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Evaluation of a Nurse-Led Patient Navigation Intervention

Follow-Up of Patients After Autologous and Allogeneic Stem Cell Transplantation

KEYWORDS

Hematopoietic stem cell transplantation

Nurse-led intervention

Patient navigation

Quality of care

Quality of life

Self-management

Background: Complex survivorship cancer care requires nurse-led interventions. Therefore, a nurse-led patient navigation intervention was developed in which trained cancer nurses gave advice and referred to other professionals during the process of recovery and rehabilitation of hematopoietic stem cell transplantation (HSCT) patients. **Objective:** The aim of this study was to understand the nature and effect of this nurse-led information and referral intervention. **Methods:** Of the 199 included patients in the intervention group, 75 completed the quality of life, quality of care, self-efficacy, and self-management behavior questionnaires at baseline and at 6 and 12 months after HSCT. A historical control group of 62 patients completed the same questionnaires 12 months after HSCT. In addition, patients' experiences with the intervention were evaluated in 2 focus groups. **Results:** Patients emphasized the holistic approach of the cancer nurses and the opportunity to discuss psychosocial domains of life. Within the intervention group, a statistically significant effect on quality of life was demonstrated over time. The differences in quality of life, self-efficacy, and self-management were not significant between the intervention group and control group. **Conclusion:** The holistic focus of this nurse-led

intervention proved to be acceptable to the HSCT patients and promising in supporting the (complex) challenges that these patients face during their process of recovery and rehabilitation. **Implications for Practice:** Nurse-led patient navigation interventions with a holistic approach when included in the daily practice of complex survivorship cancer care can support HSCT patients' information and referral needs during their rehabilitation.

■ Introduction

A hematopoietic stem cell transplantation (HSCT) is a standard procedure for patients with a hematological malignancy. In the United States alone, almost 14 000 autologous HSCTs and more than 8000 allogeneic HSCTs were performed in 2015.[1] The same trend is also observed in Europe, where 43 636 HSCT procedures were performed in 2016, an increase of 3.5% compared with 2015.[2] Over time, HSCT has become safer because of advances in the patient selection for HSCT, transplantation technology, and preventive supportive care practices, resulting in a better overall survival.[1,3] Recipients of HSCT may either receive autologous (self) or allogeneic (donor) stem cells after an intensive conditioning regimen, consisting of high-dose chemotherapy and total body irradiation to eliminate underlying disease. Allogeneic HSCT is associated with a potent antileukemic effect because of the donor immune cells attacking the residual disease of the patient.[2–5]

Despite the increasing number of successful HSCTs and the improvement of the early and long-term outcomes, the impact of the side effects of both autologous and allogeneic HSCT should not be underestimated. Especially during the first year after HSCT, patients may experience temporary or permanent symptoms (eg, fatigue, loss of appetite, pain) that affect domains of physical, mental, social, and spiritual well-being, thereby interfering with normal daily live affecting both patients' and families' roles.[6–8] In the qualitative study of van der Lans et al[9] in which 10 allogeneic HSCT patients were interviewed 1 year after their HSCT, patients had a common pattern of recovery involving 5 main phases: survive, on the receiving end, bring under control, start recuperation and retrospection. Patients indicated that they needed aftercare in the first year posttransplant. Cancer nurses can play an important role in adjusting posttransplant care to the individual needs of patients during these 5 phases of recovery, as they are specialized in supporting patients to improve their self-management and to cope with the consequences of the treatment.[9]

To improve the aftercare in the first year after HSCT, a patients' navigation intervention was developed. The intervention was based on the theoretical framework of Berezowska et al.[10] This framework comprises a cyclic process of self-management using the 5A's model, in which the phases of assessment, advice, agreement, assistance, and arrangements are distinguished. This approach is especially useful in the care of complex patients with long-term follow-up, like patients with HSCT.[10,11]

The aim of this study was to understand the nature and effect of the navigation intervention. The primary aim was to evaluate the effect of this nurse-led patient navigation intervention on HSCT patients' quality of life. In addition, the effect on quality of care and self-management was assessed.

■ Materials and Methods

Study Design

This study was conducted to evaluate the patient navigation intervention. Patients who underwent an autologous or allogeneic HSCT as treatment for their hematological malignancy were enrolled in the study. Patients in the intervention group (IG) completed their baseline (T0) questionnaire before HSCT, and their follow-up questionnaires at 6 months (T1) and 1 year (T2) after HSCT. Patients in the historical control group (CG) completed the same questionnaire 1 year after HSCT. To support the quantitative results and to gain insight into which themes of the intervention contribute to the success of the intervention, a purposive selection of patients were asked to share their experience with the patient navigation intervention in a focus group.

Sample and Procedure

Recipients of autologous or allogeneic HSCT of 18 years and older were included in the study in a consecutive order. In case of relapsed disease, patients were excluded. Patients needed to be comfortable with reading Dutch and able to sign informed consent. All eligible patients were orally and in writing informed by the principal investigator. The study protocol was approved by the Medical Ethics Review Board (MEC-2015-320).

