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# Severe mental illness and palliative care: patient semistructured interviews

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## ABSTRACT

**Objectives** To explore perceptions, experiences and expectations with respect to palliative care of patients with severe mental illness (SMI) and an incurable, life-limiting chronic illness.

**Methods** Face-to-face semistructured interviews were conducted with 12 patients (10 of them living in a mental healthcare institution) with severe mental and physical health issues in the Netherlands. A semistructured interview guide was used to elicit perceptions of, experiences with and expectations regarding palliative care. Data were analysed using inductive content analysis.

**Results** Analysis of the data revealed eight categories: perceptions on health and health issues, coping with illness and symptoms, experiences with and wishes for current healthcare, contact with relatives and coresidents, experiences with end of life of relatives and coresidents, willingness to discuss end of life and death, wishes and expectations regarding one's own end of life and practical aspects relating to matters after death. These categories were clustered into two separate themes: current situation and anticipation of end of life. Interviewees with SMI appeared not accustomed to communicate about end-of-life issues, death and dying due to their life-threatening illness. They tended to discuss only their current situation and, after further exploration of the researcher, the terminal phase of life. They seemed not engaged in their future palliative care planning.

**Conclusions** Findings of this study highlight inadequacies in advance care planning for patients with SMI. Results suggest using values, current and near wishes, and needs as a starting point for establishing a gradual discussion concerning goals and preferences for future medical and mental treatment and care.

## BACKGROUND

In the Netherlands, about 222 000 patients aged 18 years or older have a severe mental illness (SMI).<sup>1</sup> According to

Delespaul, SMI is defined as a psychiatric disorder that requires care or treatment, is accompanied by severe social and societal limitations (both as causes and effects of a psychiatric disorder), persists for a long period (at least several years) and is not transient.<sup>2</sup> Another criterium of this definition is that to achieve the treatment plan, coordinated care from professional healthcare providers in care networks is indicated.<sup>2</sup> In 2012, approximately 20 000 of such patients were in a palliative stage (unpublished communication, Groot, 2012) as defined by the WHO.<sup>3</sup> However, palliative care for patients with SMI (see [box 1](#) for an overview of the care structure for patients with SMI in the Netherlands) and physical health issues is still not widely implemented, and research on this topic for this patient group is scarce.<sup>4–11</sup> As the interplay between physical and psychiatric symptoms of patients with SMI and physical health issues makes them particularly vulnerable and complicates healthcare provision,<sup>7 12–15</sup> such research would be extremely relevant.

Previous studies have shown that palliative care needs of patients with SMI are not recognised and treated in a timely manner.<sup>16–18</sup> For such patients, palliative care is mainly restricted to on the moment crisis management, hence, the anticipation of their needs and wishes in future care is lacking. Consequently, many patients with SMI do not receive the care they need; hence symptoms remain untreated and discussions regarding their end-of-life needs are minimal.

Several challenges are identified in applying palliative care for this vulnerable group. First, their mental vulnerability and symptoms require specific attention, knowledge and communication skills to identify those in need of palliative care in a timely way. For example, patients with

**Box 1 Overview of the care structure for patients with SMI in the Netherlands**

- ⇒ The Dutch Mental Health Care (In Dutch: 'Geestelijke gezondheidszorg', GGZ) focuses on the prevention of mental illnesses, the treatment and cure of persons with mental illnesses, the participation of people with a mental illness in society, and the provision of help to people who are seriously confused/addicted and who do not seek help by themselves.
- ⇒ The severity of the care that is needed determines where someone receives care. In primary care, the general practitioner, social worker and primary psychologists provide the care. If more specialist treatment is necessary, the the general practitioner or a medical specialist will refer the patient to specialist mental healthcare which is offered in GGZ institutions. Each region in the Netherlands has several mental health care organisations. Among other things, they provide assistance to people with SMI. The help that is given can consist of regular conversations, possibly combined with medication and online help (often in outpatient treatment), part-time treatment (a few half days a week), intensive care during admission or acute admission.
- ⇒ Since a number of years, Dutch policy is aimed at reducing the number of inpatient treatment places. Aiming for more ambulatory care mainly means a different way of looking at what someone needs to lead the best and normal life possible. The residential facility is only deployed if there are no (reasonable) alternatives left to think of or to organise.
- ⇒ For more than 10 years, attention has started to focus on palliative care in mental healthcare. A number of inventory studies have been carried out and there is growth in the development of expertise of professionals in mental health care, both in terms of training and peer support by specific (palliative care) experts or consultation teams. Mental health professionals are also increasingly joining consultation teams in palliative care inside and outside hospitals. Due to the development of more ambulatory care of mental health care, less attention has been given to the development of palliative care.

