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A Process Evaluation of the Bereavement Follow-Up Programme in Critical Care at the Queen Elizabeth University Hospital, Glasgow

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Abstract

Background

Mortality figures in critical care are high with the trajectory of dying often unpredictable. The negative impact of unexpected and sudden death on relatives is well documented and can make the grieving process significantly more difficult. There is no current research in the UK that either surveys the availability of follow-up or examines individual bereavement follow-up interventions. This study is a process evaluation of the bereavement follow-up programme implemented in 2018 in the Critical Care Unit at the Queen Elizabeth University Hospital, Glasgow. The intervention consists of a condolence card given at time of death along with the *When Someone Has Died* information pack. A letter and card are sent out after three months, giving relatives the opportunity to contact the bereavement team.

Methods

This is a mixed methods study and follows the UK Medical Research Council’s guidelines for process evaluations. A process evaluation was chosen as the most appropriate method of study as it allows researchers to pick apart the complexity of interventions by looking at implementation process, acceptability, and mechanisms of change including the impact of contextual factors. The beravement follow up programme is an intervention in current practice and therefore this project aligns to a pragmatic process evalaution. Quantitaitve data from critical care mortality figures, bereavement follow-up spreadsheets for 2019 and 2020, along with a telephone questionnaire of 16 bereaved relatives over a two-month period, examine the implementation process and acceptability variables. Semi-structured interviews were carried out with 6 consultants, 3 nurses, 1 hospital chaplain, and 4 bereaved relatives who had returned for a follow-up meeting. The interviews examine the experience of the intervention through in-depth qualitative data. The results are considered in the context of a large critical care department, the organisation, and the wider social and global context.

Findings

Implementation process results show that overall fidelity is impacted by issues around giving information at time of death, collecting information on the nearest/closest friend or relative and relying on a single contact. Acceptability of bereavement follow-up is high with over 90 per cent of relatives answering the telephone questionnaire stating that critical care should contact bereaved families. However, engagement with the intervention is low, despite this, the benefits for relatives who return for a meeting based on analysis of the semi-structured interviews go beyond answering questions and clarifying events. This suggests a gap in both how the programme is offered and the understanding of the mechanisms of change in bereavement follow-up. Stakeholder data indicate that, while bereavement support is viewed as important, time and resource constraints are barriers to its implementation. Attending a meeting is a learning experience for clinicians and helps inform practice.

Conclusion and Recommendations

This is a valuable study of a current bereavement follow-up intervention in critical care in the UK. The results of the evaluation show that process improvements are important for the fidelity of the intervention. Acceptability among bereaved families is high. The simple change mechanisms of non-abondonemnt and recognition of significant loss are important. However, there are opportunities to better understand gaps in engagement with the programme, the complex change mechanisms and the optimum process for bereavement follow-up. Recommendations for the current programme are made, including the need for resources and funding. Essential to the recommendations is a greater acknowledgement of the importance of bereavement follow-up at organisational level, and more policy and guidance from professional organisations. The study has implications for the wider critical care community and opportunity for more collaborative research.

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My son, Ewan, and daughter, Helen, for reminding me what life is about, and George for always being quietly constant.

Finally, I would like to dedicate this thesis to my lovely mum, Aileen McGarrigle, who died in August 2021, before it was completed.

Author's Declaration

I declare that this thesis embodies the results of my own research, that I am the full author of this thesis and that it does not include work forming part of a thesis presented by me for another degree in this or another university.

Date 08th May 2022 Signature ________________

Abbreviations

ICS	Intensive Care Society
ICU	Intensive Care Unit
HDU	High dependency units
MHDU	Medical High Dependency Unit
MRC	Medical Research Council
NHS	National Health Service
PTSD	Post-traumatic stress disorder
RCT	Randomised control trial
SICSAG	Scottish Intensive Care Society Audit Group
SHDU	Surgical High Dependency Unit

Chapter 1 Introduction

The following thesis presents the results of a process evaluation of a current bereavement follow-up programme in the adult Critical Care Unit at the Queen Elizabeth University Hospital in Glasgow. This study, for me, is the culmination of more than 20 years' work, initially to improve end-of-life care in critical care, and laterally to introduce bereavement support services in critical care. Section 1.1 discusses the rational for the research project, section 1.2 describes the beravement follow up intervention and section 1.3 outlines the key objectives of the study.

1.1 Rationale

Death in critical care, and in particular in intensive care, is common. One in five patients will die before they leave hospital, with ultimate hospital mortality figures in Scotland for mixed intensive and high dependency units at 17 per cent (Faculty of Intensive Care Medicine 2019; Scottish Intensive Care Society Audit Group, 2021). There is increasing consensus at national level that bereavement support is important. The Department of Health's (2008) *End of Life Care Strategy* states that a vital component of care after death is the provision of bereavement support. In 2011, the Scottish government's report, *Shaping Bereavement Care*, set out a framework for bereavement support in Scotland (Scottish Government, 2011), and more recently the publication of *A Bereavement Charter for Children and Adults in Scotland* advocates available, accessible and adequate bereavement support (Support Around Death, 2020).

Worldwide the experience of death and grief has become more prominent in society since the emergence of the COVID 19 pandemic in early 2020. Images of people being cared for in critical care environments are no longer reserved for the professionals who work there and the patients and families experiencing it, but are commonplace on our television screens. Yet, the difficult and distressing experience of having a relative in critical care had been faced by many families prior to the coronavirus pandemic.

Research suggests that the sudden and traumatic nature of death in intensive care can make the grieving process more difficult. Post-intensive care syndrome-family has become a recognised term for a group of psychological problems that can burden the families of critical care patients (Zante et al., 2020). That burden increases when the relative is bereaved (Schmidt and Azoulay, 2012). The impact on families experiencing a death in critical care can be significant, with research suggesting that anxiety, depression, post-traumatic stress disorder (PTSD) and complicated grief are more prevalent among relatives whose loved ones die in this environment (Anderson, 2008; Siegel et al., 2008; Kentish-Barnes et al., 2015b).

The reasons for this are multifactorial: the trajectory of dying can be either sudden and traumatic or protracted and expected, and both can be difficult for families according to Pattison et al. (2020). The critical care environment is highly medicalised and technology driven, making it difficult for loved ones to shift their focus from treatment and cure to end of life. This transition is compounded by withdrawal-of-treatment decisions and a managed death (van Mol et al., 2020). Now, the difficult experiences of bereaved families in critical care are exacerbated by the pandemic. Unexpected death, being unable to say goodbye, and a lack of face-to-face communication and family involvement at the bedside worsen families’ grief (Pattison, 2020).

In 1998 the Intensive Care Society (ICS) made recommendations for bereavement care, and bereavement follow-up was part of those recommendations (Intensive Care Society, 1998). Despite the ICS recognising that bereavement support was important, the development of UK services and policy is limited (Berry et al., 2017). However, bereavement follow-up continues to be advocated, and in 2019 the Faculty of Intensive Care Medicine (2019) issued guidelines stating that a bereavement follow-up service should be offered where explanations of diagnosis, treatments and support can be provided.

The critical care community in Glasgow made progress in imporving end of life care planning as part of the move to the newly built Queen Elizabeth Universaity Hospital in 2015. The merger of of the three acute hospitals created the largest critical care department in Scotland, with two intensive care units (ICU), three surgical high dependency units (SHDU) and one medical high dependency unit (MHDU). However, until recently there was no ongoing contact or offer of support for bereaved families after they left critical care.

The end-of-life critical care group that had been formed to standardise practice prior to the hospital opening continued to meet regularly, and from this a smaller group formed in 2017 of five nurses who had a passion to improve bereavement support. The group proposed three bereavement initiatives: a bereavement follow-up programme for relatives, memory-making resources and an annual remembrance service.

The initiatives were approved by the management team along with a small amount of funding. The first remembrance service was held in November 2017, and resources for memory making were in place by the end of the year. Information sessions and training on the bereavement follow-up programme were carried out for a period of four weeks prior to it starting in January 2018. A link nurse for bereavement support and end-of-life care in each of the six critical care units maintained communication with the bereavement team and allowed the improvements to be rolled out. Section 1.2 describes the bereavement follow up programme at the Queen Elizabeth University Hospital in Glasgow.

1.2 Bereavement Follow-up Programme in Critical Care at the Queen Elizabeth University Hospital

The bereavement follow-up programme consists of a condolence card given out at time of death along with NHS Greater Glasgow and Clyde’s standard advisory booklet, *When Someone Has Died*. The card has a message of condolence and states that we will contact the family in three months. The details of patients who die, along with details of their nearest/closest relative or friend, are documented on a spreadsheet for each unit by the ward clerk. A letter is sent out after three months offering them the opportunity to get in touch. A second card with information on bereavement support is sent with the letter (Appendix 1: Bereavement Follow-Up Letter and Cards).

The letter and cards were approved by NHS Greater Glasgow and Clyde’s equality and diversity group. Guidance was sought on information governance, and the bereavement follow-up programme was approved by NHS Greater Glasgow and Clyde’s data protection officer. There is a General Data Protection

Regulation statement on the condolence card given to relatives at time of death and on the letter sent out to relatives after three months. This statement gives recipients the opportunity to inform the department if they wish their details to be removed from our records.

In March 2020, due to the COVID 19 pandemic, the bereavement team took the difficult decision to suspend the bereavement follow-up programme. This seemed counterintuitive to the bereavement team when they were facing unknown patient mortality from a novel virus. However, the demand placed on clinical staff to respond to increasing capacity and the restrictions imposed by national lockdown measures initially made it unfeasible to continue to offer bereavement follow-up. After the initial wave of infection, the bereavement team felt that it was important to recommence bereavement follow-up and, with consensus from the rest of the clinical team, decided that they had the capacity to support this. The programme restarted in August 2020, with adaptations to accommodate the restrictions in place for COVID 19.

In early 2019, my colleague Doreen MacEachen and I attended the NHS Greater Glasgow and Clyde bereavement steering group. Professor Bridget Johnston, who led the steering group, invited us to discuss the opportunity of evaluating the bereavement improvements. Professor Johnston sought support from Dr Margaret McGuire, NHS Greater Glasgow and Clyde's executive director of nursing, and funding was obtained from the NHS Greater Glasgow and Clyde Endowment Fund to carry out the evaluation through a masters by research at the University of Glasgow.

I proposed to evaluate the bereavement follow-up programme, while Doreen proposed to investigate the meaning of memory making. The following study is a process evaluation of the bereavement follow-up programme at the Queen Elizabeth University Hospital following the Medical Research Council's (MRC) 2014 guidelines (Moore et al., 2014).The project started in October 2019 and after disruption due to the COVID 19 pandemic was completed in March 2022. Section 1.3 outlines the key aims and objectives of the study.

1.3 Key aims and objectives of the study.

Anecdotal evidence from bereavement follow-up meetings carried out in critical care at the Queen Elizabeth University Hospital suggest that there are common themes around coping with unexpected and sudden death, and retaining and understanding information. Often the issues that come out of meetings are surprising. Sudden and unexpected death can be experienced by a relative of someone who has a life-limiting illness or has been in hospital for over a month as much as someone whose relative dies within 24 hours. Families appear to express overwhelming feelings of guilt and seek reassurance that they did all they could. They generally have a need to tell their story.

Listening to relatives has identified potential learning points for critical care. Feedback on communication, the administrative process of death certification, and environmental factors such as lack of privacy and noise levels has helped to improve and inform practice. The needs of relatives may not always be apparent to the staff, and the benefits of meetings appear to be mutual, but there is no way to evidence this other than to evaluate the service.

Efstathiou et al. (2019) stated that bereavement support has become more prominent in the literature and argued that it should be identified as a clinical and research priority. From their systematic review, they suggested that bereavement services should be evaluated from the service user’s perspective using both qualitative and quantitative outcome information.

The following study is a mixed methods process evaluation of the bereavement follow-up programme at the Queen Elizabeth University Hospital following the Medical Research Council’s (MRC) 2014 guidelines (Moore et al., 2014). This method of study allows researchers to examine the complexity of interventions looking at ‘what works, for whom and under what circumstances’. The project follows guidance for a pragmatic evalaution of a current intervention in practice and has the following research aims and objectives.

- Evaluate the implementation of the bereavement follow-up programme, inform best practice and adapt/improve the service

- Explore barriers and facilitators for bereavement support in relation to participants’ responses, potential mediators and unexpected consequences
- Highlight contextual influences on impact of delivery and acceptability of the intervention and use this to guide bereavement care in a large multi-unit critical care
- Establish resources required for future provision of bereavement follow-up based on evaluation of current service
- Assess any generalisability for wider acute care
- Share the results of the study with the critical care community and help guide the future direction of bereavement support.

The poorer outcomes experienced by loved ones of those who die in intensive care are well established, and with the growing number of deaths from COVID 19 this may be experienced by more of the population. Therefore, this would seem a timely evaluation of a current Scottish bereavement follow-up programme in one of the largest critical care units in the UK.

1.4 Chapter Summary

Chapter 1 has introduced the study along with a description of the bereavement follow-up programme in critical care. The rationale for bereavement follow-up and the justification for the study have been discussed along with a statement of the key aims and objectives. Chapter 2 discusses the integrative literature review carried out for the study and expands on the current research in bereavement follow-up in critical care prior to discussion of the literature pertaining to methods in Chapter 3. Chapter 4 describes the methods used for the study while Chapter 5 discusses the results. Finally, Chapter 6 offers a discussion, and overall conclusions and recommendations made in Chapter 7

Chapter 2 Literature Review

2.1 Introduction

A literature review is important as an overview of research. By asking questions and using different methods, it allows us to summarise and make sense of a body of literature (Aveyard, 2019). An integrative review was regarded as the most appropriate approach to reviewing the literature for conducting this process evaluation. Noyes et al. (2019) supported the merits of an integrated design for process evaluations while Fletcher et al. (2016) argued that more traditional designs for summarising the literature, such as systematic reviews, focus more on quantitative studies. They answer questions about what works, but do not address how, in what context and for whom (Fletcher et al., 2016; Noyes et al., 2019).

Torraco (2005) stated that an integrative review allows the simultaneous synthesis of studies from diverse methodologies. The initial scoping exercise for the process evaluation identified a lack of policy and guidance for bereavement follow-up in adult critical care, and a limited but varied range of research. Despite this, a recent systematic review by Efstathiou et al. (2019) of bereavement support in adult intensive care was identified, and the following outline of that review helps place this integrative review in current bereavement research and demonstrates how it will enhance our knowledge further.

2.1.1 Previous Systematic Review and UK Research on Bereavement Support

The aim of the systematic review by Efstathiou et al. (2019) was to look at bereavement support globally, examine what interventions are available to families and consider how effective they are. The study looked at primary research relating to bereavement support in intensive care published between 2014 and 2018. Bereavement support was defined as care for grieving families at the time of death and post-intensive care.

Efstathiou et al.'s (2019) study examined bereavement support from a wider perspective and included papers on patient diaries and mementos. The review highlighted a lack of research and only identified one study from the UK, by Berry et al. (2017), who carried out a telephone audit to assess the provision of bereavement care in ICU in England. The survey was based on the recommendations produced for bereavement care by the ICS in 1998 (Intensive Care Society, 1998). Although bereavement follow-up was part of the ICS recommendations, Berry et al. (2017) did not ask specific questions in relation to interventions, other than to identify the provision of information on support services following a death. In comparison, this integrative review attempts to focus on bereavement follow-up interventions. The definition of bereavement follow-up and specific aims of the review are outlined below.

2.1.2 Aim of the Integrative Review

The aim of this integrative review is to critically appraise and synthesise the evidence on the implementation of bereavement follow-up interventions in the following domains:

- The content and timing of the intervention
- The aims and outcomes of the intervention.

The different focus of this review is reflected in the methods used, and how the data are synthesised. The following definitions of critical care and bereavement follow-up set the context of the review. Critical care is the term used to encompasses intensive therapy units, intensive care units and high dependency units (HDU) (National Institute for Health and Care Excellence, 2009). Milberg et al. (2008), in the context of palliative care, defines bereavement follow-up as including a variety of activities to contact bereaved relatives after a death, including letters, cards and telephone calls. For the purpose of this review, bereavement follow-up is defined as an activity or intervention when the nearest/closest friend or relative is contacted by the critical care team after the patient has died, with the direct intention of offering bereavement support.

2.2 Search Criteria

The review follows methodology guidelines on integrative reviews by Whittemore and Knafl (2005), which include strategies to enhance rigour, similar to those adopted for a systematic review. Five databases, CINAHL, Medline, Embase, PSYCHinfo and ASSIA, were searched between 28 August 2020 and 1 October 2020. The search strategy was developed following steps outlined by Aveyard (2019). A mind map was used to brainstorm ideas, the PICOT framework (population–intervention–comparison–outcome–type) was used to guide the development of the research question, and key terms were extracted from articles found in the initial scoping exercise (Aveyard, 2019).

The search strategy employs a three-stage approach. The first stage combines terms to identify critical care and critical illness, including cardiac and neurological critical care. The second stage focuses on bereavement and the third is used to search for terms relating to follow-up interventions. The terms were combined using Boolean logic alongside advanced search techniques such as truncation and the use of “adjacent to” tools to create a rigorous search strategy. Table 1 outlines the key terms used, and the example of the Medline search demonstrates the combination of terms.

Table 1 Search Strategy

Clinical environment		Bereavement terms	Follow-up intervention terms	
Critical Care Critical Illness Cardiology High Dependency or HDU	Intensive Care Units ICU ITU Neurology	Bereavement Dying Grief	Card Condolence Contact Counselling Follow up	Letter Programme Support Service Telephone call

Example of Medline search

1. Critical illness/ (29237)
2. Critical Care/ (52493)
3. Intensive care units/ (55118)
4. (critical* adj (care or ill* or condition).tw. (743034)
5. (intensive care or ICU or intensive therapy or ITU or high dependency or hdu).tw.(171448)
6. Cardiology/ (19863)
7. Neurology/ (18301)
8. (cardio* or neuro*).tw. (2527508)
9. Or/1-9 (2754199)
10. Bereavement/ (5502)
11. Grief/ (8833)
12. (Berea* or grief* or dying).tw. (46059)
13. Or 10-12 (51766)
14. (follow up or follow-up).tw. (973966)
15. Condole*.tw. (89)
16. Support.tw. (998440)
17. (letter or card or contact or counse*).tw.(255818)
18. ((berea* or grief) adj3 (follow up or support or service or program* or counse*)).tw.(1466)
19. Or/14-18 (2145952)
20. And/9,13,20) (1602)
21. Comment/(866250)
22. Letter/ (539575)
23. Editorial/ (1096214)
24. 23 not (21 or 22 or 23) (1587)
25. Limit 24 to English language and 2014 to 2020 (551)

2.2.1 Inclusion Criteria

The primary inclusion criterion is research that is about bereavement follow-up in adult critical care. The selection of articles was based on the definitions outlined in the introduction and included cardiac and neurology units. Primary research, from peer reviewed journals, written in English from Australia, New

Zealand, Canada, Europe, the UK and the US were selected. Pilot studies and desirability studies were included, while literature and practice reviews were excluded. The search was limited between 2014 and 2020 to ensure the studies reflected current research.

2.2.2 Paper Selection

Following the removal of duplicate articles, 1622 titles were inspected for inclusion. Where there was ambiguity about the inclusion of a paper, the abstract was also reviewed. Forty-nine papers were reviewed by title and abstract, with a final 23 selected for full text review. Reference screening of selected papers was carried out to ensure that no research was missed. In addition, retrieved papers were checked against those identified in the systematic review by Efstathiou et al. (2019). In total, 18 papers were selected. Figure 1 shows the flow diagram for the paper selection.

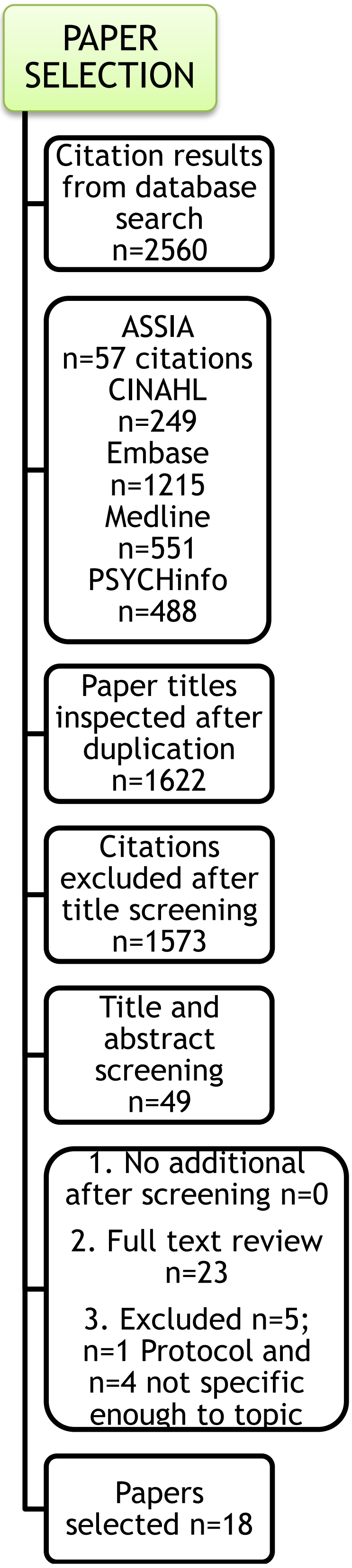


Figure 1 Flow Diagram of Paper Selection

2.2.3 Quality Assessment

Whittemore and Knafl (2005) stated that there is no gold standard for assessing methodological quality for an integrative literature review, with quality assessment complex due to the diverse nature of the literature. Hawker et al. (2002) developed a quality assessment tool to address literature that was not confined to randomised controlled trials but came from a variety of paradigms. The tool was used to assess the methodological quality of the papers for this review. It calculates a summed score between 40 (good) and 10 (poor). All of the included papers were scored but none were excluded based on quality. The scoring tool enabled a simple way of assessing the quality of the literature to make judgements about strengths and weaknesses, and weight the articles for data analysis and synthesis.

Quality was generally good, but no study achieved the highest score of 40. The national surveys scored between 28 and 34, with one paper scoring below 30 due to weaknesses in the study design resulting in a poor response rate (Egerod et al., 2019). The papers scoring higher in the intervention research were those from larger studies, with multiple sites or control groups (Kentish-Barnes et al., 2015a; Barnato et al., 2017; Kentish-Barnes et al., 2017a; Kentish-Barnes et al., 2017b; Laurent et al., 2019). Those papers that scored fair (n=21 to 30) from the intervention studies were three pilot studies and one quality improvement study. The pilot studies tended to have small numbers, two were unclear on methodology and one consulted only with professionals (Kurian et al., 2014; Santiago et al., 2017; Erikson et al., 2019). The scoring is shown in Table 2.

Table 2 Summary of Studies' Methodological Quality Using the Appraisal Tool by Hawker et al. (2002)

Author and date	Abstract/ title	Introduction/ aims	Method/ data	Sampling	Data analysis	Ethics	Bias	Findings/ results	Transferability/ generalisability	Implications/ usefulness	Total (x/40)
Barnato et al., 2017	3	4	4	4	4	1	4	4	2	3	34
Coombs et al., 2017	4	3	4	4	3	4	2	3	2	2	31
Downar et al., 2014	4	3	3	3	4	2	2	4	2	2	29
Egerod et al., 2018	4	4	4	4	4	4	4	4	2	3	37
Egerod et al., 2019	4	4	2	1	3	3	4	3	2	2	28
Erikson et al., 2019	4	4	3	3	4	4	4	3	3	3	35
Fridh and Akerman, 2019	4	4	4	3	4	4	2	4	3	3	34
Kentish-Barnes et al., 2015a	4	4	4	3	4	4	3	4	3	3	36
Kentish-Barnes et al., 2017a	4	4	4	4	4	4	3	4	3	4	38
Kentish-Barnes et al., 2017b	4	4	3	3	4	4	2	4	3	5	34
Kock et al., 2014	3	3	2	2	3	3	2	3	2	2	25
Kurian et al., 2014	2	2	3	3	3	3	3	2	2	1	24

Author and date	Abstract/ title	Introduction/ aims	Method/ data	Sampling	Data analysis	Ethics	Bias	Findings/ results	Transferability/ generalisability	Implications/ usefulness	Total (x/40)
Laurent et al., 2019	4	4	4	3	4	3	4	4	3	3	36
McAdam and Erikson, 2016	4	4	3	2	4	4	4	4	2	2	33
McAdam and Puntillo, 2018	3	3	3	3	2	3	1	3	3	3	27
Mitchell et al., 2017	4	4	4	4	4	4	4	3	3	3	37
Santiago et al., 2017	3	4	3	3	3	1	3	3	3	3	29
Schenker et al., 2015	4	4	4	3	4	4	2	4	2	3	34

2.3 Data Summary Tables

Efstathiou et al. (2019) identified a distinction between geography-based and intervention-based surveys. The papers include 11 intervention studies, six international surveys and one desirability survey. The 11 intervention studies are made up of four pilot studies, one quality improvement study, one randomised control trial (RCT), four qualitative studies and one mixed methods study. They originated from Canada, France, Sweden and the US.

