

Chronic pain 1–5 years after heart transplantation—A nationwide cross-sectional cohort study

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Abstract

Aim: To provide a multidimensional assessment of self-reported chronic pain 1–5 years after heart transplantation and its relationship with self-reported well-being, fatigue, recovery, self-efficacy and socio-economic factors and to explore differences between heart recipients and a cohort of lung recipients.

Design: This multicentre, cross-sectional, cohort study is a part of the Swedish national Self-management after thoracic transplantation study.

Methods: Six questionnaires were distributed at the heart recipients yearly follow-up (1–5 years) at three Swedish university hospitals 2014–2017.

Results: The study group comprised of 79 heart recipients, 25 women and 54 men with a mean age of 52.68 years. Chronic pain among heart recipients was common and those not in paid employment as well as those with low psychological well-being and high general fatigue reported significantly more pain. Female heart recipients were more affected by pain. General health and vitality, general fatigue, physical fatigue and reduced activity were related to the pain intensity score.

Relevance to clinical practice: As it is the duty of the healthcare system to provide adequate pain treatment, screening for pain should be a mandatory part of long-term follow-up.

KEYWORDS

chronic pain, fatigue, heart transplantation, psychological well-being, recovery, self-efficacy, symptom management, transplant-specific well-being

1 | INTRODUCTION

The rationale behind this study is the lack of evidence-based knowledge about heart recipients' (HTRs) experiences of chronic pain from a multidimensional perspective in the years after heart transplantation (Htx). To our knowledge, this is the first comprehensive, multidimensional exploration of chronic pain after Htx in relation to transplant-specific and psychological well-being, fatigue, recovery,

self-efficacy and relevant clinical and sociodemographic variables. Since the comprehensive pain assessment after kidney, heart and liver transplantation in 1999 (Forsberg, Lorenzon, Nilsson, & Bäckman, 1999), no study presented a multidimensional assessment of pain among solid organ transplant recipients (SOTRs) until the comprehensive analysis of chronic pain after lung transplantation in 2017 (Forsberg, Claëson, Dahlman, & Lennerling, 2017a, 2017b). Chronic pain has wide-ranging detrimental effects across various life

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domains and affects health-related quality of life (HRQoL) after solid organ transplantation (SOT) (Forsberg et al., 1999; Hellgren et al., 1998; Holtzman, Abbey, Stewart, & Ross, 2010). This is a concern as, in addition to the obvious aim of prolonging survival, the key goal of transplantation was to improve the recipient's quality of life (QoL) (Ponikowski et al., 2016). As health promotion is the core of transplant nursing, it is vital to understand the HTRs' symptom burden to support symptom management and thus promote health.

2 | BACKGROUND

Chronic pain is defined as pain that persists beyond normal healing time and lacks the acute warning function of physiological nociception. Commonly, pain is perceived as chronic when it lasts or recurs for more than 3–6 months. For the last 20 years, research has suggested that chronic pain is common and underestimated after SOT. A pain syndrome that is described as especially difficult to treat is calcineurin inhibitor pain syndrome (CIPS), identified by Grotz et al. (2001). In SOT recipients, the overall incidence of the syndrome ranges from 1%–17% (Prommer, 2012). The usual onset occurs 1–N = 3 months after the introduction of calcineurin inhibitors (CIs) (Smith, 2009), but the onset can take up to a year after transplantation (Grotz et al., 2001). The syndrome presents as symmetric bilateral pain in the lower extremities involving the bones of the feet, ankles and knees. It has been suggested that the main mechanism may be the vasoconstrictive effect at the level of the bone marrow vasculature (Prommer, 2012). CIPS is mainly reported in case studies of kidney recipients (Collini et al., 2006) and one lung recipient (Sahay, McBennett, & Sheers, 2013). Only one study reported CI-induced headache among 74 patients following lung, liver and bone marrow transplantation (Ferrari et al., 2005).