All participants in both the IG and CG received standard outpatient care by a hematologist. In both allogeneic IG and CG, however, patients received standard outpatient care alternately by a nurse practitioner and a hematologist.

Although not withholding patients from possible benefits of the patient navigation intervention, we compared the IG with a retrospective historical CG that did not receive the navigation intervention. The patients who received their HSCT between February 2013 and September 2014 were invited to participate in the CG in a consecutive order by phone. When interested, they were given an information letter, informed consent form, and the questionnaire.

Patients who received their HSCT between October 2015 and October 2017 were invited for the IG during hospitalization for their HSCT. When interested, they received an information letter, informed consent form, and the baseline questionnaire. Furthermore, they received the follow-up questionnaires 6 months (T1) and 1 year (T2) after HSCT. Both autologous

and allogeneic patients in the IG received the patient navigation intervention in addition to their standard outpatient care.

To evaluate patients' experiences with the patient navigation intervention, we organized 2 focus groups, one with patients who received an autologous stem cell transplantation (SCT) and one with patients who received an allogeneic SCT. Patients were selected in consecutive order and had signed for consent. The focus groups were semistructured, covering topics such as the role of the cancer nurse, supportive cancer care, referral, and the influence of the intervention on their personal life. The focus group interviews were led by trained cancer nurses, were audiotaped, and took about 90 minutes each. In addition, the 3 cancer nurses were observed during 2 of their consultations to confirm their fidelity to the intervention. Three autologous and 3 allogeneic patients of which 1 at baseline, 1 at 6 months, and 1 year were included in consecutive order. Both patient and cancer nurse signed for consent. All consultations were audiotaped.

Patient Navigation Intervention

The patient navigation intervention was based on the intervention of Berezowska et al.[10] The intervention was executed by 3 bachelor-level cancer nurses who specialized in hemato-oncology and SCT and who also worked on the hemato-oncology ward. Besides an intervention protocol, they received supplementary training in patient-centered communication, problem solving, and coaching skills by an experienced coach specialized in coaching healthcare providers. During hospitalization, patients were informed about the patient navigation intervention. The focus of the consultations was the first-year after HSCT. The patient navigation intervention consisted of two 45-minute, face-to-face consultations with a cancer nurse in the first year after HSCT: 3 to 5 months and 1 year after their HSCT. Before both consultations, patients rated their level of psychological distress and their problems during the past 7 days using the Distress Thermometer and its problem list.[12] During the consultation, patients were encouraged to prioritize these problems, supported in defining goals, and coached in their self-management skills to optimize their quality of life and posttransplant health. When necessary, the cancer nurse referred patients to more specialized healthcare professionals such as a dietician, physiotherapist, social worker, or psychologist.

Quantitative Measurements

Health-related quality of life was measured with the Dutch version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30).[13] This is a 30-item questionnaire, divided into 5 functional scales (physical, role, emotional, cognitive, and social), a symptom scale, and a global quality of life scale. All scales range in scores from 0 to 100. A higher score on the functional scale represents a better degree of functioning, whereas a high score on the symptom scale represents a higher level of symptom burden. On all scales, the Cronbach's alpha showed a coefficient greater than .70.[13,14] The special questionnaire for HSCT patients, the Functional Assessment of Cancer Therapy Bone Marrow Transplantation (FACT-BMT), a combination of 2 tools, also was used.[15] The Functional Assessment of Cancer Therapy General assesses the effect of cancer therapy on physical, social/family, emotional, and functional well-being. The bone marrow transplant subscale assesses specific BMT-related concerns and constitutes the second part of the FACT-BMT.[15,16] The reliability and validity of the FACT-BMT are satisfactory. The Cronbach's alpha of the total scale ranged between .84 and .92.[15]

To evaluate the nurse navigation intervention, a self-constructed questionnaire addressing 14 domains of daily life that may affect self-management was used.[17] The 14 domains of daily life consist of daily activities, social contacts, sexuality, leisure activities, practical matters in daily life, transport and mobility, personal care, finances, dealing with treatment recommendations, lifestyle, dealing with symptoms and side effects, shared decision making, illness-related knowledge, and emotions and spirituality. Patients rated the importance of paying attention to these domains (1 = not important, 2 = somewhat important, and 3 = very important) and the actual attention cancer nurses paid to them (1 = no attention, 2 = some attention, and 3 = much attention). To be able to measure differences, answers were dichotomized: option 1 was recoded as negative, and options 2 and 3 as positive.[17]

Patients' experiences and appreciation in the quality of patient-centered care were measured with a subscale of the Consumer Assessment of Healthcare Plan Surveys (CAHPS).[18] This subscale consists of 5 questions using a 4-point Likert scale (1 = no, definitely not to 4 = yes, definitely). The CAHPS was validated for the Dutch language (α = .90).[19]

Patients' self-management knowledge and behavior were measured with the 12-item Partner in Health Scale (PIH). All items were scored on an 8-point Likert scale, with 1 indicating poor self-management and 8 indicating good self-management. The Dutch version uses 2 subscales: (1) knowledge and coping, and (2) recognition and management of symptoms and adherence to treatment.[20,21] The Cronbach's alphas of the subscales were .80 and .72, respectively. The correlation between the subscales was 0.43.[21]

