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SPECIAL ISSUE ARTICLE

Supportive care needs of patients living with an extremely rare and unpredictable cancer: The Epithelioid Haemangioendothelioma patient experience

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Abstract

Objective: Epithelioid haemangioendothelioma (EHE) is an ultrarare vascular sarcoma with an incidence of <1/million/year and a large clinical heterogeneity. Data on supportive care needs of rare cancer patients are scarce. This study aimed to investigate the level of supportive care needs of EHE patients and its association with sociodemographic, clinical and symptom burden characteristics.

Methods: We present secondary data of a cross-sectional questionnaire study involving EHE patients recruited from the international EHE Facebook group. Data were collected using the web-based PROFILES registry. Unmet needs were measured with Supportive Care Needs Survey Short Form (SCNS-SF34).

Results: 115 EHE patients from 20 countries completed the online questionnaire. Mean level of supportive care needs was 68.4 (range 34–170), with the highest mean score on the psychological domain. Supportive care needs were associated with age, disease stage, years since diagnosis and number of tumour locations. Highly symptomatic patients (33%) reported more supportive care needs than patients with low or intermediate symptom burden.

Conclusion: Supportive care needs were found in all domains, highest in the psychological domain, and were associated with sociodemographic, clinical and symptom

Olga Husson and Marije Weidema shared first authorship

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burden characteristics. Adequate and tailored supportive care should be offered especially to highly symptomatic EHE patients.

KEYWORDS

epithelioid haemangioendothelioma, health-related quality of life, supportive care needs, social media, rare cancer

1 | INTRODUCTION

Rare cancers are characterised by an incidence of less than six cases per 100,000 people/year (Gatta et al., 2011). Collectively, they represent ~24% of all cancer cases diagnosed, higher than any single common cancer (Gatta et al., 2011; Research NCIEAG, 2017). The absence of a typical, uniform rare cancer presentation, lack of public awareness and limited experience of primary and secondary healthcare professionals with rare cancers can result in prolonged diagnostic intervals and late referral to specialist centres (Komatsubara & Carvajal, 2016; Ray-Coquard et al., 2017). There are multiple difficulties in managing rare cancers even after they are identified, including the need for coordination among multiple specialists and a dearth of clinical evidence to guide decision-making. Therefore, clinical outcomes in patients with rare cancers are often worse than those in patients with more common tumour types (Ray-Coquard et al., 2017), with, for example, five-year relative survival rates of, respectively, 47% and 65% (Gatta et al., 2011). Furthermore, patients diagnosed with a rare cancer report poorer psychosocial outcomes and impaired health-quality of life (HRQoL) when compared to the general population of cancer patients (Bergerot et al., 2018). Research in rare cancers is complex because of limited patient numbers, funding and visibility of rare cancer populations (Komatsubara & Carvajal, 2016; Ray-Coquard et al., 2017).

Epithelioid haemangioendothelioma (EHE) is an exemplar of an ultrarare cancer. EHE is a vascular sarcoma with an estimated incidence of less than 1 per 1 million people/year (Lau et al., 2011). EHE is characterised by a profound heterogeneity in clinical behaviour, both regarding tumour localisations as well as the disease course over time. EHE lesions can occur anywhere in the body, although they are most commonly localised in the liver, lungs, pleura, bone/spine and/or skin. The clinical course over time is highly variable with an indolent course of disease in some patients, even in case of multifocal or metastatic disease, whereas others suffer from quickly progressive disease and deterioration. In addition, EHE clinical behaviour is highly unpredictable, as the indolent clinical course can progress to aggressive disease at any given time. Although reported five-year relative survival of all EHE patients is about 70% (Lau et al., 2011; Shiba et al., 2018), a recent study showed that patients with pleural disease (<20%) or lymph node metastases (~30%) had a more aggressive clinical course with poor overall five-year survival

rates (Rosenbaum et al., 2020). We previously demonstrated that about one third of EHE patients have a high symptom burden and that these patients mostly suffer from pain and fatigue (Weidema et al., 2020). Moreover, EHE patients with a high symptom burden experienced significantly lower functioning in daily life and reduced HRQoL.

