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MEETING THE NEEDS OF CRITICAL CARE PATIENTS AFTER DISCHARGE HOME:

AN EXPLORATORY QUALITATIVE STUDY OF PATIENT PERSPECTIVES

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ABSTRACT

Objectives

To describe former critical care patients' perspectives on the support needed to optimise recovery.

Background

With improved survival rates in critical care, increasing focus is being placed on survivorship and how best to support patients return to former activity. Little is known about what support patients themselves view as important, and this has implications for efficacy and acceptability of services provided.

Study design

A qualitative exploratory study of the experiences of support received by critical care survivors.

Research Methodology

Semi-structured interviews were undertaken with twelve critical care survivors, recruited from a charity and a patient and public involvement group. The interviews were analysed using thematic analysis to describe patterns in the participants' experiences.

Findings

Four themes of support were described as: effective management of transfer anxiety; tailored information provision; timely access to services and a supportive social network.

Conclusion

Survivors of critical care should be equipped with information about their critical care stay, ongoing health issues and recovery; and provided with holistic care at home. Critical care follow-up was an effective way of meeting many of these needs, but needs to be flexible to be useful to attendees. Peer support groups (face-to-face and online) provided information, reassurance, a social network and an avenue for those who had longer-lasting problems than current services provide for.

Relevance to Clinical Practice

Whilst there are commonalities in the problems faced by critical care survivors, recovery is highly individualised, and current support services do not have sufficient flexibility to cater for this. This study shows that many survivors experience after-effects of critical care that outlast the support they are given. These longer-term survivors are often excluded from research studies because of fears of recall bias, resulting in poor understanding of their experiences.

INTRODUCTION

With improved survival from critical care (encompassing both care in high-dependency and intensive care) there is increasing understanding of the longer-term consequences of critical illness (Cuthbertson et al, 2010; Jones, 2014). Patient-reported symptoms are broad, encompassing physical, psychological and cognitive issues collectively described as 'post-intensive care syndrome' (PICS) (Needham et al, 2012). Patients also commonly report difficulties participating in previous social roles (Griffiths et al, 2013a; Hofhuis et al, 2008), an impact on family members (Cameron et al, 2006; Davidson et al, 2012; Sundararajan et al, 2014; Van Pelt et al, 2007) and financial implications for both the patient (Griffiths et al, 2013a) and wider health system. Mean UK 12-month secondary care costs post-intensive care unit (ICU) discharge are estimated at £49,000 per patient (Walsh et al, 2015).

Importantly, clinicians and patients do not always view recovery and quality of survivorship similarly (Stineman et al, 2009), and widely-used outcomes measures may not adequately capture patients' ex periences (Lim et al, 2016). There is little evidence addressing patients' views of their support needs during recovery from critical illness. Without understanding service users' needs there is a risk of decreased satisfaction with, and the effectiveness of, healthcare services commissioned on their behalf (Bunt & Harris, 2009; Coulter, 2006).

The aim of this study was to describe patients' views on the types of support they feel are important in aiding recovery following critical illness.

METHODS

Ethical Approval

Ethical approval was granted by X's Ethics Board, Ref: MRes/15-16/37. Participants were emailed the participant information sheet and consent form, and gave verbal consent, recorded over the telephone, prior to the interview beginning.

Reporting

This study is reported in line with COREQ (Tong et al., 2007) guidelines for qualitative research (supplementary information E1 and E2).

Participants

Participants were eligible if they were over 18, had experienced a critical care stay of at least 48 hours within the last ten years, were English-speaking and able to provide informed consent. People who had been admitted to a specialist rehabilitation unit prior to discharge home were excluded, as their experiences of recovery may be different from those without this support.

Participants were recruited through a post-ICU patient support charity and a patient and public involvement (PPI) group from a London hospital. Potential participants were emailed by the charity and leader of the PPI group with information about the study, and were asked to contact the author (X) via email if they were interested in participating. Twelve participants contacted the author, all of whom met the inclusion criteria and were recruited (Table 1), with 5 men and 7 women taking part and a range of 6 months to 9 years since critical care discharge (mean 4.9 years).

TABLE 1 HERE

Table 1: Characteristics of the participants.

