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Research Article

Filling the gaps: A mixed-methods study exploring the use of patient diaries in the critical care unit

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ABSTRACT

Background: Survivors of critical illness often take time to recovery physically and psychologically from their critical care experience. There is tentative evidence suggesting that the use of a patient or family led diary with entries by nurses, doctors and allied health professionals may help the patient 'fill in the gaps' by making sense of a time they have forgotten. Many have confused or frightening memories and a diary can aid patients and their families in the recovery after critical illness.

Aims: A mixed methods study including a qualitative exploration of the impact of diaries on critical care patients in order to describe the long-term effects of patient diaries.

Methods: A two phase study including a prospective diary intervention and evaluation and subsequent in-depth interviews, using the principles of Grounded Theory. The instruments, Post Traumatic Stress Score-14 (PTSS-14) and EuroQol (EQ-5D-3L), were used to measured post-traumatic stress symptoms and quality of life in the year after diary. A questionnaire about diary use was completed by participants and content analysis of the diary was also undertaken, alongside basic demographics to explore patient characteristics.

Findings: For the 50 patients receiving the diary intervention, those completing a diary evaluation, 95% found them helpful and 90% found it helped fill memory gaps. Mean scores for PTSS-14 (cumulative) at four months and 12 months: 30.5 (SD=10.8) and 25.7 (SD=11.7). Mean EuroQol visual analogue scores at four months and 12 months were 77.8 (SD=14.3) and 71.8 (SD=18.5) respectively. Themes from subsequent interviews with eight patients included: providing holistic care, emotional support and empathy and dealing with loss of control. Data confirmed that whilst diaries had broad value in making sense of the critical care experience and their subsequent recovery, not all were able to read them again. Integrated analysis of four data sources suggested the core themes of the diary revealed its value as: a dynamic communication tool integral to holistic care and person-centredness; a reflection of the impact of a critical care event and a resource that helped give a sense of meaning to what had happened.

Conclusion: Diaries can offer a means of providing clarity for patients who struggle to come to terms with their critical care experience and subsequent recovery, but should be given to patients with forethought and support. It remains unclear which types of patients might benefit most from diaries.

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Implications for clinical practice

- There is limited evidence regarding the use of diaries in critical care, particularly from the perspective of patients, which explores the long-term effects during peoples' recovery from critical care.
- Emerging evidence suggest diaries may be useful in helping patients piece together lost memories whilst in critical care. These diaries may also be helpful for families during the critical care admission, and after discharge when they are supporting people in their recovery after critical care.
- Whilst diaries have positive benefits, they are not beneficial to all. For some, they can help clarify events and feelings during a patients' critical care stay, but should be used with careful forethought.

Introduction

The use of critical care diaries in clinical practice has existed for nearly two decades, with indications that their use may aid psychological adjustment after critical illness (Glimelius Petersson et al., 2015; Ullman et al., 2015). In particular, diaries may aid dealing with and preventing anxiety and post–traumatic stress disorders (PTSD) (Egerod et al., 2011, Wade et al., 2016). Anxiety related to critical care experiences was noted in a third of critical care survivors during the first year of recovery (Niyakin et al., 2016). Moreover, depression prevalence peaks at around six months, with depression reaching 34% (Rabiee et al., 2016) and PTSD prevalence at one to six months post-critical care reaching 25%, with associated impact on worse quality of life (Parker et al., 2015). The format of diaries varies broadly (Beg et al., 2016), however they seem to comprise of several core elements: a written format that tends to be on paper or in a booklet; content completed by staff and families; and diaries returned to patients after their critical care stay (with or without nurse support).

Various researchers have suggested in several studies that patients may benefit from the use of a critical care diary, such as to fill in the gaps in memory and to aid debriefing at critical care follow-up (Jones et al., 2010; Egerod et al., 2011; Ewens et al. 2015; Knowles and Tarrier, 2009; O'Gara and Pattison, 2016). There is reported value of diaries in piecing together lost events, ameliorating distress and emphasising personhood or person-centred care (Ewens et al., 2015; O'Gara and Pattison, 2016; Wade et al. 2016, Teece and Baker, 2017). However, it has been suggested that diaries can be complicated documents to write for nursing staff (Ednell et al., 2017), and long-term benefits remain unclear (Ullman et al., 2015; Aitken et al., 2017), with few studies providing evidence to definitively support their use (Aitken et al., 2013).