The shift towards person-centred care relies on assessing and responding to the self-reported supportive care needs of patients (McElduff et al., 2004). Assessment of unmet supportive care needs goes beyond measuring symptoms and functioning in daily life, by directly capturing those issues that people need more help for, as well as providing a measure of the magnitude of that need (Lisy et al., 2019). Supportive care needs are diverse (Harrison et al., 2009). They can range from coping with the physical effects of cancer and cancer treatment, to psychological and psychosocial sequelae such as anxiety, depression and feelings of isolation. Access to evidence-based information throughout the cancer experience is also seen as an essential aspect of supportive care. Practical measures such as assistance with transportation, activities within the home and the provision of wigs and prostheses also fall under the heading of supportive care needs. In general, cancer patients most often report needs in the daily living domain, followed by psychological needs and health system and information needs (Harrison et al., 2009). A growing body of evidence demonstrates that identifying and attending to the needs of cancer patients may improve health outcomes, HRQoL and satisfaction with care (Okediji et al., 2017). Unmet supportive care needs are known to differ in nature and level of intensity between patients with different cancer types and phase of disease (diagnostic phase, treatment phase, post-treatment phase) (Li & Girgis, 2006; Sanson-Fisher et al., 2000); however, data on supportive care needs of rare cancer patients are scarce. EHE patients do not only face the challenges of living with an ultrarare cancer, such as difficulties finding expert healthcare professionals and lack of evidence with regard to treatment strategies, but also face a highly unpredictable disease course. Our previous findings stress the importance of tailoring the health care offered to highly symptomatic EHE patients (Weidema et al., 2020). In order to be able to provide EHE patients with adequate supportive care, we aimed to investigate the (1) level of supportive care needs of EHE patients; (2) association of the level of supportive care needs with sociodemographic and clinical characteristics; (3) association of the level of supportive care needs with symptom level; and (4) top 10 unmet needs for highly symptomatic patients.

2 | METHODS

2.1 | Population and data collection

This cross-sectional questionnaire study was initiated upon request of the international EHE patient community and was previously described (Weidema et al., 2020). In short, EHE patients (age ≥ 18 years) were invited to participate through posts in the Facebook group by one of the researchers (MW). In addition, the UK, US and Australian EHE foundations invited their members by email. Participants were recruited between May and October 2018. Participants had to confirm they were indeed an EHE patient in the informed consent form and were asked in the questionnaire whether their EHE diagnosis was histologically confirmed. Data were collected using the web-based Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship (PROFILES) registry, a data management system which allows for secure data collection of patient-reported outcomes via online questionnaires (van de Poll-Franse et al., 2011). Only English questionnaires were used. Ethical approval for the study was obtained from the local certified Medical Ethics Committee of the Radboud University Medical Center, Nijmegen, The Netherlands (File number 2017-3922). The results presented here are secondary analyses, as the primary purpose of the study was to assess HRQoL of EHE patients (Weidema et al., 2020).

2.2 | Study measures

2.2.1 | Sociodemographic and clinical characteristics

Sociodemographic and clinical information was self-reported. Comorbidity at the time of the survey was assessed by the Self-administered Comorbidity Questionnaire, evaluating the prevalence of 14 comorbidities (Sangha et al., 2003). Patients were divided into three symptom clusters (low, intermediate and high symptom burden) by previously performed latent class cluster analysis (Weidema et al., 2020). These clusters were identified based on the presence of ten, according to expert opinion, relevant symptoms, of which seven were derived from the EORTC QLQ-C30 (fatigue, nausea, appetite, insomnia, pain, constipation, diarrhoea) (Aaronson et al., 1993) and three additional symptoms from the EORTC Item Library (skin, respiratory and stomach problems) (<https://qol.eortc.org/item-library/>).

2.2.2 | Supportive care needs

The Supportive Care Needs Survey Short Form (SCNS-SF34) was used to measure patients' unmet needs. This questionnaire has been translated and validated in nine different languages. The SCNS-SF34 measures patients' supportive care needs across five domains: psychological (10 items), health system and information (11 items),

physical and daily activity (5 items), patient care and support (5 items) and sexuality (3 items) (Bonevski et al., 2000; Boyes et al., 2009). Cronbach's alpha for the five domains ranges from 0.86 to 0.96 (Boyes et al., 2009). For each item, patients indicated their level of need for help over the last month as a result of having EHE on a five point Likert scale with the following response options: 1 = no need, not applicable; 2 = no need, satisfied; 3 = low need; 4 = moderate need; and 5 = high need.

2.3 | Statistical analysis

To estimate the level of unmet needs per individual patient, a total score for needs per patient was calculated. We obtained the total score by summing the scores for all 34 items (range 34–170, higher scores indicating higher levels of unmet needs) (Hasegawa et al., 2016; Uchida et al., 2011).