The reports of chronic pain after SOT started in persons who received an abdominal organ (Jagose, Baily, & Hughes, 1997; Muñoz-Gomez et al., 1991; Naredo Sánchez et al., 1994; Pierides, Simpson, Stainsby, Alvarez-Ude, & Uldall, 1975). Those treated with cyclosporin after kidney transplantation have historically reported severe pain, restriction of movement, transient musculoskeletal pain and a leg bone pain syndrome (Collini et al., 2006; Grotz et al., 2001; Prommer, 2012; Smith, 2009). Among liver recipients, severe bodily pain was reported (Hellgren et al., 1998) together with pain in extremities or joints (Rosenblum, Rosen, Pine, Rosen, & Borg-Stein, 1993) in addition to bone pain and fractures (Textor & Hedrick, 2012). After liver transplantation, 26% of recipients in one study stated that they suffered severe bodily pain (Hellgren et al., 1998), and in another cohort, 18% reported pain in an extremity and 40% had arthralgia (Nicholas, Oleske, Robinson, Switala, & Tarter, 1994). Bone pain and fractures were also reported as the most significant non-immunological postoperative complication in liver recipients (Navasa et al., 1996). Furthermore, deterioration in bone disease led to compression fractures of the vertebrae and pain in the same patient group (Haagsma, Thijn, Post, Sloff, & Gips, 1988). Peripheral neuropathy is an undesirable complication after SOT with unexpected onset, rapid escalation of symptoms, lack of provider monitoring and poor provider response

Impact statement

This study adds:

- A comprehensive and multidimensional description of chronic pain after heart transplantation.
- Solid characteristics of heart recipients suffering from chronic pain.
- A description of the impact of chronic pain in everyday life.

to patient-reported symptoms (Textor & Hedrick, 2012). The interest in pain among thoracic organ recipients has emerged in the last 10 years. Musculoskeletal–neurologic complaints and low back pain were prevalent following Htx (Sahay et al., 2013), and patients with even mild pain after Htx reported worse HRQoL than the general population and were less likely to be employed (Holtzman et al., 2010). These studies highlighted the need for a multidimensional exploration of chronic pain after Htx. As all healthcare systems have a duty to provide adequate pain treatment, chronic pain should receive greater attention after Htx, especially as adequate pain treatment is considered a human right (Treede et al., 2015). Therefore, the aim of this study was to provide a multidimensional assessment of self-reported chronic pain 1–5 years after heart transplantation and its relationship with self-reported well-being, fatigue, recovery, self-efficacy and relevant socio-economic factors. We also explored differences between heart recipients (HTRs) and a cohort of lung recipients.

3 | METHODS

3.1 | Design and participants

This multicentre, cross-sectional, cohort study is a part of the Swedish national Self-management after thoracic transplantation (SMATT) study. The inclusion criteria were Swedish-speaking HTRs transplanted at either of the two thoracic transplant centres in Sweden performing heart transplantation, mentally lucid, not hospitalized and without ongoing treatment for acute rejection. The main reasons for exclusion were poor health status, declining participation and language barrier. The paper follows the STROBE checklist for cross-sectional studies (File S1).

3.2 | Data collection

Data were collected in the period 2014–2017. When the study began, there were in a total 303 eligible HTRs in Sweden due for their yearly follow-up 1–5 years after transplantation. Of these, 153 were invited to participate and 90 (58%) included in the study. Those not invited were mainly followed up at other cardiac outpatient clinics in Sweden or did not fit the inclusion criteria. The questionnaires were distributed at the HTRs' yearly follow-up at one of the three Swedish university

hospitals that perform most of such follow-ups. The reasons for external dropout were being included twice instead of once as intended, declining to participate, language barrier, being transplanted with several solid organs or being seriously ill. Unfortunately, the exact number of dropouts for each reason cannot be reconstructed. Ten HTRs forgot to send back their questionnaires, and no reminder was sent due to the very high nursing turnover at each outpatient clinic at the time of the data collection. Thus, the final study group comprised of 79 HTRs followed for 1 year ($N = 28$), 2 years ($N = 17$), 3 years ($N = 11$), 4 years ($N = 17$) and 5 years ($N = 6$). Age, gender distribution and clinically relevant aspects are presented in Table 1.