The effects of diaries in relation to harm are unknown (Elliot and Rattray, 2011) and have yet to be explored beyond five months in any of the existing published diaries studies to date. Aitken et al. (2017) found preferences for receiving diaries post-ICU are not related to psychological distress. Backman et al. (2010) showed an improvement in health-related quality of life scores at three years in the (uncontrolled) diary group; evidence from another study of critical care diaries suggests a reduction in new-onset PTSD with their use (Jones et al., 2010) and reduced PTSD in families (Jones et al., 2012). However, endpoints for most of these particular studies were relatively short at only three months. National Institute of Health and Clinical Excellence Quality Standards (2017) for critical illness rehabilitation requires a follow-up review at two-three months after critical care, but many patients require support long after this, with PTSD still persisting one year later in a fifth of patients (Parker et al., 2015).

Our primary aim was to explore the long-term effects of diaries, in terms of experiences. As a secondary aim we wished to qualitatively explore any potential aspects of harm in the year after completing diary. Findings from our previous research (O'Gara and Pattison, 2016) informed this, our main evaluation study, with a different population (cancer patients in critical care), which aimed to describe the long-term effects of a prospective intervention to implement patient diaries. This study also aimed to describe changes in quality of life and post-traumatic stress scores in the year after completing a diary.

Research design

The design was a mixed method study, described as an exploratory sequential study (qualitative emphasis) (Creswell and Plano Clark, 2007). This involved a two-stage study. Stage 1 included a prospective diary intervention, examination of patient characteristics and diary content analysis, using the principles of Grounded Theory in order to generate theory about how diaries might contribute to recovery. Stage 2 included in-depth interviews and questionnaire evaluation. The instruments, Post Traumatic Stress Score-14 (PTSS-14) (Twigg et al., 2008) and EuroQol (EQ-5D-3L) (Dolan et al., 1997), were used to measured post-traumatic stress symptoms and quality of life (see Fig. 1).

Setting

The study setting was a tertiary referral cancer hospital in England with a designated 19-bedded critical care unit (CCU).

Sample

A consecutive sample of 50 adult patients were invited via the surgical pre-assessment clinic. This sample included: 1) patients likely to remain in the CCU for >48 h 2) able to read and understand English and 3) minimum 18 years of age. Medical patients admitted to CCU were, where appropriate, informed about the study and asked if they wish to participate. All patients had cancer. A sub-sample of eight participants, reflecting a range of critical illness and length of stays, took part in follow-up interviews following discharge between 6 and 12 months (Fig. 1). Theoretical sampling informed the interview sampling, as per Grounded Theory approach (Glaser, 1992), to ensure that issues that arose in one patient group (e.g. specific to gender, or type of surgery) were sampled in different types of patients to test that emerging concept.

Ethics

A favourable ethical opinion was obtained from a regional health Research Ethics Committee (Ref 12/LO/1085). Patients were recruited from October 2013 to February 2014 and data were collected from October 2013 to March 2015. In situations where patients were admitted as an emergency or who were too unwell to provide written consent, their families were informed and

