


Research in haematological cancers: What do patients in the Netherlands prioritise?

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Abstract

Introduction: The experiential knowledge of patients can provide research communities with complementary perspectives on disease. The aim of this study was to identify and prioritise everyday problems and research needs of haematological cancer patients and people who have undergone a stem cell transplantation.

Methods: A mixed-method participatory research approach (the Dialogue Model) was applied, including interviews ($n = 19$), four focus group discussions ($n = 27$), a questionnaire ($n = 146$) and a stakeholder dialogue meeting ($n = 30$) with patients in the Netherlands.

Results: Patients' physical discomfort, psychosocial issues, problems with the health-care system and policy issues were highlighted. Respondents prioritise research aimed at factors potentially influencing survival, such as lifestyle, and research aimed at improving patients' quality of life, for example improving memory and concentration problems. Topics also focused on physical discomfort, causal mechanisms, and healthcare organisation and policies. Research of a social scientific character is underrepresented, and as such, patients' everyday problems are not all directly reflected in the research agenda.

Conclusions: Our findings indicate that patients, besides emphasising the importance of improving survival, have a clear desire to increase control over their lives.

KEYWORDS

haematological cancers, patient involvement, research agenda

1 | INTRODUCTION

Patients are confronted on a daily basis with the consequences of their disease and its impact on their lives. As a result, they possess unique knowledge—experiential knowledge—that is complementary to the expert knowledge of healthcare professionals and researchers (Chalmers, 1995; Faulkner & Nicholls, 2001; Telford, Beverley, Cooper, & Boote, 2002). Caron-Flinterman, Broerse, and Bunders (2005) define experiential knowledge as “the often implicit, lived

experiences of individual patients with their bodies and their illnesses as well as with care and cure” (p. 2576).

In the period 1975–2001, there have been spectacular increases in survival rates of many haematological cancers (Siegel, Miller, & Jemal, 2016). Increased survival rates are associated with increased incidences of late effects of treatment (Miller et al., 2016). As a result, there is a growing call for the involvement of patients in oncology research and care (Efficace et al., 2012; Zucca, Sanson-Fisher, Waller, Carey, & Boadle, 2017). Haematological cancer patients, often still

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affected by their disease and the treatments they have undergone, can contribute meaningfully to the research decision-making process on the basis of their experiential knowledge (Caron-Flinterman et al., 2005). A validated method to both empowering patients to voice their experiences and needs, and providing input to research communities, is to establish a research agenda from the patients' perspective (Abma & Broerse, 2010). Such a research agenda can promote a dialogue between patients, researchers, healthcare professionals and policymakers (Abma, 2006; Abma & Broerse, 2010; Pittens, 2013).

Patients are increasingly involved in the setting of research agendas (Pittens, 2013). Three arguments are often used to justify patient involvement (Telford et al., 2002). First, the *substantial* argument highlights the complementary nature of patients' experiential knowledge. Second, patients, as stakeholders most directly affected by the outcomes of scientific research, have the *moral right* to be involved in the decision-making process concerning their disease (Goodare & Smith, 1995; Popay & Williams, 1996). Third, the *political* argument stresses that the involvement of patients in research increases the legitimacy of research because it is more consistent with the needs of the target population (Collins & Evans, 2002; Williamson, 2001). On the basis of substantial, moral and political arguments, we can hence advocate the benefits of setting a research agenda from the perspective of people with haematological cancer or who have undergone stem cell transplantation (SCT).¹

2 | RESEARCH PRIORITIES OF PEOPLE WITH HAEMATOLOGICAL CANCER

The research priorities of people with haematological cancer have only sporadically been articulated: Clinton-McHarg, Paul, Sanson-Fisher, D'Este, and Williamson (2010) and van Merode et al. (2016) have investigated the research priorities of adolescents and young adults (AYAs) with haematological cancer and of people with multiple myeloma (MM) or Waldenström disease (WD) respectively. In Clinton-McHarg et al. (2010)'s study, AYAs prioritised: (a) clinical medicine aimed at finding better treatments and (b) psychosocial research aimed at improving physical, psychological, social and spiritual outcomes for patients diagnosed with haematological cancer and their families. Patients with MM or WD prioritised: (a) improved communication with healthcare professionals and (b) reduced burden of neuropathy (van Merode et al., 2016).

In both of these studies, the consulted patient community was relatively confined and people's everyday problems and concerns regarding the consequences of their disease were not investigated. It has been shown that enclave deliberation, namely the empowerment and development of a shared voice based on collective experiences, reduces the chance that patients are replicating media or healthcare professionals' priorities (Nierse & Abma, 2011).

In this study, the everyday problems and concerns of people with haematological cancer were articulated prior to the

formulation and prioritisation of their research needs in order to formulate a research agenda from the patients' perspective. In addition to extending the results of abovementioned studies to a broader target population by including the perspectives of haematological cancer patients of all ages and a wider range of diagnoses, the present study aims to contextualise people's research needs with their everyday problems and concerns. This led to the following research questions:

1. What are the everyday problems and concerns of people with haematological cancer?
2. Which research themes/topics are relevant according to people with haematological cancer?
3. To which research themes/topics do people with haematological cancer give priority?

3 | METHODOLOGY

3.1 | Research approach

To involve patients in research decision-making, a knowledge co-creation process is required in which: (a) patients' experiential knowledge is explicated, (b) integrated with expertise from researchers and healthcare professionals and subsequently (c) embedded in health research, care practice and policy (Pittens, 2013; Regeer & Bunders, 2009). A mixed-method participatory validated research approach to explicate patients' knowledge is the Dialogue Model (Abma & Broerse, 2010; Broerse, Elberse, Caron-Flinterman, & Zweekhorst, 2010). Six principles guide the model: active engagement of patients, favourable social conditions, respect for experiential knowledge, dialogue, emergent and flexible design, and process facilitation. The Dialogue Model originally comprises six phases, of which the first four were executed in this project: (a) exploration, (b) consultation, (c) priority setting and (d) agenda setting. The fifth and sixth phases (programming and implementation) of the model are more policy-oriented and will therefore be part of Hematon's follow-up policy strategy.

