Exploring patients’ experiences of a nurse-led follow-up service after critical care

This longitudinal qualitative study assessed the impact of a follow-up service to support patients following discharge from critical care.

Method
This was a mixed-method interview and questionnaire study that involved patients in the design. Patients were interviewed at different times up to 12 months after critical care discharge. Thirty-seven interviews were carried out with 28 patients. Themes included: rehabilitation from critical care; memories; uncertainty and fear; and empathy; with reassurance as a core theme. Psychological implications need to be considered and nurses’ sensitivity and preventative care can help patients deal with the stress and aftermath of critical care.

Conclusion
Follow-up services, such as the nurse-led service described here, are important in supporting patients.

Keywords
Critical care | Follow-up | Nurse-led care

AUTHORS
Natalie Pattison, MSc, BSc, RN, DipCN, is clinical nursing research fellow; Shelley Dolan, MSc, BA, RGN, is chief nurse and head of nursing research; both at The Royal Marsden NHS Foundation Trust.

ABSTRACT

Aim
To explore the impact of critical care experiences on patients’ long-term health.

Method
This was a mixed-method interview and questionnaire study that involved patients in the design. Patients were interviewed at different times up to 12 months after critical care discharge.

Results
Thirty-seven interviews were carried out with 28 patients. Themes included: rehabilitation from critical care; memories; uncertainty and fear; and empathy; with reassurance as a core theme. Psychological implications need to be considered and nurses’ sensitivity and preventative care can help patients deal with the stress and aftermath of critical care.

Conclusion
Follow-up services, such as the nurse-led service described here, are important in supporting patients.

BACKGROUND
The experience of critical care can elicit anxiety, fear and stress disorders in many patients (Cuthbertson et al, 2007; 2004). They also undergo traumatic procedures, may not be fully conscious, and may be given drugs with deliriogenic side-effects. Consequences of critical care admission include: acute stress disorders (ASD) such as post-traumatic stress disorder (PTSD); long-term flashbacks; and acute anxiety and depression (Department of Health and NHS Modernisation Agency, 2003; Hewitt, 2002). Since this research study, NICE (2009) guidance for critical illness rehabilitation was published in March (see p14).

A systematic review of PTSD in critical care survivors put prevalence as high as 64% (Griffiths et al, 2007), although there is no consensus on this. Technology, noise, bright lights and open-plan units can create a confusing atmosphere. Physiological consequences include: breathing difficulties; bowel and urinary problems; wound healing difficulties, including tracheostomy; weight loss; appetite loss; and impaired muscular function (Jones et al, 2003; Waldmann, 2002). Patients have said that nurses’ caring behaviours in relieving fear and anxiety are more valuable than technical competence (Hofhuis et al, 2008). Roberts et al (2007) also stressed the continued need for information and reassurance up to two years after discharge. A national review of critical care suggested that support could be provided by follow-up services (DH and NHS Modernisation Agency, 2003; DH, 2000). This also aims to improve relocation stress (McKinney and Melby, 2002).

A national survey (Griffiths et al, 2006) showed that 30% of UK critical care units now follow up patients, 55% with nurse-led services. Such clinics are thought to have many benefits (Broomhead and Brett, 2002). Williams and Leslie (2008) reviewed publications on critical care follow-up and found evidence for benefit difficult to quantify but that follow-up was a vital aspect of care.

Critical care follow-up can be provided by designated long-term follow-up services or by critical-care outreach services, or both.

Aim
This study aimed to assess the impact of a nurse-led follow-up service for patients with cancer undergoing major upper gastrointestinal (GI) surgery needing critical care. It also aimed to explore common themes in patients’ critical care experiences.

PRACTICE POINTS
When patients are in critical care, nurses should:

- Show patience and understanding;
- Identify (using screening tools such as the confusional assessment method for ICU) and reorientate confused or delirious patients throughout the day;
- Ensure a clear distinction between night and day using low-level lighting at night and bright lights in the day;
- Ensure good communication;
- Minimise noise levels where possible (for example by using earplugs and quiet soft-close bins).

