

# Fatigue after heart transplantation – a possible barrier to self-efficacy

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### Abstract

**Rationale:** Recovery after heart transplantation is challenging and many heart recipients struggle with various transplant-related symptoms, side-effects of immunosuppressive medications and mental challenges. Fatigue has been reported to be one of the most common and distressing symptoms after heart transplantation and might therefore constitute a barrier to self-efficacy, which acts as a moderator of self-management.

**Aim:** To explore the prevalence of fatigue and its relationship to self-efficacy among heart recipients 1–5 years after transplantation.

**Research method:** An explorative cross-sectional design, including 79 heart recipients due for follow-up 1–5 years after transplantation. Three different self-assessment instruments were employed; The Multidimensional Fatigue Inventory-19, Self-efficacy for managing chronic disease 6-Item Scale and The Postoperative Recovery Profile.

**Ethical approval:** The study was approved by the Regional Ethics Board of Lund (Dnr. 2014/670-14/10) with

supplementary approval from the Swedish Ethical Review Authority (Dnr. 2019-02769).

**Results:** The reported levels of fatigue for the whole group were moderate in all dimensions of the Multidimensional Fatigue Inventory-19, with highest ratings in the General Fatigue sub-scale. Those most fatigued were the groups younger than 50 years; pretransplant treatment with Mechanical Circulatory Support; not recovered or had not returned to work. Self-efficacy was associated with the sub-dimensions Mental Fatigue ( $\rho = -0.649$ ) and Reduced Motivation ( $\rho = -0.617$ ), which explained 40.1% of the variance when controlled for age and gender.

**Study limitations:** The small sample size constitutes a limitation.

**Conclusions:** The moderate levels of fatigue reported indicate that it is not a widespread problem. However, for those suffering from severe fatigue it is a troublesome symptom that affects the recovery process and their ability to return to work. Efforts should be made to identify those troubled by fatigue to enable sufficient self-management support.

**Keywords:** heart transplantation, fatigue, self-efficacy, self-management, symptom.

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## Introduction

Heart transplantation (HTx) is a well-established treatment for persons with end-stage heart failure, where the overall goal is prolonged survival [1] as well as improved Health-related Quality of Life (HRQoL). In addition to the medical and surgical aspects, HTx is a psychologically complex medical intervention that involves contrasting emotions, including frustration and fear of death together with intense happiness and joy of life [2]. Recovery after

HTx is challenging and many Heart Transplant Recipients (HTRs) struggle with various transplant-related symptoms, side-effects of the lifelong immunosuppressive medication [3] and the mental challenges inherent in the existential situation of being an HTR [4,5].

Self-management is defined as the ability of the individual, together with family members, the community and healthcare professionals, to manage symptoms, treatment, lifestyle changes and the psychosocial, cultural and spiritual consequences of chronic diseases [6]. Self-management has been adopted by transplant professionals as a framework for efficient support to transplant recipients in managing their chronic condition [7,8], namely the transplantation. HTRs are expected to manage a multitude of behavioural and occupational changes in

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everyday life. Self-efficacy is defined as confidence to carry out a behaviour to reach a desired goal [9] and has been shown to be associated with improvements in health behaviour and both current and future health status [10]. Self-efficacy is therefore considered to be one of the mechanisms responsible for changes in health behaviours and acts as a moderator of self-management [11], which is why self-efficacy enhancement components are important when designing and developing self-management programs [10]. However, it has been argued that an extensive symptom burden such as fatigue might reduce performance, especially physical performance, which is an important factor for the development of self-efficacy [12]. Lack of performance could potentially lead to low self-efficacy [12], which in turn is a barrier to self-management. The unfamiliar health and life situation of being an HTR has been described as a source of uncertainty and possibly of distress [4,5]. Fatigue is a prominent symptom among HTRs [12], which due to its ill-defined character might lead to uncertainty about recovering from the transplantation.

