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## Research Article

# Navigating What Is Not Known—Patients' Experience of the Life Threat Connected to Allogeneic Stem Cell Transplantation

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**Background:** Allogeneic stem cell transplantation (allo-SCT) represents a firmly established therapeutic option for patients facing (non-)malignant haematological diseases. Despite its curative potential, however, this treatment is associated with substantial morbidity and mortality rates as well as a decreased quality of life. Given this context, a scientific void needs to be addressed: How do patients deal with the existential situation of being exposed to a life threat despite the curative potential of their treatment? This study aims to explore the patients' experiences considering their life threat in the context of the allo-SCT.

**Methods:** Qualitative semistructured, in-depth interviews were conducted with patients treated by allo-SCT over the course of transplantation (before, during or after hospitalization). Interview data were interpreted using category-based qualitative content analysis.

Results: Seventeen interviews were conducted. Results revealed a strong focus on hope and avoidance of dealing with the life threat. At the same time, challenges due to the lack of alternative treatments and the uncertain course were highlighted. The data revealed that patients wished to receive support by healthcare professionals, their carers and their social environment in general. Beyond that, patients desired to obtain honest information within an open discussion about a realistic prognosis and risk of treatment and course of disease.

**Conclusion:** The findings emphasize an interplay between hope, avoidance and psychological distress in the face of the patients' life threat. To assist allo-SCT recipients in navigating their life threat during treatment, it is desirable to establish avenues that provide adequate support.

Trial Registration: German Registry of Clinical Trials: DRKS00027290

Keywords: allogeneic stem cell transplantation; existential threat; haematopoietic stem cell transplantation; palliative care; patients

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## 1. Introduction

Allogeneic stem cell transplantation (allo-SCT) provides a firmly established treatment for high-risk or treatment-refractory (non-)malignant haematological disorders, including leukaemias and lymphomas. In this procedure, stem cells are obtained from a suitable donor and transferred to the recipient patient to supplement or replace their bone marrow and immune system.

The transplantation often serves as a final curative treatment option for patients who have not responded to other therapies or who have exhausted other treatment options. Despite its curative potential for a large proportion of patients, however, the procedure is associated with a high risk of complications and mortality [1-5]. The likelihood of allo-SCT being successful varies depending on the underlying disease, as evidenced by previous studies outlining a 5-year survival rate of approximately 50% [1]. This risk is largely increased by graft-versus-host disease (GvHD) [2, 6]. Other physical symptoms may include fatigue and sleep disruptions, gastrointestinal disturbances, nausea or sexual dysfunction [7-9]. In addition, many patients suffer from psychological distress [8, 10–12]. For example, a high prevalence of anxiety and depression [13] and high rates of posttraumatic stress disorder are described within patients [14].

Hence, patients who receive an allo-SCT have the prospect of being cured, albeit at the cost of a substantially high risk of developing severe or fatal complications. How these patients navigate the simultaneous presence of hope and the dread of their life threat is still largely unexplored [14]. In their respective studies, Gemmell et al. [15] and Barata et al. [16] emphasize the pivotal role of palliative care in alleviating distressing symptoms in patients, optimizing their quality of life and providing comprehensive treatment and support to them and their families. Most importantly, both studies also indicate potential palliative care needs that may often be unmet.

Therefore, this study's objective is to explore and describe patients' experience and views considering the life threat that accompanies allo-SCT and how they deal with it to optimize the care and support of patients during allo-SCT.

## 2. Methods

2.1. Study Design. This study is part of the AlloPaS project [17], the overarching goal of which is to design a palliative–supportive intervention for patients with allo-SCT in order to enhance their coping abilities and reduce their burden. A major part of the study covers patients' perspectives on the life threat associated with the allo-SCT. For this present study, qualitative data have been collected using narrative interviews. This approach aligns with the objectives of qualitative research, which is mainly to provide a detailed and broad understanding of individual experiences and views given their specific contexts rather than to be statistically powerful and to be able to generalize findings. This research adheres to the 'Consolidated criteria for reporting qualitative research (COREQ)' [18]. The Ethical Review Committee of the Medical Faculty of the University of

Cologne has approved this part of the study as well as the study protocol (number: 20-1370\_2).

In line with the WHO definition, palliative care in this study is understood as the relief of suffering and improvement of quality of life for patients and families facing life-threatening illnesses, regardless of the treatment phase. In this context, 'supportive' is specifically used to describe palliative care measures that address particular patient needs.

