

Diary for self-observation: A self-management tool for recipients of lung transplantation—A pilot study

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Abstract

Aim: To (a) explore how the diary contributes to patient motivation for monitoring self-management and (b) explore the nurses' experience of how the diary supports the patients' self-management after lung transplantation.

Design: A quantitative and qualitative study design.

Methods: Fifteen patients and four nurses participated. Data were analysed descriptively and thematically.

Results: This pilot study shows that the diary strengthens patients' self-management in the first postoperative period. Nurses were confident that the patients were structured about self-observation when using the diary.

KEYWORDS

nurse–patient relationship, nurses, nursing, observation, self-management, transplantation

1 | INTRODUCTION

The recovery process after lung transplantation is very demanding and challenging in different ways. The patients need to re-learn their new body physically and mentally. Physically the patients must be aware of the signs, reactions and physical capacity of the body. Mentally the patients must face a new mindset. The guidelines for life after lung transplantation are complex and comprehensive; however, assistance in self-monitoring and self-management is useful (DeVito et al., 2016). Particularly, self-management improves health outcomes after a lung transplantation (Kugler et al., 2010; Schuurmans, Benden, & Inci, 2013; VanWormer et al., 2013).

2 | BACKGROUND

Patients are expected to have an active role in their own recovery but require ongoing support during this process (Lundmark, Lennerling, Almgren, & Forsberg, 2016), and therefore, it is important to pay

attention to ways adults assimilate knowledge, skills and attitudes. The importance of motivation and reflective practice in adult learning is highlighted in a review (Abela, 2009), as are the patient's ability to maintain their own health. Health literacy concerns the capacities of people to meet the complex demands of health in modern society (Sørensen et al., 2015). Weak health literacy skills are associated with riskier behaviour, poorer health, less self-management and more hospitalization and increased costs (Kickbusch, Pelikan, Apfel, & Tsouros, 2013).

Diaries to support the patients have been used in different patients' groups (Jimoh, Bunn, & Hooper, 2015; Park et al., 2017; Ullman et al., 2015) and seem to have increase self-reliance and self-management in some patient populations (Van Woensel, Roy, Abidi, & Abidi, 2015). Furthermore, diaries have been used in the pre-transplant period of candidates for lung transplantation to monitor early detection of clinical problems (Mullan, Snyder, Lindgren, Finkelstein, & Hertz, 2003).

Inspired by Norwegian colleagues and the literature a pilot study was conducted, because we wanted to try out, the use of a diary as

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a tool for assisting the patients in self-management in the early postoperative period after lung transplantation (Johnston et al., 2014). The early postoperative period is defined as the first 4 weeks after transplantation because the mean admission time after lung transplantation is 4 weeks (Maxwell et al., 2015).

To our knowledge, it has never been shown whether the use of a diary supports the patient's self-monitoring after lung transplant. Thereby the overall research question of this pilot study was *Can a diary as a tool improve the patient's self-monitoring after lung transplantation?* Thus, the aims of this paper were as follows: (a) to explore how the diary contributes to patient motivation for monitoring self-managements and (b) to explore how nurses experience the diary support patients' self-management after a lung transplantation.

2.1 | Intervention

Following the guidelines after lung transplantation, the patients are introduced to the life as transplanted. In this study, a printed diary was introduced as a supplement of the education programme. The printed diary was handed out to the newly transplanted patient at the time of preparing for discharge. The diary was presented to support the daily self-management, which require to detect early signs of infection or rejection of the new organ as: dyspnoea, coughing, fever and fatigue (Stenberg, Haaland-Overby, Fredriksen, Westermann, & Kvisvik, 2016). The diary was introduced face-to-face by a nurse to the patients and their next of kin. The nurse explained the use of the diary and answered questions. Patients were expected to start using the diary during admission, to be familiar with it at discharge. The first page was pre-printed with the observations the patients were expected to note daily; peak flow, temperature, weight and the use of pep-therapy. The diary included a bookmark (Figure 1) as a personal reminder. Furthermore, patients were encouraged to note changes in medication and notes regarding their health: dyspnoea, pain or nausea and physical activities. Finally, patients were encouraged to bring the diary, when being admitted or visiting the

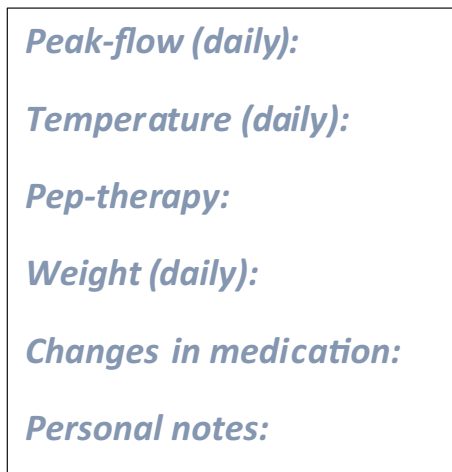


FIGURE 1 The bookmark of the diary

outpatient clinic to reflect on the observations and notes with a nurse (Smith Mark, 2001).

