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From “being at war” to “getting back on your feet”: A qualitative study on experiences of patients with systemic sclerosis treated with hematopoietic stem cell transplantation

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Abstract

Objectives: To gain insight into the experiences of patients with diffuse cutaneous systemic sclerosis during and after autologous hematopoietic stem cell transplantation.

Methods: Semi-structured interviews were conducted with patients who underwent hematopoietic stem cell transplantation in four university hospitals in the Netherlands. Interviews were transcribed verbatim and thematically analyzed.

Results: Nine male and seven female patients were interviewed, median age 47 years (range: 27–68). Patients mentioned their life was severely disrupted before hematopoietic stem cell transplantation and remained unsettled a long time after treatment. Uncertainty because of disease progression, loss of control over health and the sense of time and fear of treatment-related adverse events were common during hospitalization. After hematopoietic stem cell transplantation, patients experienced more physical limitations than they had expected, and recovery took longer and was mentally taxing. Going back to work and finding a new balance in personal relations and social life was complicated. Patients described various strategies to deal with challenges. Family and friends provided essential support, although many experienced a dwindling social circle. Most patients also appreciated peer support. All patients were satisfied with the low threshold for contact with physicians and nurses during hospitalization. However, aftercare focused on medical aspects rather than on psychological well-being and social issues. Moreover, patients would have preferred to be better prepared on what to expect after discharge, and lacked information about self-management, prognosis, optimal recovery, work, sexuality, and family planning.

Conclusion: Hematopoietic stem cell transplantation has a major physical and psychological impact on patients with diffuse cutaneous systemic sclerosis. The course of recovery after this intensive therapy was unexpectedly long for some patients and offer of support was far less pro-active post-HSCT compared to pre-HSCT and during HSCT.

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Introduction

Diffuse cutaneous systemic sclerosis (dcSSc) is a progressive, systemic autoimmune disease associated with high morbidity and decreased life expectancy.^{1–3} Treatment with autologous hematopoietic stem cell transplantation (HSCT) improves survival, quality of life, skin fibrosis, and prevents disease progression.^{4–6} Even so, HSCT carries a high risk of complications, including infections and cardiac toxicity, and treatment-related mortality in the first year following treatment is 3%–10%. In recent years, HSCT has been increasingly performed in dcSSc.⁷ However, no studies have explored the experiences of patients with dcSSc during and after this treatment.

HSCT is indicated in patients with a progressive disease course, and patients are therefore usually severely ill when the treatment procedure is initiated. In addition, it is an intensive therapy, and severe side-effects from the drugs administered throughout the course of treatment can be experienced during hospitalization. Therefore, it is important to optimally support dcSSc patients during and after this treatment.

Several studies have demonstrated a major physical and psychological impact of HSCT in patients undergoing HSCT for hematological malignancies. Throughout hospitalization, an increase in depression rate and deterioration of quality of life were observed.^{8,9} After HSCT, psychosocial distress was increased and daily functioning and quality of life were impaired up to 1 year after therapy.¹⁰ In oncology practices, psychosocial interventions before and after therapy have therefore been implemented to optimally prepare and support patients.

Yet, no studies have been performed to investigate the experiences of HSCT in patients with autoimmune diseases or dcSSc in specific. Compared to patients with hematological malignancies, dcSSc patients have a different disease course, symptoms, and prospects. Hence, more insight in the perceptions of patients with *dcSSc who are undergoing HSCT* could provide opportunities to improve patient health-related quality of life (HR-QOL). In this study, we collected data from patients in the four Dutch expert centers that perform HSCT. We investigated the experiences during and after HSCT of patients who underwent HSCT. We were particularly interested in whether there were unmet needs with regard to supportive care and rehabilitation, the impact of the treatment on social contacts, and whether patients were sufficiently informed about the implications of the treatment.

Methods

Design

An exploratory, qualitative study using thematic analysis was conducted.