The study was a collaborative effort between the Vrije Universiteit Amsterdam and the patient organisation Hematon. To optimally benefit from the knowledge co-creation process, a project team was established comprising three academic researchers (authors of this study) and three Hematon volunteers (volunteer MvdB is also author). Within this team, all substantive decisions regarding the progress and the intermediate results were discussed. Two academic researchers (AS and BdG) were responsible for the daily execution of research activities. In addition to the project team, seven leading experts in the field of haemato-oncology and funding agencies were invited to participate in an advisory board. All members of this board were interviewed prior to data collection. The board also met twice in plenary to provide advice on the progress of the study, to discuss the preliminary research findings and to assist in the implementation of the results.

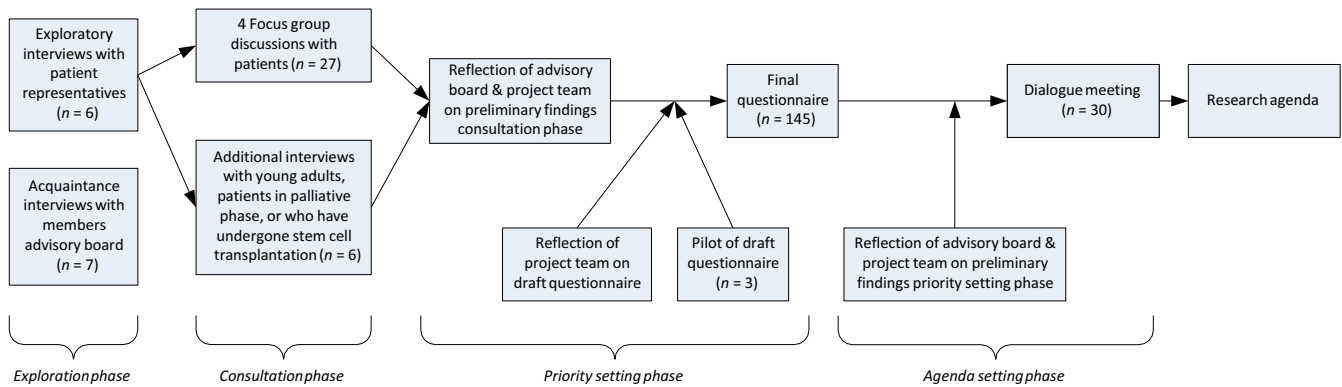


FIGURE 1 Chronological overview of the 4-phased study along the lines of the Dialogue Model (Abma & Broerse, 2010)

3.2 | Data collection

Data were collected between January and October 2016. The study can be divided into four largely consecutive phases (see Figure 1).

3.2.1 | Exploration phase

Six exploratory semi-structured interviews with patient representatives provided insights into commonly discussed everyday problems and concerns of the target population. Interviews were conducted in person, except for one interview by phone. Respondents comprised active volunteers for the patient organisation, who were also experiential experts.

Additionally, seven professionals from health care, research, funding and policy were invited for an informal interview. During this conversation, patient involvement in research in general, the project itself and the role and responsibilities of the advisory board for which they were invited were discussed.

3.2.2 | Consultation phase

Based on the findings of the exploratory phase, four focus group discussions (FGDs) and six additional semi-structured interviews were organised to further identify everyday problems, concerns and research needs of the target population. A total of 33 patients took part (see Table 1 for more details).

Based on participants' preferences, FGDs were allocated to the phase of the disease:

1. people in the "Wait & See" phase of their disease, who had been diagnosed with haematological cancer but who had not received a treatment yet,
2. people who had been treated and whose haematological cancer was "In Remission" (but not eradicated),
3. people who were declared cured over approximately 10 years ago but who experienced late side effects of the treatments ("Cured, but late side effects"),
4. people who were undergoing treatment or who had undergone an SCT ("SCT/In treatment").

Participants were recruited via Hematon, several hospitals and social care meeting venues for people with cancer. FGDs lasted 2.5 hr and comprised the following parts: (a) introduction; (b) identification of everyday problems of individuals; (c) identification of concerns; (d) proposing research ideas to address these problems, concerns and any other research topics. Any proposed solutions outside of the realm of scientific research were noted, but not further discussed.

Following the FGDs, additional interviewees ($n = 6$) were recruited through purposeful sampling to include the perspectives of underrepresented patient groups. These were an AYA ($n = 1$), someone who did not suffer from a haematological cancer but who had undergone an SCT ($n = 1$) and patients in the palliative phase ($n = 4$). Interviews were conducted until data saturation was achieved. Two interviews were conducted face to face; the other interviews were conducted by phone. The interview guide was comparable to the FGD set-up.

3.2.3 | Priority setting phase

The research ideas identified during the consultation phase were discussed within the project team to reformulate ambivalent topics and merge overlapping issues, and to specify broadly defined topics and to categorise them. The goal of this reformulation was to make the research topics broadly comparable and understandable to a wide audience; key words in each topic were briefly explained. Some 32 research ideas were categorised into six research themes, each consisting of five to six more specifically defined topics. Prioritisation of the research topics by the patient community took place through a questionnaire. Respondents were asked to rank the topics within each theme and to rank the overarching themes. In addition, respondents could add topics that they had missed in the questionnaire. These were, however, not prioritised. Following the ranking, respondents were asked to answer questions about their haematological cancer (type of haematological cancer, past and current treatments) and their personal details (age, gender, visits to meetings organised by Hematon). Last, respondents were asked to evaluate the questionnaire.

The questionnaires were available digitally and on paper and were piloted by three members of the target population to check comprehension,

TABLE 1 Participants in focus group discussions (FGD) and individual interviews in the consultation phase

Data collection	No. of participants	Gender (M/F)	Average year of birth ^a	Haematological cancer (AL/CL/NHL/HL/WD/MDS/MM/Other)	Level of education (H/M/L)	Average year of diagnosis ^a
FGD Wait & See	7	5/2	1952	4 × CL/1 × HL/1 × NHL/1 × MM	3 × H/1 × M/3 × L	2011
FGD SCT/In Treatment	6	1/5	1963	2 × CL/2 × AL/1 × NHL/1 × MM	4 × H/2 × L	2007
FGD In remission	8	6/2	1952	1 × CL/1 × AL/1 × NHL/2 × WD/3 × MM	7 × H/1 × M	2011
FGD Cured, but late side effects	6	1/5	1959	1 × AL/3 × HL/1NHL/1 × WD	4 × H/1 × M/1 × L	1986
Individual interviews	6	3/3	1956	2 × AL/1 × MDS/1 × WD/1 × MM/1 × Other: SAA	Unknown	2008
Total	33	16/17	1956 (STD: 11.04)	6 × AL/7 × CL/4 × HL/4 × NHL/4 × WD/1 × MDS/6 × MM/1 × Other: SAA	18 × H/3 × M/6 × L	2005 (STD: 11.8)

Notes: Classification of education-level based on Statistics Netherlands [Centraal Bureau voor de Statistiek].