The remaining papers reported the results from national surveys, with one of the six papers conducting a qualitative content analysis of a national survey. The national surveys were from Australia, Canada, Denmark, Europe, New Zealand, Sweden and the US. The desirability survey was from a single centre in Canada. There were no intervention studies or geographical surveys looking at bereavement follow-up practices in critical care from the UK. Table 3 provides data extraction for the intervention studies and Table 4 for surveys.

Table 3 Data Extraction for Bereavement Follow-up Intervention Studies

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
Barnato et al., 2017 US	Storytelling in the early bereavement period to reduce emotional distress among surrogates involved in a decision to limit life support in the ICU: A pilot feasibility trial	Pilot single blind trial	Pilot study. Single blind trial with control conditions. Staged enrolment of participants in five ICUs across three hospital: 53 eligible subjects, 32 consented to treatment allocation, 14 allocated to control and 18 to storytelling. Three- and six-month follow-up including Impact of Events Scale, Hospital Anxiety and Depression Scale, Primary Care Evaluation of Mental Disorders Patient Health Questionnaire, and Decision Regret Scale, along with self-reported usage of mental health support. The Inventory of Complicated Grief was included at six months. Subjective	Measure feasibility, tolerability and acceptability of a storytelling intervention to reduce stress in surrogate decision-makers of bereaved relatives in the ICU.	Four weeks: storytelling intervention, one-to-two-hour home visit or call by a trained interventionist. Three telephone assessments at two weeks (baseline), three months and six months. (Control was regarded as enhanced treatment.)	Storytelling intervention was feasible, acceptable and tolerable. There was a high treatment fidelity with 17 of 18 completing storytelling intervention and less than 1% missing data for intervention and control. Sixty-nine per cent of control and 94% of intervention participants reported feeling better or much better at six months. Symptom burden decreased between baseline and six months and was lowest in the storytelling group. No subjects required acute mental health referral.

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
			Units of Distress measured on a scale of 1–100 before and after all study feedback sessions; and final end-of-study feedback was obtained using closed-ended Likert scale and open-ended questions to establish burden of participation.			
Erikson et al., 2018 US	Family members' opinions about bereavement care after cardiac intensive care unit patients' deaths	Qualitative, exploratory, descriptive	Telephone interview using a patient and relative demographic survey and a semi-structured questionnaire. Bereaved families from a 16-bedded cardiac intensive care unit were invited to participate by letter 13–15 months after the death of a relative. From 109 letters, 15 opt-in cards were returned; n=12 took part.	Assess and categorise opinion of bereaved relatives about six bereavement follow-up interventions. Two of the six were already offered; the remaining four were described to participants.	Time of death: bereavement brochure; two weeks: pre-printed sympathy card signed by staff. Four interventions described: follow-up telephone call, memory box, counselling and memorial service. (Memory box and memorial service not included in analysis as do not meet the definition of bereavement follow-up for this review.)	The brochure was regarded as helpful; sympathy card appreciated and described as meaningful. Two family members described a neutral response. Families described it as caring and recognising their loss. Phone call: mixed response on whether a phone call would be useful. Those who would have liked a call had lingering questions, and felt it should be made in the weeks

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
						after death by a physician or counsellor. Counselling services: all families thought counselling services would be helpful in their grieving process. They did not see nurses or physicians fulfilling this role. This was a small study with a low response rate. Partially opinion based.
Kentish-Barnes et al., 2015 France	Research participation for bereaved family members: Experience and insights from a qualitative study	Qualitative	Part of larger CAESAR study. Multi-centre prospective observational study conducted by the Famirea group about end-of-life care in 41 ICUs in France. Thematic analysis based on 54 narratives from more-detailed interviews, 52 letters, and written annotations on 150 questionnaires.	Secondary aim of research was to ascertain relatives' feelings about participating in bereavement research.	Research study. Participants contacted by telephone after death of a loved one at three weeks and three months. Questionnaire completed at six months and 12 months. Telephone calls carried out by the same person – study sociologist.	Six themes: to say thank you, to help others, to express myself from a distance, to not feel abandoned, to share difficult emotions, to receive support and care. Supports the development of bereavement follow-up after a death in ICU. Supports telephone call as a method of bereavement follow-up along with contacting

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
						families over a period of time.
Kentish-Barnes et al., 2017a France	Effects of a condolence letter on grief symptoms among relatives of patients who died in the ICU: A randomised control trial	RCT	Twenty-two ICUs in France, 242 relatives randomised to intervention: n=123 received condolence letter and n=119 did not receive letter. Telephone interviews conducted by psychologist, sociologist and research nurse blinded to the study.	A letter of condolence might benefit the grieving process. Measured Hospital Anxiety and Depression Score (HADS) at one month and HADS complicated grief and PTSD-related symptoms at six months.	Condolence letter handwritten within three days of death by nurse and physician guided by five domains: recognise the death and name the deceased, mention a personal impression of the deceased, recognise the family member, offer help and express sympathy. Sent out at 15 days. Research: telephone interviews at one month and six months.	Interviews conducted for 208 relatives at one month and 190 at six months. HADS no significant difference at 30 days. Six-month HADS score significantly worse in the intervention group. PTSD score slightly higher. No difference in complicated grief. Concluded that the intervention failed to alleviate grief symptoms and potentially could make it worse.
Kentish-Barnes et al., 2017b France	“It was the only thing I could hold onto, but…”: Receiving a letter of condolence after the loss of a loved one in the ICU: A	Qualitative	Part of a larger RCT (see Kentish-Barnes et al., 2017a). Bereaved relatives who received a letter of condolence. Thematic analysis of spontaneous declarations about the letter.	Insight into the results of RCT by Kentish-Barnes et al., 2017a. Aimed to investigate the relatives’ experience of receiving a letter of condolence.	Same as RCT.	Six themes: Feeling of support, humanisation of the medical system, opportunity for reflection, an opportunity to describe their loved one, continuity, and doubts and ambivalence. Relatives describe

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
	qualitative study of bereaved relatives' experience		N=52 interviews and n=26 letters.			feelings of support, reassurance and recognition, trust, time for reflection and thanks to the medical team. Ongoing relationship and continuity with the ICU. Doubts and negative reactions. The letter invited relatives to contact the team; when this was not met with a positive response it caused relatives to become upset and angry, describing the letter as pointless and making things worse. Letters should not be sent to reduce grief symptoms but to offer support. Support offered must be available.
Kock et al., 2014 Sweden	A follow-up meeting post death is appreciated by	Clinical quality improvement study	To assess if a follow-up meeting with physicians was appreciated. Retrospective survey of	Aim of meeting was to clarify cause of death and what happened in the ICU period. Survey	Date and time of a meeting offered to families by the nurse	Forty-six of 84 family members answered the survey and had attended a follow-up

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
	family members of deceased patients		family members in university hospital in Sweden four years after the quality improvement project began.	aimed to measure satisfaction with the intervention.	before they left the hospital. Meeting with physician, nurse and nurse associate at four to six weeks. Occasionally also a social worker.	meeting. Follow-up meeting appreciated. Forty-two of 46 said important to continue. Most of the questions that families wanted addressed were medical. Majority wanted the meeting at six weeks; 91% rated the physician as important to be present at the meeting.
Kurian et al., 2014 US	Intensive care registered nurses' role in bereavement support	Pilot study Quantitative survey of nurses' views	Four ICUs at a US urban trauma centre. Two units received bereavement support training and piloted a bereavement follow-up programme and two units did not. Survey of nurses from the four units using convenience sampling.	Measure perceptions and practices of ICU nurses on bereavement support. Look at some modifications to the pilot programme.	One week: sympathy card emailed, telephone call by chaplain. Three months: bereavement folder. One year: remembrance card sent by nurse manager.	Response rate was 57%. Majority of nurses agreed that it was their role to provide bereavement support. Lack of training and education highlighted by those not in the pilot study. Low response for telephone calls with relatives and they were changed to one month. The research did not involve relatives.
Laurent et al., 2019	"You helped me keep my head above	Mixed methods	Part of the larger ARREVE study carried out in 43 French ICUs,	Bereaved relatives' experience of research participation.	ARREVE study: telephone calls at	ICU research calls highly beneficial especially between

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
France	water”: Experience of bereavement research after loss of a loved one in the ICU: Insights from the ARREVE study		studying the withdrawal of mechanical ventilation. Of 311 relatives participating in the 12-month follow-up call, 175 completed a postal questionnaire about research participation. Ten questions each with a Likert scale and an open-ended option. Descriptive statistics and thematic analysis.		three months, six months and one year. Calls carried out by a trained psychologist and measuring PTSD symptoms, stress, anxiety and depression for the purpose of research.	three and six months. Express that follow-up calls would be beneficial. Participation in research was therapeutic to bereaved relatives and can sometimes make up for lack of support. Themes: struggling – emotional and psychological impact; resilience – positive experience of research calls and recognition.
McAdam and Puntillo, 2018 US	Pilot study assessing the impact of bereavement support on families of deceased intensive care unit patients	Cross-sectional prospective pilot study	Compared family members of patients who died in two ICUs in a large tertiary hospital, one medical surgical ICU (MSICU) and the other cardiac ICU (CICU). Total n=40 participants. MSICU (n=30) and CICU (n=10). The MSICU participants (bereavement group) received a bereavement follow-up programme (established for five	Measure anxiety, depression, PTSD and prolonged grief, and satisfaction with care. Develop a bereavement follow-up scale to measure family’s satisfaction with and use of the intervention. Use a modified bereavement follow-up scale to assess opinion and need for follow-up in the non-bereavement group.	**Bereavement group** Time of death – bereavement brochure; one week – bereavement resource pack and condolence card, pre-printed and signed by staff; four to five weeks and six months – telephone call; one year – handwritten condolence card. A card sent offering continued support and	More family members in the non-bereavement group experienced prolonged grief than in the bereavement group. Depression, anxiety and PTSD scores were not significantly different. There was some difference in levels of PTSD in the non-bereavement group, but more research is needed. Satisfaction with care was high in

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
			years) and CICU (non-bereavement group) received standard care. Relatives were invited to participate by letter, 13 months after the death of their loved one. They were asked to return an opt-in card to complete a questionnaire. Those who opted in were sent the questionnaire by post or electronic link (SurveyMonkey) and were prompted after two weeks to complete the questionnaire.		remembrance on what would have been the patient's birthday. **Standard care** Some but not all families received a bereavement pack and condolence card.	both groups. Desirability and needs: bereavement brochure helpful (85%) but 68% did not use the resources; 59%, remembered receiving practical task packet and 79% found the condolence card meaningful, with the timing of both just right; 88% did not remember receiving a telephone call; 79% of bereavement group and all the non-bereavement group felt that the ICU should contact bereaved relatives; 47% in the bereavement group would prefer follow-up to last for one month. Single-centre pilot study, small numbers with significantly more participants in the intervention group than the control group.

Author, date, origin	Title of paper	Type of research	Study design	Aim	Intervention	Outcome/findings
						Timeframe of study recruitment is not reported, with lack of figures on total deaths. Overall response rate and non-respondents not captured.
Santiago et al., 2017 Canada	A pilot study of interprofessional, multi-component bereavement follow-up program in the intensive care unit	Pilot study	Single-centre pilot study at 24-bed medical/surgical ICU. N=32 deaths in 13-week study period. N=30 family members enrolled in the study, one gave no contact details and one did not want bereavement follow-up. Study team tracked delivery of intervention and relatives completed a self-administered survey (Likert scale 0-10) sent two weeks post follow-up.	Measure feasibility and determine family members' attitudes towards each component. Feasibility set at 75% for interventions. Acceptability target of 7 from a 10-point Likert scale.	Time of death: brochure. Ten days: sympathy card signed by nursing staff. Three weeks: telephone call by social worker. One year: invite to memorial service.	The feasibility target of 75% was met for the brochure and cards. Telephone call: 50%. Low response rate at 11/30. Acceptability target of helpfulness greater than 7 was not met. However, all found the card meaningful and four of seven who received a call found it helpful. Feasible to implement the programme. Suggest that all components may not be acceptable and advise a more individualised approach.
Schenker et al., 2015	Development of a post-intensive care	Case series (pilot study)	Single-centre, single-intervention case series after the development	Storytelling reduces stress from traumatic events. Measure	One week: received a condolence letter.	SUDs no higher post-intervention than pre. All participants

Author, date, origin	**Title of paper**	**Type of research**	**Study design**	**Aim**	**Intervention**	**Outcome/findings**
US	unit storytelling intervention for surrogates involved in decisions to limit life-sustaining treatment		of a storytelling guide based on evidence from previous studies: 28 eligible participants based on screening and inclusion criteria; 20 consented to be contacted. Ten of 20 met storytelling eligibility; six completed the intervention.	subjective units of distress scores (SUDs). Assess feasibility and acceptability.	Two weeks: telephone call during which they were invited to take part in a one-off face-to-face storytelling intervention.	endorsed storytelling as acceptable. Five of the six reported it as helpful, feasible and acceptable. Face-to-face meeting excluded 30% of potential participants due to travelling distance.

Table 4 Data Extraction for Surveys

Desirability survey				
Author, date, country	**Title of paper**	**Type of research**	**Study design**	**Main findings**
Downar et al., 2014 Canada	The desirability of an intensive care unit (ICU) clinician-led bereavement screening and support programme for family members of ICU decedents	Interpretivism, quantitative, descriptive	Telephone survey of bereaved relatives and a self-directed survey of staff. Telephone-administered survey of bereaved relatives from ICU in one hospital in Toronto. Survey used Inventory of Complicated Grief, including sub-threshold criteria, social difficulties inventory to diagnose social distress. Questionnaire devised to look at both the use of existing services and the desire for additional support. A letter to explain the study, stating to expect a telephone call in two weeks sent to families. Options to opt out were included. Informed consent gained. N=215 eligible, n=148 relatives lost to contact due to inaccurate contact details or loss of contact. N=32 family members completed the survey. Measured complicated grief and social distress index. Asked about desirability of follow-up. Staff: all attending physicians in two medical surgical ICU in two hospitals in Toronto were sent the survey via email. Approached nurses from two consecutive 12-hour shifts in the same ICU and offered copies of the survey. Questionnaire designed to obtain perceptions of the burden of grief, involvement in bereavement support and interest in future involvement.	Thirty-two of 64 relatives participated, 31% response rate. Important proportion of family members experienced sub-threshold Prolonged Grief Disorder and social distress. Family members desired bereavement support and screening whether they were experiencing symptoms of grief disorders or not. Relatives wanted the opportunity to meet with clinicians and ask medical questions. Staff response rate: n=57/94 (64%); 10/20 (50%) physicians and 47/74 nurses (64%). Reported providing support around the time of death but rarely post-death. There was a desire to offer more support, but clinicians only felt comfortable meeting with families. Barriers to providing support: time, training.

National surveys				
Author, date, country	**Title of paper**	**Type of research**	**Study design**	**Main findings**
Coombs et al., 2017 New Zealand	Intensive care bereavement practices across New Zealand and Australian intensive care units: A qualitative content analysis	Qualitative Inductive content analysis of free-text responses from survey by Mitchell et al. (2017).	As Mitchell et al. (2017): 68 respondents from 153 returns made free-text responses (n=124). From the free-text responses there were n=187 individual codes identified. The majority of respondents were from Australia.	Codes on bereavement practices (n=145, 77.5%), educational provision to support staff in bereavement care (n=15, 8%), and organisational challenges in delivering bereavement care (n=27, 14.4%). Ongoing support for bereaved families varied and extended over different time periods with variation in process of common elements. Example of a condolence card given, could be signed by all staff or sent by one. Main organisational challenge for bereavement follow-up was lack of funding.
Egerod et al., 2018 Denmark	Family-centred bereavement practices in Danish intensive care units: A cross-sectional national survey	Cross-sectional nationwide survey	Self-administered, computerised, cross-sectional nationwide survey of 48 Danish ICUs. One or two nurses contacted per unit, primary respondent usually nurse managers. Previously used survey tool developed by Mitchell et al. (2017). Thirty items within four sections: personal and unit demographics, model of bereavement services, workforce model and service evaluation.	Response rate of 46/48 (96%). All ICUs offered viewing of the body in ICU. Information on hospital-based follow-up for the family was provided in 72% of units; 59% offered bereavement follow-up services. These services Included an ICU visit, meeting with staff, a condolence letter, phone call, referral to priest or clergy, or other counselling. Although many interventions were common, there were variations within the elements offered. They were not evidence based and lacked formal evaluation.
Egerod et al., 2019	Elements of intensive care bereavement	Cross-sectional self-administered survey	Cross-sectional Europe-wide survey of conference delegates (approximately 400 delegates in total). Paper and	Survey completion 85/250 (34%). Respondents from 42 cities in 18 European countries: 35/85 stated that

National surveys				
Author, date, country	**Title of paper**	**Type of research**	**Study design**	**Main findings**
Denmark	follow-up services: A European survey		pen questionnaire including a cover letter distributed to 250 delegates during the opening ceremony of 2017 European Federation of Critical Care Nursing Association conference held in Belfast. Used previous validated tool as per Egerod et al. (2018). Same four sections as study above: demographics, model of bereavement follow-up services, workforce model and evaluation model.	their ICU had bereavement follow-up services. Specific element: viewing the deceased (n=77), information on hospital-based support (n=52), phone call (n=27), sympathy card (n=17) and information on community-based support (n=15). Formalised bereavement support lacking and there is a need for guidelines for bereavement services in the ICU with more research needed to find the most acceptable and effective service.
Fridh and Akerman, 2019 Sweden	Family centered end-of-life care in Swedish intensive care units: A cross-sectional study	Cross-sectional survey	Survey of 81 adult ICUs in Sweden between February and May 2017. Questionnaire and information letter mailed to the unit leaders. Questionnaire had 16 closed questions with space left for comments. Questions on bereavement follow-up included: Do you offer any kind of follow-up? If you do what kind of follow-up do you offer? Are bereaved families invited to a follow-up meeting and how and when are they invited? What professionals are involved? Remaining questions focused on keeping a diary and privacy at end of life.	Response rate 90% (n=73); 76.7% (n=56) offered bereavement follow-up but 42.2% (n=33) did not offer it for all deaths. Lack of national guidelines resulting in variation in models of follow-up. Phone call, follow-up visit or combination of two common. Condolence letters also sent. Nurses were most common profession to carry out follow-up, usually initiated by a telephone call.

National surveys				
Author, date, country	**Title of paper**	**Type of research**	**Study design**	**Main findings**
McAdam and Erikson, 2016 US	Bereavement services offered in adult intensive care units in the United States	Cross-sectional prospective survey Quantitative	Twenty-six-item online survey advertised in the American Association of Critical Care Nurses e-newsletter. Aimed at adult ICU nurse leaders. Two-section survey: 10 demographic questions, if bereavement follow-up available a further 13 questions and if not available, five questions.	Response rate: 237 responses from an estimated 1003 (24%): 62% said that they did not offer bereavement follow-up. Barriers to services: lack of education, funding, money, time and knowledge about needs of bereaved families. Interested in starting a service. Nurse mainly responsible for delivering services. Cards, brochures and calls: one month. Very few used as assessment tool. There was an interest in starting bereavement follow-up if no service available. If palliative care service was available at the hospital, the ICU was more likely to offer bereavement follow-up.
Mitchell et al., 2017 Australia and New Zealand	The provision of family-centred intensive care bereavement support in Australia and New Zealand: Results of a cross-sectional explorative descriptive study	Cross-sectional, exploratory, descriptive survey	Cross-sectional survey of all ICUs in New Zealand and Australia including neonates and paediatrics. N=229 (188 in Australia and 49 in New Zealand). Survey asked questions under four domains: unit demographics, models of bereavement services, workforce model, service evaluation. Response Rate: 153 (67%) from New Zealand	Routine care such as viewing of deceased, information giving and staff debrief common practice. Variation in bereavement follow-up service availability: 50% of respondents in NZ compared to 28.3% in Australia. Variation in intervention of those with a service: sympathy card: 20.8% in Australia and 54.2% in NZ; telephone calls: 92.3% of New Zealand compared to 76.5% in

National surveys				
Author, date, country	**Title of paper**	**Type of research**	**Study design**	**Main findings**
			and Australia (n=25 (16.3%) NZ and n=128 (83.7%) Australia).	Australia. More social worker led in Australia and nurse led in New Zealand. Bereavement support important. Needs evaluation from both outcome and process perspectives.

2.4 Data Synthesis

An integrative literature review aims to analyse, critique and synthesise the literature to create new understanding of the problem (Torraco, 2005; Whittemore and Knafl, 2005; Snyder, 2019). The results are synthesised by looking at the aims, timing and content, and outcome of interventions. The national surveys are addressed first followed by the intervention studies.

2.4.1 National Surveys

Analysis of the findings from the surveys is discussed relating directly to the integration of findings about the different elements of bereavement follow-up practices. Generalisability from surveys is difficult due to the geography-bound nature of the studies and the possibility of respondent bias due to self-reporting. However, common themes exist in relation to bereavement follow-up and they identify important barriers to provision that are relevant to this study.

Bereavement Follow-up Practices

The national surveys demonstrated varied provision of bereavement follow-up services. The survey of family-centred end-of-life care in Sweden by Fridh and Akerman (2019) had a high response rate of 90 per cent. Based on the survey results, Sweden is the country with the most-established bereavement follow-up practices, with 76.7 per cent (n=56) offering a service. A follow-up phone call or visit to the ICU or combination of the two were the most common elements. However, although follow-up was common, 33 of the 73 (42.2 per cent) did not offer it for all deaths.

The survey by Mitchell et al. (2017) in Australia and New Zealand asked questions under four domains including model of bereavement services and evaluation. They had a reasonable overall response rate of 67 per cent: bereavement follow-up was reported in 50 per cent of the units in New Zealand compared to just over 28 per cent in Australia. However, mixed and paediatric units were better represented in New Zealand which may account for this.

Telephone calls were reasonably well established as forms of follow-up in both countries, while sympathy cards were more commonly offered in New Zealand.

Egerod et al. (2018) used a modified version of Mitchell et al.'s (2017) survey to establish bereavement support practices in Denmark and Europe. The survey of adult ICUs in Denmark included neurological and thoracic units and had a good response rate of 96 per cent. Follow-up services were reported as being offered in 59 per cent of units. The authors categorised the responses to specific elements of bereavement follow-up, with the most common elements being a visit or meeting with the family, a condolence letter and a phone call.

In their European study, Egerod et al. (2019) distributed the same survey to 250 delegates attending the opening ceremony of the European Federation of Critical Care Nursing Association conference in Belfast. Of the 250 attending, 34 per cent (87) completed the survey. However, the total delegation for the conference was 400, and therefore an already low response rate represented only 21 per cent of the delegation. In addition, it was unclear if multiple respondents were from the same ICU and this may have diluted the results further. Despite weakness, the completed survey represented 42 cities in 18 European countries. Forty-one per cent stated that they had a bereavement follow-up service, although this included common practices at time of death such as viewing the body and providing information. A sympathy card and telephone call were less frequently reported at 20 per cent and 31 per cent, respectively.

Similarly, the US study by McAdam and Erikson (2016) had a low response rate of 24 per cent. However, respondents were from a relatively wide geographical area with a variety of types of hospitals and ICUs represented. From the survey, only 38 per cent of ICUs reported offering bereavement follow-up. The most common elements were a condolence card (n=56, 62.9 per cent), brochures (n=39, 43.8 per cent) and telephone call (n=32, 36 per cent); contact was commonly made within one month of the death. Significantly, the study found that ICUs in hospitals with palliative care were eight times more likely to provide bereavement support than those without palliative care.

A range of bereavement support is described in the national surveys, but much of what is consistently reported is regarded as standard bereavement care as opposed to bereavement follow-up (McAdam and Erikson, 2016; Coombs et al., 2017; Mitchell et al., 2017; Egerod et al., 2018; Egerod et al., 2019; Fridh and Akerman, 2019). In their qualitative study, Coombs et al. (2017) coded free-text responses from respondents of the Australia and New Zealand survey. Although the results were biased, with the majority of respondents from Australia, many of the bereavement codes related to standard bereavement practices that take place while the family is still in the hospital. Standard bereavement practices were described commonly across all of the surveys, including viewing the body and providing information and support immediately after the death.