3 | METHODS

The approach to this pilot study was pragmatic and real-world practice oriented because some of the nurses inspired by colleagues from Norway were aware of the possible "wins" for the patients. A mix in methods was chosen to gain data of a complementary perspective on the use of a printed diary to evaluate the pilot study. The approach for evaluating included a quantitative method and qualitative method, knowing that these two methods can complement each other (Malterud, 2001).

The quantitative part required a questionnaire completed by the patient to gain an understanding of the patient's perspective. Being aware of the random occurrence of the transplants and the organizational timeframe, it was decided to evaluate the usefulness of the diary using a cross-sectional approach. Thereby the patients were asked to complete a questionnaire with a spread of 1–9 months after receiving the diary. The questionnaire was inspired by Olsen Henning, (2006) including closed questions and with opportunities for the patient to add comments. The questionnaire consisted of 12 questions. The first part of the questions regarded the responder's level of essential physical self-observation parameters, the next part dealt with the use of the diary and the last questions explored the reasons for not using the diary. The questionnaire was tested prior to the study by two patients at the ward to qualify the understanding of the questions.

A focus group interview was conducted as the qualitative part of the evaluation, to explore the nurses' experiences of how the diary supported the patients' self-management. A semi-structured interview guide was developed to ensure consistency and facilitate openness and flexibility during the interview (Kvale, 2011).

3.1 | Settings, participants and data collection

The setting for the intervention was the National Center for Lung transplantation in Denmark. All patients who had lung transplantation between June 2017–March 2018, who were able to read and speak Danish, were eligible to participate in the intervention and were consecutively included. The patient received a printed diary as a supplementary tool of the education programme.

Two experienced nurses and the clinical nurse specialist were responsible for the project. The nurses introduced the nurses at the ward and kept track of the patients. All nurses at the ward were expected to introduce to the diary as a part of the patients' education programme and to follow-up on the use of the diary in the outpatient clinic or at admission (Adegunsoye, Strek, Garrity, Guzy, & Bag, 2017).

The evaluation of the pilot study regarding the patient perspective took place from April 2018–July 2018 as the responders were

admitted for the scheduled follow-up. The focus group interview was accomplished July 2018.

3.2 | Data analysis

The quantitative data were analysed in two parts. The answers of closed questions were analysed using descriptive method, describing and summarizing the data collected (Kirkwood & Sterne, 2003). Descriptive methods were used to create an overview of the data. The patient comments from the questionnaires were summarized and analysed inspired by Malterud (Malterud, (2017)). The comments were coded thematically to create an insight in the patients' experiences using a printed diary. The focus interview was transcribed and the text was analysed using a thematically method inspired by Malterud (2017). The quotes from the interview presenting the diversity of experience and meaning of the nurses are presented as nurse 1, 2, 3 and 4.

3.3 | Ethical considerations

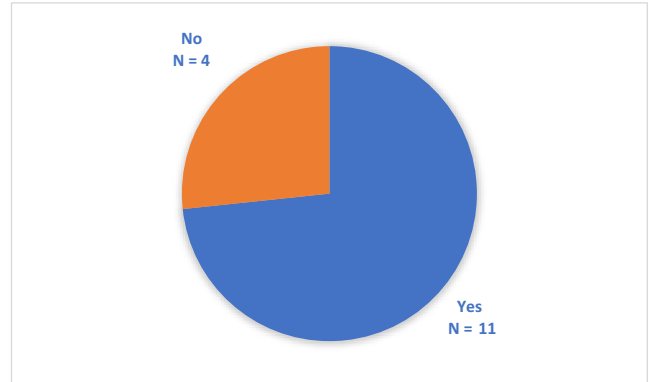
Confidentially procedures were followed and all patients participated on a voluntary basis. The patients were informed that all data would be anonymous and there were no audio-recording from the focus group interview. Ethical approval for this small study was not deemed necessary from the Regional Committee for Medical Research Ethics, because the project was not designated a medical research study. Approval from the Danish Social Sciences Data Services was not obtained either, because there were no identifying characteristics from the patients reported and therefore the project was not described law for data services.