Standardised Likert summated scales per SCNS domain were calculated according to the SCNS scoring manual (range 0–100, higher scores indicating higher levels of unmet needs) (McElduff et al., 2004).

To determine prevalence of unmet needs for an individual patient, each item of the SCNS was categorised as having 'no to low' need if they selected response options 1, 2 or 3, or a 'moderate to high' level of need if they selected response options 4 or 5 (McElduff et al., 2004). The top 10 unmet needs were determined based on the number of people indicating a moderate to high level need.

The univariate association between total SCNS score and socio-demographic and clinical variables was examined using the appropriate tests (t tests or analysis of variance (ANOVA) for continuous variables and chi-square tests for categorical variables).

The univariate association between SCNS total and domain scores and symptom clusters was assessed using one-way ANOVA.

All statistical analyses were performed with IBM SPSS Statistics (Armonk, NY, USA), version 25.0.0.1.

3 | RESULTS

3.1 | Baseline characteristics

Our cohort included 115 patients from 20 countries, with a mean age of 47 years (range 17–81) (Table 1). Most patients were female (77%), living in the USA (47%) and were not undergoing treatment at time of completion of the questionnaire (80%). All patients reported that their EHE diagnosis was histologically confirmed.

3.2 | SCNS: total and domain scores and prevalence of unmet needs

Mean total SCNS score for all patients was 68.4 ± 28.5 standard deviation (SD). Overall, EHE patients had the highest mean score

TABLE 1 Sociodemographic and clinical characteristics

Variable	EHE patients N = 115 N (%)
Gender	
Men	27 (24)
Women	88 (77)
Country (n=20)	
United States	54 (47)
Australia	15 (13)
United Kingdom	12 (10)
Canada	7 (6)
Germany	5 (4)
Belgium	3 (3)
China	3 (3)
Greece	3 (3)
Switzerland	2 (2)
Other ^a	11 (10)
Age at time of questionnaire completion	
Mean age years \pm SD (range)	47 \pm 15 (17–81)
Age at time of diagnosis	
Mean age years \pm SD (range)	43 \pm 15 (13–77)
Time since diagnosis	
Mean time years \pm SD (range)	4.5 \pm 4.3 (0–21)
Comorbidities ^b	
Mean no. \pm SD (range)	2.0 \pm 1.7 (0–8)
\geq 10% prevalence:	
Anaemia or other blood disease	18 (16)
Arthritis or arthrosis	21 (18)
Pulmonary disease	18 (16)
Heart condition	12 (10)
Depression or anxiety	38 (33)
High blood pressure	22 (19)
Over- or under-active thyroid	12 (10)
Back pain	37 (32)
Partner	
Yes	95 (83)
Level of education	
Low	12 (10)
Middle	38 (33)
High	54 (47)
Other	11 (10)
Currently on sick leave because of EHE	
Yes	7 (6)
Current state of disease	
No evidence of disease	23 (20)
Indolent (stable or slowly growing)	70 (61)
Aggressive	8 (7)
Not sure/unknown	14 (12)

(Continues)

TABLE 1 (Continued)

Variable	EHE patients N = 115 N (%)
Current localisations of disease	
Liver	65 (57)
Lung	62 (54)
Bone(s)	19 (17)
	12 (10)
Lymph node	4 (4)
Other	22 (19)
I don't know	7 (6)
Treatments received	
Systemic therapy	44 (38)
Surgery (not transplant)	58 (50)
Organ transplant	15 (13)
Radiation therapy	20 (17)
Other local therapy ^c	13 (11)
Alternative/non-traditional therapy	3 (3)
None	27 (23)
On EHE treatment at time of questionnaire completion	
Yes	23 (20)
Type of treatment	
Chemo/TKI ^d	18 (16)
Other systemic	4 (4)
Local	1 (1)

^aOne each: Brazil, Denmark, Ecuador, Estonia, France, Italy, Macedonia, The Netherlands, Poland, Portugal, Turkey.

^bThe following questions are about other illnesses that you may have. For each condition please answer "yes" or "no" as to whether you have this condition, or have had it in the past 12 months'.

^cIrreversible electroporation/Radiofrequent ablation/Cryoablation.