3.2.1 | Instruments

Six different instruments were used to answer the research questions:

1. To provide a multidimensional assessment of pain, the *Pain-O-Meter* (POM) (Gaston-Johansson, 1996) was used together

TABLE 1 Demographics, indications for transplantation and relevant medical aspects among 79 heart recipients

Variable	N (%)
Mean age	52.68 years (SD 14.63) (range 19–72 years)
Female	25 (32)
Male	54 (68)
Indications for transplantation	
Dilated cardiomyopathy (different forms)	63 (80)
Other (e.g. hereditary conditions)	7 (9)
Congenital heart disease	4 (5)
Ischaemic heart disease	4 (5)
Eisenmenger	1 (1)
Mechanical assistant device and time on ventilator	
Left ventricular assist device before Htx (LVAD)	24 (30)
>48 hr on ventilator after Htx	16 (20)
<48 hr on ventilator after Htx	61 (77)
Missing data regarding ventilator	2 (3)
Immunosuppressive medication and rejections	
Cyclosporin	18 (23)
Tacrolimus	59 (75)
Mycophenolic acid	72 (91)
Azathioprine	3 (4)
Steroids	20 (25)
Other drugs (e.g. Everolimus)	23 (29)
Persons having one or more cellular rejections	23 (29)

Abbreviation: Htx, Heart transplantation.

with questions about how pain affects daily living. The use of the POM is described in detail when exploring lung recipients' pain and to avoid duplication we refer to Forsberg et al. (2017b). The POM questionnaire used in this study allowed the patient to report a maximum of three pain locations, for which they provided information about the pain intensity in addition to the sensory and affective experience. The HTRs were also asked the following open questions: When did the pain start?, How did the pain start?, Do you take any pain killers?, How does the pain affect your everyday life? and What are your own thoughts about the reason behind the pain? The POM instrument has undergone testing for reliability and validity in different patient populations (Gaston-Johansson, 1984, 1996) and has been previously used among kidney, liver, heart and lung recipients (Forsberg et al., 1999, 2017a, 2017b).

2. The Swedish version of the *Psychological General Well-Being* (PGWB) instrument was used to explore psychological well-being and illness (Wiklund & Karlberg, 1991), where Cronbach's alpha ranges from .61–.88. It contains 22 items constituting six dimensions, that is, anxiety, depressed mood, positive well-being, self-control, general health and vitality. The PGWB-sum score is 132, and a normal sum score is considered to be between 100–105. A score below 100 indicates poorer psychological well-being (Dimenas, Carlsson, Glise, Israelsson, & Wiklund, 1996; Dupuy, 1984).
3. The Organ Transplant Symptom and Well-being Instrument (OTSWI) was used to explore transplant-specific well-being and symptom burden (Forsberg, Persson, Nilsson, & Lennerling, 2012). The 20 questions in the instrument constitute eight factors measuring fatigue, joint and muscle pain, cognitive functioning, basic activities of daily life (BADL), sleep problems, mood, foot pain and financial situation. All eight factors had satisfactory internal convergent validity as well as good item-scale discriminatory validity and together accounted for 86% of the variance. Each response relates to the discomfort of a situation or problem, assessed on a five-point scale ranging from "not at all" (0), "a little" (1), "somewhat" (2) and "quite a bit" (3) to "very much" (4). The timeframe is specified as the previous seven days. The scale has a summary score of 0–80 where lower scores indicate higher well-being. The OTSWI also measures symptom distress by the degree of discomfort from twenty transplant-specific symptoms graded from "not at all" (0), "a little" (1), "somewhat" (2) and "quite a bit" (3) to "very much" (4) (Forsberg et al., 2012).
4. The Multidimensional Fatigue Inventory (MFI-20) measures five dimensions of fatigue, that is, general fatigue, physical fatigue, reduced activity, reduced motivation and mental fatigue (Smets, Garssen, Bonke, & de Haes, 1995). A 19-item version was used in line with the results of the Swedish validation of the instrument (Lundh Hagelin, Wengström, Runesdotter, & Fürst, 2007). Fatigue in the preceding 7 days is rated on a 5-point Likert scale from "Yes, that is accurate" to "No, that is not accurate." Subscale scores range from 4–20, where a high score represents greater fatigue. Cronbach's alpha for the various subscales was >.70. Based on previous studies (Lundh Hagelin, Wengström, & Fürst, 2009; Lundh Hagelin et al., 2007), scores in the general fatigue subscale

were grouped as follows (4–11, 12–15, 16–20) and served as a cut-off for low, high and severe fatigue.