Patients

Patients with dcSSc who had undergone HSCT between January 2008 and January 2019 were recruited from the four Dutch university hospitals where HSCT is offered for this condition (University Medical Center Utrecht, Leiden University Medical Center, Amsterdam UMC, location VUmc, Radboudumc Nijmegen). To gain an understanding of the diversity in patient experiences, and in line with qualitative research strategies,^{11–13} maximum variation was sought with respect to center, treatment outcomes, disease duration, marital status, level of education, age, and gender. The researchers discussed the selection of patients with participating rheumatologists in order to achieve this group variation. Patients were informed about the study by their rheumatologist. If they were interested in participation, contact details were shared with the researcher (J.S.), who then contacted the patients and scheduled an interview, preferably after a routine appointment at the hospital. Patients who did not speak Dutch were excluded from the study. The study was evaluated by the institutional review board of all centers and classified as exempt of the Medical Research Involving Human Subjects Act (17-836/C). Prior to the interview, the goals of the study were reiterated, patients were informed about the nature of the questions, and written informed consent was obtained.

Data collection

Two investigators (J.S., F.C.C.V.R.B.) conducted the in-depth, semi-structured interviews. The interviews were recorded, transcribed verbatim, and pseudonymized.¹⁴ Interviews were evaluated and discussed between the two investigators in order to ensure a similar approach.

An interview guide with open-end questions was developed by members of the project team with backgrounds in rheumatology and psychology.¹⁵ This interview guide included questions about the patient's experiences during hospitalization for HSCT and after discharge (Supplementary file 1). Sociodemographic variables and disease characteristics were collected through a short

questionnaire. We hypothesized that quality of life and functional impairment at the time of the interview could influence the perceptions of the treatment and recovery process. HR-QOL was therefore evaluated with the validated EuroQol-5D-5L (EQ-5D-5L). This survey assesses if patients experience any limitations on five domains (mobility, usual activities, selfcare, pain and discomfort, and anxiety and depression) and using five response categories (1=no problem, 2=slight problem, 3=some problem, 4=moderate problem, and 5=extreme problem). The five dimensional scores can be calculated as an overall utility score ranging from 0 (worst) to 1 (best; no problems in any of the dimensions).¹⁶ Daily functioning was further assessed with the validated Scleroderma Health Assessment Questionnaire (SHAQ, scores range from 0 (no disability) to 3 (maximal disability)).¹⁷ Both surveys were taken on the day of the interview.

Data analyses

Qualitative analysis of the transcripts was done using thematic analysis.^{18,19} Open coding was the first step to sort the data for further interpretation. Codes are segments that simultaneously relate to each piece of data. Two researchers (J.S., C.J.M.D.B.) first read and re-read the transcripts to familiarize themselves with the data. They then independently coded the first four transcripts. They frequently met to discuss coding during the process, until consensus was reached. They developed a code list inductively, which was used for all subsequent interviews. Codes were added or renamed whenever needed. Next, the different codes were sorted into themes, based on the labels of codes and the underlying text fragments. Themes were defined, grouped, and refined as necessary, and in consensus. Subthemes are defined as recurrent themes related to bigger themes. Data saturation was assessed on a conceptual level. The analysis was supported by the software program Nvivo12.²⁰ The consolidated criteria for reporting qualitative research (COREQ) were observed and are reported in Supplementary file 2.²¹ An audit trail was kept of the qualitative analysis, codes, and themes. Statistical Package for Social Sciences (SPSS), version 25.0, was used for descriptive data analyses (median, range and percentage) of the socio-economic and disease characteristics.

Results

Sample characteristics

Nine male and seven female patients were invited to the study and all agreed to participate. Median time between HSCT and the interview was 2.0 years (range: 0.4–11.0 years; see Table 1). The median reported S-HAQ was 0.69 (range: 0–1.71) and median HR-QoL index 0.92 (range: 0.4–1.0).

Table 1. Patient characteristics.

	N=16
Median age (range)	47 (27–68)
Women/men (n)	7/9
Marital status (n)	
Married	13
Living together unmarried	2
Single	1
Household (n)	
Living alone	0
Living with parents	1
Living with partner	7
Living with partner and children	8
Educational level (n)	
Low (primary and secondary school)	5
Medium (high school)	5
High (graduate and above)	6
Relapse or immunosuppressive agents post-HSCT (n)	2
Paid job at time of interview (n)	12
Median disease duration at interview (yrs, range)	4.0 (1.8–13.0)
Median disease duration at HSCT (years, range)	1.0 (0.2–3.0)
Median time between HSCT and interview (years, range)	2.0 (0.4–11.0)
Median S-HAQ (range)	0.69 (0–1.71)
Median VAS Raynaud	0.70 (0–3.00)
Median VAS digital ulcers	0.20 (0–1.30)
Median VAS intestinal disease	0.40 (0–2.80)
Median VAS breathing problems	0.20 (0–2.80)
Median VAS general	0.80 (0–2.90)
Median VAS pain	0.15 (0–2.50)
Median EQ5D-5L index (range)	0.92 (0.4–1.0)