Data Collection

Semi-structured telephone interviews occurred between February and July 2016, were conducted at a time and location of the participant's choosing, and digitally-recorded with the participants' permission. The interviews took place over the telephone to allow the interviewer to include participants across the country, and since this method may mitigate against the power dynamics perceived between a researcher and a participant (Holt, 2010) and still allows in-depth discussion and data collection (Sturges & Hanrahan, 2004). A semi-structured interview was chosen because of the suggestion that telephone interviews may need more structure than

a face to face interview given the lack of direct interaction (Holloway et al, 2010). Prompts were used where necessary to gain richer data. The interviews lasted between 27 minutes and 1 hour and 20 minutes.

Development of Topic Guide

A topic guide was used for the interviews. For validity and applicability to the target population, this topic guide was trialed with a former critical care patient and presented at an independent PPI group. Feedback was provided on the topic guide, acceptability and feasibility of the study protocol.

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Data Analysis

A thematic analysis framework was adopted for data analysis (Braun & Clarke, 2006). Field notes were kept during and after the interview to allow reflections on the data (Seale et al, 2004). Transcripts were read repeatedly to identify general patterns and themes. Initial codes were generated with each interview, through both brief note taking at the time and when reading the transcripts. As interviews progressed these codes were refined, and discussed with the senior author (Y). Once all interviews were completed the codes were reviewed again by the first and third authors (X and Y) using NVivo (version 11.3.1 (1886)) for data management. Themes were grouped

in to initial and sub-themes (see supplementary information E3) which were evaluated and analysed for internal and external homogeneity (Patton, 1990) to ensure faithfulness to the data. These themes were then shared with the consulted PPI group for opinion on applicability and appropriateness. Finally, themes were named and summarised to ensure they described the concepts accurately.

FINDINGS

Four main themes of support need were identified. The emphasis of these themes was highly individual, with marked variability in what support participants received and mixed recovery trajectories.

Theme 1: Effective management of transfer anxiety

Participants described their experiences of transfer anxiety when moving between different hospital locations and discharge home, characterised by feelings of vulnerability and abandonment:

'that was the hardest thing because when you're in hospital you're very safe, or you feel like you are because you've got your buzzer, and when you're in intensive care you don't realise at the time but you've got the safety net of all the doctors and nurses around you'

Participant 7

Participants described three factors that were helpful in managing this anxiety: i) effective and efficient carer and nursing support at home, ii) being well-prepared for the differences between hospital and home, and iii) an 'unrushed' discharge from hospital. Some participants were very satisfied with the care and nursing support they received. They articulated the role of visiting staff in providing motivations and reassurance. However, the majority reported dissatisfaction in this regard. Criticism was largely due to carers not turning up on time, or not having sufficient time to complete tasks;

'I was waiting for home help to come and bathe me, to change my pouches, do all the other stuff, and then they don't come until after midday, and you've been sitting there waiting, soiled… That can be horrible, absolutely awful.'

Participant 9

For other participants, dissatisfaction was due to visiting staff being unfamiliar with their clinical history, meaning that some had to repeatedly describe their illness. It also resulted in lack of preparation for care tasks which prevented care from being completed. Some participants also spoke of the physical differences between the ward and home environments e.g. layout, floor surface, distances between rooms, and how therapy input prior to hospital discharge did not adequately prepare them for managing at home. The final factor creating transfer anxiety for participants was a rushed discharge, which left few opportunities to ask clinicians questions about their condition and created last minute changes to medication, notably analgesia, resulting in increased pain at home.

Theme 2: Tailored Information Provision

The need for information and reassurance appeared throughout interviews, with participants' benchmarking their own symptoms and recovery against a perceived 'norm'. Three areas of information need were identified; i) are my problems normal, ii) is my recovery normal, and iii) where can I get help? Some participants expressed frustration at not being 'warned' about possible difficulties they might face following discharge, particularly problems with breathing, sleeping, psychological issues and fatigue. An understanding of possible problems would have decreased the anxiety felt by many participants:

'there wasn't enough explaining of things like hallucinations, so I thought I was mad… and because it went on for such a long time and I did have quite bad flashbacks'

Participant 4

Verbal information provided before discharge was not valued, as participants did not understand it and often forgot it. Most participants were not provided with written or online information. Those who did said it was hugely reassuring;

'about three months later my hair started falling out but [that booklet] was really good to have because… it said one of the things… your [hair] may fall out... And so I thought 'that's OK….''