5. Recovery was explored by the Postoperative Recovery Profile (PRP) (Allvin et al., 2011). The 19 questions in the instrument cover different physical and mental symptoms, but also possible limitations in daily occupation and social life. The use of the instrument among lung recipients is described by Lundmark, Lennerling, Almgren, and Forsberg (2019) and is the same in this study. The content validity of the instrument was high, and a most items showed a high level of intra-patient reliability (Allvin, Ehnfors, Rawal, Svensson, & Idvall, 2009).
6. Self-efficacy was studied by the *Self-Efficacy for Managing Chronic disease* instrument (Freund, Gensichen, Goetz, Szecsdenyi, & Mahler, 2013), and the use is described in Forsberg et al., 2017b.

3.3 | Statistical analysis

The SPSS Statistics 23 (SPSS Inc., IBM Corporation) was used for analysing data. Single-scale ordered category data were summarized with medians and percentiles (P_{25} , P_{75}). When applicable, values of $p < .05$ (two-tailed) were considered statistically significant. The steps in the analysis were as follows:

1. Explore proportions (chi-square test) and describe the prevalence of pain, including pain locations, sensory and affective components, consequences in everyday life and personal explanation models.
2. Explore possible differences between two unpaired groups, for example, men and women, by means of the Mann-Whitney U test.
3. Explore possible relationships by means of Spearman's rho test.

3.4 | Ethical considerations

The study was approved by the Regional Ethics Board (Dnr: blinded) with a supplementary approval from the Swedish Ethical Review Authority (Dnr. blinded). All participants gave their written informed consent, and the information they provided was kept confidential and stored by the researchers in accordance with the Swedish personal data act. The participants could withdraw their participation at any time without consequences for their further follow-up.

4 | RESULTS

In total, 58% ($N = 46$) of the HTRs reported some level of persistent pain, while 42% ($N = 33$) reported no pain. The proportion of women with pain was 68% ($N = 17$) versus 54% of men ($N = 29$). Thirty-five percentage of the HTRs ($N = 28$) reported that they already had various kinds of pain before transplantation, as presented in Table 2. After transplantation, the median pain intensity for the whole group was 7.75 (POM-VAS), 15 for the affective and sensory component (POM-WDS) and 25.25 for the total pain intensity score (PIS). The

three most common pain locations were the feet, back and calves. The total range of pain locations is provided in Table 3, while sensory and affective experiences are shown in Tables 4 and 5.

The pain affected everyday life in various ways. For example, it made them unable to prepare dinner, play with grandchildren, work or take part in social activities. The personal explanation models of why the pain occurred varied. They included nerve injury, side-effects of medication, other diseases or not knowing why the pain occurred. The main self-reported treatment was Paracetamol. Some considered that they did not have enough treatment, while other considered they had enough treatment despite not taking any pain killers.

4.1 | Subgroup analysis

4.1.1 | Socio-economic factors

Sociodemographic data are given in Table 6. In total, 38% of the HTRs ($N = 30$) were younger than 50 years and 62% ($N = 49$) were older than 50 years. There were no differences in any dimension of pain between these two age groups. The proportion of HTRs with pain was not higher among those living alone than among those cohabiting ($p = .426$). Furthermore, there were no differences in the proportion of HTRs with pain when comparing patients with a higher education to those with a mandatory/primary education ($p = .092$) or when comparing those who worked to those unable to work ($p = .805$). However, HTRs who were not working reported significantly higher sensory and affective burden (POM-WDS) ($p = .04$) and had a higher total pain intensity score (PIS) ($p = .05$). The different pain intensity scores at each follow-up are displayed in table 7.

4.1.2 | Gender differences

Of the 25 female HTRs, 68% ($N = 17$) reported pain compared with 53.7% among the men ($N = 29$). There were no gender differences regarding the proportion of persons with pain ($p = .327$). However, female HTRs reported significantly worse pain intensity (POM-VAS) than men, median 10.5 for the women and median 0.55 for the men ($p \leq .001$). The women also reported more affective and sensory burden (POM-WDS), median 18, versus median 3 for the men ($p = .004$). Overall, the female HTRs reported a significantly higher pain intensity (pain intensity score) than the male HTRs, median 32.5 for the women versus median 5 for the men ($p = .001$).