AL: Acute leukaemia (lymphatic and myeloid); CL: chronic leukaemia (lymphatic and myeloid); HL: Hodgkin lymphoma; L: low education level; H: high education level; M: middle education level; MDS: myelodysplastic syndrome; MM: multiple myeloma; NHL: Non-Hodgkin lymphoma; SAA: severe aplastic anaemia (non-oncological); STD: Standard deviation; WD: Waldenström's disease.

^aData collected in 2016.

ease of use and relevance. Recruitment of respondents took place via several communication channels of Hematon and all academic hospitals in the Netherlands. The questionnaire was open for response for two months. After one month, reminder calls were sent out to members of Hematon to increase the response level. In total, 146 people completed the questionnaire. The study targeted a diversity of respondents regarding their diagnoses and treatments; in a representative sample of the target population, people with rare haematological cancers would only compose a small population of respondents (see Table 2).

3.2.4 | Agenda setting phase

The nine highest prioritised research topics were discussed at a three-hour dialogue meeting at which 30 stakeholders were present, including patient representatives ($n = 13$), haematological oncology healthcare professionals and researchers ($n = 6$), and representatives from funding authorities ($n = 6$) and the pharmaceutical industry ($n = 5$). During this meeting, the topics were discussed in two rounds of small group discussions, focusing on three guiding questions: (a) What are the unanswered scientific questions on this topic, or does it entail an implementation or communicative issue? (b) What type of research is most relevant to solve this issue? (c) What collaborations can be useful and who is responsible? Following the discussions, a plenary session provided participants the opportunity to exchange the insights.

3.3 | Data analysis

The exploratory interviews and FGDs were audio-recorded and transcribed verbatim. Summaries of interviews, FGDs, the dialogue meeting, meetings with the project team and the advisory board were sent to participants for member check within 2 weeks. The everyday problems and concerns in the interviews and FGDs were analysed through a broad interpretive thematic approach, guided by the principles of grounded theory (Green & Thorogood, 2004); the transcripts were openly coded by author [BdG] using ATLAS.ti analysis software, followed by more selective coding and categorisation. Frequent discussions with the other authors of this study guided the exploration of the themes. The causal links and relationships between the everyday problems and concerns, as identified by the participants, were visualised in a problem analysis (see Figure 2).

The qualitative data of people's everyday problems and concerns were complemented by the quantitative analysis of the questionnaire results, executed by the first author [AS]. Research topics were ranked across themes by taking equal account of the topics' position within the theme and of the themes' ranking. This calculation of the allocated points resulted in a prioritised list of all research topics. In this system, respondents could not indicate the relative weight of each of their priorities; for example, the difference in importance of their priorities was not necessarily equal between the topics, between the themes or between respondents. Therefore, to do justice to the gross prioritisation while avoiding façade precision, clusters of high, medium and low priority were created. The five most highly prioritised topics were included in the "high-priority" category. Additionally, it was decided to include the highest prioritised topic

TABLE 2 Respondents of the questionnaire in the priority setting phase

Demographics	Total ^c	Total %
Type of haematological cancer		
AL	15	9.7
CL	38	24.7
Lymphoma	49	31.8
MDS	9	5.8
MM	25	16.2
WD	14	9.1
No disease	2	1.3
Other	2	1.3
Total	154	100
Treatment (Past and current)		
Wait & See	32	15.0
Non-intensive treatment ^a	74	34.6
Intensive treatment ^a	28	13.1
SCT	50	23.4
Palliative/terminal care	4	1.9
Other	25	11.7
I don't know (anymore)	1	0.5
Total	214	100
Gender		
Male	68	46.6
Female	78	53.4
Other	0	0
Total	146	100
Age ^b		
0–18 years	1	0.7
19–30 years	4	2.7
31–45 years	18	12.3
46–60 years	61	41.8
61–75 years	57	39.0
>75 years	5	3.4
Total	146	100
Visits to meetings of Hematon		
No visits to meetings	60	40.5
Non-active (annual or fewer visits to meetings)	50	33.8
Active (more frequent than annual visits to meetings)	19	12.8
Volunteering at Hematon	19	12.8
Total	148	100

Notes. AL: Acute leukaemia (lymphatic and myeloid); CL: chronic leukaemia (lymphatic and myeloid); lymphoma (Hodgkin and non-Hodgkin); MDS: myelodysplastic syndrome; MM: multiple myeloma; SCT: stem cell transplantation (allogeneic and autologous); WD: Waldenström's disease.

^aNon-intensive treatment was translated to patients' sphere of understanding as chemotherapy, radiotherapy and/or immunotherapy in a room *without* air handling system or ship lock. Intensive treatment translated to these treatments, in a *private* room *with* air handling system or ship lock. ^bData collected in 2016. ^cNumbers do not always add to the grand total, and as in some questions, multiple answers were allowed.

of each theme in this category to ensure that all themes were represented at least once. This resulted in a "high-priority" category comprising nine research topics. A similar approach was chosen to determine which topics belonged to the "middle-priority" category; the ten next most highly prioritised topics and the next most highly prioritised topic of each theme were included in the "middle-priority" category. Twelve topics were included in this category. All eleven remaining topics were classified as "low priority." It was not possible to statistically stratify the results. However, trends in prioritisation of topics along the various treatments were examined.

4 | RESULTS

In this section, we first present the results on patients' everyday problems and concerns as identified in the consultation phase of this study. This is followed by information about the prioritisation of the research topics. Last, the results of the dialogue meeting are briefly described.

4.1 | Analysis of everyday problems and concerns

Participants in the FGDs and interviews provided a broad palette of everyday problems and concerns with respect to their haematological cancer. As is illustrated in Figure 2, the issues were clustered into four categories: problems in/around the healthcare system, societal problems, psychosocial problems and physical problems. In addition, participants identified relations between the various issues, and the root of the problem is presented at the bottom, leading to consequences higher up in the figure. A reduced quality of life is the ultimate consequence of people's everyday problems and concerns.