EQ-5D-5L, Euroqol 5 dimensions 5 levels; S-HAQ; Scleroderma Health Assessment Questionnaire (range 0–3). VAS: visual analogue scale. VAS scales ranges from 0 (no complaints) to 3 (severe complaints).

Qualitative results

The analysis of the interviews yielded two key themes: disruption and control. Themes and subthemes (patterns related to the themes) are presented below and shown in Table 2.

Disruption

Physical impairments and the psychological impact of the disease led to the disruption of daily life. Patients experienced great uncertainties about their future, loss of control over their lives, loneliness, and existential challenges from the moment they received their diagnosis, and this went on during treatment. Problems were mostly related to living with illness instead of undergoing treatment.

Table 2. Themes and subthemes derived from patients' responses in the interviews.

Theme	Subthemes	Recurrent experiences
Disruption	Expectations	The real impact of the treatment was felt during admission Expectation HSCT will stop or cure the disease Expectation to get back to work after HSCT Disappointment, recovery took much longer than expected Relief: recovery went faster than expected and uneventful. Persistent fatigue and Raynaud's phenomenon No idea what to expect after HSCT
	Patient education	Post-HSCT: concerns about relapse Sufficient information pretreatment about the procedure and risks Much emphasis on complications and side-effects No information about post-transplant period No information about recovery and self-management Stories from peers: Useful or not applicable to own situation No information about fertility and family planning
	Emotional impact	Feelings of losing control over health and time Feelings of loneliness: misunderstanding from social contacts, keep social contacts at distance (protection) Frustration about timing, HSCT should have been done earlier Feeling insecure: Going back home after long admission Processing events and impact of diagnosis and treatment is happening mostly after treatment Concerns about contracting infections Uncertainty about future: worrying about relapse Regain confidence in the future: make plans, find new jobs, family planning Feeling misunderstood Feeling isolated Loss of friendships Memory loss about the time of hospitalization Mutual coping and communication with partner: uncertainty about future, remaining limitations, doubts about family planning, and sexuality
Regaining control	Support	Partner plays important role in coping with emotions. Balancing sharing information Peer support Psychosocial support from nurse
	Coping strategies	Protection of children: not sharing all details about prospects and risks. No hospital visits. Keeping social contacts at distance: focus on therapy Continue with work, as a distraction Writing about feelings and experiences, collect pictures

HSCT: hematopoietic stem cell transplantation.

P9: "My life was paused."

P15: "I was at war, nothing else mattered."

Expectations about treatment, outcomes, and physical recovery

Information provided to the patients did not entirely meet the needs of all patients. The patients felt insufficiently prepared for the impact of the treatment, despite having received comprehensive counseling prior to HSCT. Some of the patients preferred more realistic and more practical information from a patient point of view,

for example, provided by a peer. Furthermore, some reported too much emphasis on the theoretical risks and side-effects associated with treatment. They would have preferred a more optimistic and empowering tone of counseling. The patients tried to focus on positive outcomes to cope with insecurity. Subsequently, some felt annoyed or distressed by healthcare professionals who focused on treatment risks.

P7: "I expected that HSCT would save me"

P16: "The clinicians and nurses focused so much on the negative sides of HSCT."

The patients' expectations regarding treatment outcomes and side-effects differed widely. Some patients were relieved because they experienced fewer side-effects than they had expected. Others felt overwhelmed by the side-effects of the treatment.

P2: "I felt really ill, I was not prepared for that"

P5: "It was easier than I had foreseen, I had no side-effects."

P10: "After [stem cell] mobilization, my skin was improving already, I did not expect that."

