



Research paper

Challenges during long-term follow-up of ICU patients with and without chronic disease



Hugh Davies RN, PhD, B Nurs, PG Dip (Intensive Care), MHM^{a,d,*},
 Nicole McKenzie RN, B Nurs, PG Dip (Critical Care), MPH^b,
 Teresa A. Williams RN, PhD, B Nurs, ICU Cer, PG Dip Clin Epi, M Hlth Sci (Research)^c,
 Gavin D. Leslie RN, PhD, BappSc, PG Dip (Clin Nurs), FACN^d,
 Ruth McConigley RN, PhD, BSc (Nurs), Dip Appl Sc (Nurs), MN^d,
 Geoffrey J. Dobb BSc, MBBS, FRCP, FRCA, FANZCA, FCICM^{a,e},
 Samar M. Aoun PhD, BSc Hons, MPH^f

^a Intensive Care Unit, Royal Perth Hospital, Wellington Street, Perth, Western Australia, Australia

^b Australian Resuscitation Outcomes Consortium (AUS-ROC), Prehospital Resuscitation and Emergency Care Research Unit (PRECRU), School of Nursing & Midwifery, Faculty of Health Sciences, Curtin University, Western Australia, Australia

^c Prehospital Resuscitation and Emergency Care Research Unit (PRECRU), School of Nursing & Midwifery, Faculty of Health Sciences, Curtin University, Western Australia, Australia

^d School of Nursing & Midwifery, Faculty of Health Sciences, Curtin University, Western Australia, Australia

^e School of Medicine and Pharmacology, The University of Western Australia, Australia

^f Palliative Care, School of Nursing & Midwifery, Faculty of Health Sciences, Curtin University, Western Australia, Australia

ARTICLE INFORMATION

Article history:

Received 14 December 2014

Received in revised form 8 April 2015

Accepted 15 April 2015

Keywords:

Follow-up

ICU

Telephone interview

Diary

Chronic disease

ABSTRACT

Introduction: Reflecting on researchers' experiences during follow-up of patients enrolled in research may lead to improved understanding of the challenges faced in maintaining contact when patients leave hospital.

Aims: (1) Describe the challenges researchers face when following-up patients who survive ICU. (2) Identify issues that influenced our ability to follow-up patients.

Methods: This sub-study was part of a larger "case-control" study investigating the quality of life of ICU survivors with and without pre-existing chronic disease. Patients completed self-assessment QLQ and symptom assessment before hospital discharge and at six months, plus they were asked to keep a paper diary of healthcare services used. Patient contact was maintained by monthly telephone calls. Each telephone call was logged and summaries of conversations documented. Our experience of conducting the study was reviewed by the identification of common issues which arose from the follow-up of patients. **Results:** Thirty patients with a history of chronic disease and 30 patients without underlying chronic disease were followed-up. A total of 582 telephone calls were made for 60 patients discharged from hospital of which 261 (45%) calls led to a telephone interview. Only 19 (30%) of diaries were completed and returned. We identified six challenges associated with issues that arose from the follow-up of patients. **Conclusion:** We underestimated the number of telephone calls required for follow-up after discharge. Diaries were unreliable sources of data suggesting strategies are needed to improve compliance. How patients respond to follow-up is not always predictable. Processes are needed to deal with unexpected information provided during telephone follow-up.

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1. Introduction

The importance of long-term follow-up for survivors of critical illness has received increasing attention.^{1–3} It is common for survivors of critical illness to experience physical and psychological problems when discharged from hospital after receiving treatment

* Corresponding author. Tel.: +61 8 9224 1631; fax: +61 8 9224 3668.
 E-mail address: hugh.davies@health.wa.gov.au (H. Davies).

in the Intensive Care Unit (ICU).^{4–7} This can have detrimental effects on day-to-day life and the ability of the patient to resume previous levels of activity before hospitalisation.

Telephone interviews have been used to gather information on the long-term outcomes of patients who survive critical illness and their need for and use of healthcare services when discharged,^{8–11} but there is little information on the problems that occur when using this method to follow-up patients. Another approach is to use patient diaries.¹² Diaries offer the opportunity for patients to reflect on their experiences¹³ and enable patients and researchers to better understand what happened to them in ICU.¹⁴ However, diaries are often written at the time of the critical illness episode and not of patients' experiences after leaving hospital. Little is known about how useful diaries are for the long-term follow-up of patients who survive critical illness and, similar to the use of telephone interviews for long-term follow-up, the challenges that occur in the collection of data.

