



# **WHAT NEEDS TO BE CONSIDERED WHEN IMPLEMENTING PROSPECTIVE DIARIES FOR INTENSIVE CARE PATIENTS?**

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**ABSTRACT**

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The purpose of the study was to investigate the relevant issues associated with the implementation of prospective diaries for intensive care patients. The objective was to provide suggestions to the Pirkanmaa Hospital District intensive care unit regarding diary structure, content, protocol, ethical and legal issues, benefits and/or negative effects, follow-up care, and assessment.

The literature review method was used to analyse the current scientific literature relating to the topic. Nine articles fulfilled the selection criteria and were subsequently critically appraised to evaluate their reliability. The results highlighted varying approaches to diary implementation and revealed the complex nature of the topic.

In conclusion, prospective patient diaries can be beneficial in promoting the psychological recovery of intensive care patients. However, potential negative effects have not been fully investigated. Patient diary implementation should stem from clearly defined objectives, and include a plan to assess long-term effectiveness. Clear guidelines are necessary to inform patients about diary content and protocol, and also to address numerous ethical and legal issues. Patient diaries should form part of an organised follow-up programme, including a strategy for long-term psychological support.

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Key words: patient diaries, intensive care, implementation.

## TIIVISTELMÄ

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Tutkimuksen tarkoituksena oli tuoda esiin oleellisia näkökohtia, jotka liittyvät teho-osaston potilaille aiottujen päiväkirjojen käyttöönottoon. Tavoitteena oli tuottaa Pirkanmaan sairaanhoitopiirille ehdotuksia koskien rakennetta, sisältöä, toimintaohjeita, eettisiä ja oikeudellisia näkökohtia, myönteisiä ja/tai kielteisiä vaikutuksia sekä jälkiseurantaa ja arviointia.

Kirjallisuuskatsausmetodi käytettiin analysoimaan tämänhetkistä aiheeseen liittyvää tieteellistä kirjallisuutta. Yhdeksän artikkelia täytti valintakriteerin, ja ne otettiin sittemmin kriittiseen luotettavuusarviointiin. Tulokset nostivat esille eri näkökulmia päiväkirjojen käyttöönottoon ja paljastivat aiheen moninaisen luonteen.

Loppupäätelmänä on, että aiotut potilaspäiväkirjat saattavat olla hyödyllisiä edistämään tehohoitoapotilaiden henkistä toipumista. Kuitenkaan mahdollisia negatiivisia vaikutuksia ei ole kattavasti tutkittu. Potilaspäiväkirjojen käyttöönoton tulisi lähteä selvästi määritellystä kysymyksenasettelusta, ja sen pitäisi sisältää myös suunnitelma pitkän aikavälin seurannasta. Selkeät ohjeistukset ovat välttämättömiä selventämään päiväkirjan sisältöä ja toimintaperiaatetta sekä lisäksi huomioimaan monia eettisiä ja oikeudellisia kysymyksiä. Potilaspäiväkirjojen tulisi olla osana organisoitua seurantaohjelmaa, mikä sisältää myös toimintamallin pitkän aikavälin henkiselle tuelle.

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**GLOSSARY**

ICU	Intensive care unit
PTSD	Post traumatic stress disorder
PSHP	Pirkanmaa Hospital District
CINAHL	Cumulative Index to Nursing and Allied Health Literature

## 1 INTRODUCTION

Due to advances in critical care, many patients whose medical condition would have previously resulted in death are now able to survive critical illness events (Rattray & Hull 2008, 2). It is now widely recognised that patients can develop psychological problems resulting from critical illness and intensive care unit (ICU) therapy (Strahan, McCormick, Uprichard, Nixon & Lavery 2003, 49; Gjengedal, Storli, Holme & Eskerud 2010, 176; Egerod, Storli & Åkerman 2011, 235). Many critical care survivors report that they have experienced hallucinations, nightmares and anxiety whilst in intensive care. Problems also include memory gaps, and delusional memories, which have been associated with the symptoms of post-traumatic stress disorder (PTSD) (Kiekkas, Theodorakopoulou, Spyrtos & Baltopoulos 2010, 288). Understanding of the consequences of intensive care is improving, but physical problems still take precedence over the psychological care that many patients require (Rattray & Hull 2008, 2).

In recent years, patient diaries have been introduced to help fill in the memory gaps, give a narrative to the patient's experience, and generally help patients psychologically after intensive care (Egerod et al. 2011, 235). Prospective patient diaries were first introduced in Scandinavia in the 1990's, and their use has since spread to the rest of Europe and around the world (Jones, Knowles & Tarrier 2009, 155). Diaries are kept on the patient's behalf by nurses and the patient's family during critical care, helping the patient come to terms with their illness after hospital discharge (Egerod et al. 2011, 243). Diaries can help to fill in memory gaps, and give meaning to the patient's strange experiences (Gjengedal et al. 2010, 182).

Although diaries are widely recognised as being beneficial to critical illness survivors, Phillips (2011, 42) highlights that their introduction has often been on an impromptu basis by individual intensive care units, with no generalised guidelines or structure in place. This lack of protocol has motivated the author to investigate this topic for this Bachelor's thesis. The author will research and consolidate the existing body of knowledge on prospective patient diaries, highlight the main areas concerning the implementation of diaries, and make suggestions how the Pirkanmaa Hospital District (PSHP) intensive care unit can effectively use patient diaries.

## **2 THEORETICAL STARTING POINTS**

It is necessary to clearly specify the central concepts of the study area. The following section defines the key terms, to provide the reader with a clear understanding of the fundamental concepts of this thesis.

### **2.1 CRITICAL CARE PATIENTS**

Patients are admitted to an intensive care unit when they have a life threatening illness. Critical care can last for days or weeks, patients often requiring support with breathing, circulatory problems and kidney function. The majority of intensive care admissions are urgent, often resulting from emergency surgery, multiple trauma, cardiac arrest, or following severe infections. (Jones, Griffiths & Humphris 2010, 79.)

For many critical care patients mechanical ventilation is required, involving the administration of sedatives and analgesic drugs (Jones et al. 2010, 80). Therapeutic drugs, including opiates and sedatives used in critical care can cause memory problems (Samuelson & Corrigan 2009, 83). Patients recovering from critical care often report problems recalling memories of their time in intensive care (Kiekkas et al. 2010, 288). Up to 50% of critical care survivors cannot remember their admission to hospital (Jones 2009, 3).

### **2.2 CONSEQUENCES OF CRITICAL CARE**

Many patients who survive critical illness go on to face both physical and psychological challenges after their experience in intensive care (Strahan et al. 2003, 54; Kelly & McKinley 2010, 691). The psychological effects of critical care are thought to be a result of multiple stress factors. The illness and/or physical injury combined with fear and pain are key stressors, along with unanticipated hospitalisation and facing mortality (Kelly & McKinley 2010, 691).

More recently, there has been a move towards the use of lighter sedation levels during artificial ventilation. This has led to patients having more memories of their time in



intensive care (Samuelson & Corrigan 2009, 261). Strahan et al. (2003, 54) suggests a correlation between patient sedation levels and difficulty in distinguishing memories of the ICU with hallucinations, delusions, and nightmares. Delusional memories are associated with PTSD related symptoms (Kiekkas et al. 2010, 288). Post traumatic stress disorder is a state of intense sustained anxiety which can impair daily functioning, and it is often a result of a traumatic event, where the individual experiences loss of control in a stressful or threatening situation (Clotey & Dillard 2013, 23).

It is not only the patient but also the relatives who may have stressful experiences of intensive care (Samuelson & Corrigan 2009, 262). The effects of critical illness on both patients and relatives have repercussions long after the initial event, including psychological problems (Cutler, Brightmore, Colqhoun, Dunstan & Gay 2003, 116). A significant number of intensive care survivors report that family roles and responsibilities changed, and dependency on others increased after critical illness (Kelly & McKinley 2010, 698). Strahan et al. (2003, 54) suggests that the needs of patients and families post ICU require properly resourced assessment.

### **2.3 PATIENT DIARIES**

Many intensive care patients require help in building an understandable narrative in order to overcome psychological problems after hospital discharge (Williams 2009, 281). Patient diaries can be used as a tool to help patients make sense of their experiences, and construct their own story of their illness (Egerod et al. 2011, 244). Diaries are prospective, which means that they are written while the patient is in the intensive care unit, with the intention that the patient reads it in the future, as opposed to retrospective diaries that are written after the event. (Combe 2005, 33; Hale, Parfitt & Rich 2010, 14; Phillips 2011, 38.) Mostly nurses make entries to the diary, but all healthcare professionals are encouraged to make contributions (Hale et al. 2010, 14). The diary is kept at the patient's bed side, which allows family members and friends to write about their feelings and news from home (Jones 2009, 3).

Typically diaries contain a summary of the time leading up to, and reason for, the patient's admission. This part is usually quite detailed with family members making a valuable contribution at this stage. Family members are informed of the purpose of the

diary and also given an information sheet providing basic guidelines of what to write in the diaries. (Jones 2009, 3.) A number of intensive care units choose to include a visual record of the patient's progress (Jones 2009, 3; Hale et al. 2010, 17). A photograph is taken at the beginning, and others at key stages throughout the treatment process. Photographs are regarded as confidential, stored separately, and only added to the diary on completion. (Jones 2009, 3.)

After intensive care discharge, the patients are asked, as part of their follow-up care, if they wish to read the diary. A consent form is signed, giving permission for the photographs, and a nurse is present to give emotional support the first time the diary is read. (Jones 2009, 3; Hale et al. 2010, 17.) Offering patients a coherent description of their critical illness can have a profound impact on a patient's psychological wellbeing after discharge (Jones et al. 2009, 156).

## **2.4 IMPLEMENTATION OF PATIENT DIARIES**

Over the past two decades, patient diaries have developed slowly, mainly being introduced on an idiosyncratic basis by individual intensive care units (Egerod, Schwartz-Nielsen, Hansen & Lærkner 2006, 165). Follow-up services including patient diaries have been developed to improve the recovery of patients discharged from the ICU (Samuelson & Corrigan 2009, 262).

Organisation varies between departments and the methods used are often disparate (Åkerman, Granberg-Axéll, Ersson, Fridlund & Bergbom 2010, 32; Phillips 2011, 42). The main factor that restricts intensive care unit follow-up seems to be financial constraints (Griffiths, Barber, Cuthbertson & Young 2006, 952). However, Samuelson and Corrigan (2009, 261) propose that after care follow-up including patient diaries can be implemented with comparatively modest resources.

In a study of Swedish intensive care units, Åkerman et al. (2010, 32) shows significant differences between departments in both the selection of patients and the structure of the diary. Egerod et al. (2006, 166) argues the importance of patient diaries being implemented with a clear plan for assessing their positive and negative effects. The legal issues surrounding patient diaries are very ambiguous; there are implications for,

amongst other things, ownership, content, handling, storage, and the use of photographs (Egerod et al. 2006, 165). Further research is needed to ensure adequate content, grant structure, and develop a system of evaluation and quality control (Åkerman et al. 2010, 32).

### **3 PURPOSE, OBJECTIVES, AND OUTCOMES**

The aim of this study is to perform a review of the current scientific literature relating to the topic of using patient diaries for intensive care patients. The study highlights the relevant issues that need to be considered in order to make the most effective use of diaries.

The author investigates the relevant issues, with the objective of providing suggestions associated with the implementation of prospective patient diaries. Attention is given to ensure relevance to the specific needs of the PSHP intensive care unit.

Successfully implemented patient diaries have the potential to benefit the psychological and emotional wellbeing of PSHP intensive care survivors. Further potential beneficiaries are the nurses who fill out the diaries, and the relatives of the critically ill. (Combe 2005, 34; Hale et al. 2010, 17; Jones, Bäckman & Griffiths 2012, 172.)

The study investigates how the Pirkanmaa Hospital District intensive care unit can most effectively use patient diaries by addressing the following questions;

- How to develop an appropriate structure, content, and protocol?
- What are the ethical and legal issues pertinent to patient diaries?
- Are there potential benefits and/or negative effects of implementation?
- What is the value of follow-up care, assessment, and quality control?

## 4 METHODS

This Bachelor's thesis uses the literature review method. This approach has been chosen as the most appropriate way of gathering, analysing, and reviewing the current scientific evidence-based knowledge relating to ICU patient diaries. Doing an extensive literature review can highlight gaps in current knowledge, draw attention to disparity between the evidence, and aid in interpreting the data findings (Polit & Beck 2012, 95).

A preliminary search was undertaken using the Cumulative Index to Nursing and Allied Health Literature database (CINAHL), applying the key terms; intensive care, ICU, critical care, patient diary/diaries, follow-up, and PTSD. The initial search produced 193 articles which were subsequently subjected to the first screening process. Articles that were not directly linked to patient diaries, intensive care follow-up, or patients' psychological wellbeing following ICU were eliminated. From the initial search, 28 relevant articles were found.

As suggested by Polit and Beck (2012, 96, 98), it is important to maintain a flexible approach to the data collection process and focus on the most relevant and important themes as they arise. With this in mind, the research process was developed further by using the ancestry approach to locate additional source materials and by obtaining relevant articles directly from the original author. (Polit & Beck 2012, 96, 98.) Eleven additional articles were sourced.

A second phase of screening was then undertaken, whereby the inclusion criteria required that the articles be empirical, peer reviewed, and that the contents of the research was likely to contain information applicable to the research questions. Due to the relative recentness of the topic, no age restrictions were imposed on the research. Articles were excluded if they were not in English, or if they were literature reviews. Literature reviews were eliminated, because, as recommended by Polit and Beck (2012, 95), it is important to access the primary sources of information.

After the second phase of screening, nine articles were available for review. The search and screening process is outlined in figure 1.

