’ behaviors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Doctor telling me the best treatment option</td>
<td>4.71 (0.52)</td>
<td>4.34 (0.84)</td>
<td>4.36 (0.65)</td>
</tr>
<tr>
<td>5</td>
<td>Doctor giving me full attention</td>
<td>4.59 (0.61)</td>
<td>4.18 (0.88)</td>
<td>3.92 (0.87)</td>
</tr>
<tr>
<td>26</td>
<td>Doctor taking time to answer my questions comprehensively</td>
<td>4.56 (0.82)</td>
<td>4.17 (1.05)</td>
<td>4.03 (0.84)</td>
</tr>
<tr>
<td>25</td>
<td>Doctor being told in person</td>
<td>4.35 (0.81)</td>
<td>4.37 (0.99)</td>
<td>4.47 (0.80)</td>
</tr>
<tr>
<td>23</td>
<td>Doctor being up to date on research on my type of cancer</td>
<td>4.29 (0.97)</td>
<td>4.20 (1.01)</td>
<td>4.05 (0.88)</td>
</tr>
<tr>
<td>17</td>
<td>Doctor letting me know all of the different treatment options</td>
<td>4.09 (0.93)</td>
<td>4.11 (0.96)</td>
<td>4.07 (0.88)</td>
</tr>
<tr>
<td>3 less preferred physicians’ behaviors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Doctor holding my hand/touching my arm when giving news</td>
<td>1.74 (0.93)</td>
<td>2.00 (0.95)</td>
<td>1.93 (0.80)</td>
</tr>
<tr>
<td>45</td>
<td>Doctor helping me figure out how to tell others about my cancer</td>
<td>2.29 (0.91)</td>
<td>2.36 (1.08)</td>
<td>2.40 (1.07)</td>
</tr>
<tr>
<td>42</td>
<td>Having another healthcare professional present to offer support</td>
<td>2.38 (1.10)</td>
<td>2.59 (1.18)</td>
<td>2.34 (0.91)</td>
</tr>
</tbody>
</table>

*p < 0.05.
**p < 0.01.
***p < 0.001 (Kruskall Wallis test).
SD = Standard deviation.

We also included questions about contextual factors when the information was delivered (e.g. ‘Which news were the worst to you?’ or ‘Who was present when receiving bad news?’).

Psychological Distress

We used the German version of the National Comprehensive Cancer Network Distress Thermometer [21] to measure psychological distress. This measure contains a single-item visual analogue scale ranging from 0 (no distress) to 10 (extreme distress) to quantify the global level of distress. A score of 5 or higher indicates that a patient is distressed and needs support.

Data Analysis

Statistical analyses were performed using SPSS 20.0 (IBM Corp., Armonk, NY, USA). The age groups were compared using χ² tests for categorical variables and Kruskal-Wallis test or t-test (Bonferroni-adjusted) for continuous variables, dependent on normal distribution within groups. The results are presented using descriptive statistics.

An index was developed for each subscale of the MPP to quantify the number of mismatches. This index is the ratio of desired and fulfilled communication preferences and ranges from 0 to 100. A low index indicates a high number of unconsidered desired communication preferences. Missing values of the items were coded as ‘not important’ or ‘not considered’. When patients rated all items of a scale as ‘not important’, it resulted in a correspondingly high index. Binary logistic regression was used to assess the impact of unconsidered communication preferences at scale level and age on psychological distress. A backward stepwise regression was chosen due to our explorative approach. The dependent variable was distress (1 = cut-off > 5; 0 = cut-off ≤ 5); missing values of this variable were replaced by sample mean score. All characteristics listed in table 1 and the index of unconsidered communication preferences of all MPP scales were used as independent variables. Multicollinearity was avoided by removing redundant independent variables (t > 0.8). For all analyses, a significance level of p ≤ 0.05 was applied.

Results

We approached 663 patients of which 270 patients aged between 18 and 88 years participated in the study (response rate 40.7%).

Univariate analysis revealed no significant age or gender differences between responders and non-responders. Non-responders more often suffer from urological and gastrointestinal tumors than participants (χ² (0.001; 14, n = 504) = 44.87). In our sample, n = 34 belonged to the group of young adults (18–39 years), n = 148 were middle-aged (40–65 years), and n = 88 were older patients (66–88 years). These age groups were compared in the following analyses with a focus on the young adult cancer patients. Table 1 contains socio-demographic and medical characteristics.

Content of Delivering Bad News

A total of 17 (50%) of the 34 young cancer patients received bad news once during their cancer trajectory. 13 (38.1%) patients received bad news 3 or more times. There were no significant differences between young and older patients (p = 0.18). 30 (88.2%) young adult patients perceived the disclosure of the cancer diagnosis most frequently as bad news.

When asked which news they experienced as the worst, 21 (61.8%) young cancer patients reported receiving the diagnosis, and 4 (11.8%) mentioned the effects of the illness on the family. There were no significant differences between the age groups.

Furthermore, the setting or the place where the subjectively worst news was communicated was queried. 18 (52.9%) of the young adults were alone when receiving the worst news. A little over half received the news directly in the hospital. 3 (8.8%) patients received the bad news by telephone. Overall, 18 (52.9%) of the young patients were ‘satisfied’ to ‘very satisfied’ with the behavior of the doctor while delivering the bad news. A difference concerning the overall satisfaction between the 3 age groups could not be ascertained (p = 0.18).