### *Fatigue*

Fatigue is reported to be one of the most common and distressing symptoms after HTx [13–15] and is prevalent over time [16], leading to decreased HRQoL [14]. Fatigue is also widespread among other organ transplant recipients [17–19] and found to be the most frequent symptom affecting the ability to work among liver transplant recipients [19]. Furthermore, fatigue seems to be associated with immunosuppressive medication as the most prevalent immunosuppressive-related symptoms reported were tiredness (88.8%) and lack of energy (79.5%) [3].

It has also been shown that fatigue has an adverse impact on other symptoms and negatively affects the symptom experience among patients with Chronic Heart Failure (CHF) and cancer patients undergoing chemotherapy [20,21]. In the case of patients with CHF, symptom distress was associated with higher levels of fatigue [20] thus indicating that fatigue might have a major impact on HTRs' experience of health.

Fatigue is a complex multidimensional symptom prevalent in several chronic conditions, for example cancer, multiple sclerosis and CHF [21–23], which affects daily functioning and all domains of HRQoL [24]. Furthermore, it is associated with sleep problems, anxiety and depression in liver recipients [24]. Fatigue is twice as common in woman compared to men, but no strong association with age and occupation has been demonstrated [25].

The fact that there is still no consensus on how to evaluate fatigue or how to help patients to manage it is challenging. Fatigue is a disabling symptom that patients consider important to manage, whereas doctors tend to disregard it because it is not diagnostically specific [25].

Information help and support from healthcare professionals are considered insufficient [26]. In a study by Procópio et al. (2014), fatigue was poorly reported in kidney recipients' medical records, despite the fact that it affected their ability to perform daily activities [17]. Among HTRs, general activities, enjoyment of life and mood were the factors most affected by fatigue [14]. However, time since HTx, good cardiac/physical functioning or acceptable levels of haemoglobin did not seem to correlate with fatigue intensity and interference [14]. Qualitative interviews have also revealed that fatigue is a prominent symptom after transplantation, as it contributes to uncertainty about survival, possible graft rejection and recovery [4].

Irrespective of the cause, fatigue has major impact on day to day functioning and HRQoL [25]. This highlights the need for action from the multi-professional transplant team, which has an important health promotion task in providing efficient self-management support as well as helping and guiding HTRs to understand and manage their symptoms.

As a distressing and common symptom after HTx, fatigue might constitute a barrier to performing the tasks necessary for daily life. As accomplishment is the most important driver of self-efficacy [12], it highlights the importance of exploring the magnitude of fatigue among HTRs and its possible impact on self-efficacy after HTx.

Our hypothesis is that fatigue constitutes a barrier to self-efficacy and thereby might affect HTRs self-management ability, which is necessary and expected after HTx. Therefore, the aim of this study was to explore the prevalence of fatigue and its relationship to self-efficacy among HTRs one to five years after transplantation.

## **METHOD**

### *Study design and participants*

This cross-sectional study is part of the national Self-Management After Thoracic Transplantation (SMATT) project involving heart and lung recipients. The project, which began in 2014 and will continue until 2024, includes six different cohorts, that is two cross-sectional, two prospective longitudinal and two qualitative prospective studies. Within this project, the patients were asked to fill in a total of nine different self-report instruments, measuring various aspects potentially involved in self-management, with specific focus on symptom management. The instruments used in this paper have also been employed in a published study of lung recipients [18].

The study was carried out at the two thoracic transplant centres in Sweden where HTx is performed. In addition, the largest HTx follow-up clinic was also included in order to access more potential participants. Data collection lasted from 2014 to 2017.

Adult (>18 years) HTRs due for their annual follow-up 1–5 years after HTx were consecutively included. Additional inclusion criteria were being able to read and understand Swedish, mentally lucid, not hospitalised and with no ongoing treatment for acute rejection. Previous transplantation with either an organ (heart or other organ) or tissue (i.e. stem cells) was a reason for exclusion. However, other chronic diseases may have been present among the participants. Written and verbal information was provided by a nurse during the follow-up visit, and written informed consent was obtained. It was possible to either fill in the instruments at the clinic or complete them at home and return them to the researchers in a prepaid envelope.