4.1.1 | Diagnosis and treatment of haematological cancer

Participants place the haematological cancer (the diagnosis, the disease itself and the treatments undergone) at the heart of many of their personal problems and concerns. In co-morbidity situations, participants reported a problematic process of getting diagnosed correctly and rapidly. All participants indicated the disease influences their life on various levels; the disease itself as well as the treatment causes physical problems, and participants also emphasised the psychological impact of the disease:

It feels like you're never really cured, it can return any moment. Do I have a year, or ten years to live? That uncertainty is hanging above my head. (P3, FGD In Remission)

4.1.2 | Physical problems

The haematological cancer and the treatments that participants undergo result in a wide range of physical problems. Participants regard these as a complex and interdependent set of symptoms. Extreme and/or chronic fatigue, both cognitive and physical, is the

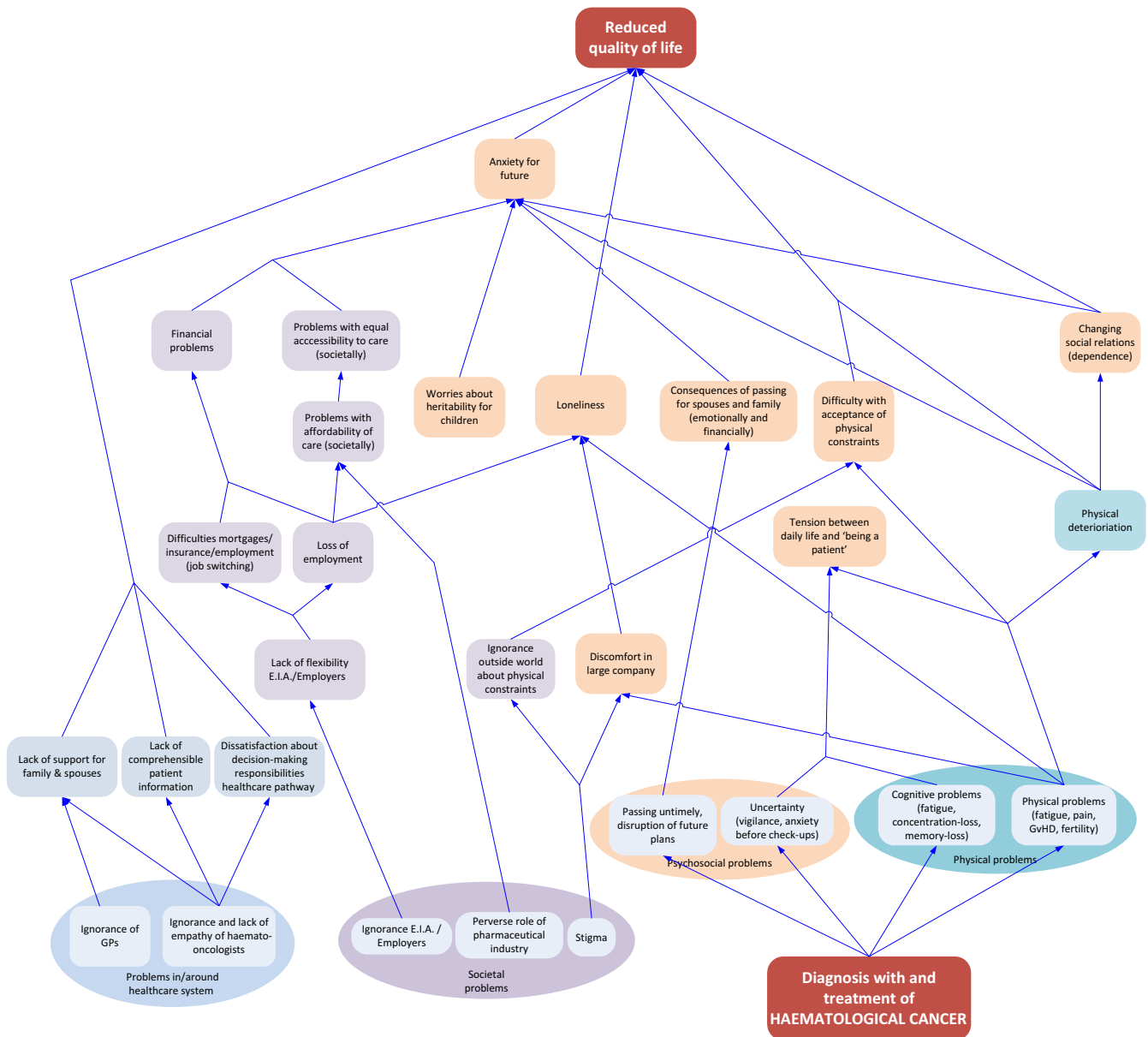


FIGURE 2 Overview of causal analysis of everyday problems and concerns of people with haematological cancer. EIA: Employees Insurance Agency [in Dutch: UWV]. In blue: problems in/around the healthcare system, in purple: societal problems, in orange: psychosocial problems, in green: physical problems, in red: cause and (ultimate) consequence

most pressing issue discussed. For many participants, this hinders their daily life substantially:

Around three pm, a blanket of fatigue covers me. [...]. I simply can't do anything anymore, not even drive home from work. (P1, FGD In Remission)

There are different types of fatigue. When your body simply isn't functioning, or a kind languor when I can't think straight anymore. And a feeling of inertia when everything just slips away. (P7, FGD In Remission)

In addition to the fatigue itself, the unpredictability and invisibility of the fatigue "the man with the hammer" hinder respondents in

making and executing daily plans. Other physical issues are chronic muscle ache (during physical effort), backache, neuropathy and plexopathy, loss of sense of smell and taste, reduced fertility, reduced sexual potency, shingles, problems with various organs (oesophagus, stomach, bowels, heart, kidney, liver, lungs) and problems with wound healing. Furthermore, allogeneic SCT is a source of severe physical problems, often collected under the umbrella-term graft versus host disease (GvHD). Often-mentioned symptoms of GvHD are ophthalmologic problems and extreme dryness of the skin. Participants also describe painful mucosa, difficulty in swallowing, and loss of hair and dental problems.

Furthermore, highly prevalent cognitive side effects of treatments, such as memory-loss and concentration issues, commonly referred to as the "chemo-brain," were discussed in interviews in

the exploration and consultation phase. An interviewee explained how it had affected her professional career as she had concentration problems:

R2: "After the transplantation I could not multitask anymore. Well, especially for a woman, that's a surprise! And it's hard, too."

Interviewer: "And why was this? That you didn't manage?"

