‘One also needs a bit of trust in the doctor ... ’: a qualitative interview study with pancreatic cancer patients about their perceptions and views on information and treatment decision-making

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Background: Information about diagnosis, treatment options and prognosis has been emphasized as a key to empower cancer patients to make treatment decisions reflecting their values. However, surveys indicate that patients’ preferences regarding information and treatment decision-making differ. In this qualitative interview study, we explored pancreatic cancer patients’ perceptions and preferences on information and treatment decision-making.

Patients and methods: Qualitative in-depth interviews with patients with pancreatic cancer. Purposive sampling and qualitative analysis were carried out.

Results: We identified two stages of information and treatment decision-making. Patients initially emphasize trust in their physician and indicate rather limited interest in details about surgical and medical treatment. In the latter stage of disease, patients perceive themselves more active regarding information seeking and treatment decision-making. All patients discuss their poor prognosis. Reflecting on their own situation, all patients interviewed pointed out that hope was an important driver to undergo further treatment also in advanced stages of the disease. Interviewees unanimously emphasized the difficulty of anticipating the time at which stopping cancer treatment would be the right decision.

Conclusions: The findings can serve as starting point for reflection on professional decision-making in pancreatic cancer and larger representative surveys on ethical issues in treatment decision-making in pancreatic cancer.

Key words: pancreatic cancer, medical ethics, treatment decision-making, informed consent, end of life

introduction

Patients with pancreatic cancer need to make difficult decisions about intensive surgical and medical treatment which, in most cases, is not curative. From an ethical perspective, information about diagnosis, prognosis and treatment has been emphasized as a key element to enable patients to make decisions which reflect their values and preferences [1].

Empirical research has consistently shown that the vast majority of patients with cancer wish to be informed about diagnosis, prognosis and treatment options [2]. There is also considerable evidence that most patients wish to share responsibility for decision-making [2]. However, quantitative and qualitative research also indicates that decisional preferences vary depending on sociodemographic characteristics, stage of disease and other external factors [3, 4].

Furthermore, it is notable that there are patient groups which have been researched intensively with regard to information and treatment decision-making preferences (e.g. patients with breast cancer), whereas there is less research on this topic which includes patients with other disease entities, especially in more advanced stages.

To our knowledge, socio-empirical research on patients with pancreatic cancer has focused so far mainly on quality of life [5, 6] and quality improvement strategies [7]. Qualitative interview studies with patients which focus on ethical aspects of information and treatment decisions can provide additional information relevant to professional practice and care of this patient group. Furthermore, the reconstruction of treatment decision-making from the patients’ perspective can point out ethically relevant shortcomings which deserve further analysis from a theoretical perspective [8].

In this paper, we report findings of a qualitative interview study with pancreatic cancer patients about their perception and preferences regarding ethical aspects of treatment decision-making. The aims of this study are, first, to reconstruct the
perception of patients with pancreatic cancer regarding the disclosure of diagnosis and treatment decision-making. Second, this study explores patients’ preferences regarding information and treatment decisions and the reasons for their preferences. The findings will be discussed against the background of clinically and ethically relevant aspects of patient information and treatment decision-making in the course of pancreatic cancer.

**Methods**

**Participants and Sampling**

Patients were invited to participate in the study by physicians of a university hospital in Germany. In light of the possible relevance of different communication content and styles regarding diagnosis, prognosis and treatment options for patients’ perceptions and views, this study was designed as single centre study. This means that at least all initial information on diagnosis, medical treatment and prognosis was conveyed by members of one medical team of the department of oncology. All patients were informed about the study by the interviewer and written informed consent was elicited. Inclusion criteria were a diagnosis of pancreatic cancer and at least one regime of chemotherapy. The sampling strategy consisted of recruitment of consecutive patients treated in the in- or outpatient setting. In addition, the interviewer (JS) could designate characteristics which were deemed relevant for this research (purposive sampling).

**Face-to-face Interviews**

Semi-structured interviews were conducted by the first author, a research fellow in medical ethics and a qualified physician in internal medicine with 4 years of clinical experience in haematology and oncology. The topic list of the interview guide had been developed by the authors based on a literature review and earlier qualitative research [8, 9]. All interviews started with an open-ended question on the patients’ perception of initial disclosure of diagnosis and treatment decision-making.