2.2. Participant Selection and Data Collection. From February 2022 to July 2022, we undertook semistructured interviews with patients who (A) were about to undergo allo-SCT, (B) were inpatients due to allo-SCT or (C) were in outpatient care for a maximum of 100 days following transplantation. This up to 100-day post-transplant time period was deemed relevant for capturing patients' peritransplant experiences in this pilot while minimizing potential recall bias.

Interviewing patients at these three distinct time points—before, during or after allo-SCT—allows, although not performed in a sequence per patient, to identify potential stage-specific challenges and an understanding of their evolving needs and experiences throughout the transplantation process. Two of the authors, A.R. (Health Services Researcher, M.Sc., female) and C.S. (Psychologist, M.Sc., female), who are both experienced in the qualitative paradigm, conducted the interviews.

An interview guide was developed by the interdisciplinary research team. The following themes were covered in the interview guide: (1) experience with haematological disease, (2) (potential) experience with life threat, (3) (potential) changes in goal of care and (4) (potential) last phase of life.

Patient recruitment was continued until achieving data saturation, which refers to a state in data collection when further interview data do not provide any new information on the content.

Patients who met the following criteria were included in this analysis: (a) indication for an allo-SCT for reasons of high-risk (SCT as consolidation) or treatment-refractory (SCT as salvage) malignant haematologic diseases, (b) age over 18 years, (c) a basic command of the German language and (d) to be able to consent. Patients were engaged in person by medical and nursing staff in outpatient and inpatient settings at the University Hospital of Cologne, Germany. In parallel, flyers were distributed, and inpatient visits were conducted by the study team to reach potential interview partners. Interested individuals received study information, a consent form, and a questionnaire about their sociodemographic data before their interview appointment.

Prior to the interview, interviewers obtained written informed consent by post or in person. In addition, the study team outlined the study objectives and content again verbally with participants before they provided written informed consent. In this process, a pseudonymized evaluation of the data was guaranteed, as was a rigid, protection-compliant handling of patient data.

Interviews were conducted either on the ward, virtually via video conferencing, or by phone. Due to the SARS-CoV-2 pandemic, as well as the sensitivity of the topic, we allowed patients to choose which form of interview they felt most comfortable with. Moreover, before the start of the interviews, we tried to create a trusting atmosphere so that participants would feel as comfortable as possible talking about a potentially stressful issue. Also, we provided knowledge about our background and the goals of the interview study.

Only the interviewer and the patient were present during interviews, which took place with a minimum of interruptions, e.g., due to necessary clinical procedures.

Patients were asked to respond freely to interview questions. Interviews were audio-recorded, transcribed verbatim and pseudonymized by a research assistant (M.L.) as well as a professional transcription office. Thereafter, audio recordings were randomly compared with transcriptions to guarantee their accuracy. Comprehensive field notes were taken following the interviews. Transcripts were not returned to participants.

2.3. Data Analysis. In order to analyse the interviews, the category-based content analysis suggested by Kuckartz [19] was used in a deductive-inductive manner. This approach was utilized to code clearly and systematically, allowing for a structured analysis.

Three independent coders (A.R., C.S. and M.L.) were responsible for this analysis. Codes were developed in an iterative process over several rounds until consensus was reached. After all coders had become familiar with the material, a code structure was developed deductively using the interview guide. In an inductive process, content from the text was then added to this structure and grouped to form categories.

For the analysis, the most current version of the qualitative analysis software MAXQDA 2022 Plus [20] was used.

#### 3. Results

In total, 17 of the 26 eligible patients contacted were interviewed. The remaining nine patients dropped out for the following reasons: subsequent death (n=1), non-participation due to the stressful subject matter (n=2), general loss of interest in participation (n=4) or study requirements no longer met (n=2).

Interview length spanned from 21 to 63 min.

The detailed sociodemographic data of the participants and medical data at the time of interview conduct can be found in Table 1.

## 4. Challenging Factors Related to Life Threat

4.1. Facing the Existential Realities Posed by Diagnosis. Patients described it as difficult to come to terms with their diagnosis and its existential threat. It was narrated as a shock, a blatant break in life that confronts one with their own

mortality. Feelings of being overwhelmed were associated with the diagnosis and the danger to one's life. Being confronted with this danger made acceptance of the diagnosis harder and complicated the tolerance of the life-threatening condition, not least because it was accompanied by the thought of potential death.