4 | RESULTS

The diary was introduced to 28 patients—the number of lung transplants in Denmark between June 2017–March 2018. One patient decided not to use the proposed diary. The evaluation period was accomplished between April and July 2018, the responders were the patients admitted for the scheduled follow-up ($N = 15$), asked to fill out a questionnaire. The responders represented the adult population with lung transplants (men: $N = 7$). A focus group interview was conducted with four nurses (14% of the total staff) to accumulate knowledge about the use of the diaries from a nurse's point of view. The nurses who participated were three nurses with <1 year of work experience in lung transplantation and one experienced nurse.

Data show that 11 of the responders were using the dairy regularly (Figure 2).

There were different reasons why four responders did not use the diary. When asked the reason for this, they answered that they forgot or did not see the need to write in a diary. As one wrote: "I have forgotten" and another answered, "I'm stable in most numbers (i.e.



N = responders

FIGURE 2 The use of the diary

weight, PEAK-flow and temperature). My weight is increasing, but I can remember it." The written comments could indicate that responders stop using the diary regularly when they feel stable, which mostly take place some months after the transplant. Of the responders who were not using the diary, two said they used it in the beginning but then stopped. One responder who had a transplantation 6 months prior to complete the questionnaire wrote: "It was really nice in the beginning especially the first three months where I wrote in it (the diary) daily. However, when I was stable and remembered my numbers (temperature, PEAK-flow e.g.), I stopped writing in it."

The results from the questionnaire showed a general satisfaction with the diary. The replies to the question: "how do you experience having a diary for self-management?" tended to be mostly positive. One responder who was 3 months from the date of transplantation wrote: "A good thing, because it is hard to remember if one or more days have passed suddenly." This suggests that the responders, despite the small sample, saw the diary as a helpful tool monitoring self-management after lung transplantation.

The diary being used as a personal tool support the fact that responders generally do not bring the diary to outpatient clinic. A total of 11 of the responders did not bring along the diary to follow-ups. At the same time, nine of the patients have been asked about the diary by healthcare professionals (see Figure 3). In the questionnaire, the responders were asked what and how often they wrote observations in the diary. Figure 4 shows the replies leaving out the section on "personal note" and that 11 of the responders described using the diary for personal notes. The frequency the specific self-observations are noted is shown in Figure 5. In addition, the diary was revealed to have a therapeutic effect for some patients. A nurse says: "I remember that patient xx when he came for his 6 weeks follow-up had had a lot of dreams and it seemed as if the fact that he could write them down in the diary had a therapeutic effect. Some of them write and write and I think it has some form of therapeutic effect." (Nurse 1). Similar to this Nurse 4 said: "A patient of mine received it (the dairy) with open arms. It helps her to divide the days. She still writes in the diary."

From the analysis of the focus group interview two themes were presented: (a) the diary as a tool for collaboration with

