# Writing a Diary for “You” —Intensive care nurses' narrative practices in diaries for patients

## A qualitative study

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# Writing a Diary for "You" —Intensive care nurses' narrative practices in diaries for patients: A qualitative study

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ABSTRACT

*Background:* Diaries written by nurses for critically ill patients have been implemented in some intensive care units as an intervention to construct patients' "lost time" and fill in their gaps in memory. Studies have shown that diaries have an impact on patients' psychological recovery after intensive care. However, little is known about how nurses view and carry out the process of writing a diary on behalf of a patient.
*Objective:* To investigate the choices nurses make in content and language, the rationale by which they make them, and how these narrative aspects shape the story of critical care that is constructed in the diary.
*Design:* The study was conducted using a qualitative approach informed by narrative methodology.
*Setting:* Three intensive care units at a university hospital in Denmark.
*Participants:* Nine nurses with experience in diary writing. Each of the participants handed in five anonymized diary notes written for different patients they had cared for.
*Methods:* The study combined textual analysis of the diary notes and a thematic analysis of individual interviews with nurses about their narrative choices when writing the diary.
*Findings:* Three prominent strategies that characterize nurses' choices of content and language were identified: 1) Making the situation of intensive care more manageable, 2) Showing acts of perceiving the patient, and 3) Constituting relations through actions and interactions. The study showed that on one hand these strategies engage the patient and depict nurses' care, empathy and support, yet on the other, reveal the nurses' power to interpret, passivize and downplay the patient's experiences.
*Conclusion:* It was demonstrated that although the diary narrative is written about and for the patient, who is referred to and addressed as *you*, the nurse's interpretations, evaluations, perceptions, and actions figure prominently throughout the diary. Narrating for a *you* to some degree relegates the patients to a secondary position in their own diary. With the power to control the diary narrative, nurses' linguistic choices may either narrow down or expand possibilities for the patient's own understanding when reading the diary after intensive care.
Permission to produce and store all data was obtained from the Danish Data Protection Agency (no. 18/60944).


## What is already known

- Diaries written by nurses for patients in intensive care have been shown to have therapeutic value for patients as a means to fill in gaps of "what really happened."
- Nurses perceive diary writing as both an act of care and a therapeutic aid for constructing patients' lost time in the intensive care unit.
- Diaries written for patients by nurses in intensive care have been shown to have an overarching narrative arc of the patient's progression from crisis to turning point to normalization.

## What this paper adds

- While written to, for and about the patient, the diary is also to a great extent the story of the nurse.
- Through different writing strategies in the diary, nurses have the power to either limit or expand the possible interpretations that can support patients' understanding of what they have been through during intensive care.
- The study points to techniques by which nurses may create a more dialogic text in the diary, relinquishing some of the interpretive control.

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## 1. Introduction

The writing of diaries by nurses for patients in intensive care has been implemented in some intensive care units (ICUs) as an intervention to alleviate the gaps in memory and psychological stress that patients often experience. ICU diaries have been shown to help patients in their recovery process by providing information about their condition and day to day experiences (Sun et al., 2021). The act of writing on behalf of another person carries with it the potential for care and empathy as well as ethical responsibilities to preserve the integrity of another's experiences (Johansson et al., 2019; Rimmon-Kenan, 2005). However, little is known about how nurses view the process of writing, specifically with respect to their choices of content and language and the rationale by which they make them.

## 2. Background

### 2.1. The ICU diary

Treatment in an ICU is often a source of both physical and psychological duress. Sedation, coma and the severity of illness may cause patients to experience gaps in memory, delusions, hallucinations and psychosis, which may be perceived by the patient as threatening and contribute to psychological morbidity (Bienvenu, 2021; Jutte et al., 2015). ICU diaries are designed to alleviate this trauma and have been adopted in some hospitals in Scandinavia, Europe, Australia and the US (Nydahl et al., 2020).

The authorship of the ICU diary can vary in practice. It can be co-authored by different health professionals and relatives, but generally the primary writers of the patient's diary are the bedside ICU nurses (Barreto et al., 2021). Diaries include information about the events of a day, the patient's activities, interactions with health care professionals and relatives, improvements and setbacks, as well as perceived emotional responses. The diary consists of written text and may include photographs of the patient and medical technology along with explanations of medical procedures. The diary is given to the patient after the ICU stay as a source of insight into what the patient has gone through (Nydahl et al., 2020).

#### 2.1.1. Diaries' psychological implications for patients

Diaries have been applied as a way to prevent post-traumatic stress disorder (PTSD) by filling patients' memory gaps with information about "what really happened" (Storli and Lind, 2009:46). The diary makes patients' experiences available for reading and reflection, which may help patients piece together a narrative of illness (Egerod and Bagger, 2010). Reading about oneself in the diary written by others is often an intense experience: it can feel "unreal," "frightening," and like "touching a tender wound," but diaries can also impart coherence to fragmented memories and provide necessary knowledge as a support for recovery (Engström et al., 2009; Pattison et al., 2019). The evidence supporting the effect of ICU diaries on ICU patients' psychological outcomes has been sparse (Ullman et al., 2015). Yet, recent systematic reviews and meta-analysis support the use of ICU diaries as they may reduce the risk of depression and anxiety and preserve health related quality of life in patients after ICU (Barreto et al., 2019; McIlroy et al., 2019). Based on a meta-analysis of ten studies, Sun et al. (2021) concluded that compared to routine nursing, the intervention of ICU diaries appears to reduce the ICU patients' incidence of PTSD, anxiety and depression within three months after discharge.