Self-efficacy was measured with the Self-Efficacy for Managing Chronic Disease 6-item scale (SECD-6). All items were rated on a 10-point Likert scale, with 1 indicating not at all confident and 10 indicating total confidence.[22] The higher the score, the higher the degree of self-efficacy. The Cronbach's alpha of the SECD-6 was .91.[23]

Data Analysis

The quantitative data were anonymized and analyzed with IBM SPSS Statistics version 24.0 for Windows (IBM, Chicago). Patients' demographic, clinical characteristics, and questionnaires were summarized using descriptive statistics (medians with their interquartile ranges, and means with SD). Scores of all QoL scales were transformed into a 0 to 100 scale. Mean scores for the EORTC QLQ-C30 and the FACT-BMT were calculated according the existing manuals. All differences were analyzed with nonparametric tests. The differences between the IG and the historic CG were analyzed using the Mann-Whitney U test.
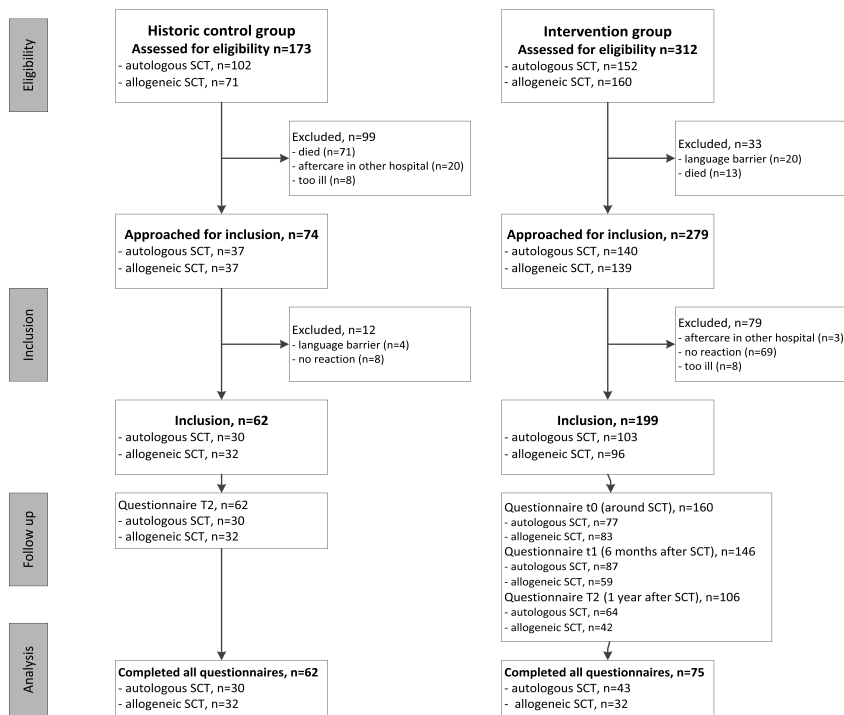
Figure 1 ■ Flowchart.

The differences over time in the IG were analyzed using related samples Friedman 2-way analysis of variance. A value of $P <$ .05 (2 sided) was considered statistically significant.

For the qualitative data, the focus groups interviews were anonymized and transcribed verbatim. Data analysis took place based on the constant comparative method.[24] Internal validation was reached by independent extraction of the codes by the principal and second investigators; the investigators read, reread and coded the transcriptions, understood the codes, and discussed the themes that emerged until consensus, after which these results were discussed by the research team. During the whole analysis process, reflections were noted in a logbook.

The observations of the consultations of the cancer nurses were anonymized, transcribed, and analyzed, and themes were

✳ Table 1 ● Patient Characteristics

	Intervention Group			Control Group		
	Autologous SCT	Allogeneic SCT	Total	Autologous SCT	Allogeneic SCT	Total
	n = 103	n = 96	n = 199	n = 30	n = 32	n = 62
Gender, male, n (%)	59 (57)	57 (59)	116 (58)	19 (63)	21 (66)	40 (65)
Age, median (IQR), y	56 (50-62)	57 (45-66)	56 (49-63)	60 (54-64)	57 (44-64)	59 (48-64)
Hematological diagnosis, n (%)						
Acute leukemia	5 (5)	61 (64)	66 (33)	3 (10)	20 (63)	23 (37)
Chronic lymphocytic leukemia		3 (3)	3 (2)	—	2 (6)	2 (3)
Myeloproliferative neoplasm		12 (13)	12 (6)	—	5 (16)	5 (8)
Lymphoma	45 (44)	16 (17)	61 (31)	13 (43)	4 (12)	17 (28)
Plasma cell neoplasm	53 (51)	3 (3)	56 (28)	14 (47)	1 (3)	15 (24)
Other		1 (1)	1 (1)	—	—	—
Marital status, n (%)						
Single, never married	12 (12)	8 (8)	20 (10)	4 (13)	4 (13)	8 (13)
Married or living with partner	90 (87)	88 (92)	178 (89)	25 (83)	26 (81)	51 (82)
Missing	1 (1)	—	1 (1)	1 (3)	2 (6)	3 (5)
Education, n (%)						
<High school graduate	5 (5)	8 (8)	13 (7)	3 (10)	2 (6)	5 (8)
High school graduate	51 (50)	48 (50)	99 (50)	18 (60)	19 (59)	35 (56)
College graduate	19 (18)	26 (27)	45 (23)	8 (27)	11 (35)	19 (31)
Missing	28 (27)	14 (15)	42 (21)	1 (3)	—	1 (2)

Abbreviations: IQR, interquartile range; SCT, stem cell transplantation.

extracted by using a semistructured observation protocol. The quality data were used to support the quantitative data and to get a better understanding of this patient navigation intervention.