Information provided immediately after the death often took the form of a bereavement brochure or pack that included signposting to bereavement support services. Results from the surveys demonstrated that bereavement follow-up practices were not as widespread as routine care; information giving at the time of death appeared, in part, to bridge the gap between standard bereavement support and offering bereavement follow-up in its simplest form. Bereavement follow-up as defined by this literature review typically took the form of a condolence card or letter and follow-up telephone call, and less often a routine family meeting. Targeted interventions such as bereavement counselling featured less, and single, therapeutic interventions were not discussed.

Barriers to Provision

Nationally the provision of bereavement follow-up was mixed with a reported lack of consistency in the delivery of interventions across all of the studies (McAdam and Erikson, 2016; Mitchell et al., 2017; Egerod et al., 2018; Egerod et al., 2019; Fridh and Akerman, 2019). In addition, Coombs et al. (2017) recognised that there was variation within a single activity. For example, there were variations in the practice of sending a condolence card: some were signed by all staff and others sent by one individual. The lack of consistency in the implementation of bereavement follow-up is compounded by a lack of policy and guidance alongside organisational barriers (Mitchell et al., 2017; Egerod et al., 2018; Egerod et al., 2019). In the European survey, respondents stated that there was a lack of formalised bereavement support with more guidance and research needed (Egerod et al., 2019). Even in countries such as Denmark and Sweden, where practices appeared more established, there was a lack of national policy and guidance (Fridh and Akerman, 2019).

This lack of support for bereavement follow-up at a policy and guidance level is reflected in organisational challenges. Coombs et al. (2017) identified a lack of funding for bereavement follow-up from the survey by Mitchell et al. (2017). The US survey found that organisational barriers were multi-faceted and included lack of education, money, time and knowledge about service design (McAdam and Erikson, 2016). Similarly, Downar et al. (2014) in their desirability survey in Toronto, Canada, highlighted that a lack of knowledge and time was a barrier to providing bereavement follow-up. Regardless of the barriers, the importance of bereavement follow-up is recognised across the national surveys and there is a general call for more evaluation and research of bereavement services (McAdam and Erikson, 2016; Mitchell et al., 2017; Egerod et al., 2018; Egerod et al., 2019; Fridh and Akerman, 2019). The content of bereavement follow-up interventions described in the national surveys is mirrored in the intervention studies.

2.4.2 Bereavement Follow-up Intervention Studies

Research papers exploring bereavement follow-up were from single-intervention studies and bereavement follow-up programmes consisting of multiple interventions that were carried out over a period of time. They commonly include a bereavement brochure, condolence card and follow-up telephone call. The intervention matrix in Table 5 summarises the information from the research on the content and timing of interventions and gives an indication of how their outcomes are measured. The overall aims and outcomes of bereavement follow-up programmes differ from the analysis of individual interventions. In order to critically appraise the literature, and analyse the research on the intervention fully, it is necessary to initially discuss the bereavement follow-up programmes in their entirety.

Table 5 Intervention Matrix

Intervention												**Outcome measuremen**		
Author, date.	Intervention type	Bereavement brochure	Timing	Condolence card/letter	Timing	Telephone call	Timing	Meeting	Timing	Storytelling	Timing	Symptom measurement	Opinion and experience	Feasibility
McAdam and Puntillo, 2018	BFUP	•	TD& 1W	•	1W/ 1Y	•	4W/6M					•	•	
Erikson et al., 2019	BFUP	•	TD	•	2W								•	
Kurian et al., 2014	BFUP	•	3M	•	1W	•	1W						•	
Santiago et al., 2017	BFUP	•	TD	•	10D	•	3W						•	•
Kock et al., 2014	SI							•	4-6W				•	
Schenker et al., 2015	SI									•	4W	•	•	•
Barnato et al., 2017	SI									•	4W	•	•	•
Kentish-Barnes et al., 2017a (RCT)	SI			•	15D							•		
Kentish-Barnes et al., 2017b (QUAL)	SI			•	15D								•	
Kentish-Barnes et al., 2015a	SI					•	3W/3M						•	
Laurent et al., 2019	SI					•	3M/6M /1Y						•	

Intervention type: BFUP=Bereavement follow-up programme, SI=Single intervention

Timing: D=Days, M=Months, TD=Time of death, W=Weeks, Y=Years

As indicated in the quality assessment, the research papers examining bereavement follow-up programmes are small studies that have inherent weaknesses such as low response rates and a lack of the kind of rigour afforded by larger studies. The US study by McAdam and Puntillo (2018) was the only one to use a control group and measure grief symptoms. Their overall aim was to measure the effectiveness of bereavement follow-up on anxiety, depression, PTSD, prolonged grief and satisfaction with care. The outcome of the study showed that bereavement follow-up reduced prolonged grief and may help lower the risk of PTSD. There was no difference in satisfaction with care or anxiety and depression.

McAdam and Puntillo (2018) did not report the study period or the total number of deaths during this period, and therefore it is unclear how many bereaved relatives did not take part. The need and desirability of the individual components of the intervention were evaluated but the researchers were unable to make judgement on any direct link with grief outcome scoring. Overall, they found that family members from both groups wanted follow-up from the ICU, with the majority reporting that it should take place for one month. This is in stark contrast to the programme that runs over the period of a year.

The pilot study by Santiago et al. (2017) was carried out over a defined 13-week period, in a 24-bedded medical/surgical ICU in Toronto, Canada. The aim of the research was to measure the feasibility and acceptability of a bereavement follow-up programme using programme implementation data and a survey of families. A feasibility target of 75 per cent was set for implementation of the individual elements and a target of 7 out of 10 on a Likert scale for family acceptability of the programme. Feasibility targets were met for all elements apart from telephone calls. The acceptability threshold of 75 per cent of the respondents rating the helpfulness of the programme as seven or greater was not met. However, response rates for the survey for relatives were low with only 11 of the 30 (37 per cent) recruited to the pilot programme responding.

The qualitative study by Erikson et al. (2019) looked at family members' opinions about bereavement care in cardiac intensive care. They interviewed relatives using a semi-structured questionnaire that explored six elements: a bereavement brochure and condolence letter which were already offered, and a further four elements that they described. Overall opinion varied across the different interventions. The opinion-based research on the different elements of bereavement follow-up are discussed below under individual interventions. Although opinion-based research is useful to help shape the content of services, it is influenced by the description of the intervention and fails to consider practical implementation and resource issues.

Kurian et al. (2014) stated that the broad aim of their pilot programme was to provide support for families to deal with their sudden loss. However, the aim of the study was to examine the perceptions and practice of nurses in relation to bereavement support rather than the effectiveness of the intervention on bereaved relatives. Therefore, the value of the study is limited. The study outcomes show that the majority of nurses agreed that it was their role to provide bereavement support, but nurses receiving bereavement programme training were more comfortable offering support.

Overall, the studies looking at bereavement follow-up programmes support the ICU contacting relatives, with one study suggesting a reduction in grief symptoms. However, there is variation in the results for the individual elements. The aims, content and timing, and outcomes of the individual elements are discussed below. It is evident from the matrix that the most-common interventions are bereavement brochures, condolence cards/letters and telephone calls. A follow-up meeting with clinicians and a storytelling intervention make up the remainder of the intervention research.

Bereavement Brochure

Bereavement brochures are featured in all of the bereavement follow-up programmes and are given to the family at time of death in three of them. In the context of this study, bereavement brochures on their own cannot be regarded as a bereavement follow-up intervention, but they appear to be a feasible starting point for bereavement follow-up programmes. They provide information and immediate support for relatives as they step away from the hospital environment.

The general aim of the brochures in all the studies is to provide information on practical tasks and signpost for grief support (Kurian et al., 2014; Santiago et al., 2017; McAdam and Puntillo, 2018; Erikson et al., 2019). Implementation rates were high with between 80 and 100 per cent receiving the brochure (Santiago et al., 2017; McAdam and Puntillo, 2018; Erikson et al., 2019). However, a participant from the study by Erikson et al. (2019) commented on the manner in which the brochure had been given to them, stating that it had been “rushed and thrown at them”. This highlights that the human interaction and the time taken and manner used by professionals when handing over written information to bereaved relatives is important.

Outcomes based on opinion and experience were mixed. In the study by Santiago et al. (2017), less than half found the brochure helpful, compared to 71 per cent in the study by McAdam and Puntillo (2018), although overall usage of the information was low at 32 per cent. Erikson et al. (2019) found that, overall, relatives felt the brochure was helpful, with participants reporting being able to access and reuse information in their own time. On the flip side, some relatives commented that there was a lack of resources available in their area or relevant to their specific circumstances (Erikson et al., 2019).

Two of the programmes sent a bereavement brochure after the family left the hospital, Kurian et al. (2014) at three months and McAdam and Puntillo (2018) after one week. In Kurian et al.’s (2014) study, the brochure contained information on bereavement support, a poem and seeds for forget-me-not flowers, while McAdam and Puntillo’s (2018) brochure reiterated information in the brochure given at time of death, gave additional advice on settling the deceased’s affairs and gave information on grief support. Fifty-nine per cent of families received the second brochure in the McAdam and Puntillo (2018) study, and only 26 per cent reported using the information. The timing of the brochure in Kurian et al.’s (2014) study was changed to one month after outcome evaluation revealed a high return rate at three months.

Condolence Letter/Card

A condolence letter or card was featured in all of the bereavement follow-up programme studies and was the subject of the only RCT (see Kentish-Barnes et al., 2017a) included in the integrative review (Kurian et al., 2014; Kentish-Barnes et al., 2017a; Kentish-Barnes et al., 2017b; Santiago et al., 2017; McAdam and Puntillo, 2018; Erikson et al., 2019). The aim of sending a condolence letter is not evident from the bereavement follow-up programmes. However, the researchers in the RCT hypothesised that a letter of condolence sent after the death would alleviate relatives' feelings of abandonment and lack of comprehension, and help satisfy their need for continuity, with the overall aim that it might benefit the grieving process (Kentish-Barnes et al., 2017a).

There was variation in the content of the condolence card: some were handwritten and some pre-printed; some were signed by staff and some by one individual. Erikson et al. (2019) found that families preferred cards to be signed by staff that had cared for their relative. Kentish-Barnes et al.'s (2017a) RCT used the most personalised and structured condolence intervention: the letter was handwritten by the physician and nurse caring for the patient, and the content of the letter was guided by the five domains described in table 3.

Condolence cards were generally used as an immediate follow-up intervention with timing across the studies ranging from three to 15 days. Erikson et al. (2019) sent a signed card two weeks after the death, with family members indicating that the timing of the card was appropriate. Similarly, 96 per cent of relatives in the study by McAdam and Puntillo (2018) rated the timing of a hand-signed condolence letter at one week as “just right”. The condolence letter in Kentish-Barnes et al.'s (2017a) RCT was sent after 15 days. There is no specific justification for the timing of condolence interventions; however, Kentish-Barnes et al. (2017a) suggested that the early timing of the intervention meets the perceived need of helping relatives cope with the immediate shift in the relationship with the ICU by emphasising the value of the clinician's relationship with the patient and reducing the pain of the bereavement.

In the pilot studies, condolence interventions proved to be highly feasible with 79 to 100 per cent of relatives receiving the condolence intervention (Santiago et al., 2017; McAdam and Puntillo, 2018; Erikson et al., 2019). The outcome of sending a condolence card is polarised by the measures used, with the experience of the intervention being more positive than that indicated by symptom-based outcome measurements. Kentish-Barnes et al. (2017a), in their

RCT, used the Hospital Anxiety and Depression Scale (HADS) at one month as the primary outcome. Secondary outcomes evaluated after six months were HADS, complicated grief (using the Inventory of Complicated Greif) and PTSD (measured by the Impact of Events Scale-Revised). At one month there was no significant difference in HADS, and at six months HADS was significantly worse in the intervention group, with slightly higher scores in PTSD. The researchers concluded that a letter of condolence failed to alleviate grief symptoms and potentially could make them worse (Kentish-Barnes et al., 2017a).

However, a second, qualitative study by Kentish-Barnes et al. (2017b), based on spontaneous declarations made by participants in the RCT, identified six themes about the experience of receiving the letter. The themes that came from the qualitative study included feelings of support and continuity, humanising the medical system and an opportunity for reflection on loved ones. The qualitative study suggests that the experience of the intervention is more positive than the grief-symptom findings indicate.

The researchers found the themes of doubts and negative reactions came from relatives’ suspicion around why they received the letter and also dissatisfaction when offers of ongoing support were not met. In particular, the letter offered relatives the opportunity to contact the clinical team; when this offer was not fulfilled it left relatives feeling upset and angry, and the sincerity of the physician was called into question (Kentish-Barnes et al., 2017b). However, the study was limited as the interviewers were blinded to the arm of the RCT and were unable to question all relatives on how they felt about receiving a letter of condolence. Therefore, analysis does not consider the experience of relatives who did not make a spontaneous declaration.

Overall, the condolence interventions in the pilot studies were appreciated and rated as meaningful or somewhat meaningful (Santiago et al., 2017; McAdam and Puntillo, 2018; Erikson et al., 2019). Relatives appreciated the card, describing it as thoughtful (Erikson et al., 2019), or reported feelings of being cared for and were touched that they had been remembered (Santiago et al., 2017). In particular, Santiago et al. (2017) found that personal messages were important. Where family members reported a more neutral response, they described the card as neither causing offence nor providing comfort (Erikson et al., 2019). The opinion- and experience-based outcomes described above are in keeping with the themes of feelings of support and continuity described in the thematic analysis of the RCT.

Telephone Calls

Telephone calls were part of the intervention in three of the bereavement follow-up studies (Kurian et al., 2014; Santiago et al., 2017; McAdam and Puntillo, 2018); the fourth, by Erikson et al. (2019), obtained relatives' opinions on receiving a call. A further two studies examined the experience of relatives taking part in bereavement research that used telephone calls as the method of follow-up (Kentish-Barnes et al., 2015a; Laurent et al., 2019). The study of relatives' participation in bereavement research, although not bereavement follow-up interventions in themselves, provides valuable insight into contacting bereaved relatives by telephone, and has direct relevance for the implications and value of their use as a bereavement follow-up intervention.

In the pilot programmes, timing of the calls varied from one week to six months after time of death, and calls were carried out by a chaplain (Kurian et al., 2014), bereavement team member (McAdam and Puntillo, 2018) or social worker (Santiago et al., 2017). There was difficulty with the implementation of telephone calls. Only 50 per cent of families in the pilot study by Santiago et al. (2017) received a call, and McAdam and Puntillo (2018) had problems with incorrect contact details so that very few participants received a call. Downar et al. (2014) used a telephone questionnaire in their feasibility study and had similar issues, with the majority of relatives being lost to research due to incomplete contact details.

Issues with the implementation of telephone calls are part of the process of refining a pilot programme for wider roll out. Qualitative research by Kentish-Barnes et al. (2015a) and a mixed methods study by Laurent et al. (2019) draw on participants from larger bereavement research projects in France: the CAESER and ARREVE studies, respectively. The main purpose of the CAESAR study was to describe end-of-life experiences in the ICU and the ARREVE study looked at the withdrawal of mechanical ventilation. Both studies used telephone calls as the method to contact bereaved relatives to obtain research data.

Participants in the CAESAR study were called at three weeks and three months, and in the ARREVE study at three months, six months and one year. Telephone calls were carried out by a trained sociologist (CAESAR) or psychologist (ARREVE). Participants from the CAESAR study liked the anonymity and distance associated with the format of a call as opposed to a face-to-face meeting, and the research suggested benefits of consistent contact over a period of time (Kentish-Barnes et al., 2015). Participants in the ARREVE study felt that the best time for a follow-up call would be between three and six months (Laurent et al., 2019).

This differs from the smaller study by Erikson et al. (2019) where 50 per cent of participants (six of 12) said they would like a telephone call within three to four weeks. However, this is opinion based rather than experiential. The participants indicated that they would like a call as they had unanswered questions, and this may be the reason for the preference of a shorter time period.

From participants in the CAESAR study, Kentish-Barnes et al. (2015a) identified six themes about the experience of telephone calls including receiving support, sharing difficult emotions and not feeling abandoned. The mixed methods study by Laurent et al. (2019) asked participants at the one-year interview for the ARREVE study to complete a questionnaire about their experience of the intervention. Relatives from the ARREVE study expressed that a telephone call outwith participation in research would be helpful. Qualitative analysis identified the emotional difficulty of the calls but also highlighted the feeling of continuity and connectedness with the ICU, which facilitated a better understanding of events. The regularity of the calls was also seen as beneficial for the bereavement process and compensated for the absence of support.

Both studies support the benefits of bereavement follow-up for relatives of ICU patients. However, as indicated above, caution is required. The process of calling relatives, including which professionals carried out the calls, was determined by the design of the research study. Participants had agreed to take part in the studies, were invested in the research and expressed an altruistic motive for taking part. The relatives were expecting the calls, and they were structured and carried out by trained researchers. This could account for the disparity in outcomes when compared to the pilot studies.

The specific aims and outcomes of a call in the pilot studies are not well established. Erikson et al. (2019) described that the reasons for a call were to find out how relatives were, answer additional questions and provide feedback. Only half of the relatives felt that a telephone follow-up call would be helpful; they cited having lingering questions answered as the main reason for wanting a call, but this may have been biased by the description of the intervention (Erikson et al., 2019). Santiago et al. (2017) found that participants who received a telephone call appreciated it, describing that the verbal support gave them hope and stating that the call was a thoughtful and caring gesture.

Follow-up Meeting

A follow-up meeting is often the result of contacting relatives to offer bereavement support, but the experience and outcome of these meetings are not well researched. As a single intervention, a follow-up meeting with a physician was the subject of a retrospective quality improvement study by Kock et al. (2014). The survey of relatives aimed to measure satisfaction with the intervention four years after the quality improvement project started. The meeting, offered by nursing staff before families left the hospital, took place four to six weeks later. Forty-six of 84 family members responding to the survey had attended a meeting; however, it is unclear from the study whether the relatives were asked if they would like to attend a meeting or were given a provisional date and had to confirm attendance later. The results do not consider those family members who either did not take up the offer of a meeting or did not attend.

The study showed that relatives appreciated the meeting and thought that it was important for the intervention to continue. Participants reported that they would prefer a meeting to take place at six weeks; 91 per cent thought that it was important that the physician was present and the main questions families had were medical. However, the aim of the meeting was to clarify causes of death and what happened in the ICU period and it was offered to relatives with this defined purpose, which could have influenced the experience of the intervention and the outcome of the study.

The desirability survey by Downar et al. (2014) supported a follow-up meeting. Using a telephone survey of bereaved relatives and a self-directed questionnaire for professionals, the authors examined the desirability of a clinician-led bereavement support and screening programme in Toronto, Canada. This is a complex and multi-faceted study using risk screening, satisfaction with care and desirability questions with relatives. The clinician questionnaire looked at perception of grief burden on families, current involvement in supporting relatives and desirability of offering further support. The study overall supports bereavement follow-up in the early period. Relatives indicated that a meeting with a professional to review events prior to the death would be helpful and clinicians felt most comfortable supporting relatives to answer clinical questions.

Storytelling

Two related studies from the US by Schenker et al. (2015) and Barnato et al. (2017) investigated a storytelling intervention to help relieve grief symptoms in surrogate decision-makers involved in end-of-life decisions. Schenker et al. (2015) explored the theory behind storytelling as an intervention and considered its feasibility through a small, single-centre case series. In both studies a single storytelling intervention lasting one to two hours took place between two and four weeks after the death. The initial study by Schenker et al. (2015) developed the theory of the intervention. Storytelling adopts a conceptual model of an intervention that uses cognitive processing and emotional disclosure to help support people after a traumatic event. The aim of the intervention was to support surrogate decision-makers of relatives in the ICU through the storytelling concept (Schenker et al., 2015; Barnato et al., 2017).

The larger study, by Barnato et al. (2017), implemented the intervention across five ICUs in three hospitals in the US. Schenker et al. (2015) implemented storytelling as a face-to-face intervention but Barnato et al. (2017) amended the design to include participation via telephone. Feasibility, acceptability and tolerability are used as the primary outcome measures for the study. Enrolment rates, delivery of the intervention, and three- and six-month follow-up were used to measure feasibility; acceptability was assessed through end-of-study feedback at six months; and tolerability was measured by acute mental health referral at six months (Barnato et al., 2017).

A range of measurements was used to assess outcomes. Participants' baseline symptom measurements were taken at two weeks and again at three and six months through telephone follow-up by a blinded assessor. Completion rates were between 89 and 100 per cent for both groups. As part of the study, Barnato et al. (2017) included nonparticipants, and seven of 21 surrogates (33 per cent) who declined to take part completed symptom assessment at six months. Overall, the study was acceptable to both the control and the storytelling participants with 67 per cent of the control group and 94 per cent of the storytelling group reporting feeling better or much better after participating. Symptom burden decreased between baseline and six months and was lowest in the storytelling group. There were no negative comments relating to the storytelling intervention, and tolerability was high with no referrals to acute mental health services.

The researchers compiled a score based on the measurements to indicate the experience of post-intensive care syndrome-family (PICS-F). The score suggested that PICS-F was lower in the storytelling than in the control group at six months, and nonparticipants who completed observation assessment at six months had a higher symptom burden than the research participants, suggesting some of the benefits came solely from participation in the research. Comments made by study participants suggested that altruistic motives and the opportunity to help others gave a positive experience (Barnato et al., 2017).

2.5 Discussion of Results

The key elements of bereavement follow-up interventions in critical care were explored through examining the evidence for the timing and content, and the aims and outcomes of interventions. With the exception of one desirability survey, the studies fell into two types: national surveys and intervention studies.

The national surveys demonstrated that there was a lack of provision in bereavement follow-up even within countries such as Sweden where practices were better established. This was compounded by poor policy and guidance at national level. Routine care for families before they left the hospital was commonly described and included the provision of information. Bereavement follow-up took the form of a condolence card or letter, telephone call to the family and less often a meeting.

This content was mirrored in the intervention studies. Information brochures at time of death are commonly described and seem an important source of support. Hewison et al. (2020), in their recent rapid review, identified timely and helpful information as one of the main forms of support needed by bereaved families. However, picking apart the studies to judge the timing and content, and aims and outcomes of interventions is difficult. Multiple variables can influence the content and timing of interventions and this is further compounded by a lack of research that comes from a variety of sources, including studies on bereavement research participants.

Several studies were carried out over the period of a year. However, in the bereavement follow-up programmes, the majority of contact took place within the first three months and single interventions, such as the condolence letters and follow-up meetings, were completed within six weeks. This immediate timeframe in the single-intervention studies appears acceptable. Relatives report the optimum timeframe as being before the six-month period and as early as one month (Downar et al., 2014; Kock et al., 2014; Santiago et al., 2017). Telephone calls were more variable and difficult to assess. In particular, the timing of the calls in the CAESAR and ARREVE studies were bound by the design of the research rather than based on judgements made about the best implementation of telephone calls as a bereavement follow-up intervention (Kentish-Barnes et al., 2015a; Laurent et al., 2019).

Evidence from research into telephone calls demonstrates that families need to feel supported, but also need to talk, give meaning to their experience and tell their story (Kentish-Barnes et al., 2015a; Kentish-Barnes, 2019; Laurent et al., 2019). This argument is supported by the research into storytelling. The storytelling studies examine a therapeutic intervention for bereaved relatives as opposed to those based on giving information and maintaining contact. This is a targeted intervention with specific aims and measurable outcomes. Although it is culturally bound to the US and surrogate decision-makers, the research has general value for storytelling as an intervention to support families after a traumatic event (Schenker et al., 2015; Barnato et al., 2017).

This is not unique to critical care: Milberg et al. (2008) carried out a study in Sweden on families' perceived need for bereavement support in the palliative care setting. The study identified that families need to talk over and over again, to put feelings into words, have consolation in their loneliness and be acknowledged (Milberg et al., 2008). Kentish-Barnes (2019) described this broader experience of bereavement follow-up as a feeling of support, continuity and non-abandonment.