#### 2.1.2. Diary writing from nurses' perspectives

Although nurses face challenges, such as an increased workload and legal concerns about diary writing, nurses emphasize that the diary is beneficial for ICU patients (Barreto et al., 2021). Studies show that nurses perceive diary writing as both an act of care and a therapeutic aid for constructing patients' "lost time" in the ICU (Flinterud et al., 2019; Gjengedal et al., 2010; Johansson et al., 2019). On the one hand, diaries provide information about what takes place (Pattison et al., 2019), and on the other, nurses interpret the patient's experience, with the resulting narrative "a story of wonder" (Gjengedal et al., 2010). In a study by Halm (2019), nurses viewed the diary as a "holistic, humanizing intervention." Ethical dimensions of diary writing come across in a study by Johansson et al. (2019), which emphasizes the importance of reflection and ethical awareness through careful consideration of the written word, to express the ICU stay honestly in order to avoid blaming or violating the patient.

#### 2.1.3. The ICU diary as narrative text

As a text, the ICU diary has distinctive characteristics that matter for the construction of a narrative for the patient. It establishes meaningful coherence among events, addresses the patient and describes them as a person, unlike the chart, which is organ-system-oriented, impersonal and addressed to medical personnel (Egerod and Christensen, 2010). According to Egerod and Christensen (2009), the diary exhibits an overarching narrative arc of the patient's progression from crisis to turning point to normalization. They emphasize that the diary is unique as a traditionally first-person genre that is written for and on behalf of another, utilizing both first- and second-person references to nurses and patients respectively. Accordingly, they describe the diary as what the narratologist Rimmon-Kenan (2005) has referred to as "a first-hand, second-person text," a "vicarious narrative" that is told for another and that thus results in a "dual perspective" and ambiguous ownership (Egerod and Christensen, 2009:269).

### 2.2. Aim of the study

As previous studies indicate, the choices that nurses make are decisive for the story of critical care in the diary. However, little analytical attention has been devoted specifically to the process by which nurses construct the narrative. Therefore, the aim of this study is to investigate the choices nurses make in content and language, the rationale by which they make them, and how these aspects shape the diary narrative.

## 3. Methods

### 3.1. Design

Our study is qualitative, informed by a narrative methodology (De Fina and Georgakopoulou, 2012; Riessman, 2008). We understand narrative as a mode of thinking, interpreting and apprehending reality (Bruner, 1991). Through the activity of narrative construction, heterogenous events, circumstances and impressions are gathered into a synthesis and given coherence with the potential for finding meaning (Ricoeur, 1991). A narrative, as a type of text, represents this construction through the discourse, based on the narrator's choices of content and language (Abbott, 2008; De Fina and Georgakopoulou, 2012). The design of our study reflects an eclectic method as we combine analysis of narrative texts and what they indicate about the process of constructing them, with what nurses say about their writing process. We completed the COnsolidating criteria for REporting Qualitative research (COREQ) checklist to ensure the quality of the study (Tong et al., 2007) (supplementary file).

### 3.2. Setting

The study was conducted from 2018 to 2019 in three mixed medical/surgical ICUs at a university hospital in Denmark with treatment capacity for a total of 20 patients. About 150 nurses were employed, among which approximately 65% had a specialization in critical care nursing.

During the last 20 years nurses in the department, as the sole authors, have written a diary throughout the ICU stay for patients who

are admitted for three days or more. Relatives are encouraged to write their own diary. The nurse-authored diary is an A5 binder with a short introduction and photographs of equipment. Nurses strive to write an electronic diary note daily for the individual patient in their care. Diary notes are printed, placed in the binder, as well as saved in the electronic health record. Patients receive their diary when they are discharged from the ICU.

New nurses are instructed in diary writing during the ICU's introduction program. All the ICUs in this department have the same guideline for nurses about how to write, which includes writing in "a personal and professional" but not "private" style, in "everyday language," as well as writing daily, to strive for coherence and chronology. According to the guideline, the content of the diary could be actions, situations, milestones, feelings, descriptions of the environment, patients' reactions and expressions, all written with the aim to support the patient's memory about the time in the ICU.

### 3.3. Study participants

The participants were nurses from the three ICUs who had experience with diary writing. They were thus purposively sampled, and we strived for variation in age and ICU experience to enhance information power (Malterud et al., 2015).

To recruit participants, the study was presented to a group of ICU nurses with a special interest in diary writing, and ten nurses volunteered for the study. One of the nurses withdrew due to change of workplace. An overview of the participants is shown in Table 1.

