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What factors contribute to cancer survivors' self-management skills? A cross-sectional observational study

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ABSTRACT

Purpose: Many cancer survivors, facing the consequences of their disease and its treatment, have medical and supportive aftercare needs. However, limited knowledge exists regarding the relationship between support needs and survivors' self-management skills. The study aim is to explore factors contributing to cancer survivors' self-management skills.

Methods: A cross-sectional study was conducted among cancer survivors (n = 277) of two outpatient oncology clinics at a university hospital in the Netherlands. Patients with head and neck cancer (n = 55) who had received radiotherapy and cisplatin or cetuximab were included, as well as patients who had undergone hematopoietic stem cell transplantation (n = 222). The primary outcome was self-management skills, assessed using the Partners in Health Scale (PIH), which comprises two subscales: knowledge and coping (PIH-KC), and recognition and management of symptoms, and adherence to treatment (PIH-MSA). Secondary outcomes were quality of life (EORTC QLQ-C30), self-efficacy (SECD6), patient-centered care (CAPHS), and social support (HEIQ). Machine learning-based Random Forest models were employed to construct associative models. Feature Importance (FI) was used to express the contribution to the model.

Results: High emotional quality of life (FI = 33.1%), increased self-efficacy (FI = 22.2%), and greater social support (FI = 18.2%) were identified as key factors contributing to cancer survivors' self-management knowledge (PIH-KC). Furthermore, greater support from professionals (FI = 36.1%) and higher self-efficacy (FI = 18.2%) were found to benefit participants' recognition and management, and therapy adherence (PIH-MSA).

Conclusions: A patient-centered relationship between nurses and cancer survivors is essential for therapy adherence and the management of aftercare needs. Training to provide this holistic self-management support is required.

1. Introduction

In the last two decades, the life expectancy following cancer treatment has risen significantly, challenging many cancer survivors to embrace healthy lifestyles to reduce the risks of late effects, deal with comorbid conditions and polypharmacy, and navigate the psychosocial implications while managing their daily responsibilities (Jefford et al., 2022). Implying that cancer care does not end once treatment is

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completed; aftercare is required (Howell et al., 2017; Jefford et al., 2022). Many cancer survivors need medical and supportive care to deal with long-term consequences of the disease and its treatment, such as fatigue, pain, anxiety, and depressive symptoms (Schmidt et al., 2022; Phillips and Currow, 2010; Emery et al., 2022). The previous cancer care paradigm primarily emphasized recurrence detection and inadequately addressed the medical, emotional and social support needs of survivors (Foster et al., 2015; Peeters et al., 2018; Halpern et al., 2015). In the new paradigm, where cancer is viewed as a chronic condition, the relationship between professionals and patients evolves into a long-term collaborative relationship where patient-centered care is important (Jefford et al., 2022; Flagg, 2015). In patient-centered care, professionals need to prioritize and address to the preferences, needs and values of patients (Flagg, 2015). Patients' self-management support can be considered an essential component in achieving the shift from an acute care model to a chronic care model (Barlow et al., 2002). Barlow and colleagues have defined self-management as ongoing adjustment to the medical, emotional and social challenges of a chronic condition in daily life, with the aim of achieving optimal quality of life (Barlow et al., 2002). For cancer survivors, successful self-management may involve proper self-monitoring, identification, reporting, and handling of symptoms, as well as addressing treatment side effects (Howell et al., 2021). Like people with other chronic conditions, cancer survivors are expected to play an active role in their aftercare which is essential in optimizing their health, quality of life, and survival (McCorkle et al., 2011; Howell et al., 2021). Offering self-management interventions may be instrumental in this regard (Boland et al., 2018; Cuthbert et al., 2019), as optimal self-management skills can indirectly improve cancer-related fatigue, self-efficacy (Xu et al., 2019), and quality of life (Van Dijck et al., 2016; Kim, 2017). In practice, self-management support is often provided by nurses (Elissen et al., 2013).

While many interventions to improve patients' self-management skills have been developed, the empirical basis for providing self-management support after anti-cancer treatment is still limited (Cuthbert et al., 2019; Jefford et al., 2022). Additionally, the current literature predominantly concentrates on frequently encountered oncological diseases such as breast, prostate, bowel, and lung cancer (Jefford et al., 2022; van Dongen et al., 2020; Hernandez Silva et al., 2019; Kim, 2017). Our study, however, addresses two less frequently encountered oncological diseases: 1) head- and neck cancer after treatment with radiotherapy and cisplatin or cetuximab, and 2) haematological malignancy after treatment with a hematopoietic stem cell transplantation (HSCT). Head- and neck cancer, involving malignancies located in the upper respiratory and food pathway above the level of the collarbones, is worldwide responsible for 4.9 percent of all cancer diagnoses (Sung et al., 2021). Around 6.6 percent of all cancer diagnoses in adults are haematological malignancies, a diverse group of cancers that affect the blood, bone marrow and lymphatic systems (Sung et al., 2021; Snowden et al., 2017). Both diseases have in common that the impact of the treatment on the patient can be huge; e.g., dealing with fatigue, pain, and anxiety, and rebuilding one's self-confidence (Lokker et al., 2013).

The relevant literature provides little information about the underlying mechanisms of self-management skill levels in cancer survivors. Studies focusing on patients with chronic conditions have revealed that limited self-management skills are often associated with factors such as unemployment or work disability, multimorbidity, and low self-efficacy (Bartlett et al., 2020). Furthermore, a qualitative systematic review has highlighted the positive influence of a supportive family on patients' self-management skills (Koetsenruijter et al., 2016; Whitehead et al., 2018). To gain a deeper understanding of the essential factors that determine cancer survivors' self-management skills, this study aims to explore the working elements of nurse-led self-management support in aftercare. By doing so, we hope to uncover valuable insights into the factors that contribute to cancer survivors' ability to effectively manage the long-term consequences of their disease and improve their overall well-being.

Table 1
Outcome measures and questionnaires.