■ Results

From October 2015 to October 2017, 279 patients who met the inclusion criteria were screened to participate in the IG, 199 of them were included. Seventy-five patients completed all questionnaires including 43 recipients of autologous HSCT and 32 recipients of allogenic HSCT. The most important reasons for not completing all questionnaires were death within the first year after HSCT or severe disease burden and subsequent inability to complete the questionnaire. In addition, recipients of autologous HSCT returned their follow-up questionnaire either too late or not at all. Seventy-four patients were invited to the CG, of whom 62 returned their questionnaire (Figure 1).

Participant characteristics are summarized in Table 1. The median age was 56 years in the IG and 59 years in the CG. More than half of the patients were male (IG 58% and CG 65%). Main indications for autologous HSCT were multiple myeloma and malignant lymphoma. Acute leukemia was the most

important diagnosis for allogeneic HSCT. Both focus groups consisted of 8 patients. For the autologous HSCT group, the median age was 52 years, with 5 patients being male. In the allogeneic HSCT group, the median age was 61 years, with half being male.

Quality of Life

In the first year after HSCT, the QoL domains physical functioning, role functioning, social functioning, and quality of life and the symptom scores improved statistically significantly in the IG over time. After a year, there were no statistically significant differences between the IG and the CG. The results of the FACT-BMT were comparable. During the first year, well-being increased in all domains except emotional well-being, although there were no statistically significant differences between the IG and the CG after 1 year (Table 2, Figure 2). QoL was also a central topic in the 2 focus groups. In both groups, fatigue was the most important problem posttransplantation.

> I still have the feeling that I have to become a mother again. That you cannot fulfill the tasks that you have as a mother. Every day struggling with fatigue: I try to get up so that I am

✳ Table 2 • Outcome Measurements

	Intervention Group	Intervention Group	Intervention Group		Control Group	
	T0, n = 159	T1, n = 146	T2, n = 106		n = 62	
	Mean (SD)	Mean (SD)	Mean (SD)	P^a	Mean (SD)	P^b
EORTC QLQ-C30						
Quality of life	60 (23)	71 (17)	75 (16)	.002	76 (20)	.590
Physical functioning	70 (22)	79 (17)	81 (18)	.000	82 (19)	.430
Role functioning	48 (31)	67 (25)	73 (25)	.000	73 (18)	.820
Emotional functioning	76 (20)	82 (19)	81 (18)	.084	85 (22)	.029
Cognitive functioning	75 (23)	79 (22)	79 (23)	.127	77 (24)	.760
Social functioning	63 (37)	74 (26)	82 (21)	.000	77 (28)	.640
Symptom scores	30 (20)	18 (15)	17 (14)	.000	17 (16)	.810
FACT-BMT						
Physical well-being	19.5 (5.9)	23.0 (4.1)	23.4 (4.2)	.000	23.4 (4.1)	.940
Social well-being	22.8 (3.6)	22.0 (4.2)	21.6 (3.8)	.007	20.7 (5.2)	.440
Emotional well-being	19.0 (3.4)	19.8 (3.2)	19.8 (3.2)	.230	20.2 (3.4)	.420
Functional well-being	16.3 (5.2)	17.9 (5.3)	18.8 (5.5)	.000	19.3 (5.4)	.820
Additional concerns BMT	25.1 (5.1)	27.7 (5.6)	28.7 (4.9)	.008	29.2 (5.6)	.910
FACT-G	77.9 (12.0)	82.8 (12.4)	83.7 (12.7)	.000	83.6 (13.3)	.620
FACT-BMT	102.9 (15.8)	110.5 (17.0)	112.4 (16.8)	.000	112.8 (17.8)	.950
Self-management knowledge and behavior (PIH)						
Knowledge and coping	6.6 (0.8)	6.9 (0.7)	6.9 (0.7)	.110	6.8 (0.8)	.970
Recognition and management of symptoms, adherence to treatment	7.3 (0.8)	7.5 (0.7)	7.4 (0.9)	.840	7.6 (0.6)	.077
Self-efficacy						
Total Score (SECD-6)	5.9 (1.8)	6.3 (2.0)	6.1 (2.2)	.026	5.7 (2.4)	.280
Patient-centered care (CAHPS)	3.8 (.4)	3.8 (.3)	3.8 (0.4)	.290	3.8 (0.4)	.550