**Data Analysis**

Principles of qualitative thematic analysis—namely the constant comparison of data, open coding, writing memos and purposive sampling—have been used to explore patients’ perceptions and views regarding information and treatment decision-making [10]. Following the transcription of the audiotaped interviews and a check of data, all transcripts were analysed. Main codes are marked in bold and quotes from the interviews were selected to illustrate the conceptualization of data. The qualitative analysis was carried out with the help of the Atlas Ti 6.1.12 programme. A selection of transcripts were analysed by three more researchers (SS, PB and SW) to gain a common understanding of the patients’ narratives and to enhance the validity of the results. Additionally, preliminary analysis of data and respective parts of the original transcripts were presented to all authors and discussed with participants of an interdisciplinary seminar on ‘empirical ethics’. The enrolment of participants and further analysis of data were stopped following ‘theoretical saturation’, which means that additional research interviews did not lead to new or enriched concepts relevant to the research questions. The decision about theoretical saturation was made by the authors and in light of the discussion in the above-mentioned interdisciplinary seminar.

**Results**

Interviews were conducted with 12 patients (six males and six females; aged between 40 and 76). Table 1 summarizes the sociodemographic data of the interviewees and disease-related information. We identified two stages of information and treatment decision-making in our qualitative analysis. These encompass typical narratives of the interviewees related to their perceptions and preferences regarding information and treatment decision-making in an earlier and a later phase of their disease. Additionally, patients’ views on treatment decision-making at the end of life were analysed as a distinct cluster of narratives which emerged during the interviews.

**Information and Treatment Decision-Making**

**Stage I: No Choice and Trust in the Physician**

All patients provided detailed information about their perceptions and preferences related to information and treatment decision-making. Regarding the early stage of disclosure of diagnosis and initial treatment decisions, patients emphasized that, in light of the new, urgent and life-threatening situation, they perceived no choice. They reported having limited interest in details of treatment-related information at this stage, but that trust in the physician was of utmost importance.

Patient: I was told that this would be the only way to treat me, in this way. It does not work differently for me. [...] Yes, and he said, ’You must do this’, otherwise you won’t live to see the next half year. (PP_3)

Interviewer: Did you want to know something specific about the operation [...]?

Patient: No. I placed my life and my illness in the hands of the specialists and said you will do this right [...]! (PP_4)

Patient: One also needs a bit of trust in the doctor or total trust in such a thing. I think if I trust a doctor, then I would do what the doctor tells me. One must really have trust. (PP_6)

The decision about the place for treatment was mostly based on recommendations by the physician/healthcare team who diagnosed the disease. Patients often consulted other people, such as healthcare professionals in their own private circle of friends and family, or other physicians, such as the patient’s family practitioner, about these recommendations. Patients enumerated a few concrete decision criteria for their choice, such as the department chosen being a ‘cancer centre’, a high volume of patients treated with the same disease or the reputation of a specific surgeon.

Patient: Yes, there where they do most of the operations. That was the most important thing. [...] X actually had a very good reputation. And as the head physician told me: Go to X, to Prof. Y. You are in good hands there. (PP_8)
stage II: information-seeking in light of experiences with disease and treatment

All patients emphasized the physical and psychosocial burdens which they had experienced in the course of their illness. Although part of the burden was attributed to the disease, interviewees also provided a number of examples of how the treatment affected their well-being.

Patient: Since we changed the therapy, I feel much better. [The last therapy] was unbearable. Mainly, I couldn’t go out, I was freezing and trembling, and saw so little of the outside. (PP_4)

A number of interviewees indicated that in the course of their increasing experience with the disease and treatment, their behaviour with regard to information and treatment decision-making had changed towards a more proactive role compared with the initial stage. Examples frequently given for more active behaviour were to ask more questions during the patient physician encounter or to negotiate about the treatment in the light of priorities which were not health-related.