^dTyrosine kinase inhibitor.

on the psychological needs domain (30.7 \pm 27.3 SD, Table 2), with 'uncertainty about the future' as mostly reported moderate to high unmet need (29%), followed by 'learning to feel in control of your situation' (24%). Mean score for the physical and daily living domain was 25.8 \pm 26.4 SD. The most frequently reported unmet needs within the physical and daily living domain were 'lack of energy' in 24% of patients and 'not being able to do the things you used to do' in 17% of patients. Needs concerning the health system and information needs domain were somewhat lower with a mean score of 24.1 \pm 24.3 SD. Patients mostly reported 'being informed about your results as soon as possible' and 'being informed about things you can do to help yourself to get well' as moderate to high unmet needs in this domain (both 17%). Unmet needs with regard to 'more choice about which cancer specialists you see' (14%) were most prevalent within the support needs domain, which had a mean score of 22.5 \pm 23.2 SD. Mean domain score was lowest on sexuality needs (15.8 \pm 23.1 SD).

TABLE 2 SCNS domain scores and most prevalent unmet needs (moderate to high) per domain

Domain	Score (M ± SD)	Most prevalent needs	Prevalence
Psychological needs	30.7 ± 27.3	Uncertainty about the future	29%
		Learning to feel in control of your situation	24%
		Fears about the cancer spreading	21%
		Worry that the results of treatment are beyond your control	21%
Health system and information needs	24.1 ± 24.3	Being informed about your test results as soon as feasible	17%
		Being informed about things you can do to help yourself to get well	17%
		Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	16%
Physical and daily living needs	25.8 ± 26.4	Lack of energy/tiredness	24%
		Not being able to do the things you used to do	17%
		Pain	11%
Support needs	22.5 ± 23.2	More choice about which cancer specialists you see	14%
		More choice about which hospital you attend	11%
		Reassurance by medical staff that the way you feel is normal	10%
Sexuality needs	15.8 ± 23.1	Changes in your sexual relationships	8%
		Changes in sexual feelings	7%
		Being given information about sexual relationships	5%

Abbreviation: M, mean; SD, standard deviation.

3.3 | Supportive care needs according to sociodemographic and clinical characteristics

Patients 40–54 years of age had a significantly higher supportive care needs score than patients ≥55 years (78.4 vs 58.3, $p=0.006$; Table 3). Patients with aggressive disease (102.1 vs 65.9, $p = 0.010$) and patients less than 5 years since diagnosis ($p = 0.042$) reported higher SCNS scores than their counterparts. Patients with ≥2 different EHE localisations reported significantly higher scores than patients with no current localisations (52.1 vs 73.1, $p = 0.047$). High symptom burden was correlated with a higher unmet needs score, both compared to intermediate and low symptom burden ($p < 0.01$). Neither sex, employment, comorbidities nor current treatment correlated with total SCNS score.

3.4 | Supportive care needs according to symptom cluster

Highly symptomatic patients reported significantly more unmet needs than patients with low or intermediate symptom burden across all five domains (Figure 1, Table S1). Patients with intermediate symptom burden reported significantly higher physical and daily living needs than patients with low symptom burden. Unmet needs of highly symptomatic patients were highest in the physical and daily living domain, whereas patients with low and intermediate symptom burden both showed the highest unmet needs score in the psychological needs domain (Figure 1).

3.5 | Unmet needs in highly symptomatic cluster

Among highly symptomatic patients, the most prevalent moderate to high unmet need was 'lack of energy/tiredness' (55%; Table 4). The second most prevalent unmet need (45%) was part of the psychological domain and concerned 'uncertainty about the future'. 'Not being able to do the things you used to do' (physical and daily living domain) was reported in 42% of highly symptomatic patients. All of the top ten unmet needs among highly symptomatic patients belonged to either the physical and daily living or the psychological domain.

4 | DISCUSSION

To date, unmet supportive care needs of EHE patients have not yet been studied. EHE patients are confronted with a cancer that is not only ultrarare, but also has an even more unpredictable clinical course than most other cancers. Our results show that EHE patients reported unmet supportive care needs in all domains. The level of needs was associated with age, disease stage, years since diagnosis, number of EHE locations and symptom level. More specifically, we revealed that highly symptomatic patients reported strikingly more unmet supportive care needs than patients with less symptom burden. Besides the difference in the level of need for supportive care, highly symptomatic patients also require a different focus of attention as they reported the highest unmet needs in the physical and daily living domain, followed by psychological needs. In contrast, for patients with low or intermediate symptom burden psychological