Choosing a single intervention versus interventions with multiple components poses a challenge for the design of bereavement follow-up. The limited number of studies makes it difficult to judge, but research participants from the CAESER and ARREVE studies liked the regularity and consistency of the contact over a period of time (Kentish-Barnes et al., 2015a; Laurent et al., 2019). McAdam and Puntillo's (2018) study of a bereavement programme showed a reduction in grief symptoms, with relatives desiring contact from the ICU. Similarly, comments made by relatives in the pilot study by Santiago et al. (2017) suggest that ongoing contact from the ICU is desirable. However, there were also varied responses to the individual components, indicating that a standardised approach might not be beneficial (Santiago et al., 2017). Downar et al. (2014) supported this, suggesting that relatives would benefit from a multi-disciplinary team approach. They proposed that clinicians support clinical questions; social workers attend to social difficulties; and psychiatrists, psychologists or spiritual care practitioners give emotional support (Downar et al., 2014).

The development of the content and timing of interventions is dependent on the aims and outcomes associated with bereavement follow-up research. However, it is arguably even more difficult to separate out the aims and outcomes than the timing and content. Separating the aim of the intervention and the aim of the research is difficult. Often the aim of the research is different from the aim of the intervention or the outcome measures used. For example, McAdam and Puntillo (2018) measured the impact of bereavement follow-up on anxiety, depression, PTSD and prolonged grief. However, there was no indication if the bereavement follow-up programme, which had been established for five years, had been originally designed with the intended outcome of reducing the measured symptoms.

There is a distinct difference between experience, feasibility and acceptability outcomes, and grief-based symptom outcomes. Feasibility and acceptability outcomes highlight implementation difficulties, such as incomplete and incorrect contact details (Downar et al., 2014; Santiago et al., 2017; McAdam and Puntillo, 2018; Laurent et al., 2019). Similar studies in other areas highlight the same issue. A pilot study of a bereavement follow-up programme in the emergency department by Cooper et al. (2020) demonstrated difficulties with incorrect and incomplete contact details. It is important to recognise these implementation difficulties when designing future studies.

Grief-symptom outcome measures versus experience-based outcomes paints a different picture. The best example of this is the RCT of a condolence letter in France (Kentish-Barnes et al., 2017a), which showed an increase in grief symptoms, while a related qualitative study (Kentish-Barnes et al., 2017b) described the benefits of receiving a letter along with the dangers of not meeting relatives' expectation of further support. Focusing on outcome measures risks oversimplifying interventions and demonstrates a lack of understanding of the mechanisms of change and the complex context of the health care setting and the bereaved. A simple example of this is seen in the study by Erikson et al. (2019) in which the manner of the professional handing over an information brochure has a significant impact on the family's experience.

Critics of trials argue that understanding social interventions is complex. For example, RCTs such as the one carried out for the condolence letter oversimplify the cause-and-effect relationship, resulting in interventions that are poorly defined and not fully understood (Bonell et al., 2012). Harrop et al. (2020) argued that researchers are using the wrong outcomes: their research study devised core outcomes for bereavement support in palliative care that contrasted with the medicalised and pathological outcomes commonly seen in the literature.

Kentish-Barnes (2019) acknowledged that bereavement follow-up studies in the ICU present contrasting results, raising questions about both the interventions and the outcome, and reflect that grief symptoms were not the best outcome measure for their RCT. Kentish-Barnes (2019) suggested looking at the broader experiences of families including the feeling of support, non-abandonment and continuity. Harrop et al. (2020) and Kentish-Barnes (2019) support the need for both qualitative and quantitative research to properly evaluate bereavement follow-up.

2.6 Conclusion

There are no current bereavement follow-up intervention studies in the UK. Academics in the field argue that existing research studies are small scale and are culturally and contextually bound with limited scope for generalisation. This makes it difficult to establish meaningful conclusions about effective practices for bereavement support (Efstathiou et al., 2019; Pattison et al., 2020). However, generally bereavement follow-up interventions are acceptable and desired by relatives who want to tell their story and not be forgotten.

Pattison et al. (2020) states that the lack of formalised support in the UK means bereavement services are disengaged from critical care, and are provided by GPs and the community, who may not understand the context (Pattison et al., 2020). Calls for more research and evaluation are valid but the challenge for researchers and policy-makers is how to progress and build on the evidence that already exists. This study suggests that intervention studies should recognise the complex social systems that bereavement follow-up interventions reside within. Studies should be carried out with clear aims and outcomes designed in collaboration with bereaved relatives using a variety of research methods. The process evaluation aims to go some way to meeting this need.

2.7 Chapter Summary

This chapter followed the methods for an integrative literature review outlined by Whittemore and Knafl (2005). The research scene was set by discussing the recent systematic review by Efstathiou et al. (2019) and placing this review in context. The focus on the timing and content, and the aims and outcomes of bereavement follow-up in adult critical care was reflected in the search criteria and paper-selection methods. Selected papers fell into two categories: surveys and intervention studies. The results from the studies were synthesised and discussed, with conclusions made for future bereavement follow-up interventions and associated research.

Chapter 3 Literature Pertaining to Methods

Chapter 2 demonstrated that evidence from the literature supporting or refuting interventions in the context of this project is limited. Conflicting results are generated from studies with symptom-based outcome measures and experience-based evidence, and single interventions versus those with multiple components. Overall there is a call for more research, with a recognised need among professionals, and a desire among bereaved relatives, for bereavement support (Egerod et al., 2018; McAdam and Puntillo, 2018).

This process evaluation is the only study of a current bereavement follow-up programme in the UK. This chapter outlines the theoretical underpinning of the project and then discusses the literature relating to the method of process evaluation. The logic model, research questions and methods used for the evaluation are outlined in Chapter 4.

3.1 Research Paradigms

All research is supported by a paradigm, which is a philosophical position or belief system that guides the researcher and makes assumptions about ontology, epistemology, methodology and methods (Rehman and Alharthi, 2016). Ontology is concerned with what exists, and our view on the nature of reality. Epistemology is about our perceived relationship with knowledge: are we part of it or external to it? Different paradigms have different ontological and epistemological views and hence different assumptions of reality and knowledge. These assumptions about reality and knowledge guide the theoretical underpinnings, methodology and methods of research (Rehman and Alharthi, 2016; Ryan, 2018).

Positivist paradigms believe that there is one reality – the facts that can be proven – and are generally associated with empirical research and quantitative methods. Interpretivism is in opposition to positivism and views reality as subjective and based on experience and understanding. Interpretivist research is associated with qualitative methods (Ryan, 2018).

Post-positive paradigms drive a road between positivism and interpretivism. Rather than being opposed to the traditional paradigms, as some suggest, they offer an alternative approach to research that attempts to solve the differences between the two using some of the strengths and rejecting the weaknesses (Ryan, 2019). Critical realism, first described by the philosopher Bhaskar(1989), is one such post-positivist paradigm. It can be described as an open system of dynamic structures, mechanisms and contexts that influence change (Kazi, 2003).

Table 6 Comparison of Research Paradigms

Paradigm/ position	Positivism	Interpretivism	Critical realism	Researcher position
Ontology	Objective reality Unproblematically apprehended	Reality socially constructed via subjective meaning, symbolic actions and social politics	Reality is 'real'but only imperfectly and probabilitiacally apprehensible	**The reality of bereavement is difficult in critical care**
Epistemology	Findings are true	Knowledge generated by understanding meaning Actions or subject findings	Objective stratified reality, probably true Consisting of structures, mechanisms and events, but imperfectly and fallibly apprehended Mediated by humans	**How relatives deal with bereavement will be affected by the environment, the clinical situation, their social circumstances and the support available**
Methodology	Experiments, surveys, quantitative methods	Qualitative	Mixed methods	**Mixed methods process evaluation**

Adapted from Guba and Lincoln (1994) and Ryan (2019).

Table 6 summarises the epistemological and ontological positions of critical realism in relation to positivist and interpretivist paradigms. The position of the researcher and their beliefs about bereavement support are shown in the final column. As a paradigm, critical realism often uses mixed methods research, drawing on the influence of both qualitative and quantitative methods. Critical realist evaluation offers a reasonable position for nursing research, allowing for the complexity and individuality of patient care while building on progressing knowledge as practice and context changes (Ryan, 2019).

Pawson and Tilley (1997) brought critical realism firmly into the evaluation domain. Critical realism or realistic evaluation, as Pawson and Tilley (1997) describe it, puts change mechanism and context at the heart of evaluation. Realistic evaluation aims to uncover context-mechanism-outcome configurations to understand “what works”, “for whom”, and “under what circumstances”.

This process evaluation is a mixed methods study that is guided by the philosophical position of critical realism. However, Moore et al. (2014) explain that this is more of a philosophy than a method of process evaluation. Process evaluations can take many forms and be carried out at many stages of implementation. This is a small, single-centre study of a current intervention, and in the view of the researcher it aligns to a pragmatic evaluation. This is addressed further in Section 3.5 after discussion of the literature pertaining to process evaluations.

3.2 Background to Process Evaluations

Process evaluations examine interventions by looking at their implementation, mechanisms of change, outcomes and context (Steckler and Linnan, 2002). During the 1960s and 1970s, large scale social reform in the US resulted in increased spending on public programmes. There was a need to justify this increased spending through government-funded evaluations but often this showed that the public health programmes had disappointing effects. Explanations for poor results were difficult to establish and there was criticism that the evaluators assessed outcome rather than programme integrity (Henry and Bornstein, 2018).

To gain insight into the reasons for programme effect or lack thereof, evaluators started to move beyond simple outcome evaluation and incorporated process evaluation into their studies (Moore et al., 2015). During the 1990s and at the turn of the century, there was an increase in the number of published studies of process evaluations. Steckler and Linnan (2002) attributed this to the increasing complexity of public interventions and the need to explain positive, modest and insignificant results.

As public and social health interventions became more complex, there was increased recognition that although parts of an intervention may not work, the intervention may still be worthwhile. This is in contrast to RCTs, which were traditionally seen as the gold standard for establishing the effectiveness of interventions. Critics of RCTs argued that they oversimplified causes and effects, failing to take account of the complexity of interventions or the complex systems that they reside within (Hawe et al., 2004; Fletcher et al., 2016). Process evaluations allow researchers to pick apart those mechanisms, highlight the complexity of interventions and the impact of contextual factors, and explain unintended outcomes (Craig et al., 2008; Moore et al., 2014).

Although the MRC rejects the arguments against RCTs, the development of their framework for process evaluation, particularly in the case of complex quality improvement interventions, recognises that a deeper understanding of the mechanisms that influence outcomes is required (Moore et al., 2014). For the research community, process evaluations offered a unique opportunity as they advocate the use of mixed methods research with a greater emphasis on the importance of incorporating qualitative research into study designs. In the context of implementation, they can be used for both formative and summative purposes and carried out during programme development, implementation, analysis and modification (Steckler and Linnan, 2002; Moore et al., 2014; Fletcher et al., 2016, Henry and Bornstein, 2018).

Alongside developments in process evaluation, the importance of intervention theory emerged and is discussed further in Section 3.4. As the relevance and number of process evaluations grew, frameworks to support their implementation emerged. The development of the MRC guidance for process evaluations between 2000 and 2014 reflects this gradual shift in the scientific community and acknowledges the growing value of the field of population and health science. The background to and current MRC guidance for carrying out a process evaluation is discussed in Section 3.3.

3.3 MRC Guidance on Process Evaluations

The original MRC framework for process evaluations depicted a linear, sequential process that led from pre-clinical feasibility testing to long-term implementation through estimation of effect size, conducted via an RCT (Campbell et al., 2000). The original framework was criticised, in particular by realistic evaluators such as Pawson and Tilley (1997) for a reliance on aggregate effectiveness. Overall it viewed research in isolation with limited recognition of the role of context or intervention theory (Craig et al., 2008; Fletcher et al., 2016).

In the years following the original MRC framework, there was a move away from viewing interventions as discrete and out of context, with social interventions seen as complex events within an equally complex system (Hawe et al., 2004). Increasingly influenced by realistic evaluation, even although it was often at odds with the scientific community, the movement towards explaining the mechanism of impact and contextual consequences had permeated the MRC's thinking (Moore et al., 2014). By 2008 the MRC updated their framework for process evaluation to reflect this.

The new framework was less linear and was based on a four-phase cyclical diagram built around the themes of implementation, mechanism of change and context (Craig et al., 2008). The cyclical framework was regarded as an improvement as it recognised the importance of process evaluations within trials. However, critics suggested that it did not provide guidance for carrying them out (Moore et al., 2015).

In 2010 a working group funded by the MRC's Population Health Sciences Research Network was set up to provide detailed guidance on carrying out a process evaluation. The MRC's guidance, *Process Evaluation of Complex Interventions,* highlights three key functions: to examine the implementation process, to understand the mechanism of the impact, and to understand the influence of context (Moore et al., 2014). The following key components should be used when carrying out a process evaluation:

- **Fidelity**: the extent to which the intervention was delivered as planned
- **Adaptations**: changes made to an intervention to fit with the context

- **Dose**: how much of the intervention is delivered
- **Reach**: how much the intervention reaches the target audience
- **Mechanism of impact**: the way that the intervention produces the intended or unintended effects
- **Context**: external factors that influence the intervention implementation and whether it is implemented as intended. This may be influenced by and have influence on implementation, intervention mechanisms and outcomes (Steckler and Linnan, 2002; Moore et al., 2014).

Moore et al. (2015) explained that process evaluations build on problem theories and causal assumptions that underpin interventions. They argued that examining the theory and causal mechanisms behind interventions helps prioritise aspects of the intervention for evaluation. The guidelines promote following a systematic approach to process evaluation with the need to develop problem theories and logic models in order to establish the research questions and study design (Moore et al., 2015). These aspects are discussed further in Section 3.4.

3.4 Problem Theories, Logic Models and Research Question Development

Many interventions are poorly theorised and the mechanisms of change are unclear. A key early task of process evaluation is to develop the theoretical understanding of the process of change. This should be done whether developing a new intervention or evaluating an existing one (Craig et al., 2008). Craig et al. (2008) stated that the default is to identify what works and replicate it. However, without an understanding of theory we cannot assume that an intervention will cause the intended outcomes. Moreover, intervention outcomes may be the result of multiple interacting causal pathways that are not fully replicated during scale-up or routinisation (Pawson and Tilley, 1997; Craig et al., 2008).

Put simply, intervention theory is a representation of an identified problem and the solution to fix it. Pawson and Tilley (1997) stated that all interventions are theories incarnate that reflect assumptions about a problem and how actions will provide change. However, there is a risk of focusing too narrowly on theory.

Theories alone can fail to explain how a problem occurs and how that problem is framed in context. There is a risk in selecting inappropriate “off-the-shelf” theories and having an over reliance on individual level theorising (Pawson and Tilley, 1997).

In practice, theories reflect assumptions and are derived from a variety of sources: academic, experiential and those relating to common sense (Pawson and Tilley, 1997; Craig et al., 2008). Moore et al. (2014) stated that it is important to acknowledge when interventions are based on assumption, and recommended that through collaboration with programme developers assumptions made about an intervention should be checked against the evidence base. Theories, depicted in a logic model, help demonstrate their implementation, mechanisms of change and the context they work within.

The logic model is a diagrammatic representation of the intervention, which helps clarify the causal assumptions of the problem theory and identify relationships between the implementation of an intervention and its context (Rehfuess et al., 2018). It is a systematic and visual way to describe an intervention that can aid in areas of planning, design, implementation, analysis and knowledge generation. Logic models look at the big picture, help explain the road ahead and show the possible resources needed for a project (Kellogg Foundation, 2004).

The Kellogg Foundation (2004) described three approaches to logic models: theory, outcome and activities. Reading from left to right, they follow a chain of reasoning of “if-then” statements, to connect the programme parts. The Kellogg Foundation logic models are criticised for being linear and process based, offering an oversimplified view of interventions. They focus on outcome rather than change mechanism and fail to integrate context. As an alternative, system-based logic models attempt to pick apart the complexity of the programme and place it within the broader context in which it takes place (Rehfuess et al., 2018).

Hence, logic models can be process orientated or system orientated and implemented at any stage: a priori, sequential or iterative (Moore et al., 2014; Rehfuess et al., 2018). There are a variety of logic models aligned to different academic theories but, generally, what is accepted throughout the MRC guidelines is that incorporating context and change mechanism is important. Practically, logic models are used as a tool to help guide research questions and data collection methods. The development of research questions along with mixed methods research design is discussed below.

The MRC guidelines recommend adopting a combination of methods: quantitative to measure process variables and qualitative to examine in-depth data about the experience of an intervention. The guidelines state that the research question should relate to the three core aims of process evaluation and be derived from the assumption made about the intervention and the evidence available to support it (Moore et al., 2014). The research questions generated from the logic model should be relevant to the stage of the project and generally address mechanisms of impact, context, implementation and acceptability. However, researchers need to be aware that not all questions will be answered and therefore they should not be overambitious in their research design (Moore et al.,2015).

3.5 Why Process Evaluation for This Study?

The bereavement follow-up programme was developed atheoretical and driven by common sense and experience-based assumptions of the core nursing team. Based on their knowledge and experience of caring for bereaved families in critical care, which often involved sudden death alongside withdrawal-of-treatment decisions, they assumed that families would benefit from more support. The assumption was that we could support bereaved families by recognising significant loss, providing ongoing contact and signposting with relevant bereavement support information.

As stated previously, it should be recognised when interventions are drawn from assumption, experience and common sense. Furthermore, Evans et al. (2015) argued that more pragmatic formative evaluation should take place, and proposed that acknowledgement by MRC that there is no “typical evaluation” gives scope for development within the framework. Evans et al. (2015) advocates for the evaluation of interventions that are already in practice but lack a robust evidence base. They suggested that such interventions still require proper evaluation including the development of a theoretical base, examination of their causal assumptions and possible unintended consequences (Evans et al., 2015). Hence, pragmatic process evaluation takes place when an existing intervention warrants evaluation. It should be used to develop a logic model, realist context, method, and outcome analysis, and if possible to refine delivery before scaling up (Fletcher et al., 2016).

Conflicting factors arising in the bereavement follow-up programme at the Queen Elizabeth University Hospital are difficult to understand in isolation. The decision to use a process evaluation as a research framework to evaluate the programme facilitated understanding complex, multifactorial aspects of the bereavement follow-up intervention."

3.6 Chapter Summary

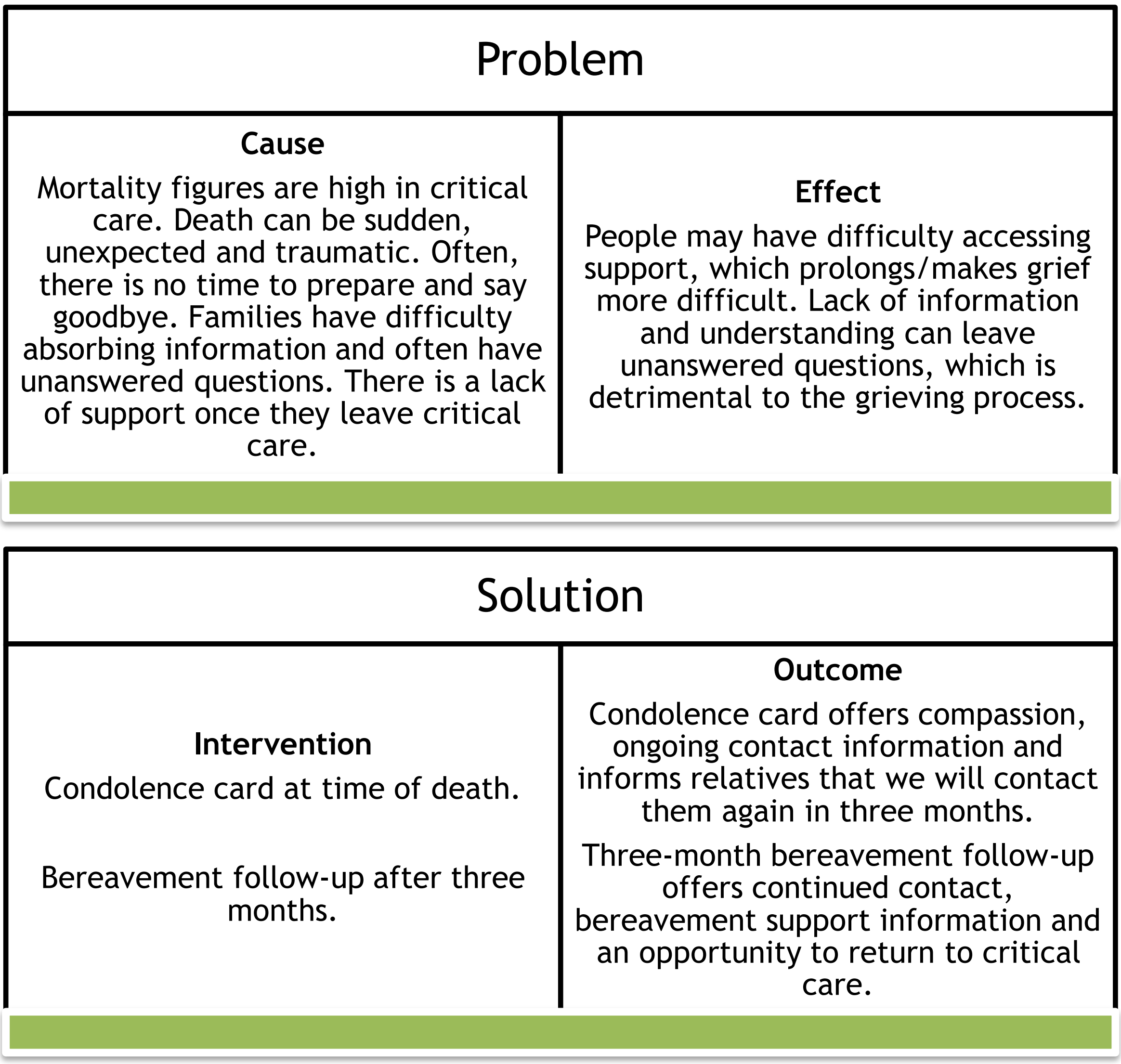
This chapter presented the philosophical position of the researcher with reference to the research method of a process evaluation. The historical development of and key literature pertaining to process evaluations aim to explain the background to this method, but are by no means exhaustive when considering the philosophy and theories within the field. The current MRC guidelines for carrying out a process evaluation have been outlined and will be used to guide the study. Key components of process evaluation along with intervention theory and logic modelling were discussed. The rationale for choosing this method of evaluation and the project's alignment with pragmatic evaluation was outlined. The design and methods used for the process evaluation are discussed in Chapter 4.

Chapter 4 Methods

4.1 Introduction

This is a single-centre study using a mixed methods process evaluation to evaluate the bereavement follow-up programme in the Critical Care Unit of the Queen Elizabeth University Hospital. Chapter 3 discussed the literature relevant to process evaluation. The MRC guidelines describe the different stages of an intervention during which a process evaluation can be carried out: feasibility testing, effectiveness evaluation and post-evaluation implementation, and for policy trial and natural experiments (Moore et al., 2014). The elements of process evaluation investigated will vary depending on the stage during which it takes place. As discussed in Chapter 3, this project is a pragmatic process evaluation of an intervention currently in practice.

Figure 2 depicts the problem and solution theory for the bereavement follow-up programme. As discussed in Chapter 3, Section 3.5, the problem theory was not formally developed prior to the design of the intervention, which was an organic process for the bereavement team based on their experience of caring for dying patients and their families. To enable the development of the basic theory underpinning the intervention the researcher discussed the assumptions that were made about bereavement follow-up with the bereavement team. The problem theory is shown in Figure 2.



Problem

Cause

Mortality figures are high in critical care. Death can be sudden, unexpected and traumatic. Often, there is no time to prepare and say goodbye. Families have difficulty absorbing information and often have unanswered questions. There is a lack of support once they leave critical care.

Effect

People may have difficulty accessing support, which prolongs/makes grief more difficult. Lack of information and understanding can leave unanswered questions, which is detrimental to the grieving process.

Solution

Intervention

Condolence card at time of death.

Bereavement follow-up after three months.

Outcome

Condolence card offers compassion, ongoing contact information and informs relatives that we will contact them again in three months.

Three-month bereavement follow-up offers continued contact, bereavement support information and an opportunity to return to critical care.

Figure 2 Problem Theory

4.1.1 Queen Elizabeth University Hospital Bereavement Follow-Up Logic Model

The problem theory describes the general theory of the bereavement follow-up programme and causal assumptions underlying the project. The formal expression of the theory facilitated the development of the process evaluation logic model. Ideally, the logic model should be developed prior to the intervention being designed; however, this was a pragmatic evaluation of an existing project, and hence the logic model was designed post-intervention. The logic model is viewed as a necessary step to conduct a process evaluation and was essential for developing the research questions.