This sub-study was part of a larger investigation that compared patient centred outcomes (quality of life, symptom assessment and survival) at hospital discharge and at six months post-discharge for patients admitted to ICU with and without pre-existing chronic disease.¹⁵ A greater understanding of the possible differences between the two groups of patients would help to determine whether the needs of each group are being met after discharge from hospital. The purpose of this sub-study was to describe the challenges we faced when conducting patient follow-up in the main study, strategies we used to promote ongoing participation and to suggest opportunities for improvement.

2. Aims

The aims of the study were to (1) describe the challenges researchers face when following-up patients who survive ICU and (2) identify issues that influenced our ability to follow-up patients.

3. Methods

3.1. Design

This observational study investigated the challenges we encountered as part of the main study in the follow-up of hospital survivors, with and without chronic disease, who were admitted to the ICU between April 2011 and June 2012. On discharge from hospital, patients were followed-up for six months using monthly telephone interviews and paper healthcare diaries. The Study Coordinator (author HD) assessed the suitability of inpatients to participate in the study, and then once discharged from hospital liaised with the Research Nurse (author NM) who was responsible for the follow-up of patients by telephone.

3.2. Participants and setting

Patients were included if they were 18 years and older, admitted to ICU with a history of chronic disease (cases) or matched by the Acute Physiology and Chronic Health Evaluation (APACHE) II score¹⁶ and age to patients with no history of chronic disease (controls). The APACHE II score¹⁶ is used to measure severity of illness in ICU: values range from 0 to 72. Patients were followed-up for six months after hospital discharge with pre-discharge and six month questionnaires, monthly phone calls to keep in touch with patients and a diary to record use of healthcare services. The APACHE II score¹⁶ definition for chronic disease was used to define patients' chronic disease in the study based on five end-stage disease conditions. A summary of the protocol used to recruit patients is shown in [Box 1](#).

Box 1: Protocol used for "case-control" study.

- Patients aged ≥ 18 years old
- Admitted to ICU
- Worst APACHE II score first 24 h*
- Identification of "Case" (acute life-threatening episode of critical illness WITH chronic disease):
 - New York Heart Association Classification IV
 - Respiratory (chronic obstructive, restrictive, vascular disease resulting severe exercise limitation, chronic hypoxia, chronic hypercapnia)
 - Renal (chronic peritoneal or haemodialysis)
 - Liver (proven cirrhosis and documented portal hypertension, prior hepatic
 - failure/encephalopathy/coma)
 - Immune-suppression conditions or treatment severe enough to suppress infection (e.g. leukaemia, lymphoma, AIDS, diffuse metastatic cancer)
- Identification of "Control" (acute life-threatening episode of critical illness WITHOUT chronic disease)
- Case versus Control comparison determined by:
 - Similar illness severity score (APACHE II score ± 2 points)
 - Similar age range (± 5 years)
- Follow-up of Cases and Controls to continue for six-months or until death

*Knaus WA, Draper EA, Wagner DP, Zimmerman JE. APACHE II: a severity of disease classification system. *Crit Care Med* 1985;13:818–29.

The recruitment of patients occurred within a Level III¹⁷ ICU at a metropolitan tertiary-referral hospital in Western Australia. The 23-bed ICU admits both medical and surgical patients including patients with trauma, sepsis, interventional neurosurgery, cardiac surgery and heart and lung transplant surgery.

3.3. Ethical considerations

Approval was granted by the hospital's Ethics Committee. Patients were informed about the study and asked if they would like to participate. The study was considered low risk and written consent was waived by the Ethics Committee. Confidentiality was assured with personal information protected against unauthorised access and patients in the study were unable to be identified. If the Research Nurse felt the patient was distressed after recollections of unpleasant experiences, the interview was stopped and patient encouraged to seek assistance from their doctor or other appropriate community services. The Study Coordinator was informed of the incident and a plan discussed with the Research Nurse to implement measures such as involvement of family members who could offer support in subsequent interviews.

3.4. Data collection

Patients discharged from ICU were interviewed on the ward by the Study Coordinator before hospital discharge, informed about the study and what was being asked of them. This was repeated in an information sheet given out at the same time. Family members were encouraged to be present and to ask questions on behalf of the patient. If they agreed to participate patients were assisted by the Study Coordinator or family member with the completion of three questionnaires as the first part of the study before hospital discharge: two Quality of Life Questionnaires (QLQ), the Australian (English) Medical Outcome Study 36-item short-form (SF-36v2TM),¹⁸ and the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C15-PALTM,¹⁹ and a Symptom

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