[a] Differences within the IG were analyzed with samples Friedman 2-way analysis of variance.
[b] Differences between the IG T2 and CG were tested with independent samples Mann-Whitney U test.
Abbreviations: BMT, bone marrow transplantation; CAHPS, Consumer Assessment of Health Plan Surveys; CG, control group; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; FACT-BMT, Functional Assessment of Cancer Therapy–Bone Marrow Transplantation; FACT-G, Functional Assessment of Cancer Therapy–General; IG, intervention group; PIH, Partners in Health Scale; SECD-6, Self-Efficacy for Managing Chronic Disease 6-item Scale.
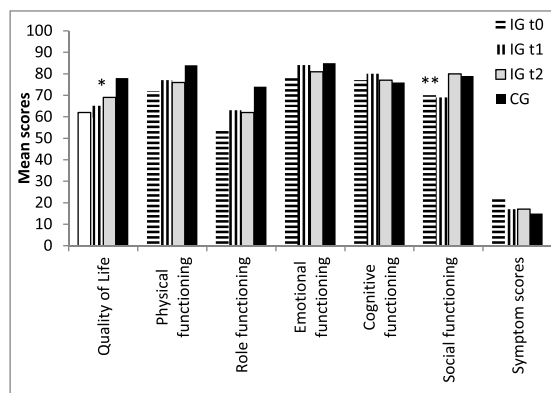
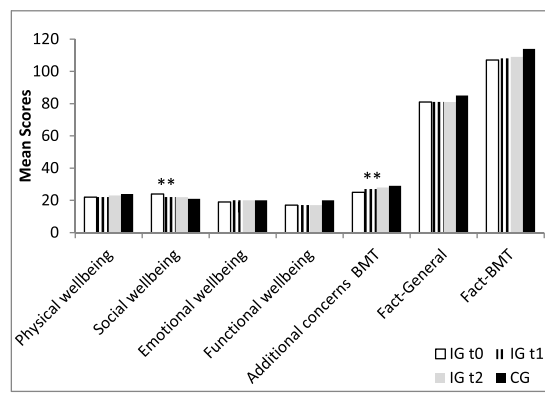**A. Patients with Autologous HSCT: EORTC QLQ C30 (n=43)**
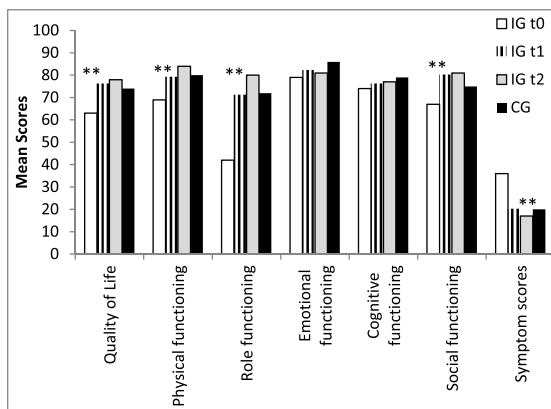
B. Patients with Autologous HSCT: FACT-BMT (n=43)
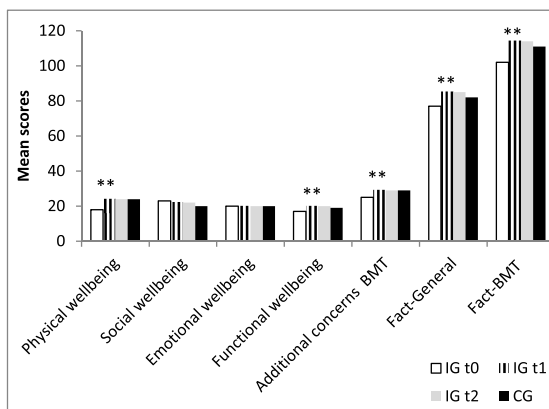
C. Patients with Allogeneic HSCT: EORTC QLQ C30 (n=32)

D. Patients with Allogeneic HSCT: FACT-BMT (n=32)

* P<..05: difference between IG T2 and CG.

**P<..05: difference within the IG.

Abbreviations: CG, control group; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; FACT-BMT, Functional Assessment of Cancer Therapy–Bone Marrow Transplantation; HSCT, hematopoietic stem cell transplantation; IG, intervention group.

Figure 2 ■ Distribution of quality of life in patients with all 3 questionnaires (n = 75). (A) Patients with autologous HSCT: EORTC QLQ-C30 (n = 43). (B) Patients with autologous HSCT: FACT-BMT (n =43). (C) Patients with allogeneic HSCT: EORTC QLQ-C30 (n = 32). (D) Patients with allogeneic HSCT: FACT-BMT (n = 32).

present at least. Besides, I have problems concentrating. I promise things to my children, but I forget what I said to them. (allogeneic HSCT)

Participants referred to their own struggle in one or more of the QoL domains. The intensity of the experienced problems differed between patients and over time. Participants described their struggle to resume their role as partner or parent while still facing various other problems.