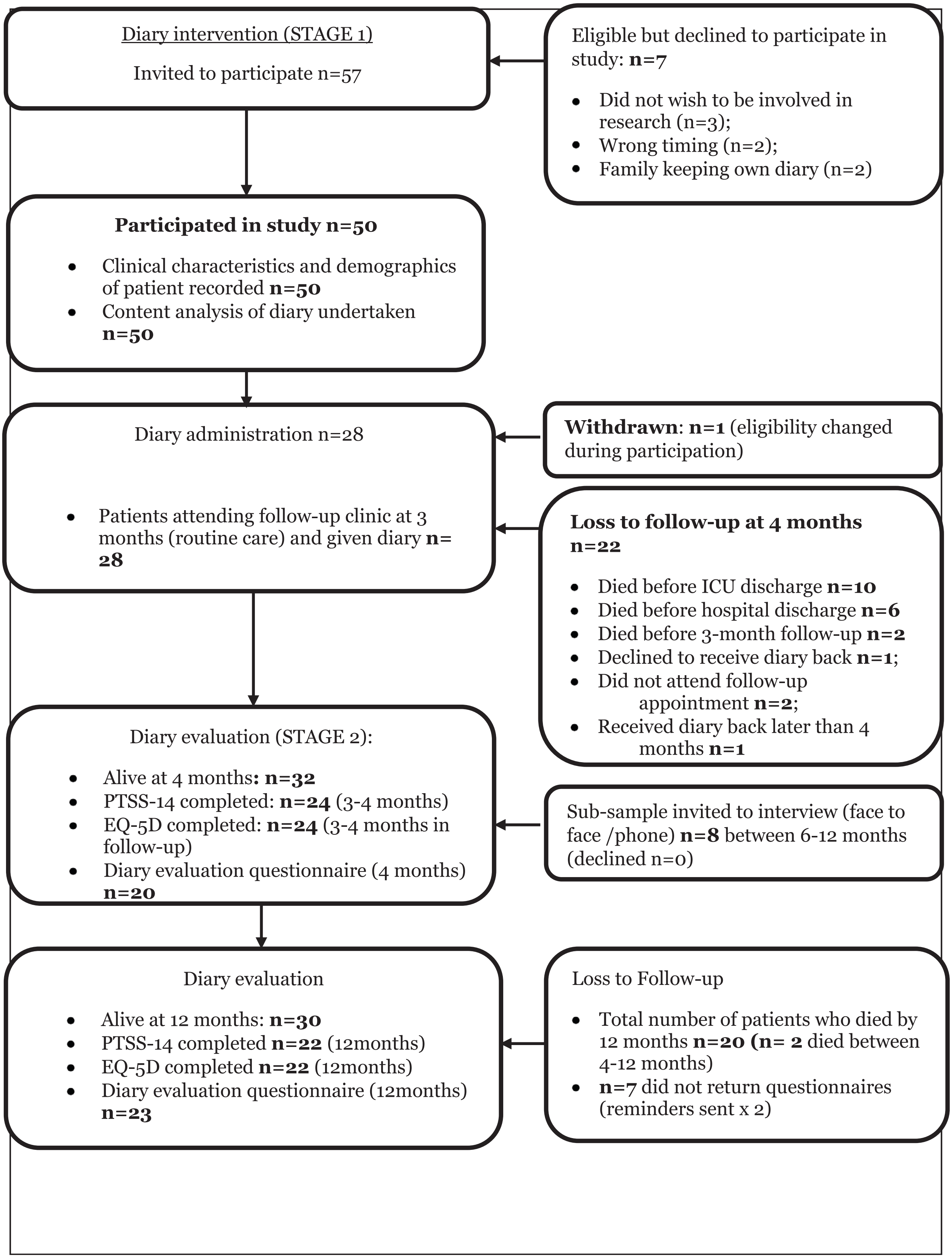

Fig. 1. Study Flow Diagram.

invited to participate and were given time to consider whether to participate (assent). When the patient recovered they were consented retrospectively and given the choice about the diary continuing or not (Mental Capacity Act, Department for Constitutional Affairs, 2005). Pseudonyms were used when presenting qualitative data to ensure participants anonymity.

Methods

Diary administration

The diary, a small A5 notebook, was commenced as soon as possible after consent/assent and was kept at the patient's bedside. Training was undertaken prior to the study involving all nursing, medical and allied health professional staff about diary use and appropriate entries. Families were supported by staff to write in the diaries, with written guidance in each diary to support use. Diaries were returned and discussed with patients at their three-month follow-up review.

Health outcome measurements

To measure PTSS scores, a 14-item self-report screening tool, the PTSS-14 was used. Each item is rated one (never) to seven (always) with a total score ranging from 14 to 98 (Twigg et al., 2008). To assess quality of life, Euroqol EQ-5D-3L data were collected at 3–4 months and 12 months (Fig. 1). The EQ-5D assesses quality of life in five domains: mobility, self-care, usual activities, pain, anxiety and depression. A visual analogue scale (VAS) score out of 100, as best possible health, forms part of the EQ-5D (Dolan et al., 1997). Data collected included severity of illness scores (APACHE II [Knaus et al., 1985], TISS [Lefering et al., 2000] and SOFA scores [Moreno et al., 1999], where available), length of CCU and hospital stay, presence of delirium and sedation scores (CAM-ICU [Ely et al., 2001] and RIKER [Riker et al., 1999]), cancer type, length of mechanical ventilation and patients' CCU and hospital outcome.