4.1.3 | Clinical factors

There were no differences between those with pre-transplant treatment with a ventricular assist device (VAD) and those without a VAD ($p = .804$). Nor were there any differences in pain between those with a long or short time on the ventilator, defined as more or less than 48 hr.

Pain locations (before Htx)	1 year N = 10	2 years N = 6	3 years N = 7	4 years N = 4	5 years N = 1	Total N = 28
Feet	4	3	1	3	1	12
Back	5		1	4	1	11
Abdomen	2		3	2		7
Thighs	2	1		1	2	6
Knees	1	2	1	1		5
Hands	1	1		2	1	5
Shoulders	3			1	1	5
Neck	4			1		5
Valves	1	2	1	1		5
Chest	1		2		2	5
Arms	1			1	2	4
Hips				1		1
Head	1					1
Heart		1				1
Multiple places		1				1

TABLE 2 Self-reported pain locations before heart transplantation separated for each follow-up year reported by 28 HTRs

Note: Each HTR was able to report several pain locations. The three most common locations are marked in grey.

Pain locations (after htx)	1 year N = 16	2 years N = 13	3 years N = 8	4 years N = 6	5 years N = 3	Total N = 46
Feet	3	7	8	4	2	24
Back	7	3	3	2	2	17
Calves	3	3	3	3	1	13
Hands	2	4		2	3	11
Chest	4	3	1	1	1	10
Knees	2	3	1	1		7
Shoulders	2	1	1	2	1	7
Head	3		2	1		6
Thighs	2	1	2		1	6
Arms	2	1	1		2	6
Neck	3		1	1		5
Abdomen			1	2		3
Heart	1				1	2
Groin			2			2
Ribs	1					1
Hips				1		1

TABLE 3 Self-reported pain locations 1–5 years after Htx among 46 HTRs (N = 46)

Note: The HTRs were able to report several locations. The three most common locations are marked in grey.

4.1.4 | Symptom burden and well-being (OTSWI, PGWB, MFI-19 and PRP)

The exploration of pain in relation to symptoms and well-being revealed no differences in the proportion of pain between those strongly fatigued and those less fatigued ($p = .478$). However, the strongly fatigued HTRs reported a significantly higher PIS ($p = .045$). Nor was there any difference in the proportion of pain between

HTRs with poor psychological well-being versus good psychological well-being ($p = .161$), although the PIS was significantly higher ($p = .043$) among the former. Those HTRs reporting pain had significantly worse transplant-specific well-being (OTSWI-sum score, $p \leq .001$) and more symptom distress compared with those without pain caused by sleeping problems ($p = .003$), joint and muscle pain ($p \leq .001$), foot pain ($p \leq .001$) and mood problems ($p \leq .001$). Moreover, they suffered from significantly higher symptom distress

TABLE 4 Self-reported sensory experience of pain 1–5 years Htx (N = 46)

Sensory sensation	1 year N = 16	2 years N = 13	3 years N = 8	4 years N = 6	5 years N = 3	Total N = 46
Dull	12	9	12	15	6	54
Stabbing	9	11	4	10	1	35
Numb	8	7	7	5	4	31
Burning	5	5	5	5	2	22
Sharp	3	2		6	4	15

Note: Each HTR was able to report several sensory experiences. The three most common sensory sensations are marked in grey.

due to headache ($p \leq .001$) and numbness in their hands ($p = .05$). Finally, HTRs with pain reported a significantly worse positive well-being ($p = .041$), general health ($p \leq .001$) and vitality ($p = .009$) according to the instrument PGWB. Those who reported pain also had a lower PGWB-sum score ($p = .008$), which indicates a lower overall PGWB. Regarding recovery, the proportion of HTRs with pain did not differ between those who were fairly recovered and not recovered. However, those slightly recovered or not recovered at all reported higher pain intensity (POM-VAS) ($p = .027$), higher sensory and affective burden (POM-WDS) ($p = .047$) and a higher total PIS ($p = .015$) than those who were fairly recovered.