The logic model shown in Figure 3 is a diagrammatic representation of the bereavement follow-up programme at the Queen Elizabeth University Hospital. Its development proved to be a valuable exercise as it demonstrated for the first time the complexity of the intervention. The logic model shows the mechanisms of change of the individual aspects of the intervention, the required resources and the expected outcomes. These are embedded in the overarching change mechanisms, system characteristics and context. The arrows between the individual components of the intervention and the mechanisms of change indicate the multifactorial influences within what might seem a simple intervention.

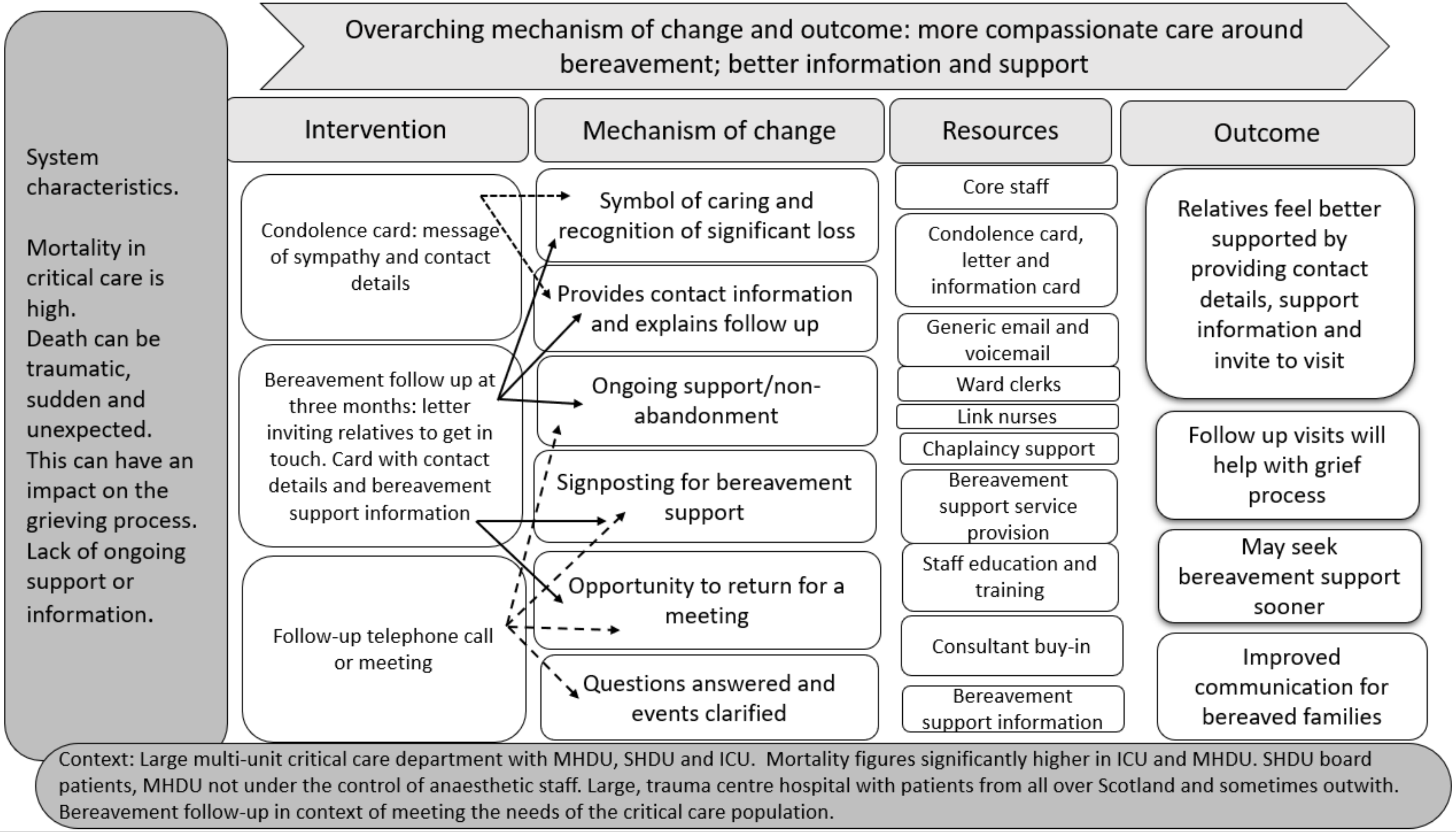


Figure 3 Bereavement Follow-Up Logic Model

4.2 Research Questions Mapped to Logic Model

Table 7 maps the research questions and data collection methods to the process evaluation domains. Along with mechanism of change and context, the research questions examine the implementation of the project through the key process evaluation indicators of fidelity, dose and reach.

Table 7 Process Evaluation Research Questions and Data Collection Methods

Domain	Research question	Data source	Analysis type
Mechanism of change/intervention impact	Does nearest friend/relative find the condolence card useful?	Relatives questionnaire/contact forms	Quantitative/qualitative
	Does nearest friend/relative find the three-month follow-up useful?	Relatives questionnaire/contact forms	Quantitative/qualitative
	Does bereavement follow-up target the bereaved?	Relatives questionnaire/ interview/contact forms	Quantitative/qualitative
	What is the relatives' experience of a follow-up meeting?	Semi-structured interview/interview documentation	Qualitative
Intervention implementation	Do staff know what information to give at time of death?	Staff questionnaire	Quantitative
	Are all deaths recorded on the spreadsheet?	Mortality figures/2020 spreadsheet	Quantitative
	What is the percentage of follow-up compared to mortality?	Mortality figures/2020 spreadsheet	Quantitative
	How many nearest friends/relatives responded to the service?	Relatives contact form	Quantitative
	What method of contact did they use to get in touch?	Relatives contact form/interview	Quantitative
	Did relatives receive the intervention as planned?	Relatives questionnaire/interview	Quantitative/qualitative
	Does nearest friend/relative want contact from critical care?	Relatives questionnaire	Quantitative/qualitative
Implementation acceptability	Would nearest friend/relative prefer to be contacted another way?	Relatives questionnaire	Quantitative/qualitative
	What is the experience of the programme?	Semi-structured interview	Qualitative
	What is the impact on the chaplaincy service?	Semi-structured interview	Qualitative
	What is the impact on visiting specialists?	Semi-structured interview	Qualitative
	Are there different needs between ICU and HDU?	All data	Qualitative/quantitative
Context	Are there any service provision barriers?	Scoping/relatives questionnaire/interview	Qualitative
	Does the programme serve the population?	Relatives questionnaire/interview	Qualitative

4.3 Public Involvement

The research and methods adopted were guided by the principles of public engagement. The project involved discussion with several bereaved relatives from critical care and this helped inform the initial protocol. The project was guided by Stacey Highfield, a bereaved relative from critical care. Stacey’s mum died suddenly and unexpectedly in critical care. At the time Stacey felt supported by staff and the keepsakes initiatives that had been implemented as part of bereavement support. Stacey kept in touch with the intensive care unit and was keen to support the bereavement team in any way possible. As the public involvement representative, she helped guide the design of the study including reviewing the layout and content of participant information sheets, questionnaire for relatives and interview guides.

4.4 Study Design

The study design used a mixed methods process evaluation. Quantitative data are used to measure the implementation process elements and qualitative data allows for a better understand of the mechanisms of change and experiences of the intervention, including unintended mediators and consequences.

The process evaluation addresses the research questions using three different sources of data. The study flow diagram is shown in Figure 4. The three-pronged approach uses existing data, relatives’ data and staff data. The data from the three strands are combined to examine the implementation process variables of fidelity, dose and reach. Acceptability and mechanism of change are addressed through the questionnaire for relatives and in-depth data from semi-structured interviews with relatives and staff.

4.4.1 Elements of Data from the Three Strands Not Collected

The critical care nursing, medical and clerical staff are key to the day-to-day implementation of the bereavement programme. The staff questionnaire was designed on Webropol to be completed anonymously by all staff and aimed to look at implementation process questions to ascertain if staff had adequate knowledge of the process in place for the bereavement follow-up programme. During the response to the pandemic, teaching across critical care was limited, staff were displaced throughout the department, and after the first wave of COVID 19 there was significant staff turnover. This, along with time constraints placed on the research project, made this part of the study both less feasible and of limited value.

Existing data included notes from meetings with relatives. The researcher planned to analyse the notes from the meetings to give a broader insight into common themes and outcomes. Due to time constraints this part of the evaluation was not carried out

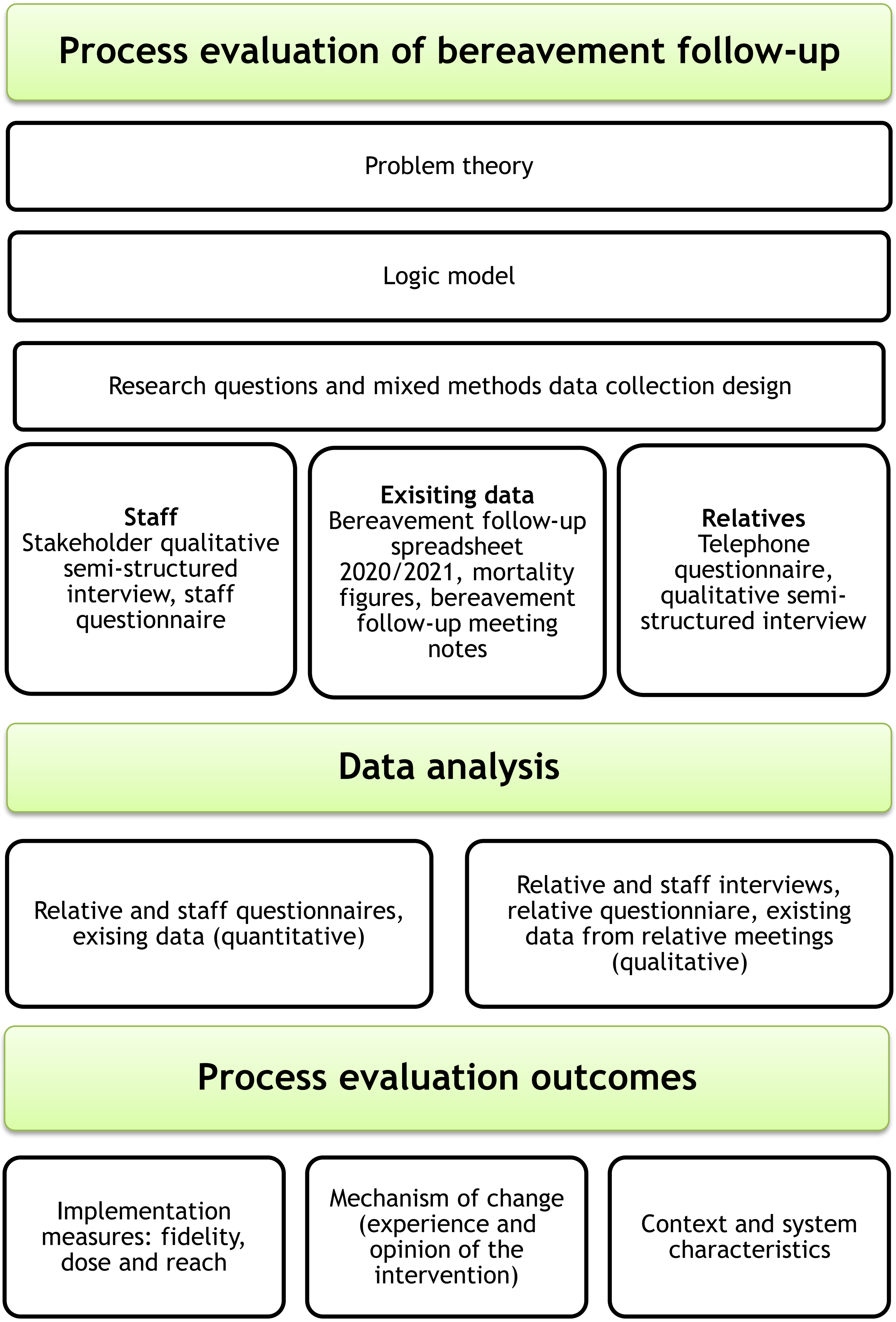


Figure 4 Study Flow Diagram

4.5 Study Site

The Queen Elizabeth University Hospital opened in 2015, bringing together three acute hospital sites from across Glasgow. The hospital is one the of the largest in the UK, with 1100 adult in-patient beds. It is adjoined to the Royal Hospital for Children and has national, regional and local services. It is the centre for major specialist services such as renal medicine, transplantation and vascular surgery, and is at the heart of the evolving West of Scotland Major Trauma Service.

The critical care department is the largest in Scotland. It has 59 funded beds spread across six critical care units, providing high dependency and intensive care to elective patients, emergency admissions and trauma patients. Since March 2020, in response to the COVID 19 pandemic, the department has been required to scale up medical high dependency and intensive care isolation capacity while continuing to provide general intensive and high dependency care. Overall, the ongoing response to COVID 19 presents many challenges, with isolation bed capacity changing according to surges in the virus. This ultimately has had a significant impact on critical care and the development of services. The specific impact on bereavement follow-up is discussed in more detail in Chapter 5

4.6 Population

The population for the study is critical care staff and bereaved nearest/closest relatives or friends of those who die in critical care. This population will generally be referred to as families or relatives throughout the thesis for ease. All staff working in critical care were informed of the study through email or regular departmental meetings, and the core bereavement team were fully briefed and involved in the design of the project. Key stakeholders include the nursing and medical staff running the project, medical staff asked to support bereaved relatives and the hospital chaplain.

The nearest/closest relative or friend of those who die in critical care includes bereaved relatives receiving follow-up information and those relatives who subsequently engage with the bereavement team. From a process implementation perspective, it also includes those relatives who did not receive information. A small number of relatives who have not received their bereavement follow-up information have sought support from the department, and this is important to consider as part of the overall evaluation. The specific sample for the study is described below.

4.6.1 Sample

The following specific inclusion and exclusion criteria were used for the sample population of the study.

Inclusion Criteria

- Nearest/closest friend or relative of deceased patient in critical care recorded on the bereavement follow-up spreadsheet
- Friends or relatives attending for a follow-up meeting
- Aged 18 years or older
- Speaks English
- Resident in the UK
- Does not show signs of cognitive impairment.

Exclusion Criteria

- Younger than 18 years of age
- Does not speak English
- Lives outwith the UK
- Involved in any ongoing complaint or serious clinical incident investigation
- The researcher was present in a professional capacity at the follow-up meeting (for qualitative interviews with relatives only).

Different sampling methods, appropriate to the population and data collection tool, were employed for each limb of the study. Consecutive sampling was used to recruit nearest/closest relatives or friends to complete a questionnaire by telephone over a period of two months. Information on the research project in the form of a participant information sheet (Appendix 2) was included in the follow-up letter sent out at three months. The participant information sheet informed relatives that they would be contacted by telephone one month later and gave them an option to inform the researcher if they did not want to be contacted. This prevented cold calling and gave participants time to consider whether they would like to take part in the project.

The estimated sample size for the telephone questionnaire was based on 2019 figures. In 2019 approximately 35 to 40 relatives received bereavement follow-up information in a two-month period. The sample size for the project was more difficult to estimate due to COVID 19 and the fluid nature of the critical care department. However, mortality figures at the peak of the pandemic are comparable to busy periods from 2019 and remained manageable for the researcher.

Purposive sampling was used to carry out semi-structured interviews with key stakeholders and relatives. The sample size for relatives who attended for a follow-up meeting is small due to limited numbers. In addition, ethical considerations and an attempt to eliminate bias meant exclusion criteria set for the study limited the researcher making contact with relatives when they had been the professional in the meeting.

The nearest/closest friends or relatives who had returned for a meeting from the start of the project to the end of 2019 were recruited retrospectively. Due to limited numbers and the time constraints on the researcher, the target sample size was between four and six. Those relatives eligible to participate received a letter inviting them to take part in the study along with a participant information sheet explaining more about the research (Appendix 2). The relatives were called one week later and asked if they would be willing to take part.

The initial research protocol aimed to recruit relatives who returned for a meeting during 2020 and early 2021. However, the bereavement follow-up programme was suspended for four months during the initial response to COVID 19. After reintroduction of the programme in August 2020 there was a limited response. This changed by early 2021, with an increase in relatives requesting support, but there was limited time remaining to recruit them to the study. Potentially the meeting notes would have captured additional information on these meetings but, as discussed in Section 4.4, this was not carried out.

The key stakeholders approached to take part in semi-structured interviews were nursing staff directly involved in bereavement follow-up (excluding the researcher) (n=4), intensive care consultants who may be requested to take part in a bereavement support meeting (n=22) and the hospital chaplain involved in supporting the bereavement follow-up programme. Interviewing 22 intensive care consultants was not feasible and a manageable sample size was determined at six consultants. To gain a balanced viewpoint this was split between three who had attended a follow-up meeting and three who had not. The stakeholders were sent an email with a participant information sheet attached (Appendix 2) inviting them to take part. To minimise bias, all of the consultants received the email and the first to respond from each group was recruited.

4.6.2 Access to Site

Approval was obtained from the lead nurse, Iain Thomson, and the clinical director for critical care, Dr Alexander Binning, to carry out the research project. As a charge nurse in critical care and lead for the bereavement follow-up programme, I have access to existing data sources. I sought permission from Dr Peter Stenhouse, clinical lead for the collection of data for the Scottish Intensive Care Audit Group in the department to have full access to the Wardwatcher database. Access to this dataset allowed collection of key routine data from all of the critical care units.

4.7 Ethics Approval

The research was conducted in line with ethical principles outlined in the World Medical Association Declaration of Helsinki (1964)(World Medical Association, 2013). This study was designated as service evaluation by the NHS ethics research officer. Ethical approval was sought from University of Glasgow’s School of Medicine, Veterinary and Life Sciences ethics committee and, as per guidance from Greater Glasgow and Clyde, Clinical Governance Support Unit local approval was obtained from Dr Alexander Binning, clinical director for critical care.

4.7.1 Ethical Issues

Bereavement is a sensitive research topic, and engagement with bereaved relatives needs careful ethical consideration. This requires researchers to consider if the benefits of the study are proportionate to any potential harm. However, overcautious reactions to bereavement research can restrict access to participants and data (Sque et al., 2014). There is a perception that relatives may experience harm from being asked to participate in bereavement research. Contrary to this, studies suggest an altruistic motive for taking part: participants want to help improve practice and support other bereaved relatives.

Contacting relatives by telephone was given careful consideration, and evidence from previous research was important when considering this method of contact. Several studies support the use of telephone calls as a method of interviewing bereaved relatives (van der Klink et al., 2010; Downar et al., 2014; Kentish-Barnes et al., 2015a; Erikson et al., 2019; Laurent et al., 2019). Kentish-Barnes (2019) quoted several studies which indicate that contacting relatives by telephone generates good response rates. Overall, from an ethical perspective there is evidence to suggest that a telephone interview is seen as supportive and relatives are keen to take part (Kentish-Barnes et al., 2015a; Kentish-Barnes, 2019).

4.8 Research Training

The experience of the researcher along with an understanding of the population they are interacting with is important, especially when considering a sensitive subject and vulnerable participant group. I have extensive experience working with distressed relatives in critical care, alongside a passion for improving end-of-life care and bereavement support. This has involved additional professional development in advanced communication, suicide-awareness training and palliative care.

However, conducting a research project requires a different perspective and additional training. In September 2019 I attended the Process Evaluation course run by DeCIPHER at Cardiff University. Prior to designing the process evaluation, I attended the University of Glasgow's Introduction to Research course for MSc nursing students, and completed the NHS Greater Glasgow and Clyde Good Clinical Practice course. I recognised that the delineation between my professional role and that of researcher would be difficult. Support through academic supervision and one-to-one training on in-depth interviewing techniques helped define the boundaries.

4.9 Data Collection Tool

The relatives' questionnaire, in-depth interviews and existing data were used to answer the research questions and examine the components of the process evaluation. The specific data collection tools used are described in detail below.

The telephone questionnaire for relatives was designed using NHS approved Webropol software (Appendix 3). The aim of the questionnaire was to obtain process implementation data and gain insight into the acceptability of the intervention. A contact form for relatives was used to record information on the unit the patient died in, length of stay, patient demographic information, relationship to the patient of the named nearest/closest friend or relative, and their contact details.

It was estimated that the questionnaire would take approximately 10 minutes to complete. Ideally the questionnaire was to be completed on the telephone with the researcher; however, relatives were also given the option to have a questionnaire sent to them by post, email or web link. This aimed to improve response rates and offer flexibility for those that wanted to participate but could not take part on the telephone.

The questionnaire was split into three sections. The first section asked three questions about unit details, length of stay and relationship to the deceased. This was pre-populated by the researcher using information from the contact form. The relationship to the deceased was checked with the participant prior to them taking part.

The subsequent 24 questions were split into two sections that aimed to examine the various points of contact that were vital for the bereavement follow-up programme. Questions 4–13 asked questions about information given at the time of death and included questions on the condolence card. Questions 14–27 asked questions about the bereavement follow-up information given at three months. The questionnaire aimed to ask process-related questions about the timing and content of the intervention and gain information on the acceptability of the programme, including preferences for alternative methods of contact. It also aimed to gain information on barriers to contacting the bereavement support team. The questionnaire mainly used closed questions with some open-ended responses available.

4.9.1 Relative and Staff Semi-structured Interviews

The semi-structured, audio-recorded interviews with relatives who had attended for a follow-up meeting aimed to gain a deeper understanding of the experience of the intervention. Interviews with key stakeholders obtained a detailed perspective on their views on bereavement follow-up. The process of meeting with relatives was examined along with the impact of providing a service from their professional point of view. The interviews were carried out virtually via telephone and videoconferencing to comply with COVID 19 restrictions.

Braun and Clarke’s (2013) recommendations for collecting qualitative data and carrying out semi-structured interviews were used to develop the interview guides (Appendices 4 and 5). The guides focused on asking questions that gathered relatives’ opinions and experiences, to help answer the research questions relevant for the bereavement follow-up process evaluation.

When carrying out the interviews the researcher was aware of the need to balance answering the research questions with allowing the interview to evolve naturally to gain rich and meaningful data (Braun and Clarke, 2013). Although the guide was loosely structured to gain the relevant information, it was open and flexible enough to avoid limiting participants’ responses. The interview guide was shared with the bereavement team, and tested on a colleague to help refine the questions and the flow of the interview.

4.9.2 Collection of Existing Data

Existing data provided the main source of information for the analysis of implementation domains. Wardwatcher is the bespoke data collection platform used by the Scottish Intensive Care Society Audit Group (SICSAG). SICSAG has maintained a database since 1995 and collects detailed information on the management of critically ill patients from all general intensive care units, mixed units and high dependency. As part of the project, I was given access to this dataset. Wardwatcher was used to extract individual unit length-of-stay data required for the relatives' questionnaire. The consultant responsible for managing the dataset at departmental level supported this with the provision of overall and individual unit mortality figures for 2019 and 2020.

As part of the bereavement follow-up process, the ward clerks in each critical care unit record on a spreadsheet all deaths along with nearest/closest relative or friend contact details. The number of deaths recorded along with analysis of incomplete contact information was used in comparison to mortality figures to help analyse the fidelity, dose and reach of the project. The bereavement team have a form for recoding information on relatives contacting the service. These forms were used to examine return rates, method of contact and outcomes.

4.10 Validity and Reliability

The concepts of validity and reliability are used to evaluate the quality of research. Validity refers to the accuracy of a measurement and the degree to which an instrument measures what it is supposed to measure, while reliability is about the consistency and accuracy of a measure (Carter and Porter, 2000). Polit and Beck (2017) argued that mixed methods researchers often avoid terms that focus purely on qualitative or quantitative methods as they are generally associated with different positivist and interpretivist paradigms. They suggested that there is the opportunity to assess the overall goodness of the data.

Creswell and Plano Clark (2017) believe that the quality of the data in mixed methods studies should be addressed by the design being used, and Ryan and Rutty (2019), with direct relevance to critical realism, stated that the measures of quality should be guided by the philosophical perspectives of the researcher. The MRC guidance outlines the common qualitative and quantitative data collection methods used for process evaluations. They focus not only on the importance of selecting methods appropriate to the topic but also integrating the results to draw meaningful conclusions (Moore et al., 2014). The different data collection methods and the consideration given to the quality are outlined below.

4.10.1 Existing Data

Moore et al. (2014) stated that it can be difficult to ascertain the quality of existing data in a process evaluation. The quality of the existing data used for this project was deemed appropriate and of adequate quality. Mortality figures came from Wardwatcher, the SICSAG database, historical bereavement follow-up spreadsheets maintained by clerical staff and bereavement follow-up engagement forms. This data was well maintained and collated by staff and bodies mainly external to the bereavement team and the researcher. Moreover, the data was compared and integrated to assess the fidelity, dose and reach of the intervention.