Primary outcome	Secondary outcomes	Questionnaire
Self-management knowledge and behaviour		- Partners in Health Scale (PIH) (Petkov et al., 2010; Lenferink et al., 2016; Battersby et al., 2003)
	Quality of life (QOL)	-European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993; Aaronson, 1992)
	Self-efficacy	-Self-Efficacy for Managing Chronic Disease 6-item Scale (SECD6) (Brady, 2011; Lorig et al., 2001)
	Quality of nursing care - patient-centered care	-American Consumer Assessment of Health Plan Surveys (CAHPS) (Arah et al., 2006; Delnoij et al., 2006; van Staa and Sattoe, 2014)
	Social support	-Health Education Impact Questionnaire (HEIQ) (Osborne et al., 2007)
	Importance vs actual attention paid to topics during nurse-led consultation session	-Self-developed questionnaire

2. Methods

2.1. Study design

A cross-sectional observational study was conducted among two different groups of patients who had successfully completed invasive cancer treatment. This study utilized baseline data from the research program NURSE-CC (Nursing Research into Self-management and Empowerment in Chronic Care) (Braat et al., 2022; van der Lans et al., 2022).

2.2. Sample and participants

This study was performed at two different outpatient clinics of the Erasmus University Medical Center Rotterdam, the Netherlands. Two different groups of patients participated in the study: patients with head- and neck cancer (HNC) treated with radiotherapy and cisplatin or cetuximab, and recipients of a hematopoietic (autologous or allogeneic) stem cell transplantation (HSCT) treated for a haematological malignancy. Both patient groups were chosen based on their involvement in the research program NURSE-CC. All patients had completed their invasive treatment up to 9 (HNC) or 12 (HSCT) months ago. In the period October 2015–October 2017, a comprehensive sampling strategy was employed to recruit study participants aged 18 years and older. Patients were excluded if they had major medical complications, experienced relapsed disease, had cognitive limitations, were dealing with acute psychiatric problems, did not speak Dutch, or already participated in other studies.

2.3. Data collection

Eligible study participants who had confirmed to be willing to participate were invited to complete the questionnaire at home on paper.

2.3.1. Outcome measures

Table 1 provides an overview of the outcome measures and questionnaires.

The primary outcome measure was self-management knowledge and behaviour measured with the 12-item Partners in Health Scale (PIH) (Petkov et al., 2010; Lenferink et al., 2016; Battersby et al., 2003). The items are scored on an 8-point Likert scale (where 1 indicates poor self-management and 8 good self-management). While the original Australian PIH had a four-subscale structure ($\alpha = 0.82$), the Dutch version has a two-subscale structure: 1) knowledge and coping (PIH-KC); 2) recognition and management of symptoms, and adherence to treatment (PIH-MSA). The internal consistency, as measured by Cronbach's alpha) was 0.80 for the PIH-KC and 0.72 for the PIH-MSA. The correlation between the subscales was acceptable ($\alpha = 0.43$) (Lenferink et al., 2016).

Secondary outcomes were quality of life (QOL), self-efficacy, patient-centered care, and social support. Quality of life was assessed with the validated Dutch version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson, 1992; Aaronson et al., 1993). The generic EORTC QLQ-C30 consist of 30 items, divided into five functional scales (physical, role, emotional, cognitive and social), a symptom scale and a global quality of life scale (range score 0–100). The Cronbach's alpha is > 0.70 for all five scales (Aaronson et al., 1993; Snyder et al., 2015).

The Self-Efficacy for Managing Chronic Disease 6-item scale (SECD-6) was used to measure self-efficacy (Brady, 2011; Lorig et al., 2001). Self-efficacy is scored on a self-rated 10-point Likert scale, with 1 indicating no confidence and 10 indicating total confidence. The Cronbach's alpha of the English version is 0.91 (Lorig et al., 2001; Brady, 2011). As a validated Dutch version was not available, we (back) translated the English version into Dutch and used in other studies (Been-Dahmen et al., 2019; Beck et al., 2019; Braat et al., 2022; van der Lans et al., 2022).

Patient-centered care was measured with the subscale 'patient-centeredness' of the American Consumer Assessment of Health Plan Surveys (CAHPS). This subscale consists of five items to be rated on a 4-point Likert scale (from 1 = no, definitely not to 4 = yes, definitely), and is validated for use in the Dutch context ($\alpha = 0.90$) (Arah et al., 2006; Delnoij et al., 2006; van Staa and Sattoe, 2014).

The subscale social support of the Dutch Health Education Impact Questionnaire (HEIQ) was used to measure social support (Osborne et al., 2007). This subscale consists of five items scored on a 4-point Likert scale (1 = total disagree and 4 = total agree); Cronbach's alpha is 0.86. Higher scores indicate higher levels of social interaction, higher sense of support, and seeking more support from others. The test-retest reliability of the Dutch version ranged from 0.61 to 0.84 (Ammerlaan et al., 2017).

Additionally, we developed a questionnaire to assess relevant topics discussed during outpatient consultations related to the self-management. In the NURSE-CC research program we developed a conversation tool, called 'the Self-Management Web' (Beck et al., 2019), using the Intervention Mapping approach (Bartholomew et al., 1998). This questionnaire was based on the topics of this Self-Management Web, examples of topics were daily activities/work, dealing with treatment recommendations, self-care, intimate relationships/sexuality (See additional file 1 for the Self-Management Web) (Been-Dahmen et al., 2019; Braat et al., 2022; Van Der Lans et al., 2022). The participants indicated in this questionnaire both the importance of addressing these topics and the level of attention given to them during nurse-led consultations. This scale consists of 15 items scored on a 3-point Likert scale (importance questions: 1 = not important, 2 = somewhat important, and 3 = very important; attention questions: 1 = no attention, 2 = some attention, and 3 = much attention). In order to measure differences, answer options 1 and 2 were recoded as negative, and 3 was recoded as positive.

2.4. Data analysis

Normally distributed data were described using the mean (SD), while non-normally distributed data were described using the median (P50) and interquartile ranges (IQR) (P25–P75). The spread and skewness of the data was assessed visually and by Kolmogorov-Smirnoff testing. Means SD, IQR, and proportions were used for descriptive analyses. Thereafter, any differences between the patient groups were established using bivariate analyses, including chi-square tests (nominal measurements) and t-tests.