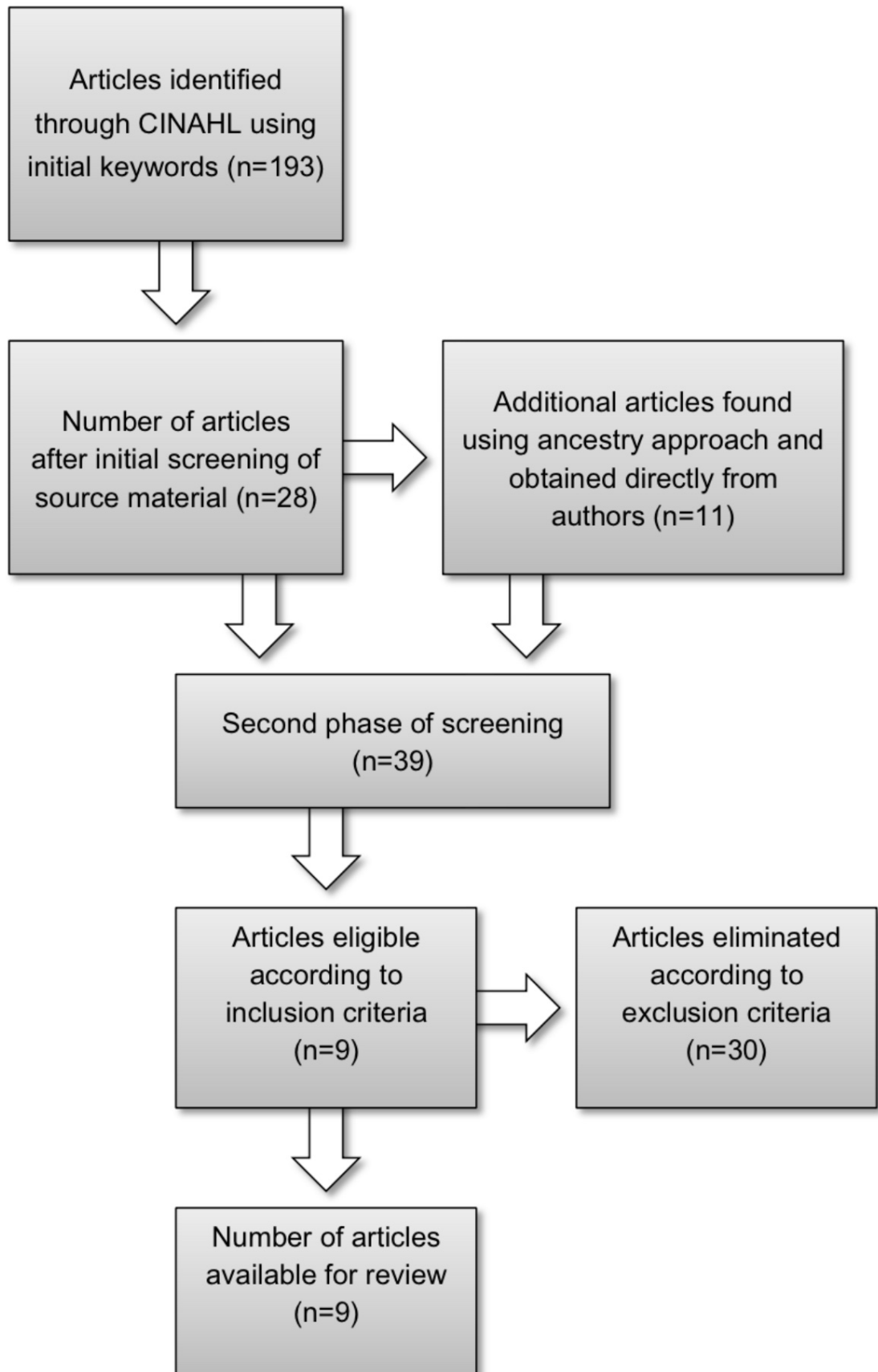


FIGURE 1. Search and screening process

Table 1 outlines the types of study included in the review, highlights the different methods used to obtain data, and summarises the main focus of the research.

TABLE 1. Studies included in the literature review

Type of study	Author, year, country	Method	Main focus
Survey.	Gjengedal et al. 2010, Norway	Telephone interviews	Diaries in Scandinavian intensive care units.
	Egerod et al. 2006, Denmark		
	Åkerman et al 2010, Sweden		
Interview. Qualitative.	Engström et al. 2008, Sweden	Interview at 12 months	Patients' response to diaries.
	Storli & Lind 2009, Norway	Interview at 6 months and 18 months	Patients' perspective of follow-up care.
Evaluation.	Samuelson & Corrigan 2009, Sweden	Questionnaire	Diaries used in follow-up care.
Description	Hale et al. 2010, UK	Descriptive	Description of diary use.
	Jones 2009, UK	Descriptive	Description of diary implementation.
Randomised control trial.	Jones et al. 2010, UK	Assessment at 3 months	Can diaries reduce PTSD post ICU?

Polit and Beck (2012, 111) suggest that when making a literature review, it is not only important to report factual information, but also to evaluate the reliability of the evidence provided. The quality and reliability of the articles under review should be assessed in order to establish if the results are believable and reflect the truth. A distinction is made between a thorough critique, and a critical appraisal as part of a literature review. Whilst thorough critiques are used to comprehensively evaluate individual articles, the purpose of critical appraisal as part of a literature review is to assess the quality of a body of evidence. (Polit & Beck 2012, 111, 118.)

The nine articles under review were assessed using a critical appraisal tool adapted from Polit and Beck (2012, 112-118). The critical appraisal tool is shown in Appendix 1. Changes were made to the original critical appraisal tool presented by Polit and Beck (2014, 112-118), because it was not the intent of the author to comprehensively review

the individual articles, but to assess their overall reliability. The major strengths and weaknesses of the studies are highlighted in an evaluation matrix shown in Appendix 2. For the purpose of this study, the critical appraisal process was not used as a method of screening the articles, but rather to establish the quality of the body of evidence. In this manner, the articles under review accurately reflect the current knowledge available on the subject.



## **5 RESULTS**

This section of the thesis contains a review of the nine articles under investigation. The purpose is to outline the common themes, and also highlight differences and contradictions between the studies. The results have been organised into sections according to the four themes outlined in the mind map of the main themes presented in Appendix 3. The four sections reflect the research questions outlined in section 3. A summary of the information provided in each section is provided in Appendix 4 in the form of thematic matrices.

### **5.1 CONTENT, STRUCTURE, AND PROTOCOL**

#### **5.1.1 Diary content**

In the survey conducted by Gjengedal et al. (2010, 179), the participants indicated that patient diary content should be personal and easily understood, but that the text should not be private. Medical terms were avoided or explained in easier language. Some participants took an objective approach, constructing a descriptive text, and focusing on the environment to base the patient in reality. Others focused their text on what the patient might be thinking, or what the situation may mean to the patient. The study indicates that a mixture of both these approaches is necessary to enable reflection at a later date. (Gjengedal et al. 2010, 178-182.)

Gjengedal et al. (2010, 181) also suggest that the content of diaries can help the recovering patient fill gaps in their memory, and determine which memories are based in reality. Descriptions of the ICU environment were indicated as not only being of importance to the patients, but also to family members. The survey highlights that nurses should pay particular attention to the content of diaries because of the potential risks of causing offence. The study also points out that the content of patient diaries was not only made up of contributions from nursing staff and relatives. Attempts made by the patient to communicate on paper, while unable to speak, were added to the diaries in some departments. (Gjengedal et al. 2010, 178-182.)

In the descriptive study conducted by Hale et al. (2010, 16), emphasis is placed on the importance of contributions from the complete multidisciplinary team, as well as family members and friends. It is indicated that providing a complete narrative of the patient's ICU experience is important, and is therefore suggested that entries should be made to the diary at least once a day. Particular attention is brought to the final entry of the diary when the patient is discharged from the ICU. It is highlighted as a symbolic moment, which should be regarded as a positive step on the patient's journey of continuing rehabilitation. (Hale et al. 2010, 16,17.)

In the survey conducted by Åkerman et al. (2010, 30), most of the ICUs made daily entries to the diaries, with some contributing every shift. The content is described as patient focused, giving a description of the patients' care, and commenting on significant events and changes in status. Some departments focused more generally on the patients and their environment, whereas others included more medical information, such as procedures and test results. The study emphasises that the diary language should be easy to understand and that medical slang should be avoided. The findings also reveal that it was most common for only nurses to write in the diaries, although a small number of departments engaged doctors as diary contributors. Relatives were also largely encouraged to participate, and in a few departments, diaries were started by nursing staff and then handed over to family members for them to continue. (Åkerman et al. 2010, 30.)

In a study into the patient's response to ICU diaries, Engtsröm et al. (2008, 63) indicate that the entries written by family members were regarded as the most important to patients. Relatives wrote in a more personal way about their experiences, whereas nurses focused more on medical treatment and procedures. The study highlights the importance of the content being personal, easily understood, and having a human touch. (Engtsröm et al. 2008, 63, 64.) The content of patient diaries is described by Jones et al. (2010, 2) as an easy to read account of the patients' day to day ICU stay, using photographs as a visual accompaniment.

In a survey of Scandinavian ICUs by Egerod et al. (2006, 164), half of the units studied had some form of guidelines on the language style to be used in the diaries. The language was kept in the second person, and the tone was professional. The study points out the difficulty in maintaining a caring tone without sounding patronising. The

participants emphasised that the diary content should differ from official documentation. Most departments tried to avoid an overlap of information between the diaries and the official medical records. However, it is highlighted that a strict separation of medical treatment and diary narrative was at times difficult to achieve. A few units restricted the writing to only the nurses, whereas most encouraged participation from family and friends also. The study highlights a minority of departments that used two diaries, one for nurses, and one for relatives. None of the participants of the study assisted the patient themselves to write in the diary. However, the study briefly examines the future of patient diaries, exploring the idea that diaries would evolve during the patient's illness. A diary started by nurses while the patient is unconscious may be continued by the patient him/herself as his/her condition improves. (Egerod et al. 2006, 162-166.)

Storli and Lind (2009, 45-55) investigate the patients' perspective of ICU follow-up care. The study outlines the diary being used as the basis for dialogue during the follow-up clinic. The nurse writes open questions, addressed to the patient, in order to initiate the reflection process at a later date. Entries were not necessarily made on a daily basis, and often it was left to the discretion of the nurse to decide what would be potentially most meaningful to the patient. The style of the text is described as a dialogue between the nurse and the patient. The nurse attempts to construct a story while addressing the patient directly, even if he/she is unconscious. Photographs are used to support the text. (Storli & Lind 2009, 47, 49, 50.)

Jones' description of diary implementation (2009, 3) indicates that the whole multidisciplinary team may contribute to the diary. Physiotherapists can, for example, illustrate the progress of the patient. The aim is that an entry is made to the diary daily, even if it is just to indicate that the patient's status is unchanged. The patients' relatives are encouraged to write about their own feelings and emotions, as well as events from home that the patient has missed due to being in hospital. (Jones 2009, 3.)

Samuelson and Corrigan (2009, 256) characterise the content of patient diaries as a description of the patients' day-to-day experience of the ICU. Everyday language is preferred, using no abbreviations or jargon. (Samuelson & Corrigan 2009, 256.)

### 5.1.2 Diary format

Egerod et al. (2006, 162) noted in their study of Scandinavian ICUs that most of the participants used an A5 format and had some form of standardised structure, for example, using a pre-printed introduction explaining the diary. Other participants used an A4 size, while many had no standard format. It was common for diaries to include some form of explanation or pictures of the standard ICU equipment. It is also highlighted that the choice of cover for the diary varied greatly between departments; some chose a picture of the hospital, or a generic picture of an ICU patient. Other participants chose inspirational colours and images such as flowers in an attempt to encourage hope. Not all departments put so much thought into the symbolism of the covers and simply used unmarked generic notebooks. Two of the units encouraged participation from the relatives in deciding the appearance of the diary. The research goes on to point out that some ICUs stored the diary in the nurses' office, whereas others opted to keep it at the patient's bed side. The study reports that there was an assumption that no unauthorised people would read the diary. The third option was to store the diary as part of the patient's medical notes. The study points out that the unresolved legal status of patient diaries has an effect on not only their content, but also how they are handled and stored. (Egerod et al. 2006, 162-165.)

In Hale et al. (2010, 16), the diary team made the decision to use A4 bound notebooks, and encouraged entries from nurses, relatives, and members of the multidisciplinary team. The completed diaries were photocopied, transferred on to disc, and stored with the patients' official medical records. Unwanted original diary versions were destroyed after two years. (Hale et al. 2010, 16,17.)

Gjengedal et al. (2010, 179) highlight that there are varying practices regarding protocols, content, and how the diaries are handed over to the patient. Most of the participants used a loose-leaf diary in order for pages to be removed and rewritten. All of the departments paid attention to the appearance of the cover, and attempted to add symbolism with the use of pictures or poems. Most diaries contained an introduction which provided information about the ICU and the purpose of the diary. A summary of the patient's story was often included at the beginning and also some form of conclusion. All entries in the diaries were signed and dated by the contributor. The diaries were stored at the bedside, however, some departments locked the diaries away

before being proof-read and handed over to the patient. (Gjengedal et al. 2010, 179, 180.)

Åkerman et al. (2010, 30) report that most of the participants used guidelines regarding the structure of the diaries. An introduction section was intended to provide information as to the diaries' purpose, followed by a short history of how and why the patient came to the ICU. A few departments included pictures and explanations of the most frequently used ICU machines. In most cases, a small A5 notebook was used, with nurses making entries on a daily basis. However, the study highlights that the chosen structure for diaries varied greatly between the participants. Some of the departments chose to have separate sections within the diary for nurses and for family members. In nearly all cases the diary was kept at the patient's bedside. (Åkerman et al. 2010, 30.)

Jones (2009, 2) also says that the diary was stored at the patient's bedside. However, any photographs were kept in a locked cabinet and added to the diary upon completion. For the diary itself, a small notebook was used, which has a plastic cover to protect it and to facilitate wiping it clean. (Jones 2009, 2, 3.)

### **5.1.3 Criteria for including or excluding patients from the diary scheme**

Gjengedal et al. (2010, 178) state that criteria for inclusion or exclusion from the diary scheme varied across all the departments in the study. Two thirds of the departments excluded patients who were not ventilated. Some participants estimated the expected ventilator time, and started a diary if it was anticipated that the patient would be ventilated for more than three days. Others based their decision on the patient's chances of survival. Another approach was for the nurse to judge if the patient would benefit from having a diary. Some based their decision on a combination of all these factors. Writing patient diaries was not compulsory for any of the participants. The study implies that not all patients eligible for a diary actually received one. (Gjengedal et al. 2010, 178.)

Åkerman et al. (2010, 30) highlight some inconsistencies in how patients were selected for inclusion in the diary scheme. However, generally there was a pre-designed target group of eligible patients. The study found that the ICUs which had a follow-up clinic

were more systematic in their decisions to include or exclude patients from the diary system. The median time to initiate a diary was three days; however, it sometimes took longer, and occasionally eligible patients did not receive a diary at all. (Åkerman et al. 2010, 30-32.)

Egerod et al. (2006, 162) also note that inclusion criteria varied greatly between departments. Generally the main criteria were that patients be ventilated and sedated. The decision to start a patient diary was inconsistent. Mostly it was not based on designed criteria; often the decision was made by the patient's own nurse. It is suggested that the decisions were based more on the individual's intuition rather than protocol. One unit chose to only start diaries for unconscious patients, while another excluded patients who were mentally challenged. There were also differences in the time it took to initiate the diaries. The study shows a variation from three days up to two weeks. (Egerod et al. 2006, 162, 164.)

Research into the effect of diaries on post traumatic stress disorder by Jones et al. (2010, 8) highlights that according to the UK national guidelines, the treatment of PTSD should be aimed specifically at high risk groups rather than blanket approaches. It is implied that only ICU patients exhibiting high levels of symptoms would be included in the diary scheme. However, the study suggests that all patients who are in the ICU longer than 48 hours should have a diary. (Jones et al. 2010, 8.) The criteria for inclusion into the diary system outlined in Hale et al. (2010, 16) are patients aged over 16 years who have been ventilated and sedated for 48hrs and likely to have a prolonged ICU stay.

#### **5.1.4 Photos**

Gjengedal et al. (2010, 179) report that the motivation for including photographs in patient diaries is to demonstrate progress. The focus is not on the patient's face but more on the big picture, the patient in the ICU setting, surrounded by the ventilator and other equipment. The study highlights the importance of protecting the patient's dignity, stating that a fine line exists between frankness and causing offense. There is an assertion that obtaining retrospective consent for photos is ethically justifiable. However, the choice of pictures is of great significance, nurses must demonstrate

wisdom and use good clinical judgment. The authors also argue that the participants showed respect for the patients in considering which photographs should be included in the diary. (Gjengedal et al. 2010, 179, 180, 182.)