Questionnaires/interviews

A 15-item questionnaire was administered at four and 12 months regarding the use of diaries, which had been reviewed and pilot-tested for face and content validity by the patient and public involvement group (a group, predominantly comprising of patients, who reviewed the study). Questions were rated on a five-point Likert scale and included assessment of harm: '*I wish I had never read the diary*'*; 'Reading the diary upset/s me*', as well as positive reflection of the diary, such as: '*My family finds reading the diary helpful*' and '*Reading the diary helps me fill in memory gaps*'. In-depth interviews were carried out by GOG or NP (both ICU nurses by background) either at the hospital or over the phone, audio-recorded and transcribed verbatim.

Diary content

Following patient and public involvement in the design of the study, a further suggestion was made to analyse each diaries' content. Thematic analysis was therefore undertaken on the content of the diaries in order to explore the differences between entries from different groups, use of language, style and content (Braun and Clark, 2006).

Analysis

The five data sources were analysed separately and then together, using cross-case analysis (Miles and Huberman, 1994) and aided by a mixed methods matrix, in order to provide explanation for contrast and to compare across datasets.

Interview data were analysed using Grounded Theory principles (Glaser, 1992). Open coding was applied, where the data is considered sentence by sentence, to gain an understanding of the meaning. Preliminary categories were developed for the emerging themes and codes given to demonstrate the categories and emerging themes. Selective coding was then applied, where one systematically codes in regard to a core concept, which is linked to data themes and an explanation or theory is proposed (Glaser, 1992). Constant comparative technique allowed the generation of categories and identification of each category's property by contrasting and comparing incidents, and testing against the literature, ultimately reaching theory generation. The team analysed separately and together to enhance trustworthiness and dependability of the data (Lincoln and Guba, 1999).

The patient diary evaluation questionnaire included an open-ended question to elicit a free text answer, which were analysed qualitatively using content analysis (Weber, 1990).

The quantitative data from the questionnaires (PTSS-14; EQ-5D) and CCU diaries questionnaire were reported as frequency and percentages. Continuous normally distributed variables were reported as mean (M) and standard deviation (SD) and skewed data were reported as median (Mdn) and interquartile range (IQR). Continuous data were analysed using paired-sample t-tests for the longitudinal data (PTSS-14; EQ-5D). Statistical significance was set at 0.05. The EQ-5D was coded as either: 1, 2 or 3, with 1 = no problem; 2 = some problems; 3 = extreme problems. Health states were converted into a single utility score (Dolan et al., 1997). PTSS-14 data was analysed and reported as a total cumulative score (Twigg et al., 2008).

Findings

The findings are presented in five sections: 1) Demographic data (patient characteristics); 2) Diary evaluation; 3) Quality of life (EuroQol, EQ-5D-3L) and post-traumatic stress scores (PTSS-14); 4) Diary content themes and 5) Questionnaire data.

Fifty people participated; participant characteristics are outlined in Table 1. By 12 months, 40% of participants had died (see Fig. 1).

Patient characteristics

The characteristics of patients who received diaries were as follows (Table 1):

Diary evaluation

The diary evaluation questionnaire was completed by 20 out of 30 participants at around four to six months and 23 participants at 12 months. All professions wrote in the diaries, as well as family members and, rarely, patients. Of those who responded, 95% (n = 19) found diaries helpful and 90% (n = 18) found diaries helped fill memory gaps. Of these, nobody reported that they wished they

Table 1
Patient Characteristics.