Before constructing machine learning-based associative models, we created a correlation matrix using Pearson or Spearman correlation coefficients, depending on the data distribution. Cohen recommended $r = 0.10$, $r = 0.30$, and $r = 0.50$ to be considered small, medium, and large in magnitude, respectively (Cohen, 1992). Based on this correlation matrix, we assessed collinearity. In the final phase, associative models were constructed using machine learning-based Random Forest models (RF). Random Forest models offer the advantage of providing more robust and precise effect measures and can handle non-linear effects (Pluth and Brose, 2022). Two RF-models were constructed, with the primary outcomes (PIH-KC & PIH-MSA) as dependent variables and the remaining outcomes as independent variables. The data were divided, with 75% allocated to the training set and the remaining 25% to the test set. Two RF-models were constructed for each of the primary outcomes, and hyperparameter tuning was performed by creating a 10-fold CV-Grid to optimize the final model. In order to gain insight into the relative importance of each included independent variable, we calculated feature importance (FI), which represents the contribution of each outcome in the model as a percentage. Algorithmic precision was measured using explained variance (R^2), Mean Absolute Error (MAE), Mean Squared Error (MSE) and Root Mean Squared Error (RMSE).

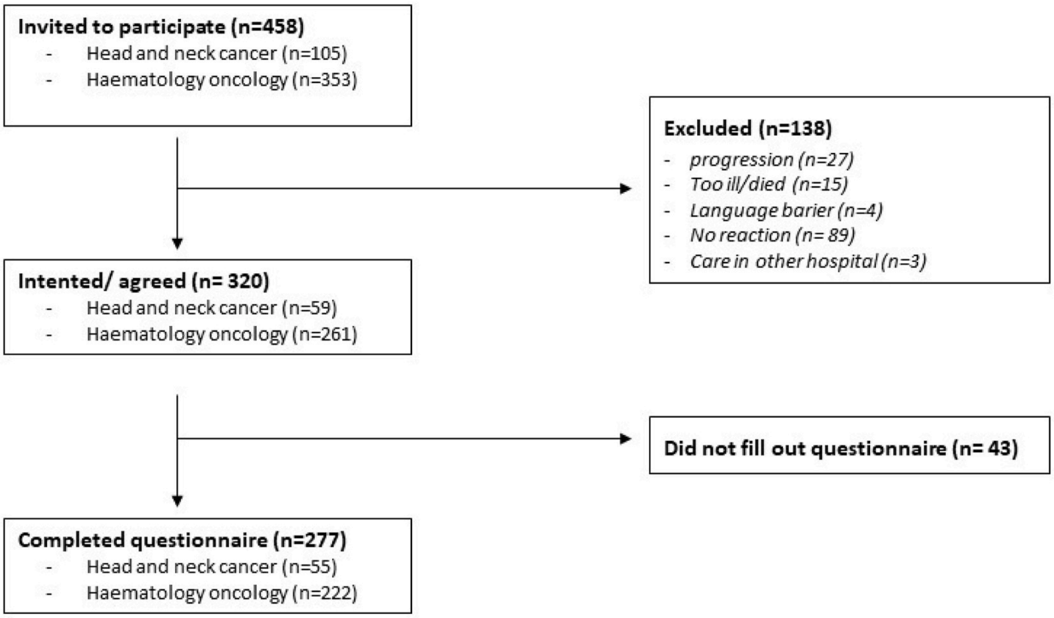

Fig. 1. Flowchart of respondent inclusion.

Table 2
Sample characteristics.

Variables	Hematopoietic stem cell transplantation (HSCT) (n = 222)	Head and neck cancer (HCN) (n = 55)	Total (n = 277)	P
Gender (n; %)				
male	131 (59.0)	41 (74.5)	172 (62.1)	<0.001
Age (mean; sd)	54.8 (11.6)	61.4 (6.9)	56.1 (11.1)	<0.001
Marital status (n; %)				
Living alone	21 (9.5)		39 (14.1)	<0.001
Living with partner	198 (89.2)	18 (32.7)	235 (84.8)	
Missing	3 (1.4)	37 (67.3)	3 (1.1)	
Education (n; %)				
Primary school or none	18 (8.1)	10 (18.2)	28 (10.1)	
Secondary school/lower vocational education	76 (34.2)	12 (21.8)	88 (31.8)	
Secondary vocational education	60 (27.0)	14 (25.5)	74 (26.7)	
Higher education	64 (28.8)	16 (29.1)	80 (28.9)	
Missing	4 (1.8)	3 (5.5)	7 (2.5)	
Education (n; %)				
Lower	94 (42.3)	22 (40.0)	116 (41.9)	NS
Higher	124 (55.9)	30 (54.5)	154 (55.6)	
Missing	4 (1.8)	3 (5.5)	7 (2.5)	
Employment (N; %)				
Paid employment, yes	106 (47.7)	23 (41.8)	129 (46.6)	NS
No paid employment	104 (46.8)	29 (52.7)	133 (48.0)	
Missing	12 (5.4)	3 (5.5)	15 (5.4)	

P-values <00.05 were considered statistically significant. All analysis were performed in Python, and the base code is available at https://github.com/HR-Data-Supported-Healthcare.

Machine learning-based Random Forest models (RF) were employed to construct associative models. Feature Importance (FI) was used to express the contribution to the model and was expressed in percentages.

2.5. Ethical considerations

Eligible study participants were first informed verbally about the study, and subsequently received an information letter and consent form. All were contacted by phone to inform whether the information was clear, and whether they were willing to participate. Only those who returned their informed consent form could participate in this study. Patients were assured of confidentiality: data were processed anonymously, and medical staff did not have access to the non-anonymous data.

The Medical Ethics Committee of the Erasmus University Medical Center approved the research protocol (MEC-2015-317).

3. Results

Four hundred and fifty-eight cancer survivors were invited to participate in this study. Eventually, 277 individuals returned the questionnaire. See Fig. 1 for the flowchart for inclusion. Response rates were 52.4% (n = 55) in the HNC-group and 62.9% (n = 222) in the HSCT-group. Ages between the groups differed significantly ($p < 0.001$). Patients with HNC were older ($t = -4.05$; $p < 0.001$), more of them were male ($\chi^2 = 19,28$; df = 3; $p < 0.001$), and were living alone ($\chi^2 = 19,28$; df = 3; $p < 0.001$). There were no significant differences in lower or higher education (χ2 = 0.011, df = 1, p > 00.00.05) or paid employment between the two patient groups (χ2 = 0.65, df = 1, p > 00.00.05).