Hale et al. (2010, 17) claims that including photographs in diaries can enlighten the patient to the severity of his/her illness and clarify why the recovery process takes so long. Engström, Grip and Hamren (2008, 64) report that discharged patients expressed that the photographs provided proof of their ordeal, even though looking at them was not easy and felt unreal.

Åkerman et al. (2010, 30) report that of 43 ICUs studied, 63% took photographs of the patient. The objective was to take photographs daily, but this was rarely achieved. No consensus existed over what type of photograph should be taken. Some units asserted that patients who had lost body parts or been badly injured, would be helped in recovery by photos taken during their treatment. Others never took photos if the patient's appearance had changed, for example by a swollen face. (Åkerman et al. 2010, 30, 31.)

Egerod et al. (2006, 162) found that photographs of some of the ICU machines were sometimes included with brief explanations. The study highlights that photographing the patient raises both legal and ethical issues. Some units overcame potential problems by including a generic ventilated patient picture. Other units took photos, and then obtained consent when the patient regained consciousness. A few departments encouraged the relatives to take pictures. The legal stance regarding photography varied throughout the participants, one lawyer stating that the patient has the right to take legal action against those obtaining photos without consent. (Egerod et al. 2006, 162, 164.)

Storli and Lind (2009, 49) state that the use of photographs can potentially positively serve the patient in two ways. First, by providing a link between memories of bodily sensations and the physical reasons, for instance an endotracheal tube or a constrictive face mask. Secondly, photographs also provide a record of progress made in recovery, a realisation of how bad their situation was, and how much they have recovered. However, the study also highlights the possible negative impact in the potential to be offensive, gruesome or undignified. Some participants assert that there are certain things a patient should not see. (Storli & Lind 2009, 49, 50, 53.)

Jones (2009, 3) reveals that initially the patient's family was asked for permission to take photos until discharged patients complained that relatives had made the wrong decisions. It is also highlighted that the preconception existed that burns patients would not want pictures taken, when in fact, they were eager to see a record of the progress made. Now patients decide on discharge if they want the photos. (Jones 2009, 3.)

Jones (2009, 3) goes on to report that a photo was taken on admission, then again as the patient's condition changed, and at significant events. Photos are stored separate to the diary in a locked cupboard. A space was left in the diary where the photo may be inserted later. When the patient received the diary they signed a consent form for both the diary and the photographs. Bereaved families may receive the diary but not the photographs. (Jones 2009, 3.)

Samuelson and Corrigan (2009, 257) state that photographs of the patient were taken only after their relatives were informed. The report also suggests that this was done despite the fact that formal consent was not required. (Samuelson & Corrigan 2009, 257.)

### **5.1.5 Instructions and guidelines**

Jones' description of patient diaries (2009, 3) states that guidelines are kept with the diary at the patient's bed space. The patient's relatives are given information about the purpose of the diary, and also a guidance sheet to give an idea of how they should write in the diary. (Jones 2009, 3.) In later research, Jones et al. (2010, 2) contend that guidelines for the diaries given to the participants ensured consistency.

Hale et al. (2010, 16) report that guidelines were given to the patient's relatives explaining what should, and should not, be written in the diaries. Family members were urged to write positive things, and discouraged from using the diary as a means of communicating complaints. The instructions also encouraged the inclusion of drawing and cards. A marker was placed at the bedside to serve as a reminder that the patient has a diary in progress. Further, diaries were used as part of the daily ward round discussion. (Hale et al. 2010, 16, 18.)



Gjengedal et al. (2010, 180) claim that all participants in the study expressed the view that national guidelines are required. The guidelines varied between the participants from extremely detailed to just covering a few main concepts. The study argues that funding should be directed towards producing national guidelines in order to improve the quality of diary writing. (Gjengedal et al. 2010, 178, 180, 182.) Samuelson and Corrigan (2009, 261) argue that a tool for evaluating the effectiveness of follow-up programmes is required, along with the development of national guidelines.

Åkerman et al. (2010, 31) contend that there is a difference between the stated purpose of patient diaries, and the plan instigated for how the purpose is to be achieved. Some had written a purpose statement, whereas others had not. The study also argues that there were varying degrees to which the implementation was based on literature, stating that there were no general or national guidelines, or that guidelines were unclear. The authors also assert that there is a lack of scientific research into using diaries as part of a follow-up programme. Further, there are difficulties in meeting the patient's rehabilitation needs appropriately as part of the follow-up care because of an absence of guidelines regarding diary content and structure. (Åkerman et al. 2010, 30-32.)

According to Egerod et al. (2006, 161), the majority of participants had goals set for the patient diaries. However, only five of the 19 departments had a written statement. Five participants had no such purpose or statement at all, and none of the departments had implemented diaries as part of development or research. The study suggests that diaries were introduced with no clear guidelines or plan to assess their effect. The absence of published, peer-reviewed literature in the introduction of patient diaries is also highlighted as a concern. (Egerod et al. 2006, 161, 162, 166.)

#### **5.1.6 Attitudes towards diary implementation**

The general attitude of nursing staff towards the introduction of patient diaries appears to be positive according to Egerod et al. (2006, 162). Nurses who were initially skeptical testified that positive feedback from patients and relatives facilitated a change in attitude (Gjengedal et al. 2010, 180). Others expressed a sense of pride in diary writing as it made evident their tacit knowledge and caring practice (Egerod et al. 2006, 163).

Jones (2009, 2) indicates that nurses at the patients' bedside are in the best position to write a diary on their behalf. However, she goes on to state that compelling nurses to do so would be counterproductive. (Jones 2009, 2.) Egerod et al. (2006, 162) reveal that in some units where nurses were not enthusiastic about diary implementation, the process was left optional. Further, the research reveals that the medical staff was rarely involved in the diary writing process (Egerod et al. 2006, 163).

Jones et al. (2010, 2) indicate that the work involved in writing diaries amounts to just a few minutes per day. The introduction section can take longer, explaining why the patient came to the ICU, but the day-to-day work requirement is described as minimal. (Jones et al. 2010, 2.) However, Åkerman et al (2010, 31) state that one of the main reasons given for negative attitudes towards the diaries was the perceived increase in work for the staff. Nurses felt that diaries would add to an already overwhelming amount of paperwork, and others expressed concerns that it would add to the general nursing workload. (Åkerman et al 2010, 31.)

Objections to an increased workload were not the only concerns highlighted in the articles. Hale et al. (2010, 18) highlights that some nurses were worried that uncertainties about the legal aspects of the diaries may leave them vulnerable to legal challenges. Åkerman et al. (2010, 31) attribute negative attitudes towards diaries to a lack of adequate guidelines about the content. Nurses also expressed the opinion that writing about the patient's care and procedures in layman's terms was a challenge (Hale et al. 2010, 18). Others expressed difficulty in writing on behalf of somebody who is unconscious, suggesting that it requires experience and a special connection with the patient (Åkerman et al. 2010, 30).

Åkerman et al. (2010, 31) further suggest that enthusiasm for diaries and successful implementation is reliant on adequate staff education. Teaching programs included teaching boards, pamphlets, and mock diaries. Feedback from diary meetings and staff education are highlighted as crucial approaches to increase enthusiasm amongst staff members. (Åkerman et al. 2010, 31.)

### **5.1.7 Quality control**

Gjengedal et al. (2010, 178) discovered that most units had a diary team whose responsibilities included motivating staff to the use of diaries, staff training, and quality control. The diary team checked the quality of each diary before it was given to the patient. Sometimes a re-write of the original text was required. Some other units, however, had no quality control in place. The report suggests that malpractices may be prevented by ensuring good leadership and by providing clear guidelines. The need for a systematic follow-up programme is also highlighted. (Gjengedal et al. 2010, 178-182.)

Åkerman et al. (2010, 30) state that 70% of the units in the study had a dedicated team responsible for the administration of diaries, feedback, and follow-up groups. They were also responsible for introducing the use of diaries to other nurses. (Åkerman et al. 2010, 30.) Jones et al. (2010, 2) report that all participants had a specific diary group responsible for overseeing the diaries, and writing the introduction. Storli and Lind (2009, 47) point out that the diaries were proof-read before being handed over to the patient.

Jones (2009, 3) describes that the patients are contacted after discharge, either by telephone or face to face if they are still on the general wards. They are asked if they would like to see their diary. If they are not ready, the diary is stored and the patients are asked about it again when they attend the follow-up in the outpatient clinic. If they still do not want the diary, it is then stored for a further year, unless the patient asks for it to be destroyed. (Jones 2009, 3.)

## **5.2 ETHICAL AND LEGAL ISSUES**

### **5.2.1 Legal ownership**

Åkerman et al. (2010, 30) reveal that diaries were regarded as the patients' property. No formal permission was sought even though the hospital lawyers gave conflicting advice about the legal status of the diary. (Åkerman et al. 2010, 30.) The research of Samuelson and Corrigan (2009, 257) and Gjengedal et al. (2010, 180) also state that a decision was made that the diaries and photographs were not part of the official hospital records, but were the property of the patient.

Egerod et al (2006, 163) note that the participants sought advice from attorneys but received varying guidance. Diaries authored by nurses are regarded as legal hospital documents (in accordance with the patients' bill of rights), whereas when authored by the relatives, they are regarded as private journals. The status of the diary was described as ambiguous, since it is not a formal medical record, but yet it is more than a private journal. Diaries co-authored by both relatives and nurses gathered conflicting legal views and were both accepted and rejected. Most units adopted the view that the diary was the patient's own property. (Egerod et al 2006, 163.)

Jones' descriptive study (2009, 2) also states that advice was requested from the hospital's legal department. Patients were asked to sign a consent form retrospectively for the photographs taken, and to transfer the care of the diary into their ownership. Photocopies of the diaries were filed in the medical notes. It is also noted that bereaved families are also allowed to receive the diary. (Jones 2009, 2, 3.)

### **5.2.2 Decisions and assumptions made on the patient's behalf**

All the articles under investigation reveal that the ethical issues relating to patient diaries are numerous. The research on the topic highlighted particular ethical complexity in situations where healthcare staff and relatives find themselves in a position of making decisions based on assumptions on behalf of the patient. Gjengedal et al. (2010, 178), for example, reveal that the decision of which patients should receive diaries was based on whether the nurses thought the patient would benefit. Examples are given of nurses choosing not to start diaries for patients with severe cerebral damage, dementia, or mental retardation, based on their own judgment. (Gjengedal et al. 2010, 178.) In addition, Åkerman et al. (2010, 30) found that diaries were assumed to be the property of the patient, even though their legal status was unresolved.

Egerod et al. (2006, 162) state that most of the participants had no formal criteria regarding the decision to start patient diaries, but often the decision was left to the patient's nurse. Some asked permission from relatives, and others did not. Nurses started diaries at their own discretion, and the decision whether or not to take photos was also left to the nurses' initiative. Some nurses put thought into the cover of the diary in an attempt to create a mood or add symbolism. Others used plain notebooks,

and some involved the relatives to participate in decisions about the look and format of the diaries. None of the units encouraged the patients to participate in their own diaries; the reasons given were that even if the patients were awake, they could not focus properly or that their handwriting would be too shaky. The nurses viewed the patients as incapable of writing their own diaries and viewed the patients as sedated, passive and bedridden, whereas the study proposes that many ICU patients are in fact awake, active and able to communicate. The study states that nurses may need to challenge their preconceptions of the ICU patients' capabilities and needs. (Egerod et al. 2006, 162-165.)

Regarding photographs taken of the patient, Storli and Lind (2009, 50) express the view that the patient must be spared from seeing certain potentially disturbing images. The decision of exactly what constitutes a disturbing image is taken by the healthcare professionals on an individual basis. (Storli & Lind 2009, 50, 53.)

Jones' description of diary implementation (2009, 3) reports that originally the patients' family was approached to ask permission for photographs to be taken. This was later revised when retrospectively some patients expressed that their family had made the wrong decision in not allowing photos. Further, initial preconceptions that the ventilated burns patients would not want photographs to be taken were revised when conversations with discharged patients highlighted that they would have liked to have photos from when their burns were at their worst in order to chart their progress. For these reasons, diaries are now started, and photographs taken, with consent only being asked at the point of discharge from the ICU. (Jones 2009, 3.)

### **5.2.3 Confidentiality**

Egerod et al. (2006, 163) state that in order to address the issue of patient confidentiality, some units used two separate diaries for staff and relatives. The study also indicates that although it is considered a basic human right to hold a private diary, if a spouse does not have access to information shared in secret between a nurse and a patient, this may adversely affect a long-term relationship. Further, in some cases, relatives would use the diary as a means of communicating with other family members. One unit draws attention to a situation where the parents chose to publish their child's

ICU diary to the Internet. This not only exposed the patient, but also breached the confidentiality of the nurses' diary entries and signatures. (Egerod et al. 2006, 163-165.)

Hale et al. (2010, 18) highlight the challenge of family dynamics regarding patient diaries. Diversity among families led to questions regarding issues of who is the rightful next of kin. The study noted that where possible the patient decided. (Hale et al. 2010, 18.)

Gjengedal et al. (2010, 178) report that most of the units in the study encouraged relatives to write their own diary, or to write on separate sheets of paper, which could be added at a later date. All the units in the study advised that although the diary language should be personal to the individual patient, it should not be of a private nature. (Gjengedal et al. 2010, 178, 179.) Åkerman et al. (2010, 30) note that some units had separate sections in the diary for nurses and relatives, whereas others did not allow contributions from family members at all. However, Jones (2009, 3) outlines that if relatives felt that their diary entry was too private to share with others, they were encouraged to write on a separate sheet, which was sealed and taped into the diary for the patient to read at a later date.

### **5.3 POSITIVE AND NEGATIVE IMPACT**

#### **5.3.1 Positive impact of diaries**

Jones (2009, 3) claims that patients have reported that diaries give a clearer understanding of their critical illness than what they were able to obtain from the family. Others stated that when there were gaps in their memory, or if their memory was completely absent, the diaries completed the gaps, and were available at any time to re-read. The study acknowledges that reading the diaries can be an emotional process, requiring support, but the general consensus was that they are worthwhile. Further, it is suggested that diaries provide patients with a better understanding of their diagnosis, and tend to be more realistic about their expected recovery times. (Jones 2009, 3, 4.)

Engström et al. (2008, 64) assert that patient diaries gave patients an understanding of what had happened to them physically, helped them to understand how ill they had

been, and also explained why it took so long to recover physically. The study claims that the diary gave a chronological order to events enabling the patient to construct a picture of who was present and what had happened. The findings suggest that despite causing strong feelings, diaries are regarded as an important support long after the ICU stay. (Engström et al. 2008, 64.) According to Åkerman et al. (2010, 30), ninety four percent (n=61) of the participants reported that patients had expressed the opinion that the diary was important.

Storli and Lind (2009, 48) note that some saw the diaries as beyond the level of service and care expected, almost like a gift. Participants described them as a door opener for future care relationships. Despite some patients being anxious about the content, it was suggested that the very act of making the diary signals its good intention. Further, it was not just about filling in the memory gaps, but linking events to experiences and perceptions. It is maintained that diaries can provide a framework for follow-up conversations, and can aid reflection after the ICU experience. (Storli & Lind 2009, 48.)