FIGURE 3 The use of the diary in collaboration with healthcare professionals

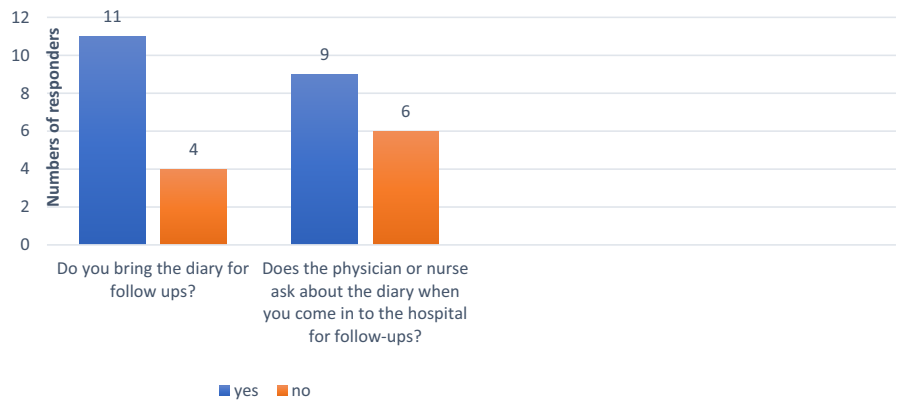


FIGURE 4 Personal notes and changes in medication

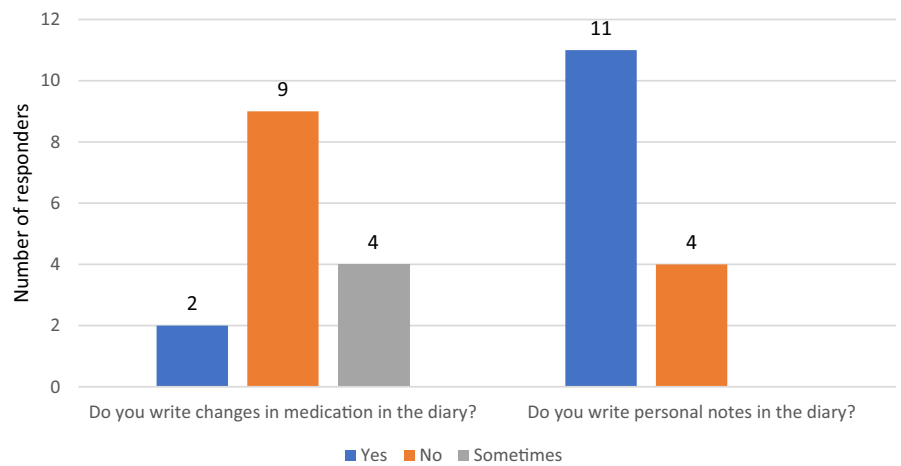
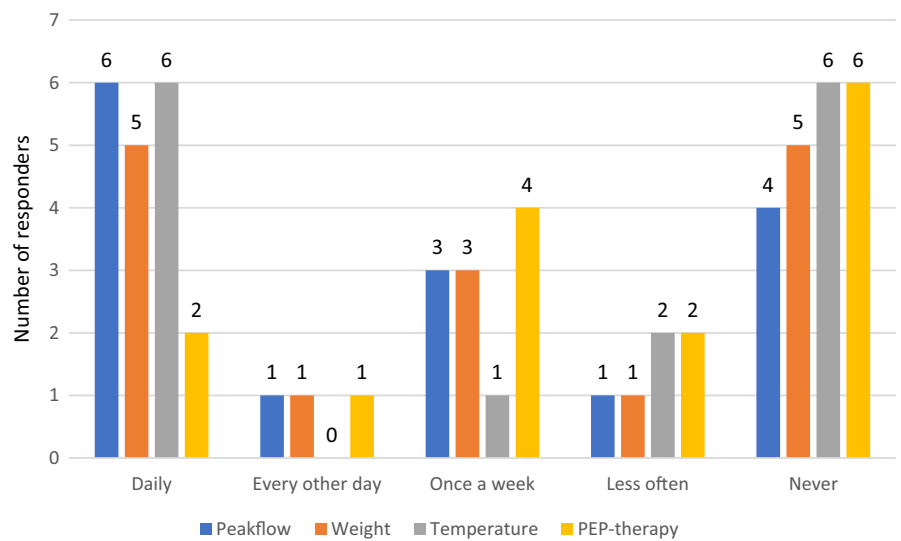


FIGURE 5 Frequency of noting self-observations



healthcare professionals and (b) the diary as a helpful tool for patients' self-management. Firstly, the nurses found that the diary is a personal tool and there are limitations in strengthening the collaboration between nurses and patients. There was little focus on the diary when the patients came for follow-ups. The nurses said that they rarely actively asked about the diary in the outpatient clinic, because the diary was not a full integrated part of the outpatient clinic programme. More often, the nurses experienced that the

patients would bring up the diary if they had a specific problem and wanted to remember exact dates or similar details. A nurse said: "if you don't ask them, then it is their tool, I don't ask them to bring the book to follow-ups but sometimes they will look up something, then I know they are using it and getting a routine when it comes to self-management" (Nurse 2).

One of the patients who received a diary after lung transplantation was admitted to hospital during a routine follow-up as the lung

capacity had decreased. The decreasing peak flow was noted in the diary but without appropriate reaction. The problem was discovered when visiting the outpatient clinic and indicates the importance of healthcare professionals to reach out and attend dialogues with the patient regarding the notes. The questionnaire showed that responders experienced that nurses asked about the diary when they came in for follow-ups. This was contradicted when the nurses in the focus group interview said that they seldom asked about the diary during routine follow-ups. Nurse 2 said: *"In my experience there is a lot of focus on this conversation (about the diary) in the beginning but as more time passes, I forget to ask about the diary and the patients, they don't mention it either."* Nurse 3 says: *"They don't show it when they come in for follow-ups, only when I ask them and I don't do that on a regular basis."* The focus group interview was limited to four nurses and thereby, difference in the nurses' and patients' experience of the diary as a tool for collaboration, might not represent all nurses.