After critical care, at follow-up, nurses should:

- Be aware of symptoms of ASD and PTSD, being cautious about reawakening distress and ensuring a sensitive approach;
- Offer patients reassurance about their feelings after critical care and length of recovery.

METHOD
This was a longitudinal qualitative study in a large tertiary referral cancer hospital in the UK. Patients took part who had spent 48 hours or more in the critical care unit.

The nurse consultant in critical care or the critical care outreach nurse made follow-up visits on the ward at days 1 and 5 after patients had been discharged from critical care. Another appointment was timed to coincide with their first outpatient surgical review and again at six months. Ten patients were invited to act as a patient expert advisory group and review all the plans for ward visits and the research documentation.

Ethical considerations included awareness of the symptoms of PTSD and ASD and awareness of reawakening distress. Ethical approval was granted, and the research design
stressed all patients were free to withdraw at any time. Strict confidentiality was maintained.

Patients were interviewed using open-ended interviews based on grounded theory. They were asked to describe their experience of critical illness and its impact after discharge from critical care. They also completed questionnaires on the follow-up service six and 12 months later.

The questionnaires were analysed using statistical package SPSS. The interview data was analysed using a grounded-theory approach. The validity of the questionnaires was assessed through the patient expert advisory group.

RESULTS
Twenty-eight patients took part in interviews, of whom 22 completed questionnaires. Thirty-seven interviews were carried out. None of the patients reported no benefit from attending the follow-up clinic, although some said they were unsure (Table 1, p18). Themes emerged under four main categories (Fig 1), with reassurance as a core theme.

Rehabilitation from critical care

- Cancer-specific issues
  There were specific issues not found in other literature, such as GI effects directly from major cancer surgery. Some led to interventions such as repeated oesophageal stenting. Sarcoma patients outlined issues related to pain, mobility and wound healing.

- Interrelationship between issues
  Interrelationships between psychological and physiological problems were noted as a result of operations and cancers. These affected recuperation from critical care as well as body image, masculinity and femininity. Patients who had been intubated in critical care found this difficult to manage. Communication was impaired to the point of not being able to convey basic needs at times and this caused feelings of depression among some. Pain after critical illness and cancer surgery was a difficult issue for a few; the presence of pain may indicate the consequences of major surgery, but also lead to fears of cancer recurrence, which needed reassurance.

- Nursing ability to meet needs
  One-to-one nursing provided reassurance for critically ill patients. On the whole, care was positively reviewed, with specific instances of poor care being put in a context of overall good care. Nurses’ ability to care for relatives, as well as patients, was noted by many respondents, for example: ‘I couldn’t believe it, there is always someone there… They were just incredible…’

  The poorer aspects of care, though infrequently mentioned, seemed to reflect instances of nurses’ intolerance or lack of understanding and consideration. In the three situations where nurses had let their impatience show, patients were quick to emphasise this did not reflect their whole experience and care was otherwise good.

- Longer-term needs
  Some patients said how useful the critical care follow-up clinic was as part of the recovery process. Talking through feelings about critical care and cancer was highly valued.

- Fatigue
  ‘Pacing oneself’ after critical illness was something that some found easier than others. Patients talked of feeling ‘knocked out’.

Despite having cancer, not all patients defined themselves as ill. Work was viewed as a sign of normality. However, the second interview revealed that, for three patients, working proved too much and they had to relinquish responsibility, cut hours or stop altogether.

Memories – real and unreal

- Memory
  Patients found their memory could be distorted when in a critical care environment and some found this distressing. The ability to recall varied, with a significant number appearing to remember nothing or very little but, on cautious further inquiry, remembering certain incidents. A small number found they were able to recall things at the second interview, when more time had elapsed: ‘Sometimes I’ve closed my eyes and I’ve tried but the only thing that I’ve really remembered is that [bad] dream.’

- Dreams, hallucinations and nightmares
  These were recounted by numerous participants, including disturbing nightmares and ASD or PTSD symptoms. They often
One patient at follow-up experienced persecutory paranoia and expressed insight into the experience of people with suicidal tendencies as a result of memories of his critical care stay.