"You have cancer now [...] I don't know what I imagined before, but I think it was just different [...] As a person affected, you are first of all very intensively occupied with this condition: 'You have cancer, and it is life-threatening.' And then it rattles around up there. And then sometimes there are reactions that you simply can't foresee." (Patient no. 14)

4.2. Transplant as the Sole Chance for Survival. Allo-SCT often signifies a last chance, a prerequisite, for patients to be treated curatively and survive. To interviewees, the fact that no alternative treatments remained felt like a loss of control, as their life had been placed completely in the hands of healthcare professionals (HCPs). Most patients expressed a positive outlook, viewing the allo-SCT as a prospect for a cure and representing a source of hope. However, patients partly indicated that this treatment dependency was also distressing for them. The feeling of being unable to manoeuvre one's own life and having no alternatives, let alone being in this life-threatening situation at all, partially reinforced a loss of religious faith in some cases. This preoccupation primarily affected patients during their inpatient stay (B), or those in outpatient care (C).

"What is so extreme and what is also difficult for me is this lack of alternatives. [...] And this lack of alternatives is something that sometimes gets to me to a greater or lesser extent. And I can't do anything myself; I can only wait." (Patient no. 13)

4.3. Uncertainty Causing Anxiety and Fears. The life threat seemed to be the foremost challenge for all patients, as it involved uncertainty about their future health condition. Patients were plagued by anxiety and worries, as the risks associated with treatment were constantly present. They were especially preoccupied with concerns about whether the treatment would be effective and what would happen if side effects and major complications occurred that increased their life threat (e.g., fear of GvHD or transplant failure in general, as well as fear of recurrence). Some patients who had already undergone allo-SCT (B and C) explained that their immunodeficiency and consequent physical post-transplant symptoms were constant reminders of their own vulnerability, the potential complications of the allo-SCT, and the possibility of treatment failure.

"What is more present, what comes with the treatment, is the immune deficiency. [...] It's always buzzing around in your head that, you know, a fungal infection in the lungs,

ejec, 2025, 1, Downloaded from https://onlinelbrary.wiley.com/doi/10.1135/ecc/8743444 by Bibl. der Universitat zn Koln, Wiley Online Library on [10/11/2025]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-ad-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons Licensia

Table 1: Participants' sociodemographic and medical characteristics (N=17).

TABLE 1: Participants sociodemographic and medical characteristics	(1V = 17).
Gender (male/female/diverse)	
Male	15
Female	2
Age	
Median (range)	62 (24–75)
Religiosity	
Religious	9
Nonreligious	6
No answer	2
Mother tongue	
German	16
Spanish	1
Family status	
Single	3
Widowed	1
Married/in a steady relationship	11
Divorced/separated	2
Living situation	
Alone	4
With (spouse) partner	11
With children	5
With friends	1
With parents	1
Educational qualification	
No vocational qualification/not in vocational training	2
In vocational training	1
Vocational training completed	4
Completion of professional/master craftsman/academic training	10
Time of treatment	
(A) Were about to undergo allo-SCT	4
(B) Were currently inpatient because of allo-SCT	7
(C) Were in outpatient care for a maximum of 100 days after allo-SCT	6
Underlying haematological disease	
Acute myeloid leukaemia (AML)	10
Myelodysplastic syndrome (MS)	3
Acute lymphatic leukaemia (ALL)	1
Myeloproliferative neoplasm (MPN)	1
Lymphoma	3
Multiple myeloma	1
Haematopoietic cell transplantation comorbidity index (HCT-CI)	
Median (range)	2, 5 (1–6)
Number of allo-SCTs (planned)	
First	15
Second	2
GvHD	
Yes	14
No	2
No answer	1
Note: The table of general and general the growth of participants due to growth a cleating	

Note: The tally of responses can exceed the number of participants due to multiple selections.

or something similar, could mean the end. So, it wouldn't look so good in any case, would it? It accompanies you and also strongly influences your everyday life." (Patient no. 7)

Patients feared death and its agony, as well as mental breakdown, due to their constant worries about the life threat. They also expressed concerns about their carers and social environment as well as how others would cope after their own death.