The patients experienced more physical limitations after HSCT and their recovery took longer than they had expected. The rehabilitation process was mentally taxing, partly due to uncertainty with regard to the level of improvement. Moreover, patients felt disappointed or insecure because of persistent symptoms and limitations, like low energy levels, limited hand function and Raynaud's phenomenon. These symptoms affected return to work as well. Patients with high S-HAQ scores (>1.50) and low HR-QoL (<0.75) reported unfulfilled expectations from the treatment effects and limitations in rehabilitation more often compared to patient with high HR-QoL and low S-HAQ scores.

P3: "It was a major setback: I could not even climb the stairs."

P7: "It took long to notice effects of the therapy."

Emotional recovery is a long-term process: loss of control and loneliness

During the HSCT procedure and hospitalization, patients felt they had no/little control over their body. They further mentioned that they had lost their sense of time during treatment. Some had no memory of the events during hospitalization. Patients searched for support in processing the events, and some kept a diary or took photos during hospitalization for that purpose.

P9: "Talking to peers is easier, they understand me."

P13: "Some events, I cannot recall at all."

P14: "Support from a nurse during the admission and afterwards helped me a lot."

In addition, many patients felt lonely and sometimes misunderstood by family and friends, which even led to loss of friendships. Some patients deliberately kept their loved ones, particularly their children, at distance to stay focused, and because they did not want them to worry.

P6: "They expect that I can participate in all social events, but I often feel exhausted."

P8: "I felt lonely, also with friends around. Nobody can really imagine how it feels."

P9: "It is hard sometimes, we both have to process it in our own way."

Loss of control and insecurity were recurrent themes at the end of the long hospitalization period. Most patients did not know beforehand when the discharge day would be because this depended on the repopulation of the bone marrow or the management of complications. Therefore, the time of discharge often came as a surprise. The patients who experienced complications felt particularly insecure and feared to contract infections, and that the disease would relapse. Moreover, they did not feel prepared to go home.

P10: "There is sufficient information about risks and procedures, but nobody tells you what to expect afterwards, you just go home."

P11: "Things went so fast, still after years I need to process all that has happened."

P15: "After I had been so ill, I suddenly had to go home, I was terrified!"

Uncertainty about the future complicated reintegration in society and work, and family planning. It also put a strain on relationships of some patients. Some struggled to find purpose or to redefine their role in their family or in relationships. Half of patients sought psychological support in the first year after HSCT. Most patients were not interested in psychological support before and during treatment. Furthermore, patients desired to be better informed about what to expect with regard to physical or mental rehabilitation, about the time needed to recover, relapse rates, and non-medical information including work, social contacts, sexuality, and family planning.

P2: "I live by the day and make no further plans, because it is uncertain."

P7: "It was difficult to find my place in society again."

(Re)Gaining control

Family and friends provided support and this was of key importance, although some patients thought it also complicated the relationship. Therefore, patients also appreciated help from persons who were not "emotionally involved," such as a specialized nurse or peer support from other patients. Patients much appreciated the easy access to nurses and physicians during hospitalization.

Participants described various strategies to deal with the challenges outlined above. Half of the patients mentioned that they focused on positive outcomes and tried to avoid negative aspects. Second, taking action to recover by adhering to a diet and doing sports during and after admission helped patients to find distraction and regain control over their lives.

Others ways to regain control were setting new goals together with their family, or with regard to work.

In the first years after HSCT, the majority of patients stayed away from social events to avoid confrontation with the outside world and because they felt pressured to justify to others that they were not fully recovered yet. On the long term, most patients managed to cope with these issues and (partly) returned to their “old life.”

P9: “Slowly I got back on my feet, except it was not the same life I had before I got ill.”

P9: “We had plans, and then I got sick. Now we try to make new plans,”

P12: “Fortunately, I could easily get back to my old job after the therapy.”

Discussion

HSCT is an effective but risky treatment option for patients with poor prognosis dcSSc. Hitherto it was unknown how patients who have undergone the treatment have experienced the process and their recovery. In this study, we investigated experiences of HSCT and process of recovery using in-depth interviews in 16 patients who have undergone HSCT.

We observed that HSCT has a major physical and psychological impact both during hospitalization and still a long time after discharge and also that patients eventually found a way to set forth their lives. In particular, they lacked information on what to expect with regard to treatment outcomes and prognosis and needed more time than they had expected to process everything that had happened and to recover physically. They had difficulties with resuming social contacts and work, and patients sometimes faced problems in their relationships and with their sexual health.