During the data collection period, a total of 303 HTRs were due for their annual follow-up one to five years post-HTx and thereby potentially eligible for inclusion. Of these, 153 were invited to participate and 90 (58%) were consecutively included in the study. Among the reasons for exclusion was being included twice, declining participation, language barrier, being transplanted with several solid organs and being seriously ill. The exact figure for each dropout reason cannot be reconstructed. Questionnaires from ten HTRs were not returned. Thus, the final sample comprised 79 HTRs who were due for follow-up at 1 year (n = 28), 2 years (n = 17), 3 years (n = 11), 4 years (n = 17) and 5 years (n = 6). Indications for transplantation, medications and demographics are presented in Table 1.

### Instruments

The Swedish version of the Multidimensional Fatigue Inventory-20, in which one item was removed (MFI-19) based on the psychometric evaluation [27], is divided into five dimensions: General Fatigue (GF), Physical Fatigue (PF), Reduced Motivation (RM), Reduced Activity (RA) and Mental Fatigue (MF) [28]. The five-grade Likert scale ranges from 'yes that is accurate' to 'no, that is not accurate'. Sub-scale scores range from 4 to 20, where a higher score indicates greater fatigue. The timeframe is specified in the instrument as the last few days [28]. Cronbach's alpha coefficient varied between 0.67 and 0.94. Inter-item correlation varied between 0.21 and 0.90. The GF sub-scale has been shown to be most sensitive to changes in fatigue and can therefore be used as a short screening instrument [28]. In the present study, cut-offs in the GF dimension were based on clinical experience and consequences for the patients' everyday life [29] but were not statistically tested.

The German version of the Self-efficacy for managing chronic disease 6-Item Scale (SES6G) [30] was used to measure the self-efficacy score. Translation into Swedish was made by the research group. The scale consists of 6 items graded into ten steps on a Likert scale from 1 'not at all confident' to 10 'totally confident'. The mean score

**Table 1** Demographics of the included heart recipients (n=79)

|   | Frequency n and proportions (%) |
|---|---------------------------------|
| <b>Demographics</b>                                       |                                 |
| Median Age (years)  | 56 years (IQR 43–64)            |
| ≥50   | 49 (62)                         |
| ≤49   | 30 (38)                         |
| <b>Gender</b>   |                                 |
| Female  | 25 (32)                         |
| Male  | 54 (68)                         |
| <b>Living arrangements</b>                                |                                 |
| Living alone  | 20 (25)                         |
| Single with children                                      | 3 (4)                           |
| Cohabiting without children                               | 32 (41)                         |
| Cohabiting with children                                  | 13 (17)                         |
| Other   | 10 (13)                         |
| Missing   | 1 (1)                           |
| <b>Education</b>  |                                 |
| Compulsory  | 7 (9)                           |
| Second level  | 46 (58)                         |
| University  | 26 (33)                         |
| <b>Employment status</b>                                  |                                 |
| Employed (full time/part time)                            | 32 (40)                         |
| Unemployed  | 33 (42)                         |
| Own company-working                                       | 9 (11)                          |
| Own company-not working                                   | 3 (4)                           |
| Missing data  | 2 (3)                           |
| <b>Work ability</b>                                       |                                 |
| Able to work fulltime/part time                           | 54 (68)                         |
| Unable to work or study                                   | 20 (25)                         |
| Missing data  | 5 (7)                           |
| <b>Indications for transplantation</b>                    |                                 |
| Dilated cardiomyopathy (different forms)                  | 63 (87)                         |
| Other (e.g. hereditary conditions)                        | 7 (9)                           |
| Congenital heart disease                                  | 4 (5)                           |
| Ischaemic heart disease                                   | 4 (5)                           |
| Eisenmenger   | 1 (1)                           |
| <b>Mechanical assistant device and time on ventilator</b> |                                 |
| Mechanical circulatory support (MCS)                      | 24 (30)                         |
| <b>Immunosuppressive medications and rejections</b>       |                                 |
| Cyklosporin   | 18 (23)                         |
| Tacrolimus  | 59 (75)                         |
| Mykofenolatmofetil (MMF)                                  | 72 (91)                         |
| Azatioprin  | 3 (4)                           |
| Steroids  | 20 (25)                         |
| Other (e.g. Certican)                                     | 23 (29)                         |
| Persons with one or more rejections                       | 23 (29)                         |

can thus vary between 1 and 10, where higher values indicate stronger self-efficacy. The SES6G showed good convergent construct validity (Spearman rank correlation 0.578) as well as high internal consistency (Cronbach's alpha 0.93) [30]. No psychometric evaluation of the Swedish version was made.

