TITLE

Providing critical care patients with a personalised discharge summary; a questionnaire survey and retrospective analysis exploring feasibility and effectiveness

INTRODUCTION

This paper reports on the potential value and feasibility of providing patients with a personal discharge summary of their critical care stay. We postulated that the use of a discharge summary (provided in conjunction with a discharge information pack) would help patients better understand the medical treatment they received and fill in gaps about their time in critical care, which can be forgotten (Jones et al., 2000; Löf et al., 2008) or distorted due to physical illness, drugs or lack of communication.

Patients commonly receive copies of hospital discharge or outpatient letters and in some specialities (for example, midwifery) may hold their own medical notes. On discharge from critical care, summaries detailing the patient’s condition, therapeutic interventions and other relevant data, are also provided to ward doctors, nurses and other allied health care professionals (AHPs). In contrast, the information the patient receives is usually limited to ad-hoc verbal information and/or a generalised discharge information booklet (Bench and Day, 2010; Wickham and Wong, 2012).

The rationale for patient discharge summaries draws on previous research around the use of patient diaries (Knowles and Tarrier, 2009; Jones et al., 2010; Garrouste-Orgeas et al., 2012). Patient diaries were introduced as a therapeutic means of helping patients recover from critical illness in the 1980s (Egerod et al., 2011). It is generally agreed that diaries can help the patient recover from their critical illness (Egerod et al., 2011) by encouraging reflection on what they have experienced, thereby enabling understanding (Robson, 2008) and enhancing the ability to contextualise both their illness and in-hospital treatment. Randomised controlled trials have demonstrated that patient diaries can reduce anxiety, depression (Knowles and Tarrier., 2009; Garrouste-Orgeas et al., 2012) and post-traumatic stress disorder (Jones et al., 2010; Garrouste-Orgeas et al., 2012).

The production of a patient diary is, however, intensive of time and effort and may not always be feasible or suitable for all patients. Diaries are usually completed over a period of days or weeks, often producing lengthy material (Phillips, 2011). Although this detail may be valuable later on in the recovery period, the difficulty of absorbing such information at the point of discharge is evident from literature highlighting the poor concentration of patients at this time (Bench and Day, 2010; Bench et al., 2011).

In contrast to an extended diary, a patient discharge summary is brief, enabling patients to start the process of reflection immediately after discharge to the ward. Several authors describe having a front page summary in patient diaries explaining why the patient was admitted to Intensive Care (Åkerman et al., 2010; Gjendal et al., 2010). Patient discharge summaries extend this concept by additionally including information, written using lay terminology, about a patient’s treatment, key points of medical significance and how patients reacted during their stay (Bench et al., 2012), for example, whether they were in distress or had delirium. Although medicalised information is unlikely to be of benefit to the physically and psychologically vulnerable critical care patient, a brief discharge summary, written in lay language, may offer the immediate information that is needed to help patients recover during the early critical illness rehabilitation phase.

AIMS AND OBJECTIVES OF THE STUDY

Using data collected during a pilot randomised controlled trial (RCT) evaluating the effectiveness of a critical care discharge information pack (Bench et al 2012), the aims of this study were to determine the feasibility of providing patients with a personalised discharge summary, written by nurses as part of the intervention, and to explore the views of patients, relatives and nurses about its value i.e., the perceived impact of its use on the critical care discharge and early critical illness recovery period. For the purposes of this study, feasibility is defined as ‘the extent to which it is possible’ to use patient discharge summaries successfully in this population group.

Specific objectives were:

1. To explore whether a patient discharge summary improves the critical care discharge experience for adult patients

2. To assess the feasibility of discharge summaries as perceived by adult patients, relatives and nurses

3. To identify any resource implications and factors that might aid or hinder the effectiveness of patient discharge summaries

METHODS

We conducted a single centre pilot RCT funded by the National Institute for Health Research (NIHR ) Research for Patient Benefit (RfPB) stream (ISRCTN, 2011). The intervention evaluated during this trial was a User Centred Critical Care Discharge pack (UCCDIP), which included on its front page a patient discharge summary written by the critical care nurse. The aims and outcomes of this RCT, and the intervention, are fully described in Bench et al. (2012). This paper focuses on the findings of a questionnaire survey of recruited participants and on a retrospective analysis of the patient discharge summaries completed during the trial.

