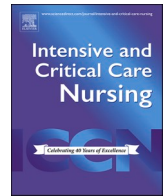




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Research Article

Photographs in burn patient diaries: A qualitative study of patients' and nurses' experiences

Siri Daltveit ^{a,*}, Lena Kleppe ^b, Marie Opsanger Petterteig ^c, Asgjerd Litleré Moi ^{a,b,d}^a Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Inndalsveien 28, 5063 Bergen, Norway^b Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, PO Box 1400, 5021 Bergen, Norway^c Department of Anaesthesia and Intensive Care, Haukeland University Hospital, PO Box 1400, 5021 Bergen, Norway^d Faculty of Health Sciences, VID Specialized University, Ulriksdal 10, 5009 Bergen, Norway

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ABSTRACT

Objective: To explore burn patients' and burn intensive care nurses' experiences of the photos in patient diaries. **Design:** A qualitative inductive study using thematic analysis was performed. We conducted individual interviews with six former burn patients (age range 20–77 years; four women), and two focus groups with 11 burn intensive care nurses (age range 38–61 years; all women). Data from patients and nurses were analysed together, and the findings reported according to the consolidated criteria for reporting qualitative research (COREQ).

Setting: A Norwegian burn centre where the writing of diaries including text and photos has been practiced for approximately two decades.

Findings: Three main themes were derived from the combined analysis of the two data sets: hesitating when facing photos; visualising others care; and visualising the trajectory from burn trauma to recovery. Although the patients worried beforehand about what they would see in the photos and the nurses feared to select frightening photos, the photos were welcome, and several patients said they would have liked even more. The photos filled in gaps of memory, told more than words, and did not lie. Photos of family, friends or staff demonstrated shared actions that supported memories and recovery.

Conclusion: Both the burn patients and the burn intensive care nurses considered photos to be an essential part of the diary that gave context and provided a factual presentation of the patients' pathway of treatment, care and recovery.

Implication for clinical practice: Tailored information about photo content should be offered to patients before a diary is handed over to them. Nurses should attempt to include photos covering the patients' entire stay at the burn centre, as well as photos of family, friends and staff. Individual nurses should be supported in their practical selection of photos for the diary.

Introduction

Burn injuries include thermal, chemical and electrical damage to the skin and deeper tissue structures (Cimino et al., 2020). As burn intensive care has improved, a growing number of patients survive severe burn injury (Bayuo and Wong, 2021; Cimino et al., 2020; Onarheim et al., 2023). However, burn patients may experience a variety of acute and long term physical and psychological challenges including scarring, chronic pruritus, posttraumatic stress disorder and depression, all of which can affect quality of life after discharge (Cimino et al., 2020; Gauglitz and Williams, 2021; Jeschke et al., 2020). In the acute phase and during intensive care, face injuries, removal of hair, generalized

oedema during the resuscitation phase, as well as dressings covering large parts of the body, will unavoidably and dramatically alter the patient's appearance. Many patients also require several operations to promote healing (Gauglitz and Williams, 2021), further altering their appearance. Moreover, burn patients often confront persistent scarring, skin discolouration and skin contractures which make the changes of their appearance a lifelong condition (Cimino et al., 2020).

Burn intensive care patients may experience lack of factual memories, delusions, and hallucinations (Gullick et al., 2014; Moi and Gjengedal, 2008), and distorted memories have been shown to be an important predictor of the development of emotional and cognitive problems after intensive care (Karnatovskaia et al., 2014). To fill in

* Corresponding author.

E-mail address: siri.anett.daltveit@hvl.no (S. Daltveit).<https://doi.org/10.1016/j.iccn.2023.103619>

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memory gaps and prevent psychological impairment, the practice of writing diaries for intensive care patients started in Scandinavia in the early 1990s (Egerod et al., 2007; Åkerman et al., 2010; Gjengedal et al., 2010), and today, this is common practice in many western countries (Moi et al., 2018; Nydahl et al., 2020). Although there are conflicting results as to the effectiveness of this intervention, three recent meta-analyses have demonstrated that patients who received a diary during the intensive care unit (ICU) admission had a significantly reduced rate of post-traumatic stress disorder (PTSD), anxiety and depression, as well as improved quality of life (Gazzato et al., 2022; Hu et al., 2023; Sun et al., 2021).