Patient: But now I am going forward. Today I am asking until I know what I want to know. I am also now a bit further forward. (PP_2)

Patient: During the operation, one abandons oneself, all parallel planning was put aside; then with the recovery, the desire to go into private planning again returns. And schedule of the chemo, it competed with the holiday [...].(PP_10)

One ‘focus of interest’ in information-seeking reported by all participating patients were supportive measures which, in some cases, included complementary or alternative treatment. Although physicians were mentioned as informants regarding these measures, the patients reported that family members, friends and also other patients played an important role with regard to this information.

Patient: For example, Mr. X [... ] who has the same story as I, we’re talking intensively with each other about our nutrition [...]. I’m not so keen on natural healing. It was never my cup of tea. But now I have a very different situation. (PP_5)

Table 1. Characteristics of interviewees and disease at time of interview

<table>
<thead>
<tr>
<th>Interview-ID</th>
<th>Age</th>
<th>Gender</th>
<th>Nationality</th>
<th>Family status</th>
<th>Education</th>
<th>Stage of disease at time of diagnosis</th>
<th>Time since diagnosis</th>
<th>Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>PP_D_1</td>
<td>70</td>
<td>Male</td>
<td>German</td>
<td>Married, one child</td>
<td>Abitur (A-Level)</td>
<td>UICC IV</td>
<td>8 months</td>
<td>Private</td>
</tr>
<tr>
<td>PP_D_2</td>
<td>71</td>
<td>Female</td>
<td>German</td>
<td>Married, one child</td>
<td>No information</td>
<td>UICC IB</td>
<td>12 months</td>
<td>Public</td>
</tr>
<tr>
<td>PP_D_3</td>
<td>71</td>
<td>Male</td>
<td>German</td>
<td>Married, three children</td>
<td>Mittlere Reife (GCSE)</td>
<td>UICC III</td>
<td>11 months</td>
<td>Public</td>
</tr>
<tr>
<td>PP_D_4</td>
<td>76</td>
<td>Male</td>
<td>German</td>
<td>Widowed, two children</td>
<td>Hauptschulabschluss (Certificate of secondary education)</td>
<td>UICC IIB</td>
<td>14 months</td>
<td>Public</td>
</tr>
<tr>
<td>PP_D_5</td>
<td>61</td>
<td>Male</td>
<td>German</td>
<td>No information</td>
<td>No information</td>
<td>UICC IV</td>
<td>7 months</td>
<td>Public</td>
</tr>
<tr>
<td>PP_D_6</td>
<td>40</td>
<td>Female</td>
<td>Italian</td>
<td>Married, two children</td>
<td>No information</td>
<td>UICC IIB</td>
<td>10 months</td>
<td>Public</td>
</tr>
<tr>
<td>PP_D_7</td>
<td>62</td>
<td>Female</td>
<td>Spanish</td>
<td>No information</td>
<td>No information</td>
<td>UICC IIA</td>
<td>12 months</td>
<td>Public</td>
</tr>
<tr>
<td>PP_D_8</td>
<td>56</td>
<td>Female</td>
<td>German</td>
<td>No information</td>
<td>Abitur (A-Level)</td>
<td>UICC III</td>
<td>6 months</td>
<td>Public</td>
</tr>
<tr>
<td>PP_D_9</td>
<td>67</td>
<td>Female</td>
<td>German</td>
<td>Married, one child</td>
<td>Mittlere Reife (GCSE)</td>
<td>UICC IB</td>
<td>13 months</td>
<td>Private</td>
</tr>
<tr>
<td>PP_D_10</td>
<td>60</td>
<td>Male</td>
<td>German</td>
<td>Married, one child</td>
<td>Abitur (A-Level)</td>
<td>UICC IV</td>
<td>6 months</td>
<td>Private</td>
</tr>
<tr>
<td>PP_D_11</td>
<td>72</td>
<td>Male</td>
<td>German</td>
<td>Married</td>
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<td>UICC IB</td>
<td>6 months</td>
<td>Public</td>
</tr>
<tr>
<td>PP_D_12</td>
<td>70</td>
<td>Female</td>
<td>German</td>
<td>Married</td>
<td>Mittlere Reife (GCSE)</td>
<td>UICC IIB</td>
<td>11 months</td>
<td>Public</td>
</tr>
</tbody>
</table>

treatment at the end of life: hope and challenges of anticipatory decision-making

All patients explicitly discussed the poor prognosis of pancreatic cancer and its threat to life. In the context of their reflections on treatment at the end of life, several interviewees provided spontaneous examples of family members or friends who had died in circumstances perceived by the interviewees as overtreatment.