Some dreams and hallucinations had roots in the critical care experience. Others came to have meaning several months later.

**Influences on disorientation**

Disorientation was multifaceted. The critical care setting, the position of the windows in the unit, lack of distinction between day and night due to lighting, the monitors, noise, being unable to see the clock, sepsis, sedation and analgesia all contributed to patients’ disorientation. ‘I did have some very funny dreams, I know that, and I thought that things had actually happened that hadn’t happened… they hadn’t happened but I was convinced.’

Hallucinations and paranoid delusions while in critical care led to mistrust of doctors and nurses. This was especially so when practitioners appeared to concentrate on the monitors rather than the patient – one described ‘doing battle with the monitors’. This served to alienate patients to a degree. At follow-up several participants recalled feelings of mistrust and reflected that now they could see how those feelings were irrational, but at the time sincerely believed in their delusions.

**Uncertainty, fear and the future**

**Uncertainty about cancer**

All patients had to contend with a cancer diagnosis (and, for some, recurrence). Fears about cancer recurring or spreading, or about dying, had huge significance for psychological recovery. Patients talked of becoming neurotic about every twinge. Yet, as mentioned earlier, some did not define themselves as ill. This theme of uncertainty is sadly emphasised in that several died and several more patients’ disease progressed before the study was completed.

**Fear of transfer**

Apprehension about transferring to the ward, or relocation stress, was also a recurrent theme, one issue anticipated and addressed by the ward visits. On the critical care unit, patients came to rely on being monitored and having one-to-one nursing presence all the time.

Transfer to the ward prompted fresh fears about being alone after critical illness, although many realised, on reflection, that transfer signified improvement and recovery.

**Future and fortune**

The future also encompassed feelings of being lucky. This unexpected theme was raised by patients who said they were lucky to be alive.

Resignation about eventual death was also evident but some of these patients still talked about being fortunate. Luck was seen in terms of how the diagnosis-to-treatment trajectory occurred and also in outcomes. Critical illness had positive consequences for some in that it gave them a greater appreciation of life.

**Preparedness and forewarning**

Visiting the critical care unit beforehand and meeting staff seemed, for some people, to be useful in allaying fears. Being told about the drains, monitors and invasive measures helped patients to feel prepared.

However, this was not always the case for all. It was not helpful to three of the participants. Despite warning about the side-effects of sedation, one patient had a bad experience and, understandably, could not rationalise his situation at the time owing to its effects.

**Adjustment and moving on**

Depending on the degree to which flashbacks, memories and dreams occurred, the ability to move on varied. This correlated with how long patients spent in critical care. Those who spent longer there and experienced a more difficult illness trajectory said it was harder to move forward.

Telling patients about monitoring, lines, drains, drugs and their side-effects and procedures helped prepare them. However, two still had horrific experiences. The difference between forewarning patients and trying (and failing) to reassure them at the time of the effect then becomes evident.

**Empathy**

Patients also showed signs of empathy and concern for others, in both the critical care unit and on the ward. They said that people they knew had died from cancer and expressed sadness and empathy for them and their families. The individuality of the cancer and critical care experience linked into the theme of empathy. Despite frequent common aspects in the interviews, an overriding sense of individual experience prevailed and some words of comfort, although well intentioned, caused frustration.

**Core theme of reassurance**

Receiving reassurances in actions and words from critical care staff, both in critical care and at follow-up, helped patients to think positively about the future. In the critical care unit, several needed reassurance about frightening feelings.