ICU patients have reported that photos are an important part of the diary (Holme et al., 2020; Åkerman et al., 2013), even when the images can be difficult to view (Engström et al., 2009; Strandberg et al., 2018). Rather than only being told by others, the photos had enabled the patients to imagine what it had been like in the ICU, the severity of their situation and the progress of their treatment (Åkerman et al., 2013; Strandberg et al., 2018). However, ICU nurses have conveyed being fearful of insulting patients and not using photos respectfully when there is a change in body image (Johansson et al., 2019).

Diaries written by nurses have been offered to ICU patients, including burn patients, for decades (Egerod et al., 2007; Åkerman et al., 2010; Gjengedal et al., 2010). However, knowledge about the possible usefulness of photos in diaries for burn patients is lacking. Since the appearance of burn patients may undergo dramatic acute and long-term changes, it is of value to understand how photos in ICU diaries may be perceived by this patient group and their caregivers. Hence, the aim of this study was to explore burn patients' and burn intensive care nurses' experiences of the photos in patient diaries.

Methods

Design

A qualitative inductive study, using thematic analysis according to Braun and Clarke (2006, 2022) was performed to obtain a deeper understanding of the meaning of the content of ICU diaries written for burn patients. Individual interviews with former burn patients and focus groups with burn ICU nurses were chosen for data collection. In all interviews, the diary photographs represented a central topic, and the findings from the analyses of this part of the data is reported here. The consolidated criteria for reporting qualitative research (COREQ) were used to guide the reporting of study methods (Tong et al., 2007).

Setting

The study was conducted at a national burn centre in Norway. The centre is located at a university hospital and has eight beds, including four intensive care beds. Each year, approximately 140 patients of all ages and from all over the country are admitted when in need of treatment from the specialized multidisciplinary burn care team (Onarheim et al., 2023). The patients' median total body surface area (TBSA) burnt and median length of stay (LOS) is approximately 4.5 % and 10 days, respectively.

In line with national recommendations (Holme et al., 2020; Storli et al., 2011), adult burn patients in need of mechanical ventilation are offered a diary containing text and photos. The diaries are written, and photos taken by the nurses at the burn centre. A group of these nurses designated "the diary team", facilitates the initiation and writing of diaries, as well as ensures the quality of the diary. The quality assurance includes reading and editing the diary to ensure that the content does not compromise the patients' integrity and dignity before handover to the patient (Gjengedal et al., 2010; Storli et al., 2011). If the patient chooses to receive the diary, it is usually handed over by a nurse from the diary team when the patient is seen for an out-patient control visit about three months post discharge. The handover is accompanied by a follow-

up dialogue with the nurse from the diary team. If physical handover is not possible, the patients receive the diary by mail, followed by a telephone call from a nurse from the diary team.

Ethics

The study was approved by the Regional Committee for Medical and Health Research Ethics (REC number 2017-1523) and conducted according to the Declaration of Helsinki. Potential burn patient and ICU nurse participants received an invitation letter describing the aims of the study and the procedure for the interviews, and all participants signed a letter of consent. All participants were informed that participating in the study could involve a risk of distress and discomfort, and that they could withdraw from the study at any time without having to give a reason. They were also informed that all data would be stored on a hospital research server, audio files deleted immediately after transcription, and that they were guaranteed confidentiality and anonymity when disseminating the study findings.

Recruitment

Recruitment of former burn patients: The inclusion criteria for burn patients were age of 18 years or more at the time of injury, admission to the burn centre during the last five years and having accepted and received a diary post discharge. The patients also had to understand and speak Norwegian. Eligible patients were identified by the burn centre's nurse diary team before information and invitation to participate in the study were sent to eligible patients by mail. Patients who volunteered to participate, returned their written consent, and were then contacted by the research team for further information. No patient dropped out after having agreed to participate in the study.

Recruitment of ICU nurses: For nurses to be included, they had to have a position at the burn centre and have written diaries for burn patients. The research team first presented the study at a staff meeting. Then, an invitation letter was distributed to all the nurses at the burn centre. The nurses who saw that they fulfilled the inclusion criteria and volunteered to participate, returned their written consent to the research team who then initiated further contact. No nurses dropped out after having agreed to participate in the study.