The postoperative recovery profile (PRP) was used to measure the self-reported degree of recovery [31]. The

instrument contains 19 questions and evaluates both mental and physical symptoms and their effects on daily occupation and social life. The instrument has a four grade scale, that is none, mild, moderate and severe. The recovery level is based on the number of 'none' answers. Nineteen 'none' answers equals fully recovered with a descending gradient down to <7 'none' answers, meaning not recovered at all. The content validity of the instrument was high and a vast majority of the items showed a high level of intra-patient validity [31].

### Statistical analysis

The SPSS Statistics 24 (SPSS Inc., IBM Corporation, Armonk, N.Y., USA) was used when analysing data, which were mainly ordinal. Descriptive statistics (patient demographics, socio demographics, medical indication and medical treatment) are presented with frequencies. Due to the small sample size at each follow-up year, we considered all patients as one group. When testing for differences between two un-paired groups, we applied the Mann–Whitney *U* test.

In order to test for relationships between the different phenomena, we employed Spearman's Rho.

Hierarchical multiple regression was used to assess whether the MF and RM dimensions in the MFI-19 instrument could explain the variation in self-efficacy after controlling for the influence of age and gender.

### Ethical considerations

The study was approved by the Regional Ethics Board of Lund (Dnr. 2014/670-14/10) with supplementary approval from the Swedish Ethical Review Authority (Dnr. 2019-02769). All data collected were handled in accordance with Swedish regulations for the protection and storage of data.

## Results

### Patient characteristics

Demographics, indication for transplantation and immunosuppressive medication are presented in Table 1. The whole group of HTRs ( $n = 79$ ) comprised 68% men and 32% women. The median age was 56 years (IQR 43–64) and 33% had pretransplant Mechanical Circulatory Support (MCS). The response rate varied between the instruments: SES6G 89% ( $n = 70$ ), MFI-19 97% ( $n = 77$ ) and PRP 81% ( $n = 64$ ).

### Fatigue

The levels of fatigue in each sub-dimension for the whole group as well as for each individual year are presented in

Table 2, where the reported levels of fatigue were moderate in all dimensions of the MFI-19. The highest levels were seen in the GF sub-dimension, where 38% reported a high fatigue level [12–20], but with 62% reporting a low fatigue level [4–11].

Results from the Mann–Whitney *U* test comparing fatigue between two un-paired groups showed that those HTRs reporting a high level of fatigue [12–20] in the GF sub-dimension had a significantly lower level of self-efficacy ( $p \leq 0.001$ ) than those reporting a low level of fatigue [4–11]. Women reported significantly higher levels of GF than men ( $p = 0.041$ ). HTRs < 50 years reported a significantly higher level of GF ( $p = 0.029$ ) and MF ( $p = 0.018$ ) than those >50 years. RM also tended to be higher in this group ( $p = 0.056$ ). HTRs who were not working reported significantly higher levels of fatigue in all fatigue dimensions; GF ( $p = 0.024$ ), PF ( $p = 0.013$ ), RA ( $p = 0.042$ ), RM ( $p = 0.028$ ) and MF ( $p = 0.006$ ) compared to those working part time or full time. HTRs who did not feel recovered reported significantly higher levels of fatigue in all dimensions compared to those who felt reasonably recovered: GF ( $p = 0.008$ ), PF ( $p = 0.017$ ), RA ( $p = 0.003$ ), RM ( $p = 0.007$ ) and MF ( $p = 0.003$ ). In addition, those who received MCS before transplantation reported significantly higher levels of fatigue in the RA ( $p = 0.05$ ), RM ( $p = 0.045$ ) and MF ( $p = 0.006$ ) dimensions compared to those without pretransplant MCS. There was also a tendency ( $p = 0.06$ ) that PF was higher among those who underwent MCS before transplantation. Finally, those living alone reported a significantly higher level of fatigue in the GF ( $p = 0.035$ ), PF ( $p = 0.015$ ) and RA ( $p = 0.013$ ) dimensions. A tentative difference was also seen in MF ( $p = 0.06$ ) compared to those cohabiting.