**Setting**

The study took place in a single National Health Service (NHS) Foundation Trust in Central London, England. Data were collected from two critical care units within the hospital, which comprised a mixed medical, surgical and trauma patient population, defined as requiring either level 2 (High dependency) or level 3 (Intensive) care (DH, 2000).

Ethical approval

The study was sanctioned by Charing Cross (08/H0711/110) and Central London Research Ethics committee (REC3) (10/H0716/75) and the local Research and Development committee of the participating hospital.

**Participants**

Inclusion criteria (Box I) for the RCT were based on recommendations from the Department of Health for best practice around critical care discharge (NICE, 2007) and on previous studies examining psychological well being post discharge (for example, Jones et al., 2010). Only trial patients (*n*=51) and relatives (*n*=33) from the intervention arm of the RCT were included in this study. In addition, all qualified critical care and ward nurses (*n*=367), working in departments involved in the trial, were offered the opportunity to complete a questionnaire.

**Implementation**

Using a template and guidelines developed by the research team’s service user representative, the patient discharge summary was completed by the critical care bedside nurse and given to the patient prior to their discharge to a general ward (see Bench et al., 2012 for an example). To ensure consistency in style and to reduce the chance of the summary causing harm, training was provided prior to the start of the trial. All critical care nurses were invited to attend a session, which introduced them to the patient discharge summary and the guidelines for its completion. During these sessions, opportunities for discussion and for practice in completing discharge summaries were provided. The research team then offered ongoing support, as necessary, to ensure that the summary was written in lay language and followed guidelines provided. Drafts were checked for insensitive information and advice was given on grammar and spelling before the final summary was given to the patient.

**Data Collection**

**Relevant demographic and medical details of patient participants were retrieved from the hospital database/medical records. A photocopy of the patient discharge summary was taken by the research nurse prior to it being given to the patient and notes made detailing the level of assistance required, the grade of nurse completing the summary, the staff-patient ratio and other factors, which might have influenced its completion.**

**Patients and relatives completed a questionnaire before** hospital discharge. Where necessary, the data collector facilitated their completion by reading aloud questions and writing down responses. Questionnaires were placed in the post trays of all nursing staff with a covering letter including instructions on how they should be completed and returned. The research team also visited the critical care units and wards, handing out questionnaires and reminding staff to complete them.

Questionnaire design (Table I) was based on best practice guidelines (McColl et al., 2001; Hulley et al., 2007) and items reflected key themes identified from a meta-synthesis of users’ experience of critical care discharge (Bench and Day, 2010), a focus group study (Bench et al., 2011) and a review of the effectiveness of existing critical care discharge information (Bench et al., 2013). Closed questions (which required participants to select yes /no options or to categorise their views into definitely/agree, possibly/not sure, not at all/disagree) were chosen so that the questionnaire did not appear onerous and so that it could easily be completed. A free text section was also included offering participants the opportunity to share other views.

**Insert Table I here**

Although no specific pilot of the questionnaires was conducted; content and face validity were enhanced by collaborating with service user groups including the ICUSteps charity (ICUSteps, 2013) and other former patient, relative and health care staff volunteers. These personnel reviewed the questionnaires for clarity, use of lay language and other pertinent issues, enabling any problems related to structure, content or interpretation of questions to be addressed.

**Data Analysis**

Readability of the patient discharge summaries was assessed using the Flesch Reading Ease (FRE) readability score (Flesch, 1948), which rates text on a 100-point scale based on the average number of syllables per word (ASW) and words per sentence (ASL-average sentence length), using the formula:*FRE = 206.835 -(1.015 x ASL)-(84.6 x ASW).* The higher the score, the easier it is to understand the document, with texts scoring >60 commonly considered acceptable for literate adults.