SMI, severe mental illness. GGZ, geestelijke gezondheidszorg.

schizophrenia or other psychotic disorders have limitations in processing perceptual information and differ in the verbalisation of pain and discomfort, leading to misinterpretation or even ignoring pain perception by the patient or healthcare provider.<sup>19–21</sup> Furthermore, patients with SMI tend to present symptoms in an atypical way or resist screening or treatment, which may lead to unnoticed somatic symptoms.<sup>22–24</sup> In addition, complex pharmacological interactions between drugs for somatic and psychiatric disorders may induce undetected side effects or complications.<sup>25</sup> A lack of knowledge, skills and experience of many healthcare professionals in treating patients with SMI, palliative care or both,<sup>22,25</sup> in addition to a lack of integration and involvement between palliative and mental healthcare<sup>6, 17</sup> further

complicates adequate palliative care provision to this patient group.

Previous studies mainly focused on healthcare professionals' perspectives on palliative care for patients with SMI.<sup>7, 12, 21, 22</sup> Only a few studies provide insights into the treatment preferences of patients with SMI themselves. Two of the latter concluded that patients with SMI were able to engage in medical advance care planning in response to the hypothetical end-of-life health state scenarios.<sup>26, 27</sup> However, little attention has been given to providing insights into how patients with SMI think and speak about palliative care and how they experience the care being offered.<sup>28, 29</sup> We only found one qualitative study exploring perspectives and expectations of patients with schizophrenia about the end-of-life care, which identified 'absent of fear of death', 'skilled companionship' and 'preserving quality of life' as major themes.<sup>30</sup> Such knowledge is necessary to provide appropriate palliative care. In order to address this knowledge gap, the aim of the current study was to explore perceptions, experiences and expectations regarding palliative care of patients with SMI and additional severe physical health issues.

## METHODS

### Study design and participants

Due to the explorative nature of the topic, a qualitative study was performed, consisting of individual face-to-face, semistructured interviews. Participants were patients (aged 18 years or older) meeting all criteria of SMI as defined by Delespaul,<sup>2</sup> with an advanced stage of a life-limiting chronic illness. A purposive sample was determined using a two-way approach: (1) patients primarily treated in mental healthcare and presenting physical palliative care needs, and (2) patients treated in palliative care presenting mental health issues.

### Ethics statement

The study was conducted following the guidelines approved by the Dutch ethical review committee (CMO-nr 2011/128) and adhered to the World Medical Association Declaration of Helsinki. A written consent form was obtained from all participants after they were informed of the study's purpose and confidentiality policies.

### Procedure

Healthcare professionals from three dedicated mental healthcare institutions in the Netherlands, general practitioners and professionals from the palliative care consultation team of the Radboud University Medical Center recruited patients between June and December 2012. Healthcare providers gave a written information leaflet to eligible patients and provided some information regarding the study. The leaflet was developed in collaboration with members of one mental healthcare institution's client council. Based on their advice, it was decided not to use the term 'palliative care' in the leaflet;