The other theme: *the diary as a helpful tool for patients' self-management* shows the diaries were a helpful addition to the already existing education programme for patients after lung transplantation. Nurses found the diaries helpful in monitoring self-management at home. A nurse said: *"They (the patients) get a routine, where they keep an eye on themselves, so I think it creates tremendous safety. It is our way of keeping an eye on the patient without monitoring every step we can ask them, what you have written in your diary today, for example, temperature"* (Nurse 1). Nurse 3 said: *"In my experience they (the patients) use it a lot, I mean they write in the diary daily."*

Before the diaries were introduced, patients were expected to do the same measurements, but there was no expectation for them to write them down. Nurse 4 concluded: *"In my opinion it was a good idea to introduce the diary. They (the patients) learn to get the routine to monitor themselves."* This is supplemented by Nurse 1, who said: *"Instead of it being us who need to be in control of them doing them every day, then it becomes a thing that they (the patients) do themselves and it is a huge improvement in getting the routine. It gives me confidence as a nurse, when they've learned the routine with the diary and then are discharged, that they will actually do the measurements."* This suggests that the introduction fits well with and even improves the existing education programme.

5 | DISCUSSION

Previous research has shown that interventions have to be meaningful to the patients to be completed (Sanderson, Phillips, Gerald, DiLillo, & Bittner, 2003). Thereby using a printed diary might not be accomplished by the patient feeling stable.

In the early period after lung transplantation, the recipients experience a rapid change in physical function (Rosenberger, Dew, DiMartini, DeVito Dabbs, & Yusen, 2012). They have a feeling of optimism and anticipation of steadily improving lung function. This postoperative optimism may present a barrier to patients participating in self-management after transplant. Patients may not see

the need to carry out self-care activities, because they feel stable. A qualitative study of lung recipients described this initial phase as "naivety" (De Vito et al., 2004). Postoperative normalization in lung function made recipients feel immune to transplant-related complications even though healthcare providers instructed them about the high incidence of acute graft rejection during the early postoperative phase. Some of the responders in the present study may have stopped writing in the diary because it did not feel important to them to write down self-observations. These responders might have had an experience of being invulnerable, because of experiencing no problematic complications so far.

After lung transplantation, some patients may experience long-term, severe cognitive impairments, such as problems remembering and concentrating (Smith, Blumenthal, Hoffman, Davis, & Palmer, 2018; Smith et al., 2014). Delirium affects up to 80% of mechanically ventilated patients (lung transplant recipients) in intensive care units (Sher, Mooney, Dhillon, Lee, & Maldonado, 2017) and is associated with increased morbidity and mortality. In a study, mild cognitive impairment was observed in 67% of post-transplant recipients (Cohen et al., 2014), that might be the reason why the diary is such a helpful tool for the recipient in the early postoperative phase.

Diaries written by nurses in intensive care units have been beneficial for patients and relatives, preventing post-traumatic stress, anxiety and depression (Nielsen, Angel, Egerod, & Hansen, 2018). Remembering the large number of patients who are affected by delirium in intensive care unit (Sher et al., 2017) illuminates how important it is to support the patient in regaining a healthy psychosocial life. Written reflections on personal dreams, hallucinations and experiences from the early postoperative phase can help the patient to verbalize the need for mental support (Nielsen et al., 2018) and perhaps some of the responders have used the diary for therapeutic reasons.

Patients who have had lung transplantation are encouraged to perform self-management behaviours to maximize health outcomes. A study found that goal orientation as a tool may offer a novel approach for promoting adherence and health-related quality of life after lung transplant (Zaldonis et al., 2015). This study shows willingness from the recipients of lung transplantation in using a diary and the diary was helpful in monitoring the daily self-managements. This group of patients might be open to use other tools to promote better health outcomes.