### 3.4. Data collection

#### 3.4.1. Diary notes

Each participant selected and handed in five anonymized diary notes that they had written for different patients, prior to the interviews. Each diary note was between one-half and two A5 pages. The notes were data for the textual analysis, but were also occasionally used in the interviews as examples the nurse could reflect upon.

#### 3.4.2. Interviews

Individual semi-structured interviews were conducted with nurses on the basis of an interview guide (Brinkmann and Kvale, 2018) designed to elicit their perspectives on their narrating practices. The semi-structured method was chosen to ensure that nurses addressed the aspects of narrative that were the focus of the textual analysis, yet also had the opportunity to elaborate on issues that they found relevant for writing diaries and that could contribute to the richness of the data. Questions in the interview guide (supplementary file) included nurses' rationale for selecting the content for the diary and what professional and personal competences they draw upon in interpreting and writing about patients' signs.

The interviews were conducted by the first author, who had no prior relations to the nurses. They took place in a quiet room, lasted 45 to 90 min, and were digitally recorded and transcribed verbatim by a student assistant.

**Table 1**
Participants' characteristics.

| Characteristics | Participants (N = 9) |
|---|---|
| Gender | |
| Male | 1 |
| Female | 8 |
| Age | |
| ≤30 years | 4 |
| 31–40 years | 3 |
| ≥41 years | 2 |
| ICU | |
| ICU 1 | 3 |
| ICU 2 | 4 |
| ICU 3 | 2 |
| ICU experience | |
| ≤2 years | 4 |
| >2 years | 5 |
| Special education in critical care | |
| Yes | 4 |
| No | 5 |

### 3.5. Ethical considerations

The study was conducted according to the principles of the Helsinki Declaration (WMA, 2013) and approved by the ICU's research committee. The nurses received oral and written information about the study and signed a written consent before the interview. Before disclosure to the researchers, all diary notes were anonymized to ensure that they contained no personal data. Permission to produce and store all data was obtained from the Danish Data Protection Agency (no. 18/60944). All data were handled with confidentiality in a secure Microsoft Sharepoint project room.

To ensure anonymity in our findings, nurses are referred to as "N" for "nurse" with an identifying number, i.e. N1 refers to Nurse 1. Diary quotations are attributed to the nurse number and the number of the diary entry, i.e. N1,5 refers to diary note number 5 from Nurse 1.

### 3.6. Data analysis

We carried out a structural narrative analysis of ICU diary notes (De Fina and Georgakopoulou, 2012; Riessman, 2008) to investigate choices of content, organization and language of diaries and what these indicate about the nurses' narrative processes. This was combined with a thematic analysis of semi-structured interviews (Brinkmann and Kvale, 2018; Riessman, 2008) with the nurses who wrote the notes, which provided insight into their rationales for their choices as writers and their views on the writing process.

To prevent nurses' views from influencing the textual analysis, each nurse's notes were analyzed prior to the analysis of interviews. The textual analysis employed a set of narratological concepts for the activity of constructing a narrative. The first, "evaluation devices" (Bruner, 1991; Labov, 1972), refers to expressions that indicate how narrators assess events as being noteworthy or significant, thus motivating the selection of content as being "worth telling" (Baroni, 2014). Because evaluations are informed by narrators' attitudes and values, they can be an indicator of the norms and rationale by which the narrator selects or omits some aspects. Our second set of concepts relates to "narrative voice" (Ricœur, 1976), and how the narrator, subject and receiver are positioned. Because the diary notes are written *to* a patient, they exhibit second-person (*you*) narration (Mildorf, 2013). Analysis of personal pronouns like *I* and *you* and the portrayal of subjects' agency can illuminate interpersonal relations of telling for, to and about another (Mildorf, 2013).

In the interview analysis (Brinkmann and Kvale, 2018), we identified recurring themes of how nurses interpret the verbal and nonverbal signs of patients, make choices about content and language, and interpret the guideline for writing. From both the textual and thematic interview analyses we extracted a set of "strategies" for writing that recurred across all data sets. Finally, we discussed these strategies in light of theory from the dual perspectives of narratology and nursing.

The study was carried out by an associate professor of language and communication at a university and a research nurse affiliated with the ICUs. The coupling of humanities and nursing perspectives enabled us to connect in-depth narratological analysis of the diary to theoretical and practical knowledge of critical care nursing for an enhanced understanding of how textual details are shaped by the context of intensive care.

## 4. Findings

The findings show three prominent strategies that characterize nurses' choices of content and language: 1) making the situation of

intensive care more manageable, 2) showing acts of perceiving the patient, and 3) constituting relations through actions and interactions. Below, we present how each strategy is developed textually and how it is reflected in interviews.

### *4.1. Making the situation of intensive care more manageable*

A common strategy was to make the ICU experience more manageable by using language that reduces the distress of critical care. These became apparent in nurses' evaluations of patients, situations and treatment. In addition to straightforward descriptions and acknowledgements of patients' suffering, four techniques that downplay unpleasantness are characteristic of the diaries: minimizing, euphemizing, normalizing and maintaining positivity. Several techniques may appear in the same entry.