Two researchers independently assessed each summary for compliance with the guidelines. For each of the 6 guideline points, a score of 0 was given if there was no information relevant to the point, 1 for partial coverage of a point and 2 if the point was fully covered. In addition, assessors provided an overall subjective rating of quality (Table II). Any differences in ratings were resolved by consensus. Researcher ratings were then compared with those given by the service user representative of the research team, who is a former ICU patient. Inter-rater reliability was assessed using a weighted Cohen’s kappa. Kappa values between 0.41–0.60 were considered to reflect a moderate level of agreement, with lower scores reflecting less and higher scores more agreement between assessors (Landis and Koch 1977, Viera and Garrett 2005).

**Insert Table II here**

Quantitative questionnaire data were reported descriptively using frequencies (*n*) and percentages (%). During the original RCT data analysis, qualitative questionnaire data from all trial participants were collated, coded and categorised using Nvivo7 and Burnard’s (1991) framework for content analysis provided a guide for the inductive process used to identify key themes.

For this study, qualitative data from trial participants and nurses, which specifically addressed the patient discharge summaries and the study objectives were extracted from this dataset and anonymous quotations selected to evidence accurate interpretations of the original data. Quotes are reported using the codes in Table III.

**Insert Table III here**

RESULTS

The key sample characteristics of the trial participants who recieved a patient discharge summary can be seen in Table IV. In addition to data provided by the patient (*n*=42) and relative (*n*=21) sample, 170 (46%) of the critical care and ward nurses returned a completed questionnaire. Nurse participants were predominantly junior staff nurses (*n*=127, 65%), with 46 (55%) of the critical care sample (*n*=84) qualified for > 5 years. Ward nurses (*n*=86) had varying levels of experience (1->20 years) of caring for critical care patients recently discharged to a ward.

**Insert Table IV here**

On the day the patient discharge summaries were written, the critical care staff: patient ratio was most commonly 1:2 (*n*=38, 75%), with the remainder (*n*=13, 25%) of time having a 1:1 ratio. Thirty eight (76%) summaries were completed by band 5 (junior) nurses and 24 (48%) of the nurses had a critical care qualification.

Structure, readability and compliance with guidelines

The mean length of discharge summaries (*n*=51) was 132 words (range 55-497). Readability scores ranged from 45.8- 84.1 (mean 68.04, SD 9.22), with 42 (82%) scoring >60 (acceptable for literate adults).

For adherence to guidelines, researchers awarded summaries a median overall score of 8 out of 12 (range 3-12), whereas the service user representative awarded a median overall score of 7 (range 2-11). There was a moderate level of agreement between researchers (*k*=0.54-0.65), however, overall scores (0-12) given by the service user representative were generally lower than those awarded by the researchers, with some differences of up to 5 points evident. There was most agreement for guideline item no.1 (*k*=0.78, 86%) and least agreement for guideline item no. 3 (*k*=<0.02, 43%). For guideline item no. 5 (how has the patient seemed), there was agreement on 19 occasions that a 0 should be awarded, indicating that little information on patients’ experience had been included in many of the completed summaries.

Subjective ratings of overall quality varied, with the modal category awarded by the service user representative being ‘good’ (*n*=26, 51%) and that by the researchers being ‘average’ (*n*=23, 45%). Despite an overall moderate level of agreement between assessors (*k*=0.54, 53%), differences of up to two categories were apparent in some cases.

Field notes indicated that despite an intention to intervene as little as possible, some help in completing the patient discharge summaries was common, with at least one draft being of such poor quality that it was deemed unsuitable to give to the patient.

User experience[[1]](#footnote-1)

Patient participants found the discharge summary to be a particularly useful component of UCCDIP (the discharge information pack), which they felt had helped them make sense of and accept their critical illness experience:

*“I had no memory of leaving my brother’s home or travelling to XXX so this has again given me some concrete information… it helped to fill in the gaps in my memory” (P54U)*

These views were supported by the nurse participants, who felt that the summary was of value to both the patient (*n*=151, 100%) and the ward staff (*n*=79, 96%):

*“I think it has potential to promote recovery and help the patient come to terms with what has happened” (C6, Band 5: <1yrs experience)*

In particular, ward nurse participants felt that providing a patient with a discharge summary written in lay language helped the ward nurse understand what had happened to the patient and enabled them to “*answer any questions ask (sic) by patient” (W84, Band 5)*, thus assisting them in providing on-going psychological support during the early in-hospital recovery period.