<div align="right">Participant 5</div>

Several participants wanted to be able to telephone or email a critical care specialist who could answer questions in the acute period following discharge home. For some, this reflected the interim period prior to attendance at an ICU follow-up clinic where they could discuss these concerns in person. Recognition and naming of the problems that participants were experiencing was an important role of follow-up services. For those who could not attend these services, contact with clinical specialists would have been valuable;

'I would have liked to have had access to a critical care specialist… so I could have said 'I can't cope with this; I feel like my lungs aren't working and I can't breathe…'. And somebody could have said… 'this is normal'.

<div align="right">Participant 7</div>

Whilst some of these participants sought reassurance from their general practitioner (GP), most suggested that the GP was not familiar with the speciality of critical care to adequately provide this role:

'to find that the GP doesn't know really much about what you've gone through it's a bit… worrying'

<div align="right">Participant 2</div>

Most participants reported that their recovery from critical illness took longer than they had expected. This made it difficult to know how hard they should push

themselves when returning to work or progressing physical recovery. The role of peer support groups, either face-to-face or via an online forum helped participants gain reassurance about their feelings and experiences, and adjusted expectations of the timeframes for recovery. They could also act as a catalyst for participants seeking support for problems that they had previously been unable to name:

'I found the [ICU recovery charity] website and started reading the blog, and I sort of went 'oh.... There's other people like me.' And that was the bit where I started to accept that I needed some help.'

Participant 7

Important individual differences in recovery trajectories also appeared through participants' stories. Whilst some described themselves as recovered around six months after discharge, more described it as a much longer process, and some questioned whether they were fully recovered several years later:

'I think it took six months to physically recover. I think that the psychological side of it…the experiences that I've have had made me realise that they were much deeper experiences than I'd appreciated at the time. I think it's taken me –five years later I feel well-adjusted – I understand the psychological side much more.'

Participant 11

Theme 3: Timely Access to Services

All participants in this sample received at least one type of support via hospital or GP referral, or independently accessed. Most participants reported difficulties accessing services that catered for their specialist needs:

'I was in the gym with OAPs, and they'd had heart attacks and that, and that was difficult because I was the only younger person there. And the OAPs were catching up on news, sitting on machines and not moving off them and just talking.'

Participant 8

Other limitations included long waiting lists, no services in their area, or a GP who was not aware of relevant local services.

Psychological services were the most frequently requested and most urgently prioritized by most participants. The psychological impact of critical illness was also cited as the most frequent limiting factor to full recovery:

'it was such a slow process…it was only afterwards that…I realised how unsettled my world was as a result of, not the physical… here, but the mental side of it… it took me 3 or 4 years'

Participant 3

Several participants did not request psychological help until several years after their critical care stay, due to unfamiliarity of these problems as common consequences of critical care and possible treatment. Some participants felt that psychological difficulties should be 'expected' by clinicians after critical illness to avoid delays in accessing therapy, and increased availability of services, to prevent long waits (in one case, 9 months) for therapy. Participants who had access to a follow-up clinic reported useful onward referral to specialist services for their critical care-related symptoms.

However, some participants mentioned problems with the design of follow-up clinics. The appointments occurred three months after discharge, during which time many experienced anxieties in the absence of reassurance. In addition, some participants were unable to attend follow-up clinics for practical e.g. limited mobility, or psychological such as fear of returning to the hospital. This has implications for where and how to hold a follow-up clinic. Some participants suggested appointments over the telephone to overcome the problem of travel and/or location. Some participants suggested more flexibility in timings of the follow-up clinic, to allow for the differing needs of patient at different stages in their recovery:

'if you'd taken a snapshot of me at three months, and one at six months, it would have been a dramatic difference, and if you'd taken a snapshot at twelve months, you wouldn't have realized I was the same person'

Participant 2

A lack of support and information resulted in 'patient-led' recovery through independent researching of conditions, progressing physical recovery through self-directed goals and seeking help e.g. directly contacting a critical care unit for a 'debriefing'. Participants highlighted the challenges with this form of self-advocacy, including disorientation experienced in the first weeks and months of getting home which compounded identifying problems and sourcing help:

'as the patient…you're still not with it… trying to come to terms with what has happened is quite a big task, let alone thinking about… how am I gonna cope? You need to almost be handed these things on a plate'

Participant 2

Theme 4: A supportive social network

All participants raised the importance of social support from family and friends, visiting carers or support groups. Family and friends assisted with practical tasks, coordinated hospital visits, and provided moral support and motivation. In some cases, this involved a family member giving up work to provide full-time care. Family and friends also often provided unofficial psychological support, helping participants view their recovery in a more positive light:

'I can visualise myself as a tree being supported by countless fibres holding me up, they may not realise it but they kept my head above water when it would have been very easy to go down'.

Participant 3

Visiting carers, e.g. district nurses supported emotional wellbeing and reassurance about recovery, and helped to provide social support, particularly but not exclusively

to those participants living alone. One participant prioritised the value of the social aspect of his care visits over their role as carers:

'I didn't have many visitors, so it was really nice to have them just to chat to'

Participant 1

Some participants suggested that they would have benefitted from increased social support, with one suggesting a 'tea group', one suggesting phone calls from other survivors 'just to check in' and others attending support groups for several years after leaving hospital because of the friendships created in the groups.

'there's a small group of us who are not in contact apart from the meetings, but we feel very comfortable talking about things together. And that is a bit special.'

Participant 11

DISCUSSION

This study identified four themes of support needs reported by survivors of critical illness who had been discharged home for up to 10 years following ICU admission, and highlights the longevity of impairments in this population. These are synthesized as a transitional process in Figure 1, albeit acknowledging considerable individual overlap in stages e.g. a supportive social network could assist all three other support areas.

FIGURE 1 HERE

Figure 1 - Themes of participants' experiences of support

A key finding in this study was survivors feelings of anxiety once home after critical care, relating to a perceived loss of safety away from continual monitoring and care, in keeping with the findings of Bench & Day (2010). There was a strong desire for information about the critical care stay and reassurance about any potential repercussions, which played an important role in recovery. This information needs to

be provided in a readable format for patients who are often struggling to concentrate and comprehend complex information (Bench et al, 2011), but evidence suggests that brief discharge summaries may be of benefit (Bench et al, 2014). The support needs expressed by the current cohort mirror those from other critical care survivor cohorts, where a temporal change is also demonstrated (Czerwonka et al, 2015; Lee et al, 2009).

The protracted psychological consequences of a critical care stay were strongly illustrated by the current sample: compared to a relatively quick physical recovery, psychological recovery often took years, a finding seen in other studies (Berkius et al, 2013; Hofhuis et al, 2008). For participants not receiving critical care follow-up appointments, their psychological issues took longer to be identified and therefore receive appropriate help. The literature is clear that psychological intervention is likely to improve recovery (Aitken et al, 2016) and that people who do not receive adequate psychological input may need more follow-up (Haraldsson et al, 2015).

The value of follow-up clinics in providing reassurance to attendees about their symptoms and recovery was another finding. However, a more flexible model of service provision might improve accessibility; occurring at different time points in recovery, offering more than one appointment (Prinjha et al (2009), or occurring at a site away from the hospital, over the phone or via email (Pattison et al (2015). Contact details for a critical care clinician during the interim wait time for a follow-up appointment was suggested. Several participants stressed the lack of coordination in their care, and the potential benefit of a key worker within critical care, akin to a specialist nurse role. A recent large-scale study (Ramsay et al, 2016; Walsh et al, 2015) investigated the effect of a rehabilitation assistant (RA) for patients on the ward after critical care. Patients who were visited by the RA reported much higher satisfaction with their care. The authors attribute a large part of this to the coordinating, 'case-manager' role played by the RA, who helped to communicate discharge plans and problems on the ward, and enhanced the individualisation of the support received by patients. The role of specialist nurses is well-documented in long-term conditions (Blue et al, 2001; Griffiths et al, 2013b; New et al, 2003)

reducing admissions to accident and emergency and increasing communication with the multi-disciplinary community (Waters & Read, 2015).