Diary entries show recurring expressions that linguistically minimize the degree or scope of unpleasantness of an intervention through adverbial expressions like "some," "a little" and "a tiny bit" (Table 2, supplementary). One note described a taxing day involving an operation for the patient as "a little hard" (N4,1) and a patient is often given "a little" sedative. Minimizers can occur alongside intensifying expressions like "a lot" or "very." A related sub-strategy is the use of euphemistic language that tones down physical discomfort, delirium and violent reactions to care and treatment, especially intubation. Euphemisms are indirect and milder formulations that can be seen, for example, in negation of an adjective, as in "not so pleasant" rather than a more direct "unpleasant." A third sub-strategy to downplay the difficulty of critical care is to normalize unpleasant bodily and emotional responses by reassuring the patient that these are common in the extraordinary situation of intensive care.

In the diary note below, we highlight the evaluations of the patient's situation, condition and responses that illustrate some of the above-mentioned strategies:

> You are still **somewhat bewildered and confused**. It seems like you are not oriented to time and place. You have difficulty understanding some of the things we do that are **not so pleasant**. For example, we suction the mucous from your lungs with the help of a thin plastic tube. […] You have **difficulty accepting** that we do this. You become **very upset** and **seemingly angry**. […] Your thoughts are presumably **somewhat** incoherent and your perception of the situation **can be different** than the staff's and your family's.
>
> You can't calm down enough to be able to sleep. When you become very upset we've given you **a little medicine**. It must definitely **not be pleasant** for you to feel this way. It is **not uncommon** that you can feel this way when you've been through what you've been through. (N3,5).

A final strategy is a focus on positivity, both through descriptions of improvements in the patient's conditions and through expressions of encouragement. The most prevalent example is wishing the patient "a good recovery," which closes most notes (Table 2). Yet positivity can be a way of finding small steps forward, even in major setbacks. Positivity can describe a patient's mental state, optimistic attitude or resilience. Many notes emphasize physical progress, with formulations that subtly reflect nurses' criteria for assessing the patient.

In the note below, the nurse minimizes the difficulty of speaking and being understood and adds praise, encouragement, a record of progress and the nurse's own evaluating remark, "Fortunately":

> You are still intubated and really want to try to tell [us] a lot, but it is a little difficult for us to understand the long sentences. In the day shift you had written some messages on paper and used a spelling board to communicate with the nurses. That was well done, even though it had been a little frustrating not to be able to talk. Fortunately, it's going better with your breathing and we've been able to reduce a lot of the help you get from the ventilator (N7,5).

Notes show narrative choices that reflect nurses' evaluative perceptions of intensive care and the attempt to make it bearable for patients. In interviews, nurses shared considerations on how they represent unpleasant experiences. Their responses reflect how narrating on behalf of another involves navigating between an honest record of "what happened" and an apparent desire to protect the patient:

> It [creating a balance] can also mean turning it around, "your infection count is really high, but we give you some antibiotics that will probably help you, so that you'll be better tomorrow." So one packs it in a little in that way (N8).

A recurring rationale for "packing things in" is that patients are "not themselves" in intensive care:

> But it's because that I know that there are things they wouldn't do if they were themselves. So it… it would be far from my mind to scolde them … or write that they were bloody irritating, that "you kept on pulling the IV lines, I've told you several times" (N3).

Similarly, nurses express the tendency to spare patients from blame by reformulating or omitting violent or "irritating" behavior. This is illustrated by the following example, where the nurse explains what they would omit, and even to the interviewer, euphemistically refers to the patient's violent behavior as being "agitated" and as "unfortunate":

> Well I definitely leave out the kind of thing that is just really unfortunate … I could never write details about them being agitated or mad or that they shouted at us or…. I don't think there's any reason that they should be left with that afterwards. That feeling that they've been irritating to us (N4).

While sparing patients from reports of aggressive actions is mentioned by nurses, so is the importance of documenting the unpleasant aspects of intensive care. This may enable patients to recognize the difficult experiences they have been through, and it may validate the patient's perceptions of what has occurred, according to one nurse. Another suggested that it could be a resource for patients to know how they made it through bad days:

> "I'm thinking that if it were me… that they had written to, then I'd be happy that they don't always write that everything is … good, because it's not, you know. […] Well, that they are also told if they have had some bad days and how they got through them" (N2).

### *4.2. Showing acts of perceiving the patient*

A second prominent strategy is seen in nurses' depictions of their acts of perceiving patient's verbal and bodily expressions and physiological changes. Diary entries tell, for example, that the nurse is present and observing the patient by reassuring that there is "always someone looking after you" (N3,3). Another entry states, "You can't say to me that you are in pain of course, but I can see it, for example, when you grimace" (N3,5). The ways and degree to which nurses explicitly reference their presence, and by doing so write themselves as an actor into the text, vary. Reports of seeing and sensing are ways of documenting that the nurse is interpreting and making inferences on the basis of the "evidence" of the patient. "You often lie with your arms over your head, which looks very natural and relaxing for you" (N4,2), and "With the help of a lift, you have been lifted over to an armchair

where you sat for about an hour and relaxed. It looked really nice and comfortable" (N4,2).