Table 3
Overview of the importance of self-management topics according to patients.

	Hematopoietic stem cell transplantation (HSCT)*(n = 222)*	Head and neck cancer (HCN) *(n = 55)*	Total *(n = 277)*	
	Mean (sd)	Mean (sd)	Mean (sd)	P
Importance of paying attention to self-management topics according to patients (scale 1 = not important, 2 = somewhat important, 3 = very important)				
• Dealing with symptoms, side-effects	2.8 (0.5)	2.8 (0.4)	2.8 (0.4)	NS
• Illness-related knowledge	2.7 (0.5)	2.8 (0.4)	2.8 (0.5)	NS
•Being in control with treatment process, Shared decision-making	2.7 (0.6)	2.7 (0.5)	2.7 (0.6)	NS
•Dealing with treatment recommendations	2.7 (0.5)	2.6 (0.6)	2.7 (0.6)	NS
•(adjusting) Life-style	2.5 (0.7)	2.5 (0.6)	2.5 (0.7)	NS
•Social network	2.5 (0.7)	2.2 (0.8)	2.4 (0.7)	<0.05
•Emotional or psychological well-being, giving meaning to life	2.3 (0.8)	2.2 (0.7)	2.3 (0.7)	NS
• Daily activities, work	2.3 (0.7)	2.1 (0.7)	2.3 (0.7)	<0.05
• Self-care (washing, dressing)	2.3 (0.8)	2.1 (0.8)	2.2 (0.8)	NS
• Leisure activities	2.2 (0.8)	2.0 (0.8)	2.2 (0.8)	NS
• Household chorus (practical matters in daily life)	2.1 (0.8)	2.0 (0.8)	2.1 (0.8)	NS
• Finances	2.0 (0.8)	1.9 (0.9)	1.9 (0.8)	NS
• Intimate relationships, sexuality	1.9 (0.8)	1.7 (0.8)	1.9 (0.8)	NS
• Transport, mobility	2.2 (0.8)	2.1 (0.8)	2.2 (0.8)	NS
Actual attention paid to self-management topics in outpatient clinic (scale 1 = no attention, 2 = somewhat attention, 3 = much attention)				
• Dealing with symptoms, side-effects	2.4 (0.7)	2.5 (0.6)	2.5 (0.7)	NS
•Dealing with treatment recommendations	2.4 (0.7)	2.5 (0.6)	2.4 (0.7)	NS
• Illness-related knowledge	2.4 (0.7)	2.5 (0.6)	2.4 (0.7)	NS
• Being in control with treatment process, Shared decision-making	2.2 (0.8)	2.2 (0.8)	2.2 (0.8)	NS
•Social network	2.2 (0.8)	2.0 (0.7)	2.2 (0.8)	<0.05
•(adjusting) Life-style	2.1 (0.8)	2.3 (0.7)	2.1 (0.8)	NS
•Daily activities, work	2.1 (0.8)	1.8 (0.7)	2.1 (0.8)	<0.01
•Emotional or psychological well-being, giving meaning to life	2.0 (0.7)	1.8 (0.7)	2.0 (0.7)	NS
•Leisure activities	2.1 (0.8)	1.7 (0.8)	2.0 (0.8)	<0.01
•Self-care (washing, dressing)	1.9 (0,8)	1.8 (0,8)	1.9 (0.8)	NS
•Household chorus (practical matters in daily life)	1.8 (0.8)	1.8 (0.8)	1.8 (0.8)	NS
•Transport, mobility	1.8 (0.8)	1.8 (0.8)	1.8 (0.8)	NS
•Intimate relationships, sexuality	1.6 (0.7)	1.4 (0.7)	1.6 (0.7)	NS
•Finances	1.5 (0.7)	1.6 (0.8)	1.5 (0.7)	NS

Table 4
Overview of primary and secondary outcomes and measurements in the patient groups.

	Hematopoietic stem cell transplantation (HSCT) *(n = 222)*	Head and neck cancer (HCN) *(n = 55)*	Total *(n = 277)*	p-value
	Mean (SD)	Mean (SD)	Mean (SD)	
Self-management knowledge and behaviour (PIH)				
Subdomain knowledge and coping	46.7 (5.8)	46.4 (6.7)	46.7 (5.9)	0.738
Subdomain recognition and management of symptoms, adherence to treatment	37.1 (3.8)	34.3 (6.5)	36.6 (4.6)	<0.001
Patient-centered care (CAHPS)	19.1 (1.9)	18.5 (2.8)	18.9 (2.1)	0.103
Quality of Life (EORTC QLQ C30)				
Global quality of Life scale	64.8 (22.9)	76.3 (20.0)	67.0 (22.8)	0.001
Functional scales				
• Physical functioning	73.5 (22.0)	85.2 (16.9)	75.8 (21.6)	<0.001
•Role functioning	55.2 (32.4)	82.7 (22.4)	60.5 (32.5)	<0.001
•Emotional functioning	78.9 (21.2)	79.4 (23.2)	79.0 (21.5)	0.893
•Cognitive functioning	75.5 (22.9)	86.8 (20.5)	77.7 (22.8)	0.001
•Social functioning	66.7 (28.0)	81.4 (22.1)	69.5 (27.5)	<0.001
Symptom scale	26.7 (19.5)	15.6 (13.5)	24.4 (18.9)	<0.001
Self-efficacy (SECD6)	35.2 (11.9)	33.4 (14.7)	34.8 (12.5)	0.362
Social support (HEIQ)	18.6 (2.4)	18.7 (1.9)	18.6 (2.3)	0.673

Sample characteristics are shown in Table 2.