4.1.5 | Relationship between pain, different kinds of well-being and self-efficacy

There was a moderate relationship between transplant-specific well-being (OTSWI-Sum) and VAS ($r_s = .606$, $p \leq .001$), POM-WDS ($r_s = .590$, $p \leq .001$) and PIS ($r_s = .609$, $p \leq .001$). Thus, low transplant-specific well-being is related to high pain intensity. Furthermore, there was a weak relationship between PGWP (PGWB-sum) and VAS ($r_s = -.356$, $p \leq .001$), POM-WDS ($r_s = -.408$, $p \leq .001$) and PIS ($r_s = -.413$, $p \leq .001$). There was also a relationship between the PIS and general health (GH) ($r_s = -.516$) and vitality ($r_s = -.328$). Thus, high pain intensity is related to low PGWP. There was also

a relationship between PIS and general fatigue ($r_s = .422$, $p \leq .001$), physical fatigue ($r_s = .402$, $p \leq .001$) and reduced activity ($r_s = .353$, $p \leq .001$). Finally, there was no relationship between self-efficacy and the PIS ($r_s = -.139$).

4.2 | Comparison with lung transplant recipients

We compared the HTRs with 74 lung recipients (LUTRs) with self-reported pain who were also included in the SMATT study and previously reported by Forsberg et al. (2017a) and Forsberg et al. (2017b). The rationale behind this comparison is that LUTRs have experienced thoracic surgery and are under lifelong immunosuppressive medication. There is no multidimensional pain assessment performed with the same instrument after general thoracic surgery, and thus, the LUTRs were considered the most relevant group for comparison. There were no statistically significant differences in the POM-VAS, where the HTRs reported a median of 7.75 and LUTRs a median of 7 ($p = .893$). Nor was there any difference ($p = .309$) in the affective or sensory component (POM-WDS), with a median of 15 for the HTRs and 14 for the LUTRs. Finally, the PIS median was 25.25 for the HTRs and 21 for the LUTRs ($p = .420$). The median scores at each yearly follow-up in the comparison between HTRs and LUTRs are shown in Table 8, which illustrates relevant clinical but not/no statistically significant differences.

TABLE 5 Self-reported affective experience of pain 1–5 years after Htx (N = 46)

Affective experience	1 year	2 years	3 years	4 years	5 years	Total
Annoying	20	13	10	19	7	69
Tiring	14	8	3	9	7	41
Troublesome	14	4	5	11	1	35
Miserable	2	2	2	7		13
Nagging	6	2		4		12
Unbearable	3	4		2	3	12
Suffocating	1	3	5		2	11
Terrifying	6	2			1	9
Agonizing	1	1	2	3	2	9
Torturing	2			3		5
Killing				1		1

Note: Each HTR was able to report several affective experiences for each pain location. The three most common affective experiences are marked in grey.

5 | DISCUSSION

In this study, we present a comprehensive picture of chronic pain after Htx where the main results are as follows:

- Chronic pain among HTRs is common.
- HTRs who do not work report significantly more pain.
- HTRs with low psychological well-being and high general fatigue report more pain.
- Those who self-reported that they were not recovered reported more pain.
- Female HTRs report being more affected by pain than men.
- There is a relationship between the PIS and general health and vitality. General fatigue, physical fatigue and reduced activity are related to the PIS.

5.1 | The magnitude of the problem

More than half of the HTRs reported persistent pain; thus, chronic pain is an important clinical issue that must be addressed. In addition, we now have a detailed picture of the pain locations, the sensory and affective experience, consequences in daily life and the HTRs' understanding of the cause of pain. The fact that HTRs experience chronic pain is in line with previous studies (Forsberg et al., 1999; Holtzman et al., 2010). The participants in this study differ to a large extent from the general European population, where 20% experience chronic pain (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). We were surprised by the fact that there were no significant differences in pain intensity between HTRs and LUTRs regardless of follow-up. The lack of significant differences was most likely due to sample size. However, there was a clinical difference illustrated by different median levels of pain, especially 1 year after transplantation where HTRs report a median PIS of 27.45 and lung recipients a median of 15 and these differences remained after 5 years. Clinically, it might be relevant to consider the diversities when screening for pain and in the subsequent treatment. The fact remains that as many as three out of four report pain after thoracic transplantation. Experiencing pain in the feet, back and calves as a HTR is in line with results from other studies performed with SOTR (Collini et al., 2006; Forsberg et al., 1999, 2017a, 2017b; Grotz et al., 2001; Hellgren et al., 1998; Holtzman et al., 2010; Muñoz-Gomez et al., 1991; Prommer, 2012; Rosenblum et al., 1993; Stiefel et al., 2012; Udomkarnjananun, Townamchai, Virojanawat, Avihingsanon, & Praditpornsilpa, 2018). The pain locations suggest that the pain is not due to the sternotomy as the sternum was reported as only the fifth most common location. It is interesting that HTRs might experience less pain from the operation area than those undergoing, for example, coronary artery bypass grafting (CABG) where 11%–56% of individuals who undergo surgery via sternotomy experience pain 1 year after the operation (Fletcher et al., 2015). Nevertheless, we must consider the fact that poorly managed postoperative pain