Well, in the beginning it is of course step by step, a small step forward and 2 steps back. It certainly took a year until I was finally a little bit normal, and then you are not even talking about the items work or contact with friends or family. (autologous HSCT)

## Evaluation of the Patient Navigation Intervention

Participants were asked to evaluate the quality of care by rating which domains they perceived as important and which domains were addressed during the consultation with the cancer nurses (Figure 3, Table 3). All 14 domains were rated as important by at least 70% of the participants, except for finance, which was rated as important by approximately 50% of participants. The importance of the 14 domains did not change over time.

In the IG group, domains such as daily activities, social contacts, sexuality, leisure activities, practical matters of daily life, transport and mobility, finances, dealing with symptoms and side effects, and emotions and spirituality were addressed significantly more often by the cancer nurses as compared with patients in the CG. Participants in the autologous IG
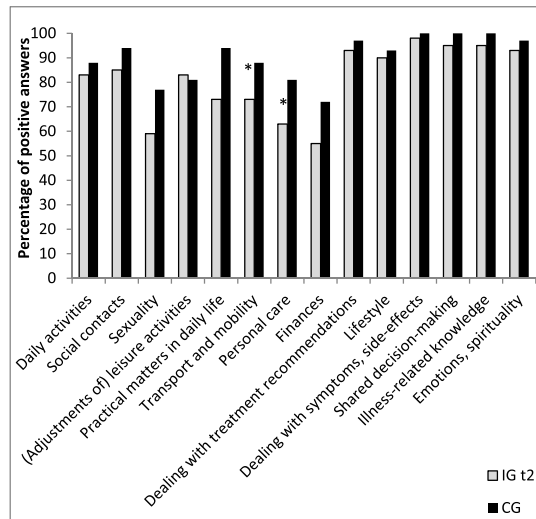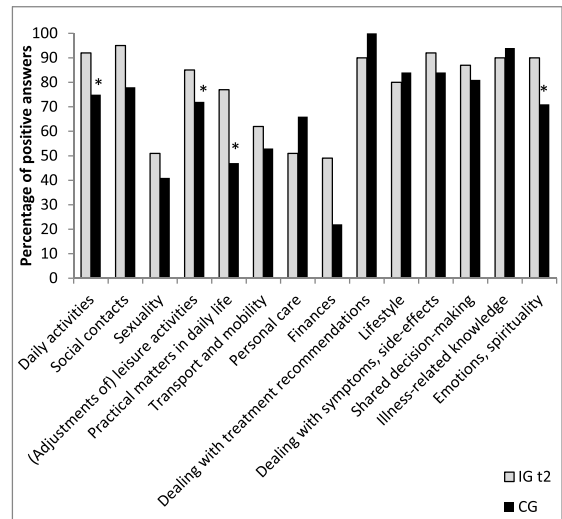
A. Domains perceived to be important
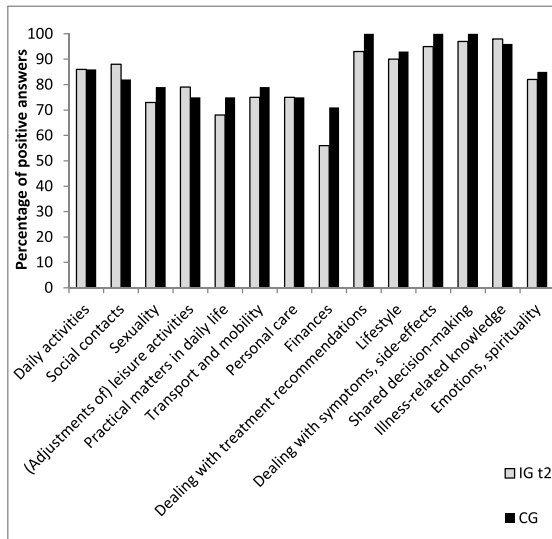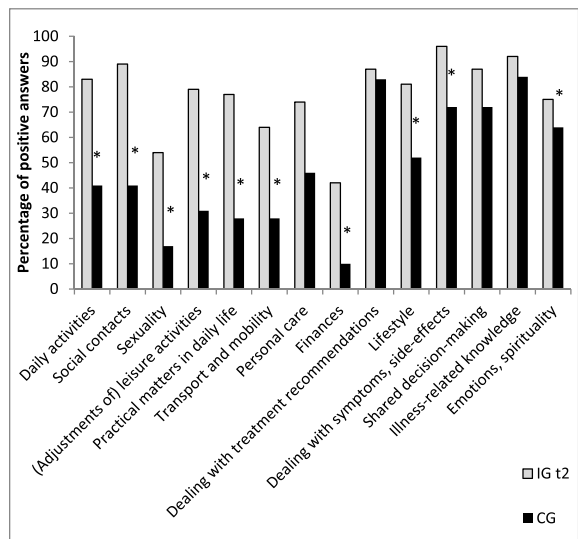
B. Domains of importance addressed by the Cancer Nurse

C. Domains perceived to be important

D. Domains of importance addressed by the Cancer Nurse

*P-value <.05.

Abbreviation: CG, control group; HSCT, hematopoietic stem cell transplantation; IG, intervention group.