R2: "No oversight. Your memory needs to keep track: if I first do this, then I can do that next, because then afterwards I'll return there... Well, that was never my strongest suit, but the transplantation puts a magnifying glass on your weaknesses." (R2, Individual interview)

4.1.3 | Psychosocial problems

From the diagnosis throughout the course of the disease, participants note the emotional and psychological impact of the disease on their lives. A poignant issue is the uncertainty that accompanies the disease: many participants fear its return or revival. Participants express an increased vigilance towards their body, and they have to cope with unpredictable episodes of fatigue. To them, the diagnosis is a lifelong sentence:

P3: "I was naive to be thinking, in a few years I'll be my old self again."

P1: "But that won't happen..."

P3: "Never" (FGD SCT/In Treatment).

The fear of an untimely death also disrupts participants' future plans. Concerns about their own death are often linked to worries about the practical, financial and emotional well-being of their family members:

For my spouse, it [untimely death] will be a financial burden, I think, [...] She will have to continue on her own. The children will miss their dad. They are a little older [...] but still, losing your father at that age is terrible. (P5, FGD Wait & See)

Acceptance of one's physical constraints and deterioration is often experienced as difficult. Participants feel a tension between their lives "as a patient" and their daily routines:

You're living in two worlds, so to say. There is the world of being a patient, having been diagnosed and frequently visiting the hospital for check-ups. Lying in

bed in the morning, thinking: what am I feeling? Is this a warning sign? And then there is just my normal life, going to work and fully enjoying all the fun things of life. (P7, FGD Wait & See)

Also, social relations with spouses and relatives change as participants are apprehensive of becoming emotionally and practically dependent due to physical deterioration. Marriage is often put to the test, as partners are also affected:

You don't get cancer by yourself, you have to fight it together [as spouses]. If you both deal with the anxiety in a different way, there are two parallel circuits. That can be harder than expected. (P4, FGD In Remission)

Related to changing social relationships, loneliness is fuelled by societal problems, such as loss of employment, as well as by people's physical fragility and by restrictions on being in large groups due to the suppressed immune system after treatment:

After the transplantation from a donor, you have to follow a number of commands. [...] Don't go to the supermarket, no theatre visits, [...]. If you have visitors, no more than 6 in your living room, etcetera. In the beginning, you agree to take these measures until you grow stronger and you don't have to take medication, which suppresses your immune system anymore. But 2.5 years later, I'm still on this medication. [...] It's a lonely life. (R4, individual interview)

4.1.4 | Problems in/around healthcare system

Participants have unmet expectations of their healthcare providers. Ignorance and a lack of empathy of haematological oncologists are frequently mentioned. Many participants feel they are not treated as a person; they experience a lack of recognition and understanding for what they, as patients, are going through:

It's tough, but in the medical world we are all just a number. (P2, FGD Cured, late side effects)

For their relatives, support is even scarcer. Although participants can show an understanding of their specialists' professional distance, unclear, incomprehensible and ill-timed information provision means that less support is available to them. Following hospital discharge, participants are often especially disappointed by the limited knowledge of their family doctor (GP) regarding their disease and its long-term consequences:

Then you arrive at the GP on duty [...] and sometimes they will draw conclusions which don't make any sense at all. Then you'll think, whatever, I'll just go back home. (P2, FGD SCT/In Treatment)

Regarding participation in decisions regarding healthcare, some participants feel that other patients should take more control. However, not everyone wants shared decision making; some people prefer to hand over all responsibility to their treating physician. Especially in acute situations, it can be difficult to make decisions with long-lasting consequences, for example regarding treatment options which can affect patients' fertility:

"Sometimes you have to decide within 4 hours for the rest of your life!" [regarding a fertility-saving surgical procedure] (P6, FGD SCT/In Treatment)

4.1.5 | Societal problems

Many participants consider the word "cancer" stigmatising; bystanders are said to "jump on the brakes" when they hear about the diagnosis. A respondent explains that the treatments and severe GvHD have changed her appearance. On the streets, people stare at her, express their unsolicited compassion or seem to gossip about her. Her children are told by peers their mother looks "weird." Such experiences add to tension between participants' "daily life" and their "patient life," increasing their loneliness.

In addition to the stigma, participants face incomprehension as their disease is "invisible," while their physical constraints are not:

People don't see from the outside that you're ill on the inside. That is difficult, also for the outside world. (P3, FGD Cured, late side effects)

In addition, many participants experience problems at work. Provision of alternative employment or adjusted employment circumstances is often problematic, and employers are afraid their sick employee will be expensive. Some participants report disputes with their employers, during which support is lacking. Often, loss of employment is particularly painful as participants would like to maintain an active role in society:

Well I do remember, the moment I received that call from the UWV [employee insurance agency] to tell me I was unfit for work, yes that gave me some good cries. (P1, FGD SCT/In Treatment)

Participants criticise the lack of flexibility and the ignorance of the Employee Insurance Agency (in Dutch: UWV), which is the government agency responsible for helping unemployed people find suitable work:

You're simply in a treadmill, and you're being sent from pillar to post. My situation is rather extraordinary because my employer doesn't want to discharge me, because he then needs to pay a transition fee, even when the employee has been ill for two years. That is very demotivating. (P4, FGD SCT/In Treatment)

These factors contribute to the loneliness experienced by participants. In addition, the financial aspect of participants' inability to work is discussed. Insurance sometimes covers participants' loss of income insufficiently on the long term. Gaining a mortgage or taking out new insurance can be problematic because of people's medical record, reducing their financial status further.

4.1.6 | Anxiety for the future and a diminished quality of life

As the haematological cancer directly affects personal futures, participants describe an anxiety about their future, diminishing their current quality of life. In addition, factors such as loneliness and difficulty with accepting physical deterioration contribute to an experienced lower quality of life. Many participants fear physical deterioration, dependence on family or social care, and a long and painful deathbed:

For me, I'm worried to die in a really ugly way.

Interviewer: "What do you mean with ugly?"

Well, that your body really collapses and that you get a lot of pain, and that you can't do anything anymore. And that the family also can't take it any longer. (P3, FGD In Remission)

They also want to receive more, truthful information about the palliative phase of their care pathway. Participants with a strong desire to stay independent expressed the wish to commit euthanasia when necessary. On a societal level, participants are concerned about the continued accessibility and affordability of health care, acknowledging the high costs of treatment and low prevalence of specific diseases. However, these issues are discussed with less urgency than people's more personal worries.