Characteristic	(Patients n = 50)
Age	M = 58.9 years (SD = 12.9)
Gender	Male 60% (n = 30); Female 40% (n = 20)
CAM ICU positive	CAM ICU positive 14% (n = 7)
Length of Stay: Critical Care	Mdn = 12.5 days (IQR = 6–23.5)
Length of Stay: Hospital	Mdn = 31.5 days (IQR = 17.5–57.25)
SOFA score	M = 9.7 (SD = 5.5)
Acute Physiology And Chronic Health Evaluation II (APACHE II)	M = 21.1 (SD = 5.43)
Therapeutic Index Scoring System-28 (TISS)	M = 40.7 (SD = 10.5)

had not read the diary, although one respondent was equivocal (neither disagreed or agreed). When asked whether 'Staff entries meant the most', 80% (n = 16) strongly agreed or agreed, 10% (n = 2) neither disagreed or agreed and 10% (n = 2) disagreed. Only 40% (n = 8) agreed it was useful for their families to read the diaries, with 15% (n = 3) disagreeing; 55% (n = 11) agreed it was helpful to go over the diary with the follow-up, but one person strongly disagreed.

Quality of life and post-traumatic stress symptom scores

Quality of life was seen to decrease over time, although these decreases were not statistically significant. At four months, the EuroQol (EQ-5D-3L) visual analogue scale score (ranging from 0 to 100) decreased from a mean of 79.1 (SD = 13.9) to 71.5 (SD = 18.7) by 12 months, (t = 1.78; p = 0.09). The EQ-5D-3L utility scores also reflected this decrease with a change of mean from 0.79 (SD = 0.19) to 0.75 (SD = 0.28), (t = 0.55; p = 0.59). The mean post-traumatic stress symptom scores (PTSS-14) increased over time from a mean of 26.7 (SD = 13.4) at four months to a mean of 31.3 (SD = 14.4) at 12 months, however, this difference was not statistically significant (t = −1.65; p = 0.12).

Diary content: thematic analysis

Table 2 outlines the five broad themes from the diaries: *Emotional Impact, Loss of Control and Vulnerability, Communication Challenges, Encouragement and Engagement, Expressions of Empathy and Rapport.*

Emotional impact

Entries reflecting emotional consequences of the impact of patients being in critical care, were prominent in all entries, acknowledging the effect on both patients and families, and the interwoven nature of emotional and physical sequelae.

> *'You're doing so much better, [patient name] – we know its hard but we're all here to support you and get you back on the road home... to see your grandkids and all the family!' [R14, nurse entry]*

> *'Feel like I am making progress... Speaking valve on for nearly 2 h, wonderful... A bit worried about all the stress that my wonderful husband, X, has gone through.' [R21, patient entry]*

One patient made an extensive entry regarding her feelings about her critical illness and cardiac arrest. However, she preferred not to receive her diary back, stating she wished to move on. Families of patients who died were offered the diary as part of a bereavement follow-up; four people refused, with some saying it was too hard to go back.

Loss of control and vulnerability

Family entries often displayed vulnerability about their own feelings about the situation, which tied in with expressing empathy for their loved one, highlighting the impact on the whole family unit:

> *'... today they said they started giving you drugs to support your blood pressure – I got a bit emotional – [nurse's name] has been very attentive and has referred me to someone to talk to.' [R39, family entry]*

Patient entries focused particularly on the loss of physical, and to some degree psychological, control, emphasising their vulnerability and the consequences of this feeling, such as despondency, anxiety and depression, as seen below:

> *'Feeling despondent and really want the tube out now, maybe tomorrow but I suspect not. Feel like I will never get out of here...' [R21, patient entry]*

Encouragement and engagement

Encouragement was also noted throughout, with physical progress cited as a milestone, such as siting on the edge of the bed for the first time, and the majority of these entries had a light/positive tone:

> *'I'm so proud of you! Your strength is amazing, what you've been through shows you are a fighter. Never forget you can do anything, I will always be by your side helping you through.' [R12, family entry]*

Entries also referred to appearance and the physical impact of critical care illness, acknowledging difficulties, but also trying to engage with patients:

> *'You said you couldn't recognise yourself ... [that] you looked like a 'freak'. We spoke about your hair ... you want to shave it all off. I have summoned the barber!' [R48, nurse entry]*

Expressions of empathy and rapport

Some entries also referred to the holistic nature of care, not just focusing on the physical and more obvious demands but striving to attend to patient individual and family needs, demonstrating rapport:

> *'Another nurse called Lucy was singing to you, which instantly made me feel all was OK.' [R25, family entry]*

However, other entries demonstrated little personalisation of the diary:

Table 2
Analysis and coding.