**Table 1** Topics discussed during the semistructured interview

Topics	Subtopics
Beginning of the illness	<ul style="list-style-type: none"> <li>▶ First symptoms</li> <li>▶ First contact with a medical professional</li> <li>▶ (Medical) treatment, care, and support</li> <li>▶ Changes in social contact, work, and residency</li> <li>▶ Current treatment, care, and support</li> </ul>
Other symptoms or diseases	<ul style="list-style-type: none"> <li>▶ Diseases and symptoms</li> <li>▶ First contact with a medical professional</li> <li>▶ (Medical) treatment, care, and support</li> <li>▶ Changes in social contact, work, and residency</li> <li>▶ Current treatment, care, and support</li> </ul>
Further information about current treatment, care, and support	<ul style="list-style-type: none"> <li>▶ Place of treatment</li> <li>▶ Involved disciplines =&gt; Tasks of involved disciplines</li> <li>▶ Opinion about the treatment =&gt; Example(s) and explanation of positive and negative experiences</li> <li>▶ Improvement suggestions</li> </ul>
End of life care	<ul style="list-style-type: none"> <li>▶ Perception of the fact that the illness is incurable</li> <li>▶ Patient's end of life =&gt; Meaning, Involvement of others, Subjects discussed with others</li> <li>▶ Expectations about final stage =&gt; Treatment and support, Involved disciplines</li> <li>▶ Experiences with end of life care so far =&gt; Positive and negative experiences</li> <li>▶ Needs and wishes</li> </ul>

it was expected that the participants would associate it with terminal care and that they, therefore, would decline to participate. Instead 'severe (chronic) psychiatric disorder' was used in combination with sentences about the end-of-life care (ie, that the respondents would be questioned about their own end of life).

Patients who were willing to participate were contacted by one of the researchers who provided additional information verbally about the study's purpose and confidentiality issues. After written informed consent was obtained, an individual face-to-face, semistructured interview was conducted with each participant by one of the researchers. Based on a literature search and discussion within the project team, a semistructured interview guide was developed and used in the interviews to elicit perceptions, experiences and expectations regarding palliative care (table 1). The interview began with an introduction and proceeded to general questions about the onset of the illness, other symptoms or diseases and further information on current treatment, care and support. Specific questions on the end-of-life care were introduced and discussed during the last part of the interview. Participants were interviewed by NZ, a psychologist and experienced nurse in mental healthcare and were conducted at the present place of residence of

the respondent (ie, at the mental health institution or their home address). Interviews were audiotaped and fully transcribed for analysis.

### Analysis

Four interviews were independently analysed by two researchers (IK and MG) using inductive content analysis, with the help of ATLAS-ti (V.8). In between the analysis of each of these interviews, the researchers met and discussed the codes attached to the text segments. This consensus and knowledge were incorporated into the analysis of the next interview. In this manner, a codebook was built. This codebook was the starting point for analysing the other eight interviews. These eight interviews were analysed by one researcher (IK), who discussed the parts of the transcript that were not in line with the previously agreed codebook, with one of the other researchers (MG). Ultimately, the emerging categories and themes were discussed among three researchers (IK, MG and YE) and definitive categories and themes were determined by consensus.

## RESULTS

### Characteristics of participants

Twelve patients participated. Ten of them were living in a mental healthcare institution and 2 at home. Three of them were male individuals. Their ages ranged from 48 to 84 years, with a median age of 67 years. All interviews took place at the residencies of the respondents and lasted for approximately 45 min (range from 20 to 60 min). Except for one interview in which the participant's wife was present, no other persons attended the interviews.

All 10 participants who lived in a mental healthcare institution stayed at a long-term care ward and had spent at least 15 years in mental healthcare. Their psychiatric diagnoses were depression, bipolar disorder, schizophrenia or substance abuse. Their physical illnesses were diabetes, chronic obstructive pulmonary disease, chronic heart failure or incurable cancer. All participants were treated for both their psychiatric and physical health issues and used medication for both types of conditions.

Different types of healthcare professionals (ie, general practitioners, medical specialists, nurses, psychiatrists, psychologists, personal counsellors, social workers, spiritual counsellors, pastors and physiotherapists) were involved in the care of the participants. The types of professionals that coordinated the care varied per participant. Participants living at home received most of their care from their general practitioner and mentioned that he or she was the coordinator of the care process.