4.2 | Research agenda

In this section, the quantitative analysis of the prioritised research needs is presented. This prioritisation is interpreted with the input gathered during the consultation phase and the dialogue meeting. All research themes and individual topics on the research agenda are presented in Table 3.

In the high-priority cluster, the top-5 topics belonged to two main research themes; "factors influencing survival" (24.6% of all allocated points) and "improving well-being and quality of life" (20.8% of allocated points). The methodological choice was made to include one topic of each of the other four research themes ("relieving physical discomfort," "understanding mechanisms of disease," "improving organisation of healthcare (system)," "policy issues") in the highest priority category. These topics are marked with an * in Table 3. These themes were awarded 17.9%, 14.9%, 12.3% and 9.5% of the allocated points respectively. Below, we elaborate on the topics that were assigned to the high-priority category.

4.2.1 | Factors influencing survival

The role of lifestyle was the highest prioritised topic in this theme. To participants in FGDs, lifestyle revolves around the prevention of the disease, as well as improving the quality of life and chances of survival. The underlying experienced problem contributing to this research topic is a lack of control in the occurrence and course of the disease; participants feel they can fight their feelings of helplessness and passivity by taking control of their lifestyle:

Well I think nutrition gives you some hold on life, and I think it's nice to have the idea that you can actually do something, next to taking all these terrible pills. (P4, FGD SCT/In Treatment)

The topic of the effects of standardised check-ups on survival was also highly prioritised. Participants describe a level of arbitrariness in the continuation of check-ups after they have been declared cured, while their vigilance continues to exist:

There is this vigilance, you're continually alert. [...]. It's difficult whether to take yourself seriously, you keep wondering whether you're a hypochondriac or whether it is wise to be on the alert all the time. (P2, FGD Cured, late side effects)

Participants to FGDs advocate research into the effects of standardisation of aftercare. Also, they would like to improve the efficacy of these check-ups and be provided with information regarding the late side effects of treatments. Some participants experience the check-ups as an emotional burden because it reminds them of the possible return of the disease.

Participants also highly prioritised research into the role of environmental context on survival. "Environmental conditions" can vary between bacteria in the domestic sphere, toxic substances or air pollution, and research can span the influence of environmental conditions on the occurrence of the disease, as well as its effect on people's survival after treatment.

4.2.2 | Improving well-being and quality of life

Improving memory and concentration problems ("chemo-brain") is highest prioritised in this theme. Research questions can focus on the mechanism of occurrence, prevalence and effective relief strategies. For example, in the consultation phase, an interviewee was curious about the efficacy of existing or new training schemes, such as neuro-feedback training, to improve patients' memory and concentration.

The lack of emotional and practical support for participants' family members was an often-mentioned issue in the FGDs. Participants want to know which support schemes can be effective in improving the well-being and quality of life of their spouses and children, and how this would affect their own quality of life. Attendees at the dialogue meeting agree that haematological oncologists generally pay

little attention to the emotional well-being of family and friends, assigning such care to the oncological nurse mentoring the patient.

4.2.3 | Relieving physical discomfort

Relieving the long-term side effects of treatments was considered the most important research topic in this theme. Participants who were diagnosed and treated for their haematological cancer in the distant past face ignorance and a lack of interest in relieving the long-term side effects of the treatments:

I notice that physicians and researchers prefer to focus on the large group of patients with whom they can truly achieve something in the curation part. The late effects, especially when the numbers of patients are small, then it gets tricky. Every time I hear again, we're sorry, but we don't know what your risk is because we've never studied it. (P2, FGD Cured, late side effects)

As the survival rates of people with haematological cancer have increased, the group of survivors experiencing late side effects is growing. Attendees at the dialogue meeting suggested utilising an existing database of side effects of treatments to map out more extensively the side effects of current and new treatments. Their rationale was that only when the late side effects are properly inventoried will it be possible to study how to relieve them.

4.2.4 | Understanding mechanisms of disease

Many participants highly prioritised the topic of "personalised medicine," namely treatment approaches aimed at customising the therapy to the individual patient to maximise its chance of success and reduce overtreatment. This topic was classified as fundamental research because it includes recent developments in, for example, immunotherapy. To some participants, immunotherapy was a "buzzword" because they were particularly interested in improving their chances of being cured:

Now that immune system, [...] directed by immunotherapy, that is supposedly *the* solution. [...] It's the personalised solution to make your immune system work for you to destroy those cancerous cells. (P2, FGD Wait & See)

Attendees at the dialogue meeting plead for international collaborations to encourage a focus on this research topic. At the same time, they warn against false hope; they consider it the responsibility of patient organisations and haematological oncologists alike to temper the high expectations of some patients regarding this topic.

4.2.5 | Improving organisation of healthcare system and policy issues

More interdisciplinary collaboration between medical and non-medical professionals, such as haematological oncologists, psychologists,

TABLE 3 All research topics under the accompanying research theme, with relative importance of each topic within the theme and the relative importance of the themes as well as the assigned priority clusters

	Assigned priority cluster	Relative priority topics (%)	Relative priority theme (%)
Theme: Factors influencing survival			
The role of lifestyle on survival	High	23.8	24.6
The effect of standardised check-ups on survival	High	22.9	
The role of environmental conditions on survival	High	19.3	
The effect of vaccinations on survival	Middle	18.0	
The effect of self-medication on survival	Middle	16.0	
Total		100	
Theme: Improving well-being and quality of life			
Improving memory and concentration problems due to treatments	High	29.7	20.8
Improving the support of spouses and family	High	21.7	
The role of a sense of meaning on patients' quality of life	Middle	18.9	
Dealing with changes in need for physical intimacy as a consequence of diagnosis and treatment	Middle	15.8	
The contribution of emotional support to patients' quality of life	Middle	13.9	
Total		100	
Theme: Relieving physical discomfort			
Relieving the long-term side effects of a variety of treatments	High ^a	21.9	17.9
Relieving chronic fatigue	Middle	20.4	
The prevention of overtreatment	Middle	16.3	
Relieving the symptoms of GvHD after SCT	Middle	15.7	
The effect of rehabilitation on the physical discomfort due to treatments	Middle	14.7	
The effect of treatment on physical sexuality	Low	10.9	
Total		100	
Theme: Understanding mechanisms of disease			
Focusing treatments on individual patients.	High ^a	20.8	14.9
The causal mechanisms of haematological cancers	Middle	20.4	
The functioning of new medication in practice	Low	17.4	
The emergence and prevention of GvHD after SCT	Low	15.2	
The relationship between haematological cancers and other disorders	Low	13.8	
The differences between men and women in getting a haematological cancer, and how they are affected by treatments	Low	12.4	
Total		100	
Theme: Improving organisation of healthcare system			
The effect of an interdisciplinary approach to haematological cancer on the well-being of the patient.	High ^a	24.1	12.3
Improving the decision-making with patients concerning acute topics	Middle ^a	21.6	
Improving the knowledge of extramural healthcare professionals (e.g. the GP), about haematological cancers and its treatments	Low	19.4	
The effect of a care-coordinator on the well-being of patients	Low	18.0	
Changing the "directive-culture" in the organisation of haematological oncology care	Low	16.9	
Total		100	