Data collection

The interviews were performed from February 2018 to March 2020. All participating burn patients and intensive care nurses were given a code ((P1-6) and (N1-11), respectively) that linked them to the data obtained and the quotations presented in this paper. All interviews were digitally recorded after obtaining participant approval. All interviews started by repeating of the information provided in the invitation letter.

Individual semi-structured interviews were conducted to obtain an understanding of the patients' experiences of using the diaries (Polit and Beck, 2021, p. 514). An interview guide containing five topics with follow up questions on a) the handover, b) the accompanying dialogue with the ICU nurse, c) the content (including text, photos, lay-out), d) the feelings and meaning, as well as e) the use of the diary was employed. The specific questions intended to explore the patients' experiences of the photos included:

"How was it to look in and read the diary for the first time? What were your thoughts? What were your emotions?"

"What are your thoughts on the content of the diary? Of the text? Of the photos? Of the lay-out? Did you miss anything?"

"How have you used the diary? Has anyone else (family, friends, health care professionals) read it? Has the diary meant anything to your relatives?"

The interview guide was developed based on previous literature, i.e. the national recommendations for the use of diaries to patients in ICUs in

Norway (Holme et al., 2020; Storli et al., 2011) and other relevant research literature (Kallio et al., 2016; Krueger and Casey, 2015, p. 47). In addition, members of the burn centre's diary team gave input. Four of the interviews were conducted in a remote room at the hospital, and two were conducted by telephone.

Data from the nurses was collected through two focus group interviews performed in a remote room at the hospital during the nurses' working hours (Polit and Beck, 2021, p. 511). As the intensive care diary can be understood as a practice that the nurses create together, we collected data on this subject by letting the nurses discuss it together in focus groups (Kitzinger, 1995). The focus groups consisted of ICU nurses working in the same burn centre, allowing for homogenous groups. The focus group sessions were led by the first author, whereas another member of the research team served as co-moderator, taking notes. The moderator asked for confidentiality within the group to create a comfortable atmosphere where all could talk freely. In addition, the moderators facilitated the conversation so that all participants were encouraged to express their opinion.

An interview guide containing five topics with follow up questions on a) the burn centre's routines for diaries (including promotion, initiation, writing, handover and accompanying dialogue), b) the diary content (including text, photos and lay-out), c) quality, d) the nurses' perception on how patients experience the receipt of a diary, as well as e) possible impact on the nurses themselves from writing in a diary was employed. The specific questions intended to explore the burn ICU nurses' experiences of the photos included:

"What are your thoughts on the content of the diary? Of the text? Of the photos? Of the lay-out? Should photos be integrated in the text or given as an attachment?"

"What should be taken photos of?"

"What should not be taken photos of?"

The interview guide was based on previous literature, i.e. the national recommendations for the use of diaries to patients in ICUs in Norway (Storli et al., 2011; Holme et al., 2020) and other relevant research literature (Kallio et al., 2016; Krueger and Casey, 2015, p. 47). In addition, members of the burn centre's diary team gave input.

Data analysis and rigour

The transcribed interviews from both former burn patients and burn intensive care nurses were analysed together, using inductive, data-driven thematic analysis according to Braun and Clarke (2006, 2022), allowing for the exploration, interpretation and identification of patterns of meaning across all interviews. The analyses were structured into six phases: becoming familiar with the data, latent coding, generating initial themes, developing and reviewing themes, refining, defining and naming themes, and finishing the writing process (Braun and Clarke, 2006, 2022).

To ensure trustworthiness, the analyses were led by the first author, but all members of the research team knew all the data and participated in all steps of the analyses through a series of meetings until the final themes were confirmed. The authors strove to be reflective and open to the participants experiences, and to avoid fitting the data with their own assumptions (Braun and Clarke, 2022). All four authors are intensive care nurses. Authors SD, LK and MOP all hold a Master of Science degree and have experience from qualitative research. Author ALM is professor of nursing science, with extensive experience from qualitative and quantitative research, as well as burn patient related research. Authors LK, MOP and ALM have practical experience from working with burn patients, but none of the authors were involved with the treatment and practical follow up of the patients participating in this study.