	Professional	Family	Patient
Initial codes	1867	1122	122
Grouped in categories	134	56	25
Themes	6	4	3
	Emotional impact *Encouraging widely (patient and family)* *Engagement (with patient and family)* *Providing holistic care* *Communication* *Physical*	*Communication (with patient and staff)* *Gratitude* *Rapport* *Empathy (for patient, other family members and staff)*	*Loss of control* *Emotional impact/Anxiety* *Vulnerability/Insecurity*

> *'You had a stem cell transplant at X which was successful, however you developed some infections in the chest, kidneys. You were also showing signs of confusion... [R16, nurse entry]*

Affection and admiration for the patient and gratitude to staff also featured, positively demonstrating the relationship between staff, patient and loved ones:

> *'... I want to express my love and thanks to you all for caring for me, lifting my spirits and carrying me so far...' [R2, patient entry]*

Entries at times of transition to dying, showed staff were appropriately able to express empathy to the family whilst maintaining a patient-centred approach:

> *'... whatever happens today you can be sure that you will be loved and remembered for many people. Keep looking after them. [Wife's name]: keep strong and I wish you all the best for you and your daughter. You should be very proud of your strength. All the best.' [R47, nurse entry]*

However, not all diaries contained entries at these times, despite these transitions taking place, suggesting that some staff may have struggled with such entries.

Interviews

Eight interviews took place ranging from 29 to 63 minutes. Time from recovery ranged from six to nine months. Data from open codes (7 1 6) and selective codes (13) were further refined into six emergent themes: *Need for detail; Impact of critical illness on self; Impact of illness on others; Diary as a multifaceted tool; Shifting locus of control and Varying ability to move on*. There was an overarching core theme of diaries as a ***Means of Supporting the Emotional Legacy***, characterised by facets from each emergent theme, outlined below.

Need for detail – '*...it put things back together for me...*'

Some patients commented on their poor recall of events in CCU, and how the diary was useful in helping them make sense of their time there. One person was unable to recall any of their time in critical care and the diary was their only record of their stay; another person realised they had undergone a second operation after reading their diary. For some, the diary was seen as a record of events that allowed the patient insight into their experience and aided with emotional adjustment:

> **"***...because every [entry] was dated, I was able to follow a pattern, see how long things were and you know at what point I perhaps remember things happening so it puts things in a time period for me... I don't think it's done much for the recovery but it has created situations such that I can sort of think about things and ask questions, that's the main thing..." [R13]*

Impact of critical illness on self – *'...well enough for a normal life...'*

Patients commented on the impact of their acute critical illness on themselves both physically and emotionally. For some, these impacts were short lived; for others the effects were ongoing and perhaps permanent requiring adjustment and acceptance of the consequent impact on their quality of life:

> *"Well, I was back to work in I think 5 weeks...I went back part-time initially and then within 2 weeks I was full-time, I think." [R18]*
>
> *"I still have nausea, still get sick about once a week, they have investigated but found nothing. And I am tired, have had to retire from work which is hard, but I feel in general I am doing ok." [R21]*

Expectations of recovery are also highlighted, with some patients expressing hope for a return to near previous physical state, and disappointment for not achieving that goal.

Impact of critical illness on others – '*...you can feel from what they're writing ... what they're going through...*'

Patients commented on the impact of their critical illness on their significant others, with the diaries acting as a reminder of the care and attention received. It offered insight into the experience of their loved ones. For some, there were feelings of guilt at being the cause of such anxiety:

> *"...you feel guilty, my God their running around, they're in there everyday, you know, waiting, they're leaving work and they're coming here and they're sitting around and, so there is that feeling of kind of 'I'm causing all this trouble', ...so I suppose there's guilt, and there's that...that sense of relief that they care [R39]*

Diary as a multi-faceted tool – '*...it just reminds me of how very unwell I was and how far I have come...*'

Diaries were seen as useful when marking progress over time, allowing patients to see how far they had come since their critical illness both physically and emotionally.