To our knowledge, no studies have demonstrated the long-term effect of a diary intervention. However, the use of a tool for self-management decreases over time, which suggests that the long-term effects might be limited (Mattila et al., 2010). Yet, the answers from the questionnaire indicate that using the diary in the first couple of months after a transplantation enforces patient's knowledge and awareness of their own health. Later, the diary becomes less important in monitoring self-management as self-monitoring has become an integral part of life over time.

Optimal outcome after lung transplantation can only be obtained if patients are supported in adhering to a lifelong therapeutic

regimen (De Geest, Dobbels, Fluri, Paris, & Troosters, 2005). Among other things, this regime consists of a lifelong medication regimen, including immunosuppressive drugs and monitoring for signs and symptoms related to complications. A systematic review found that "Medical side-effects" is the most reported patient-related reason to be non-adherent and thereby to jeopardize graft survival (Korb-Savoldelli et al., 2010). Attention and interest from the nurses to recognize and encourage the patient's use of the diary might be the inspiration for the patient to continue self-monitoring and to be open for a dialogue with the nurse about the challenges in everyday life.

Self-management should be learned and monitored in collaboration with healthcare professionals. This could help ensure that patients react appropriately to self-management (Zaldonis et al., (2015)). It is important to help and support patients overcoming barriers promoting post-transplant education (Neyhart, 2008). Some of the barriers identified in the early postoperative period include inadequate health literacy, compressed time of discharge teaching due to mandate for decreased length of stay, sedating effect of pain medication, distractions (such as pain, fatigue and anxiety), language barriers, information overload and cultural differences. Health literacy is shown to be one of the strongest predictors of health status and well-being and an association between inadequate literacy and adverse health outcomes (Neyhart, 2008). To enhance post-transplant education different possibilities are available, but most of all it is important to assess the patient's preferred educational format (Neyhart, 2008). Handing out a diary might be a good tool to support the patient's repetition of the items in self-observation and for the nurse to get an insight into the patient's cognitive competences and readiness for education (Neyhart, 2008).

Quality healthcare outcomes depend on patients' adherence to recommended treatment regimens (Martin, Williams, Haskard, & Dimatteo, 2005). Therefore, this fact must be communicated to and understood by patients and might lead to a stronger partnership between healthcare professionals and patients through the continuity of care (Martin et al., (2005)). A more structured integration of the diary by healthcare professionals as a part of scheduled follow-ups might enforce the collaboration and hopefully more patients would detect and react to signs of infection or rejection.

Life as a lung transplant is also a life with a chronic disease and it is evident that patients with chronic diseases need skills related to self-care to improve their ability to think critically and to make informed decisions related to health (Kambhampati, Ashvetiya, Stone, Blumenthal, and Martin (2016)). Patients need information from the pre-transplant stage (Neyhart, 2008) and then onwards to enable good self-care management (Rees & Williams, 2009). To reach the optimal patient outcome, it is important to enable patient participation and for patients' self-care needs to be addressed. Extra time in the outpatient clinic may be required and care plans can help to facilitate this discussion. To support patients with their self-care management, both sharing of medical and nursing knowledge and recognition of the value of patient's knowledge and experiences are vital. Nurses relate well to patients who want to discuss self-care management (Rees & Williams, 2009).

5.1 | Limitations

This pilot study is small and carried out in one site. However, the group is representative of lung transplant patients, referred to age and gender, thereby the diary intervention can inspire other transplantation centres to integrate a diary in the education programme for the patients after transplantation. This intervention and evaluation do not address the benefits of the health of the patients. There is no control group or baseline for comparison which suggests that one cannot conclude whether the diary had a positive effect on the overall health, that is hospitalizations or the patient's ability to react appropriately to changes in their self-management measurements.

6 | CONCLUSION

This pilot study showed that nurses and patients might benefit from the use of a diary. The form and layout were straightforward, easy to understand and meaningful to use in clinical practice for the patients and nurses. The diary might strengthen the patients' self-management in the early postoperative period and patients were satisfied with the diary as a tool for remembering important observations. Later, when the patients experienced their health as stable, they did not prioritize, forgot to use the diary or were sure they could remember important observations. Like the patients, the nurses were focused on the diary in the early postoperative period. The nurses saw that the patients did their measurements themselves and the nurses felt sure the patients would continue doing so. The results from this pilot study indicate that the use of a diary as a part of the education programme for the newly transplanted patient might optimize the patients self-management, however further research is needed.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

LE: Conceptualization of the study. LE and JG: Study design. LE and JG: Writing of the first manuscript. All revised the manuscript critically and have given their final of the version to be published.

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