Jones et al. (2010, 7) argue that a diary given at one month after discharge from the ICU can reduce the incidence of post traumatic stress disorder. It is further claimed that diaries work in a similar way to cognitive behavioural techniques used to treat PTSD. Encouraging the patient to build their own story changes the way they think about their illness. The study reveals that feedback from patients was positive, with many reporting that they read the diary a number of times. (Jones et al. 2010, 7, 9.)

Samuelson and Corrigan (2009, 259) claim that positive feedback, explanations, and support provided by diaries enabled patients to move on. Hale et al. (2010, 18) proposes that providing ICU patients with a follow-up programme means that they remain in the support system after ICU discharge. The study also suggests that diaries encourage more involvement from relatives in the patient's care. (Hale et al. 2010, 18.)

Some of the studies reported patient diaries also having a positive impact on relatives. Samuelson and Corrigan (2009, 262) claim that a thorough follow-up programme helps both patients and relatives to move on, while Jones et al. (2010, 7) propose that relatives may suffer from post traumatic stress disorder. In this scenario, diaries may help to make the story of events clearer, and also open up the channels of communication between relatives and the patient. (Jones et al. 2010, 7.) Egerod et al. (2006, 164) note

that an unexpected positive outcome of patient diaries was in clarifying misunderstandings between relatives and patients.

Hale et al. (2010, 17) suggest that in the event of a patient dying, the final diary entry can be of particular importance to relatives by providing an account of the final stages. Jones (2009, 4) also maintains that diaries can help bereaved family members to accept what has happened. It is suggested that relatives are given a deeper understanding of the process their loved ones have gone through. (Jones 2009, 4.)

A further dimension outlined in the studies was the potential positive impact of diaries on nurses. According to Åkerman et al. (2010, 30), hospital staff can use the diaries to develop their patient care. Fifty percent of the ICUs in the study expressed that nursing practices could be changed as a result of patient diaries. Egerod et al. (2006, 166) suggest that there are benefits to hospital staff from patient diaries. Hale et al. (2010, 17) report the potential positive impact that when a patient dies, the final entry can assist the nursing staff by giving them the chance to reflect and receive closure.

Gjengedal et al. (2010, 180) state that positive feedback from patients about diaries improves enthusiasm amongst nurses to write them in the future. The report highlights several ICUs which stated that patient care might be improved through diaries increasing the nurses' perceptions of the patient's expressions. Some participants noted a change in their focus, from solely medical to more human. Further, conversation between the nurse and the patient might help clarify a diary event for both the patient and the nurse. The report also suggests that the feedback from patients gave nurses more understanding of what would be important to write about. The diary writing process keeps the nurses continuously aware that the patient is a person, and encourages the nurse to wonder how an event is perceived by the patient. Participants described a shift in their focus to see the patient as a human being. (Gjengedal et al. 2010, 180, 182.)

### **5.3.2 Negative impact of diaries**

According to Åkerman et al. (2010, 31), some ICUs reported unwillingness from the patient to relive the time spent in critical care. Further, the effects that the diary has on the patient have not been fully studied and warrant further investigation. The report



implies that although there is a strong belief that diaries have a positive impact, there is very little data to support this assumption. (Åkerman et al. 2010, 31.) Storli and Lind (2009, 53) maintain that reading text about your own experience may be painful.

Egerod et al. (2006, 164) highlight that reliving their illness through reading the diary can leave some patients traumatised. Additionally, some nurses relied on the patient's relatives to make decisions on how the diary should be used. The ethics of this was not taken into account. The findings suggest that there is a risk that the formal hospital documentation may lack the information about caring practices and patient perceptions if this type of data is only documented in the patient diaries. If the diary leaves the hospital with the patient, then this aspect of the documentation will be lost from the patient's official records. It may be unclear to nurses where to write which information. Further, in cases where relatives may not participate in the diary process, the diary becomes a private document between a nurse and a patient, and a spouse may feel excluded at a time when family bonds are of great importance. (Egerod et al. 2006, 164-166.)

## **5.4 FOLLOW-UP AND ASSESSMENT**

### **5.4.1 Diary handover**

According to Hale et al. (2010, 17), the follow-up programme consists of the patient being invited back to the department four weeks after discharge, at which point the diary is handed over. The patient meets with one of the dedicated diary teams, and may also meet with one of the ICU consultants if they wish. The patients are encouraged to bring relatives with them and given time to ask any questions they may have. The photographs are given to the patient at this point, and they are encouraged to take the diary home to read it at their own pace. Patients are given a contact number to call if they have any further questions at a later date. Photocopies of the completed diary are kept for two years, and then stored on disc as part of the patient's official notes. Diaries which are not collected are destroyed after two years. (Hale et al. 2010, 17.)

Gjengedal et al. (2010, 180) highlight the need for sensitivity when handing over the diary to the patient. It also maintains that the patient must have the opportunity to reject

the diary and the photographs. The majority of units in the study handed over the diaries after discharge, whereas other participants' approaches to diary handover were more random. The study claims that many of the participants express a desire to improve the system of how diaries are handed over. (Gjengedal et al. 2010, 180.)

According to Åkerman et al. (2010, 30), less than ten percent of the participants in the study handed the diary over as part of a follow-up clinic. The majority handed the diaries over as the patient was moved from the ICU to one of the general wards. The follow-up protocol varied between departments, but it was most common for there to be some kind of visit while the patient was still on the general ward, and then follow-up at around two months following discharge from the ICU. (Åkerman et al. 2010, 30.)

Egerod et al. (2006, 164) state that patients are given the diary when they are discharged, and the department does not keep a copy. Some participants gave the diary to the patient's relatives, or simply let the diary go with the patient to the general wards along with the rest of their belongings. In these cases, the nurses had no idea at what point the patients read their diaries, if ever. The study highlights that diaries were introduced without a proper follow-up plan, and also that it is unknown how the patients reacted when they read their diaries, if indeed they read them at all. The study maintains that ethical issues regarding the practice of diary writing were not properly addressed by the nurses introducing the system, and that potentially some of the patients may have been traumatised by reading about their experiences without any support. (Egerod et al. 2006, 164, 165.)

Storli and Lind (2009, 47) report that the diary is used as a basis for conversation between the nurse and the patient about their experiences. It is conducted after the patient is discharged from the ICU, but the patient is encouraged to re-visit the ICU department before discharge from the general wards. The study highlights that the diary must be handed over with caution. The nurses discuss guiding the patient through the entries, some starting at the back of the diary when the patient is closer to recovery. The patients are warned that the experience may be difficult, and they are encouraged to go at their own speed. (Storli & Lind 2009, 47, 49, 53.)

According to Jones' description of diary implementation (2009, 3), the patients are contacted by telephone, or on the general ward, and asked if they would like to receive

their diary. If they are not ready, the diary is stored and they are asked again around two months later when they come to the ICU outpatient clinic. Before the diary is handed over, a consent form is signed giving permission for the photographs. A member of the diary team goes through the diary with the patient to ensure everything is understood. Medical terms are explained, plus the diary includes a glossary of the most common equipment and terms. In cases of bereavement, the critical care liaison nurse writes a letter to the relatives, inviting them to come in to the hospital to receive the diary. An appointment is made, and either the liaison nurse, or a member of the diary team hands the diary over. In order to avoid the potential upset of returning to the intensive care unit, the appointment is held in a different part of the hospital. Bereaved families are given a copy of the diary, but not given any photographs. (Jones 2009, 3.)

Jones et al. (2010, 3) report that the intervention group was given the diary one month after discharge, and the control group at three months. The diary was handed over by either a research nurse or a doctor. The diary and photographs were explained to the patient but no advice was given as to how the patient should use the diary. Most of the handovers were done in the outpatients department, with a few happening at the patient's own home. If the patient lived a long distance from the hospital, the discussion was conducted over the phone. In these cases, the diary was sent by recorded delivery with instructions that the patient should not open the diary until the nurse rang at a given time. The nurse would then go through the diary with the patient by using a photocopy. The study maintains that patient feedback about the diaries was positive, with patients reading their diaries a median of 3 times. Only one patient in the study had not read the diary at all. 84% of the intervention group had given the diary to friends, family, or colleagues to read. The study revealed that less than 2% thought that meeting with the nurse was what helped them most, whereas 49% expressed that reading the text was most helpful. 15% said that the combination of text and pictures was of most help, with 15% saying it was the photographs alone. (Jones et al. 2010, 3, 6, 7.)

Samuelson and Corrigan (2009, 256) note that upon discharge from the ICU department, the diary accompanied the patient to the general ward to enable the relatives and ward staff to continue writing in the diary. A nurse from the diary team then visited the patient within three days to explain the purpose and content of the diary. Between two and three months after the patients were discharged from the ICU, they were invited to a 90-minute follow-up consultation. The visit included explaining what happened

during their hospital stay and the handing over of the diary and photographs. An opportunity was given for the patient and relatives to express their perceptions and talk about their experiences. There was a discussion about long-term rehabilitation and health problems. Finally the patient and relatives had the opportunity to re-visit the ICU department. The study stresses the importance of a doctor and a psychologist collaborating with the after care nurse, to offer support and make referrals. The consultations did not use the interview technique. Instead, emphasis was placed on the patient and relatives expressing their experiences, and being listened to. (Samuelson & Corrigan 2009, 256, 259-261.)

#### **5.4.2 Emotional processing, dialogue**

Gjengedal et al. (2010, 181) describe how a patient's memory from their ICU experience can be seen in a new perspective as the result of the conversations that emerge from reading the patient diary. It is suggested that the resulting position can be beneficial to both the patient and the nurse. (Gjengedal et al. 2010, 181.)

Engström et al. (2008, 63) highlight that to some patients, the content of the diary did not feel real; they doubted its truth, and stated that it felt like reading someone else's story. The feeling of unreality came from reading personal factual events, yet having no memory of them. Many questions arose and confirmation of the narrative was desired. The process of reading the diary for the first time is described as grief filled, and it is reported that many patients struggled to get through it. Patients were fearful to start reading the diary, and expressed an expectation that it would not be easy. The findings reveal that reading the diary for the first time might evoke strong emotions and reactions. Many reported crying the first few times they read the diary. Some patients, who started to read, found it too traumatic to continue and had to come back to it at a later date. The feeling of fear is described as decreasing the more times the diary was read. Other participants describe overcoming the difficulties of reading the account by starting at the end and working backwards. The study emphasises that it is important to be prepared before reading the diary. The report also suggests that taking advantage of the content could only happen after repeated readings, and some participants described how the strong emotions subsided after reading it a few times. Many patients talked of the diary having a humbling effect on their lives – they no longer wanted to take life for

granted, and they had a newfound desire to make positive life changes. (Engström et al. 2008, 63, 66.)

Storli and Lind (2009, 49) state that reading a book which chronicles one's own experience of survival can be very emotional. The study discusses the diaries being an outlet in order for experiences to emerge. The follow-up sessions took a conversational form. It is suggested that if the diary text poses open questions, the patient can use them as a starting point for their own reflection, or to interpret their emotions. The act of presenting the diary to the patient is likened to the giving of a gift, and the symbolic nature is discussed. It is sometimes interpreted that the nurses have gone beyond what was expected, over and above the patient's basic health needs. It is also described as opening the door for a dialogue to start between the patient and follow-up nurse. (Storli & Lind 2009, 47-49.)

According to Jones (2009, 3), the participants state that when patients see photographs taken during their treatment for the first time, it can be emotional. Patients may need support when they read what their relatives have written about them. Despite this emotion, the patients expressed that diaries are nonetheless beneficial. (Jones 2009, 3.) In a later study, Jones et al. (2010, 8) acknowledge that a nurse with experience is required at the point of diary handover in order to clarify its contents to the patient. Samuelson and Corrigan (2009, 258) highlight the vulnerability of the patient at the follow-up consultations. It is further suggested that there is the potential to uncover disturbing memories and cause distress, if patients and relatives are not treated with respect and sensitivity. (Samuelson & Corrigan 2009, 258.)

### **5.4.3 Resources, financial accountability**

Gjengedal et al. (2010, 182) state that most participants in the study gave responsibility to a dedicated diary team or individual. Responsibilities included diary writing, supervising, motivating, and education. It is highlighted that in general, extra resources are not allocated to diary writing, although some units received support to set up the initiative. According to nurses, the lack of resources limits the further development of the practice of patient diaries. The study implies that more resources should be directed

towards diary practice, including quality control in the form of national guidelines. (Gjengedal et al. 2010, 180, 182.)

According to Åkerman et al. (2010, 31), university hospitals were more likely to assign dedicated diary staff, whereas smaller hospitals did not have the resources to do so. The study also links the lack of resources of certain hospitals to the lack of research and education regarding patient ICU diaries. (Åkerman et al. 2010, 31.)

Jones et al. (2010, 8) acknowledge that there is a financial cost in implementing a dairy system. Costs include commitment from nurses to make regular entries and document significant changes using photograph, and also time for an experienced nurse to offer support and answer questions when the diary is handed over. But the study argues that it does not require many more resources than are needed when providing and unstructured chat. The study further argues that it is cost effective when compared to the potential resources required to provide cognitive behavioural therapy at a later date. (Jones et al. 2010, 8.) According to Samuelson and Corrigan (2009, 259), a nurse led patient diary initiative, including a multidisciplinary after care follow-up clinic, can be implemented using relatively small resources.

#### **5.4.4 Follow-up programme**

Gjengedal et al. (2010, 182) argue that the diary is just one part of the whole follow-up programme. Over 50% of the participants offered systematic follow-up for patients, which included diaries as part of the programme. The study highlights a link between high levels of diary writing, and a systematic follow-up programme, whereas hospitals in which diary writing was lower demonstrated more random follow-up activity. The diary was seen as a central part of the follow-up programme and formed the basis of the conversations. Nurses also reported a benefit of follow-up to be that it highlighted ways in which to improve their diary writing. The study suggests that a lack of resources is the main obstacle to implementing a follow-up programme. It also contends that introducing patient diaries without a systematic follow-up programme is unwise. (Gjengedal et al. 2010, 178, 180-182.)

Åkerman et al. (2010, 32) acknowledge that providing a follow-up programme requires extra financial resources, and suggests that the content should be tailored to the needs of the individual patient. Also highlighted is the fact that, proportionally, many more county ICUs than district ICUs offered systematic follow-up programmes. The report argues that there is a lack of scientific research into using diaries as part of a follow-up programme. (Åkerman et al. 2010, 30-32.)

Engström et al. (2008, 64) suggest that follow-up visits to the ICU were beneficial in clarifying links between the diary and the patient's memories. The study highlights that the diary was used as a central part of the follow-up, and provided a way to initiate conversations about the patient's time in the ICU. It is also suggested that it is important for the patient to meet the person who wrote their diary, and that having someone read the words aloud gave it greater meaning. (Engström et al. 2008, 64, 66.) In contrast, Egerod et al. (2006, 166) found in their study of Danish ICUs, that the diaries did not form any part of a follow-up programme.

Storli and Lind (2009, 46) reveal that follow-up programmes varied not only in content, but also in the philosophy on which they were based. The study highlights the importance of follow-up nurses having individual knowledge of the patient's story. It goes on to describe the return visit to the department as a form of exposure therapy. The authors expressed surprise at how a potentially traumatic visit received positive feedback from patients. (Storli & Lind 2009, 46, 50.)