A common strategy is to conclude an entry with "I'll see you tomorrow" (Table 2), so that seeing is equated with the nurse's presence, which in turn creates temporal orientation and continuity through their relation. Diary notes often depict the nurse's close attention to the patient and the fact that the patient is seen and responded to through words or actions. Some notes include specific references to nurses using sight along with other senses to imagine how the patient feels:

> You register when I'm around you at your bed. I see this in the way you wrinkle your brows, squint your eyes or open them. […] I sense that you are weak. In the periods when you're awake, we can communicate with each other. You can shake or nod you head when I ask if you're in pain […]. Maybe you feel that your body is heavy and very weakened (N2,2).

Here the patient is able to communicate with intention through the body, and the nurse records acts of seeing and sensing by both the nurse and the patient. The commonly used adverb "maybe" appears. This serves as a polysemous gesture to the nurse's own reservation about making an interpretation on behalf of the patient, a genuine wondering about whether the patient can feel, and an uncertainty about what the patient feels. This questioning suggests how the nurse–patient relation is constituted through the diary discourse. Although the subject of the diary is the patient, the perceiving nurse is a strong presence, not only in the situation of care, but in the language of the diary itself.

"Maybe" is one of many modality markers, linguistic indicators of the writer's evaluation of factuality or certainty. Others are verbs like "seems like" and the modal verb "can" that express different degrees of possibility (Table 2). As they draw attention to an evaluating subject, they make the writer manifest textually. At the same time, however, they help the writer modify the degree to which something is assessed as true, positioning the nurse as less certain. A similar strategy is the use of a question, directed doubly at patient and nurse, which intensifies the uncertainty of "maybe": "Maybe the music helps you on the way to sleep?" (N5,5). Finally, unmodalized expressions are also common in the diaries, in evaluations such as "you are/were [tired]" and "it went fine" (Table 2), which convey interpretive certainty.

The act of perceiving patients is also brought up in interviews. Nurse 2 explains that entries are based partly on what she observes and partly on what she is able to measure and verify. She exemplifies this with the evaluation, "you are immensesly tired" (N2,3): "Then it's a blend of something I observe with something the patient shows me" (N2). Similarly, another nurse, in commenting on the uncertainty of knowing how patients feel, contrasts what can be measured with what the patient exhibits: "Well, you cannot know, when you can't ask the patient. But then you have to look at the numbers that are on the screen and see how the patient's face looks" (N6).

An awareness of indicating the interpretive work of perception is addressed by Nurse 6: "It's on the basis of what I see, you know. I can't know if the patient feels that way. So I can write, 'perhaps you sensed…' or you can put a question mark after what you've written."

Nurse 3 explains that the diary is a way of conveying to the patient that she observes and tries to understand what he is communicating through bodily signs and facial expressions: "I try to tell him [in the diary] … because he was able to feel that he couldn't say anything … that the needs that he has – I try to read them in other ways."

### *4.3. Constituting relations through actions and interactions*

Closely related to the descriptions of perceiving is the strategy of depicting actions and interactions of patients and nurses. By means of evaluations and linguistic choices like pronouns, nurses depict themselves and patients as having varying degrees of activity.

The diaries are written primarily in the second person, to and about *you*, using a variety of techniques to address and position the patient by describing their actions, states and experiences. Many entries depict the patient as a subject in sentences telling what the patient has done during the shift: "You sat in an armchair 1 ½ hours tonight and you watched some film on TV" (N4,3). In some cases, the nurse describes the patient as the iniatator of interaction: "You write to me on your notepad that your body feels restless" (N5,5); "You express that you want to go on living" (N9,1). In examples like these, the patient is positioned as an active "doer" and the nurse is the receiver, though not always explicitly present in the text.

Sometimes the patient is depicted as a "doer," albeit couched within the nurse's evaluation: "You've managed the first 12 h without the ventilator fine. You have a little trouble coughing everything up, it has gotten better and better during the evening" (N4,3); "You use your PEP-flute very diligently" (N1,4). "You handled it really well" (N6,5). It is by embeddig the patient's actions within the nurse's evaluation, that those actions are ascribed value. In other cases, the "you" is depicted as the passive receiver of others' actions: "You got your hair washed and dried, and then you got a thorough scalp massage" (N4,3). "You had a tube placed down your throat" (N9,1); "The physical therapist will come again tomorrow, so you can receive your rehabilitation training" (N1,5).