"I don't really give a shit about [my life changes], it's more about the people around me. For them, it's more difficult than for me." (Patient no. 11)

## 5. Patients' Coping

5.1. Risk Awareness. Some patients described their struggle to come to terms with the diagnosis, the therapy and the associated life threat. Potential treatment risks were taken into account, and worst-case scenarios had been thought

through thoroughly. This awareness of therapy risks could act as a foundation for coping with the life threat. At the same time, however, this awareness did not exclude the hope of a cure and might coexist with the coping mechanisms named below.

"I can assess risks, and I can perhaps deal with probabilities. So, I would rather do something like that than play the lottery, because I know the probabilities." (Patient no. 14)

5.2. Focus on Hope. Patients conveyed a sense of hope when dealing with a potential life threat, which was often the decisive factor in the decision for allo-SCT. Those who had not undergone their transplant yet (A) firmly believed that the treatment would be effective and were frequently confident that side effects or complications would not affect them. Patients who had already experienced side effects after their transplant reported a belief that complications would decrease in the future. Therefore, an emphasis on recovery is present both during (B) and after hospitalisation (C). Going into treatment with a strong sense of optimism was considered necessary by many patients, as they described a positive attitude as a prerequisite for survival. This hopeful outlook became more apparent when patients shared thoughts about their future, describing how they looked forward to higher levels of vitality, enabling them to pursue hobbies or travel.

"And if it has gone relatively well so far, there is hope that it can also possibly lead to a cure. [...] I need optimism to go into a last chance with high risks. I must be positive." (Patient no. 1)

5.3. Avoidance. Patients often addressed the issue of a potential life threat evasively or did not wish to touch on it at all. Most patients expressed their desire to avoid confronting thoughts about their mortality. At the same time, they admitted the existence of thoughts about this threat but mentioned actively repressing them for the sake of their mental state.

"I don't worry about that at all. Because if you fixate on the side effects, then you wait for them to come. Then you pay much more attention to it, and then you notice much more." (Patient no. 11)

Moreover, some said they preferred to keep thoughts of mortality at the back of their minds for the time being. Thus, thoughts of mortality were present but 'far away for the moment' (Patient no. 6).

"And I think, so some psychologists in the seventies were saying you shouldn't repress. But I think that's nonsense. I just repress it. We all have to die sometime. And I'm in such good hands here, and I feel the same way, that I don't even allow that thought." (Patient no. 17)

## 6. Supportive Factors Concerning Life Threats

6.1. Preserving Inner Balance. To cope with the life threat, some patients explained that a sense of inner serenity helped them. In situations perceived as burdensome, they turned to themselves and described becoming quiet. Partly, this was accompanied by a need for autonomy in a few patients, which was associated with a sense of control. This balance was partially reinforced by the maintenance of structures in the patients' everyday lives.

"Yes, my greatest source of strength is first of all my own [...] inner peace somehow." (Patient no. 4)

6.2. Former Experience of Crisis. Former experiences of crisis, such as previous severe diseases or other adversities that have been overcome, gave patients confidence to face the life threat accompanied by their transplant. These former obstacles served as positive examples, helping them to deal with their condition and supporting their trust in previous coping strategies. Notably, before allo-SCT (Group A), previous experiences of crisis were seen as mental support for the upcoming treatment.

"I have already survived a stroke. I have already survived paralysis of the hands and legs. So I was already in acute danger of death in both cases. So I thought: So, you'll survive that here, too." (Patient no. 2)

6.3. Faith (Religion/Spirituality). Several patients revealed that faith and spirituality guided them in their uncertainty surrounding the course of the disease and therapy. Moreover, their faith community reportedly provided mental support and created a sense of belonging. These patients explained that they felt encouraged and empowered by their own prayers or the prayers of others.

"As I said, I am Christian, and I know that a lot of people from my church have prayed for me. That has also given me great strength." (Patient no. 2)

In addition, faith made the thought of death more bearable because it was not necessarily associated with finitude. Thus, faith helped patients manage the uncertainty of their future health conditions.

"Faith helps me in life now. But if you are extremely religious, death is something else, because it is the transition, so to speak, into a next life." (Patient no. 7)

6.4. Carers and Social Environment. Patients' social contacts were perceived as particularly helpful in dealing with the live threat. These included friends, family, religious communities or even neighbours. Above all, the role of spouses or steady partners was especially prominent. They were described as providing strength and reinforcing the patients' hope for a cure. Moreover, social contact helped to distract patients

and enabled them to openly discuss concerns, giving them an opportunity to talk about any uncertainty and make it more bearable.