### Categories and themes

Saturation was reached after the sixth interview; during the following interviews, no new codes emerged. Analysis of the codes revealed eight categories: perceptions on health and health issues, coping with illness and

**Table 2** Themes, categories and examples of narratives

Theme	Category	Examples of narratives
Current situation	Perceptions of health and health issues	<ul style="list-style-type: none"> <li>▶ Despite experiencing shortness of breath, I feel quite healthy. For the rest, I am healthy. (Participant 1)</li> <li>▶ I do feel all right, I can do whatever I want. Only those medicines, those are a little unpleasant. Four times a day, but yeah, those are due to my diabetes. (Participant 8)</li> </ul>
	Coping with illness and symptoms	<ul style="list-style-type: none"> <li>▶ You're facing your problems alone. (Participant 3)</li> <li>▶ I am feeling okay. Here I am busy the whole week, consequently I do not feel depressed. (Participant 8)</li> <li>▶ Every day I pray. When I am praying, I know I become calm. (Participant 6)</li> <li>▶ However, there is nothing she (the pastor) can do about it. (Participant 7)</li> </ul>
	Experiences with and wishes for current healthcare	<ul style="list-style-type: none"> <li>▶ They told us I would get radiotherapy, but when I went to the doctor, he told me it was out of question. (Participant 3)</li> <li>▶ At all times, people may walk in. I do not like that. Sometimes I think; 'I really like to be alone'. (Participant 6)</li> <li>▶ Actually, I may be delighted to live here because I would not be able to get this at home. Here I get the attention, the good morning, the good evening and the good afternoon... ..There is always someone who sympathises with me. (Participant 9)</li> <li>▶ They (nurses) take good care of me. They are good in understanding people and they are doing their best. (Participant 5)</li> </ul>
	Contact with relatives and coresidents	<ul style="list-style-type: none"> <li>▶ No, I do not contact my relatives at all. (Participant 10)</li> <li>▶ I have good contacts with coresidents. Very good contacts. (Participant 4)</li> </ul>
Anticipation of end of life	Experiences with the end of life of relatives and coresidents	<ul style="list-style-type: none"> <li>▶ I did not know she was ill... ..And after that, I suddenly heard she had passed away. (Participant 12)</li> <li>▶ I tend to avoid being involved with end of life of others (coresidents). (Participant 2)</li> </ul>
	Willingness to discuss end of life and death	<ul style="list-style-type: none"> <li>▶ No, I don't talk about death, it is an unpleasant matter, it makes me sad. (Participant 10)</li> <li>▶ I was not thinking about death before you asked me these questions and I don't like it. It's a sad question and that is why I am not going to answer it. (Participant 4)</li> </ul>
Anticipation of end of life	Wishes and expectations regarding one's own end of life	<ul style="list-style-type: none"> <li>▶ Silently, painless, quickly, accompanied by relatives and friends I have chosen. (Participant 12)</li> <li>▶ You only die once so at least (I want) a shoulder to lean on. (Participant 7)</li> <li>▶ I want the professionals to support me and end it quickly when necessary. (Participant 1)</li> </ul>
	Practical aspects relating to matters after the death	<ul style="list-style-type: none"> <li>▶ I want to be buried and I want the funeral to take place in this chapel here. I already informed them about this. (Participant 9)</li> </ul>

symptoms, experiences with and wishes for current healthcare, contact with relatives and coresidents, experiences with end of life of relatives and coresidents, willingness to discuss end of life and death, wishes and expectations regarding one's own end of life and practical aspects relating to matters after death. These categories were clustered into two separate themes: current situation and anticipation of end of life. Themes, categories and examples of patient narratives are provided in [table 2](#).

### Current situation

Within the theme '*current situation*', five categories could be distinguished. Regarding their '*perceptions on health and health issues*', participants living at home began the interview by elaborating on their physical problems and only provided superficial information about their psychiatric health issues; information about the extent of their mental problems and the psychiatric care they received was only provided after further exploration by the researcher. The opposite applied to the participants living in mental healthcare institutions. Despite reported physical and psychiatric health issues such as pain, depressive symptoms and psychoses, the participants' perceived general health status was generally reasonable.