TABLE 3 Patient characteristics and SCNS total score

Variable	N	SCNS score (M ± SD)	p-value
Age (3 categories)			
17-39 years	40	69.9 ± 26.2	0.006 (vs ≥55 y)
40-54 years	35	78.4 ± 31.3	
≥55 years	40	58.3 ± 25.4	
Sex			
Male	27	68.3 ± 31.6	0.976
Female	88	68.5 ± 27.7	
Partnered			
No	20	78.2 ± 32.3	0.094
Yes	95	66.4 ± 27.4	
Level of education			
Low	12	63.6 ± 28.3	0.672
Middle	38	71.7 ± 28.7	
High	54	66.1 ± 27.2	
Other	11	73.6 ± 35.9	
Current employment			
No	44	66.2 ± 30.2	0.501
Yes	71	69.9 ± 27.6	
No. of comorbidities			
0	20	57.2 ± 26.5	0.129
1	33	68.6 ± 31.3	
≥2	62	72.0 ± 27.1	
Disease stage			
Stable (NED+indolent)	93	65.9 ± 27.8	0.001 (vs stable) 0.010 (vs not sure)
Aggressive	8	102.1 ± 23.8	
Not sure	14	65.9 ± 25.1	
Years since diagnosis			
<2 years	34	81.2 ± 31.5	0.000 (vs >5 y)
2 - 5 years	41	70.2 ± 25.9	
>5 years	39	55.2 ± 23.2	
Current no. of EHE localisations			
0	13	52.1 ± 17.6	0.047 (vs 0 loc.)
1	43	67.0 ± 29.8	
≥2	59	73.1 ± 28.4	
Current treatment			
No, never had Tx for EHE	27	68.0 ± 26.6	0.258
No, but had past Tx for EHE	65	65.6 ± 27.9	
Yes	23	77.0 ± 31.9	
Symptom cluster ^a			
Low	31	51.1 ± 26.1	0.062 (vs low) <0.001 (vs low) <0.001 (vs intermediate)
Intermediate	46	64.7 ± 22.1	
High	38	87.2 ± 27.0	

Abbreviations: M, mean; NED, no evidence of disease; SD, standard deviation; Tx, treatment; y, years.

^asymptom clusters established in (Weidema et al., 2020).

FIGURE 1 SCNS domain scores per symptom cluster. Mean SCNS domain scores per symptom cluster and for the total cohort of patients

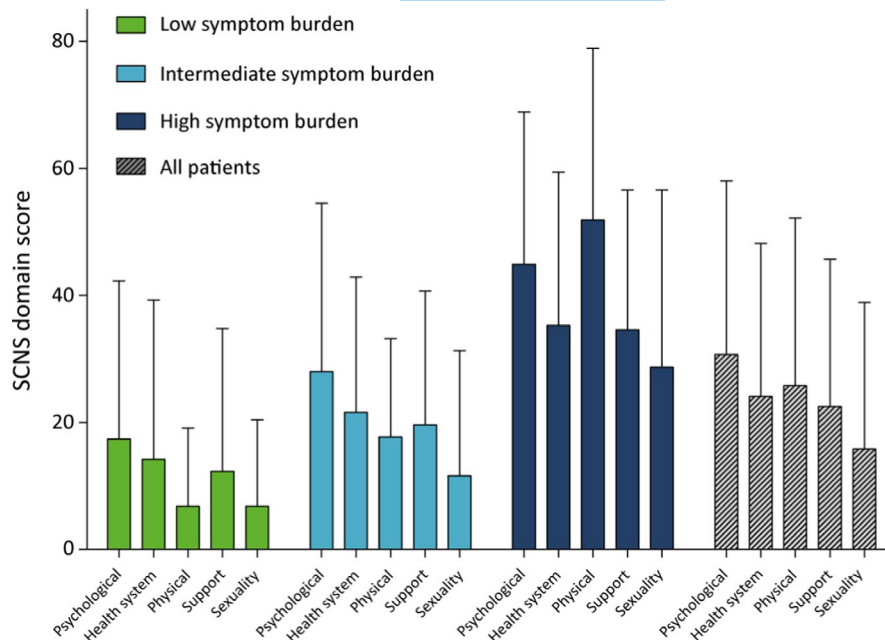


TABLE 4 Most prevalent unmet needs (moderate to high) within the highly symptomatic cluster.