Nurses are prominent in the diaries, represented by the pronouns "I" and "we." For example, patients' actions are often grammatically embedded in subordinate clauses where the nurse-narrator's "I" comes first in the main clause: "I had to 'wake' you by talking to you, so I asked you a lot of questions that you answered on your notepad" (N5,3). Nurses often foreground themselves and their actions: "I have turned on a bit of relaxing music for you" (N5,5); "I have tried a whole lot of different things, but it's as if nothing feels completely ok to you" (N1,1); "In the attempt to help you find some calm tonight, I have repeatedly tried to tuck you in well" (N2,5).

In uses of "we," sometimes the pronoun has clear reference to the patient and nurse: "You haven't been awake at all in the hours we spent together today" (N4,2). In other cases, it is less clear whether reference includes the patient: "You've been in the shower with the greatest pleasure. Afterwards we fixed your hair […] and you were moisturized with lotion from top to toe" (N2,1). "We" can also refer to the health professionals, excluding the patient, but with some ambiguity of reference: "We have drained a great deal of fluid from your body" (N1,3); "We do what we can to help you" (N9,1). The ambiguous use of pronouns can lead to unclarity about who has been present and involved in the situations described. Through the pronouns "I" and "we" and the emphasis on efforts to help the patient, nurses and their work become prominent in the text.

Recording the efforts of the nurse is mentioned in the interview with Nurse 2:

> It is also important for me as a nurse who has taken care of a patient, where he is extremely confused and turns night and day upside down and can't find calm at all, then I think that it is nice to tell that we have done more than just medicate. That is, we have lots of other things, that we also try to do.

In interviews, nurses reflect on their use of "you" and "I" when writing, and emphasize that it is important to include a "you" in the diary, as it is written to and for the patient:

> But if I were to sit and read a diary and had been critically ill and didn't know anything about what had happened, if it just said, 'I, nurse, have just given you this … I just helped you,' but there wasn't anything about 'you have…' then I wouldn't feel it was about me, but the nurse who has described what she has done for me during the day. That's why I mix 'you' and 'I' (N8).

## 5. Discussion

From the narrative analysis of diary notes and thematic analysis of interviews, we identified three narrative strategies expressed in the diaries: making the situation of intensive care more manageable, showing acts of perceiving the patient, and constituting relations through actions and interactions. Below, we discuss their implications for shaping the patient's story, by combining theories about the affordances of narrative and nursing care. These enable us to identify tensions that arise through writing strategies that on one hand engage the patient and depict nurses' care, empathy and support, and on the other, reveal the nurses' power to interpret, passivize and downplay the patient's experiences.

Narration offers an ongoing means of creating order in disorder through the activity of selecting and deselecting the events and actions, people and settings that constitute the narrative, and organizing them into a coherent structure (Ricoeur, 1991). Our findings show how nurses, through choices of language and content, bring order to the unpredictable and distressing experiences of critical care. Narrative becomes a tool for making these experiences more manageable, that is, dealt with or controlled with as little difficulty as possible. One way that "managing" occurs is through minimizing and euphemizing expressions that reduce the scope or degree of negative aspects such as physical distress and disorientation. Downplaying becomes a way of shifting attention away from, or concealing aspects of, undesired events and behavior. In addition, diary narratives counter negative experiences like setbacks or delirium with reassurances that these are common, as well as with reports of progress, however slight.

Strategies of managing imply the presence of a narrator who makes judgments about what is desired or not, a subjective position from which events are more or less intentionally evaluated for their relevance for the narrative (Labov, 1972). In our analysis, attention to evaluative language and selections of content enables us to infer what nurses find significant, and perhaps gives cues to why. An evaluating nurse-narrator is not "neutral" or "objective," but is informed by cultural, social and historical situatedness, ideological and professional influences, and personal experiences and preferences (Daiute and Nelson, 1997). The strategy of downplaying is part of the evaluative process in which nurses judge patients' conditions, and is traceable in the diary language. Evaluations seem to reflect what Jocalyn Lawler terms *minifisms*, "verbal and behavioral techniques which assist in the management of potentially problematic situations by minimizing the size, significance or severity of an event involving a patient" and are "methods of bringing a situation under control" (Lawler, 1994:166). These are part of a repertoire of strategies for protecting the patient's integrity and protecting both nurse and patient from the risk of social discomfort or embarrassment. Minifisms offer nurses a way to create an "acceptable social space," sparing the patient potentially negative perceptions, limiting distress, and mitigating situations, projecting that "everything is 'business-as-usual'" (Lawler, 1994:167).