(Continues)

TABLE 3 (Continued)

	Assigned priority cluster	Relative priority topics (%)	Relative priority theme (%)
Theme: Policy issues			
The preservation of equal accessibility to medication and treatment	High ^a	24.9	9.5
Reducing the costs of medication	Middle ^a	21.5	
The effect of the regulation and deregulation of the pharmaceutical industry on the development and accessibility of medication	Low	18.5	
The evaluation of policy aimed at "orphan drugs" ^b	Low	18.3	
Improving the societal support of patients	Low	16.9	
	Total	100	
		Total	100

^aThe topic is assigned to the "high-priority" or "middle-priority" cluster as the topic was prioritized highest or next-highest within the theme, but it does not belong to the top-5 highest or top-10 next-highest prioritized topics, respectively. ^bOrphan drugs are drugs for rare diseases, for which the pharmaceutical industry receives governmental R&D support due to low expected revenues.

social workers and occupational physicians, was the highest prioritised topic in this theme. In the consultation phase, many participants brought to the fore that such collaboration is important for improvement of the well-being of patients:

If you don't exactly fit the bill, then it gets complicated. And these multidisciplinary teams don't function properly yet. (P1, FGD Wait & See)

Some participants broaden this collaboration by specifically calling for a holistic view of the patient and the inclusion of complementary medicine practitioners to the range of collaborating healthcare professionals. Participants also note differences between hospitals in the interpretation of rules and regulations regarding funding and accessibility of treatments and medication. They therefore prioritise the preservation of equal accessibility to medication and treatment.

4.3 | Stratification of research priorities

Although no statistical stratification could be attempted due to the small number of respondents, it was possible to observe prioritisation trends in the largest treatment groups (see Table 1): Wait & See phase, non-intensive treatment; intensive treatment; and SCT. The group of respondents who had received or were receiving palliative care was too small ($n = 4$) to be meaningfully included in this stratification, while the group "other" ($n = 25$) was presumed too diverse. No change in prioritisation of the overall research themes was observed. However, a shift in a few research topics could be found; for example, people in the Wait & See phase give less prominence to the topic "Relieving the long-term side effects of a variety of treatments" than other respondents. Also, prevention and relief of the symptoms of GvHD are especially highly prioritised by people who have undergone an SCT. These shifts in priority are not surprising given the stage of respondents' disease. Albeit limited, this stratification

indicates that most priorities are shared equally across the different groups of respondents.

4.4 | Dialogue meeting

At the dialogue meeting, all highly prioritised research topics were discussed in small groups. Additionally, the research agenda and implications for its implementation were discussed plenary. Attendees noted that some research topics are confined to the Dutch situation. For example, more interdisciplinary collaboration in the healthcare system is considered to be a context-specific research topic. Attendees considered that several research topics call for an international approach as the findings can be generalisable and the costs for clinical research are generally high (e.g. personalised medicine). In addition, they agreed that the next steps regarding the research topics are variable. Some topics need more research attention, such as relieving long-term side effects of treatment. In other cases, healthcare professionals and researchers could benefit from knowledge generated outside of haematological oncology. For example, support structures for patients' spouses and families could be based on similar schemes in practice in breast cancer care. On the whole, the attendees at the meeting expressed their willingness to assist in the implementation of the research agenda and they were all eager to continue the dialogue with Hematon on further collaboration.

5 | DISCUSSION

The research themes presented in this study generally correspond to the earlier work on research priorities of people with haematological cancers, as investigated by Clinton-McHarg et al. (2010) and Merode et al. (2016). The most highly prioritised research themes identified in our study correspond to the findings of Clinton-McHarg et al. (2010), namely that AYAs with haematological cancer prioritise clinical medicine and psychosocial research. This also

links to the strained balance between spending research money on improvement of survival rates and on improving patients' quality of life. However, as the study by Clinton-McHarg et al. (2010) does not specify any subdomains except psychosocial research, a more fine-grained comparison with our findings is difficult. Merode et al. (2016) investigated the research priorities of people with MM or WD. The prominence of the problems in the healthcare system as encountered in the consultation phase of our study resembles their conclusion that "aspects concerning communication (involving the patients in decision making process, supplying good information, having good communication skills) were regarded as very important by the participants" (van Merode et al., 2016, p.15). However, the prioritisation of the topics by respondents in the study of Merode et al. (2016) differs somewhat from our study because communication problems were not prioritised highly by our participants.

On the research agenda, a number of topics are specific for haematological cancers. Research to alleviate physical discomfort caused by treatments, in particular the side effects of GvHD, is quintessential for haemato-oncology, and it could contribute to improving patients' health-related quality of life (Frodin, Lotfi, Fomichov, Juliusson, & Borjeson, 2015). However, research into other everyday problems and research needs, such as employment, fatigue, well-being, regaining control and lack of support for patients' relatives, can be, and increasingly are, addressed by the general oncological research field (Curt et al., 2000; Kim, 2007; Stenberg, Ruland, & Miaskowski, 2010). Participants' complaints about impersonal care and a lack of empathy of physicians are consistent with general literature on oncological patients' perspectives on good-quality care (Attree, 2001). Last, similar to our participants, US oncological patients also experience direct and indirect financial costs of cancer care on top of the emotional and physical hardships of the disease itself (Kim, 2007). This indicates that some everyday problems and research needs may transcend the national health systems' context.

5.1 | Contextualisation of the main research findings

A strength of the present study is the contextualisation of patients' research needs in the light of their everyday problems and concerns. For example, the research priority "effect of lifestyle on survival" indicates that people with haematological cancer have the desire to gain control over their lives. Patients want evidence-based directives to change their lifestyle as they want to combat their sense of helplessness. Similarly, the topic "physical (late) side effects of treatment" was intensively discussed during the consultation phase, and research into relieving this burden was highly prioritised.