Figure 3 ■ Importance of paying attention and actual attention paid to the domains of care of the aftercare per group. Patients with autologous HSCT: (A) domains perceived to be important; (B) domains of importance addressed by the cancer nurse. Patients with allogeneic HSCT: (C) domains perceived to be important; (D) domains of importance addressed by the cancer nurse.

reported that the cancer nurse paid statistically significantly more attention to 10 of the 14 domains as compared with participants in the CG (Figure 3B). In recipients of allogeneic HSCT, there was a statistically significant difference between the IG and the CG on the domain's daily activities, leisure activities, practical matters in daily life, and emotions and spirituality (Figure 3D).

Despite these positive results, the CAHPS, SECD-6, and PIH did not show statistically significant differences between the IG and CG (Table 2).

The focus groups provided insight into how quality of care was experienced by participants themselves (Table 4).

The expertise of the cancer nurse motivated me to visit her. You do not know all the side effects of the treatment in advance. During the consultations you discuss your symptoms and experiences and she gives you confirmation. For me the consultations were important and valuable because she encouraged me and that enabled me to take the lead in my physiologically and mental recovery. (autologous HSCT)

From the focus groups, 4 themes were distinguished:

1. *Competences of the cancer nurse.* The cancer nurse played an important role in the care after the HSCT through supporting patients, giving

Table 3 • Importance of Paying Attention and Actual Attention Paid to the Domains of the Aftercare

Topics	Domain Perceived to Be Important, %						Domain of Importance Addressed by the Professional, %					
	IG T0	IG T1	IG T2	CG	P	P	IG T0	IG T1	IG T2	CG	P	P
	n = 156	n = 137	n = 98	n = 61	IG	T2-CG	n = 156	n = 137	n = 98	n = 61	IG	T2-CG
Daily activities	84	83	85	87	.378	.880	80	87	87	59	.802	.000
Social contacts	84	86	87	88	.762	.239	89	92	91	61	.614	.000
Sexuality	60	67	67	78	.564	.091	56	67	53	30	.795	.004
(Adjustments of) leisure activities	79	82	81	78	.622	.814	81	87	82	52	.916	.000
Practical matters in daily life	73	79	70	80	.125	.111	71	77	77	38	.134	.000
Transport and mobility	78	79	74	83	.449	.048	65	72	63	41	.207	.030
Personal care	75	72	70	78	.185	.024	69	73	64	57	.843	.569
Finances	58	59	56	72	.737	.014	41	46	45	16	.275	.002
Dealing with treatment recommendations	94	98	93	98	.963	.093	84	91	88	92	.403	.822
Lifestyle	90	94	90	93	.651	.391	79	89	80	69	.096	.169
Dealing with symptoms, side effects	97	96	96	100	.520	.049	91	94	95	79	.311	.001
Shared decision making	93	95	96	100	.379	.058	80	87	87	77	.680	.177
Illness-related knowledge	95	96	97	98	.171	.134	91	93	91	90	.873	.184
Emotions, spirituality	79	85	88	90	.071	.166	75	83	81	68	.037	.001

Abbreviations: CG, control group; IG, intervention group.

feedback, and being an expert in the field of HSCT. Participants indicated that the cancer nurses were easily accessible and considered them as an important sparring partner during the aftercare process. The holistic attitude of the cancer nurse helped patients to show their vulnerability.

2. *Topics.* Knowledge of HSCT and the relationship of trust with the cancer nurse that was already built during hospitalization for HSCT contributed to the fact that, during the aftercare intervention, participants felt comfortable to discuss all aspects of life and well-being that concerned them.

3. *Self-management support.* Participants indicated that they felt encouraged and empowered by the cancer nurses and that this strengthened their physical and emotional well-being. It helped them regain control of their lives again. The combination of treatment-specific knowledge and the holistic focus encouraged cancer nurses to tailor the support to the individual participant needs, enabling them to adapt it to their own situation.

4. *Referral.* Participants described the cancer nurses as being well-informed about relevant healthcare professionals when they needed more specialized treatment or supportive cancer care. They were satisfied about the timing and the choice of healthcare professionals the cancer nurse referred them to (Table 4).

Fidelity

Observation of 6 consultations confirmed that the cancer nurses performed the intervention as referred to in the predefined protocol. The cancer nurses discussed all domains of daily life with the participants and addressed the domains that were important for them. The cancer nurses encouraged participants in their self-management by reflecting and prioritizing their problems and defining their goals in feasible and concrete steps.

■ Discussion

In the current study, the effect on a nurse-led patient navigation intervention on quality of life and quality of care in recipients of an autologous or allogeneic HSCT during the first year of recovery posttransplantation was evaluated. This study shows a statistically significant improvement over time on nearly all QoL domains in the first year after HSCT, although no difference in QoL between the IG and CG was detected. In addition to the physical aspects of QoL, participants emphasized the importance of the 14 domains of daily life and the opportunity to discuss these more holistic and practical domains during their consultations with the cancer nurses.