Rank	Need	Prevalence	Domain
1	Lack of energy/tiredness	55%	Physical and daily living needs
2	Uncertainty about the future	45%	Psychological needs
3	Not being able to do the things you used to do	42%	Physical and daily living needs
4-6	Pain	34%	Physical and daily living needs
	Worry that the results of treatment are beyond your control	34%	Psychological needs
	Learning to feel in control of your situation	34%	Psychological needs
7-8	Fears about the cancer spreading	32%	Psychological needs
	Concerns about the worries of those close to you	32%	Psychological needs
9-10	Feeling unwell a lot of the time	29%	Physical and daily living needs
	Anxiety	29%	Psychological needs

needs, health system and information needs and support needs were more prominent than physical needs.

4.1 | Supportive care needs

Overall, previous studies regarding unmet supportive care needs of cancer patients vary greatly in methods of measuring and reporting (Harrison et al., 2009), thus limiting the possibility to compare our results with previous findings. In our study, we calculated the total SCNS score, aiming to provide an estimation of the level of needs per individual patient, rather than only reporting the most prevalent needs for the entire population. To the best of our knowledge, a total SCNS score was only once reported before, for Japanese inpatient advanced cancer patients receiving rehabilitation (96 ± 31 SD vs. 68 ± 29 SD for our total EHE cohort and 87 ± 27 SD for high symptom burden group) (Uchida et al., 2011). Although this suggests that the level of unmet needs in highly symptomatic EHE patients is

comparable to patients with advanced cancer, results from patients with other cancer types and disease stages would be required for adequate comparison. Although the SCNS-34 is a frequently used questionnaire, most studies only report mean domain scores or the most prevalent needs for the entire population.

Of the studies that did also report standardised SCNS domain scores, one heterogeneous cohort of cancer patients ($n = 439$) reported similar domain scores compared to our entire EHE cohort (McDowell et al., 2010). These patients had an average time of 87 weeks since diagnosis and 80% had already completed treatment and therefore not fully comparable to ours. Most other studies reported higher mean domain scores compared to our total EHE cohort, although the distribution of needs among the different domains varied per population and per study. For instance, Chinese breast cancer patients after treatment mostly reported health system and information needs (57 ± 28 SD) (Wang et al., 2018), whereas another study with breast cancer patients from Malaysia (≥ 1 year after diagnosis) found psychological needs to be highest (53 ± 22 SD)

(Edib et al., 2016). In a large cohort of about 400 Australian cancer patients, all top 10 unmet needs were in the physical or psychological domain (McDowell et al., 2010).

The highest needs in our total EHE cohort were in the psychological (uncertainty about future; feeling in control of the situation, fears and worries) and physical and daily living domain (lack of energy/tiredness, not being able to do the things you used to do). This is congruent with the findings of Srikanthan et al., (2019) who found the top five needs of newly diagnosed sarcoma patients included understanding one's illness and treatment, fears and worries, worry about family and friends, sleep and making treatment decisions. Nevertheless, our results are slightly in contrast with the findings of a recent study showing that the domain scores of the SCNS of a patient sample with rare diseases were significantly higher compared to a reference sample of patients with cancer (Depping et al., 2021). Domain scores of our total EHE cohort were lower compared to the rare disease cohort. Furthermore, rare disease patients had the highest scores on health system and information, psychological and physical needs, while EHE patients had the highest scores on psychological needs. Although a comparison with rare diseases should be taken with caution, given the differences in, among others, the progress (chronic vs. sub-acute), age (mostly occur in children vs. can occur at any age) and the origin (genetic vs. multifactorial), patients affected by rare diseases and rare cancers both need to be treated in a specialised care unit as their condition requires a high level of expertise as well as multidisciplinary care. The domain scores of EHE patients with a high symptom burden were quite similar to the rare disease patient sample and much higher than the reference sample of cancer patients. It could be that highly symptomatic EHE patients better reflect the rare disease population covering mostly patients with chronic diseases with limited curative options (Depping et al., 2021).