4.10.2 Telephone Questionnaire

The questionnaire design was guided by the domains of the process evaluation and questionnaires used in previous bereavement follow-up research. The questionnaire was reviewed by all of the bereavement team and tested on members of the public. Changes were made throughout this process to ensure that the questions were clear and asked what they were designed to ask. Testing of the questionnaire in its different formats ensured answers were consistent and reliable when carried out on the telephone with the researcher and independently either on paper or online.

4.10.3 Stakeholder Interviews

The MRC guidelines state that it is often impractical or unnecessary to include all relevant stakeholders. There were ten stakeholder interviews in total but the number of consultants interviewed was limited to six from the 22. This was deemed appropriate and manageable for a single researcher. The method of recruiting consultants for interview was on a first-come basis to reduce researcher bias. The interview guide was reviewed and tested by the bereavement team.

4.10.4 Interviews with Bereaved Relatives

A semi-structured interview with bereaved relatives was deemed a valid tool for this process evaluation. This captures fewer participants but is appropriate for more sensitive issues and gives the opportunity to explore individual experiences in depth. The interview guide was reviewed by the public engagement participant for the study and tested prior to data collection.

The overall quality of the project was supported by following the MRC guidance for process evaluations. Appropriate methods were used to gather data and the results were integrated to help answer the research questions. Ethical guidelines were followed throughout the project and are discussed in more detail in Section 4.11.

4.11 Issues Relating to Consent

Different methods of consent were used for the various methods of the study and approved by the University of Glasgow's School of Medicine, Veterinary and Life Sciences ethics committee. The method of consent and any issues relating to consent are discussed below.

4.11.1 Relatives' Questionnaire Consent

Verbal consent was obtained prior to relatives completing the telephone questionnaire. Participants who agreed to complete the questionnaire consented to answer on the basis that their responses were anonymous. Consent was assumed for those who agreed to participate via a self-administered questionnaire by post or web link. Relatives' details were obtained from the existing spreadsheet used to send out the bereavement follow-up letters. A relatives' telephone questionnaire guide (Appendix 4) was created for each potential participant and a unique identifier attached to keep track of calls; this was destroyed once data collection was complete.

4.11.2 Semi-structured Interview

Informed consent was obtained from both relatives and staff taking part in semi-structured interviews. Relatives were contacted by letter and invited to take part in an audio-recorded semi-structured interview, and staff were contacted by email and asked to participate. Staff and relatives agreeing to take part were given the opportunity to ask questions before written informed consent was obtained (Appendices 6 and 7). All of the interviews were carried out virtually due to COVID 19 restrictions. The consent process was completed prior to the interview. Relatives signed and returned the consent form via post, while staff completed their form and returned it to the researcher in the department.

4.12 Data Analysis

The data analysis techniques rely on using research tools appropriate to each limb of the study. This is outlined in Figure 4 (above) and involves a mixture of simple descriptive statistics and qualitative data analysis as described below.

4.12.1 Questionnaire Analysis

The questionnaire was designed using Webropol software. Once data collection was complete the software was used to produce a simple report showing initial results and areas for further development. The dataset was then exported to SPSS for greater manipulation of the information. Simple descriptive statistics with comparisons between different months, gender and length of unit stay were examined. Answers obtained from open-ended questions provided some qualitative data to further explain the descriptive statistics gained from the closed questions.

4.12.2 In-depth Interview Analysis

The qualitative data from semi-structured interviews were transcribed verbatim by a University of Glasgow approved transcription service. The transcripts were uploaded to NVIVO by QSR International, where they were organised and coded for qualitative analysis. The dataset was explored using thematic analysis such as that outlined by Braun and Clarke (2013). Themes were identified about the experience of relatives attending a bereavement follow-up meeting. Coding of staff transcripts looked at both the experience of interacting with bereaved relatives and the professionals' views on bereavement follow-up. The relative and staff interviews were coded and analysed separately but were then compared to explore relationships between the identified themes from both groups.

4.12.3 Existing Data Analysis

Simple descriptive statistics describe mortality figures, bereavement follow-up data and relatives' return rates. The relatives' contact forms provided information on the method of contact, relationship with the patient and the unit that the patient died in. As discussed in Section 4.4, the qualitative analysis of notes from relatives' meetings was not completed.

4.13 Chapter Summary

Chapter 4 has outlined the methods used for the process evaluation of the bereavement follow-up programme. The logic model guided the development of the research questions. The mixed methods approach integrates data from multiple sources, as outlined in the project flow diagram (see Figure 4). The questions were mapped to the domains of the process evaluation with an indication of the data collection methods that would be used to answer them. The study site and the population were described, giving context to the study, while the specific sampling methods used for staff and relatives were discussed. Ethical issues and consent were given careful consideration. The data collection tools used are outlined in more detail followed by a summary of the data analysis methods employed. Chapter 5 outlines the results of the process evaluation.

Chapter 5 Results

5.1 Presentation of Results

The following chapter presents the results of the process evaluation. Table 8 provides an overview of the results. A summary of the key data collected from the different strands of the project – existing data, relatives’ data and stakeholders’ data – is presented first in Section 5.2. Following this the results are integrated and presented under the core process evaluation domains.

5.2 Summary of Key Information from Data Strands

A summary of key information from the different data strands is important to provide a framework for the discussion of the results under the process evaluation domains. The key information presents analysis of existing routine data and the key response rates and demographic information for the questionnaires and the semi-structured interviews.

5.2.1 Existing Data

The main sources of existing data are mortality figures, information from the bereavement follow-up spreadsheet and details from the contact sheets of those relatives that engage with the intervention. The mortality figures compared with data from the bereavement follow-up spreadsheet are used in later discussion for the fidelity, dose and reach of the intervention. Similarly, data from the relatives’ contact sheets are used for process implementation evaluation, adaptation, and mechanism of change analysis.

Table 8 Overview of Results

Domain	Measures	Data	Overview of findings
Intervention Implementation and acceptability	Fidelity Dose Reach Acceptability of intervention including adaptations	Bereavement follow-up spreadsheet Mortality figures Relatives contact form Relatives questionnaire Semi-structured interview	Dose delivered based on complete relative contact information was between 50% and 75% Intervention acceptability high with over 90% wanting contact from critical care Forty-three per cent received information at time of death Fifty-three per cent received condolence card Incomplete recording of nearest/closest friend or relative details impacts on dose delivered Relatives' contact with the programme low <3% Voicemail dominant contact method Stakeholders had positive experience of delivering intervention but worry about complaints Barriers for clinical team, especially time and resources
Mechanism of change/ Intervention impact	Recognition of significant loss Ongoing support and non-abandonment Providing contact information and explaining follow-up Signposting Opportunity to have questions answered and meet with clinical team	Relatives questionnaire Relatives contact forms Semi-structured interviews	*When Someone Has Died* booklet and condolence card given at time of death helpful and meaningful but information not used by relatives Simple mechanisms of change such as recognition of significant loss and non-abandonment important despite low engagement Relatives would not find a visit helpful and deal with grief in their own community Relatives unsure of what they would want and hint at unmet need Bereavement follow-up information vital trigger for relatives making contact Evidence that bereavement follow-up information is shared with wider family and friends Experience of a meeting goes beyond answering questions and clarifying events: provides closure, absolves relatives of guilt and allows them to move on in their grief Stakeholders support bereavement follow-up Emotional and time burden for clinical stakeholders Important as a learning experience and to inform practice Chaplain's professional role and relationship with bereaved families is significantly different
Context	Organisational Environmental Societal Political	All data	Bottom-up organisational structure impacts on time and resources Lack of policy and guidance for bereavement follow-up services Participants sought bereavement support within their own social network and community Significant impact from COVID 19 More research required to understand the needs of a large critical care department and any adaptation that would improve engagement Research and design on interventions need to involve bereaved families

Mortality Figures

The SICSAG mortality figure for mixed high dependency and intensive care units is 13 per cent. Overall mortality for critical care at the Queen Elizabeth University Hospital is between 8 and 11 per cent, with mortality figures in intensive care significantly higher than those of surgical high dependency. Medical high dependency has a similar number of deaths to intensive care but, with a higher number of admissions, their mortality figure is lower.

The mortality figures for 2019 and 2020 are shown in Tables 9 and 10. Mortality figures for 2019 reflect a stable year prior to the COVID 19 pandemic. Table 10 shows figures for 2020. The number of critical care beds is left blank as bed capacity varied across critical care. This variation was for several reasons. The first wave of patients suffering from COVID 19 impacted Scotland at the end of March 2020. At the peak of the pandemic, the number of intensive care beds increased from 18 to 40, and MHDU beds from nine to 24.

Table 9 Critical Care Mortality Figures 1/1/2019 to 31/12/2019

Unit	Number of beds	Number of Admissions	Number of deaths	Per cent
ICU	18	870	193	22.4
MHDU	9	942	63	6.7
SHDU	26	2515	78	3.1
Total	**53**	**4327**	**334**	**8**

Due to the volatility of the COVID 19 infection rates and hospital admission, the critical care floor remains flexible with changing demand and capacity for intensive care and medical high dependency isolation beds. In addition, in October 2020, the establishment of the Major Trauma Centre at the Queen Elizabeth University Hospital resulted in a permanent increase in intensive care capacity, giving a total of 22 intensive care beds and eight high dependency beds across three hybrid units.

Table 10 Critical Care Mortality Figures 1/1/2020 to 31/12/2020

Unit	Number of beds	Number of admissions	Number of deaths	Per cent
ICU	Variable	727	177	24.3
MHDU	Variable	456	44	9.6
SHDU	Variable	1508	50	3.3
COVID ICU	Variable	136	61	44.8
COVID MHDU	Variable	146	10	6.8
Total critical care	Variable	**2973**	**342**	**11.5**
Total COVID	Variable	**282**	**71**	**25**

Despite the COVID 19 pandemic, overall mortality figures for critical care, and in particular intensive care, are not significantly higher in 2020. During the peak of the pandemic, planned surgery was cancelled to increase capacity for isolation beds. Contingency plans were implemented to care for non-COVID 19 intensive care patients in specialist units such as neurological intensive care. In addition, although patients suffering from COVID 19 had a high mortality rate, they also had a longer length of stay. However, this should not detract from the fact that almost half of patients admitted with COVID 19 died, which has significant implications for the complex social and political context that the project is set in.

Regardless of COVID 19 mortality, in general one in five patients in intensive care at the Queen Elizabeth University Hospital will die. These figures support the rationale for bereavement follow-up as discussed in the Introduction. The differences in mortality figures across different critical care units may have implications for the implementation of bereavement follow-up.

Bereavement Follow-up Figures

The nearest/closest friend or relative contact information is recoded on a bereavement follow-up spreadsheet by the ward clerks for each patient who dies. Table 11 shows collated data from the bereavement spreadsheets for 2019 and 2020. The data are collated per unit and show the number of deaths recorded on the spreadsheet, and the number with complete contact details.

This number is displayed as a percentage to give an indication of the percentage of relatives that would receive follow-up.

Table 11 Recording of Complete Nearest/Closest Relatives' Information

Unit	2019			2020		
	Deaths recorded	Complete data	Per cent	Deaths recorded	Complete data	Per cent
SHDU	25	15	60	30	25	83
SHDU	20	14	75	25	18	72
SHDU	14	13	57 (five months missing)	34	19	56
ICU	94	70	74	73	41	56
ICU	95	81	85	65	39	60
MHDU	55	40	73	70	44	63
Total	**303**	**233**	**75**	**297**	**186**	**63**
Total deaths	**334**	**31 missed**	**91**	**342**	**45 missed**	**87**

Uptake of Bereavement Follow-Up

The uptake of bereavement follow-up between 2019 and 2020 is shown in Table 12. Compared to mortality figures, the number of relatives contacting the service is low. The most common method of contact is a telephone call, with the majority of loved ones dying in ICU. Although the follow-up letters are sent to the nearest/closest friend or relative, most meetings were attended by more than one family member or friend.

Table 12 Bereavement Follow-Up Contact 2019–2021

2019						
Unit	**Month of bereavement**	**Month of contact**	**Prompted by condolence card or three-month follow-up Y/N**	**Method of contact**	**Relationship**	**Outcome**
ICU	Oct 2018	Jan 2019	Y (three-month follow up)	Telephone	Husband	Meeting with ICU consultant and bereavement support nurse. Husband and daughter attended.
ICU	Nov 2018	Feb 2019	Y (three-month follow up)	Telephone	Sister	Meeting with ICU consultant and bereavement support nurse. Sister, husband and brother. Referral on to surgical team.
ICU	Jan	April	Y (three-month follow up)	Telephone	Husband	Meeting with ICU consultant and bereavement support nurse. Scottish Association for Mental Health booklet and referral to chaplain.
ICU	May	May	Y (condolence card)	Telephone	Daughter	Meeting with ICU consultant and bereavement support nurse. Daughter and son.
ICU	March	June	Y (three-month follow up)	Telephone	Wife	Meeting with ICU consultant and bereavement support nurse. Wife and daughter.
SHDU	April	Aug	Y (three-month follow up)	Telephone	Wife	Meeting with respiratory consultant and bereavement support nurse. Wife and daughter.
SHDU/ICU	May	Aug	Y (three-month follow up)	Telephone	Son	Meeting with ICU consultant and bereavement support nurse. Son, son's partner, daughter and wife.
ICU	July	Nov	Y (three-month follow up)	Telephone	Husband	Meeting with ICU consultant and bereavement support nurse. Husband and daughter.

2020						
Unit	**Month of bereavement**	**Month of contact**	**Prompted by condolence card or three-month follow-up Y/N**	**Method of contact**	**Relationship**	**Outcome**
ICU	Dec 2019	Jan 2020	N	Visited critical care	Sister	Meeting with intensive care consultant and bereavement support nurse. Three sisters.
MHDU	Aug 2019	Jan 2020	Y (three-month follow up)	Telephone	Partner	Meeting with intensive care consultant and bereavement support nurse. Partner and friend.
ICU	March	July	Y (three-month follow up)	Telephone	Son	Two support calls from nurse 50/30 minutes. Bereavement support advice from GP, and counselling from Cruse Bereavement Support. Meeting not required.
COVID 19 pandemic-bereavement follow up suspended						
ICU	Aug	Aug	Y (condolence card)	Telephone/email	Son	Find out more about the bereavement support service. No further input.
MHDU	Nov	Nov	Y (condolence card)	Telephone/email	Son	Telephone support by nurse 30 minutes. Given information on support organisations. Referral on to chaplaincy. COVID 19

2021						
Unit	**Month of bereavement**	**Month of contact**	**Prompted by condolence card or three-month follow-up Y/N**	**Method of contact**	**Relationship**	**Outcome**
MHDU	Nov 2020	Jan 2021	Y (condolence card)	Telephone	Son	Telephone support from nurse. Referral to chaplaincy, meeting offered. COVID 19
ICU	March	March	N	Telephone call to consultant	Wife	Requested support information. Email sent to relative, letter and card posted early. COVID 19
ICU	Jan	April	Y (three-month follow up)	Telephone	Wife	Telephone support by nurse. Ongoing contact (three calls).
MHDU	Feb	April	N	Telephone call direct to MHDU,	Daughter	Zoom meeting with ICU consultant and bereavement support nurse. COVID 19
SHDU	Nov 2019	May 2021	Y (three-month follow up)	Telephone (three-month follow-up)	Wife and daughters	Meeting with vascular surgeon and bereavement support nurse. Patient's wife and daughters.
ICU	Feb	May	Y (three-month follow up)	Email	Wife	Feedback email commenting on difficult communication. Reply by bereavement support nurse. Apology and ongoing support information provided. COVID 19
MHDU	March	June	Y (three-month follow up)	Telephone call	Wife	Meeting with consultant and nurse. Wife, daughter, son and son-in-law. COVID 19
ICU	April 2020	May 2021	N	Telephone call to consultant	Sister	Meeting with consultant and support nurse. Two sons and three sisters. COVID 19
MHDU	Aug 2021	Feb 2021	N	Referral from consultant	Daughter	Meeting with consultant and bereavement support nurse. Wife and son.

5.2.2 Relatives' Data

The relatives strand of the process evaluation includes the telephone questionnaire carried out using Webropol and in-depth interviews. The response rates and demographic breakdown of participants are presented below.

Telephone Questionnaire for Relatives

The questionnaire was carried out one month after relatives received their bereavement follow-up letters. Those receiving their letters in January and February had been bereaved in October and November and were called during February and March, respectively. Seven relatives contacted during March had not received the information in February. The information was re-sent to six of seven of those relatives and permission to call them again at the end of April was obtained. The final calls were completed by the beginning of May 2021.

Response Rate

In total, 32 relatives with complete contact details were contacted during January and February. The response rate from the telephone questionnaire is broken down by month of call and is shown in Table 13.

Table 13 Response Rate

Month of bereave-ment	Month of follow-up	Month of call	Number of follow-ups	Number of responses	Per cent response rate
October	January	February	14	11	78
November	February	March/ April	18	5	28
Total			**32**	**16**	**50**

The majority of respondents answered the questionnaire on the phone with the researcher, and those who requested to complete it by post did not return it; one participant completed it via the web link. Table 14 shows the spread of respondents across the different critical care units.

Table 14 Respondents per Critical Care Unit

Critical care unit	Number of respondents	Per cent
Unit 1 SHDU	2	12.5
Unit 2 ICU/HDU	3	18.7
Unit 3 ICU/HDU	2	12.5
Unit 4 ICU/HDU	5	31.2
Unit 5 MHDU	3	18.8
Unit 6 SHDU	1	6.3

There was a higher number of respondents from the hybrid units, and this reflects their increased mortality rate. However, there was reasonable representation from both high dependency and intensive care. There is a significant difference in response rates between October and November. The reason for non-respondents per month is shown in Table 15.

Table 15 Reasons for Non-Response

Reasons for non-responders	October		November		Total
	n	Per cent	n	Per cent	
Post, not returned	2	67	2	15	4
Email, not returned	0	0	0	0.0	0
Declined to participate	0	0	4	31	4
No answer to calls on more than three attempts on three different occasions	0	0	5	38	5
Information not received, declined to have it sent	0	0	1	8	1
Invalid/missing telephone number	1	33	1	8	14
Total	**3**		**13**		**16**

Figure 5 shows the comparison of non-respondents between the two months. In general, relatives during the month of February were easier to contact and more likely to participate.

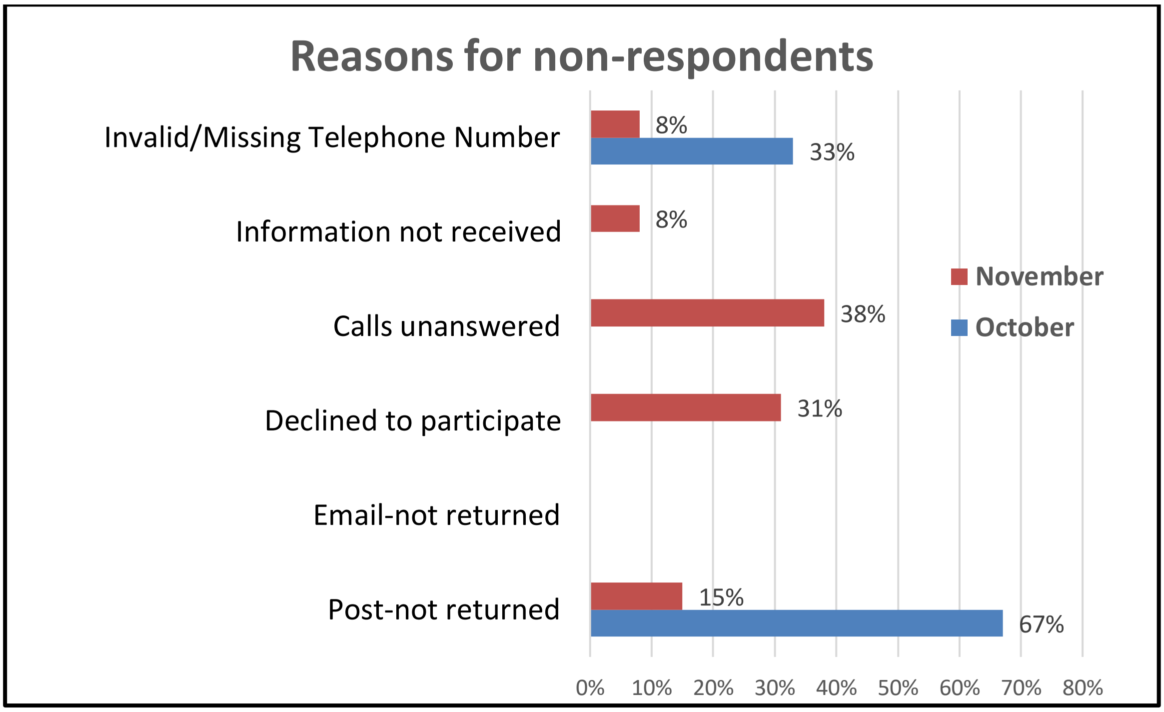


Figure 5 Non-respondents in November and October

There are potential reasons for the difference in response rates that relate to the timing of the bereavement and the experience of end of life. During November, the Queen Elizabeth University Hospital was under extreme pressure as Glasgow experienced a spike in COVID 19 infections. In critical care there was pressure for general intensive care beds with two units being used for COVID 19 isolation. During this time it became necessary to create capacity in intensive care and move patients at end of life to the HDUs.

Furthermore, visiting was restricted and all communication was conducted by telephone. The researcher found elements of anger and less willingness to participate from those whose loved ones died in November. In addition, those relatives had experienced the death closer to Christmas when there was a pending lockdown for a second wave of COVID 19. The difficulty in contacting people via the telephone is possibly due to bereaved spouses electing to stay with family during this period.

Demographics

The respondents' demographic details are shown in Tables 16 and 17. Table 18 shows the relationship of the respondent to the deceased.

Table 16 Gender of Participants

Gender	Number of respondents	Per cent response
Male	7	44
Female	9	56
Total	**16**	**100**

There is a relatively even split between male and female respondents. There was no significant difference in the gender or relationship from the people who did not respond. It was not possible to collect the age group for non-respondents.

Table 17 Age of Respondents

Age Range	Number of respondents	Per cent response
26-35	1	6.3
46-55	3	18.8
56-65	2	18.8
66-75	7	43.8
>75	2	12.5
Total	**16**	**100**

Over 70 per cent (n=12) of respondents were between 46 and 75 years of age, and 44 per cent (n=7) were over the age of 65. This dominant age range is in keeping with the relationship to the deceased, with over 80 per cent of respondents being a spouse or partner.

Table 18 Relationship to Deceased

Relationship	Number of respondents	Per cent response
Spouse	12	75
Partner	1	6.3
Parent	1	6.3
Son/daughter	2	12.5
Total	**16**	**100**

5.2.3 In-depth Interviews with Relatives

Relatives who attended for a follow-up meeting were invited to participate in a semi-structured interview. Figure 6 shows the recruitment of participants. Four semi-structured interviews took place. Due to the restrictions in place for COVID 19, the interviews were carried out virtually via Zoom and over the telephone.

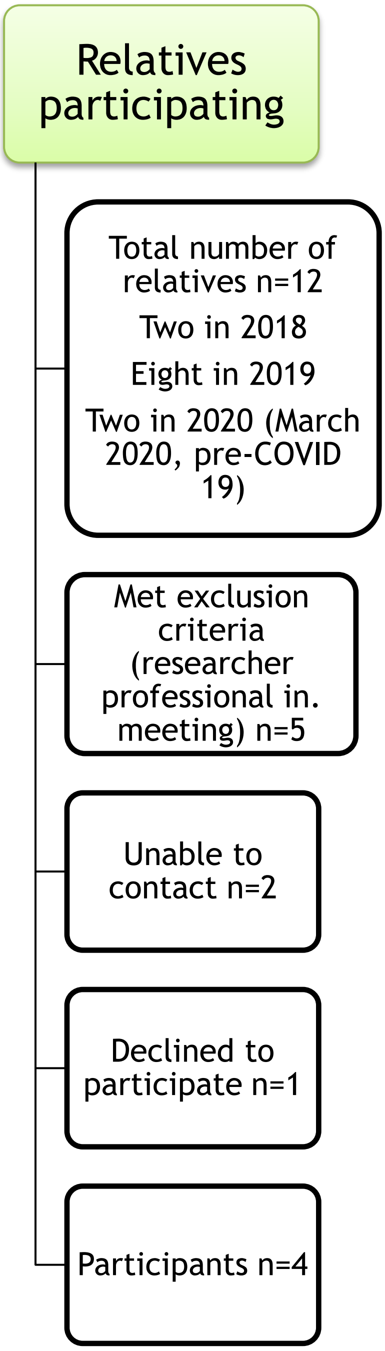


Figure 6 Participating Relatives Flow Diagram

The demographics of the participants, the unit their loved one died in, and how long after the bereavement the meeting took place is shown in Table 19 (alias used to protect anonymity). All the participants' loved ones had died in intensive care, and at the time of interview they had been bereaved for more than 18 months. Three spouses and one daughter took part with an average age of 55.