Communication Preferences

Table 2 shows the 3 communication preferences which were rated as most important in the different age groups. The 3 most
important items as rated by the younger cancer patients are to be assigned to the scale ‘Professional Expertise/Patient Orientation’. A comparison between the age groups showed significant differences in these 3 most important communication preferences.

The 3 communication preferences which were less important could be found in all age groups equally. Assessing communication preferences on scale level, a significant difference exists between the young and oldest patients in the scale ‘Professional Expertise/Patient Orientation’ (p < 0.01). Younger patients prefer more items of this scale. There were no differences compared to the middle-aged patients.

Unconsidered Communication Preferences and Psychological Distress

Another question was whether the proportion of unconsidered patient-sided communication preferences had an impact on psychological distress. The 3 communication preferences which were least taken into account were that the doctor had i) not given a written summary of the information (55.9%), ii) had not provided information about new experimental therapies (44.1%), and iii) had not informed the patient about available support services (44.1%). Significant differences between these 3 communication preferences with regard to age group could not be identified (p > 0.1). Also, the calculated index of mismatches showed no significant differences between the age groups (p = 0.91).

To assess the impact of age and number of mismatches on psychological distress, we conducted a logistic regression analysis. In these analyses, even after controlling for other psychological distress-related symptoms, the variables shown in the final regression model (table 3) were statistically significant and independent predictors of more severe distress symptoms.

Patients with children had a lower risk of developing psychological distress. The risk of distress increased also in patients with advanced stages of cancer.

As most relevant MPP-D subscale indices, the model showed ‘Privacy/Confidentiality’ and ‘Clarity/Directness’ as significant effects. When items of these subscales were not taken into consideration in a medical consultation, patients showed higher psychological distress.

### Discussion

This study investigated the content of bad news and patient-sided communication preferences when receiving bad news, especially in patients aged between 18 and 39 years.

The diagnosis of a cancer disease provided the worst news for patients of any age. Young adult cancer patients reported the familial and social consequences as second worst news. This was in line with our expectations, as younger cancer patients are in the prime of life and active on many levels. A cancer disease interrupts the normal life of a young adult with potentially far-reaching consequences for age-associated developmental steps such as career or raising children [22].

In the majority of cases, bad news was delivered by the doctor in private at the hospital regardless of the age of the patient. Contrary to previous studies indicating higher satisfaction with communication in older patients, the present study showed no age differences [23, 24]. The identified communication preferences of young adult cancer patients were comparable to previous findings [20]. Above all, patients wanted professional expertise and patient orientation. All age groups were in agreement regarding the 3 communication preferences they valued the least: Direct physical contact, another healthcare professional, and help of the doctor with informing relatives were unimportant when receiving bad news. These results are quite similar to a study by Brown et al. [25], where patients rated ‘Doctor holding my hand’ as the lowest item in the ranking. Another question was the impact of unconsidered communication preferences on psychological distress. The desire of young adults to receive a written summary, information on experimental therapies, and information on support services was less frequently met. The unmet needs for information and support have been well-established in several studies with young adult cancer patients [7, 26]. Especially the need for age-appropriate internet resources is often unmet. Zebrack [26] emphasized the high demand for information regarding diet and nutrition, exercise, infertility, and complementary and alternative health services. Also, 35–80% of young cancer patients have unmet needs for psychological counseling, peer support, and religious counselling. As might be expected, the risk of psychological distress is higher in patients with advanced disease.
stages. Having a child is the most important effect in our regression model and could be a protecting factor for distress. Previous studies focused on psychosocial distress of cancer patients who have children, but results are inconsistent [27, 28]. The 2 dimensions ‘Privacy/Confidentiality’ and ‘Clarity/Directness’ have a small but significant impact on psychological distress. The regard for privacy could lead to lower psychological distress whereas clarity of the conversation could result in higher psychological distress. This link should be clarified in further studies.

The generalizability of our findings is limited due to the relatively small sample of young adults. Also, subgroup analyses within this age group were not possible. In addition, communication preferences were not assessed at baseline, disabling us from detecting potential changes in communication preferences caused by the cancer disease. Due to the long period of time since having received the worst news, the patients’ statements could be biased.

Conclusion

In general, there were only a few differences with small effects between the age groups. However, due to the small sample size of young patients, a final conclusion should not be drawn regarding age differences and communication preferences. The disclosure of a cancer diagnosis and other bad news has to be seen as an individualized and dynamic process. On average, patients in our study were satisfied with the patient-physician communication when receiving bad news. However, the quality of communication could benefit from communication skills training programs which are aimed at assessing individual communication needs [29, 30]. This is especially necessary in the field of pediatric oncology, because communication training of trainees enrolled in an accredited pediatric hematology/oncology fellowship program is currently lacking [31]. Successful communication between doctor and patient also improves factors such as medication adherence or medical decision making [32, 33]. Specifically in the field of young adult cancer patients, it is important to examine the impact of unconsidered communication preferences on willingness to participate in clinical trials which tends to be lower in this age group [34]. Finally, future studies should observe the impact of failed patient-physician communication according to patient-sided preferences on long-term survivors, which is particularly relevant for young adult cancer patients. The majority of studies concerning communication have focused on the patient-physician dyad. It would be useful to also investigate more closely the communication process between cancer patients and other healthcare professionals (nurses, social workers, psychologists).

Disclosure Statement

The authors of the study report no financial interests or potential conflicts of interest.

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References