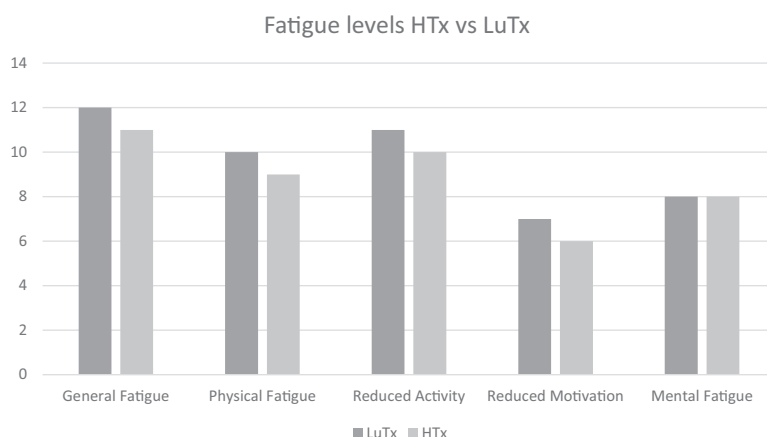
Comparison with lung recipients (Fig. 1), who are part of the SMATT project, revealed no differences in reported fatigue except in the GF dimension, where lung recipients reported significantly higher levels of fatigue than HTRs ( $p = 0.046$ ). Finally, there were no differences in fatigue level between those who reported having had a rejection episode and those who had not or between those with a higher educational level (university) and those with only an elementary education.

### Relationships between self-efficacy and fatigue

The relationship between self-efficacy and all sub-dimensions of fatigue is presented in Table 3. The strongest correlations were seen in the sub-dimensions RM ( $\rho = -0.617$ ) and MF ( $\rho = -0.649$ ). Therefore, to conclude we wished to assess the ability of MF and RM to explain the variance in self-efficacy. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. In step 1, MF and RM were entered

**Table 2** Fatigue in the whole group of heart recipients (n=79) and at each follow-up year

| Time since Tx<br>(Heart recipients) | General Fatigue Median (IQR) | Physical Fatigue Median (IQR) | Reduced activity Median (IQR) | Reduced Motivation Median (IQR) | Mental Fatigue Median (IQR) |
|-------------------------------------|------------------------------|-------------------------------|-------------------------------|---------------------------------|-----------------------------|
| All (n = 77)                        | 11.00 (7.00–13.00)           | 9.00 (6.00–13.00)             | 10.00 (6.00–13.00)            | 6.00 (4.50–9.50)                | 8.00 (4.00–12.00)           |
| 1 year (n = 27)                     | 11.00 (7.00–12.00)           | 10.00 (7.00–13.00)            | 10.00 (7.00–13.00)            | 7.00 (5.00–9.00)                | 9.30 (5.30–13.30)           |
| 2 years (n = 17)                    | 11.00 (6.00–15.00)           | 11.00 (5.50–14.50)            | 11.00 (4.50–13.00)            | 5.00 (4.00–9.50)                | 8.00 (4.00–11.35)           |
| 3 years (n = 11)                    | 13.00 (8.00–16.00)           | 9.00 (8.00–16.00)             | 11.00 (9.00–14.00)            | 7.00 (6.00–11.00)               | 10.70 (6.70–16.00)          |
| 4 years (n = 16)                    | 8.00 (7.00–11.75)            | 8.50 (6.00–13.00)             | 8.00 (7.00–11.75)             | 7.00 (4.25–11.25)               | 6.68 (4.00–9.23)            |
| 5 years (n = 6)                     | 10.50 (4.75–4.50)            | 8.50 (4.75–14.75)             | 9.00 (5.00–14.75)             | 6.50 (4.75–14.75)               | 9.35 (4.00–12.33)           |



