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Experiences and needs of patients with incurable cancer regarding advance care planning: Results from a national cross-sectional survey

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Abstract

Introduction Patients faced with incurable cancer may experience a lack of support from their physician throughout and after treatment. Studies on the needs and experiences of these patients are scarce. In this study, we explored the needs and experiences of patients diagnosed with incurable cancer regarding the conversation, in which they were told that their cancer was incurable, the care received after this conversation, and their preferences regarding end of life conversations.

Methods Data were cross-sectionally collected through a national online survey in the Netherlands (September 2018). Descriptive statistics and correlation coefficients were reported and subgroups were compared.

Results 654 patients (mean age 60 years; 58% women) completed the survey. Patients were primarily diagnosed with breast cancer (22%) or a hematological malignancy (21%). Patients reported a strong need for emotional support during the conversation, in which they were told their cancer was incurable (mean score 8.3; scale 1-10). Their experienced satisfaction with received emotional support was mediocre (mean score 6.4; scale 1-10). Of those patients who felt like they did not receive any additional care (37%) after the diagnosis, the majority expressed a clear need for this kind of care (59%). Mostly, support pertained to psychosocial issues. Regarding conversations about the end of life, most patients (62%) expressed a need to discuss this topic, and preferred their healthcare provider to initiate this conversation.

Conclusion Care for patients with incurable cancer can be further improved by tailoring conversations to specific needs and timely providing appropriate supportive care services.

Introduction

Globally, there were an estimated 18.1 million new cancer cases in 2018 and the number of patients diagnosed with cancer is still on the rise [1]. An increasing number of patients survive their cancer diagnosis primarily because of improved uptake of screening and advancements in treatment modalities. Still, a total of 9.6 million people worldwide die each year because of cancer. Worldwide, cancer is therefore expected to become the leading cause of death in every country in the 21st century [1].

The majority of patients receive some form of palliative care during the last phase of their life to improve or maintain quality of life (QoL) of patients and their caregivers [2]. Previous research, primarily consisting of large randomized clinical trials, has shown that the provision of early and comprehensive palliative care services may lead to improved patients outcomes and care concordant with patients' personal preferences [3,4]. However, the quality of such care as well as implementation in current clinical practice varies widely across settings. In line with this, several studies also reported that patients with cancer experience improvements in QoL, reductions in experienced anxiety and depression, care concordant with patients' personal preferences, and possibly even longer survival [5–9].

In recent years, however, several studies also reported that patients with cancer in the palliative phase of their care trajectory report feelings of abandonment or experience a lack of support from their treating physician [10,11]. Care needs in palliative care, but also during end of life (EOL), should be discussed extensively, routinely, and early throughout the disease course [3,12]. This process is defined as Advance Care Planning (ACP) and has become increasingly important because it improves the consistency of care with patients' goals and can improve patient satisfaction and quality of life [13,14]. Yet, physicians may not always engage in such care in a timely manner due to time constraints, a fear that transitioning to palliative care may “take away hope”, or a lack of clarity as to who should provide such care i.e., the

general practitioner (GP) or the treating oncologist [15–19]. Moreover, previous research reported that the quality of conversations regarding ACP can be improved [20,21], but also that patients' individual needs may not always be met [17,22]. Studies on the preferences and experiences of patients with incurable cancer regarding these conversations are scarce. We therefore aimed to explore the needs and experiences of patients diagnosed with incurable cancer regarding the conversation in which they were told that their cancer was incurable, the care received after this conversation, and their preferences regarding EOL conversations.

Methods

Study design and participants

We performed a cross-sectional survey among patients diagnosed with incurable cancer. Data were collected through a national online survey in the Netherlands that was conducted during the first two weeks of September 2018.

Survey development and content

The online survey was developed by the Dutch Federation of Cancer Patient Organizations (NFK). The project group responsible for the development of the survey consisted of a project leader, a researcher, and nine patient advocates of member organizations (i.e., patients in the palliative phase of their disease, and patient advocates otherwise experienced in the field of palliative care). This project group discussed the content of the survey. Additionally, three experts in the field of palliative care in the Netherlands were consulted to check and finalize the content of the survey. The final survey consisted of 32 questions: 28 quantitative and four open questions (Appendix I). Throughout this manuscript, responses to the qualitative questions were used to illustrate experiences and needs of patients. These responses were not qualitatively analyzed. Several questions were conditional, meaning that certain questions were automatically skipped depending on the response of the participant.