Concerning '*coping with illness and symptoms*', patients stated that they were accustomed to their illness

and symptoms and that they generally were not inclined to discuss them or search for social support. Some of the participants stated that they aimed to distract themselves by participating in activities in order to decrease negative thoughts. Being religious, praying and attending church on a regular basis were also mentioned as methods of coping with the illness and symptoms. A few of the participants contacted a pastor or spiritual counsellor on a regular basis and viewed this as a positive experience. The conversational topics with the pastor or spiritual counsellor varied from everyday subjects to personal concerns. However, they did not believe that a pastor or spiritual counsellor could solve their problems.

Analysis of the data concerning '*experiences with and wishes for current healthcare*' revealed that participants living at home complained about not being well informed by some of their healthcare professionals regarding their diagnosis and treatment options and not receiving all the care they needed. For example, they did not understand why it had taken so long to diagnose their somatic illness. They also emphasised the need to receive accurate information, despite their psychiatric illness. From their perspective, providing overall high-quality care meant paying attention to their somatic problems, in addition to their psychiatric problems.

The participants living in mental healthcare institutions differed in their opinions about their healthcare

professionals and the palliative and mental care being offered. Those with a negative perception of their professionals were also not satisfied or comfortable with living in a mental healthcare institution; they preferred living at home. They explicitly expressed the need to be left alone by their healthcare professionals. The participants who were positive about the care being offered replied that they were contented to live in a mental healthcare institution as in their experience, the institution could offer them all the care they needed.

Regarding *'contact with relatives and coresidents'*, all participants indicated that they had few or no informal care providers. Most participants stated that their relatives did not contact or visit them often. The participants living in a mental healthcare institution indicated that they had positive experiences interacting with their coresidents.

Concerning their *'experiences with end of life of relatives and coresidents'*, analysis of the data revealed that some of the participants were not aware of a coresident having a severe illness in its terminal phase. They only discovered this information after they had been confronted with the funeral director. However, other participants emphasised that they did not feel the need to interact with dying fellow patients.

#### Anticipation of end of life

This paragraph describes the three categories that can be distinguished within the theme *'anticipation of end of life'*, beginning with *'willingness to discuss end of life and death'*. When asked about their own death, all participants were reluctant to answer. They were visibly uncomfortable speaking about this topic. After further inquiry, most of them conveyed that talking and thinking about death made them feel sad; and as they had already suffered enough, they did not like to discuss it further. Most of the participants rarely thought about their own death or talked about it with their relatives or healthcare providers.

When asked about *'wishes and expectations regarding one's own end of life'*, all 12 respondents were realistic. They all knew that they would not recover from their somatic condition and had no need for new treatment possibilities. They only desired comfort, peace and the means to discuss their thoughts and concerns if they felt the need to. They also considered experiencing no pain or unnecessary suffering to be important aspects of their end of life.

All participants preferred to stay in their current residency as long as possible and live the remainder of their life there: they did not want to be moved to a hospital or hospice. They expected and hoped that the same professionals who currently were taking care of them would be involved in their end-of-life care too. According to the patients living in a psychiatric hospital, affection was a key component of effective palliative care.

Despite their reluctance to discuss their end of life, most participants had arranged *'practical aspects*

*regarding matters after death'*, such as obtaining funeral insurance and deciding whether they wanted to be buried or cremated. Furthermore, most participants had made a list of people they wanted to be present at their funeral. Wishes and plans were barely discussed with relatives and clinicians.