Findings

A sample of six patients (four women and two men) and 11 burn ICU

nurses (all female) participated in the study. The patients' mean age was 51 years (range 20–77 years). Their mean TBSA burnt was 31.5 % (range 5 to 50 %) and the mean LOS was 52 days (range 11–94 days). All had received mechanical ventilation (mean 12 days (range 1–39 days)). The mean time from discharge to the interview was 13.5 months (range 3–44 months). The mean patient interview time was 39 min (range 22–62 min). The two focus groups consisted of five and six intensive care nurses, respectively. Their mean age was 53 years (range 38–61 years). In average, they had worked as a nurse for 20 years (range 13–38) and 13.9 years (range 3–25) in the burn centre. The focus group interviews lasted for one hour and 20 min and one hour and 30 min, respectively.

As a result of the analysis, three themes were derived: hesitating when facing photos, visualising others care, and visualising the trajectory from burn trauma to recovery. Photos were regarded as an important part of the diary by both patients and nurses, allowing for the filling of gaps of memory, as well as trustworthy illustrations of how sick the patients had been and how their recovery had progressed.

Hesitating when facing photos

The patients felt nervous before receiving the diary and worried what the photos would show. The nurses acknowledged that photos of burn injuries might evoke strong emotions in patients and feared that photos might insult the patients, leading them to put much time and effort into the process of selecting photos for the diaries. Thus, facing photos gave a feeling of hesitance in both patients and nurses.

The patients especially feared seeing photos of open wounds and operations. One patient said he feared the photos so much that he was reluctant to open the diary: *"Should I dare open the book"* (P5). However, the patients reported that after they had looked in their diary, they realized the photos were not as graphic as they had feared. This gave them a feeling of relief, and as one of the patients stated: *"It was not as bad as I thought. I thought the photos would be worse"* (P2). Still, some patients felt that the photos were uncomfortable and shocking to view: *"And these photos, sometimes, even though they are nice photos, it is still a shock to see that you have been so helpless"* (P4). Seeing oneself intubated and without control of one's own mind or body was emotionally difficult for some of them. One patient said that he could not recognize himself with bandages covering half of his face, and some patients used the word "weird" when describing how they felt seeing themselves vulnerable and unrecognizable. However, despite describing the photos as strong and emotional, and sometimes feeling hesitance before viewing them again, the patients still wanted them. None of the patients had photos in their diary that they wished were not there, and several of the respondents would have liked even more photos. As a patient put it: *"Could preferably have been more photos"* (P6).

The nurses reflected on how burn patients might experience the photos in diaries, especially since they knew that photos of burn injuries could be both shocking and feel unrealistic for lay people. They discussed how the patients could feel about seeing photos of themselves in such vulnerable situations and emphasized the photos' potentially negative impact. Hence, they carefully considered which photos to take and which photos that should be included in the diary. They felt hesitancy and put a lot of time and effort in the selection and made sure that the photos incorporated were dignified. They did not want to expose the patients to photos that might be difficult for them to see or share with others. As a nurse explained: *"They are never photos where they are exposed with open wounds or... it is only with bandages"* (N5).

Visualising others care

Photos showing others care were important for both patients and nurses. These photos documented that the patients had not been left alone but were constantly cared for by family or staff who took part in the activities that led to recovery. Photos of family, friends or staff gave context and revealed shared actions during the patients' stay that

supported their memories and recovery.

The content of the photos varied and some of the patients had photos of both relatives and staff, while others did not. Most patients who only had photos of themselves would have liked to have photos of both family members and staff taking care of them. As patient stated: “*So, it would have been nice to have some photos of them in action (...). I think it would have given a little meaning to the photos, if you know what I mean*” (P4). The patients who had photos of family and staff in their diary viewed this as positive, and one patient who had a photo of herself with a physiotherapist said that this photo was very important to her. Photos including staff revealed the care they had received during their stay at the burn centre. A patient said: “*There were several photos that sort of confirm that I was well taken care of whilst I was at the hospital*” (P3). Several participants reported that the photos were important not only to themselves but also to their relatives. The participants had experienced that their relatives found the photos as emotionally powerful reminders of the time at the burn centre, where they too had spent a lot of time.

The nurses said that photos of relatives or other close ones were important to include in the diary and that such photos could prove to the patients that they had had visitors, even if this was lost to memory. As a nurse expressed: “*We take photos with relatives, so that they can see, oh, they were here, while I was sick*” (N11). Photos showing family or friends involved in acts of caring or rehabilitation, supported memories and demonstrated their contributions to the patients’ recovery and well-being.

