

Developing and setting up a patient and relatives intensive care support group

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ABSTRACT

Aim: The purpose of this article was to highlight the need to provide support for patients and relatives following critical illness and discharge from hospital and how this can be improved through the establishment of user support groups.

Background: Critical illness predisposes patients to extended physical and psychological ill health with the potential for a reduced quality of life. The authors' personal experience, patient feedback and current literature suggested that there was a need for further support during their recovery.

Methods: Building on an existing formal follow-up service, Intensive Care Unit (ICU) Support Team for Ex-Patients established a patient-centred forum, where patients and relatives could share experiences with others who had also been through critical illness by holding drop-in sessions. Feedback from those attending these flexible and informal sessions indicates that support was needed and that patients and families have found benefit in sharing experiences with others who can empathise, having been through critical illness themselves.

Conclusions: Our experience has shown there is a need that can be met simply with minimal investment of time and funding but that addresses a gap in patient support that otherwise goes unmet. Although this was a service development in one local area, it could be adapted to ICU patients and relatives more widely.

Key words: Adult intensive care • Families • Follow-up clinics • Practice development/innovation • Psychological issues during and after discharge from intensive care • Psychological support for patients/carers

INTRODUCTION AND BACKGROUND

According to Griffiths and Jones (2002), the early years of critical care medicine mainly focused on what could be done and to whom. Intensive care was considered a 'service stop-over' with little thought as to where patients came from and where they were going. Research regarding surviving intensive care and the impact of critical illness (Eddleston *et al.*, 2000; Angus and Carlet, 2002; Broomhead and Brett, 2002) highlight a variety of serious consequences in survivors of intensive care. Further studies recognised that the experience of critical illness predisposes patients to extended physical and psychological ill health with potential for a reduced quality of life (Cuthbertson *et al.*, 2005; Griffiths *et al.*, 2006).

Scragg *et al.* (2001) and Griffiths and Jones (2002) report that anxiety, depression and post-traumatic stress disorder (PTSD) as well as muscle weakness, fatigue, sexual dysfunction, polyneuropathies, itching and hair loss are common in patients who have had a long period of intensive care.

The need to support intensive care patients and families was recognised in both 'Critical to Success' (Audit Commission, 1999) and 'Comprehensive Critical Care' (Department of Health, 2000). It was recommended that National Health Service (NHS) hospitals should provide a rehabilitation service for the critically ill with intensive care follow-up being one of the preferred methods of meeting this requirement. However, a recent survey (Griffiths *et al.*, 2006) reported that 70% of intensive care units (ICUs) in the UK did not provide a follow-up service, with funding being the main limiting factor. Follow-up clinics have a number of advantages for doctors and nurses to provide a valuable opportunity to help patients understand their ICU experience (Griffiths and Jones, 2002; Rattray and Crocker, 2007). They also provide an opportunity to improve patient-centred

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outcomes by increasing knowledge and awareness of the longer term effects of recovery from critical illness (Broomhead and Brett, 2002). There is no one accepted model for the delivery of follow-up. Services provided can be doctor or nurse led, a combination of both and may include support from other disciplines such as psychologists and physiotherapists (Crocker, 2003; Griffiths *et al.*, 2006). Milton Keynes Hospital Department of Critical Care (DoCC) runs a 1-day per week nurse-led follow-up service. Patients and families are given the opportunity to discuss issues linked with their stay in ICU, to visit the unit and meet with those who have cared for them. Additionally, the follow-up service allows patients and relatives to explore ways of managing their recovery and address some of the issues they may encounter.

The NHS-based Expert Patients initiative was a training programme that provided opportunities to people living with long-term chronic conditions (Donaldson, 2003). This initiative together with respect for patient and public involvement led us to look more closely at supporting a patient-focused service. According to a recent review (Cayton, 2004), patient involvement increases patient satisfaction, improves confidence and trust, reduces anxiety and leads to better professional relationships. The Expert Patients Programme recognised that patients who understand and manage their conditions feel more in control of their illness. Feelings of low self-esteem, stress and lack of confidence were found to be prevalent among patients with chronic conditions (Expert Patients Programme, 2007) and seem to be shared by patients recovering from intensive care. ICU-discharged patients show symptoms of anxiety and depression with a proportion of this distress appearing to be directly associated with ICU treatment (Scragg *et al.*, 2001; Broomhead and Brett, 2002). Evidence has shown that the legacy of critical illness can have widespread and long-term ramifications for both patient and family (Pattison, 2005). Both physical and psychological problems are varied (Broomhead and Brett, 2002; Crocker, 2003). A report by Angus and Carlet (2002) for the Brussels Roundtable reiterated these serious complications with reference to reduced quality of life for patients and stress on family and friends.