In a few instances, however, patients and relatives felt that the information included in the discharge summaries was too basic and/or had not reflected the patient’s experience:

*“Wasn’t relevant to what happened to me in ICU. Biggest problem was hallucinations-these weren’t mentioned” (P41U)*

Feasibility[[2]](#footnote-2)

Some nurse participants (*n*=40, 26%) felt patients might be too unwell at this point in their recovery to make use of a patient discharge summary. Field notes also highlighted that many patient participants were unable to recall receiving any written information.

Although time constraints were vocalised as a barrier to writing the summaries, most (*n*=20, 71%) were written in less than 15 minutes. Nurse participants found the guidelines provided useful and 22 (79%) said they did not find writing the discharge summary difficult. Despite some concerns that less experienced staff might find writing summaries *“a difficult task to achieve” (C63, Band 7: >5 yrs experience),* junior critical care nurses stated that they were *“easy to do” (C15, Band 5: 1-2yrs experience).*

Nurses’ motivation to write the discharge summaries varied. Some were very enthusiastic, others less so. Field notes suggest that one of the reasons why nurses were reluctant to write discharge summaries were that they did not know the patient well enough. Notes also recorded concerns expressed by some nurses about how information of a sensitive or personal nature should be included. For example, if the patient was admitted due to deliberate self harm or if there was an illness that the patient did not wish to be disclosed to relatives or friends.

Time taken away from other nursing duties and the extra workload on top of an already busy shift were other commonly cited problems. In several cases nurses were looking after two patients that were being discharged to the ward and had to write two summaries, before admitting other patients. In addition, the poor grammar and spelling evident in a number of the summaries may also have been related to time constraints. There was, however, no obvious correlation between poorly written summaries and nurses with English as an additional language.

A discharge summary was seen to be *“only as good as the nurse who has written it” (C54, Band 7: >5 yrs experience)*. Nurses’ perceptions of the importance of helping patients understand their experience and their role in supporting critical illness recovery may, therefore, have impacted on how well they completed the summaries. Nurses indicated that the quality of a patient discharge summary depended on the skill and motivation of the nurse completing it, the amount of time they had and other workload pressures:

*“Very stressful with workload and high risk of information being wrong (due to other pressures and interruptions on unit)” (C2, Band 5: >5 yrs experience)*

Overall, nurse participants felt that with some changes, the patient discharge summary could be a valuable part of a holistic rehabilitation package. In particular, it was felt that it should be better incorporated into existing admission and discharge processes and paperwork. A number of practical suggestions to improve the utility of a patient discharge summary, including the use of a more continuous record akin to a diary and a pre-set computer version, which could be typed, were also made.

DISCUSSION AND IMPLICATIONS FOR PRACTICE

Our results support those of numerous other studies that comprehension and concentration are significant problems for many patients during the critical care discharge period (Bench and Day, 2010). A primary aim of the patient discharge summary is to provide brief details of the critical care experience. In contrast to other similar interventions, such as patient diaries, they allow patients an earlier opportunity to understand what they have been through.

Questionnaire data support that a patient discharge summary is likely to be of value during the critical care discharge period, supporting our postulation that it may help fill in the gaps in patients’ memory. Importantly, however, the content of summaries needs to address aspects considered relevant by patients and not be so basic that they are deemed superficial. An interesting finding was that patient discharge summaries may also be of value to ward nurses, helping them to better understand the patient experience and better support patients’ ongoing recovery. This suggests that the anxiety, depression and lack of confidence frequently experienced by ward nurses when taking over the care of critically ill patients (Whittaker and Ball, 2000; Haines et al., 2001) might also be improved by the use of patient discharge summaries.

There are resource implications associated with this intervention, but these are minimal. Data from studies of patient diaries (Knowles and Tarrier, 2009; Jones et al., 2010; Garrouste-Orgeas et al., 2012) suggest that providing additional resources to facilitate the use of reflective interventions may be worthwhile and cost-effective in the longer-term.