Samuelson and Corrigan (2009, 257) found that the follow-up was undertaken by a multidisciplinary team consisting of doctors, psychologists and nursing consultants. The best time for the follow-up was chosen as two to three months after discharge from the ICU. It was argued that at this point, any psychological problems had had time to surface. It was also suggested that extra support should be given by visiting the patient early on, one to three days after discharge from the ICU. At this point, the patient is still on the general hospital ward. During the early visit, the patient and relatives are given an information sheet, the telephone number of a helpline, and an invitation to the follow-up two to three months later. The follow-up consultation lasted for 90 minutes, and the study suggests that this amount of time is required in order to create a relaxed atmosphere and for the patient to feel listened to without being interrupted. Further, the

study argues that in order to be of any benefit to the patient, sufficient time must be allowed for the discussion. (Samuelson & Corrigan 2009, 256-260.)



## 6 DISCUSSION

### 6.1 Discussion of the findings

There are variations between the studies as to the specific content of patient diaries, but overall the results concur that diaries are intended to be distinct from the patients' official hospital notes. Further, the content is assumed to be written in everyday language, by both relatives of the patient, and the whole multidisciplinary team. (Egerod et al. 2006, 163; Engtsröm et al. 2008, 64; Jones 2009, 3; Akerman et al. 2010, 30; Gjengedal et al. 2010, 179; Hale et al. 2010, 16; Jones et al. 2010, 2.) Some of the studies report diary formats which include some form of information about the purpose of patient diaries (Egerod et al. 2006, 162; Åkerman et al. 2010, 30; Gjengedal et al. 2010, 179). Two of the studies also report the practice of providing guidelines of how and what to write (Hale et al. 2010, 16; Jones et al. 2010, 2).

The structure and format of the diaries also vary greatly across the studies. This diversity may be a result of the relative newness of the topic, and lack of guidelines for diary implementation. A few studies discussed the format in relation to issues of privacy and patient confidentiality (Egerod et al. 2006, 165; Åkerman et al. 2010, 30). However, only one of the studies mentions the hygiene issues of diaries (Jones 2009, 3). This is somewhat surprising, considering that it is generally indicated that the diaries are stored at the patient's bedside (Egerod et al. 2006, 164; Jones 2009, 3; Åkerman et al. 2010, 30; Gjengedal et al. 2010, 180).

The extent to which patient confidentiality is investigated within the research is limited. Several of the studies highlight an approach whereby nurses and relatives used separate diaries (Egerod et al. 2006, 163; Åkerman et al. 2010, 30; Gjengedal et al. 2010, 178). Hale et al. (2010, 18) mention challenges of family dynamics. However, there are no data directly confronting issues such as infidelity within relationships, estranged family members, or family feuds.

A loose-leaf diary structure, as highlighted by Gjengedal et al. (2010, 179), would allow pages to be written independently by nurses and relatives, and then compiled into the diary which would be stored elsewhere. This would not only address the issues of privacy between all parties, but also provide a hygienic solution with relation to diary storage.

The research reveals diversity between the studies regarding the criteria for inclusion to the patient diary programme. Further, inconsistencies are also highlighted within individual departments as regards which patients are included to or excluded from the diary scheme. (Egerod et al. 2006, 162, 164; Åkerman et al. 2010, 30-32; Gjengedal et al. 2010, 178.) Gjengedal (2010, 178) highlights an approach whereby the selection is based on the nurse's assumptions of whether the patients would benefit from a diary. It would be most desirable for the standard of care offered to patients to be consistent and uniform rather than based on assumptions. The development of guidelines clearly defining the criteria of which patients are given a diary would go some way towards removing the inconsistencies in how patients are selected.

Many of the articles advocate the practice of photographic documentation as part of the diary process (Jones 2009, 3; Engström et al. 2008, 64; Gjengedal et al. 2010, 179; Hale et al. 2010, 17). The assertion is that photos of the patient have the potential to illustrate the progress of their illness, and also help the patient to link memories of sensations to reality (Engström et al. 2008, 64; Storli & Lind 2009, 49; Gjengedal et al. 2010, 179; Hale et al. 2010, 17). However, there is also potential for photos to have a negative effect (Storli & Lind 2009, 53). It is noticeable that the potential negative effects of photographs have not been fully investigated in the research. There is also a lack of consensus regarding the legality of taking photos of patients, which may be attributed to the differing laws within the countries represented by the research. Therefore the decision whether to include photos must be based on the privacy laws of the country in question. Additionally, guidelines should clarify when and how the consent for photos should be obtained from the patient.

The review highlights a necessity for general or national guidelines to give direction and foundation to patient diaries (Egerod et al. 2006, 161; Samuelson & Corrigan 2009, 261; Åkerman et al. 2010, 31; Gjengedal et al. 2010, 180). Egerod et al. (2006, 161) highlight the absence of a purpose statement in many of the departments studied.

Further stating that none of them had implemented diaries as part of development and research. Åkerman et al. (2010, 31) also highlight a shortfall in written purpose statements, and questions the extent to which using diaries as part of a follow-up programme is based on scientific research. If national guidelines are not realisable, it is necessary for individual hospital districts to formulate a purpose statement defining the objective of patient diaries. Samuelson and Corrigan (2009, 261) argue that it should also incorporate a plan for evaluating their effectiveness.

The studies that investigated the attitudes of staff towards the introduction of patient diaries report that generally their reception was positive (Egerod et al. 2006, 162; Gjengedal et al. 2010, 180). In places where negativity was encountered, this was attributed to the perceived increased workload, ambiguities surrounding the legal aspects, and general lack of guidelines (Åkerman 2010, 31; Hale et al. 2010, 18). Jones (2009, 2) asserts that forcing nurses to participate in patient diaries is counterproductive. Egerod et al. (2006, 162) report that when negative attitudes were met, diaries could be left optional. However, this approach creates an inequality in the standard of care afforded to the patient, and demonstrates a lack of guided protocol supporting the diary process. Adequate staff education, as advocated by Åkerman et al. (2010, 31), and clearly defined guidelines would appear to be fundamental in increasing enthusiasm for patient diaries.

The research highlights that there is discord between the articles as to whether diaries are the patient's own property, hospital property, or somewhere in between (Egerod et al. 2006, 163; Jones 2009, 2; Samuelson & Corrigan 2009, 257; Åkerman et al. 2010, 30; Gjengedal et al. 2010, 180). The legal status of diaries generally appears to be an area that has not been fully investigated. It would be important to establish if signing a consent form really is legally binding in transferring the ownership of the diary. When implementing diaries, it would be important to outline at which point consent should be obtained from the patient. In addition, some thought would have to be given to the protocol in the event of the patient dying.

The majority of articles in the literature review held the position that diaries have a positive effect on patients. The suggested ways in which patients can benefit from a diary are numerous. Diaries can give patients a clearer understanding of their illness, as well as filling in memory gaps (Jones 2009, 3). They give chronological order to events,

thus providing a clearer understanding of what has happened (Engström et al. 2008, 64). Storli and Lind (2009, 48) highlight the benefits of diaries linking events to experiences and perceptions, while Jones et al. (2010, 7) claim a reduction in the incidence of PTSD.

According to some studies, positive impact is not limited to the patient. Hale et al. (2010, 18) contend that diaries encourage more involvement from relatives in the care process, also highlighting how important diaries can be to relatives in the event of the patient's death. Even the nurses writing the diaries can be affected positively (Egerod et al. 2006, 166; Hale et al. 2010, 17; Åkerman et al. 2010, 30). Additionally, nurses' patient care may be improved by writing diaries according to Gjengedal et al. (2010, 180).

In contrast to the abundance of evidence endorsing the positive effects of patient diaries, the data examining any potential negative impact was sparse. Egerod et al. (2006, 164) highlight a complication if information is recorded in the diary instead of official hospital records and then lost when the patient takes the diary home. Egerod et al. (2006, 164) also suggest that reading the diary may leave some patients traumatised. Åkerman et al. (2010, 31) suggest that the belief in the positive effect of diaries is an assumption supported by very limited data. This assertion of Åkerman et al. (2010, 31) is the closest any of the reviewed articles comes to directly tackling the question of potential negative impact. Here a gap is exposed in the current available evidence, and further investigation is required.

The research is in agreement that the point at which the diary is handed over to the patient can be very emotional (Samuelson & Corrigan 2009, 258; Storli & Lind 2009, 49; Engström et al. 2008, 63). The process of reading the diary for the first time can evoke strong emotions and reactions (Engström et al. 2008, 63). It is clear from the data that the handover point should be organised and considered in order to avoid the scenario reported by Egerod et al. (2006, 164) where, upon discharge, the diary simply goes with the patient's other belongings.

In general, patient diaries constitute just one aspect of a larger follow-up programme (Engström et al. 2008, 64; Samuelson & Corrigan 2009, 257; Gjengedal et al. 2010, 182). In fact, it is suggested that implementing diaries without a follow-up programme is unwise (Gjengedal et al. 2010, 182). Egerod et al. (2006, 165) go as far as to suggest

that reading their diaries for the first time without any support may traumatise patients. Samuelson and Corrigan (2009, 257) suggest that follow-up involves a multidisciplinary team, including doctors, psychologists, and nursing consultants. Evidence suggests that in places where no follow-up plan was instigated, the patients' reaction to their diaries were unknown. In fact, it could not be known if they had read their diaries at all. (Egerod et al. 2006, 164.) Despite diaries often forming part of an ongoing follow-up programme, it is unclear from the data if the long-term effects on the patient have been fully investigated.

## **6.2 Limitations of this study**

The paucity of evidence on the subject of patient diaries may be attributed to the fact that it is a relatively new topic. As a result, the choice of articles available was limited. The literature review contains articles only from northern European countries and the UK, and only articles written in English. This may limit the transferability of this thesis. Nursing practice may vary in countries not represented in the study, and it is therefore possible that this constrains the extent to which the findings can be generalised.

The critical appraisal of the reviewed articles highlighted some weaknesses regarding their trustworthiness. The degree to which some of the findings are subject to researcher bias calls into question the confirmability of some of the articles. It must also be noted that this literature review was conducted exclusively by the author, and therefore may be subject to personal bias on the part of the researcher.

## **6.3 Ethical considerations**

While it is not possible to directly obtain consent from the original participants of the research under review, it must be implied that consent has been given for the original data to be used in further studies. In the author's estimation, the articles under review were conducted in an ethical manner. The ethical principles safeguarding the participants, as outlined by Polit and Beck (2014, 152-156), have been upheld. The author has endeavoured to respect the original researchers' intentions by representing their work in a fair and accurate manner. The findings of the literature review were

systematically collated in thematic results matrices in order to represent the data objectively.

As advocated by Polit and Beck (2012, 97) the author has undertaken every aspect of this study with an impartial attitude, making every effort to avoid personal bias. The author declares no conflict of interest that affects this Bachelor's thesis process, and bears the cost of any expenses incurred during the process.

## **7 CONCLUSION**

### **7.1 Conclusions and implications**

The evidence suggests that prospective patient diaries can be beneficial in promoting the psychological recovery of ICU patients. However, potential negative effects have not been comprehensively investigated. Patient diary implementation should stem from clearly defined objectives of the diaries' purpose, and include a plan to assess their long-term effectiveness. Clear guidelines are necessary to inform diary content and protocol, and also to address the numerous ethical and legal issues associated with the implementation of the diaries. Patient diaries should form part of an organised follow-up programme, including a strategy for psychological support after hospital discharge.

The implications for clinical practice are numerous. This study has consolidated the current scientific evidence available on the subject. It exposes the gaps within the current body of knowledge, and highlights the areas where further investigation is required. The research also reveals the complex nature of the topic, drawing attention to the multifaceted implications associated with the implementation of patient diaries.

### **7.2 Suggestions for the Pirkanmaa Hospital District**

This section outlines the author's suggestions for the Pirkanmaa Hospital District regarding what needs to be considered when implementing prospective diaries for intensive care patients. The suggestions are first represented in the form of a mind map (see figure 2). A Finnish language version of the mind map and suggestion statement can be found in Appendices 5 and 6 respectively.

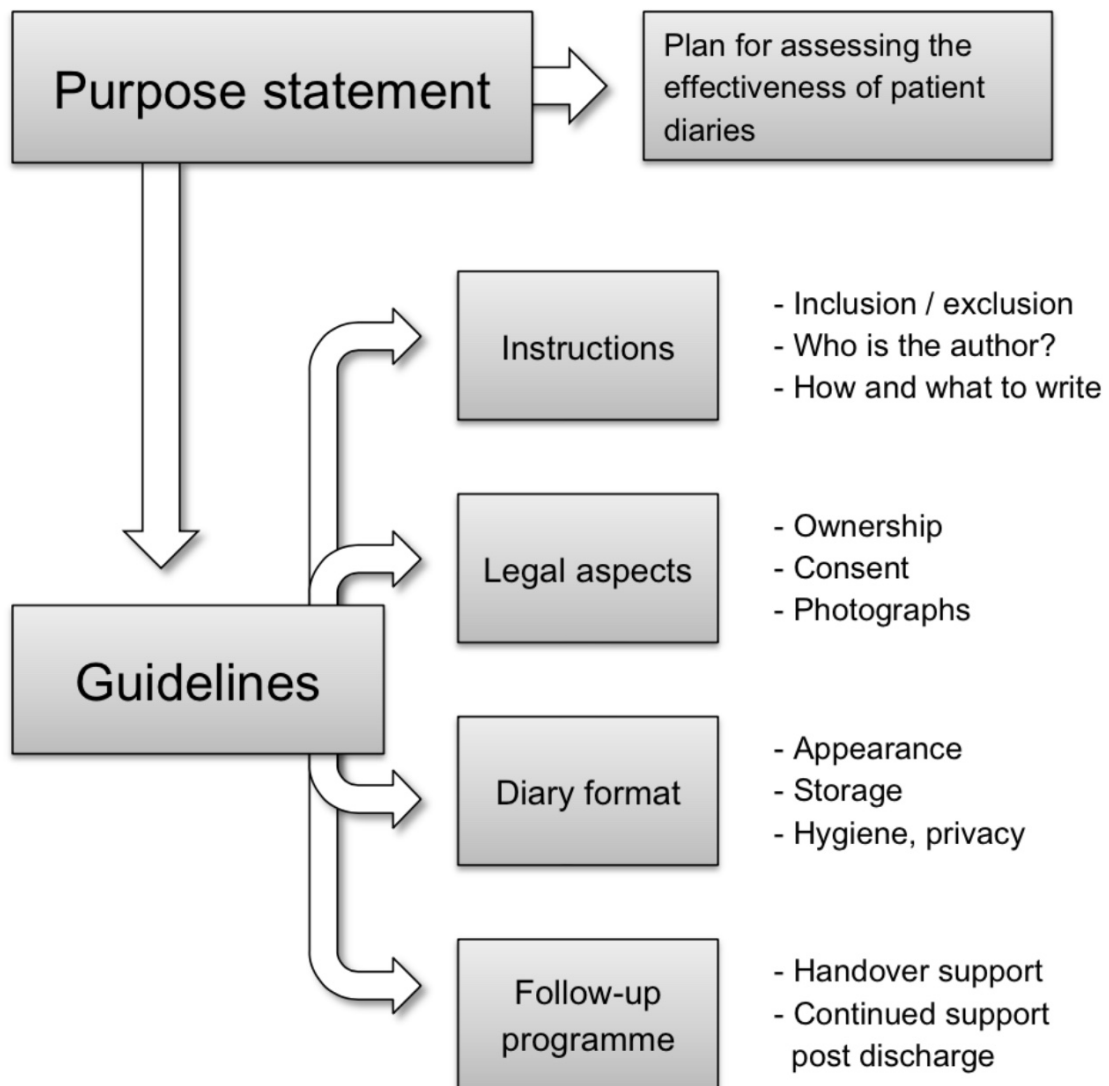


FIGURE 2. Suggestions for the Pirkanmaa Hospital District mind map

### Suggestions for the Pirkanmaa Hospital District

In the absence of national guidelines regarding patient diaries, it is suggested that individual hospital districts should establish their own purpose statement. It is necessary to clearly define the reason for patient diaries, who will be served by them, and how. Research suggests that patient diaries are most effective when introduced accompanied by a coordinated follow-up programme. A plan should also be incorporated for assessing the effectiveness of patient diaries, including the long-term consequences for patients.