It is apparent from the evidence that there are a number of advantages to implementing after-care clinics in order to help patients and relatives cope with the impact of critical illness. The positive effect from helping discharged patients and their families cope and adjust after a traumatic, sometimes life-changing experience, was further recognised through an annual audit of the follow-up service and a department-based research project.

A recurring theme expressed by patients and relatives who attended the post-ICU follow-up sessions

was that it would be beneficial for them to meet with others who had shared similar experiences. This was confirmed by a DIPEX (2006) study into the experiences of intensive care patients, which found that some had expressed a desire to talk to others who had been through similar experiences but had been unable to find any support groups specific to ICU patients.

GETTING STARTED

Since the introduction of follow-up sessions at Milton Keynes Hospital DoCC in 2000, many patients and family members conveyed a desire to do something to help repay the debt of gratitude they felt they owed to critical care and to help those who might face similar situations in the future. Embracing the principles of patient and public involvement, an invitation was sent to former intensive care patients from the previous 18 months inviting them and their family members to a meeting in November 2004. The aim of the meeting was to confirm whether the belief was correct, that there was a need for support beyond follow-up and to brainstorm ideas as to how that need could be met. The response to the invitation was very positive and the need was agreed but finding a method of meeting this took several more discussions. The committee, which formed as a result of the meetings, had 10 members and consisted of 2 critical care nurses, 5 former patients and 3 family members. Kline (1999) suggested that committees of no more than 12 people are key to making an effective group to allow people to feel comfortable enough to contribute their ideas and participate fully.

Our committee members came from diverse backgrounds but had a shared understanding of the challenges faced in recovering from critical illness. This commonality engendered mutual respect for each other and appreciation of our differences enabled us to benefit from our diversity. By recognising that people are not homogenous and embracing those differences, the talents of each individual can be drawn upon to benefit the collective and stimulate the creative process (Kline, 1999; Carter and Mullins, 2007).

The nurse members were a senior sister who ran the DoCC follow-up service and had the original idea for a support group assisted by a senior staff nurse who wanted to help. Membership of the group was on an entirely voluntary basis and the staff members received no additional training to help with the endeavour.

In 2005, ICU Support Team for Ex-Patients (ICUsteps) was formally set up to address the identified need. We decided to hold informal drop-in sessions where recent patients and their relatives could meet and talk to others further down the recovery journey. Involving ex-patients and family members in the service brings benefits both in being able to pass on some of the insight

they have gained and in being able to provide an opportunity to more recent patients to talk with someone that can empathise with their experiences.

The effectiveness of self-help groups for a range of patient types has been well documented. There has been a significant growth in the number of single-issue health self-help groups over the past 30 years. Group participants reported the benefits included contact with other people, increased self-confidence and gaining knowledge from those who shared similar experiences (Adamsen and Rasmussen, 2001; Munn-Giddings, 2006). McLeod (2003) concluded that such groups can be resourced without the need for professional agencies, reducing the funding required, and that those participating benefit from the experience of talking to others. As our committee became more focused, we developed a formal framework to our meetings with an agenda circulated in advance and ensured that all group members were given an opportunity to contribute. Those groups that develop and apply a specific set of ground rules, such as sharing all relevant information, making decisions by consensus and expecting all group members to participate, are more likely to be effective (Schwarz, 1994; McLeod, 2003).

The diversity of backgrounds of our group's make up has proven to be one of our greatest strengths. Each of the members brings his/her own skills, expertise and experience to the group, whether technical, medical or social. In literature by Adamsen and Rasmussen (2001) and Wituk *et al.* (2002), there is a trend towards professional involvement in self-help groups. Although the patients and relatives coming to a drop-in can relate to those group members who have been patients and relatives themselves, the nurse members of our group play an important role in helping the visitors with the transition from follow-up to drop-in. They support the difficult step of new visitors coming to their first drop-in by being a familiar face for those who have been through intensive care in Milton Keynes and by using their knowledge and skills to establish a rapport with new people who have not.