Disparities between the FGDs/interviews and prioritisation of the research topics can also be observed. For example, participants in the consultation phase discussed frustrations about healthcare provision and societal issues, such as employment issues and financial troubles, as an additional burden on top of the distress of the disease itself. However, these topics were not highly prioritised on the research agenda. Instead, respondents in the priority setting phase put more emphasis on the importance of understanding

factors influencing survival. A possible explanation for this disparity could be that the participants' wish to cure the disease was regarded as self-explanatory in FGDs and interviews. The questionnaire indicates that the implicit emphasis on improving survival in the consultation phase should not be mistaken for a low priority.

The contextualisation of patients' research needs reveals that a direct relationship with patients' everyday problems and concerns cannot be assumed. Patients may consider other strategies than research (e.g. policy measures) more appropriate to address certain everyday problems, whereas research topics may be prioritised without addressing one specific everyday problem or concern (e.g. personalised medicine). Although it is beyond the scope of this article, it could be interesting to examine more in depth to what extent patients' lived experiences are complemented by public discourse or replication of their healthcare providers' opinion, and to what extent people's prioritisation is motivated solely by their experiential knowledge or also by other sources of information. Studies on the medicalisation and pharmaceuticalisation of society (e.g. Williams, Martin, & Gabe, 2011), on enclave deliberation (Nierse & Abma, 2011) and on effective inclusion strategies for patients in knowledge co-production processes (Elberse, Caron-Flinterman, & Broerse, 2011) can be valuable in this debate as they all explore the nature of experiential knowledge from a different point of view.

5.2 | Methodological considerations

The mixed-method approach, in which everyday problems and concerns and research topics were covered in depth by FGDs and interviews and in breadth by the questionnaire, is one of the strengths of this study. Through our methodological approach, we have attempted to stay as close to the lived experiences of the target population as possible. The combination of close collaboration throughout the project with patient representatives on the one hand, and including patients without any representative function in the consultation and priority setting phase on the other, has contributed to this effort. By stimulating enclave deliberation (Nierse & Abma, 2011) and by paying attention to verbal, behavioural and circumstantial inclusion strategies for patients (Elberse et al., 2011), the results provide a rich account of the patient perspective.

During the study, some difficulties were encountered regarding the recruitment of patients for the FGDs. As a result, two separately planned FGDs ("SCT" and "in treatment") yielded too few patients and were therefore merged in one FGD. To achieve data saturation, six additional interviews were organised with under-represented groups of participants. In these interviews and in the questionnaire, few new topics emerged, indicating data saturation. The questionnaire also yielded fewer respondents than we had aimed for. As a result, we were obliged to dispense with statistical stratification of the research topics. Additionally, it should be noted that the survivors of potentially deadly haemato-oncological disease were found to value research into well-being, while it is possible that those who have died might have placed greater emphasis on finding a cure for the disease.

Although we attempted to cover this knowledge gap by interviewing several people in the palliative phase, it is possible that the emphasis of the entire patient population on a cure is underestimated.

Last, the methodology paid no explicit attention to cost-benefit ratios of different research topics or to the international research landscape. Research costs were discussed in meetings with the advisory board, in a number of FGDs and at the dialogue meeting. In the priority setting phase, however, respondents' attention was not diverted to optimising resource allocation strategies but instead focused on their research needs, irrespective of financial, organisational or logistical constraints. It is proposed to include this dimension more extensively in the next steps regarding the implementation of the research agenda.

5.3 | Recommendations for implementation

To move from a research agenda to effective implementation of the prioritised themes, a number of recommendations can be formulated. As described by Pittens, Elberse, Visse, Abma, and Broerse (2014), collaborations with researchers, healthcare professionals and funding agencies should be encouraged to get to the heart of the various research topics. Such dialogues facilitate the effective implementation of the research agenda into research practice. In the follow-up, programming phase, Hematon will contact relevant teams of researchers and healthcare professionals in order to translate the research themes into specific topics and questions. The dialogue meeting can be considered a fruitful starting point for this endeavour, as it kindled enthusiasm for the research agenda amongst key stakeholders in the field, including researchers, policymakers and members of scientific advisory board. Keeping the momentum is crucial in this phase; as other stakeholders need time to become accustomed to the inclusion of the patients' perspective, the timing of the research agenda in relation to developments in the field is important (Pittens et al., 2014). With this research agenda, Hematon possesses a valuable tool to obtain a seat at the decision-making table, thus empowering their patients' position.

6 | CONCLUSIONS

This study aimed to formulate a research agenda by and for people with haematological cancer by investigating the everyday problems and concerns of the target population with regard to their disease, and by identifying and prioritising research themes from their perspective. The study yielded a wide range of interconnected problems and concerns. At the individual level, participants experience a cascade of psychosocial and physical issues due to the diagnosis, the disease itself and the accompanying treatments. Fatigue is discussed as requiring urgent research attention, as well as the feeling of uncertainty which participants experience. In addition, fear of physical deterioration and changing social relations, especially losing one's independence, contribute to people's anxiety about the future. Societal issues, such as ignorance and lack of flexibility

amongst employers, and troubled interactions with healthcare providers, are also mentioned. These factors contribute, directly or indirectly, to participants' experienced reduction in quality of life.

The highly prioritised topics on the research agenda indicate that, in addition to improving patients' experienced well-being, questionnaire respondents want resources to be allocated to research into lifestyle factors contributing to improved survival rates. Research into mechanisms of disease, and research of a social scientific nature into the organisation of healthcare and related policy issues, is prioritised to a lesser extent.

7 | COMPLIANCE WITH ETHICAL GUIDELINES

No approval of an accredited Dutch medical research ethics committee was needed for this study as it did not involve medical research or any form of invasion of the participants' integrity. Throughout the course of the study, the privacy and confidentiality of all participants' contributions were respected; the interviews and FGDs were recorded after verbal consent and all transcripts, summaries and contributions to the questionnaire were anonymised. Only two researchers (BdG and AS) had access to the keys of the transcripts.

CONFLICT OF INTEREST

The authors do not have any financial conflict of interest to declare.

DISCLOSURE

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ENDNOTE

¹For the purpose of conciseness, we will refer to the target population (people with a haematological cancer and/or who have undergone a stem cell transplantation, or who have been declared cured of such a disease) as "people with a haematological cancer."

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