Autonomy in recovery was problematic for participants due to poor concentration, emotional lability and difficulties with problem-solving, necessitating reliance on others until these symptoms improved. This illustrates the potential vulnerability of those patients who live alone or who do not have an obvious advocate to arrange help where necessary, particularly if they are not linked in to ongoing care services. Importantly, most participants did not find their GPs were informed enough about post-intensive care syndrome to be able to direct them to appropriate services, suggesting that GPs needed better information about the problems faced by this patient group – a finding corroborated by Bench et al (2016).

Lastly, the role of family, friends and social contact was highlighted through the interviews. High levels of self-rated social support seemed to be protective against the development of PTSD (Deja et al, 2006; Pedersen et al, 2002), and may help to mitigate against the reduction in quality of life after critical care (Tilburgs et al, 2015). This study suggests a similar wide-reaching effect of social support, helping with feelings of anxiety and low mood, facilitating attendance at hospital appointments and providing informal care services, much in a 'social assistive' role as discussed by Iwashyna and Netzer (2012). The significance of peer-support was another key finding in this study, as shown in other studies (McPeake & Quasim, 2016; Mikkelsen et al, 2016).

STRENGTHS AND LIMITATIONS OF THIS STUDY

This study benefits from being conducted using a robust methodology and in line with established reporting guidelines for qualitative research (Tong et al, 2007). Broad inclusion criteria were adopted, including the timeframe for discharge from hospital, to capture the experiences of a range of survivors of critical illness. Many studies to date have focused on the short- to medium-term period up to one year following hospital discharge (Griffiths et al, 2013a; Herridge et al, 2009; Jackson et al, 2003) but there is limited data on long-term recovery (Cuthbertson et al, 2010),

especially of the timeframe reported here. However, this does create a potential problem with recall bias, particularly given the propensity to cognitive deficits and decline after critical care (Sukantarat et al (2005). Whilst the author acknowledges this potential caveat, the vivid stories related by participants suggests this was not a major problem in this study, and instead has given these survivors an opportunity for their stories to be part of our understanding of the recovery trajectory. In this small sample, it was not possible to determine any differences in experiences between participants who were recently discharged from critical care and those discharged at a later point, except that those discharged within the last five years were more likely to have received critical care follow-up.

In addition, the author used a convenience sample of members of a charity who have expressed interest in research and a PPI group. These participants may differ from those of people who are not actively involved in research.

RECOMMENDATIONS FOR PRACTICE

- Flexible critical care follow-up should be available and offered to all critical care patients. To improve acceptability, this might need to occur at different time points in recovery for different individuals, or occur at a site away from the hospital, over the phone or via email.
- Written/online information should be provided to patients and relatives before discharge home
- Early recognition of the psychological consequences of critical care and prompt access to psychological services is vital
- A social network is important for recovery, including peer-support networks in the form of online forums or face-to-face meetings
- Future research should investigate the recovery of survivors discharged over 2 years ago, who are often excluded from research studies due to fears of recall bias, but continue to experience difficulties that they are not supported with. It may be useful to determine whether the needs of this group differ from those of more recently discharged survivors.

CONCLUSION

Critical care survivors require a well-planned hospital discharge, access to specialist services in the community, and personalised information to facilitate individual recovery. Psychological support was particularly prioritized, with additional benefits noted from social support, both formal and informal. This study highlights the need for flexibility in models of critical care follow-up to cater for the diversity of support needs and recovery trajectories across survivors; these services should be directed by specialist critical care clinicians as opposed to general practitioners whose knowledge may be insufficient to adequately manage post-critical care symptoms. Lastly, the longevity of difficulties faced by this population is demonstrated, and suggests research should include longer periods of follow-up.

IMPACT

What is known about this topic:

- Survivors of critical care can experience a range of physical, psychological, cognitive, social and financial difficulties.
- Interventions such as follow-up clinics and rehabilitation programmes have been set up to support survivors with these problems, but the evidence for them has been mixed.
- Little is known about what survivors themselves value as important during their recovery.

What this paper adds:

- This paper demonstrates the highly individual nature of recovery, and the difficulties that current support services have in providing sufficient flexibility to cater for this.
- It also shows that many survivors experience difficulties for several years after leaving hospital, long after their support services have finished.
- These survivors are often excluded from research studies due to fears of recall bias, and therefore we do not have sufficient understanding of their needs to support them or learn from their experiences.

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