Table 19 Demographics of Participants in Semi-structured Interviews

Relative	Relationship to loved one	Gender	Age	Year of visit	ICU/HDU	Length of stay
Brian	Husband	Male	63	2018	ICU	10 days
Lucy	Wife	Female	62	2019	ICU	<24hrs
Peter	Husband	Male	53	2019	ICU	<24hrs
Collette	Daughter	Female	43	2019	ICU	<24hrs

5.2.4 Stakeholders' Data

The key stakeholders, namely the bereavement team, consultant anaesthetists and the chaplain, were invited to participate in an in-depth interview. The first question in the interview guide was about the stakeholder's professional role and experience. The responses to this question are summarised in Table 20, followed by a more-detailed discussion.

Table 20 Stakeholder Demographics

Professional role and participant code	Length of experience in current role (years)	Part of bereavement group	Taken part in a bereavement follow-up meeting
Consultant A	2	No	No
Consultant B2	5	No	No
Consultant C	1	No	No
Consultant D	5	No	Yes
Consultant E	17	No	Yes
Consultant F	8	Yes	Yes
Charge nurse A	5 (11 in critical care)	Yes	Yes
Staff nurse B	9	Yes	No
Charge nurse C	6 months (7 years in critical care)	Yes	Yes
Chaplain	4	Yes	Yes

Professional Role and Experience

The length of experience for the consultant group ranged from one year to 17 years. However, all the consultants have approximately 16 years of undergraduate and postgraduate training prior to taking up their post as a consultant. The consultants had dual roles: five were anaesthetists and intensivists with a proportion of time spent in critical care and theatres; one was dual trained in acute medicine and intensive care and their time was split evenly between medical high dependency and the other critical care units; consultant F was part of the bereavement group.

The nursing staff had between five and 10 years of experience in critical care, and two were charge nurses. This was in addition to experience in other clinical environments and pre-registration nurse training. The nursing staff interviewed were part of the bereavement group. One had not taken part in a follow-up meeting but had been involved in supporting relatives on the telephone and arranging meetings.

The hospital chaplain had been in post for four years. Initially the chaplain was involved with the bereavement team to provide spiritual support and conduct the critical care remembrance service. The relationship between the bereavement team and the chaplain grew and their role in assisting with bereavement support developed. The chaplain commented:

> I only ever wanted to be part of what I was welcomed into rather than going all guns blazing, oh, I could help with this, oh, I could do that, or, oh, could we do this, because it didn't feel like the appropriate way to approach it because I'm not part of that integral team that has come up with the idea, who has been developing it.

This comment highlights the different role of the chaplain from that of the clinical team. The chaplain comments on the process of becoming more involved as the programme developed and professional relationships evolved.

The key data sets the scene. The results are drawn from the different data collection strands and integrated under the process evaluation domains of intervention implementation and acceptability, mechanism of change, and context.

5.3 Intervention Implementation and Acceptability

In this section, data from the sources above are integrated under the process evaluation domains of intervention implementation and acceptability. The results are used to evaluate the dose, reach and overall fidelity of the intervention. Acceptability is looked at from both the relatives' and stakeholders' perspectives.

5.3.1 Fidelity, Dose and Reach

The fidelity measures whether the intervention was delivered as planned. This is based on a combination of dose, reach and other indicators of overall fidelity. The fidelity of the intervention based on dose delivered is better in 2019 than in 2020, with a higher number of relatives receiving the intervention. The comparison of mortality figures and complete closest/nearest friend or relative data for 2019 and 2020 shown in Section 5.1 gives an indication of the overall dose delivered for the three-month follow-up letter. Overall, recording of deaths was good but complete nearest/closest friend or relative contact information was less thoroughly collected. In 2019, there were 334 deaths: 297 were recorded on the spreadsheet and 233 had complete information. In 2020, there were 342 deaths: 297 were recorded on the spreadsheet and 186 had complete information. This represents a delivery intervention dose of 70 per cent and 54 per cent, respectively.

The recording of nearest/closest friend or relative information is part of the routine 'My Admission Record' documentation. In critical care, four out of six units use electronic patient record keeping; however, recording this information is still part of the admission process. Omissions in the collection of this information is common, particularly with emergency admission: the urgency of treatment often supersedes asking relatives routine questions. To improve information collection, prompts were placed intermittently on the unit's safety brief and posters were used to highlight the process for bereavement follow-up.

Several factors have resulted in less-thorough collection of contact details in 2020. Due to restrictions on visiting and the changed process of registering a death during COVID 19, there has been more of a focus on accurate telephone numbers and email addresses as opposed to a home address. Several of the critical care units had gaps in ward clerk cover for a period. In general, a high turnover of nursing staff, coupled with visiting staff, and a lack of teaching time resulted in a workforce that was less aware of the importance of collecting this information for bereavement follow-up. In addition, the process relies on the ward clerks identifying all deaths and transferring the information onto the bereavement follow-up spreadsheets.

The provision of the information booklet *When Someone Has Died* is standard practice across NHS Greater Glasgow and Clyde. In critical care, the condolence card is included in the information pack and is the first point of contact for the bereavement follow-up programme. This differs from a condolence card or letter that is sent out to relatives after they leave the hospital. The card offers a message of condolence, informs recipients that they will receive further contact in three months and provides contact details for the bereavement support team and the hospital chaplain.

There is currently no method for recording if the information pack and condolence card are given to relatives at time of death. The telephone questionnaire for relatives aimed to capture this information to give an indication of dose. Less than half of the respondents in the telephone questionnaire, 43.8 per cent, received the booklet, with 25 per cent unsure if they had received it or not. A small number were unsure if they had received the information, highlighting the difficulty with remembering events and retaining information at a stressful time. Slightly more, 56.3 per cent, received the condolence card, with two participants unsure.

The process is to include the condolence card with the information brochure, but there is a variety of staff dealing with families including medical and nursing staff and the card is sometimes given out separately. Multiple family members present at the time of death means that different people can take away different pieces of information.

Part of the criteria for answering the telephone questionnaire was that the participant had received the three-month follow-up information. Respondents' information from the telephone questionnaire shows that seven relatives in the November cohort did not receive the three-month follow-up letter, suggesting that external factors such as people moving house and failings in the postal system are factors in the dose received. The figures for dose received and delivered do not represent the full reach of the programme.

Giving information at time of death, although standard practice, relies on staff awareness and adherence to the process. However, pressure on staff made standard practice more difficult during the response to COVID 19. Time pressures, awareness of correct practice by visiting staff, access to stores (especially for COVID 19 isolation units) and the absence of relatives impacted on information given at time of death.

The implementation process was mixed, with problems outlined above. However, in comparison to the number of relatives receiving bereavement follow-up information, engagement with the intervention is extremely low. During 2019, eight relatives were supported by the bereavement programme, with the majority experiencing the death of a loved one in intensive care. All of them made contact after their three-month follow-up letter and seven had a meeting with a consultant and nurse. One meeting was with a consultant from another speciality.

During 2020, five relatives made contact, three prior to the COVID 19 pandemic. From those three, two were prompted by follow-up, one of which resulted in a meeting. One relative who had not received any follow-up information visited critical care and requested a meeting. The two relatives who made contact post-COVID 19 used the information from the condolence card and neither resulted in a follow-up meeting.

The lower response rates in 2020 can be attributed to the suspension of the bereavement follow-up programme between March and July. The programme restarted in August 2020 and has continued to be in place throughout subsequent COVID 19 peaks. Initially, there was a limited response, with only two calls by the end of 2020. However, between March and June 2021 there was an increase in requests for support. There is the possibility that the response to the pandemic and the isolating nature of lockdowns prevented relatives getting in touch. For example, one relative who made contact in April 2021 had been bereaved in early 2019. They stated that they waited as they realised how busy the staff would be responding to the pandemic.

In 2021, nine relatives were supported by the bereavement follow-up team. The method of contact was more varied, and four of the nine were not prompted by bereavement follow-up information. Several relatives had been bereaved during the period the programme was suspended. A number of bereavement follow-up meetings were initiated by the relative contacting consultants. This suggests reduced fidelity of the programme due to COVID 19.

In 2021, there were changes to how relatives interacted with the bereavement support team. There was an increase in the nursing staff providing support on the telephone. In addition, the generic email was used more frequently, and the first virtual meeting was carried out via Zoom. These changes show adaptations to the bereavement follow-up programme to improve fidelity. They are partly driven by COVID 19 restrictions but are also influenced by the increased experience of the bereavement team.

Overall, although the number of relatives making contact was low, the fidelity of the intervention was good with all the relatives followed up by the bereavement team. The analysis of in-depth interviews shows that for those relatives who contacted critical care the intervention was delivered as planned. The meetings were prompted by the bereavement follow-up programme. Three relatives requested a meeting after the three-month follow-up letter, and one immediately after the death using the information on the condolence card. The respondents describe the process of attending for a meeting. Collette talked about the condolence card given at time of death.

> It was like a card with the rest of the paperwork. Aye, that was vital, because I wouldn’t have known about that service …. Do you know what it was: I wouldn’t have wanted to contact you because I wouldn’t want to bother you.

This was a common theme, with all the participants stating that they would not have made contact without prompting from the bereavement follow-up programme. This insight is important as there is a consensus in critical care that families are welcome to return to meet with the clinical team. However, relatives are generally unaware that this is a possibility. From the participants’ perspective, the follow-up information gave them permission to make contact.

The bereavement follow-up programme aims to support the bereaved relatives and friends of loved ones who have died in critical care. The difficulty in assessing the reach of the programme is defining who is the bereaved. The death will affect many people including wider family and friends, but the bereavement follow-up programme is based on a single contact.

However, there is evidence that reach extends beyond the single contact. Over 60 per cent of respondents in the telephone questionnaire had shared the information with other family or friends. Information on the uptake of bereavement follow-up shown in table 12 demonstrates that over the last three years most meetings were attended by more than one person. Generally, there was a mixture of spouses, partners, siblings and friends.

Similarly, two of the meetings described in the in-depth interviews were attended by more than one person. One participant, Collette, was the deceased’s daughter, and the nearest/closest friend or relative was her mother, who did not attend the meeting. In addition, participants shared the experience of the follow-up meeting with other family members. The three participants who were spouses describe protecting their adult children from their grief experience but subsequently sharing information from the meeting with their family. Peter described sharing the experience with his grown-up children:

> They’re older children, but I had a meeting with them after it and told them, right, this is what happened, this is what they’ve said.

In contrast, Collette’s mother encouraged her to attend the meeting along with her brother to help them cope with the death of their father. This shows the grief experience of the wider family and the need for parents to continue to protect and support older children. Generally, grief is experienced in the context of the wider family and social networks, suggesting bereavement support can reach beyond those who engage with it.

In contrast, the challenges of family dynamics can prevent bereavement support reaching the intended audience. This is highlighted by a open response comment from the telephone questionnaire. This participant was responding to the question of whether they would have preferred a telephone call. They stated:

> I have three sons and three daughter in laws and they support me but I don't always tell them how I am feeling. I don't read the letters that come into the house so a telephone call would be better.

The comment is made by an elderly lady and indicates the need for multiple support formats to improve the reach of the programme. For this relative the family support network is a barrier, and a phone call would have allowed them to talk without the knowledge of their family. There is an element of unmet need because the invite was in the written format.

This respondent offers one opinion but there was a mixed response to the question of adapting the service to include a telephone call. This poses further questions about the acceptability and adaptation of the bereavement follow-up programme, discussed in Section 5.3.2.

5.3.2 Acceptability of Intervention Including Adaptations

The acceptability of the intervention was measured by the telephone questionnaire and by the in-depth interviews. The final section of the questionnaire aimed to target the acceptability of the intervention by asking participants about their opinions on the timing of the intervention, alternative methods of contact, and any interaction they had with other forms of bereavement support. The final questions were based on the overall feelings and acceptability of the critical care department maintaining contact.

Table 21 Timing of Three-Month Bereavement Follow-Up

Opinion on timing	Number of respondents	Per cent
I have no opinion on the timing	3	18.7
The right time	10	62.5
Not the right time	3	18.8

Table 21 shows respondents' opinions on the timing of the follow-up letter and card: 62.5 per cent felt that it came at the right time; of the 18.8 per cent that felt it was not the right time, two out of three respondents commented that they would have liked it earlier and one felt that the timing would depend on the individual.

Thinking about the timing of the intervention based on the needs of the individual is supported by the relatives who engaged with the programme. Both the condolence card and the three-month follow-up were prompts for accessing support. The participants in the in-depth interviews who made contact after the three-month follow-up felt that they needed this time to pass. However, Collette was prompted by the condolence card given at time of death. The immediate timing was appropriate as Collette's brother had not been present when their father died. Both siblings attended the meeting roughly six weeks after the death.

The respondents from the questionnaire had not contacted critical care. Their thoughts on making contact are shown in Table 22.

Table 22 Contacting Critical Care Bereavement Support

Making contact	Number of respondents	Per cent
I have made contact	0	0.0
I plan to make contact	0	0.0
I am still thinking about making contact	2	12.5
I would not find a visit helpful but may keep the details for the future	5	31.2
I would not find a visit helpful	6	37.5
Other	3	18.8

The majority of respondents stated that there was not anything preventing them contacting the bereavement team. The respondents who gave a reason said they were uncertain of what they would want and how it would be helpful.

Participants were asked if they would have preferred to be contacted by telephone. The responses were divided: 50 per cent said that they would not have liked a call, 25 per cent said yes and 25 per cent were unsure. This is comparable to previous opinion- and experience-based research on telephone calls. There were mixed feelings about the nature of a telephone call and the possibility that it might not be made at a suitable time to talk. Several free-text comments from relatives demonstrate the varied feelings about being contacted by telephone:

> A phone call is a one-off and it might not be the right time. A letter, you have the information and you have time to reflect on it.

In contrast the relative below stated they would prefer a telephone call as it would have taken the onus off them to make contact:

> I think a phone call for myself would be better as I would find it easier to talk rather than make contact.

This comment suggests an unmet need similar to that highlighted previously. For some people making initial contact is difficult, and multiple support formats would make the intervention more accessible. Participants were asked if they had sought support from other sources. Table 23 shows their responses.

Table 23 Accessing Bereavement Support from Other Sources

Source of support	Number of respondents	Per cent
General practitioner	2	12.5
Local community groups	0	0.0
Private counselling	1	6.3
Bereavement support organisations	1	6.3
Online support groups	0	0.0
No	7	43.8
Other (Please state)	7	43.8

Note: Figures do not add up to 100 per cent as participants were able to choose more than one option.

The free-text answers from the “Other” response were:

- Family friends/local community
- Family and friends
- Church friends
- Breathing Space (free and confidential telephone and web based service for people in Scotland suffering a low mood, anxiety or depression.

- Family/friends
- Family
- Family and friends

The majority of respondents had not pursued bereavement support from other health care or formal support organisations. Informal support by friends/family and the local community including church groups is the most common type reported in the free-text response. Despite this, the acceptability of bereavement follow-up was high with 94 per cent (n=15) of respondents stating that they felt critical care should contact bereaved relatives after their loved one has died. The mechanisms of change associated with this are discussed further in Section 5.3.

The intervention was acceptable among stakeholders. They all expressed the importance of offering families support, but the process of taking part in a meeting was more complex. The preparation and time burden of carrying out a meeting was a significant consideration in the process. Preparing for a meeting included practical aspects such as setting time aside and making sure their clinical duties were covered. Nursing staff on the bereavement team made practical arrangement for a meeting such as booking a room and liaising with family to arrange a suitable date and time. In addition, there was preparation involved in reading clinical notes. Along with the preparation came the anticipation of what the family would want and preparing for anticipated questions. Consultant F described:

> Just trying to get a feel for a lot of what happened and were there any challenges or how things went, and what might be the questions or thoughts or expectations for a meeting with the family.

Stakeholders describe the period before a meeting when they get together to discuss the case and plan for the meeting. Consultant E described this as a pre-brief that includes a plan and role allocation:

> So just a pre-brief, role allocation, and in that you can, between you, have a little bit of … then in that you've also got an opportunity just to have a rough idea how you're going to flow, and where your get-

> out clauses are, you know, clear points where it needs to stop, how you'd stop.

Similarly, the nursing staff prepare for a meeting with some of the same anticipation. Nurse C stated:

> I would try and talk to the nurses who were involved in caring for the patient. So, I try and go in knowing the story, rather than … like for the meetings I've done, I have always gone in knowing the story rather than going in cold.

These comments suggest a need to know the family story and clinical history but also to have a plan to negotiate difficult situations. This preparation along with carrying out the meeting poses a burden on the clinical staff's time. Nurse A and Consultant D described the time pressures associated with a meeting.

Nurse A:

> And I wasn't working that day. I came in on a day off to allow that time, because I think if I'd been at work, there's a lot of pressure to prepare mentally to give to a family and then to go back to work and just pick up where you left off.

And consultant D:

> But I mean, that's not particularly a quick job; that's to be done in quite a lot of detail.
>
> Timewise is really important, so it can't fit into a time slot that you think will fit into your day, I think it needs to be it goes on as long as it needs to go on.

Both consultants and nursing staff acknowledge that time is important. Interestingly, participants in the in-depth interviews worried about taking up too much of busy clinical staff's time; but time and being listened to was important to them. Peter described the importance of time and not being rushed:

> I felt if I wanted to just be in there for three hours, they would have sat there for three hours, it was like, know what I mean …. Twenty-minute meeting or half-an-hour meeting, you've got a meeting planned, that was it, know what I mean? It wasn't, you've got 15-minute booking or a 15-minute slot or a half-an-hour slot; you've got a booking, know what I mean?

Participants commented on the importance of there being no time restraints on the meeting. Reassuringly, the results of the semi-structured interview with stakeholders recognise the importance of putting an unquantified amount of time aside for families. This goes beyond what relatives expect but appears to be what is required.

Comments from consultant D suggest the need to be flexible with time. The length of meetings varies and is longer than stakeholders expect. Allocating time to prepare and carry out a meeting is a burden for clinical staff trying to fit it into their working week. For nurse A this was best achieved by arranging to come in on a day off. For nursing staff on duty, getting time away from the clinical environment is difficult. In addition, nurse A comments on how difficult it is mentally to return to a clinical shift.

In contrast the chaplain was less concerned with preparation and made no mention of burden on their time.

> I find it helpful to have quite a blank canvas so that our conversation takes us through it so that side of it, very comfortable with. That person could have thrown absolutely anything at me, and I might not have been prepared for it, but I'd be prepared for the fact that I might not be prepared for it, if that makes sense, because I think that that's a really important part of spiritual care. That's where it's maybe different to other forms of listening support is that I'm not trying to assess something or turn it into something. I'm really just there with what's heavy in their heart at that moment and sometimes that varies.

The above reflects the different focus of the chaplain's role. This contrasts with the clinical stakeholders' approach to a meeting. Rather than anticipating the reasons for a meeting and setting an agenda there is a focus on what is important to the family. This is perhaps to be expected, as the medical and nursing staff have a clinical focus with prior relationship and responsibility.

Complaints

Clinical stakeholders' prior relationship comes with a concern about complaints and being blamed for any perceived failings in clinical care. Nurse A described her feelings about a meeting:

> The doctor and I were a little bit apprehensive thinking, would they be upset with us, would there be a bit of blame? But actually there was no blame.

And consultant D when reviewing the notes for a meeting suggests that they were looking for reasosn the family might have for a meeting that were based around errors and failures. Howeverm they state that:

> There wasn't a big error or a failure to communicate or anything unusual.

The preparation is dominated by anticipating the reasons for the meeting, and in particular the fear of complaints. However, when stakeholders reflected during the research, they acknowledged that the meetings were not associated with complaints. Fear of complaints is more dominant in the stakeholders who had not attended a follow-up meeting. This is perhaps understandable, as their baseline experience for meeting families is often due to complaints. The complaints process can be complex and difficult as consultant B2 explained:

> I think people vary. It's very rare that you get a complaint about a single issue, you know. There's a fair bit, and I only see a fraction of stuff … Often it's a complex message you get which is that, you know, X and Y were fantastic but A, B and C were not and, you know, they may be things, they may be people, they may be events. … And often the complaint will include a face-to-face meeting. But generally it's

> at the service level, the lead for, you know, whoever the complaints come in to and I suppose it's a different … if they've been angry enough to put in a complaint or unhappy enough to put in a complaint I guess it's they're not quite on the same wavelength [inaudible 00:12:49] because it's viewed as being an adversarial … rightly or wrongly, it's viewed as being an adversarial chat.

It is understandable that stakeholders who had experienced meeting a family through the complaints process would be apprehensive about it. The experience of a complaints meeting described above contrasts with the supportive nature of a bereavement follow-up meeting. The experience of taking part in a bereavement follow-up meeting is discussed further in mechanism of change and intervention impact. The fidelity, dose, reach and acceptability of the intervention is discussed above. There are mixed results for the intervention based on fidelity, dose, reach and acceptability. The mechanism of change gives a deeper understanding of the intervention.

5.4 Mechanisms of Change/Intervention Impact

The mechanisms of change and intervention impact were primarily measured by the telephone questionnaire for relatives, discussed in Section 5.4.1, and the themes from the in-depth interviews with both relatives and stakeholders, in Section 5.4.2.

5.4.1 Relatives' Feelings and Opinions about Bereavement Follow-Up

Respondents were asked how helpful they found the NHS Greater Glasgow and Clyde's information brochure, *When Someone Has Died*, given at time of death. Of the seven participants who reported receiving the information booklet, all found it very helpful or helpful. Several participants who did not receive the information made comments in the free-text box regarding the need for information at the time of death.

> Older son found dealing with the death certificate. Difficult to get the information that he needed. More support or help with the death certificate.
>
> I would have liked information on how to arrange a funeral and pay for the cost of it when you are on benefits.
>
> Probably would have helped to have some practical information especially on all of the administration type things that you need to do.

Therefore, it is important that clinical areas find a process to give routine information to maximise immediate bereavement support. Similarly, participants were asked to give the condolence card a meaning rating. The rating is shown in Table 24.

Table 24 Condolence Card Meaning Rating

Response	Number of respondents	Per cent
Very meaningful	2	22.2
Meaningful	1	11.1
Somewhat meaningful	4	44.5
Not meaningful	2	22.2

The majority rated the card as meaningful to some degree, with 22.2 per cent rating it as not meaningful. None of the respondents reported using the information on the card and only three, 33.3 per cent, remembered that it stated they would receive further contact in three months. However, no one responded that they would rather not have received the card.

Similarly, participants were asked if they had used the information on the card sent out after three months. Respondents reported that they had not used the contact details or information on bereavement support in the card, but 56.3 per cent stated that they had kept the card, and over 60 per cent had shared the information with other family or friends. Over 80 per cent found the card and letter very helpful or helpful. Those respondents who did not find the card helpful, stated that they thought others might. From this point of view, they thought it could be useful.

Free-text comments from the respondents gave a deeper insight into the meaning of the intervention.

> I thought that it was very useful and meaningful and let me know that I was not forgotten.
>
> At least you had the decency to contact us.

This supports the change mechanisms of recognition of significant loss and non-abandonment depicted in the logic model. There was recognition that, even although the respondent did not take up the offer of support, it was essential to offer it in case someone else needed it. On this basis contact from critical care was felt to be worthwhile. One respondent simply said:

> I think what you are doing is a good thing.

Overall, the intervention was meaningful. Although relatives did not make contact, value and meaning were placed on being remembered. The analysis of data from the semi-structured interviews explores the experience and meaning of engaging with bereavement follow-up.

5.4.2 Relatives' Experience of a Meeting

The participants in the semi-structured interviews with relatives were initially asked to tell the researcher about the events that led their loved one to be admitted to critical care. For three out of the four participants there was a strong desire to tell their story. This element was evident throughout the research and appeared to be a feature of the bereavement follow-up meeting.