3.1. Self-management topics addressed and perceived to be important

Participants were asked to rate which topics they perceived to be important, and which topics were addressed during the consultation sessions at the outpatient clinic (Table 3). The topics perceived as most important were social network (M = 2.4; SD = 0.7), dealing with treatment recommendations (M = 2.7; SD = 0.6), (adjusting) life-style (M = 2.5; SD = 0.7), dealing with symptoms and side effects (M = 2.8; SD = 0.4), being in control of treatment process, and shared decision making (M = 2.7; SD = 0.6), and receiving illness-related knowledge (M = 2.8; SD = 0.5). The topics actually addressed in the consultation sessions were dealing with treatment recommendations (M = 2.4; SD = 0.7), dealing with symptoms and side-effects (M = 2.5; SD = 0.7), and illness-related knowledge (M = 2.4; SD = 0.7). Therefore, a

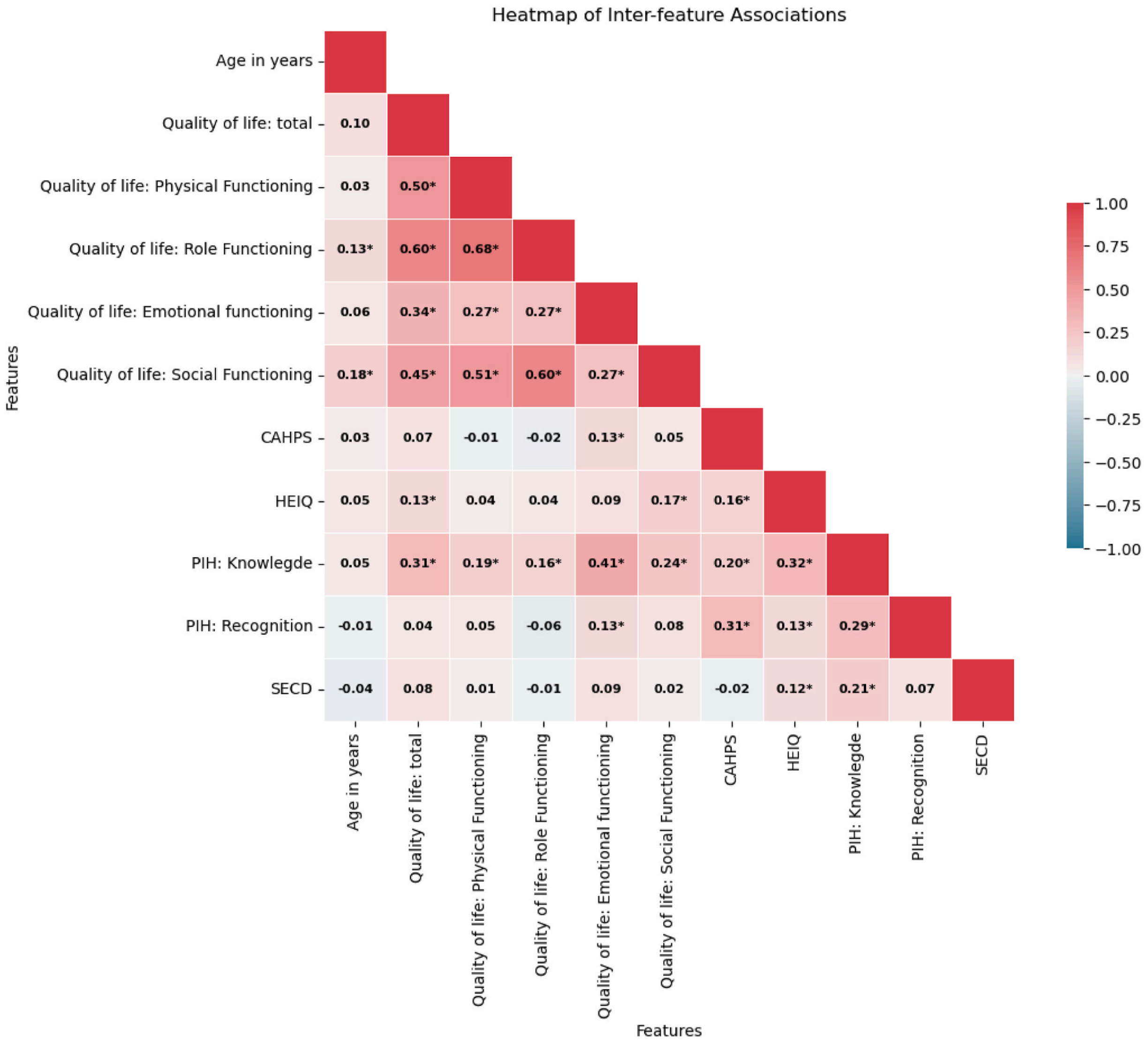

Fig. 2. Inter-feature associations
* $p < 0.05$.

discrepancy existed between patient-reported areas of importance and the topics being addressed (i.e., important topics were not being discussed) in the following areas: social network, (adjusting) life-style, and being in control of treatment process, and shared decision making. The patients in the HSCT-group considered attention to daily activities or work and attention to social network as more important than did the patients in the HCN-group ($p < 0.01$). These topics also arose more often during consultations in the HSCT-group, as did attention to leisure activities ($p < 0.05$). There were no other striking differences between both groups.

3.2. *Differences in the outcomes of the different patient groups*

3.2.1. *Primary outcome*

No significance difference in self-management knowledge and coping was measured between the HCN- and HSCT-group (PIH-KC) (HCN: M = 46.4; SD = 6.7) vs. HSCT: M = 46.7; SD = 5.8; p = 0.74). However, a significance difference was found between both groups

Table 5
Model characteristics and performance metrics.

Model	Tuning parameters	R^2	MAE	MSE	RMSE
PIH-KC[a]	*Max depth: 5* *Min samples leaf: 2* *Min samples Split: 10* *N estimators: 500*	0.50	0.56	0.46	0.67
PIH-MSA[b]	*Max depth: 10* *Min samples leaf: 4* *Min samples Split: 10* *N estimators: 100*	0.18	0.67	1.01	1.00

[a] PIH-KC: Partners in Health Scale – Knowledge and coping.
[b] PIH-MSA: Partners in Health scale – recognition and management of symptoms, and adherence to treatment.