The holistic focus and the role of the cancer nurse addressed most of the challenges that patients face during the first year after HSCT. Hematopoietic stem cell transplantation patients are confronted with a prevailing fatigue, should redefine their previous roles, must adopt a healthy lifestyle and therapy compliance, and have concerns about work and finance.[6–8] Evaluation of this intervention showed that the cancer nurse is ideally suited in supporting patients with these more holistic and practical domains. In studies of complex survivorship care, these 2 items were also seen as the most important concepts of the used interventions.[17,25–27]

In general, autologous procedures have less impact on QoL. These patients are expected to recover to their baseline levels of functioning between 2 and 4 months after transplantation.[28] Consequently, the assumption is that these patients do not need additional aftercare.[28] However, in the current study, we demonstrated that patients after an autologous HSCT benefit most of the nurse-led aftercare intervention.

Unlike the autologous CG, patients from the allogeneic CG reported receiving more support from their healthcare professionals during standard care (Figure 3D). Because this patient group received outpatient care alternately by a nurse practitioner and a hematologist, it seemed that the nurse practitioner had already discussed many of the 14 domains during their consultations.

Table 4 • Quotes From Patients Who Participated in the Focus Groups	
Quality of Care	
Competences of the cancer nurse	"I was actually so happy that I could have a conversation with her, she has helped me to feel good about myself. I had quite some problems with emotions and when I was invited again by her, I thought yes!" (autologous HSCT)
	"What struck me the most was that she was very accessible. I immediately dared to be open, honest, and vulnerable. I felt free to speak about my fears and everything that kept me busy. Already during our first meeting I felt familiar and safe with her." (allogeneic HSCT)
Topics	"She gave insight into what life after the SCT looks like. I did not know what to expect." (allogeneic HSCT)
	"Every area was discussed. During the first consultation it was more explanation about the rules to be aware of after SCT. For example, to be aware of the effects of the sun after the treatment of HSCT. By discussing these specific SCT items in the presence of my parents, both my parents and I were reassured." (allogeneic HSCT)
	"She asked me what I wanted to discuss. For me it was more the emotional well-being. I have 4 children and no partner. I could not discuss everything with them. I missed a sparring partner. We were open in our communication, she gave advice, also about the situation at home, and how I could handle it." (autologous HSCT)
Self-management support	"The expertise of the cancer nurse motivated me to visit her. You do not know all the side effects of the treatment beforehand. During the consultations you discuss your symptoms and experiences and she gives you confirmation. For me the consultations were important and valuable because she encouraged me and that enabled me to take the lead in my physiologically and mental recovery." (autologous HSCT)
	"During the discussions you became aware of the situation where you were in. By answering the questions, you became aware of your own well-being." (autologous HSCT)
	"I feel guilty that I survived the SCT while fellow patients did not survive. This is an emotional burden. She said that I survived and was allowed to. By talking about these feelings, I felt better and give me the feeling that could continue my life." (autologous HSCT)
Referral	"For me the referral was just in time. It all got too much for me. She said, 'I'm going to arrange help for you because that is necessary right now.' She knows that I always try to solve my own problems, therefore she encouraged me to be open for this help." (allogeneic HSCT)
	"After discharge, I had a lot of trouble with being together 24/7 with my partner. I thought that I was being patronized, limited by the side effects and I could not do my own things anymore and she referred me to a psychologist to talk about these feelings. And a day later I received an email, she had found a good psychologist in my neighborhood." (allogeneic HSCT)

Abbreviations: HSCT, hematopoietic stem cell transplantation; SCT, stem cell transplantation.

One of the added values of nurse practitioners is their ability to combine nursing and medical perspectives in their daily consultations.[26,29] Still, the additional value of the nurse-led patient navigation intervention, even in this group, is visible in this study, especially for the more practical and emotional domains of daily life. Cancer nurses should therefore be recognized as key members of the survivorship care team.[30–32]

Despite the significant improvement of QoL over time in the IG, no differences in QoL were observed between the IG and the CG 1 year after transplantation. This improvement of QoL in the IG might be explained by a gradual improvement of the medical situation and the physical and psychosocial recovery after HSCT.[6,8,28] Nevertheless, the focus groups provided us additional in-depth insight into the impact of the treatment on their daily life during the first year after HSCT. This could help cancer nurses support these patients in their challenges when they go through the 5 phases of recovery and rehabilitation.[9]

■ Strengths and Limitations

Only 47% of the included participants in the IG completed all 3 questionnaires secondary to patient death, transplant-related complications, or feeling too ill to complete the questionnaires. This is a single-center study. The concept of this intervention is relatively new and tested in a very specific patient group. Therefore, the generalizability of this intervention is limited.

No statistically significant effect of the intervention was observed between the IG and the CG on self-management or self-efficacy. In previous studies that evaluated self-management interventions, cancer is noticeably absent because of the complex, multifaceted, and dynamic nature of the disease and its treatments.[17,20,33] Complex treatments such as SCT may merit more condition-specific measurements.

■ Conclusion

We developed and implemented a nurse-led patient navigation intervention for patients after HSCT. This intervention is a promising and valuable model in supporting patients' unmet needs and guiding them along their rehabilitation. The holistic approach of the cancer nurses seems to be an important theme of the intervention. Nurse-led patient navigation interventions for patients after HSCT should be part of the daily practice of cancer survivorship care.

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