Accompanying the statement of purpose should be clear guidelines outlining how patient diaries should be implemented. The guidelines should include unambiguous inclusion and exclusion criteria specifying which patients should be involved in the



diary scheme. The intended authors of the diary should be clearly defined. Additionally, basic instruction should be given, for both nurses and relatives, on how and what to write.

The legal aspects of patient diaries should be considered, particularly in relation to who is the legal owner of the diary. In addition, legal advice should be sought regarding patient consent. The guidelines should offer clear instruction how and when consent for the diary is to be obtained. A legal decision must also be made in relation to the inclusion of photographic documentation.

With regard to the format of patient diaries, the guidelines should consider not only their appearance, but also their storage requirements. A standardised loose-leaf format is suggested in order to address issues of hygiene and privacy.

An integral part of the diary process is the follow-up programme. As such, the guidelines should detail the proposed diary handover criteria, and outline how the patient will be emotionally supported at this critical point. A strategy may also be presented of the intended long-term support that will be implemented after hospital discharge.

### **7.3 Suggestions for further study**

According to the data, most of the research into the effectiveness of patient diaries focuses around the first few months after discharge from the ICU. Further research is needed into the effects of patient diaries over a longer period of time, with specific regard to the patients' point of view.

The study brought to light many ethical and legal issues associated with the implementation of patient diaries. Further investigation into the legal issues surrounding retrospective consent would be a significant addition to the current body of evidence.

Despite some of the articles hinting towards potential negative impact of patient diaries, no research confronted the question directly. Further research is needed into the possible adverse effects of patient diaries on both patients and relatives.

## 8 REFERENCES

- Åkerman, E., Granberg-Axéll, A., Ersson, A., Fridlund, B. & Bergbom, I. 2010. Use and practice of patient diaries in Swedish intensive care units: a national survey. *Nursing in Critical Care*, 15 (1), 26-33.
- Clottey, M. & Dillard, D. 2013. Post-traumatic Stress Disorder and Neonatal Intensive Care. *International Journal of Childbirth Education*, 28 (3), 23-9.
- Combe, D. 2005. The use of patient diaries in an intensive care unit. *Nursing in Critical Care*, 10 (1), 31-4.
- Cutler, L., Brightmore, K., Colqhoun, V., Dunstan, J. & Gay, M. 2003. Developing and Evaluating Critical Care Follow-up. *Nursing in Critical Care*, 8 (3), 116-25.
- Egerod, I., Schwartz-Nielsen, K.H., Hansen, G.M. & Lærkner, E. 2006. The extent and application of patient diaries in Danish ICUs in 2006. *Nursing in Critical Care*, 12 (3), 159-67.
- Egerod, I., Storli, S.L. & Åkerman, E. 2011. Intensive care patient diaries in Scandinavia: a comparative study of emergence and evolution. *Nursing Inquiry*, 18 (3), 235-46.
- Engström, Å., Grip, K. & Hamren, M. 2009. Experiences of intensive care unit diaries: Touching a tender wound. *Nursing in Critical Care*, 14 (2), 61-67.
- Gjengedal, E., Storli, S.L., Holme, A.N. & Eskerud, R.S. 2010. An act of caring - patient diaries in Norwegian intensive care units. *Nursing in Critical Care*, 15 (4), 176-84.
- Griffiths, J., Barber, V., Cuthbertson, B. & Young, J. 2006. A National Survey of Intensive Care Follow-up Clinics. *Anaesthesia*, 61 (10), 950-955.
- Hale, M., Parfitt, L. & Rich, T. 2010. Feature. How diaries can improve the experience of intensive care patients. *Nursing Management*, 17 (8), 14-18.
- Jones, C. 2009. Knowles RE and Tarrier N. Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: a randomized control trial. *Nursing in Critical Care*, 14 (3), 155-6.
- Jones, C. 2009. Introducing Photo Diaries for ICU Patients. *Journal of the Intensive Care Society*, 10 (3), 2-4.
- Jones, C., Bäckman, C., Capuzzo, M., Egerod, I., Flatten, H., Granja, C., Rylander, C. & Griffiths, R. 2010. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomized, controlled trial. *Critical Care*, 14(5) 1-10.
- Jones, C., Bäckman, C. & Griffiths, R.D. 2012. Intensive care diaries and relatives' symptoms of posttraumatic stress disorder after critical illness: a pilot study. *American Journal of Critical Care*, 21 (3), 172-6.
- Jones, C., Griffiths, R.D. & Humphris, G. 2010. Disturbed Memory and Amnesia Related to Intensive Care.

- Kelly, M.A. & McKinley, S. 2010. Patients' recovery after critical illness at early follow-up. *Journal of Clinical Nursing*, 19 (5/6), 691-700.
- Kiekkas, P., Theodorakopoulou, G., Spyratos, F. & Baltopoulos, G.I. 2010. Psychological distress and delusional memories after critical care: a literature review. *International Nursing Review*, 57 (3), 288-296.
- Phillips, C. 2011. Use of patient diaries in critical care. *Nursing Standard*, 26 (11), 35-43.
- Polit, D.F. & Beck, C.T. 2012. *Nursing research: generating and assessing evidence for nursing practice*. 9<sup>th</sup> edition. Philadelphia : Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Rattray, J.E. & Hull, A.M. 2008. Emotional outcome after intensive care: literature review. *Journal of Advanced Nursing*, 64 (1), 2-13.
- Samuelson, K. & Corrigan, I. 2009. A Nurse Led Intensive Care After-care Programme; Development, Experiences and Preliminary Evaluation. *Nursing in Critical Care*, 14 (5), 254-63.
- Storli, S. & Lind, R. 2008. The meaning of follow-up in intensive care: Patients' perspective. *Nordic college of caring science*. 45-56.
- Strahan, E., McCormick, J., Uprichard, E., Nixon, S. & Lavery, G. 2003. Immediate follow-up after ICU discharge: establishment of a service and initial experiences. *Nursing in Critical Care*, 8 (2), 49-55.
- Williams, S.L. 2009. Recovering from the psychological impact of intensive care: how constructing a story helps. *Nursing in Critical Care*, 14 (6), 281-8.

## 9 APPENDICES

### 9.1 Appendix 1. Critical appraisal tool

- Was the aim of the study justified and stated clearly?
- Was the design of the research appropriate in order to facilitate the aims?
- Was the sample size appropriate to the method?
- Were appropriate data analysis methods used?
- Were the findings clearly presented and summarised effectively?
- Was the study conducted in an ethical manner?
- Were there implications of the study to clinical practice?
- Does the study appear to be trustworthy?

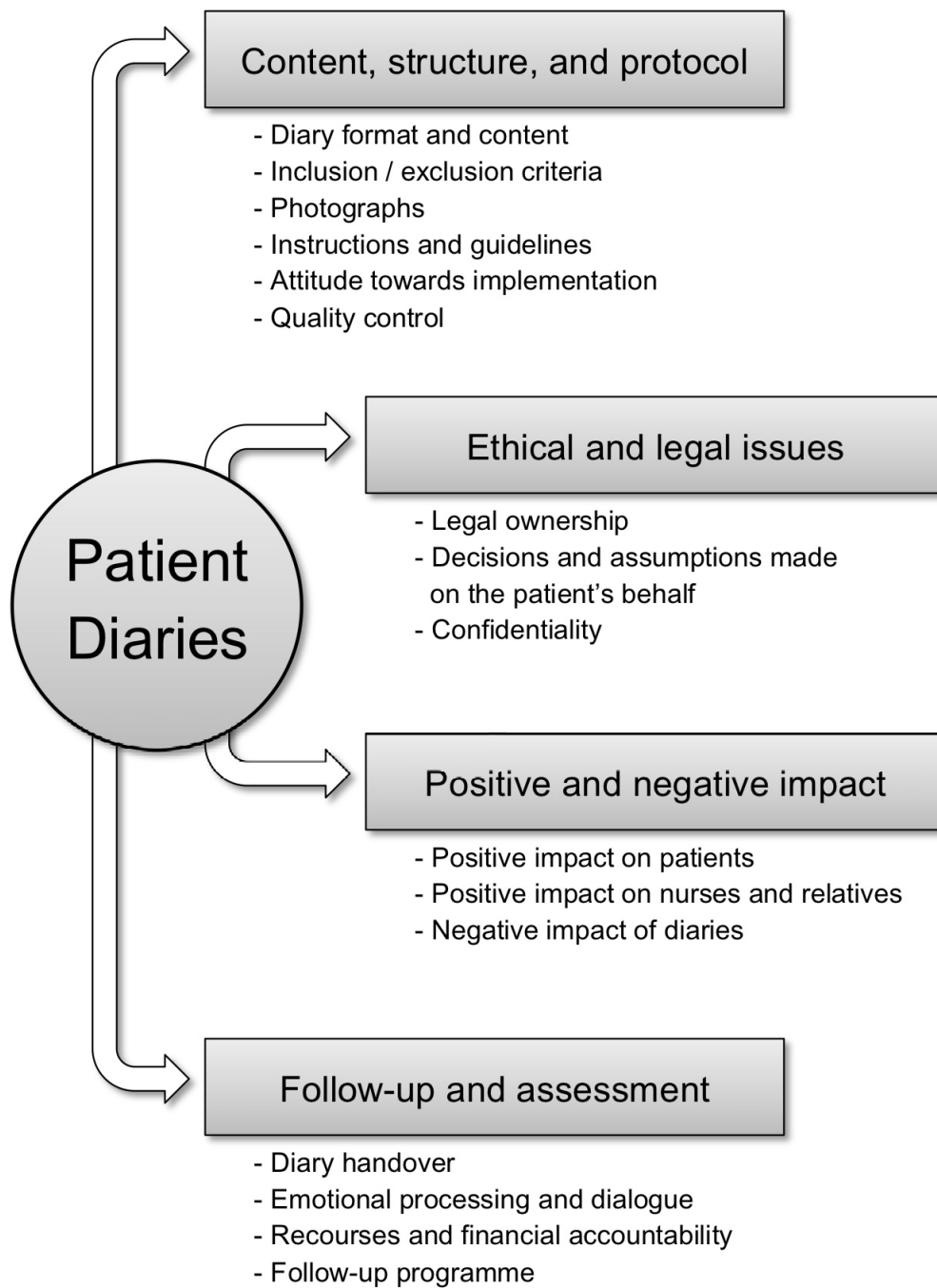
The critical appraisal tool was adapted from Polit and Beck (2014, 112-118). The tool was used to assess the major strengths and weaknesses of the articles under review, and to evaluate the reliability of the body of evidence.

## 9.2 Appendix 2. Evaluation matrix

Table adapted from Polit and Beck (2014, 119).

Author, publication year and country	Strengths	Weaknesses
Egerod et al. 2006. Denmark	Descriptive design, qualitative interviews were verified after the initial interview, thus increasing validity.	Small sample size. Most participants had been involved in the implementation of diaries, which may have led to bias. Some informants had written papers on the subject of patient diaries.
Engström et al. 2008. Sweden	Design: qualitative interviews were appropriate to meet the aim of describing patients' experience of diaries.	Only 9 participants, therefore difficult to generalise the findings. Original interviews were translated from Swedish into English. Participants were only interviewed once.
Jones 2009. UK	Comprehensive description of implementation, content, and follow-up care.	Limited to one hospital.
Samuelson & Corrigan 2009. Sweden	Large study sample. The research evaluates the complete follow-up programme.	Design: evaluation questionnaire was the only approach used. Patients with a positive attitude were more likely to participate.
Storli & Lind 2009. Norway	Interviews made at both 6 months and 18 months. Covers the complete follow-up programme.	Small study group. All participants from the same programme, from only one hospital.
Åkerman et al 2010. Sweden	Used both qualitative and quantitative approaches. Large study sample.	Only one person performed the interviews, which may have increased observer bias.
Gjengedal et al. 2010. Norway	Design method appropriate for the aims. Study group covers a wide range of department sizes.	Participants were all active members of diary groups within their departments, which may have led to bias.
Hale et al. 2010. UK	Includes example diary entries and comments from patients and families.	Description is limited to one hospital.
Jones et al. 2010. UK	Large study group across 12 different departments. Appropriate study design, randomised control trial.	Some participants were interviewed by telephone, which may have compromised the accuracy of the PTSD diagnosis.

### 9.3 Appendix 3. Mind map of main themes



## 9.4 Appendix 4. Results matrices

### Content and format results matrix

1(17)

Author, publication year and country	Content	Format
Egerod et al. 2006. Denmark	<p>Unresolved legal status affects content.</p> <p>Diary content should differ from official documentation.</p> <p>Future of patient diaries.</p> <p>Half of the units had guidelines.</p> <p>Language kept in the second person, tone professional.</p> <p>Patient never writes, usually nurses, often relatives encouraged, few had separate diaries.</p> <p>Attempt to avoid overlap of information.</p>	<p>A5 format and standardised structure, pre-printed introduction. Other participants A4 size, many had no standard format.</p> <p>Explanation or pictures of ICU equipment.</p> <p>Choice of cover varied greatly.</p> <p>Some ICUs stored the diary in the nurses' office, others at the patient's bedside. Assumption that no unauthorised people would read the diary.</p> <p>Also stored as part of the medical notes.</p> <p>Unresolved legal status has an effect on content, also how they are handled and stored.</p>
Engström et al. 2008. Sweden	<p>Easily understood, personal, human touch.</p> <p>Entries written by family members were regarded as the most important.</p> <p>Relatives wrote in a more personal way.</p> <p>Nurses focused more on medical treatment and procedures.</p>	
Jones 2009. UK	<p>Multidisciplinary.</p> <p>Daily entries.</p> <p>Relatives encouraged to write about their own feelings and emotions.</p>	<p>The diary is stored at the patient's bedside. Photographs are kept in a locked cabinet and added to the diary upon completion.</p> <p>For the diary itself, a small notebook is used which has a plastic cover so that it can be wiped clean.</p>
Samuelson & Corrigan 2009. Sweden	<p>Everyday language, no abbreviations or jargon. A description of the patient's day to day experience of ICU.</p>	
Storli & Lind 2009. Norway	<p>Diary is a basis for dialogue during the follow-up.</p> <p>Open questions initiate reflection.</p> <p>Entry frequency not daily, left to nurse to decide.</p> <p>Dialogue between nurse and patient.</p> <p>Photos support the text.</p> <p>Addresses the patient even if unconscious.</p>	

(continues)

Åkerman et al. 2010. Sweden	Daily entries. Patient focused. Descriptive. Significant events. Varied focus. Easy language. Nurses wrote, some doctors. Relatives encouraged. Some started by staff, continued by relatives.	Most of the participants used guidelines. Introduction section. Short history of how and why the patient came to ICU. Pictures and explanations of ICU machines. Small A5 notebook. Chosen structure for diaries varied greatly. Separate sections within the diary for nurses and for family members. Diary kept at the patient's bedside.
Gjengedal et al. 2010. Norway	Attention to content: not causing offence. Descriptions of the environment Should be personal and easily understood, but should not be private. Medical terms avoided. Objective vs. patient focused approach. Fills memory gaps.	Varying practices regarding protocols, contents and how the diaries are handed over to the patient. Loose leaf diary in order for pages to be removed and rewritten. Attention to the appearance of the cover, attempted to add symbolism with pictures, poems. Introduction provided information about ICU and purpose of the diary. Summary of the patient's story. Entries signed and dated. Stored at the bedside, some departments locked the diaries away before being proof-read and handed over to the patient.
Hale et al. 2010. UK	Contributions from multidisciplinary team, family members and friends. Providing a complete narrative of the patient's ICU experience Entries once a day. Final entry-symbolic moment, positive step on the patient's journey.	Diary team made the decision to use A4 bound notebooks, encouraged entries from nurses, relatives, and members of the multidisciplinary team. Completed diaries are photocopied, transferred on to disc, and stored with the patients' official medical records. Unwanted original diary versions are destroyed after two years.
Jones et al. 2010. UK	The content of the diaries in this study was an easy to read account of the patients' day-to-day ICU stay, using photographs as a visual accompaniment.	