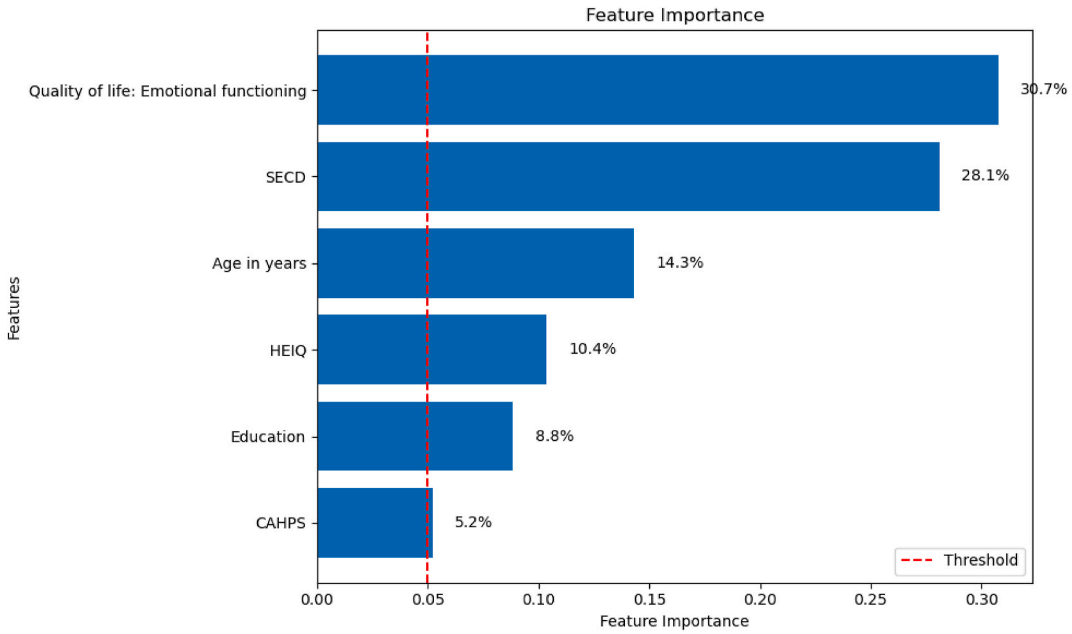

Fig. 3a. Feature importance PIH-KC

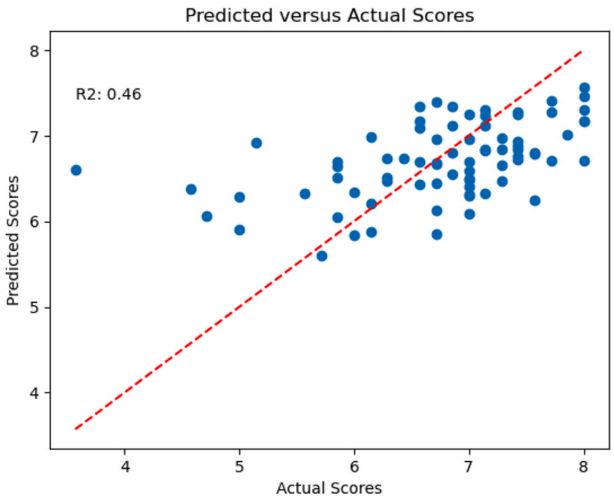

Fig. 3b. Performance RF-model PIH-KC

regarding recognition and management of symptoms, adherence to treatment (PIH-MSA) (HCN: M = 34.3; SD = 6.5 vs. HSCT: M = 37.1; SD = 3.8; $p < 0.001$).

3.2.2. *Secondary outcomes*

Significant differences between the HCN-group and HSCT-group were found regarding the global quality of life scale (HCN: M = 76.3; SD = 20.0 vs. HSCT: M = 64.8; SD = 22.9; $p < 0.001$), physical functioning (HCN: M = 85.2; SD = 16.9 vs. HSCT: M = 73.5; SD = 22.0; $p < 0.001$), role functioning (HCN: M = 82.7; SD = 22.4 vs. HSCT: M = 55.2; SD = 32.4; $p < 0.001$), cognitive functioning (HCN: M = 86.8; SD = 20.5 vs. HSCT: M = 75.5; SD = 22.9 $p < 0.001$), social functioning (HCN: M = 81.4; SD = 22.1 vs. HSCT: M = 66.7; SD = 28.0; $p < 0.001$) and the symptom scale (HCN: M = 15.6; SD = 13.5 vs. HSCT: M = 26.7; SD = 19.5; $p < 0.001$) (see Table 4). Only the domain emotional functioning of the physical QOL scale did not differ significantly between the HCN- and HSCT-group (HCN: M = 79.4 vs. HSCT: M = 78.9; p = 0.90). No significant differences between both groups were found regarding patient-centered care, self-efficacy and social support.

3.3. *Inter-feature association*

Fig. 2 depicts the correlation matrix of all potential variables for the ML-model. The heatmap shows several low (r = 0.10–0.30) to strong (r > 0.50) statistically significant correlations with regard to the primary outcome. For the PIH -KC, statistically significant correlations ranged from 0.16 (low) to 0.41 (moderate) in terms of QOL-scores (all domains), HEIQ, CAHPS, SECD. For the PIH-MSA domain, statistically significant correlations ranging from 0.13 (low) to 0.31 (moderate) in terms of quality of life: emotional functioning, HEIQ, CAHPS. Within the QOL-scores, statistically significant correlations were observed, ranging from 0.27 (low) to 0.68 (strong), indicating potential sources of collinearity.

3.4. *Machine learning modelling*

The model characteristics after hyperparameter tuning and performance metrics are presented in Table 5. When considering the RF-model for the PIH-Knowledge domain, the FI and performance are visualized in Fig. 3a and b. The most contributing factors in terms of FI were: Quality of life (QOL): Emotional functioning (FI = 33.1%), self-efficacy (SECD) (FI = 22.0%), social support (HEIQ) (FI = 18.2%), age in years (FI = 14.3%), patient-centered care (CAHPS) (FI = 8.1%). This indicates that higher emotional quality of life, higher self-efficacy, more social support and patient-centered support from professionals contributed to cancer survivors' self-management knowledge and coping. Furthermore, older age was also associated with improved self-management knowledge and coping skills of cancer survivors.