It was agreed that it would be inappropriate to hold these sessions at the hospital. Experience from follow-up clinics suggested that patients found it very stressful to return to the unit, a point confirmed by our service user group members. Sharland (2002) explains that when choosing the venue, it is important to have a convenient and accessible location. Additionally, the environment should promote comfort, safety and relaxation and encourage communication between participants. Dates were set for the first two drop-in sessions, a meeting room at the YMCA was booked as the venue and the focus moved to developing a strategy for promoting the new service.

PUBLICITY

In order to make people aware of the group and the initial drop-ins, we discussed and agreed an approach that would attempt to reach as wide an audience as we could, targeting those most likely be interested, at minimal cost. We felt that a logo was necessary to help provide a brand for the group and a visual hook that people could identify across different sources (Olins, 2002). The strapline, which was part of the logo, was critical to capturing the attention and understanding of those who could relate to our purpose, 'empathy, not sympathy'. The hope was that through seeing this, people would be engendered with a confidence that we could understand what they had been through.

We were unable to find a precedent on how other patient support groups had tackled promoting their first events and so had to develop our own approach. We decided to do this by means of a poster which members of the group took to every doctors' surgery and pharmacy in Milton Keynes as well as to any other prominent noticeboards we could find. We registered our website, which started as a single page containing the same information as the poster. The logo was central to our initial advertising campaign to catch the eye of the reader on a noticeboard and bring them in to read the detail. To help further, each poster had an envelope attached to the bottom containing business card-sized slips with the details of the drop-in and the address of our website that could be taken away.

In designing the group's website, accessibility was a goal from the outset. Although our group is not required to be accessible under the Disability Discrimination Act, it was felt that following W3C guidelines on accessible websites was the correct course to follow particularly given our target audience (World Wide Web Consortium, 1999).

The former patients in our group knew that being able to talk to others about what they had been through helped their healing process but that it was difficult to take the first step and start talking about what you have experienced. To this end, the experiences of the group members were documented and published on the site. It was felt this would encourage visitors and help them recognise that they would be understood. This step was taken in recognition of how the internet has changed the way that people learn about health and illness. Health sites and discussion boards are among the most popular resources on the web (Eaton, 2002).

Information was sent out to all recent intensive care patients from Milton Keynes Hospital whether they had come to follow-up or not. Staff rapport at the bedside while in the ICU with patients and families was already used to share the information about follow-up

and this was expanded upon to let them know about drop-ins and the website. Leaflets about the group were printed and copies left in the relatives' room.

The hospital issued a media briefing about us that established our credentials and as a direct result two local radio interviews were given and the local ITV news studio gave us 3 minutes of coverage during prime time viewing.

FUNDING

An initial gift of £120 was given by the colleagues of one of the group's founders. This provided a start-up fund that would otherwise have needed to be sourced from elsewhere. Through prudent use, this initial donation was sufficient to cover the costs for the venue and refreshments for the first two drop-in sessions and the purchase of an internet domain name and hosting for a year.

A local employer was able to help by providing the group with some laptops that were scheduled for disposal. This enabled members of the committee who did not have computers to communicate via e-mail, share documents and access the website.

CHARITABLE STATUS

A past president of the Milton Keynes Rotary Club advised that we should seek charity status in order that we could approach organisations such as his for funding. In addition to providing possible sources of funding, charitable status would afford public confidence that our group was bona fide and give the wider recognition that being officially registered and regulated provides (Charity Commission, 2007).

The process of applying for charitable status began in January 2006 by approaching the Milton Keynes Council for Voluntary Organisations (MKCVO) for assistance. At this time, the Charities Act 1993 stipulated that organisations with annual income in excess of £1000 per annum were required to apply for charity status although from April 2007, the Charities Act 2006 increased this threshold limit to £5000 per annum (Charity Commission, 2006). The MKCVO were also able to provide support and advice on the more general aspects of running a voluntary organisation. If initial funding had not already been secured, they could have assisted with an application for a start-up grant.

Following charity registration in November 2006, ICUsteps was added as a stakeholder by the National Institute for Health and Clinical Excellence on their guideline for Care of the Acutely ill Adult Patient in Hospital (NICE, 2007) and contacted by the NHS Health Technology Assessment Programme to review a research proposal on insulin therapy from a patient's perspective.