Patients talked about feeling reassured at follow-up about a physical or psychological symptom or emotional issue. This helped them resolve certain fears about their illness, and led to an understanding of how after-effects have implications long after discharge. Moving on and adjusting to life after critical illness was an important area in which follow-up provided reassurance. There were issues that could be addressed soon after discharge on the ward, as well as long-term issues in the follow-up clinic. This also

---

**TABLE 1. QUESTIONNAIRE FINDINGS**

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benifited from follow-up service (quite a bit or very much)</td>
<td>78.6% (n=22)</td>
</tr>
<tr>
<td>Recommend to friend or relative</td>
<td>71.4% (n=20) (Unsure: n=1)</td>
</tr>
<tr>
<td>Were there any negative aspects to follow up? (yes/no)</td>
<td>No: 60.7% (n=17) (Yes: n=11)</td>
</tr>
<tr>
<td>Was there a benefit in having the opportunity to talk about the critical care experience?</td>
<td>Yes: 67.9% (n=19) (No: n=6)</td>
</tr>
</tbody>
</table>
related to seeking assurances about cancer recurrence from doctors.

Where cancer had spread, the focus of reassurance changed to promoting comfort and treatment.

**DISCUSSION**

Follow-up not only gave an outlet for describing recuperation but also provided the opportunity to deal with any problems.

Patients were pleased to hear in the follow-up clinic how their suggestions and concerns had been addressed, such as using quiet bins and low lighting at night, and supplying earplugs. Positive patient experiences were marked by compassion, honesty, good communication and humour.

This study took an innovative, prospective approach to developing and evaluating critical care outreach and follow-up with patients’ input. Several areas for consideration were raised.

**Critical illness rehabilitation**

The psychological effects of critical illness in the literature were evident in this study (Roberts et al, 2007; Pattison, 2005; Roberts and Chaboyer, 2004; Jones et al, 2003). The issues were both immediate and long term.

Elements of dissociative amnesia may explain why some patients could not recall anything (Löf et al, 2008). They may not remember traumatic events as an avoidance strategy, temporary protective psychological mechanism and/or symptoms of ASD or PTSD (Stoddard and Todres, 2001).

Jones et al (2003) found that Hospital and Anxiety Depression Scale scores are greater in critical care patients with delusional memories than those without. The advantage of this study’s longitudinal approach meant that patients were sometimes able to recall more or perhaps disclose greater depth of feeling about their experience during the second interview.

The effects of sedation, anaesthesia, pyrexia, sepsis, drugs, noise, environment and lack of orientation found in research (for example Roberts and Chaboyer, 2004), and those outlined in this study highlight the need to consider both extrinsic and intrinsic factors in psychological aftercare.

Fear of cancer recurrence affected patients’ ability to rehabilitate. Although surgery may have been successful and the patient survived critical care, the cancer could recur or spread. Sensitivity to patient feelings was extremely important, as outlined by Hofhuis et al (2008), since the slightest negative action or reaction by nurses can lead to feelings of not being cared for or supported. Attributing problems to critical illness or cancer alone was not possible, since the elements reported could have resulted from a number of causes.

Follow-up provided a form of continuing care for patients who found it hard to adjust after critical care. Support took practical forms of referrals to rehabilitation teams, psychological medicine and care, and organising social support mechanisms. The inclusive research method helped the follow-up team to determine needs.

Telling patients about the unit, issues around transfer from critical care, physiological effects and psychological impact can help in preparing them. Patients remained surprisingly positive, showed empathy, and talked about being lucky and moving on.

**REFERENCES**


**Löf, L. et al (2008)** ICU patients’ recall of emotional reactions in the trajectory from falling critically ill to hospital discharge: Follow-ups after 3 and 12 months.

However, the characteristics of those participating may incline them to certain feelings such as positivity (McGrath, 2004), indicating responder bias.

The characteristics and prognoses of the two groups of patients taking part may have influenced their responses. In addition, the study’s longitudinal design meant that not all patients completed all phases since some died or were not able to complete.

**CONCLUSION**

This study shows patients and their families see the nurse-led follow-up clinic as an essential part of recovery and healing, and all participants said that they benefited from the service. The follow-up clinic is an important part of the critical care trajectory. Critical care and follow-up nurses can have a positive impact on patients’ experiences.

This study is described in greater detail in Pattison et al (2007).

---

Nursing Times 19 May 2009 Vol 105 No 19 www.nursingtimes.net