Visualising the trajectory from burn trauma to recovery

Both the patient and the nurses saw the photos as imperative for giving a factual description of the patients’ stay at the burn centre, and that one could read the whole story by just looking at the photos.

The patients felt that they needed these photos because they had little memory of the first part of their hospital stay. What they had been told by their relatives seemed unlikely until it was confirmed by the photos. The photos gave them an understanding of how sick they had been, as stated by a patient: “*They were hard times. I can see it from the photos, they were hard times...*” (P4). Moreover, seeing their severe, helpless state during the first days of hospitalization helped them to accept that their rehabilitation took time.

The patients who lacked photos from the last part of their stay at the burn centre, when the focus was on rehabilitation, missed such photos in their diary. They thought they looked very ill in most of the photos, and that photos documenting recovery, e.g. of themselves visiting the hospital cafeteria, were lacking. A patient stated: “*I was a little sad when I got the diary because my memories from the hospital are not visible there. My memories are also the good parts...*” (P3).

The nurses believed that photos could express more than words, and that a diary with few photos seldom was a good diary. They further claimed that patients might need to see photos of how serious the situation had been to fully understand how great a progress they had made, as stated by a nurse: “*...and you can see the dressings shrink, there are fewer and fewer bandages*” (N8). Further, another nurse described how photos were taken with this in mind: “*I try to take photos to show the patients what it was like when they came to the burn unit, so they can get an understanding of how serious it was*” (N3).

The nurses described how they tried to include photos of highlights and milestones in the patients’ recovery. This meant to include photos that illustrated the progress the patients had made, e.g. by taking a photo of the first time post admission that the patient managed everyday activities, such as sitting up in a chair. The nurses reported that seeing this progress in the photos also helped to motivate themselves in their work. A nurse said: “*And you can see the progress, you know...*” (N9). The nurses considered it best practice to add to the diary for as long as the patients were hospitalized. They emphasized that it was important to add photos from the whole stay at the burn centre and not forget to document what happens during the phase of recovery.

Both the patients and the nurses considered the photos as an essential part of the diary that increased quality and made it possible to factually illustrate the trajectory from burn injury to recovery. The patients all expressed gratitude for the diary and felt that the photos included were important for them to understand what they had gone through. The photos allowed them to see for themselves, not being dependent on the description by others. The photos were the part of the diary they most frequently revisited. Lastly, the patients emphasized the importance that they thought the diary and photos would have for them in their further recovery.

Discussion

Burn intensive care patients are offered a diary written by nurses to fill in gaps in their memory from their stay at a burn centre. However, systematic knowledge of the usefulness of this practice is scarce for this patient group. In the present study, we interviewed former burn patients and burn intensive nurses on their experiences of the use of photos in patient diaries. All participants valued the factual contributions that the photos gave, allowing for context and documentation of the patients’ pathway towards recovery. However, both patients and nurses feared that photos could be frightening and cause worry. Three themes were derived from the combined experiences of burn patients and burn intensive care nurses: hesitancy when facing photos, visualising others care, and visualising the trajectory from burn trauma to recovery.

The participating patients feared their first encounter with the diary, and being hesitant and nervous about what the photos might show. Concern about seeing the photos for the first time may have been related to fear of seeing open wounds or disfigurement, but also to how appearance is valued in society. In burn patients, visible scarring or dissatisfaction with appearance has been associated with depression, social barriers and posttraumatic stress (Gauglitz and Williams, 2021; Martin et al., 2017; Van Loey, 2020). It has also been reported that burn patients who value physical appearance highly are more likely to struggle with adjusting to their injury (Corry et al., 2009). Our participants appreciated that the photos were emotionally less stressful than they had expected, but still, they found them shocking and uncomfortable (Engström et al., 2009; Strandberg et al., 2018). Despite this, the patients still wanted them, and for the burn patients, the photos gave factual and chronological information that amplified the diary text and gave credence to the stories told by family (Åkerman et al., 2013; Højager Nielsen et al., 2019). Adapted and realistic information on both the text and photos in the diary, may reduce the patients’ hesitation and uncertainty and maybe induce even more patients to accept and make use of a diary from their stay at the burn centre.