The survey started with a selection question. Respondents had to confirm that “they have cancer and (probably) will not be cured”. Only participants who selected “yes” were included in the current study. Hereafter, participants were asked to complete nine questions regarding sociodemographic characteristics. The remaining 22 questions were subdivided in three main themes: 1) Experiences regarding the conversation, in which patients were told that their cancer was incurable (N=7). In this theme, some questions were asked about emotional support, i.e., the ability of the healthcare provider to show empathy, compassion, and genuine concern for

the patient; 2) Experiences regarding the prevalence and type of care received after this conversation (N=7). This was defined as every form of care provided by the hospital after patients learned that their cancer was incurable; and 3) Experiences and needs regarding EOL conversations (N=8).

Five of these 22 questions, all related to the rating of satisfaction or importance, were scored on a 10-point scale ranging from 1 (not satisfied/important) to 10 (very satisfied/important). All other questions consisted of multiple answer options. No privacy-sensitive data were collected in the survey and all data were analyzed anonymously. Only patients who completed the entire survey were included in the current analyses.

Data collection

Data were collected through the online survey tool “Survey Monkey” [23]. A total of three different distribution channels were used. First, the NFK requested 18 of its cancer patients organizations to invite their members or donors to complete the survey. This was either done through a direct e-mail, an announcement in the organizations’ newsletter, or by a message on the website. Second, the “Doneer Je Ervaring” (Donate Your Experience) panel received an invitation to complete the survey. This panel, consisting of patients with cancer, regularly completes questionnaires about their patient experiences. Last, NFK and a number of relevant partner organizations in the Netherlands, such as the Dutch Cancer Society (KWF Kankerbestrijding) and the Netherlands Federation of Patients (Patiëntenfederatie Nederland), were asked to spread the open link to the survey through social media and email.

Statistical analyses

As this study was designed as an explorative survey, no minimum sample size was calculated. However, to be able to estimate proportions with a confidence of 95% and a

precision of 5%, a minimum sample size of 385 participants was required. For nominal variables, percentages per answer are given. For continuous variables, depending on the distribution, either mean and standard deviation or median and range were calculated. We calculated the correlation between 'satisfaction regarding the duration of the conversation' and 'experienced emotional support during the conversation' using the Pearson correlation coefficient. We defined subgroups based on gender (men vs. women) and on age (≤ 60 years of age vs. > 60 years of age). Subgroups were compared by an independent sample t-test or a Mann-Whitney U test based on the distribution. For all analyses, a p-value ≤ 0.05 was considered statistically significant. All analyses were performed using IBM SPSS Statistics version 25 [24].

Results

Characteristics of study population

In total, 1,104 participants started the online survey. Of these patients, 221 did not meet the inclusion criteria (i.e., they did not identify themselves as having incurable cancer) and 229 patients did not complete the full survey. For this study, we included 654 patients. Descriptive characteristics are provided in Table 1. The mean age was 60 years (SD 11.03 years) and 58% (N=378) identified as female. Most patients were diagnosed with breast cancer (N= 144, 22%), directly followed by hematological malignancies (N=135, 21%) and prostate cancer (N=124, 19%). Most patients were treated in a teaching hospital (N=283, 43%) and the median time since the conversation during which they were told that their cancer was incurable was 2 years (interquartile range 1-4). Several responses from the qualitative questions were selected to further illustrate our findings and are provided in Figure 1.