Patient: And then I remember, it was I believe the day before or the day before that, she [patient’s mother] died. I told Mr XXX [...], please leave my mother to die in peace [...], and then in the afternoon, they finally switched of some of these machines [...].(PP_1)

Reflecting on their own situation, all patients interviewed pointed out that hope was an important driver to undergo further treatment also in advanced stages of the disease. Interviewees unanimously emphasized the difficulty of anticipating the time at which stopping cancer treatment was the right decision.

Patient: Well, I think one gets used to reality, but, as Schiller said: ‘Still on the grave, he plants on hope’. (PP_1)

Patient: [... ] but I really couldn’t say that’s the limit now, at this point I don’t want to go on anymore. Perhaps, only sometimes when I will get to the point where they say that there is nothing more that can be done [...].(PP_8)
The responses of the interviewees when asked about who should make decisions about the limitation of cancer treatment in advanced stages of the disease could be split into two groups. One referred to the physicians’ expertise and recommendation as a decisive basis also for decisions about the limitation of treatment. According to this, deciding about the limiting of treatment was a task of the physician, as it was with any other treatment decision.

Patient: So, as it is at the moment, I plan to do everything that Dr. X says and I’m really doing it. Do I know what is good for me, and how far do I have to go? (PP_9)

In contrast, a second group emphasized their right to make decisions about the limitation of treatment in advanced cancer. These patients based their views mainly on the argument that, in the case of advanced treatment factors, such as personal experience with the treatment, and the fact that personal values relevant to these decisions are paramount, such factors are outside the professional domain.

Patient: […] well, so a chemo-patient who just went from chemotherapy to chemotherapy also becomes a specialist. […] And he drifts more and more into a life decision, a life situation, where he knows that he has to now take decisions and responsibility for himself, and this can’t be done by a doctor […] That is another basis for decision-making. (PP_11)

discussion

This is, to our knowledge, the first qualitative interview study with patients diagnosed with pancreatic cancer which focuses on ethical issues of information and decision-making. In the light of the short average life expectancy and the variety of intense surgical and medical treatments which may be offered to these patients, this patient group provides a good model to explore ethical aspects of treatment decision-making against the background of a poor prognosis. In the following, we discuss potential implications of our findings with a focus on patients’ emphasis on trust during the early stage of their illness, and the challenges associated with patients’ hope in the context of treatment decision-making at the end of life.

trust and information in treatment decision-making about pancreatic cancer

All patients reported that it was of utmost importance following diagnosis to decide where and by whom the treatment should be carried out. The narratives of patients regarding the importance of trust in the treating physician and comparably little need for specific information during the initial stage of information and treatment decision-making have similarities with findings from a qualitative study of McKneally and Martin [11] with patients with oesophageal cancer. Patients’ emphasis on trust in their physician/healthcare team seems relevant from an ethical and clinical perspective. From an ethical perspective, the strong focus on (specific concepts of) autonomy has been criticized in the ethico-legal debate [12], whereas the role of trust currently receives increasing attention in the theoretical debate on ethical aspects of the patient–physician relationship [13]. It should be pointed out that physicians who make recommendations adopt considerable responsibility. Based on our empirical–ethical analysis, we argue that physicians as trustees should promote an exchange of relevant preferences and values with their patients to have a sound basis for their recommendations. Furthermore, transparency with regard to the criteria which guide physicians’ recommendations—for example, concerning a colleague recommended as the surgeon for the difficult and outcome-relevant operation—seems a perquisite to justify the role of a trustee physician in such a situation.