Our data suggest that it is possible for nurses in a busy critical care unit to write patient discharge summaries, if they are provided with appropriate guidelines and support. We found that nurses’ perceptions of the usefulness and feasibility of patient discharge summaries varied, a factor which might impact on future motivation to complete them. Some nurses may not consider facilitating ongoing recovery an important part of their role. Reinforcing the importance of rehabilitation as part of critical care (NICE, 2009) is therefore an important priority for all health care professionals.

We gave the summary to patients immediately prior to their discharge from critical care. Despite it being a brief intervention, many still felt unable to engage with the information at this point or during the early days on the ward, with some patients completely unaware of having received it. During the critical care discharge period, patients often experience heightened anxiety, due in part to feelings of confusion and disorientation (Bench and Day, 2010; Jones et al., 2010). These problems may have negatively impacted on their engagement with the patient discharge summaries. It would be interesting to explore whether also giving the discharge summary to relatives, who could then pass on the information at a later time point, might be of help for such patients.

Findings highlight the importance of combining written resources with effective verbal information (Bench et al., 2013) and support the further development of critical care follow up roles. Follow up personnel can aid interaction with written information (Endacott et al., 2009), providing opportunity for discussion about the content of discharge summaries. This could enhance patients’ understanding and facilitate the early critical illness recovery phase through improved perceptions of progress. Future research needs to assess not only the impact of combining patient discharge summaries with in-hospital critical care follow up, but also the most appropriate time for giving patient discharge summaries, an issue which also remains in debate with the use of patient diaries (Phillips, 2011).

Nurses did not always know their patients well enough to write a patient discharge summary. This could impact on communication between health care professionals, and the delivery of effective handovers, an area of practice vital for optimum patient safety and quality of care (NICE, 2009; Williams et al., 2010; Wickham and Wong, 2012). Further research also needs to explore who might be the best people to write patient discharge summaries. Patient diaries are commonly completed by nurses and/or relatives (Roulin et al., 2007; Phillips, 2011). In our study, it was the bedside critical care nurse who completed the summaries but the potential impact of other health care professionals, for example, doctors and AHPs contributing or leading their completion merits investigation. The format in which summaries are written (hand written vs computerised, free hand vs template) also warrants further exploration. Since completion of our study, guidelines on writing patient discharge summaries have been produced by the project team, which are freely available to download from the ICUSteps website ([www.icusteps.org](http://www.icusteps.org)).

Limitations

This study had a small sample and used data extracted from a pilot RCT. The patient discharge summary was also incorporated into a broader information pack (UCCDIP) making it difficult to determine the relative effects of each component. Perceptions of experience and feasibility were also limited to patients, relatives and nurses, thus omitting the views of medical staff and allied health care professionals. Results should therefore be viewed as preliminary and require further investigation.

CONCLUSION

Findings from this study suggest that a patient discharge summary is likely to be a useful adjunct to existing discharge information strategies, by helping patients understand their critical care experience, a first step towards recovery. Further work is required, however, to determine when and how it should be provided. With appropriate training and support, our findings suggest that it is possible for nurses to write effective patient discharge summaries in a busy critical care environment and that such information may help facilitate early recovery, but this still needs to be demonstrated in terms of patient outcome.

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FUNDING

This report presents independent research commissioned by the NIHR under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0110-21026). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the rest of the UCCDIP project team (Dr Philip Hopkins, Intensive Care Consultant, Kings College Hospital; Peter Milligan, Statistician, King’s College, London; Dr Tina Day, Lecturer in Adult Nursing, King’s College, London; and Professor Lucy Yardley, Health Psychologist, University of Southampton). In addition, Professor Alison Metcalfe (Professor of Health Care Research at King’s College, London) is acknowledged for her role as Principal academic PhD supervisor and Rebecca Brodrick (Staff nurse, King’s College Hospital) for her contribution to the review of literature around patient diaries. Finally, thanks are extended to all patients, relatives and health care staff involved in this project, and to the ICUsteps charity for their continued support.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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1. All percentages based on no. of participants answering specific question [↑](#footnote-ref-1)
2. All percentages based on no. of participants answering specific question [↑](#footnote-ref-2)