## Inclusion / exclusion criteria and photos results matrix

3(17)

Author, publication year and country	Inclusion/exclusion criteria	Photos
Egerod et al. 2006. Denmark	<p>The criteria for inclusion in the diary scheme varied greatly. Generally the main criteria were that patients be ventilated and sedated. Decision to start a patient diary was inconsistent. Mostly it was not based on designed criteria, often decision was made by the patient's own nurse. Decisions were based more on individual's intuition rather than protocol.</p> <p>One unit chose to only start diaries for unconscious patients, while another excluded patients who were mentally challenged. Differences in the time it took to initiate the diaries. Variation from three days, up to two weeks.</p>	<p>Photographs of some of the ICU machines were sometimes included with brief explanations.</p> <p>Study highlights that photographing the patient raises both legal and ethical issues. Some units overcame potential problems by including a generic ventilated patient picture. Other units took photos, then obtained consent when the patient regained consciousness, others encouraged the relatives to take pictures. Legal stance regarding photography varied throughout the country, one lawyer stating that the patient has the legal right to take legal action against those obtaining photos without consent.</p>
Engström et al. 2008. Sweden		<p>Discharged patients expressed that the photographs provided proof of their ordeal, even though looking at them wasn't easy and felt unreal.</p>
Jones 2009. UK		<p>Family asked for permission to take photos until discharged patients complained that relatives had made the wrong decisions. Preconceptions existed that burns patients were assumed to not want pictures. Now patients decide on discharge if they want the photos. Photo taken on admission, then again at as the patient's condition changes and at significant events.</p> <p>Photos stored separate to diary in a locked cupboard; a space is left in the diary where the photo may be inserted later. Patient signs a consent form for both the diary and the photographs. Bereaved families may receive the diary but not photographs.</p>
Samuelson & Corrigan 2009. Sweden		<p>Photographs of the patient were taken only after relatives were informed, even though formal consent was not required.</p>

Storli & Lind 2009. Norway		Use of photographs can potentially positively serve the patient in two ways, by providing a link between memories of bodily sensations and the physical reasons. Also provides a record of progress made in recovery. Also negative impact in the potential to be offensive, gruesome or undignified. Asserts that there are certain things a patient should not see.
Åkerman et al. 2010. Sweden	Inconsistencies in how patients were selected for inclusion however, generally there was a pre designed target group of eligible patients. ICUs that had a follow-up clinic were more systematic in their decisions to include or exclude patients from the diary system. Median time to initiate a diary was three days, however, it sometimes took longer and occasionally eligible patients did not receive a diary at all.	Of 43 ICUs studied 63% took photographs of the patient, the objective was to take daily photographs but this was rarely achieved. No consensus existed over what type of photograph should be taken. Some units asserted that patients who had lost body parts or been badly injured, would be helped in recovery by photos taken during their treatment. Others never took photos if their appearance changed, for example, by a swollen face.
Gjengedal et al. 2010. Norway	Criteria varied across all the departments. Two thirds of the departments excluded patients who were not ventilated. Some estimated the expected ventilator time and started a diary if the patient would be ventilated for more than three days. Others based decision on patient's chances of survival. The nurse judged that the patient would benefit from having a diary. Some based decision on a combination of all factors. Writing patient diaries not compulsory. Study implies that not all patients eligible for a diary actually got one.	Motivation for taking the photos is to demonstrate progress. Focus is not on the patient's face but more of the big picture, the patient in the ICU setting surrounded by the ventilator and other equipment. Highlights the importance of protecting the patient's dignity, stating that a fine line exists between frankness and causing offense. Asserts that obtaining retrospective consent is ethically justifiable. Choice of pictures is of great significance, nurses must demonstrate wisdom and use good clinical judgment. The participants showed respect for the patient in considering which photographs should be included in the diary.
Hale et al. 2010. UK	Criteria for inclusion in the diary= over 16 years, ventilated and sedated for 48hrs, and likely to have a prolonged ICU stay.	Photos can enlighten to the severity of their illness and clarify why the recovery process takes so long.
Jones et al. 2010. UK	According to the UK national guidelines, treatment of PTSD should be aimed at specifically high risk groups rather than blanket approaches. Only ICU patients exhibiting high levels of symptoms would be included in the diary scheme. However, all patients in ICU longer than 48 hours should have a diary.	

**Instructions and guidelines, and attitudes results matrix**

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Author, publication year and country	Instructions and guidelines	Attitudes
Egerod et al. 2006. Denmark	<p>The majority of participants had goals set; only five of the 19 departments had a written statement. Five had no purpose or statement at all. None of the departments had implemented diaries as part of development or research. Diaries were introduced with no clear guidelines or plan to assess their effect. Absence of published peer reviewed literature in their introduction</p>	<p>Diaries giving sense of pride to nurses. Not all nurses enthusiastic. Generally positive attitude. Patient and relative feedback good. Diaries sometimes optional.</p>
Jones 2009. UK	<p>Guidelines are kept with the diary at the patient's bed space. Relatives are given information about the purpose of the diary, Also a guidance sheet to give an idea of how they should write in the diary.</p>	<p>Nurse at bedside in best position to write diaries. Forcing staff to write is not beneficial.</p>
Samuelson & Corrigan 2009. Sweden	<p>Tool for evaluating the effectiveness of follow-up programmes is required, along with the development of national guidelines.</p>	
Åkerman et al. 2010. Sweden	<p>Difference between the stated purpose of patient diaries, and the plan instigated for how the purpose is to be achieved. Some had written purpose statement some did not. Varying degrees to which it was based on literature. No general or national guidelines, or guidelines unclear. Lack of scientific research into using diaries as part of a follow-up programme. Difficulties in meeting the patient's rehabilitation needs as part of the follow-up care because of an absence of guidelines regarding content and structure.</p>	<p>Added to already high amounts of paperwork. Added to the general workload. Lack of guidelines about content. Challenging writing for an unconscious patient, experience required, along with patient connection.</p>

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Gjengedal et al. 2010. Norway	All participants in the study expressed the view that national guidelines are required. The guidelines varied between the participants from extremely detailed, to just covering a few main concepts. The study argues that funding should be directed towards producing national guidelines in order to improve the quality of diary writing.	Initial scepticism diminished after positive feedback and research.
Hale et al. 2010. UK	National guidelines are required. Guidelines varied between the participants from extremely detailed, to just covering a few main concepts. Funding should be directed towards producing national guidelines in order to improve the quality of diary writing.	Concerns about legal challenges disrupting implementation. Difficulties talking in layman's terms. Successful implementation relies on teaching.
Jones et al. 2010. UK	Guidelines for the diaries were given to the participants to ensure consistency.	Minimal work apart from writing the introduction.

**Legal ownership, decisions and assumptions, and confidentiality results matrix**

Author, publication year and country	Legal ownership	Decisions and assumptions made on the patient's behalf	Confidentiality
Egerod et al. 2006. Denmark	<p>Sought advice from attorneys but received varying advice. Status of the diary described as ambiguous, not a formal medical record, yet more than a private journal. Diaries authored by nurses are regarded as a legal hospital document (in accordance with the patients' bill of rights), whereas when authored by the relatives it is regarded as a private journal.</p> <p>Diaries co-authored by both relatives and nurses got conflicting legal views and were both accepted and rejected. Most units adopted the view that the diary was the patient's own property.</p>	<p>Most of the participants had no formal criteria, often decision left to the patients nurse. Some asked permission some did not. Nurses started diaries at their own discretion, photos also down to nurse's initiative.</p> <p>Some nurses put thought into the cover, others used plain notebooks, some relatives participate in decisions about the look of diaries.</p> <p>None of the units encouraged the patient to participate; reasons given; they could not focus properly or handwriting too shaky. The nurses viewed the patients as sedated, passive and bedridden, whereas the study proposes that many ICU patients are in fact awake, active and able to communicate. Nurses may need to challenge their preconceptions.</p>	<p>Some units used two separate diaries for staff and relatives.</p> <p>The study also indicates that although it is considered a basic human right to hold a private diary, if a spouse does not have access to information shared in secret between a nurse and a patient; may adversely affect a long term relationship.</p> <p>In some cases relatives would use the diary as a means of communicating with other family members.</p> <p>Situation where the parents chose to publish their child's ICU diary to the internet. Not only exposed the patient, but breached confidentiality of the nurses' diary entries and signatures.</p>
Jones 2009. UK	<p>Sought advice from hospital's legal department- a photocopy of the diaries is filed in the medical notes. Patients are asked to sign a consent form retrospectively for the photographs taken, and to transfer the care of the diary (ownership)</p> <p>Bereaved families are also allowed to receive the diary.</p>	<p>Originally patients family was approached to ask permission for photographs, later revised when some patients expressed that their family had made the wrong decision.</p> <p>Initially preconceptions that burn patients would not want photographs. conversations with discharged patients → would have like photos in order to chart their progress.</p> <p>For these reasons diaries are started and photos taken with consent being asked upon discharge.</p>	<p>If relatives felt that their diary entry was too private to share with others they were encouraged to write on a separate sheet which was sealed and taped into the diary for the patient to read at a later date.</p>

Samuelson & Corrigan 2009. Sweden	A decision was made that the diaries and photographs were not part of the official hospital records, but were the property of the patient.		
Storli & Lind 2009. Norway		View is expressed that the patient must be spared from seeing certain potentially disturbing images, the decision of exactly what constitutes a disturbing image is taken on an individual basis.	
Akerman et al. 2010. Sweden	Diaries regarded as the patients' property. No formal permission was sought even though the hospital lawyers gave conflicting advice about the legal status.	Diaries were assumed to be the property of the patient even though their legal status was unresolved.	Some units had separate sections in the diary for nurses and relatives; others did not allow contributions from family members at all.
Gjengedal et al. 2010. Norway	All the participants regarded the diary as belonging to the patient.	The decision on which patients to initiate dairies was based on whether the nurses thought the patient would benefit. Examples are given of nurses choosing not to start diaries for patients with severe cerebral damage, dementia, or mental retardation.	Most encouraged relatives to write their own diary, or write on separate sheets of paper, added at a later date. Advised that although the diary language should be personal to the individual patient, should not be of a private nature.
Hale et al. 2010. UK			Highlights the challenge of family dynamics. Diversity among families led to questions regarding issues of who is the rightful next of kin. Where possible the patient decided.

## Positive and negative impact results matrix

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Author, publication year and country	Positive impact	Negative impact
Egerod et al. 2006. Denmark	Unexpected positive outcome was in clarifying misunderstandings between relatives and patients There are benefits to hospital staff from patient dairies.	Reliving their illness through reading the diary can leave some patients traumatised. Some nurses relied on the patient's relatives to make decisions on how the diary should be used; the ethics of this were not taken into account. Risk that the formal hospital documentation may lack the information about caring practices and patient perceptions if this type of data is only in the patient dairies. If the diary leaves with the patient then this aspect of the documentation will be lost from official records. May be unclear to nurses where to write which information. In cases where relatives may not participate in the diary process the diary becomes a private document between a nurse and a patient, a spouse my feel excluded.
Engström et al. 2008. Sweden	Gave an understanding of what had happened to them physically, helped them to understand how ill they had been. Explained why it took so long to recover physically. Gave a chronological order to events enabling them to construct a picture of who was present and what had happened. Caused strong feelings but regarded as important support.	
Jones 2009. UK	Gives a clearer understanding of their critical illness than they got from family. Dairies completed memory gaps and were available at any time to re-read. Although it is acknowledged that reading the dairies can be an emotional process requiring support, the general consensus is that they are worthwhile. Provide patients with a better understanding of their diagnosis and are more realistic about their expected recovery times. Can help bereaved family. Relatives have a deeper understanding of the process their loved ones have gone through.	

Samuelson & Corrigan 2009. Sweden	Positive feedback, explanations and support enabled them to move on. A thorough follow-up programme helps both patients and relatives to move on.	
Storli & Lind 2009. Norway	Seen to some as beyond the level of service and care expected, almost like a gift. Door opener for future care relationship. Some were anxious about the content, but the very act of making the diary signals its good intention. Not just about filling in the gaps. Can aid reflection after ICU experience. Provides a framework for follow-up conversations.	Reading text about your own experience may be painful.
Åkerman et al. 2010. Sweden	94%(n=61) reported that patients had expressed that the diary was important. Hospital staff can use the diaries to develop their patient care. 50% of ICU's in the study expressed that nursing practices could be changed as a result of patient diaries.	Some ICUs reported unwillingness from the patient to relive the time spent in critical care. Also the effect that the diary has on the patient has not been fully studied and warrants further investigation. Although there is a strong belief that diaries have a positive impact, there is very little data to support this assumption.
Gjengedal et al. 2010. Norway	Positive feedback from patients about diaries improves enthusiasm amongst nurses to write them in the future. Several ICUs stated that patient care may be improved as diaries increased the nurses' perceptions of the patient's expressions. Some noted a change in focus from solely medical to more human. Conversation between the nurse and patient can help clarify a diary event for both the patient and the nurse. The feedback from patients gave nurses more understanding of what would be important to write about. Diary writing process keeps the nurses continuously aware that the patient is a person. Encourages the nurse to wonder how an event is perceived by the patient. Participants described a shift in focus to see the patient as a human being.	