TABLE 6 Socio demographical data among 79 HTRs 1–5 years after Htx

Variable	N (%)
Marital status	
Single	15 (19)
Married/Cohabiting	51 (65)
Divorced/separated	13 (16)
Living arrangements	
Living alone	20 (25)
Single with children	3 (4)
Cohabiting without children	30 (38)
Cohabiting with children	13 (17)
Other	10 (13)
Missing	3 (3)
Level of education	
Primary	7 (9)
Second level	46 (58)
University level	26 (33)
Employment status	
Employed (full time/part time)	32 (40)
Not employed	33 (42)
Own company-working	9 (11)
Own company-not working	3 (4)
Missing data	2 (3)
Working ability	
Able to work fulltime/part time	54 (68)
Unable to work or study	20 (25)
Missing data	5 (7)
Sick leave or retired	
Temporary sick leave full time/part time	18 (23)
Permanent sick leave full time/part time	14 (18)
Retired	14 (18)

might lead to chronic pain (Gan, 2017), which underlines the need for a strict postoperative analgesic regimen.

The study design does not allow us to describe the cause of the pain, but the locations give us an indication that it might be caused by side-effects of medications, for example, immunosuppression and statins. It is well known that calcineurin inhibitors cause CIPs, which leads to peripheral neuropathy (Grotz et al., 2001; Prommer, 2012) and that statins cause musculoskeletal and joint pain (Rang, Dale, Ritter, Flower, & Henderson, 2012). There was consistency in how the HTRs reported pain in the different instruments. For example, back pain was specified in affective and sensory pain as well as marked on the body template, specified as a symptom in the OTSWI and how it affected daily life was described in words. A strength of this study is that the heart recipients/HTRs reported the same sites and how the pain affected them in their daily life (and as a disturbing symptom) in the different instruments used.

TABLE 7 Self-reported pain intensity after Htx divided into follow-up year (N = 46)

Follow-up year	POM-VAS median	POM-WDS median	Pain Intensity Score median
1 year (N = 16)	9.75	14	27.45
2 years (N = 13)	7	17	22
3 years (N = 8)	7.25	10.5	20.5
4 years (N = 6)	6.25	15.25	23
5 years (N = 3)	21	28	49

TABLE 8 Self-reported pain experience 1–5 years after Htx among both HTRs (N = 46) and LUTRs (N = 74) divided into each follow-up year

Follow-up year	POM-VAS median		POM-WDS median		Pain Intensity Score median	
	Heart	Lung	Heart	Lung	Heart	Lung
1 year	9.75	6	14	11	27.45	15
2 years	7	9	17	15	22	21
3 years	7.25	6.5	10.5	11	20.5	19
4 years	6.25	8.5	15.25	16	23	29
5 years	21	11	28	15	49	21.5

Note: Although there were clinical differences in the median level of pain among the groups, they were not statistically significant.

5.2 | Socio-economic aspects

Those not in paid employment reported higher sensory and affective burden and a higher PIS. Being able to work is a strong aspect of quality of life (Cavallini, Forsberg & Lennerling, 2015) and an indicator of how the person has integrated into society after transplantation (Cavallini et al., 2015). Resuming work is one of the most important markers of a successful transplantation and highly prioritized by those waiting for an organ. Even after transplantation, a return to work is a prioritized goal but the extent to which SOTRs manage to do so varies, ranging from 12%–83% (Cavallini et al., 2015). There are some possible obstacles when discussing re-entry into the labour market such as being off work for more than 2 years prior to the transplantation, heavy work and psychological as well as physical factors (Cavallini et al., 2015). Our result raises the question of whether chronic pain might constitute a psychological or physical barrier to resuming work or re-entering the labour market. A HTR who is not working/in employment is likely to need support because our society strives for a quick return to work, which is also highly prioritized by SOTRs. However, the care system of today offers limited support for dealing with this reality.