Like the patients, the burn intensive care nurses all felt that photos were an essential part of the diary but knowing that a photo can potentially be both insulting and frightening, they could feel uncertain and hesitant over what the nature of the photos to be included should be. In this balance between doing good and avoiding harm, much like the dilemmas of writing in diaries (Johansson et al., 2019), the nurses put a lot of time and effort into the selection and did their best to ensure that the photos incorporated were dignified. However, they also acknowledged that what is considered a proper photo in a diary may vary between patients and between staff. To meet this, establishing descriptive routines and offering mentoring e.g. from a nurse diary team may reduce uncertainty and support the nurses in their selection of photos (Johansson et al., 2019).

The burn patients who had photos of family or friends in their diaries valued these highly. The burn intensive care nurses also considered such photos to be important, especially as they provided context and revealed shared caring actions that supported the patients’ memories and recovery. Photos of relatives in diaries have earlier been reported to serve as emotional support (Storli and Lind, 2009) and as proof that the person had not been left alone (Combe, 2005). Many burn patients experience dramatic changes to their appearance, making them fear they have

become worthless to others (Moi et al., 2008). Photos showing the presence of family during the hospitalization may improve the patients' self-esteem and belief in future (Moi and Gjengedal, 2008; Moi and Gjengedal, 2014). Moreover, critically ill patients report that relatives helped them feel safe during their hospitalization (Flinterud et al., 2022; Nielsen et al., 2023), and that partners served as a tie to reality and life outside the hospital (Moi and Gjengedal, 2014). Showing to the patient that family and friends were present at burn centre also in periods lost to memory can help strengthen the relationship between patient and family (Brandao Barreto et al., 2021; Johansson et al., 2015). By including photos of relatives, nurses can support both the patient and their relatives, facilitate greater life satisfaction among patients, and help prevent psychological challenges for patients and their next of kin after discharge.

Photos of nurses and other staff were also valued by the patients, reminding them of staff that constantly cared for them and took part in the activities that led to their recovery. Although this was not clearly documented in our study, it is possible that having photos of staff members in the diary may be of special value for those with no family or friends who can visit them in hospital. Overall, photos of significant others, both family, friends and staff, served as proof and reminders of important human encounters, which again indicate the importance of humanized intensive care (Nielsen et al., 2023).

The burn patients and nurses both reported that it was important that the photos showed the whole chronological trajectory from admission to recovery. This is consistent with earlier reports from general ICUs (Åkerman et al., 2013), and in line with the national recommendations for the use of diaries to patients in ICUs in Norway (Storli et al., 2011; Holme et al., 2020). The inclusion of photos of different situations and activities can give meaning and context to the diary. Tripathy et al. (2022) found that photos showing patient progress were encouraging to them, whereas others have demonstrated the value of diary completeness and continuity (Strandberg et al., 2018; Åkerman et al., 2013). The recovery phase of burn care often overlaps with the intensive care treatment and is provided in the burn centre (Bayuo and Wong, 2021). Our study revealed that the patients who lacked photos from their recovery phase felt this as a disappointment.

Strengths and limitations

This first study on the experiences of burn patients and burn intensive care nurses on the use of photos in patient diaries contained strong dialogues and yielded rich information on the subject of interest, aspects that may support information power (Malterud et al., 2016). Moreover, the analyses were conducted by all authors, increasing the credibility of the findings. On the other hand, the relatively small sample size may represent a limitation. The burn centre where this study was performed is a certified burn centre according to European guidelines (European Burns Association, 2017), but since this is a one-site study, transferability may still be limited. The data that came from the focus group discussion were rich, but it cannot be excluded that hierarchy, verbose participants or group thinking may have limited the participants' opportunity to share their views. In order to limit these risks, the groups consisted of ICU nurses from the same burn centre but with varying work experience and age. The moderator ensured a comfortable atmosphere, and by using an interview guide where the number of questions were adapted to the number of participants and the time available, all participants had an opportunity to speak and engage themselves in the group discussions.

Conclusion

Both the burn patients and the burn intensive care nurses considered photos to be an essential part of the diary that gave context and provided a factual presentation of the patients' pathway of treatment, care and recovery. Since both patients and nurses felt hesitant when facing the

photos, we suggest that tailored information should be offered to patients before the diary is handed over and that nurses should be supported in their practical selection of photos for the diary through mentorship and education. We encourage further studies on this topic.

CRediT authorship contribution statement

Siri Daltveit: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Lena Kleppe:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing. **Marie Opsanger Petterteig:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing. **Asger Litteré Moi:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Validation, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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