#### DISCUSSION

In this interview study exploring perceptions, experiences and expectations of patients with SMI and additional severe physical health issues, regarding palliative care, the interviewees appeared not accustomed to speaking and thinking about their end-of-life issues, death and dying due to their life-threatening illness. They tended to discuss only their current situation and, after further probing by the researcher, the terminal phase of life. They discussed and considered less regarding the period in between 'current' and later 'dying' in which palliative care needs and anticipation of end of life are applicable. Previous research however has shown that timely discussion of end-of-life issues with patients with SMI appeared possible when the Healthcare Preferences Questionnaire (HCPQ) was used.<sup>26 27</sup> An explanation for these different findings may be that using a questionnaire like the HCPQ in which hypothetical health state scenarios are presented, makes it easier for patients to discuss end-of-life issues compared with using open-ended questions as we did. Another explanation may be that it is easier to discuss hypothetical scenarios compared with their own real situation, which requires a high level of overseeing their current situation that may be limited in patients with SMI. Surprisingly, most participants in this study had considered and arranged various practical aspects regarding their death (eg, funeral insurance). However, few had informed relatives or others concerned about their plans.

Consistent with previous findings,<sup>12 31</sup> this study also indicates that most patients with SMI testify they feel a lack of concerned, informal care providers like family or friends. Consequently, they tend to fully depend on their professional caregivers. As informal caregivers can play a crucial role in supporting severely ill patients without SMI,<sup>32</sup> this finding needs to be considered when developing palliative care approaches for patients with SMI. Involving a trusted professional caregiver may be suggested to help patients with SMI initiate the conversation about death and dying.

Another element that should be considered when providing palliative care to this patient group is our finding that those interviewees living in mental healthcare institutions did not mention their physical issues without prompting. This is in line with the review of Felker *et al*, who also found that patients with SMI are less able to communicate about their physical issues than about their psychiatric ones.<sup>23</sup> Moreover, both mental healthcare professionals and general healthcare professionals tend to focus on mental rather than on physical problems, which further contributes to the high rates

of undiagnosed and untreated physical illnesses in this group.<sup>33</sup>

In contrast to the reluctance of participants in this current study to talk about their future palliative care planning, most of them spoke extensively about their current situation. Tilburgs *et al* found that in people with dementia, discussing current and short-term goals was considered a facilitator by community-dwelling individuals with dementia, family caregivers and health-care providers.<sup>34</sup> Similarly, discussing current and near-future needs and goals with patients with SMI may be a promising starting point to explore future palliative care planning.

### Strengths and limitations

A strength of this study is that this is one of the first studies that focused on the view of the patient with SMI. Besides, participants had different psychiatric and somatic problems, which made it possible to present a broad perspective on palliative care for patients with SMI. Despite the general reluctance to discuss end-of-life issues, we were able to interview patients with SMI on this topic. It should however be noted that it was difficult to explore underlying values and attitudes concerning this topic; a lot of the information provided by the participants remained at a superficial level. The findings of this study therefore need to be interpreted with caution.

Our study has several limitations. Despite the carefully constructed interview guide, all participants were reluctant to answer the questions in which they were invited to anticipate their own death. Either participants were not accustomed to talking about their death, or they were hesitant because they were not familiar enough with the interviewer to discuss such personal and delicate issues. Therefore, serial interviewing over a longer period of time discussing sensitive topics such as death and dying is suggested in future studies, aiming to establish a relationship of trust.<sup>35</sup> It is also suggested to involve a trusted professional caregiver to initiate the conversation about death and dying. These approaches may enable patients to feel comfortable providing more information about the support they would like to obtain during the end-of-life process, in addition to talking about their quality of life and experiences in care during the process. Another advantage of serial interviewing is that it allows us to gain in-depth insight into the palliative care process and to longitudinally assess whether patients' wishes and needs are being met.

Furthermore, differences between patients living in mental healthcare institutions and patients living at home (n=2 in this study) need to be explored more thoroughly in further research, as well as revealing differences of perspectives on palliative care between individuals with and without SMI. Despite these limitations, the findings of this study add new insights to the body of knowledge on palliative care for patients with SMI.

## CONCLUSIONS

Findings of this study highlight inadequacies in advance care planning for patients with SMI. Results suggest using values, current and near wishes, and needs as the starting point for establishing a gradual discussion concerning goals and preferences for future medical and mental treatment and care.

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