When considering the RF-model for the PIH-Recognition domain, the FI and model performance are visualized in Fig. 4a and b. The most contributing factors in terms of FI were: patient-centered care (CAHPS) (FI = 36.1%), self-efficacy (SECD) (FI = 18.2%), age in years (FI = 15.7%), emotional functioning in quality of life (QOL) (FI = 11.3%), education (FI = 8.6%), social support (HEIQ) (FI = 6.5%). This indicates that more patient-centered support from professionals, higher self-efficacy, greater emotional quality of life and more social support contributed to cancer survivors' recognition and management of symptoms, and adherence to treatment. Moreover, older age and higher educational levels were also associated with these self-management skills in cancer survivors.

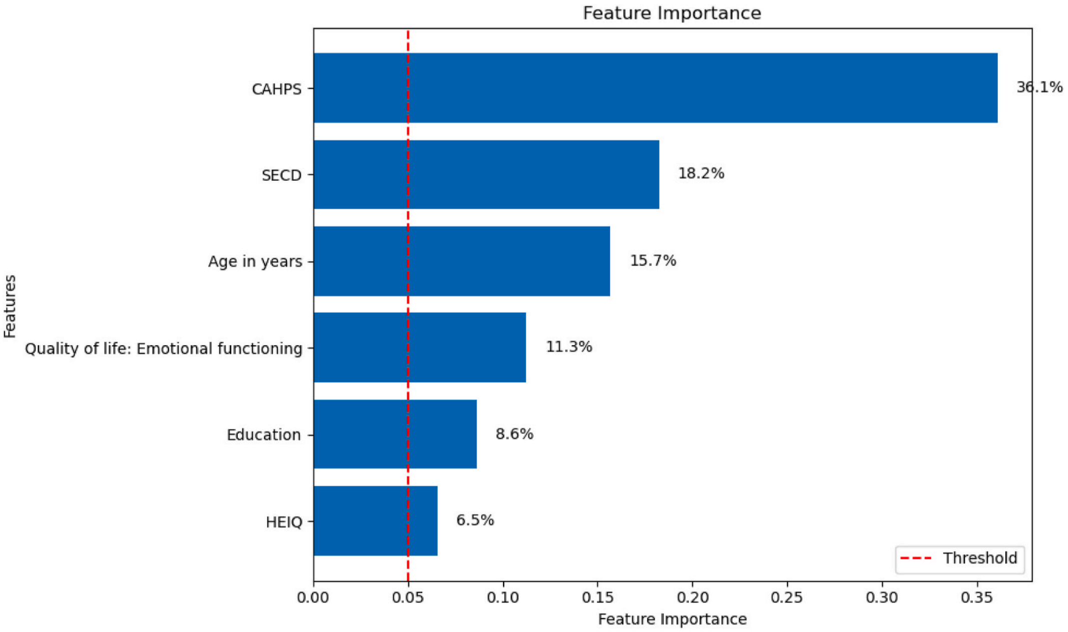

Fig. 4a. Feature importance PIH-MSA.

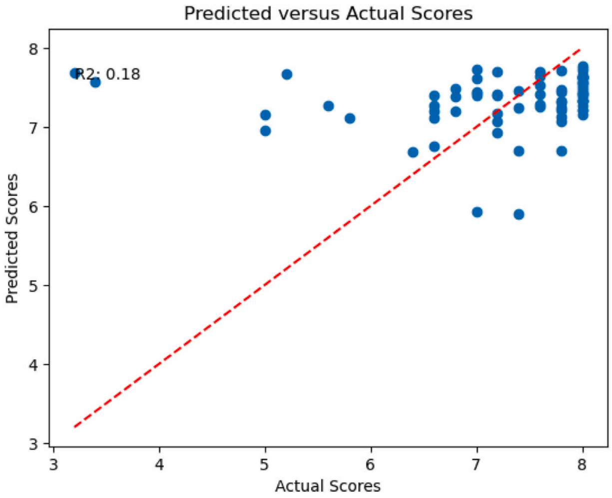

Fig. 4b. Performance RF-model PIH-MSA.

4. Discussion

The aim of this study was to explore the working elements of nurse-led self-management support in aftercare by gaining more insight into factors independently associated with self-management skills of head-and neck cancer survivors' and recipients of hematopoietic stem cell transplantation. Higher emotional quality of life, greater self-efficacy, increased social support, and support from professionals contributed to the study participants' self-management knowledge and coping (PIH-KC). Besides this, it appeared that more support from professionals, greater self-efficacy, better emotional quality of life and increased social support contributed to the study participants' recognition and management of symptoms, adherence to treatment (PIH-MSA). Older age and higher education levels were only associated with the PIH-MSA.

In our study, providing patient-centered care was found an important factor to strengthen recognition and management of symptoms, along with adherence to treatment. Previous research has demonstrated that patient-centered interactions promote treatment adherence and result in improved health outcomes (Robinson et al., 2008; Strandås and Bondas, 2018). This study adds that patient-centered care also promotes self-management skills. This finding aligns with a prior qualitative review from Noordman et al. who described that patient-centered care contributes to enhanced implementation, acceptance, and application of self-management interventions (Noordman et al., 2023). More research into the relationship between patient-centered care and self-management in different patient groups is needed. Based on these findings, supportive self-management interventions could be developed in co-creating with patients and healthcare professionals. In a good nurse-patient relationship, nurses fulfil the biopsychosocial support needs of their patients. Patients actively participate as members of the healthcare team (Leslie and Lonneman, 2016), fostering a relationship built on mutual trust (Dinç and Gastmans, 2013). The provision of patient-centered care is considered in the literature as the core of nursing and offers nurses a unique opportunity to make a distinct contribution to patient care (Ortiz, 2018; McCormack and McCance, 2006). To facilitate nurses in regarding patients as equal partners, it is important that they understand the concept of patient-centered care and receive support and supervision in delivering it (Boström et al., 2014). The first impression nurses make and their body language are crucial in building a relationship of trust with patients. For this reason, nurses should receive training in practice to recognize and managing their own emotional and physical skills (Ekman et al., 2022). Importantly, embracing patient-centered care has been associated positively with nurses' job satisfaction (Gustavsson et al., 2023). To be able to provide patient-centered aftercare, nurses need to move beyond their medical focus and develop an attitude of patient-centeredness (McCormack and McCance, 2006). Implementing patient-centered care in oncology nursing, however, requires that nurses adapt an alternative role of providing chronic care, which may be challenging (Boström et al., 2014; Gustavsson et al., 2023). Previous research highlights the need for further research into effective strategies for preparing oncology nurses and other health care professionals to deliver patient-centered care (Truant et al., 2019). It is important to underscore that self-management support is an well-established concept in chronic care, but despite the grow of cancer survivors and their challenges to deal with long-tern consequences this concept is less common used in oncological care. Two previous studies have highlighted the importance of additional research to explore how patient-oriented self-management support can be more seamlessly integrated in cancer care (Budhwani et al., 2019;