4.2 | Sociodemographic and clinical characteristics associated with supportive care needs

Evidence has shown that sociodemographic and clinical factors influence the pattern of unmet needs perceived and expressed by cancer patients (Cuthbert et al., 2020; Harrison et al., 2009; Okediji et al., 2017). In our study, the total level of needs of EHE patients significantly correlated with age, showing higher unmet needs for patients between 40 and 54 years compared to patients ≥ 55 years of age. Although different cutoff values for age groups were applied, in two large previous studies a correlation between relatively younger age and higher unmet supportive care needs across different domains was found (Sanson-Fisher et al., 2000; Williams et al., 2018). In contrast, other smaller studies that examined the relationship between unmet needs and age did not find a significant correlation (Aranda et al., 2005; Hasegawa et al., 2016; Jansen et al., 2016; Sanders et al., 2010). Whether age is indeed correlated to the level of unmet needs could partly depend on the chosen cutoff value to define different age groups, but could also be influenced by personal factors such as experiencing higher demands of the personal and professional

environment by relatively younger patients. In our EHE cohort, disease-specific characteristics of having aggressive disease or ≥ 2 tumour localisations (compared to no current localisations) were also significantly correlated to a higher level of unmet needs. These findings are in line with previous evidence of significantly higher levels of need in patients with advanced cancer compared to patients with localised disease (Harrison et al., 2009). For most cancer types, the correlation with having more tumour localisations would not be a surprising finding (Sanson-Fisher et al., 2000), but for EHE clinical behaviour can still be rather indolent despite having multiple tumour localisations as overall survival was previously shown to be independent of single or multiple organ involvement (Lau et al., 2011).

Interestingly, there was no significant difference in the level of unmet needs between patients who had not yet received treatment for EHE, those who had received treatment in the past and those who were undergoing treatment at time of the survey. This may partly be a reflection of EHE disease burden even in case of stable disease, but can also reflect the stress and needs around living with a rare disease without being treated for it. This might be comparable to patients on watchful waiting (e.g. prostate or lymphoma patients) (McIntosh et al., 2019) or those living with 'chronic metastatic disease' (Kida et al., 2021). Nevertheless, scores for EHE patients who are undergoing treatment may also be relatively lower than expected since these patients are more likely to have more frequent hospital visits and therefore easier access to supportive care. Previous research has shown significant differences in type of needs between patients in treatment versus those out of treatment, but also between patients undergoing different treatment regimens (Harrison et al., 2009).

We did not find significant differences in needs for sex, partner status, educational attainment, employment status and number of comorbid conditions. Based on sex, there is no agreement on the influence of specific sex on unmet needs as some studies have reported that females tend to have more unmet needs in the psychological domain, especially if they lived alone (Okediji et al., 2017). On the other hand, some others have reported that while females may have higher levels of need in specific domains, males have a higher tendency to report a need if they have specific types of cancers such as lung, colon or rectal cancer (Okediji et al., 2017). Others did not find sex to be a predictor of unmet (psychological) needs. Higher educational attainment, employed and comorbid conditions have been found to be associated with more unmet supportive care needs (Cuthbert et al., 2020; Lisy et al., 2019; Okediji et al., 2017).

All these findings illustrate how the levels and distribution of unmet needs differ between populations, which may also be influenced by for example the provision of health care and supportive care in the country of origin.

4.3 | Supportive care needs of highly symptomatic EHE patients

We previously demonstrated that about one third of EHE patients experienced a high symptom burden with a significant impact

on HRQoL (Weidema et al., 2020). The current study adds to this knowledge by showing that highly symptomatic EHE patients have strikingly more and different unmet supportive care needs compared to those of the entire group. The association between physical symptom burden and unmet physical and daily living needs has been previously demonstrated in breast cancer patients (Bredart et al., 2013), where the presence of specific symptoms (including fatigue and pain) was predictive of higher scores on the physical and daily living domain. The correlation between greater unmet needs and a higher total symptom score was previously demonstrated in a large cohort of cancer survivors (Molassiotis et al., 2017). Another study with 117 cancer patients (breast, prostate or lung cancer) undergoing treatment, however, suggested sleep disturbance to be the only specific symptom associated with greater unmet needs in these patients (Snyder et al., 2008). This might correspond to our previous finding that highly symptomatic EHE patients experienced remarkably high levels of fatigue and insomnia (Weidema et al., 2020).