IMPLEMENTATION

When the first drop-in took place we found that the practicalities of introducing new visitors to the group occurred as we had anticipated. In a triage-like process, the nurse members introduced visitors to other members of the group who shared the most similar experiences. When visitors came in they did not have to talk about themselves. The group member would share their own experiences until the visitor felt relaxed enough to talk about what they have been through.

The drop-ins were scheduled to run for 2 hours and it was anticipated that visitors would come and go during that time but generally they arrive fairly soon after the session begins and depart not long before the end. The aim was to also have an additional 15 minutes after the meeting for group members to discuss how the drop-in had gone. In practice, this has often been difficult to do because visitors, having made the physical and emotional effort of coming to the drop-in, do not want it to end.

The first drop-in was attended by 5 visitors and since then attendance has averaged around 10–12 ex-patients and relatives per session. Patient flows through intensive care units contribute to attendance levels being unpredictable. Variances in length of stay in the unit and general ward as well as individual patient's ability to cope will affect the number of patients who may wish to come to a drop-in at any given time. Although it has not happened, if a drop-in was held that had no visitors, it would not be a sign that they were no longer needed, simply that the flow was at a low point and perhaps a sign that further promotion of the event could be required.

The age range of attendees has varied from 27 to 80, reflecting the general population of intensive care patients. Most come with a friend or relative to the drop-in, which provides them with support particularly when coming for the first time. This also has the benefit of giving them someone to talk to about the drop-in and the issues that were raised after they leave. As further group funding was secured, the location of the drop-ins was changed to a more comfortable meeting room at a local golf club.

EVALUATION

To evaluate how the new service was perceived, we approached a number of patients and relatives who had attended several events. We invited them to discuss what influenced their decision to come to the first drop-in session. Although some had found out about the drop-ins by other means, most had been told by ICU staff who were aware of them. They had been

advised that they may find it helpful to talk to other people who had been through similar experiences to realise they were not alone in their concerns and worries.

'... actually talking to someone who's been through the same sort of thing as I have, filling in the blanks really, cause I have no recollection of actually being in hospital. Speaking to other people that have slight memories ... and [understanding] the processes that I underwent whilst in there really helped me a lot'. (Male patient 1)

By coming to drop-ins, patients and relatives confirmed our belief that further support was needed following discharge from hospital.

'... we weren't really talking to anybody who actually knew at the time just what had happened. All of a sudden you're out and there's nothing ...' (Female relative 2)

'Just knowing someone else had been through what I had and they did know what I was on about, rather than family and friends saying "Oh, I know how you feel" cause that annoyed me, cause they don't. Nobody would'. (Female relative 1)

It had been a concern from our earliest discussions that people may become dependent on the group, but in practice this has not been the case. This may be in part down to the situation in Milton Keynes where the drop-in service was a supplement to an existing follow-up clinic. In situations where there was no prior rehabilitation support, a patient-led group may not be the ideal support mechanism; however, it can provide patients with a pathway to getting the help they need. Patients from outside the area who did not have the support of follow-up have attended ICUsteps drop-ins. In these cases, we have been able to help direct them to other more appropriate sources of support, including one who was later diagnosed with PTSD. For people to come to their first drop-in can be difficult, not knowing what to expect and probably never having talked to anyone in detail about what they have been through.

'Just speaking to other people helped ... just to get it off your chest ... to speak to someone that's been through it'. (Male patient 1)

'I just think the more you talk to people about it, the easier it gets, really. And obviously these people understand'. (Male patient 1)

When visitors come to their second drop-in, they are further into their recovery and know what to expect.

It is a much less difficult step both physically and emotionally.

'I became aware that the healing process is like a staircase, it's in stages and at each stage you're at, you need the expertise of the group members to carry you through it. You can't do it on your own, they've been there, you haven't so you need to be carried through and that became more obvious to me on the second visit than the first one'. (Male patient 2)

'He really likes to chat to Arthur because he can see what he's like now to possibly what he was like. He couldn't do things and now he can and it's nice to see the difference and he aims to carry on and get, like, back to normal'. (Female relative 2)

Over subsequent visits as their recovery continues, patients are able to, and want to, help new people coming in until they reach a point where they politely decline to come any more because they have a sense of closure and do not feel they need to.