Kantilal et al., 2022).

The findings from this study also highlight that nurses' aftercare support contributes to enhancing cancer survivors' self-efficacy and emotional quality of life, which is essential for therapy adherence and skills to manage their lifelong aftercare needs. These finding align with previous research on self-management interventions which has shown that self-efficacy is a central mechanism for improving patients' self-management skills (Lorig and Holman, 2003; Farley, 2020). However, the success of such interventions depends on the chosen strategies to overcome barriers and maintain desired behaviours (Farley, 2020). Patients' self-efficacy tends to increase when they are able to solve (health-related) problems (Bodenheimer et al., 2002). Consequently, many self-management interventions focus on increasing patients' self-efficacy and quality of life. Interventions that not solely focus on education, but rather on increasing patients' motivation and self-efficacy appear to be most effective (van Hooft et al., 2017). However, a cancer survivor's well-being and self-efficacy in coping with the consequences of a cancer treatment can vary widely in the year following treatment (Foster et al., 2015). By employing empathic listening, heightened awareness, tender care, nurses can foster health-promoting interactions that positively impact the health, quality of life, and overall well-being of cancer survivors (Haugan, 2021).

Cancer survivors in our study who experienced more social support had better self-management knowledge and coping skills (PIH-KC). In the literature, it was described before that cancer survivors perceive the presence of relatives in consultation sessions as supportive. Relatives can provide emotional support, information support (e.g., asking questions or recalling information), and participate in the decision-making process regarding medical decisions (Laidsaar-Powell et al., 2013). Previous literature about self-management also indicates the importance of relatives in promoting positive health (Whitehead et al., 2018). Patients benefit from self-management support from different sources, where relatives have their own unique contribution (Dwarswaard et al., 2016). Still, nurses should be aware that informal caregivers do not always have a positive influence on patients (Vassilev et al., 2014), and that the family member's cancer also has a big impact on the relatives. All in all, it seems to be important that nurses not only focus their self-management support in aftercare on the survivors, but also involve the relatives. While previous research has acknowledged the crucial role of relatives, it is noteworthy that many self-management interventions barely involve cancer survivors' relatives (Cuthbert et al., 2019; Donald et al., 2018; van Hooft et al., 2020). Nurses and other healthcare providers are recommended to involve relatives more frequently in their self-management support to cancer survivors. There is a need for further research and theory to clarify how nurses can provided this support effectively to cancer survivors and their relatives.

4.1. Strengths and limitations

A strength of this study was that a full sampling method was used to include as many patients as possible. One possible limitation of this study is that it included only two different groups of cancer survivors, with fewer head and neck cancer survivors compared to hematological cancer survivors. The group of patients treated with radiotherapy and cisplatin or cetuximab constitutes only a small part of the total head-and-neck cancer population, which is why we were not able to include more head-and-neck cancer patients. This demands further research about self-management skills among cancer survivors. Moreover, it is essential to acknowledge the limitation associated with using self-reported data, because patients may potentially either exaggerate or under-report the challenges they face in their lives.

In this study, we utilized baseline data from two other NURSE-CC studies that assessed the feasibility of nurse-led self-management support interventions (Braat et al., 2022; van der Lans et al., 2022). All participants had competed their invasive cancer treatment up to 12 months prior to inclusion in the study. As a result, the time elapsed since the completion of invasive treatment varied among the participants in this study. However, the conversation tool designed to promote self-management (additional file 1) was implemented after data collection for this study and had no effect on the baseline data we used. Another limitation was that our self-developed questionnaire to assess relevant topics discussed during outpatient consultation related to self-management has not been validated yet. This questionnaire is also used in other studies (Been-Dahmen et al., 2019; Braat et al., 2022; van der Lans et al., 2022).

5. Conclusion

The study results underscore the need of head and neck cancer survivors and recipients of hematopoietic stem cell transplantation to receive patient-centered care from nurses in order to enhance their emotional quality of life and self-efficacy in managing their lifelong aftercare needs. A collaborative relationship between nurses and patients appears to be the corner stone of therapy adherence and the ability to manage long term consequences of cancer treatment. Therefore, nurses should invest in collaborative and trustworthiness relationships with their patients. Additionally, relatives should be involved more intensively in the self-management support provided by healthcare professionals because their support is crucial in strengthening cancer survivors' coping skills. More research is needed into the effectiveness of training techniques to equip nurses provide this kind of tailored holistic self-management support to head- and neck cancer survivors, recipients of hematopoietic stem cell transplantation, other cancer survivors, and their relatives.

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CRediT authorship contribution statement

Janet M.J. Been-Dahmen: Writing – review & editing, Writing – original draft, Visualization, Supervision, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Heleen van der Stege:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Wendy H. Oldenmenger:** Validation, Conceptualization. **Cora Braat:** Validation, Resources, Conceptualization. **Mariska C.M. van der Lans:** Validation, Data curation, Conceptualization. **Mark Scheper:** Visualization, Validation, Software, Methodology, Formal analysis, Conceptualization. **AnneLoes van Staa:** Validation, Supervision, Methodology, Funding acquisition, Conceptualization. **Erwin Ista:** Writing – review & editing, Writing – original draft, Validation, Supervision, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors have no conflict of interest to declare.

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Appendix A. Supplementary data

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