> *"I sort of kind of took different things from it when I read it a second time ... I suppose it was more of an emotional response when you first read and then the second time, once you've got that emotional response sorted then you look more into the facts and details of what's gone on..." [R39]*
>
> *"Well I think it's [the diary] a very good idea...because as I say you know, in a way it is a special situation in your life..." [R8]*

Rollercoaster of control – '*things were up and down all the time...*'

Loss of control was highlighted, extending into the long-term recovery. Diaries were seen as an accurate account of a time that is unclear for some patients; timing of return was also important. Patients reported being better able to relate to a 'real time' account of their experience, allowing them to own it and thus offering some control.

> *"I wasn't conscious when all this was going on...you know you're kind of, you're sort of understanding how your family are feeling at that time, basically...I suppose the bits that were backdated mean a bit less, to be honest with you, in a way, they are,...they are not written as it happening, somehow it's not so, not so real... in terms of understanding what happened, you know, and just being able to sort of, kind of know what was going on in that time when I wasn't really conscious, you know that was important..." [R39]*

> *"The patient should perhaps be asked when they would like it back, so that they're in control of the timing...yeah, that's probably the best." [R18]*

> *"I think I felt more able to read it when I was at home really and see what did go on and what was said." [R11]*

Varying ability to move on – *'no longer 'stuck' in CCU...'*

Patients commented on their ability to move on from their critical illness. While some saw the experience resolutely in the past, for others, it was remembered vividly and as 'real'. This may be linked to residual impacts of their critical illness, ongoing health and treatment or to current deteriorated physical or psychological states.

> *"No, the diary didn't help my recovery, but I do think it may be useful for others who are less able to piece memories together. I haven't read my diary again and don't think I will do..." [R45]*
>
> *"When I got home I realised I hadn't got it, and...in fact I think I went to the trouble of either phoning somebody and saying 'what's happened to the diary? ...so I was a bit concerned that it might get lost in the mire, sort of thing..." [R13]*

Data triangulation and the interrelationships between the datasets can be seen in Fig. 2 (supplemental file). These data outline how diaries, for some, could be a way of managing the emotional legacy. The mixed methods matrix (supplemental file) outlines the integration of the different datasets, emphasising this emerging theory: Means of Supporting the Emotional Legacy, where the diary is a dynamic communication tool, integral to holistic care and person-centredness. It is a reflection of the impact of a critical care event and a resource that helped give a sense of meaning to what had happened. As a highly personal document, some wished to revisit and others did not, which related to a sense of how past events were viewed as shaping future well-being. In giving meaning, diaries were particularly important in very seriously ill patients with protracted stays as it located the events within human interactions (family and professional), often providing a record of intimate feelings and a way of dealing with missing chronology.

Discussion

This study has outlined the effect of a diary intervention in a critically ill cancer population, demonstrating how diaries can influence recovery. The emerging theory *Means of Supporting the Emotional Legacy* emphasised how having a diary can help making sense of the critical care experience, but not all were able to read them again, despite recognising their value. Patients described how it was as valuable having professionals write in them as family members, creating a chronology of events that happened, but also remembering staff who became important to them. The large proportion of patients who died reflect diagnosis, severity of critical illness and the fact that sicker patients were commenced on diaries. Patients stayed on average 1.9 days longer and were sicker (as demonstrated by their higher TISS and APACHE scores) than national average (Intensive Care National Audit and Research [ICNARC], 2017).

The three main themes that emerged from the mixed method analysis emphasised the overall value of diaries as a dynamic communication tool where families, patients and staff can contribute; integral to holistic care and person-centredness; and a reflection of the impact of a critical care event. For most participants, diaries appeared to have broad value in piecing together events, and filling in memories, as the literature also attests (Egerod et al., 2011; Jones et al., 2010; Teece and Baker, 2017), but with notable exceptions. The value patients found in their own entries, often just prior to discharge, was also important. We did not find any clear evidence for harm in the interviews or the diary evaluation questionnaire; however, this was not the primary aim and the study was not designed to establish this definitively but instead to explore possible issues related to harm. However, guilt (as referred to in the interviews) may have been induced or become more pronounced by reading the diaries, and therefore could lead to psychological harm. Although our findings were not statistically significant, there was a slight increase in PTSS and quality of life scores over time. However, the PTSS reference threshold is 45 (Twigg et al., 2008), and it is unclear what worsening scores under this threshold mean in clinical practice. Recent evidence points to a 21.7% incidence of PTSD in cancer survivors at six months (Chan et al., 2018). These changes in scores are likely due to the population, many of whom were either receiving further treatment or experienced cancer recurrence, as reported previously in a follow-up study (Pattison et al., 2015). It may also be worth questioning in future work how, or if, diaries influence recovery trajectories (either worsening or enhancing psychological recovery or influencing perceptions on the value of the diary in recovery). At present, this is an unknown.