4.4 | Clinical implications

In daily practice, it is of utmost importance to identify which needs a particular patient experiences and then determine the adequate support needed. Assessing supportive care needs enables service providers to identify gaps in existing services and prioritise resource allocation to those aspects of care that need improvement. The current study shows that EHE patients need supportive care in a broad range of domains. HRQoL could be improved by implementing interventions on different levels of a patients' ecosystem (Depping et al., 2021): The individual level (e.g. psychological), the patient's microsystem (e.g. social and work environment or contact with healthcare providers) and higher order levels, that is the healthcare system or the general public. Furthermore, it should be recognised that managing rare cancer patients is challenging for medical professionals given the limited time they have in combination with the inherent heterogeneity of the rare cancer population. Their primary focus is on early and correct diagnosis and finding the right treatment and therefore supportive care needs might be overlooked. A rare cancer specific needs screening tool could be developed and implemented in clinical practice. Based on this assessment by healthcare professionals, individual assistive measures could be taken. Given the fact that unmet needs were highest in the psychological and physical domains, emphasis could be placed on teaching self-management skills as well as empowering patients with education (e.g. survivorship care plan) to take more control of their cancer journey (e.g. proactively reporting psychological / physical problems and needs) (Molassiotis et al., 2017) and psychological support. Furthermore, the provision of comprehensible written/oral information could help address patients' information needs. One way to address the need to be in contact with other patients with the same condition, next to the EHE Facebook group which already fosters a sense of community and support, could be to involve expert patients. To further improve care for patients with rare cancers, access to experts and treatment

could be facilitated by improving referral pathways and implementing tele medical measures (even more important in COVID19 times) with specialised clinicians, nurses and mental healthcare workers.

4.5 | Limitations and future perspectives

We were able to study a relatively large sample of patients with a very rare cancer, thus providing the first report of their supportive care needs. However, there are some limitations of our study. First, because of the international setting of the study, we included patients from 20 different countries. As supportive care needs have been reported to differ between patients from different countries (with different health systems) (Molassiotis et al., 2017), this may have influenced our outcomes. Also, since patients could only complete questionnaires online in English, we might have missed patients because their English is insufficient or patient who did not have access to the Internet (potentially elderly patients), leading to bias. Second, time since diagnosis in our study varied from 0 to 21 years, potentially resulting in recall bias, while unmet needs may also change over the course of a disease trajectory (Armes et al., 2009; McDowell et al., 2010). Third, our cohort mostly consisted of members of the International EHE Facebook group, in which they have access to peer support and the expertise of other patients and EHE foundation board members. It is likely that we primarily reached patients who, it can be presumed, are highly educated and well-integrated into care structures (Depping et al., 2021) and not completely representative for the EHE population. Fourth, we probably missed patients with more aggressive disease due to a quick decline in health (i.e. survivorship bias). These factors might have resulted in some underestimation of the level of unmet supportive care needs, in particular serious pain. Fifth, when comparing our results to studies of common cancers (e.g. breast cancer), we found that EHE patients reported lower mean domain scores, which is interesting given the unclear cancer pathway of ultrarare cancer patients and the fact that they face many more challenges than common cancer patients (Drabbe et al., 2021). A plausible explanation is that the SCNS is not specifically developed for rare cancer patients. We therefore might have missed important (unmet) supportive care needs of particular relevance for rare cancer patients, for example coping with stigmatisation, referral to expert centre (Depping et al., 2021; Drabbe et al., 2021). There is no questionnaire available assessing the needs of rare cancer patients. Future research should qualitatively assess the needs to get a more in-depth view and examine the possibilities to develop a rare cancer specific instrument. Last, given patients were recruited via Facebook, clinical characteristics were self-reported by the participants, which is a less reliable method than extraction of these data from medical records.

Future research should focus on the needs of informal caregivers of rare cancer patients, as informal caregivers in general are critical in maintaining and improving the HRQoL of people living with cancer; however, their supportive care needs often exceed those of the patient (Lambert & Girgis, 2017).

5 | CONCLUSION

In conclusion, EHE patients report supportive care needs in all domains and those needs are associated with specific sociodemographic, clinical and symptom burden characteristics. Psychological needs were high in all symptom burden groups; highly symptomatic patients also reported high needs in the physical domain, while EHE patient with low or intermediate symptom burden reported more needs into the healthcare system and support domains. Rare cancer healthcare professionals are experts in the disease, diagnosis and treatment, but are not necessarily expert in addressing supportive care needs. Greater awareness among healthcare professionals and proper assessment of the unmet needs, especially among highly symptomatic EHE patients, could help to offer them adequate and tailored supportive care.

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CONFLICT OF INTEREST

No potential conflict of interest was reported by the authors.

DATA AVAILABILITY STATEMENT

The data presented in this study are available on request from the PROFILES registry. The data are not publicly available due to privacy.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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