**Fig. 1** Comparison of median fatigue levels for each sub-dimension of the MFI-19 between lung recipients (n=117) and heart recipients (n=79).

into the model and explained 39% of the variance in self-efficacy ( $p < 0.0005$ ). MF made the strongest unique contribution ( $\beta = -0.419$ ,  $p < 0.001$ ) compared to RM, which was ( $\beta = -0.286$ ,  $p = 0.022$ ). By using hierarchical multiple regression in step 2, we also controlled for the effect of age and gender. The model as a whole showed that MF and RM explained 40.1% of the variance in self-efficacy when controlled for age and gender.

**Discussion**

The main result of this study is that the reported level of fatigue among HTRs can be considered low to moderate. Higher levels of fatigue were reported by those younger than 50 years or with pretransplant MCS treatment as well as those not working or who reported not being recovered. Previous qualitative research [4,12] reports that fatigue is a prominent symptom among some HTRs, which is the reason we aimed to explore its magnitude among HTRs. The reported degree of fatigue in the whole group of HTRs could be considered low to moderate, with the highest degree in the GF dimension. Although this indicates that fatigue might not be a widespread problem among HTRs, the fact that seriously ill patients were excluded from the study might have affected the result,

**Table 3** Association between self-efficacy and each fatigue dimension among heart recipients (n=79).

|   | General Fatigue (GF) | Physical Fatigue (PF) | Reduced Activity (RA) | Reduced Motivation (RM) | Mental Fatigue (MF) |
|---|----------------------|-----------------------|-----------------------|-------------------------|---------------------|
| Self-efficacy Correlation Coefficient. $\rho$ | -0.504               | -0.529                | -0.510                | -0.617                  | -0.649              |

as those who reported not being recovered had higher levels of fatigue. It is essential not to underestimate the consequences for those suffering from fatigue, which makes it necessary to establish a clinical routine to identify those with a profound fatigue burden and provide them with symptom management support. Being able to make sense of the symptoms, receiving a diagnosis together with information about the symptoms, adopting strategies that promote activities, managing barriers, maintaining social participation and sufficient support from caregivers have been identified as important for patients with fatigue [26]. Table 2 indicates that higher levels of fatigue exist among HTRs, particularly at the 3-year follow-up in the GF, PF and MF dimensions and at

the 2-year follow-up in the GF and PF dimensions. Therefore, we suggest that those HTRs reporting high fatigue need continuous symptom management support.

Previous research has shown that the impact of fatigue had greater effect than the intensity on physical and mental aspects of HRQoL [14], suggesting that the actual degree of fatigue might be of less importance. Therefore, vigilance is necessary when using these measures alone to evaluate HTRs' experience of the consequences of fatigue in everyday life. Instead, they should be viewed as a foundation for a dialogue between healthcare professionals and the HTR.

Those HTRs reporting the highest fatigue scores were in the groups younger than 50 years; pretransplant MCS treatment, not recovered or not returned to work, thus indicating those to be the target groups for evaluation and possible interventions. It is interesting that HTRs younger than 50 years reported higher levels of fatigue than those over 50 years. One reason might be that HTRs younger than 50 years and their significant others have higher expectations on everyday life in terms of family activities, return to work and social adaptation. A large gap between what is experienced and actually achieved might negatively affect the level of fatigue.

Women reported a higher degree of GF than men, which is in line with the general population [25]. Fatigue among female HTRs has been shown to be associated with physiological and psychological factors [15]. Women are also more burdened by chronic pain after HTx [32], thus highlighting the need to specifically focus on female HTRs when supporting symptom management.

Pretransplant MCS treatment seems to have impact on experiences post-transplant. It has previously been shown that HTRs who underwent MCS treatment pre-transplant had lower self-efficacy than those without such treatment [33] and the present study reveals that this group also reports a higher degree of fatigue. This is an interesting and important finding, as the transplant candidates who underwent MCS were probably in better physical condition at the time of the transplantation than those without MCS. However, it is important to acknowledge the effort involved in experiencing existential events, such as first undergoing MCS and then transplantation, which extends the uncertain existence [34].