Experiences during the conversation in which patients were told their cancer was incurable

The majority of patients (N=524, 86%) had the conversation, during which they were told their cancer could not be cured anymore, with their treating physician in the hospital. The remaining patients had this conversation with another physician (N=71, 11%), a nurse (N=10, 2%), or with their general practitioner (N=8, 1%). The mean score for patients' satisfaction with emotional support, as provided by the health care providers during this conversation, was 6.5 (SD 2.64). We did not observe differences for gender or age. The importance of the support offered by the health care provider was rated as 8.4 (SD 1.79). Women rated the importance significantly higher than men (8.6 vs 8.1; $p=0.001$), as did patients ≤ 60 years compared to patients >60 years of age (8.6 vs 8.2; $p=0.028$). Patients rated their satisfaction with the duration of the conversation as 7.3 (SD 2.46), with no differences for gender and age. We observed a

strong correlation between the satisfaction regarding this duration and experienced emotional support ($r= 0.832$, $p<0.001$).

Experiences regarding the prevalence and type of care received after this conversation

The majority of included patients ($N=415$; 64%) were offered any type of care by the hospital after they were told that their cancer could not be cured, 28% ($N=180$) did not receive any additional supportive care and 8% ($N=59$) of the participants answered that this was unknown or not applicable. The importance of this form of support was rated as 8.7 by all respondents (SD 1.59), with women rating this aspect higher than men (8.9 vs 8.5, $p=0.005$). We observed no significant differences between older and younger patients.

Patients who received care ($N=415$) rated their satisfaction with this support as 7.5 (SD 2.07). The most common forms of offered care was treatment aimed at extending life by preventing tumor growth ($N=325$, 81%), continuous access to one key contact person (i.e., a case manager) within the hospital ($N=227$, 57%), information or advice regarding physical symptoms ($N=182$, 46%), and provided treatment aimed at alleviating physical symptoms ($N=161$, 40%). All offered forms of provided care services are detailed in Table 2.

Of the patients who stated that they did not receive any type of care or could not remember ($N=239$, 37%), the majority expressed a clear need for support ($N=141$; 57% of these patients). We did not observe any differences between men and women ($p=0.61$). Younger patients stated that they were more in need of care compared to older patients (≤ 60 : 77% vs > 60 : 63%, $p=0.03$). Most of the patients that did not receive any type of care reported a need to one key contact person ($N=73$, 55%), need for support for their family and loved ones ($N=57$, 43%), or information or advice regarding psychological symptoms ($N=57$, 43%; Table 3).

Experiences and preferences regarding conversations on EOL

Most patients (N=405; 62%) expressed a need to talk about EOL, 21% (N=139) reported no need for a conversation about EOL, and the remaining 17% (N=110) of patients stated that they were undecided. Women expressed a greater need to talk about the EOL than men (80% vs 67%, $p=0.001$). Of the patients that expressed an interest in discussing these topics (N=405), the majority would prefer to talk about this with their partner (N=317, 80%), their GP (N=302, 76%), their children (N=258, 65%) and their treating physician in the hospital (N=249, 63%).

Patients who wanted to talk about these topics differed in their opinion about the ideal moment for such a conversation: 58% (N=226) preferred to do so after their health declines, 44% (N=174) “when it feels right”, 39% (N=155) shortly after the diagnosis, and 23% (N=92) preferred to have this conversation when death is near. With regards to the content of such conversations, these patients reported a need to discuss medical issues, such as euthanasia or palliative sedation (N=298, 77%), treatment of pain or other refractory symptoms (N=262, 68%), and medical care in the last phase of life (N=240, 62%). Other pertinent issues related to worries regarding family and loved ones (N=221, 57%), saying goodbye to their loved ones (N=216, 56%), or their funeral (N=195, 51%).

In 22% (N=122) of the patients, a health care provider initiated the conversation regarding the EOL. In most cases, this was done by the GP (N=82, 73%), but also by the treating physician in the hospital (N=30, 27%), a case manager in the hospital (N=9, 8%), or by a psychologist (N=9, 8%). Overall, patients rated the importance of this health care provider initiative 7.1 (SD: 2.47). Women (7.4 vs. 6.7; $p=0.001$) and younger patients (7.4 vs. 6.8; $p=0.001$) appeared to value this initiative more.