Treatment at the end of life: hope and challenges for anticipatory decision-making

Reflections on the possible limitation of cancer treatment in advanced stages of the disease were a challenging and, simultaneously, important part of all the interviews. All patients emphasized that, with regard to their own situation, it was difficult to anticipate when cancer treatment should be limited. Hope and the wish to stay alive were strong drivers for patients’ willingness to undergo further treatment. Interestingly, we could not detect differences regarding patients’ ‘hope’ in our sample between patients with different stages of disease and therefore different prognosis. From an outside perspective, this comes as surprise insofar as hope in the sense of desire or expectation for longer term or survival or even cure in patients with stage III or IV comes close to ‘illusion’ in the sense of a misinterpretation of facts. Next to the limits of small samples in qualitative studies, one reason for the lack of difference in the narratives of patients with a different stage of disease may be that during the interviews patients often avoided to discuss their prognosis in detail. However, another reason may also be that the objective differences with regard to the 5-year survival between different stages of disease do not change patients’ perceptions. The narratives on patients’ hope resemble findings of earlier research on patients’ hope in treatment decision-making and many patients’ strong desire for treatment in the last phase of life [14, 15]. In combination with the findings on physicians’ reluctance to make decisions about treatment limitation in advanced cancer [16], it comes as little surprise that patients receive chemotherapy or other cancer treatment up to weeks or even days before death [17, 18]. Moreover, the narratives on patients’ hope, at least in part, may explain the results of more recent quantitative research according to which patients with incurable cancer often overestimate the possible benefit of palliative chemotherapy [19].

In the ethico-legal debate, the issue of limiting cancer treatment has most often been analysed with reference to patients’ values and their right to refuse even life-sustaining treatment. However, the data collected in this study and in other qualitative studies on this topic in the context of cancer care [9, 16] point out that a frequent and, at the same time, challenging situation is that of hope for improvement by the patient in combination with clinical uncertainty regarding the outcome of further treatment. Although there are some data which show that more cancer treatment in advanced cancer is associated not only with a worsening quality of life, but is also life-shortening [20], there is currently little evidence which could guide patients and physicians in these situations. In the
light of the aforementioned ethics and evidence-related challenges regarding the individual treatment decision, and bearing in mind the societal costs associated with cancer treatment at the end of life, we argue that patient-oriented research which can inform patients and physicians about benefits and risks of treatment during the last phase of life is an important cornerstone for improved treatment decision-making in advanced cancer.

limitations

When interpreting the findings of this study, methodological limitations must be taken into account. First of all a selective memory and socially desirable answers may have influenced the narratives of the interviewees. Second, due to the inclusion criteria, we did not interview patients not receiving at least one cycle of chemotherapy. The narratives of patients who were not offered chemotherapy or who refused treatment may differ from the presented findings. Furthermore, the small sample of interviewees which had all been treated in one university centre for oncology is not representative of patients with pancreatic cancer who are treated with chemotherapy in Germany. Therefore, the perceptions and views elicited in this study may not cover the whole range of experiences and views of patients with pancreatic cancer due to the limited number of patients. Given the limits in this study to explore differences in patients’ perceptions and views against the background of the individual patients’ diagnosis and prognosis in this study, we suggest that research focusing on such difference (e.g. in patient groups with better overall prognosis) could further inform clinical practice. Last but not least, it should be pointed out that different from the paradigm of quantitative research in qualitative research interpretation of data is integral part of the analysis of narratives. Therefore, other researchers may differ not only regarding the discussion of findings but also the interpretation of the gathered data.

conclusion

This study provides insight into the perceptions and preferences of patients with pancreatic cancer regarding information and treatment decision-making. Based on our empirical–ethical analysis, we argue that physicians as trustees should promote an exchange of relevant preferences and values with their patients previously to have a sound basis for their recommendation. Furthermore, and in light of the scarcity of evidence and the ethical challenges associated with decisions about limiting treatment, we suggest that patient-oriented research which can inform patients and physicians about benefits and risks of treatment during the last phase of life is an important cornerstone for improved treatment decision-making in advanced cancer.

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disclosure

The authors have declared no conflicts of interest.

references

Diabetes mellitus, insulin treatment, diabetes duration, and risk of biliary tract cancer and hepatocellular carcinoma in a European cohort


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Background: Evidence on associations between self-reported diabetes mellitus, diabetes duration, age at diabetes diagnosis, insulin treatment, and risk of biliary tract cancer (BTC) and hepatocellular carcinoma (HCC), independent of general and abdominal obesity is scarce.

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