"Yes, my wife strengthens me; that's no question. And she also takes care of me in a way that I didn't expect otherwise. But that's good, of course. And of course, the circle of friends is there too. [...] all this gives you a bit of peace, a bit of strength, and perhaps also a bit of serenity." (Patient no. 1)

6.5. HCPs. HCPs were frequently mentioned as a source of strength. Nursing staff and medical staff were particularly highlighted as being close to patients because they worked with them. However, patients also emphasised the relevance of other professional groups, such as those specialised in psychotherapy, palliative care, pastoral care, or sound therapy (e.g. singing bowls), who were described as having a calming effect.

A close relationship with these HCPs was perceived as valuable as it helped patients to feel seen. Considerable importance was attached to communicating with an honest and attentive professional counterpart who could take their fears and concerns to heart.

"I have never experienced such a relaxed atmosphere as here. So, I knew of many competent people who are medically absolutely top-class here. This has been totally confirmed by the behaviour of medical as well as nursing staff. And that gives so much strength that you don't get all these other, I say, destructive thoughts at all." (Patient no. 17)

6.6. Information and Knowledge. Patients indicated a clear need to understand their disease and its potential course including the life threat. They reported that this knowledge provided them with a sense of control, while open discussion of treatment risks reduced their brooding about existential concerns. This knowledge also prevented patients from reading anything into unclear communication or dubious sources on the internet when searching for information about their disease and life threat.

Additionally, personal interactions with other patients, whether in support groups, online forums or face-to-face, were also considered a valuable source of information. This interaction enabled a direct exchange of experiences with other patients, which was assessed as enriching.

"When I specifically asked [my doctor] about it, he of course knew exactly how high the mortality rate is (...) Yes, and to inform me about it without me specifically asking about it would have been good. That would have taken away a lot of my fears. And if the university hospital cannot provide films or something similar, then at least link to other universities or other hospitals. So that is very important, this social media today, because the patients also inform themselves there." (Patient no. 7)

However, there were also dissenting voices against this attitude that saw overly transparent communication as potentially overburdening.

"And I don't know if that's favourable when you have one patient and you overwhelm him with the full truth. Well, that can be too much for them (...) I think it is probably important during the medical information talk that you first find out what kind of person this is. Does he want to hear the truth? Or does he not care?" (Patient no. 14)

#### 7. Discussion

This is the first study to explore the experiences and views of patients with allo-SCT regarding the life threat due to the underlying disease and the allo-SCT itself. It reveals that patients employ avoidance when confronted with their life threat, while emphasizing their focus on hope. Prominent challenges faced included the unpredictability of the disease's course as well as the lack of alternative treatments. HCPs, the patients' carers and the social environment have been shown to pose a crucial supportive role. A desire for honest communication and comprehensive information considering prognosis and potential treatment options was underscored.

Firstly, it is worth highlighting that, independent of individual patient needs, initial structures such as psychooncological support, pastoral care and palliative care on a consultation basis as well as through regular interdisciplinary meetings are already in place to address the potential life-threat in patients.

The prominent role of hope for patients is to be emphasized. It encouraged patients in their decision to undergo allo-SCT and provided them with a source of strength. Also, it is crucial in caring for these patients to support and strengthen hope by many ways and by all professionals including psycho-oncology and palliative care specialists. A positive attitude regarding the allo-SCT and hope to get cured help the patient (and carer) for a better outcome and to cope with the life threat and uncertainty. Prior studies found that positive emotional experiences and constructs, such as hope, relate to health-promoting behaviours in patients with haematopoietic stem-cell transplantation [21, 22].

A similar phenomenon has been observed by Sachs et al. [23], who show that terminally ill patients use hope to actively act against their life threat. Falling into hopelessness, by contrast, threatens their ability to cope with their disease. Despite their fundamental difference in prognosis compared to this patient group, allo-SCT recipients can exhibit a similar response when confronted with an existential threat: an inherent ability to maintain hope and resilience. This focus on hope may carry a protective function and result in physical and psychological benefits [24–26].

Chen, Kuo and Tang [27] note that advanced and terminally ill cancer patients often do not maintain an accurate prognostic understanding. At first glance, the burden of diagnosis may contradict the patients' narrative of hope, for which Vehling et al. [28] provide a possible explanation:

patients' concerns and attitudes alternate between a sense of loss and a general commitment to life. These fluctuations vary widely among patients.