The findings suggest a need to target diaries at the right people, in order for them to gain the most from diaries; however, what was not clear from this research is how this is determined. This is an ongoing concern in the literature (Ullman et al. 2015). We did not explore the impact for families, but some qualitative research suggests there may be value for them, with a view to preventing PTSD symptoms (Johansson et al., 2015; Nielsen and Angel, 2015). A novel aspect to this study was the analysis of diary content, emphasising the varied contributions that comprise a diary. The value reported by patients regarding professionals' diary entries may relate to how milestone events are documented, with clear chronology, contrasting to more emotional content from families. Nielsen and Angel's (2016) found nurses' entries were useful and the relatives' view was that patients appreciated family entries. Patients' views, however, were not sought in these reported studies. Interestingly, our diary evaluation questionnaire showed patients did not strongly believe it was useful for families to read the diaries, and it may be that there is perceived value in families completing diaries during an ICU stay, but not necessarily re-reading them.

Research suggests there should be a common framework for the development and delivery of diaries (Beg et al., 2016). This study does not present a framework, but it does reveal some of the complexities relating to delivery, including nurse support needed to go through the diary. A lack of framework, combined with perceived medico-legal ambiguity and lack of evidence of effectiveness (Ullman et al., 2015), has created hesitancy in widespread use in some areas (Ewens et al., 2015; Nair et al., 2015). Therefore, there is a compelling argument for large-scale robust evidence to evaluate diary interventions, establish target populations, and to create guidelines for best practice. Any guidelines should also allow for novel diary innovations, such as visual diarising described by Ednell et al. (2017).

Strengths and limitations

Strengths include the mixed method evaluation and this being one of the first studies to conduct a thematic analysis of each diary's content, alongside interviews and questionnaires. Another approach would be to compare the quantitative data to the quantitised qualitative data to explore further relationships. Limitations to this research are several-fold: first, a large proportion of patients died during follow-up, and these deceased patients were possibly the sickest patients who might have derived most benefit from the diaries had they survived. Second, this was not a randomised controlled study and no formal power calculation was carried out, therefore only limited conclusions can be drawn. Families were not included, and despite possible benefit, increased resources would be required for this in the context of often limited critical care follow-up services. We also did not know the underlying psychological morbidity of the population, which may have had an impact on the scores over time, and the interview data. There is also a response bias in the diary evaluation questionnaire; a high proportion of those who completed this questionnaire reported it was useful to read them, but overall, four people declined to read them, hence the questionnaires do not reflect the whole study population. The needs of the study population may differ from the general population. However, the qualitative data resonate with similar work, including our previous research in the general critical care population, suggesting similarities across critical care patients despite specialty.

Conclusion

This study showed how diaries can be a *Means of Supporting the Emotional Legacy* and provide some clarity for patients who struggle to come to terms with their critical care experience and subsequent recovery. However, diaries should be given to patients with forethought and support. While this study did not show any clear evidence of harm there should be further work exploring this aspect of diary interventions, as well as research to establish the best patients to target for greatest benefit. Future work on how diaries might influence recovery trajectories is needed, in terms of motivation, self-efficacy and psychological well-being.

Conflict of interest

None.

Ethical statement

I confirm that this research is all our work and that this paper is not being considered for publication or has been published elsewhere. The study was submitted to a Research Ethics Committee and given a favourable opinion (12/LO/1085), all participants gave written informed consent and the study was conducted in accordance with Good Clinical Practice principles, Declaration of Helsinki, 1996 and the Research Governance Framework (Department of Health, 2005).

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.iccn.2018.10.005.

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