

Exploring the use of Video Diaries for Family Members of Intensive Care Patients, by Sheila Rodgers

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Due to COVID-19, intensive care (ICU) patients were not allowed visitors or had severely restricted visiting at the end of life. All visiting has been prohibited apart from exceptional but limited visiting by one or two family members at the end of life. This prohibition applies to all patients and is anticipated to continue for a significant period. Whilst many non-ICU patients are keeping in touch with family through phone/video calls, most ICU patients cannot communicate this way as they are unconscious or extremely weak and cannot speak on the phone or video call their family. Before these visiting restrictions, family members of ICU patients were already known to suffer significant psychological distress and now face increased distress as they are unable to visit or have had their visiting severely limited.

Family members of ICU patients face significant psychological stress due to the patient's severity of illness and uncertainty of outcome. Prior to lockdown, the risk of family members of ICU members developing anxiety and depression was already identified as high. In the context of the COVID-19 and lockdown, it appears likely that there will be substantial increases in anxiety and psychological distress. Family members often become the main source of support for patients at home during their recovery, with thirty-five percent of these family members suffering from clinically relevant post-traumatic stress disorder symptoms.

In June 2020, NHS Scotland introduced video diaries as an emergency measure to try to support communication with families and reduce distress. Co-created paper ICU diaries by staff and family members are not possible during the COVID-19 outbreak therefore video diaries using secure remote communication software (vCreate) are being implemented as an emergency measure in ICUs in Scotland. Diaries used in some intensive care units are usually written by both staff and family members and contain information about events occurring in the ICU: what the patient's family were thinking and feeling, what was happening in the patient's family life at home, and more. Healthcare staff record and send videos and photos to family members to supplement telephone updates. Staff inform family members about general progress rather than detailed clinical information and discuss with family members what they want to see on the videos. Videos/photos may include the patient and their surroundings of staff only. Family members can also upload photos and videos to be shared with the patient. These diaries help patients and family members make sense of their ICU experiences and benefit both patients and family members by reducing psychological distress. The diaries may have a positive impact but there is a risk they could also have negative effects.

This innovative approach has never been used in adult ICUs before and the impact on families as a social group is unknown. Whilst a positive impact is anticipated, there is a risk that this intervention could have negative impacts on the families as well. We urgently need to explore the use of video diaries to understand their potential impact on communication and psychological distress of family members, alongside testing feasibility and acceptability of measures for a larger subsequent study.

OBJECTIVES

The aim of this study is to explore the use of video diaries by adult family members and healthcare staff, and to test acceptability and feasibility of measures of psychological well-being and distress.

1. What are family members (of ICU patients) experiences of using video diaries ?
2. What are ICU healthcare staff experiences of using video diaries?
3. How acceptable and feasible is it to measure family members' psychological wellbeing?
4. How acceptable and feasible is it to measure family members' psychological distress?

We have completed our data collection and are now in the final stages of data analysis. Plummer (1995) developed a sociology of stories which for him was concerned with the 'social role' of stories rather than the 'formal structure', for example how stories are produced and read or how they change and the role they have in different contexts. 'Stories as joint actions' provides a useful model to explore and understand the experiences of diaries from multiple perspectives by acknowledging joint actions occurring with and around the diary throughout different stages of the critical illness journey. Our analysis in this study is therefore informed by Plummer's approach.

Team

Dr Sheila Rodgers is an Honoray Fellow in Nursing Studies at the School of Health, University of Edinburgh, and an Honorary Nurse Consultant in Critical Care at NHS Lothian. She has a broad range of experience as a Senior Lecturer in Nursing and former Head of Nursing Studies at the University of Edinburgh. Her clinical experience is focused in Critical Care, Surgical Nursing and Care of Older People.

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Dr. Corrienne McCulloch is Lead Research Nurse and NRS Clinician in the Edinburgh Critical Care Research Group with NHS Lothian and an Honorary Fellow in Nursing Studies at the University of Edinburgh.

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Professor Natalie Pattison holds a Florence Nightingale Foundation Clinical Professor of Nursing position funded jointly by the University of Hertfordshire and East and North

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References:

1. McPeake J, et al (2016) Caregiver strain following critical care discharge: An exploratory evaluation. *Journal Critical Care*. 35:180–1840.
2. Herridge, M., et al. (2016). Recovery and outcomes after the acute respiratory distress syndrome (ARDS) in patients and their family caregivers. *Intensive Care Medicine*, 42(5),725-738.
3. Davidson, J. E., et al. (2012). Family response to critical illness: Post intensive care syndrome–family. *Critical Care Medicine*, 40(2),618-624.
4. Garrouste-Orgeas, C., et al. (2012). Impact of an intensive care unit diary on psychological distress in patients and relatives. *Critical Care Medicine*, 40(7),2033-2040.
5. Plummer (1995) *Telling Sexual Stories: Power, change and social worlds*. Routledge, London.

6. McCulloch, C. (2017). *Critical Care Diaries: A Qualitative Study Exploring the Experiences and Perspectives of Patients, Family Members and Nurses*. PhD thesis, University of Edinburgh.