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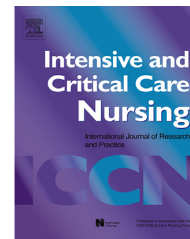

After critical care: Patient support after critical care. A mixed method longitudinal study using email interviews and questionnaires

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KEYWORDS
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Quality of life

Summary
Purpose: To explore experiences and needs over time, of patients discharged from ICU using the Intensive Care Experience (ICE-q) questionnaire, Hospital Anxiety and Depression Scale (HADS) and EuroQoL (EQ-5D), associated clinical predictors (APACHE II, TISS, Length of stay, RIKER scores) and in-depth email interviewing.
Methods: A mixed-method, longitudinal study of patients with >48 hour ICU stays at 2 weeks, 6 months, 12 months using the ICE-q, HADS, EQ-5D triangulated with clinical predictors, including age, gender, length of stay (ICU and hospital), APACHE II and TISS. In-depth qualitative email interviews were completed at 1 month and 6 months. Grounded Theory analysis was applied to interview data and data were triangulated with questionnaire and clinical data.
Results: Data was collected from January 2010 to March 2012 from 77 participants. Both mean EQ-5D visual analogue scale, utility scores and HADS scores improved from 2 weeks to 6 months, ($p = <0.001$; $p = <0.001$), but between 6 and 12 months, no change was found in data from either questionnaire, suggesting improvements level off. These variations were reflected in qualitative data themes: rehabilitation/recovery in the context of chronic illness; impact of critical care; emotional and psychological needs (including sub-themes of: information needs and relocation anxiety). The overarching, core theme related to adjustment of normality.
Conclusions: Patient recovery in this population appears to be shaped by ongoing illness and treatment. Email interviews offer a convenient method of gaining in-depth interview data and could be used as part of ICU follow-up.
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Implications for Clinical Practice

- Follow-up after critical care is not a linear process of improving recovery.
- Consideration needs to be given to how follow-up is shaped by ongoing chronic illness disease and treatment.
- Email might offer a convenient way of following up patients after critical care, especially in hard to reach populations.
- Email interviews can yield good quality, rich qualitative data.

Introduction

The admission of patients to critical care for supportive treatment of critical illness has been shown to cause significant physical and psychological sequelae (Audit Commission, 1999; Cuthbertson et al., 2004, 2010; Jones et al., 2001; NICE, 2009). Guidance suggests that critical care services should also address long-term sequelae, including post-traumatic stress disorder, anxiety and depression (NICE, 2009) and long-term consequences of critical illness have family and individual costs including diminished areas of health-related quality-of-life, sleep, reduced ability to return to work and leisure activities (Audit Commission, 1999; Cuthbertson et al., 2010; Graf et al., 2008; Rattray and Hull, 2008); recovery from critical illness may continue to affect patients and their carers, and some extensively so (Adamson et al., 2004). Follow-up services have been established across much of Northern Europe and beyond, to address such issues. There is weak evidence regarding the efficacy of interventions to address emotional and psychological consequences, which can persist for many years (Ringdal et al., 2010; Zetterlund et al., 2012). Research in critical care follow-up centres on post-traumatic stress disorders, anxiety/depression and physical function (NICE, 2009). Follow-up also has a role in patients seeking to make sense of their ICU experiences (Storli and Lind, 2009) and to find reassurance about their experiences (Pattison et al., 2007; Prinjha et al., 2009), although one RCT found no effect on long-term quality of life (Cuthbertson et al., 2010), however there have been criticisms for only using nurses in rehabilitation programmes and a manual-based approach (O'Connor et al., 2009; Wright et al., 2009). However, this study importantly reinforced the longer term consequences of critical care with approximately 25% requiring referral for physical problems and the same number for psychological problems. Whilst revisiting the ICU environment and the use of ICU diaries have been shown to be beneficial to patients as part of the follow-up process, allowing for debriefing and giving patients a way of filling in missing time (Backman and Walther, 2001; Engstrom et al., 2008, 2009, 2013) and an improved long-term -related quality of life (QOL) (Backman et al., 2010), a gap still exists to explore patient needs for support after critical care and to consider a different model of follow-up.

Models of follow-up

Follow-up is traditionally face-to-face, however in an era increasingly led by Internet activity (United Nations Statistics Division, 2013) there is a role for exploring other methods. The value of telephone follow-up in managing issues after hospital discharge has not been fully established (Mistiaen and Poot, 2006). Email is a burgeoning area of follow-up and it has been used in hard-to-reach or vulnerable populations such as in HIV (Cook, 2012). Several Cochrane reviews of research in the area of email use in healthcare attest to the extent to which it is used (Atherton et al., 2009a,b,c). For some patients email consultation can provide an interface between a face-to-face appointment and no appointment at all (Wedderburn et al., 1996; Ellis et al., 1999). In follow up, email has particular use, for example after an appointment (Katz et al., 2003) or when further information or clarification is needed (Patt et al., 2003).

Materials and methods

Email as a research method

Email interviewing is a research method that allows flexibility in participation for users (Kivits, 2005; Meho, 2006; O'Connor et al., 2008) which is novel in healthcare research (Bjerke, 2010). Email has particular value in generating qualitative research data. Online or email-based surveys as research methods have been around since the early 1990s, but using email interviews as a primary method for obtaining in-depth qualitative data is relatively novel. Internet usage across the world has increased exponentially with overall usage estimated at over two billion (United Nations Statistics Division, 2013). In this context, email usage is bound to increasingly permeate all aspects of health care including research. Email interviews in research offer an alternative method for patients to engage in research (Kivits, 2005; Meho, 2006; Murray and Harrison, 2004) and allow research participation at the patient's convenience in terms of place and time, can keep costs low (Chen and Hinton, 1999) and can also make it easier to maintain the longitudinal aspect of the research (O'Connor, 2006). Initial contact in email interviewing is usually brief with rapport-building a priority and then longer interviews take place several contacts into the correspondence. It is well placed in research around sensitive issues since the absence of face-to-face contact minimises discomfort. It is unobtrusive, encourages honesty and openness, and affords participants time to reflect on their experiences. It has been argued that email allows a democratisation of exchange (Boshier, 1990). This implies that because respondents can consider their replies, or have an opportunity to ask questions/write anything in return, without being directed in a certain direction immediately (as with face-to-face or telephone interviewing).

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