Discussion

Main findings

The results from this national survey conducted among 654 patients diagnosed with incurable cancer showed that these patients are in strong need of emotional support during the conversation in which they are told that their cancer is incurable. However, their satisfaction with perceived emotional support was mediocre. Patients also emphasized the importance of care from the hospital after this conversation, and patients that did not receive such care specifically described a high need for support related to psychosocial issues. The majority of patients also expressed a strong desire to have conversations regarding needs near the EOL and preferred such conversations to be initiated by their healthcare provider. In addition, the best moment to initiate such conversations may differ strongly between patients.

Interpretation of our findings

Based on these findings, we conclude that there are significant opportunities to further improve the healthcare for patients with incurable cancer. First, patient satisfaction regarding the level and quality of provided emotional support during the conversation in which they were told that their cancer was incurable was relatively low. However, patients did rate adequate provision of emotional support as highly important. This is in line with former guidelines and previous research, that emphasize the importance of adequate and timely emotional support for patients with advanced cancer [3,17,25–27]. For bad news conversations, there is limited quality evidence that a setting with privacy, non-technical words, empathy and room for emotions might improve patient satisfaction[28]. We also observed a strong correlation between the duration of the conversation and the satisfaction regarding provided emotional support. To our knowledge, this correlation has not been identified previously and further promotes an enhanced awareness and understanding among care providers to take their time when having

these conversations. Although we realize this might cause an extra burden on time constraints of individual healthcare providers and personnel and financial problems for the healthcare system, we also think it is very important to optimize the care for patients in such a vulnerable moment. Further, interventions targeted at educating or supporting physicians to better provide or express emotional support during such important conversations are needed.

Our data also provides evidence that patients were introduced to a variety of different supportive care experiences after they had heard that their cancer was incurable. The majority of this care pertained to physical aspects. However, of those patients who did not receive any type of additional care (28%), the majority expressed a clear need for psychosocial support. This finding is in line with the study by Johnson et al. (2016) which concluded that patients primarily value emotional, relational and social support as important factors of ACP [17]. We therefore recommend to be aware of this need and offer care accordingly.

The majority of patients included in this study indicated a clear need to discuss issues near the EOL. Surprisingly, however, 21% of patients reported that they would prefer not to talk about such issues at any time point. Possible explanations for this may relate to an avoidant coping strategy or not seeing the possible benefit of discussing EOL (e.g. because of low health literacy). Since discussing EOL is a key component of ACP [13], this is an interesting finding that likely requires future research. This is further exemplified through recent studies concluding that the majority of healthcare providers believe all patients with an incurable disease should be actively involved in discussion regarding their EOL care [13,17]. Patients also expressed a diverse view regarding the timing of such conversations. In line with recent literature, most patients did agree that the healthcare provider should initiate these conversations [17]. Because of our findings, we recommend healthcare providers to take the initiative, but be sensitive as to whether the patient would like to discuss this topic at that moment. In the Netherlands, as well as in countries with a similar healthcare system, the care

for patients with cancer is primarily delivered through medical specialists and nurses within the hospital. In addition, all Dutch patients are registered with a GP and this care provider may sometimes be involved in care for patients who receive active anticancer therapy in the hospital. The GP is primarily responsible for care provision as soon as patients “transition” to palliative care [29,30]. The fact that the majority of patients felt that their GP was the most suitable healthcare provider to discuss their EOL with, is likely reflective of this system.

Strengths and limitations

The current study was based on a nationwide survey and included a sufficiently large and varied sample size. Another strength of this study was the number of detailed questions regarding the last phase of life of patients with incurable cancer. This provided us with an opportunity to generate recommendations about how to improve healthcare regarding this specific phase in a cancer trajectory. However, such recommendations should be further analyzed in future studies before implementation is feasible. In addition to these strengths, several limitations should be addressed as well. One major limitation is that our survey was accessible to all patients diagnosed with an incurable cancer which may have led to a selection bias. Although speculative, patients might be more eager to participate when they are either relatively healthy, very unsatisfied, or very satisfied with their healthcare. Unfortunately, we do not have data regarding these parameters and our results should therefore be interpreted with this in mind. However, sociodemographic as well as clinical characteristics showed that our sample was diverse and represents the most frequently diagnosed tumor types in Western countries. We also recognize that the memory of patients regarding this initial conversation may very well be clouded by their emotional state of being at the time. We did not include any data to further study this phenomenon, but this possible limitation should be kept in mind whilst interpreting our findings.