Minifisms, euphemisms and narratives of progress appear to suggest that aspects of intensive care are matter-of-fact or trivial. However, the fact that they have made their way into the narrative suggests on the contrary that they are so significant that they must be "toned down" in order to be dealt with. This indicates an evaluative rationale according to which patients need protecting from the very pain, disorder, and messiness that they themselves have been through, marking certain experiences as undesirable. This also positions the nurse as a narrator who, in making decisions about what patients need protecting from, exerts control over the version of the patient's story that is communicated in the diary. This reflects the suggestion made by Johansson et al. (2019) that nurses need to consider every word in order not to blame, scare or violate the patient. However, as Lawler (1994) writes, understatement may render some experiences "invisible". The notes are marked by conspicuous absences of the sometimes aggressive physical behavior that accompanies delirium, anger and fear towards nurses, depictions of blood and excrement and lack of bodily control. Patients seeking understanding about these aspects may not recognize themselves in the text. In interviews, nurses explain that "patients are not to blame, they are not themselves," which brings the notion of "blame" into the situation of intensive care and then erases it through the writing process. In creating what Lawler (1994) calls a "sanitized" text, nurses may perpetuate the taboos they intended to protect patients from. Viewed through the work on symbolic disorder as "matter out of place" by Douglas (2002), the narrative strategies used in writing the diary could be characterized as textual "containment." By bringing order to the liminal situation of the ICU patient, nurses thus make the unpredictability and complexity of intensive care manageable, not only for the patient, but also for the nurse.

The work of nursing requires continuously perceiving patients through sight, hearing and touch, and interpreting patients' bodily and verbal signals (Martinsen, 2006). Our findings show that nurses record such acts of perceiving and interpreting in the diary. In narratological terms, the nurse functions as "the focalizer," which refers to "who sees" or "perceives" (Rimmon-Kenan, 2002), the subject from whose position the presentation of events is oriented (Bal, 2009). Perception does not entail simply "registering," but includes cognitive, emotive, and ideological orientations (Genette, 1980; Rimmon-Kenan, 2002) as well as professional judgment (Martinsen, 2006).

Although the diary is the patient's (the *you*'s) story, everything in it is focalized through the nurse. The diary can thus be seen as documentation of the nurse's acts of perceiving the patient and environs, which are represented by the nurse-narrator. The findings show that the nurse-narrator sometimes explicitly references their presence as focalizer in the text. The nurse's perceptions dominate, so that the story of the patient to a great extent consists of the story of the perceiving nurse.

The way the nurses record the act of perceiving can be seen to reflect Martinsen's (2006) distinctions between different ways of seeing and interpreting. According to Martinsen, seeing with an "attentive participating eye" entails "attunedness" and presence. This is exhibited in the diary notes where nurses' openness towards the patients' signs is expressed. A second eye, "the recording eye," involves drawing on professional knowledge to classify what is seen. Here, professional knowledge dominates the interpretation and "fixes" meanings (Martinsen, 2006). This is reflected in the findings in the unmodalized expressions of interpretive certainty, where the nurse's understanding is dominant. A third eye, the "doubt's" eye, arises when the professional knowledge of the nurse comes into play in the interpretation of what the patient shows (Martinsen, 2006). We see this when, in describing acts of perceiving and interpreting, nurses use markers of uncertainty, such as modal verbs (may) and adverbs (maybe) and questions. By explicitly referencing acts of perception and wondering (Storli and Lind, 2009) and expressing uncertainty, the nurse becomes more visible in the text, yet relinquishes some of the control over the meanings of perceptions. This opens a space for doubt and reflection on behalf of the patient reading after intensive care.

In the tension between the dominant presence of the nurse and the attempt to empathetically represent patients' perceptions, the diary texts demonstrate a similar tension at the heart of witnessing. "Witnessing" denotes "seeing," but in situations of care entails much more than its visual aspect; "Bearing witness is a human mode of coexistence" (Naef, 2006:146). Witnessing requires the witness's personal presence and is an ethical response that acknowledges the subjectivity and uniqueness of the other. However, when the presence of focalizers and narrators dominate the text, they risk a "degree of appropriation" (Rimmon-Kenan, 2005) [that is] inevitable in any attempt to tell the story of another and raise the question "whose story is it?" This is reflected in the ambiguous ownership of the ICU diary narrative, as described by Egerod and Christensen (2009) and as shown in our analysis.

The patient diary has been described in studies as "an act of care" (Gjengedal et al., 2010). The relationship of care between nurse and patient is characterized as asymmetrical, where interactions are based

on dependence and power (Delmar, 2012). This is especially the case in intensive care, where the patient may be speechless and dependent on medical equipment and health professionals (Lykkegaard and Delmar, 2013). Consequently, the patient is dependent on others for the construction of a narrative of "what really happened."

Our findings show that the asymmetry in the nurse–patient relation extends to the narration of the diary, where it is reflected and reproduced in elements of content and language. In terms of content, this relation is apparent in the nurse-narrator's various ways of representing actions and interactions. Sometimes the patient is represented as an active initiating subject. Here, the patient exhibits what Laerkner et al. (2017) have demonstrated is a sense of "bounded agency": the patient is able to communicate bodily, but unable to execute actions on their own. Sometimes the patient is depicted as a passive receiver of others' care and attention where the actions of the nurse are emphasized. Similarly, nurse-narrators' evaluations and their foregrounding of their efforts to help the patient give prominence to nurses' practice, professional competences and values. This corroborates the findings of Egerod and Christensen (2009) that the patient diary also becomes the nurse's story.