'As I got stronger I felt that I've got something to offer to people who've been discharged from hospital more recently and this has been borne out by recent conversations at recent meetings. So yes, I feel that I can receive and I can also give. That's the benefit there'. (Male patient 2)

'I'd like to think I can help other people by coming'. (Male patient 1)

This feedback confirmed our initial suspicions that former ICU patients and their families find it very helpful to talk to people who can empathise with them and who will listen reassuringly, having shared a similar experience previously.

'If people are interested in coming and they're going for a reason, it doesn't matter where it is. You're still going to get the same support'. (Female relative 1)

'It's the people that you talk to. It doesn't matter where you talk to them. It's the main issue really, it's talking'. (Male patient 1)

DISCUSSION

As it became apparent that there was a tangible requirement for intensive care patient support groups, we decided to formalise our group and became a registered charity. With the recognition that charitable status afforded, we have been able to raise the profile of this need in a number of areas.

The development of the ICUsteps website (<http://www.icusteps.com>) has included several channels for visitors to engage with our group. Through commenting on articles, contributing to the bulletin board or by email we have received contacts from a variety of sources including medical organisations, hospitals and former intensive care patients. A number of those patients who contacted us desperately needed help in coming to terms with their experiences. Because of a variable level of after-care following discharge from hospital, many of the patients who have contacted us had not received follow-up or even information leaflets about the known impact of critical illness. While not a substitute for these essential services, drop-ins provide an opportunity to talk about their time in intensive care, and share experiences and coping strategies. Confronting these issues at a drop-in is emotional and can be distressing for some visitors. In the absence of clinical resources, such distress is managed by group members with understanding, empathy and care. While not ideal, anecdotally this is favourable to facing the same distress at home, either alone or with someone who did not understand what they were experiencing.

As an informal support group, we have no authority to make referrals for patients but have been able to provide reassurance and guidance in raising matters with health care professionals appropriate to their needs. The professional involvement in the group has also enabled informal medical avenues to be approached.

Our promotional material has always been targeted to recovering ICU patients and we have never been contacted by a bereaved relative. Our strength in being able to help others comes from a commonality of understanding that is shared with other recovering ICU patients. This understanding does not migrate across patient groups and in order to help, people need to be directed to an appropriate support organisation.

The ongoing development of intensive care and the desire of those working with the critically ill to develop

and share best practice has allowed us to spread the knowledge and benefits we have found through our experiences to those with an interest in rehabilitation.

Knowing the benefits support provides, ICUsteps wants to help other groups form and to evangelise the importance of recognising that recovery from critical illness does not end on discharge from hospital.

CONCLUSIONS

Our group began because a perceived need was identified that patients and relatives required further help and support following a period of critical illness. Supporting evidence highlighted the physical and psychological impact of critical care (Broomhead and Brett, 2002; Jones *et al.*, 2004; Paparrigopoulos *et al.*, 2006) and at each stage of our group's development the need for support has been reinforced to the point that it is no longer just a perception.

Through the development of ICUsteps, the group members had talked to each other about their time in ICU. During this process, the impact and liberation that comes from talking openly about such a traumatic event with someone who can understand became clear. To make visitors feel more at ease and more able to relate, group members would tell them about their own illness and rehabilitation. This encouraged the visitors to reciprocate with their experiences and share in these benefits by doing so.

When we began our drop-ins 3 years ago, we believed that it met a need that patients and relatives had to share experiences with others who could understand what they had been through, having been through it themselves. Over this intervening time, we have repeatedly had this belief confirmed and continue to meet this need in the Milton Keynes area. Other areas of the country are less fortunate and until such times as follow-up and access to patient support groups is universal, patients and relatives will continue to find their recovery to be a more difficult experience than it needs to be.

WHAT IS KNOWN ABOUT THIS TOPIC

- Critical illness predisposes patients to physical and psychological ill health following discharge from intensive care.
- It is recommended that NHS hospitals should provide a rehabilitation service for the critically ill.
- Patient involvement increases patient satisfaction, improves confidence and trust, reduces anxiety and leads to better professional relationships.

WHAT THE PAPER ADDS

- That patients and their families find it helpful to meet and talk to others who have been through similar experiences.
- There is a need for patient support following discharge from hospital that can be met simply with minimal investment of time and funding but that addresses a gap in patient support that otherwise goes unmet.

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