Conclusion

The results of this survey showed needs of patients with incurable cancer are not always met. The level and quality of provided emotional support during the conversation, in which patients are told that they have incurable cancer, can be vastly improved. Psychosocial support should be structurally offered to all patients after these conversations. Last, our results clearly indicate that most patients prefer their primary healthcare provider (i.e., their GP) to initiate EOL conversations. However, it is important to realize that patients differ in their needs and preferences regarding ACP. Physicians should therefore ask patients about such preferences in a timely manner to enable truly patient-centered care for patients with incurable cancer.

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Conflict of interest

The authors have no relevant conflicts of interest to declare.

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Authorship and Data

All authors made a substantial contribution to the concept, design and writing of the manuscript. The authors have full control of all primary data and allow the journal to review the data if requested.

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Tables and figures

“The physicians barely showed any empathy and instead primarily focused on discussing additional treatment options or procedures.”

“The experienced support throughout the conversation, in which you hear that your cancer is no longer curable, is so important for the rest of your disease trajectory, as it reduces the boundary to ask for further help or support.”

“My urologist, oncologist as well as my general practitioner all offered various forms of support throughout my disease trajectory. However, I did not feel like I needed any of it.”

“I realize now that additional support from the hospital is very important. I was usually the one who had to ask for this.”

“I feel like the patient should initiate conversations regarding the end of life. At first, I did not want to discuss anything because of my fear.”

“I really appreciate it when physicians provide an opening to discuss end-of-life care. I feel like it is important for my physician to know what my thoughts and preferences are.”

Figure 1: Selection of illustrative quotes

Table 1: Characteristics of the study population

	N=654
Age mean (SD)	60 (11.03)
Gender, female N (%)	378 (58%)
Type of cancer	
Breast cancer	144 (22%)
Hematological malignancy	135 (21%)
Prostate cancer	124 (19%)
Lung cancer	83 (13%)
Colorectal cancer	32 (5%)
Gynecological cancer	27 (4%)
Other	109 (17%)
Type of hospital	
Academic hospital	160 (25%)
Teaching hospital	283 (43%)
General hospital	199 (30%)
Other	12 (2%)
Years since diagnosis of incurable disease (median (IQR))	2 (1-4)
≤ 2 years	255 (39%)
2-3 years	200 (31%)
≥ 3 years	199 (30%)
Years since last anticancer treatment (median (IQR))	0 (0-1)
Abbreviations: IQR, interquartile range; N, number; SD standard deviation	

Table 2: Types of provided care as experienced by 415 patients who experienced additional care

	Provided support
Treatment aimed at extending life	81%
Contact with a key person within the hospital	57%
Information or advice regarding physical symptoms	46%
Treatment aimed at alleviating physical symptoms	40%
Information or advice regarding psychological symptoms	27%
Referral to psychiatrist/psychologist or social worker	20%
Attention and support for family and loved ones	19%
Information or advice regarding patient organizations or walk-in consultation services for cancer patients and their families	19%
Referral to a different hospital	14%
Referral to a dietician	12%
Information or advice regarding social problems	9%
Referral to GP	8%
Referral to home care or district nurse	6%
Information or advice regarding euthanasia and palliative sedation	5%
Referral to a healthcare chaplain	4%
Information or advice regarding hospice care	1%

Table 3: Types of requested care as experienced by 239 patients who did not receive additional care

	Requested support
Contact with a key person within the hospital	55%
Attention and support for family and loved ones	43%
Information or advice regarding psychological symptoms	43%
Information or advice regarding physical symptoms	41%
Treatment aimed at extending life	35%
Information or advice regarding social problems	33%
Information or advice regarding patient organizations or walk-in consultation services for cancer patients and their families	29%
Referral to psychiatrist/psychologist or social worker	28%
Information or advice regarding euthanasia and palliative sedation	22%
Referral to a different hospital	22%
Referral to home care or district nurse	8%
Referral to a dietician	7%
Referral to a healthcare chaplain	5%
Information or advice regarding hospice care	5%
Referral to GP	4%