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Hale et al. 2010. UK	Patients are seen post ICU because of the follow-up. Diaries encourage more involvement from relatives in the patients care. In the event of a patient dyeing the final diary entry can be of particular importance to relatives by providing an account of final stages. If a patient dies, the final entry can assist nursing staff by giving the chance to reflect and receive closure.	
Jones et al. 2010. UK	<p>A diary given at one month after discharge from ICU can reduce the incidence of PTSD.</p> <p>Diaries work in a similar way to cognitive behavioural techniques used to treat PTSD. Feedback from patients was positive with many reporting that they read the diary a number of times.</p> <p>Relatives may suffer from PTSD- Diaries may help to make the story of events clearer, and also opens up the channels of communication between relatives and patient.</p>	

## Diary handover and emotional processing results matrix

12(17)

Author, publication year and country	Diary handover	Emotional processing
Egerod et al. 2006. Denmark	Patients given diary when discharged, department does not keep a copy. Some gave diary to the patient's relatives or let the diary go with the patient to the wards with their belongings. Unclear at what point the diaries were read, if ever. Diaries were introduced without a proper follow-up plan. Unknown how the patients reacted when they read their diaries. Ethical issues not properly addressed, potentially some of the patients may have been traumatised by reading about their experiences without any support.	
Engström et al. 2008. Sweden		<p>To some patients the content didn't feel real; they doubted its truth, felt like reading someone else's story. Reading personal factual events yet having no memory of them. Many questions arose and confirmation of the narrative was desired. Reading the diary for the first time described as grief filled, many patients struggle to get through it. Patients were fearful to start reading the diary, expressed an expectation that it would not be easy. Reading the diary for the first time evoked strong emotions and reactions. Many reported crying the first few times they read the diary. Some patients, who started to read, found it too traumatic to continue and had to come back to it at a later date. Others describe starting at the end and working backwards. Important to be prepared before reading.</p> <p>Taking advantage of the content could only happen after repeated readings; strong emotions subsided after reading a few times.</p> <p>Humbling effect on their lives, not wanting to take life for granted, and a newfound desire to make positive life changes.</p>

Jones 2009. UK	<p>Patient is contacted by telephone or on the general ward and asked if they would like to receive their diary. If they are not ready the diary is stored and they are asked again around two months later when they come to the ICU outpatients' clinic. Before the diary is handed over, a consent form is signed giving permission for the photographs.</p> <p>A member of the diary team goes through the diary with the patient to ensure everything is understood.</p> <p>In cases of bereavement, the critical care liaison nurse writes a letter to the relatives inviting them to come in to the hospital to receive the diary.</p> <p>An appointment is made and either the liaison nurse or a member of the diary team hands the diary over. To avoid the potential upset of returning to the intensive care unit, the appointment is held in a different part of the hospital. Bereaved families are given a copy of the diary, but are not given any photographs.</p>	<p>When patients see photographs taken during their treatment for the first time, it can be emotional. Patients may need support when they read what their relatives have written about them. Despite this emotion, the patients expressed that diaries are nonetheless beneficial.</p>
Samuelson & Corrigan 2009. Sweden	<p>diary accompanied the patient to the general ward to enable the relatives and ward staff to continue writing in the diary. A nurse from the diary team visits the patient within three days to explain the purpose and content.</p> <p>Between two and three months after discharge- invited to a 90 minute follow-up consultation.-includes explaining what happened during their hospital stay, and handing over the diary and photographs. An opportunity is given for the patient and relatives to talk about their experiences.-discussion about long term rehabilitation and health problems.-opportunity to re visit the ICU department.</p> <p>The study stresses the importance of a doctor and a psychologist collaborating with the after care nurse to offer support and make referrals.</p>	<p>The study highlights the vulnerability of the patient at the follow-up consultations. There is the potential to uncover disturbing memories, and cause distress if patients and relatives aren't treating with respect and sensitivity.</p>

Storli & Lind 2009. Norway	The diary used as a basis for conversation. Conducted after the patient is discharged from ICU, patient encouraged to re visit the ICU diary must be handed over with caution, the nurses talk about guiding the patient through the entries, some starting at the back of the diary The patient is warned that the experience may be difficult, and patients are encouraged to go at their own speed.	Reading a book that chronicles own experience of survival can be very emotional. Follow-up sessions take a conversational form. If diary text poses open question, patient can use this as starting point for own reflection. Presenting the diary to the patient is likened to the giving of a gift, the symbolic nature is discussed. Described as opening the door for a dialogue to start between the patient and follow-up nurse.
Åkerman et al. 2010. Sweden	Less than 10% of the participants handed the diary over as part of a follow-up clinic, majority handed the diaries over as the patient was moved from ICU the follow-up protocol varied between departments, most common for there to be some kind of visit while the patient was still on the ward, then follow-up at around two months following discharge.	
Gjengedal et al. 2010. Norway	Need for sensitivity when handing over the diary. Patient must have opportunity to reject the diary and the photographs. The majority handed over the diaries after discharge; other participants' approaches to diary handover were more random. Many of the participants express a desire to improve the system of how diaries are handed over.	Patient's memory from their ICU experience can be seen in a new perspective as the result of the conversations that emerge from reading the patient diary. The resulting position can be beneficial to both the patient and the nurse.
Hale et al. 2010. UK	Patient invited back to the department four weeks after discharge. patient meets with one of the dedicated diary team, and may also meet with one of the ICU consultants if they wish. The patients' are encouraged to bring relatives with them, given time to ask any questions. Photographs are given to the patient at this point, and they are encouraged to take the diary home to read it at their own pace. Patients given a contact number if they have any questions at a later date. Photocopies of the complete diary are kept for two years and then stored on disc as part of the patient's official notes. Diaries which are not collected are destroyed after two years.	

<p>Jones et al. 2010. UK</p>	<p>Diary was handed over by either a research nurse or a doctor, the diary and photographs were explained to the patient but no advice given as to how the patient should use the diary.</p> <p>Handovers were done in the outpatients department, with a few happening at the patient's own home, or over the phone.</p> <p>In these cases the diary was sent by recorded delivery with instructions that the patient should not open the diary until the nurse rang at a given time.</p> <p>Patient feedback about the diaries was positive, with patients reading their diaries a median of 3 times. Only one patient in the study had not read the diary at all. 84% of the intervention group had given the diary to either friends, family, or colleagues to read.</p> <p>Less than 2% thought that meeting with the nurse was what helped them most, 49% said reading the text was most helpful. 15% said combination of text and pictures was of most help, 15% saying photographs alone.</p>	<p>It is acknowledged that a nurse with experience is required at the point of diary handover in order to clarify its contents to the patient.</p>
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## Resources and follow-up results matrix

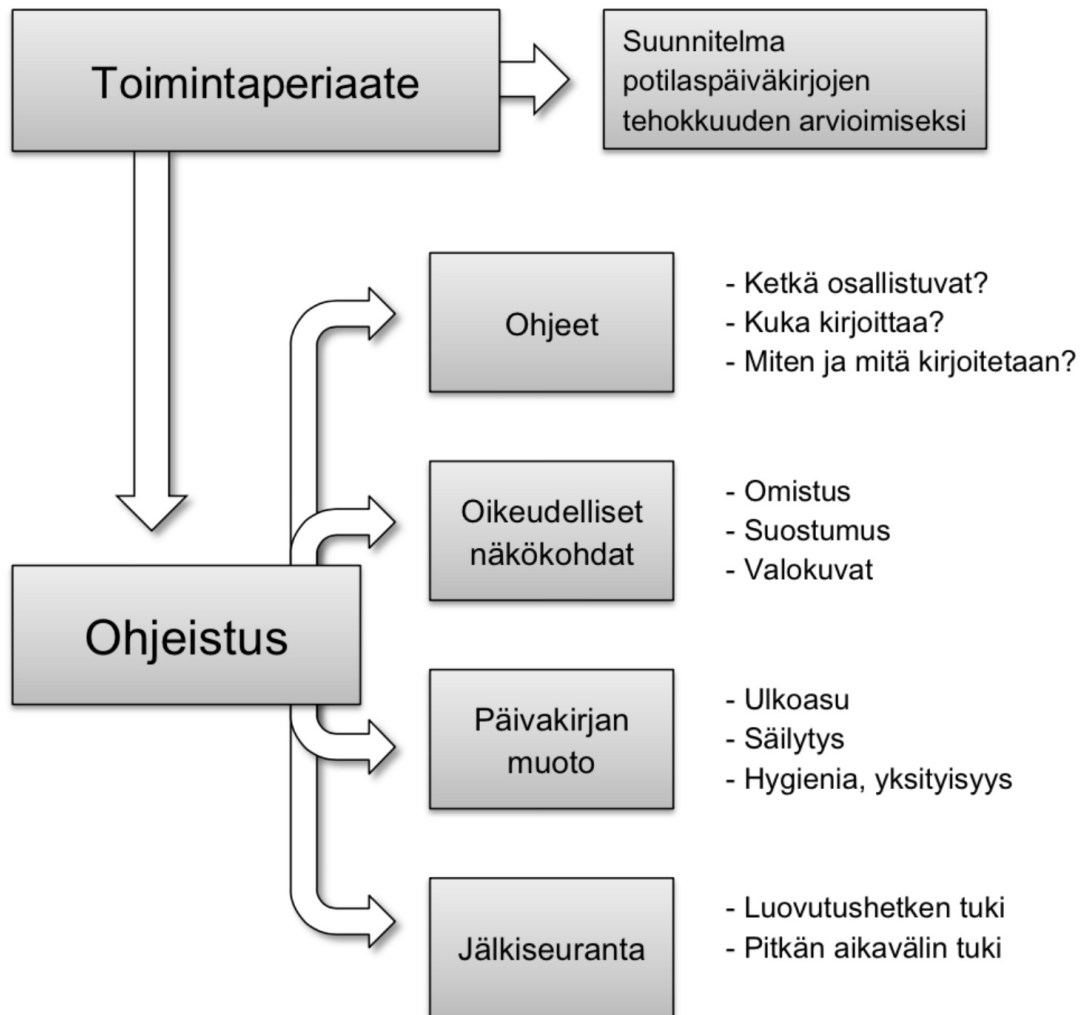
16(17)

Author, publication year and country	Resources	Follow-up
Egerod et al. 2006. Denmark		The diaries did not form part of a follow-up programme.
Engström et al. 2008. Sweden		Follow-up visits were beneficial in clarifying links between the diary and the patient's memories. Used as a central part of the follow-up, and provided a way to initiate conversations. Important for the patient to meet the person who wrote his/her diary, having someone read the words aloud gave it greater meaning.
Samuelson & Corrigan 2009. Sweden	Arguments that a nurse-led patient diary initiative, including a multidisciplinary after care at follow-up clinic can be implemented using relatively small resources.	Follow-up was undertaken by a multidisciplinary team consisting of doctors, psychologists and nursing consultants. The best time for the follow-up was two to three months after discharge. At this point, any psychological problems had had time to surface. Extra support should be given by visiting the patient early on, one to three days after discharge. At this point the patient is still on the general hospital ward. During the early visit, the patient and relatives are given an information sheet, the telephone number of a helpline, and an invitation to the follow-up two to three months later. The follow-up consultation lasted for 90 minutes, this amount of time is required in order to create a relaxed atmosphere, and for the patient to feel listened to without being interrupted. In order to be of any benefit to the patient, sufficient time must be allowed for the discussion.
Storli & Lind 2009. Norway		Follow-up programmes varied not only in content, but also in the philosophy on which they are based. Important for follow-up nurses to have individual knowledge of the patient's story. Return visit to the department is a form of exposure therapy. Surprise at how a potentially traumatic visit received positive feedback.

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Åkerman et al. 2010. Sweden	University hospitals were more likely to assign dedicated diary staff, whereas smaller hospitals did not have the resources to do so. Links the lack of resources of certain hospitals to the lack of research and education regarding patient ICU diaries.	Providing a follow-up programme requires extra financial resources, suggests that the content should be tailored to the needs of the individual patient. Proportionally, many more county ICUs than district ICUs offered systematic follow-up programmes. Lack of scientific research into using diaries as part of follow-up.
Gjengedal et al. 2010. Norway	Most left the responsibility to a dedicated diary team, or individual. Responsibilities include diary writing, supervising, motivating, and education. Extra resources are not allocated to diary writing, although some units received support to set up the initiative. Lack of resources limits the further development. More resources should be directed towards diary practice, including quality control in the form of national guidelines.	Diary is just one part of the whole follow-up programme. Over 50% of the participants offered systematic follow-up for patients which included diaries. Link between high levels of diary writing with systematic follow-up programmes. Hospitals in which diary writing was lower had more random follow-up activity. The diary was seen as a central part of the follow-up programme, and formed the basis of the conversations. Benefits in highlighting ways in which to improve nurses' diary writing. Lack of resources is the main obstacle to implementing a follow-up. Introducing patient diaries without a systematic follow-up programme is unwise.
Jones et al. 2010. UK	There is a financial cost in implementing a dairy system. Costs include commitment from nurses to make regular entries and document significant changes using photography. Time for an experienced nurse to offer support and answer questions when the diary is handed over. This doesn't require many more resources than are needed when providing and unstructured chat. Cost effective when compared to the potential resources required to provide cognitive behavioral therapy at a later date.	

## 9.5 Appendix 5. Finnish version of suggestion mind map





## 9.6 Appendix 6. Finnish version of suggestion statement

### **Ehdotuksia Pirkanmaan sairaanhoitopiirille**

Koska potilaspäiväkirjoihin liittyvät kansalliset ohjeet vielä puuttuvat, ehdotetaan jokaisen yksittäisen sairaanhoitopiirin luovan ja vahvistavan omat toimintaperiaatteensa. On välttämätöntä myös selvästi määrittää, keitä potilaspäiväkirjojen käyttö palvelee ja kuinka se sen tekee. Tutkielma esittää potilaspäiväkirjojen olevan tehokkaimpia yhdistettynä koordinoitun seurantaohjelman kanssa. Suunnitelmaan pitäisi myöskin sisältyä potilaspäiväkirjojen tehokkuuden arviointia potilaiden pitkän aikavälin seurannan vaikutuksista.

Mitä tulee toimintaperiaatteisiin, niin niiden tulisi selvärajaisesti ohjeistaa päiväkirjojen sisältöä. Yleisohjeiden pitäisi myös selvästi eritellä, keitä potilaita päiväkirjajärjestelmä koskisi. Päiväkirjan kirjoittajat tulisi myös jollakin tavalla rajata. Ja kirjoittajienkin (siis esim. hoitajien ja sukulaisten) olisi tiedettävä, kuinka ja mitä kirjoittaa.

Potilaspäiväkirjojen oikeudellisia näkökulmia tulisi miettiä vielä varsinkin sen kannalta, kuka on päiväkirjan laillinen omistaja. Lisäksi asioita suhteessa potilaan suostumukseen pitäisi tutkia. Olisi hyvä olla myös tarkkoja selvityksiä siitä, kuinka ja milloin potilaan suostumus hankitaan. Laillinen päätös tarvitaan lisäksi kuvallisen dokumentoinnin suhteen.

Paitsi potilaspäiväkirjojen ulkoisen asun ohjeistukseen, tulisi myös säilytykseen kiinnittää huomiota. Hygienian ja yksityisyyden varmistamiseksi voisi standardoitu irtolehtiä sisältävä kansio sopia tarkoitukseen.

Olenaisena osana päiväkirjaprosessia on jälkiseurantaohjelma. Ohjeistusten pitäisi sisältää kriteerit päiväkirjojen luovuttamisesta, kuin myös siitä, miten potilasta henkisesti tuetaan tässä kriittisessä vaiheessa. Lisäksi kotiuttamisen jälkeen toteutettavasta pitkäaikaisesta tuesta on tärkeä olla strategia.