We identified major stressors and various coping mechanisms during hospitalization. A major stressor was the uncertainty about treatment outcome and prognosis. Half of the patients used positive coping and “made a positive story” to hold on to. Healthcare professionals’ focus on risks of complications did not fit with this coping strategy and patients therefore did not appreciate it. Problem-focused strategy was used in more than half of the patients. Many patients focused on their lifestyle, so they felt they could contribute to a better treatment outcome. Another coping strategy was distancing themselves

from their current health problems, to avoid being confronted with emotions and fears, and to keep control of the situation. Some patients found distraction by engaging in other activities. This strategy was also described after HSCT, that is, patients stayed away from social events to avoid being confronted with remaining limitations or the slow recovery process. Others, on the contrary, sought social support to help them cope.

Identification of these stressors could help health care professionals to improve support of patients in clinical practice. The diversity of experiences and needs of patients we observed in the interviews, however, points out that there will not be one approach that fits all. Preferably, patients’ needs should be evaluated on an individual level. In addition, family members may have to be involved more, in order to reduce the risk of patients feeling lonely and getting into relationship problems, and to support mutual coping.

In line with our findings, other studies in patients undergoing HSCT for hematological malignancies have also reported the high physical and psychological burden of HSCT, even a long time after completing therapy.^{10,22} Patients with dcSSc might experience even more physical complaints post-HSCT, because of the involvement of multiple organs in this condition. Coping strategies during and after HSCT, similar to the ones we identified, have been described in patients with hematological malignancies.²³ Moreover, the use of active and avoidant coping styles was associated with more distress during and after the first months after HSCT.^{24,25} Psychological interventions to help reduce distress, have therefore been implemented in oncology practice, and indeed have shown to help alleviate distress in patient undergoing HSCT.²⁶ Of note, most patients in our study reported that they initially felt no need for psychological support before or during the therapy, but many sought psychological help after treatment.

Rehabilitation therapy following HSCT was not routinely offered to the patients in our study. Half of the patients referred themselves to a physiotherapist, psychologist, or occupational therapist, showing an unmet need in these patients. In a study among 201 patients who were treated with HSCT at a hematology department in the United States, 26% received rehabilitation therapy early after transplantation.²⁷ These patients had worse functional scores prior to HSCT compared to the patients who were not referred to this type of therapy. Their functional performance increased significantly after the rehabilitation intervention. The beneficial effects of rehabilitation interventions on fatigue and social health in hematologic patients who underwent HSCT, were shown in a cross-sectional study (n = 171).²⁸ Rehabilitation therapy prior to HSCT was further demonstrated to be safe and effective in a pilot study including 29 patients.²⁹ Altogether, provision of more extensive supportive care in hematology patients has shown its benefits, and the problems identified in this

study suggest that more extensive support may also be beneficial to patients with dcSSc who are undergoing HSCT. Further research is needed to determine if, and what sort of, strategy could help optimize physical and mental recovery after HSCT, and support coping with (temporary) disabilities post-HSCT.

Our study has some limitations. First, there is a risk of recall bias. For some patients, HSCT took place several years ago. Second, perceptions may be colored by current health status and HR-QoL, which was remarkably good in most patients. Yet, we observed some differences in expectations and experiences of rehabilitation between patients with high HR-QoL and less functional disabilities, compared to patients with low HR-QoL and poor daily functioning at the time of the interview. Third, healthcare provision in general has changed over the years, so problems reported from experiences a decade ago might already have been addressed in current care. In this rare condition, however, it was not possible to include more patients who recently underwent HSCT. A strength of this study is that we included a relatively large group of patients from different hospitals and in different health states. Moreover, it is, to our knowledge, the first study addressing the patient experience of HSCT.

In conclusion, our study provides insight into the experiences of patients with regard to HSCT and recovery phase after hospitalization. HSCT clearly has a major impact on daily functioning and quality of life. Patients should be better informed about the course of recovery after this intensive therapy and the psychosocial impact of it. Diverse ways of support (i.e. peer contacts, a rehabilitation program, or job coach) should be offered proactively during and after HSCT. The identified unmet needs in our study can be used as a starting point to develop strategies to optimally support patients.

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Supplemental material

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