As allo-SCT is often considered the last chance for a cure, patients perceived a burden due to the lack of alternatives. At the same time, the treatment was intertwined with feelings of uncertainty, owing to the treatment's uncertain outcome, the likelihood of a palliative course and a fear of disease recurrence, as underlined in previous studies [29, 30]. Also, uncertainty was identified to be a significant predictive factor for symptoms associated with posttraumatic stress in patients undergoing allo-SCT [29]. Dunn, Arber and Gallagher [31] reinforce these findings, noting that allo-SCT recipients, despite the curative intent of their treatment, face existential crises that can contribute to considerable life disruptions, both psychosocially and physically.

Further, patients expressed a need for information regarding their potential life threat and a realistic prognosis. This might encompass comprehensive information about a potential palliative course, which could in turn support patients when faced with a potential end of life. In accordance with the patients' focus on hope, it is imperative to note that their will to survive and their commitment to candid communication regarding the life threat are not inherently contradictory. Therefore, HCPs must bolster the patients' hope while maintaining honest communication without ignoring the real prognosis. Affirming this, our results also underscore the importance Gemmell et al. [15] ascribe to the role of HCPs, who can provide essential information to patients about their treatment options. They indicate that the involvement of early palliative care can satisfy previously unmet needs, such as symptom control, emotional support and assistance with decision-making processes. Relatedly, Barata et al. [16] note that patients with a better understanding of palliative care tend to have more positive attitudes toward this type of care. In light of our study's findings, however, this aspect should be approached with caution, as some patients expressed concerns about (potential) harm related to facing the risk of dying at an inopportune time (i.e., around the allo-SCT itself). Nevertheless, education should be easily available to those who request it, as prognostic understanding was deemed 'extremely' or 'very' important by 88.9% of patients, according to El-Jawahri et al. [32].

## 8. Strengths and Limitations

We recruited significantly more men than women for this study, limiting deeper insight into the experiences of women and other genders. Our analysis also focuses solely on patients with a potential for cure. Moreover, despite our best efforts, we were not able to recruit patients after changes in goals of care by limiting life-sustaining therapies and near the end of life, restricting our understanding of their views.

Likewise, it would be a matter of interest to learn whether patients' perspectives on their situation change over the course of treatment, which could not be determined in a single interview by a patient. Despite these caveats, it should be emphasised that this study provides a wide range of insights due to its sample size. The inclusion of patients at different time points along the transplant trajectory should also be highlighted. This allows for a multifocal view of patients at various stages of treatment. Notably, the fact that interviews were collected from both outpatients and inpatients provides a comprehensive understanding of their experiences.

## 9. Conclusion

Patients see allo-SCT as their last chance for a cure. They tend to be reluctant to confront the life threat, even when they have hope and seem to be dealing with the issue. HCPs have a crucial role in addressing and supporting these emotions. At the same time, maintaining comprehensive and honest communication and educating patients about various treatment options are paramount—best at the time of diagnosis or indication of allo-SCT. Therefore, using accessible and low-barrier approaches (e.g., brochures, videos and conversation opportunities) might increase the patients' well-being during the treatment course.

To examine individuals' perceptions of their life threat further, it would be valuable to conduct a study of patients' understanding, especially of those potentially facing a palliative course, focussing on their cognitive processing and its impact on their decision-making. This could deepen our understanding of patients' individual needs and perspectives, helping to further improve communication and care practices.

## **Data Availability Statement**

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions.

## **Ethics Statement**

The Ethical Review Committee of the Medical Faculty of the University of Cologne has confirmed that no ethical approval is required (number: 20-1370\_2). Research was carried out in accordance with the relevant guidelines and regulations of this ethical review committee and the Declaration of Helsinki.

#### Consent

The authors have nothing to report.

## **Conflicts of Interest**

The authors declare no conflicts of interest.

## **Author Contributions**

S.T.S., U.H. and M.H. designed the study and coordinated the research project. A.R. and C.S. conducted all interviews with patients. A.R., C.S. and M.L. were involved in the data analysis. A.R. wrote the first draft of this article. B.S., A.P. and R.V. contributed to the interpretation of the analysis results. They contributed by providing key feedback and revising this manuscript's draft. All authors read and revised the manuscript. All authors approved the final manuscript version and agreed with its submission.

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