When comparing reported fatigue levels from HTRs with those reported by lung transplant recipients (LuTRs) in a previous study in our project [18], we found no differences in fatigue except in the GF dimension, where LuTRs reported significantly higher scores ( $p = 0.046$ ). This was somewhat surprising based on our clinical experience where HTRs are often viewed as being in a much better position than LuTRs in terms of survival, complications and the risk of graft rejection. However, previous studies in the SMATT project have revealed a tendency for HTRs to experience more pain than LuTRs [32] and

that LuTRs seem to adapt and manage their symptoms faster than HTRs [35,36]. This highlights the importance of exploring the differences between HTRs and LuTRs to deepen the understanding of the struggles in their respective recovery processes. Such knowledge might also lead to revised clinical expectations after thoracic transplantation.

As mentioned in the introduction, fatigue might be an underestimated symptom that is not generally focused on by clinicians, despite the fact that patients describe it as troublesome [25]. This discrepancy between clinicians and patients might constitute a potential source of uncertainty about the symptom, how it is experienced and how patients choose to describe it. Those HTRs with a high level of general fatigue in our study reported significantly lower self-efficacy, demonstrating that there is an association. Other studies have revealed that fatigue might affect the experience of and ability to manage other symptoms [20,37]. A self-efficacy instrument for fatigue self-management has been developed by Hoffman et al. (2011), showing that the severity of fatigue had a direct influence on perceived functional status [37]. They also demonstrated that perceived self-efficacy was an important aspect of optimising self-management for fatigue and perceived functional status in cancer patients [37]. This indicates that fatigue has a major effect and is not just a symptom, which underlines the importance of identifying those troubled by fatigue and developing sufficient support to help HTRs to understand and manage it.

Furthermore, our findings reveal that fatigue is associated with self-efficacy, especially in the RM and MF dimensions. However, it is worth noting that these dimensions had the lowest reported incidence of fatigue in the group of HTRs; thus, while reduced RM and MF seldom occur, they are troublesome for those concerned. Fatigue also seems to have an impact on HRQoL and daily activity [38], which are aspects with the potential to affect self-management ability among HTRs.

#### *Methodological considerations/limitations*

In Sweden, about 65 HTx are performed each year [39], which is a relatively small number. Nevertheless, this explorative design is still of great value for identifying important aspects of HTRs' experiences and enabling healthcare professionals to understand what kind of support is needed. Due to the small sample size, it was not relevant to analyse the differences for each yearly follow-up. However, the data for the whole group give an indication of the magnitude of the problem. Due to staff turnover and limited resources at the out-patient clinic, reason for dropout was not documented in a consistent way, which is a limitation in describing the sample. The cross-sectional design has limitations in terms of detecting changes in the experience of fatigue and the

correlations with self-efficacy. Another limitation is that the instrument only measures the incidence of fatigue and does not define how to interpret the scores in relation to how it affects the individual's everyday life, thus leading to different interpretations of fatigue levels and their impact.

## Conclusions

Fatigue is not a widespread problem after HTX as evidenced by the moderate levels. However, for those suffering from severe fatigue it is a troublesome symptom affecting their ability to return to work and the recovery process, as well as possibly acting as a barrier to self-management. Efforts should be made to identify those troubled by fatigue in order to provide sufficient self-management support and targeted person-centred health promotion after HTX.

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## Author contributions

Matilda Almgren contributed to data collection, data analysis and drafting article. Pia Lundqvist contributed to critical revision of the article. Annette Lennerling contributed to data collection and critical revision of the article. Anna Forsberg contributed to design, data analysis, statistics, critical revision of the article and obtaining funding.

## Ethical approval

The study was approved by the Regional Ethics Board of Lund (Dnr. 2014/670-14/10) with supplementary approval from the Swedish Ethical Review Authority (Dnr. 2019-02769).

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