

The End is Just the Beginning: Involving Bereaved Next of Kin in Qualitative Research

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Introduction

- Older people make up an **increasing proportion** of patients **admitted** to critical care and often have **poorer outcomes**, especially in the context of COVID-19 (1).
- Little is known** about the experiences of older patients in ICU and there is **limited literature** on the experiences of bereaved relatives (2).
- Barriers** to recruitment of bereaved NoK to research studies include:
 - Reluctance to impose what might be seen as an additional burden on families during the aftermath of a bereavement
 - Difficulty in accessing bereaved loved ones to invite participation in research
 - Fear of or actual rebuttal by ethics committees due to concerns such as is it ethical to recruit to research when a person is vulnerable due to grief and is it ethical to discuss stressful events
- Bereaved next of kin (NoK)** may be the only way to **access the experiences** of patients who do not survive.
- The ongoing ESCALation of the eLderly (Age>65years) to criTical carE with covid 19) (**ESCALATE**) study is a qualitative research project which seeks to understand the experience of patients and NoK where the patient was **65 years** when **admitted to intensive care** in the UK with a primary diagnosis of confirmed or suspected **COVID-19** respiratory failure.

Results

- Recruitment was limited by **only 40% of bereaved NoK having postal addresses recorded** on the hospital systems.
- Bereaved NoK of **40** patients were contacted by letter and follow up telephone call and **14** bereaved NoK agreed to participate.
- Following questionnaire review, **11 bereaved NoK met the inclusion criteria and were recruited for the study** (consistent with response rates for patients and NoK of survivors).
- In 1 interview, the bereaved NOK had **brought 2 additional relatives**, who also wanted their story to be heard.
- 8/11 female; 5/11 Black, Asian or Minority Ethnic.**
- All apart from 1 of the interviewed bereaved participants completed** the interview according to the interview topic guide. In the case of this 1 participant, the interviewer suggested terminating the interview when the bereaved NOK mentioned they had a headache. The interview lasted 47 minutes and the participant offered to be interviewed again on another occasion.
- Each interview lasted approximately **45 minutes**.
- Bereaved relatives were keen to share their experience (figure 1 & 2) and some **volunteered additional information** with the interviewers, such as resources they had created for their local community, personal diaries and additional reflections.

Objectives

To describe successful involvement of bereaved next of kin in critical care-based research based primarily at a North West London teaching Hospital.

Methods

Patient and public involvement from an intensive-care focused charity and local palliative care team advice was sought in order to develop recruitment strategies such as **detailed, sympathetically worded participant information packs** (3).

The study has received **REC and HRA approval**, ref. 20/PR/0779.

In keeping with the literature (4), the **window for recruitment and interview was approximately one year following bereavement**.

Recruitment was via **postal invitations with follow up telephone calls** if no response after a minimum of one week.

Potential participants were sent **questionnaires** to guide selection for recruitment. These contained: **demographic questions**; subjective **assessment of frailty** prior to admission; abbreviated and validated **Impact of Event scale** about the ICU stay (5); a validated **decision regret scale** (6) about the decision to admit to ICU; and a **free-text box**. They were then invited to be interviewed.

Semi-structured interviews were performed over video conference or telephone call, due to the ongoing COVID-19 pandemic.

Framework analysis is currently being undertaken (7).

"Thank you for making me feel so comfortable. And you've got a lovely way about you, which makes me feel that I was able to share my memories and my experiences." **Figure 1**

"Whatever you want to ask me". **Figure 2**

- Participants reported that they were **happy to be interviewed** if it would **help others** in a similar position (figure 3) and several explicitly said that they were **glad we had made contact** (figure 4).

"It's my pleasure. If my honesty or my insight can help anyway with your investigation, in terms of going forward with these sort of studies. Then I know Mum, looking down, would be extremely happy as the family are." **Figure 3**

"Again, thank you very much for reaching out to me, and allowing me to express my views." **Figure 4**

Conclusions

- Bereaved relatives of critical care patients are willing to engage in qualitative research.
- Recruitment is challenging due to practical constraints but we suggest could be improved through meticulous documentation of contact details and involvement of bereavement services in research.
- By seeking the views of bereaved loved ones, we have the potential to improve care for critically unwell patients at end of life.

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