5.3 | Pain and overall symptom distress

The PIS was higher among the strongly fatigued and those with poor psychological well-being. The HTRs with pain also reported significantly worse transplant-specific well-being and more symptom distress. Moreover, the HTRs with pain were in the slightly recovered or not recovered at all groups. This is in line with the findings from the

Swedish lung cohort reported in the SMATT study (Forsberg et al., 2017a, 2017b).

5.4 | Gender differences and its consequences

Even though there were no gender differences in the proportions of patients experiencing pain, the results show that when HTRs experienced pain, women were significantly more burdened and reported higher pain intensity than men. This finding is supported by Fillingim, King, Ribeiro-Dasilva, Rahim-Williams, and Riley (2009), who also reported that as a group women more often experience pain and at greater risk of developing depression related to pain. The reason is not clear but might be due to hormone levels, social construction and social roles (Fillingim et al., 2009). This is in accordance with our results, which indicate that women who report a higher PIS, more affective and sensory burden experience a greater negative impact in daily life and lower psychological well-being. As distressing symptoms might hamper self-management and HRQoL, efforts should be focused on HTRs' overall experience of symptom distress.

5.5 | Pain and self-efficacy

Self-efficacy is defined as the perceived capability to perform a specific action required to achieve a concrete goal (Bandura, 1997). We assumed that self-efficacy would be seriously limited after Htx when the recipient experienced pain. One positive thing finding was that pain was not related to self-efficacy at all. Thus, pain is not viewed as a major setback or complication that hampers self-efficacy, as discussed by Almgren, Lennerling, Lundmark, and Forsberg (2017).

5.6 | Methodological considerations, strengths and limitations

This study has several limitations which are mainly the same as described in Forsberg et al., 2017, a reporting on findings from lung recipients' experienced pain in the SMATT project. To avoid duplication, we refer to Forsberg et al., 2017a, for general limitations due to the cross-sectional design and different timing of follow-up as well as consideration regarding the POM. The recruitment of patients during the study period was affected by organizational difficulties at both outpatient clinics caused by the sudden and unexpected staff turnover during data collection. The advantage of using the OTSWI is that it is a transplant-specific instrument with good psychometric properties (Forsberg et al., 2012). A limitation is that the reliability has not yet been fully tested regarding stability and sensitivity to change. Another limitation is that the instrument measuring self-efficacy was not specifically validated or tested for reliability in the transplant population. As fatigue is a complex phenomenon, we argue that the use of the MFI-19 was a strength due to the fact that it covers five aspects of fatigue.

6 | CONCLUSION

In conclusion, managing pain is a dynamic process. Pain comes and goes and might change in character over time (Dodd et al., 2001). Implementing pain screening to identify those HTRs burdened with pain is essential for the creation of adequate symptom management support and pain treatment. Our results show that the HTRs experiencing pain are most likely to be found among those not working, not recovered, more burdened by other symptoms and who have worse psychological well-being. All these distressing factors increase the risk of limited symptom management and subsequently self-management, thus making pain an area of concern for all transplant nurses in particular and transplant professionals in general.

7 | RELEVANCE TO CLINICAL PRACTICE

In transplant medicine and long-term management of HTRs, there is an obligation to provide self-management support including symptom management. Thus, the provision of adequate pain assessment and treatment of chronic pain is clinically essential. To screen all HTRs for pain should be mandatory in the Htx outpatient clinic, as when the persons with pain are identified, it is likely that those with extensive mental and/or physical symptom distress will also be detected. It is impossible to remove the immunosuppressive medication. However, it is possible to promote strategies to manage the pain and still find an acceptable level of health and well-being. Here, the transplant nurse plays a vital role with her/his focus on everyday life. When there is a strong affective component in the pain experience, psychological counselling together with SSRI medication might

be considered. It might also be possible to reduce the dose of statins. Regardless of whether a pharmacological or non-pharmacological strategy is employed, a person-centred, multiprofessional approach is instrumental for confirming the HTR's suffering and subsequently restoring and maintaining her/his dignity.

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CONFLICT OF INTEREST

There were no conflicts of interest.

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