Relations of power and dependence are reflected and reproduced linguistically, where pronoun reference plays an important role. Nurses' choices of pronouns are to some degree constrained by the context of critical care and the diary genre, where nurses write to and for a "you." The pronouns "you," "I" and "we" reflect the relationality of human beings (Gergen, 2009; Mildorf, 2013). The pronouns are deictic, which means that they can only be understood through a shared knowledge of the context in which they occur (Fludernik, 2011). In narrating to and about a "you," the narrating I "assumes the other person's position at least temporarily" which creates the potential for "showing understanding for and empathy with the other person" (Mildorf, 2013:193).

Although the use of "you" may be said to invoke and acknowledge the presence of the other (Buber, 1958; Gergen, 2009), the narration about and for "you" linguistically relegates the addressee, here, the patient, to the *second*-person. In the diaries, we find that the nurse narrator becomes the authoritative *first*-person "I" of the text. The voice of the person whose story is told is displaced to the nurse, with the result that "even the actions presented in the second-person can be said to be safely tied to the experiencing-I's" position (Mildorf, 2013:188). This "I" is the perspective from which the narrative choices are made.

In addition, we find that nurses incorporate the first-person plural "we" as the subject of actions; yet, as Fludernik (2011) asserts, the collective pronoun can have ambiguous reference. (Fludernik, 2011). For the patient reading after intensive care, unclear references may prevent them from identifying themselves and others in the text, leading to uncertainty about their relations with others, their inclusion or exclusion, as well as the status of their own agency. Unraveling the ambiguities of reference when reading requires, according to Egerod and Christensen (2009), contextual knowledge, which the patient in critical care may lack and that the diary is intended to provide.

Because narrative is a means for creating order, the shaping of another's experiences into one's version of narrative is an act of power. According to Delmar (2012) the moral exercise of power entails acting in ways that expand the other's room for action. However, as we have shown, nurses, through their choices of language and content, may actually narrow down the space for patients' understanding of what they have been through. They may thus, as Egerod et al. (2011) point out, hinder patients' recovery. On the other hand, our study also points to techniques by which nurses may relinquish some of the interpretive control and give greater space to patients. These include the use of modality to indicate less interpretive certainty, questions about what the patient is experiencing, and references to their own acts of interpretation, all of which create a more dialogic text. This may be an exercise of power that opens spaces for the patient's own interpretation, helping them, as Storli and Lind (2009) put it, to make the connection between the diary and the patient's own experiences.

### 5.1. Limitations

In this study we focus only on nurses' writing and reflections about their narrative choices. Therefore, our discussion of the ambiguous ownership of the diary narrative does not include the perspectives of other professionals or relatives. The sample comprised nine nurses and 45 diary notes from one intensive care department in a Danish university hospital. Thus there is a risk that the data might reflect local approaches to diary writing; however, the format and style resemble international practice (Nydahl et al., 2020). Furthermore, while nurses may interpret the local guideline differently, our findings show strategies that are shared among nurses, despite their individual interpretations. Participants' awareness that their notes would be subjected to analysis may have made them more attentive to their writing, thereby influencing the data. In interviews, there may have been the risk that nurses gave socially desirable responses when describing their writing practice. In anticipation of this, we included examples of nurses' own diary notes, so they could reflect on their actual writing practice. Nurses' diary notes were taken out of the context of the overarching diary narrative. Therefore, our analysis does not account for the progression over time explored in other studies (Egerod and Christensen, 2009; Lindberg et al., 2015).

## 6. Conclusion

The ICU diary has been characterized as a narrative of "what really happened" during critical care, to support recovery by filling in the gaps in patients' memory. As we have shown, in constructing that narrative for the patient, nurse-narrators make choices in language and content in accordance with three narrative strategies: Making the situation of intensive care more manageable; Showing acts of perceiving the patient; and Constituting relations through actions and interactions. Although the narrative, written for a "you", is ostensibly about the patient, the nurse's interpretations, evaluations, perceptions and actions figure prominently throughout the diary. Consequently, a part of the story that the patient will piece together about the ICU experience will be based on a narrative constructed by nurses who have the power to decide what is appropriate for the patient to know. Accordingly, the diary linguistically reflects and reproduces the asymmetry of the nurse–patient relation.

As we show, the tensions inherent in *you*-narration are evident in the diary. Narrating for a "you" to some degree relegates the patient to a secondary position in their own narrative, but it also affords possibilities for the nurse to imaginatively place themselves in the position of the patient, paving a way for empathy. Similarly, having control over the diary narrative, nurses' may through their linguistic choices either narrow down or expand possibilities for the patient's own understanding. Our study contributes to an awareness that in filling in gaps of "what really happened," the nurse's narrative choices and omissions may create new uncertainties for the reader of the ICU diary.

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## CRediT authorship contribution statement

Cindie Aaen Maagaard: Conceptualization, Data curation, Methodology, Analysis, Investigation, Methodology, Writing - Original draft preparation, Reviewing, Editing.

Eva Lærkner: Conceptualization, Data curation, Methodology, Analysis, Investigation, Methodology, Writing - Original draft preparation, Reviewing, Editing.

## Declaration of competing interest

None.

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