Critical Care Grief Experience and Their Story

Three of the participants had experienced a sudden and unexpected death with their relative spending less than 48 hours in critical care. However, unexpected death was also experienced by Brian, whose wife had a known cancer diagnosis and a longer length of stay. Brian's wife, during initial treatment for her cancer, experienced a cardiac arrest. Interestingly, he described the feeling of being stripped of time day by day as medical staff tried to prepare him for the worst outcome.

> So, that always was the most, it was the two biggest things for me, was that, the suddenness of it, you know, from November the 30th, which was the Thursday, the day they let her home, in the afternoon, until just what it was, you know. At that point, it was 12 to 18 months. And by, let's say, the first week in January, there's nothing else we can do.

Although his wife had a life-limiting condition with a prognosis of 12 to 18 months, Brian still describes the death as sudden. Sudden and unexpected death is based on the perception of the family rather than what the professional might consider it to be.

The traumatic experience associated with sudden and unexpected death was evident in all of the interviews. Throughout the interviews, participants replayed and talked about the events that led to the admission. This was particularly evident in the interview with Lucy, whose husband collapsed at home.

> Because when I was shutting my eyes at night it was just like flashbacks of him coming into the living room and talking about the football. And I'm thinking, for that five minutes – not even five minutes – if I had followed him into the room, would I have been able to save him? And then him lying in the bed and then the nurses, the doctors and the ambulance people working on him. And the noise and all that. That was all I heard.

In stark contrast to vivid memories, participants also describe poor recall of information, which is associated with denial regarding the severity of the illness. Poor recall and an inability to retain information generally led relatives to engage with bereavement follow-up. The reasons for a meeting are broken down into four themes.

Reason for a Meeting

Initially participants stated that unanswered questions and seeking clarification of events were the main reasons for contacting critical care. However, analysis of the data suggests the reasons for a meeting were more complex and often interconnected. The four interconnected themes are depicted in Figure 7.

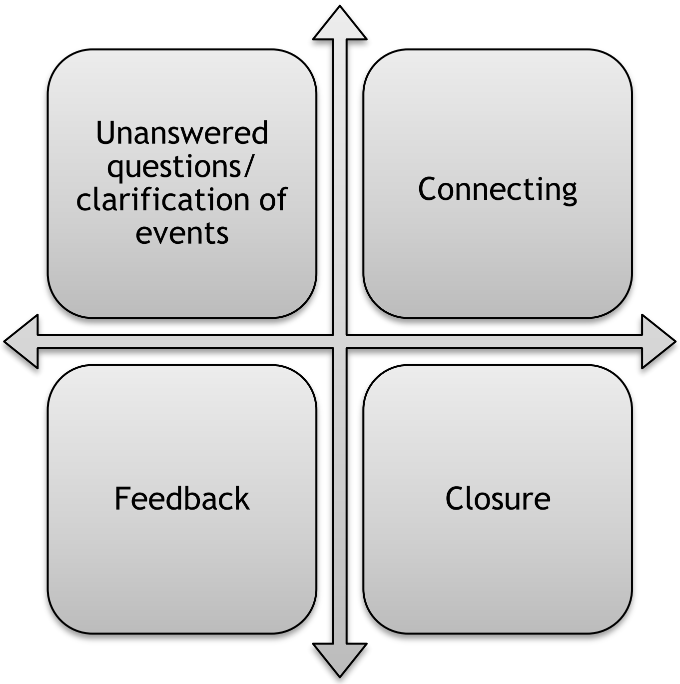


Figure 7 Reasons Relatives Attend for a Bereavement Follow-up Meeting

Connecting

As described above, relatives generally felt a need to tell their story. Part of this was the importance of physically connecting with the clinical team and the hospital environment. This is evident from Collette’s experience; she described the physical aspect of returning to the hospital and talking to the clinical team:

> I’ve got to be really honest with you, see to talk about my dad again and I know it’s traumatic and I know we’re talking about him going back into hospital, but see to listen to the doctor telling it, their way, and I just … it was … and he had a really calm and gentle voice when he was telling us, do you know what I mean? … We just … I know I just really appreciated listening to him and I, kind of, felt I was back there again. So, it was … the time spent with him was really nice, and once

> he had told us, obviously, about everything that had happened, that we showed him the pictures and stuff like that.

The desire to reconnect with the hospital, the clinical team and her father was a significant part of the meeting for Collette. She described the importance of sharing pictures of her father:

> Because I had brought a picture of my dad, because my dad at the end he was quite agitated, but my dad was such a happy, loving, funny man, but he was quite agitated at times and he was getting a wee bit annoyed and my mum was saying to him during it like, oh, don't get annoyed at the doctors, and he was going, I know, I know, I know, but … but we realised now my dad was just really seriously ill.
>
> You know what I mean, and, so for me to be able to go back, listen to that doctor, and then for me to then tell him, listen, this is my dad, and show him a picture, and say this is … so, it was lovely for me to be able to show a picture of him and just to show him … what a lovely person he was.

For Collette it was important to remember her father and share those memories with the clinical team, who had only met him as an ill and agitated man.

There was a general sense from all of the interviews of reconnecting with the clinical team. This was associated with the acceptance of the events that led to their loved one's death and came through addressing unanswered questions and clarifying events.

Unanswered Questions and Clarity of Events

Unanswered questions and clarity of events were common features. Peter described how the initial conversation with the bereavement team identified that he was struggling with the death of his wife and had many unanswered questions:

> And I had phoned them, and I think they actually realised that I wasn't actually coping, and I still had questions, which I couldn't ask

> at the time, because I couldn’t cope with it, and then it was arranged for the nurse that was with her and the doctor, it was the following week, to meet me in the actual hospital.

Although unanswered questions are a common reason given for a meeting, the issues that unfold during a meeting appear to be more complex. Often there are multiple subtle underlying issues that emerge. Clarifying events is a common theme that is partially related to unanswered questions. The need for clarity shows how much relatives’ inability to absorb information at this time impairs their understanding of events. The participants describe blocking and blurring of events.

Blocking difficult information is a significant feature for relatives. Brian’s wife had a cardiac arrest while being transferred from a specialist oncology centre to the Queen Elizabeth University Hospital. He described how his lack of understanding of his wife’s deterioration was impacted by not absorbing key information:

> The question was, how could it change so quickly? Now, I didn’t find out until that meeting that, and to this day, my sons differ, they say, no, no, they told us. But my wife arrested in the ambulance.

Lucy had a similar experience in the hospital but over a shorter timeframe. She described the first few hours after her husband was transferred to the Queen Elizabeth University Hospital:

> But for the first maybe couple of hours I was under the impression that xxx would have got better even though everyone else round about me knew that he wasn’t.

From the interviews there is evidence that blocking information and poor recall is a coping mechanism when dealing with a traumatic event. Relatives describe a blur along with hope that their loved one will get better. Peter described this in the comment below:

> At the time it was traumatic, didn't really take anything in, I've got to be honest with you, just didn't take it in.

He went on to describe how clarifying events at the bereavement follow-up meeting helped him understand events:

> [You think] I'll mind that, but you actually don't, and it was just nice to actually sit down in a sort of calmer atmosphere and they were sort of telling me stuff I didn't understand, actually put it in my sort of terms there.

This sense of peace and calm was common and all the participants described a feeling of closure and acceptance after the meeting. Participants recognised that this was not the end of their grief journey but they were able to accept the events around their loved one's death.

Closure and Acceptance

Acceptance came through answering questions and clarifying events. In addition, the participants had a sense of guilt and a need to be reassured that there was nothing more either they or the clinical team could have done. The reassurance gave them a sense of acceptance. This was particularly the case for the three participants whose loved ones had died within a very short timeframe. Lucy, Peter and Collette commented on the importance of acceptance and closure.

Lucy talked about her feeling of guilt and the need for reassurance that she had done all she could:

> Could I have done anything else? Was there anything that I should have asked that I never asked? So when I got all these answers back I said, well do you know what, that wasn't my fault. It wasn't my fault that he died.

Similarly Peter stated:

> This is something that helps me to … well, I mean, could I have done anything better, could I have done this, could I have done that? I got answers to that.

And Collette finds comfort from the fact that there was no more that could have been done:

> I know that sounds bizarre, but I could see my dad again, and I was like, do you know what, that's … there's nothing that was going to stop my dad from dying that day. Absolutely nothing.

Through acceptance came closure. Closure was consistently mentioned during the interviews. Answering questions, physically connecting with the hospital and clinical team and the reassurance that everything had been done brought closure. However, this was not an end to grief, but something that allowed the participants to move forward.

Peter stated:

> Closure – not closure, but that type of thing. Not closure of the full thing, but closure to my questions.

Collette described closure in relation to the suddenness of the illness and dying trajectory:

> I mean, just closure in terms of how quick he went into hospital and what had happened, because it was a bit of a whirlwind for us to be honest with you, but it brought closure to that to say, well, there was nothing that any of those doctors could have done that would have saved my dad.

Similarly, Lucy, whose husband collapsed at home, got closure from reassurance that there was nothing more she could have done. Brian, whose wife had a pre-diagnosed condition and a longer stay in critical care, described closure as a more gradual process:

> You know, a say, I got answers, I'm not saying that those answers made the loss of her any better, because I don't think there's any answer would make the loss of her any better.

Along with the relatives' need to connect and get clarity on events and closure was the desire for them to feed back to the clinical team. Meetings are a two-way process and potentially can provide valuable feedback and important learning points for the clinical team.

Feedback

The feedback was mainly positive, and participants had a desire to thank the clinical team for the care they provided and for all they had done. More negative comments were made cautiously by participants. They were careful to explain that they were not complaining or blaming. Collette describes regret that they had gone home, and when asked to return to the hospital she had not been given more time with her dad. In this meeting the consultant brought up regretting not letting the family into the room sooner. The fact that the doctor acknowledged and remembered this aspect of events was important.

In contrast, although Brian had more time with his wife, there was a burden that came from breaking bad news.

> It felt, when we were speaking to the doctors, and to the consultant, they were there when you needed them, but as time wore on, you only really seen them because they were going to tell you that, you know, instead of 18 months, it's now 12 months, instead of 12 months, it's nine months. It just felt as if, you got to a point where, I didn't actually want to see a doctor.
>
> Because I felt as if, if I had to see the doctor, it was just to give me more bad news.
>
> And I don't know whether that's right or wrong. I think it was just a case of, even though in the back of my mind I knew that she wasn't going to, you know, she wasn't going to survive this, I just still didn't want to hear that point of, I'm sorry, there's nothing else we can do.

Brian had a negative experience in how the clinical team communicated. This is partly due to his inability to accept the poor prognosis and in the final sections of the above part of the transcript he recognises this. However, this can be seen as a learning point for medical staff to re-assess how they communicate at such a difficult time.

Following the reasons for a meeting, participants went on to describe the significance of the meeting including sharing the experience with the wider family.

Significance of a Meeting

The meeting was a significant step for relatives. They described an immediate benefit after engaging with bereavement support. Peter, who returned for a meeting after the sudden death of his wife, stated:

> But definitely if I hadn’t come back, to tell you the truth, I don’t even think I would have been here.

For Peter the experience of a meeting appeared to be lifesaving. The bereavement team had arranged for Peter to meet with the chaplain immediately after the meeting with the clinical team for ongoing support. He continued to receive listening-ear support for a period of six weeks. The importance of ongoing support from the chaplain is highlighted by the statement below

> I’d finished that meeting with them, there was … immediately after that I was meeting with the chaplain, and xxx was absolutely wonderful, xxx was absolutely great, absolutely … five or six meetings with them.

Lucy describes a similar life-altering experience after a bereavement follow-up meeting. Prior to the meeting, Lucy replayed the events of her husband collapsing at home and was unable to sleep. During the interview she stated how she began to remember more positive end-of-life experiences from the time in the ICU.

> But it wasn't until I remembered them putting the wee bear on xxx's thumb and I remembered them doing all that …. I remember them cutting a bit of his hair … I hadn't remembered all that before.
>
> And that night when I shut my eyes I could still only see what had happened that night. But even within a couple of nights, all I was remembering then was xxx with the tubes in and the wee bear on his finger.

The meeting enabled her to move on from reliving the traumatic event and allowed her to begin to remember other parts of the critical care journey. Overall, participants describe the meeting as vital in their ability to move on and live with their loss.

5.4.3 Stakeholders' Experiences of Bereavement Follow-Up

The stakeholders' experience of taking part in a bereavement follow-up meeting changed their view of the expectation of relatives. As discussed previously the clinical team have a prior relationship with and responsibility for the patient and there is a concern around complaints. However, the stakeholders commented on the unexpected reasons for a meeting and the importance of picking up on this.

Unexpected Reasons for Meeting

While answering questions and clarifying events was important, the ability to listen and decipher unanticipated reasons for a meeting was vital. This is expressed by consultant D who described meeting with a family who had a lingering feeling of guilt:

> And so I think it was a bit of a learning experience somewhat for me in that you have to get to the deeper issue and once you find it that's what the conversation has to be around. 'Cause it's not just about going and telling facts as you want to present them, it's probably about finding the issue that is troubling the bereaved relative and then dealing with that …. So I don't think that meeting would have been anything like as useful to them if I'd been there on my own …. The expertise in the meeting was to pick up on the not explicitly said

> but the kind of hinted-at guilt feeling that was obvious … I could see how I could have missed that and gone into explanations.

Consultant D highlights the ability of the nurse to pick up on the underlying issues. The medical staff take on the role of explaining clinical events, and often the role and skill of the nurse in the meeting is as a listener. Nurses A and C described this.

Nurse A:

> I think we pick up on feelings or emotions that aren't directly being acknowledged, so almost saying, you sound …. There was one meeting I did where it was with a husband who had lost his wife to suicide, and I remember specifically at one point saying to him, you sound incredibly hurt, and he just was like, yes, and then went on to talk about how he was feeling.

Nurse C:

> … power of using silence and the power of really listening. So that … I felt that really helped me in my skills as a professional. And that … you know, was able to put it onto the, of, end-of-life bereavement communication. And I think most of that is about really listening and being open to hearing what the family are trying to tell you or trying to ask.

However, there was also shock about the level of anger expressed by relatives, even although it was not directed at the clinical team. Consultant E stated:

> And I felt I uncovered a guy who was deeply troubled, very angry, and really not moving on in the grief process.

Although anger was not directed at the clinical team, it was still difficult for the stakeholders deal with. The emotional burden of carrying out a bereavement meeting was a common theme.

> And I think the emotional burden is something that, you know, we need to recognise, that it's putting on the consultants to do these meetings, and the nursing staff that are involved as well. Because they are quite emotionally draining.

Meetings were viewed as a positive experience, but the emotional burden expressed above by consultant E was iterated by the clinical stakeholders. They experienced both physical and mental fatigue. Stakeholders felt the need for a debrief, and worried that they did not have the skill or resources to support people. This is evident from consultant E who carried out the first meeting that took place after the programme was set up:

> And we had a kind of folder of box-file stuff, but it didn't feel very organised. And I'm not sure, I suspect we probably did help him, but at the end of it, I don't think we had helped him, and we both felt quite shaken up by the experience.
>
> I think that's the, where I felt least, I felt at sea with that interview that we had, is that I felt like I didn't have the skill set that this man needed.
>
> But like a lot of the sort of follow-up stuff, I worry about what you uncover. And I only feel comfortable if I know that, I know what to do with what I uncover.

After the meeting the consultant took the time to share her experience with the bereavement group. Several learning points and changes were implemented that allowed the programme to develop. Improvements suggested by the stakeholders are discussed at the end of this section.

5.4.3.1 Feelings about Bereavement Support

For those consultants that had not taken part in a meeting, their frame of reference came clouded in part by previous experience of complaints. However, they all thought that bereavement support was important and would be keen to support meeting a family. Consultant A expressed concern about the current level of support offered to bereaved relatives immediately after death. This causes anxiety for consultants who are stretched and busy with clinical duties.

> And I think it’s one of the things I’ve been quite anxious about, that we don’t necessarily … The current model, I think we struggle to support families in the immediate period after a bereavement … I think that’s my anxiety is that I don’t know enough about what happens or what sort of support they get in the community to be reassured that they’re well supported.

Similarly, consultants B2 and C expressed their perception of unmet need after families leave critical care.

Consultant B2 stated:

> Most of the time we don’t see the end of their grieving process because it’s only just started, but we’ve wrapped things up.

And Consultant C:

> But there are sometimes family members that their situation is just a bit more complex. For example, if they’ve got young kids or there’s other issues at home where you need to … or you as a doctor looking after that patient and have an interest in their family, almost like there should be somewhere that you could refer them to and have confidence that they’ll get picked up.

There is a genuine sense of compassion and concern for relatives. This group of stakeholders recognises that although their job is finished, bereaved families are entering a world where there is limited support. Three consultants – A, B2 and C – had taken part in meetings with bereaved families outwith bereavement follow-up. They all felt that being supported in those meetings within a formal structure would have been helpful. Consultant C expressed this:

> Whereas, if there was actually a proper process that you knew … again like having time set aside and there was the backup of having nursing

> staff there as well and actually a pre-designated location, it would be private … If you knew there was actually a process and the families who were coming through that might, you might identify need bereavement follow-up, to know that actually you can almost slot them into appointments and a time. Even the meeting itself would be minuted and that you would have backup after the meeting as well.

Formal process and governance when meeting with bereaved families was deemed important along with support from nursing staff and help in practical matters such as securing a room. The importance of a formal process was recognised along with the barriers to bereavement support provision and suggested improvements. These are considered in the context of the critical care department, the environment and organisation. This is followed by a discussion about the impact of wider social and political aspects.

5.5 Context

5.5.1 Critical Care Department

The context of the setting can impact the reach of the intervention. The Queen Elizabeth University Hospital covers a large geographical area, with some relatives living a distance from the hospital; this is even more so with the introduction of the major trauma centre. Returning to meet with the clinical staff as part of the bereavement follow-up programme may not be possible for those living further away. However, adaptations including telephone support and virtual meetings introduced during the COVID 19 pandemic could provide solutions to this.

There may be different needs between the high dependency and intensive care units. Mortality figures are higher in ICU and MHDU. The majority of relatives engaging with bereavement follow-up were from intensive care or medical high dependency and there may be an argument for targeting the intervention within the department. However, the individual units do not work in isolation and there is a need to understand the flow of the department.

Disruption to critical care during the pandemic along with reorganisation associated with the major trauma centre blurs delineation between intensive care and high dependency. There is movement across the critical care floor with patients transitioning between intensive care and surgical and medical high dependency. The three hybrid units offer a mixture of intensive care and high dependency, with patients in one unit transitioning between intensive care and high dependency.

Perhaps not insignificantly, given their lower mortality rate, there have been meetings with relatives from SHDU. Planned surgical admissions can also result in unexpected death. Given the positive outcome demonstrated from meetings, it would seem important to continue to offer the programme across the critical care floor.

5.5.2 Critical Care Environment

The critical care environment and its burden on families was a recurrent theme. This is a highly technical and clinical environment. The high mortality rates, particularly in ICU, the trajectory of dying, complex decision-making and withdrawal-of-treatment decisions were highlighted by stakeholders as impacting on the bereaved families.

Despite the environment, comments from the open-response option at the end of the telephone questionnaire were from relatives expressing appreciation for the care they received. These comments demonstrate the importance of good communication and compassionate care throughout the patient’s journey and during end of life. The way that people were treated was important.

> They couldn’t have been better and the way they treated us was good.

That importance of staff supporting families at end of life was expressed.

> I thought the people in ICU were fantastic. Couldn’t have done more to help us. And that really helped at the time.

The comment below indicates that the experience of critical care had been traumatic but was made bearable by the way that the relative had been supported. Dignity, compassion, communication and information were key.

> The way we were dealt with in critical care under such horrible circumstances was great. The way the staff dealt with xxx with dignity and compassion, we couldn't have asked for any more. I was kept up to date at every step and there is no more information that I would have wanted.

And a general feeling of support from the staff was expressed.

> At the time the staff were amazing and provided so much support.

> Almost immediately after xxx went into the hospital the support was good.

A mother speaking about the death of her son described the elements that made the experience of bereavement in critical care better:

> No, I think the support in the hospital was wonderful. They put xxx in a private room and allowed us to be with him and I felt so grateful for that especially during COVID when families were not always with each other. Even the consultant surgeon came and spoke to us and I thought that was really great. I got to go in the ambulance with him. I don't know how I would have coped if I had not been able to be with him.

The importance to the mother of being with her son throughout the journey is evident along with privacy and good communication at end of life. Many of the free-text comments relate to the importance of good bereavement care prior to the patient's death. The responses highlighted common elements from the literature including good communication, privacy, dignity and compassion.

5.5.3 Organisational

The bereavement programme was established from the bottom up. While stakeholders commented on the passion and commitment this required, they also expressed concerns about the limitations. The bereavement group commented on their passion for bereavement support. Nurse C stated:

> The idea that there are people who haven't asked to meet us, but may still have these questions that are haunting them, I think is a horrible thing to think of, and I think that's why we all believe in what we're doing.

The consultant in the group had been approached to provide medical support to the team. They supported the governance of the intervention and liaised with other medical staff to organise meetings. In contrast, the nursing staff had a more invested interest as they had led on the development of the programme. There was a sense of professional achievement and pride based on the commitment and care they put into it from inception to delivery. The comment from nurse A sums this up:

> It's an absolute honour to have been part of a group that has considered this group of people, this vulnerable group of people. And to acknowledge that what … one of the life events that they have to go through and it's given me a lot of job satisfaction and personal satisfaction.

Along with professional achievement, there was an element of job satisfaction and the opportunity for development beyond what was possible in the traditional nursing role.

Despite the commitment of the nursing staff there was concern about the emotional burden of the project and the continued motivation and investment of their own time along with concern about burnout. Nurse C commented:

> You have to give quite a lot, we've found … You have to give quite a lot to make the bereavement service work and to make the full

> service work, and I think if you don't have that then there is absolutely no point in saying you want to be part of the service.

And nurse B stated:

> Motivation would be an issue because we are tired, we're stretched.

The commitment of the bereavement group and concern about burnout was also commented on by other stakeholders. Consultant C stated:

> I think that the team is doing an amazing job with limited resources that you've got, but I definitely don't want you to burn out.

The context of the bereavement follow-up within the current organisational structure was evident in the stakeholders' discussion about barriers to bereavement follow-up and potential improvement.

Barriers and Improvements

Lack of time and resources were the most frequently mentioned barriers to the provision of bereavement follow-up. Suggested improvement focused on funding to achieve allocated non-clinical time, and administrative support. There was a need for greater governance and structure for meetings. Suggestions from the interviews were:

- A core group of consultants with a specific interest in bereavement follow-up
- Debrief sessions
- Links with community support organisations
- Ability to refer to other professionals, especially counselling and psychology
- Action points from meetings with completion deadlines
- A follow-up call after a meeting
- A second offer of support after initial three-month follow-up.

The discussion above places bereavement follow-up in the context of the critical care department, the environment and the organisation. The social and political context that the intervention operates in had a significant impact on bereavement follow-up at this time.

5.5.4 Social and Political Context

The bereavement follow-up programme started in 2018, but the evaluation of the intervention was carried out during the COVID 19 pandemic. Considering bereavement follow-up in the social and political context of the pandemic is important. The impact of the pandemic is a common thread running throughout the results, with significant impact on the delivery of the intervention and the evaluation.

COVID 19 had a major impact on the critical care department with fluctuating demands on capacity and peaks in mortality figures. There is evidence that the pandemic affected the fidelity of the bereavement follow-up programme. Relatives contact details were more thouroughly collected pre pandemic, there was reduced engagement with the programme and there were changes in the pattern of engagement post pandemic. The effects on staff and society were evident from stakeholder interviews and relatives' data.

The stakeholder interviews took place at the end of 2020 towards the beginning of the second Scottish lockdown for COVID 19. The stakeholders reflected about their experience of the pandemic and the significant pressures this placed on the ability of staff to care for patients. In particular, communication with families was more difficult. Most of the communication was via a daily telephone call undertaken by the medical staff. This differed from normal times when nurses at the bedside would carry out most of the day-to-day communication. The consultant group commented on the burden of communicating with relatives and the loss of support from the nursing team.

The impact of the pandemic on the experience of bereavement can be seen from a comment made by a respondent in the telephone interviews. They expressed a desire to have earlier contact from critical care after their loved one had died. More specifically they stated:

> At the time the staff were amazing and provided so much support. But afterwards it would have been nice to hear from critical care and I would have found it useful sooner. I'm not sure what they could offer but there would be a sense of comfort because everything was done over the phone and even when we visited everyone had masks and gowns and gloves on. The reason because it is critical care, and the situation is so unique. I had never experienced anything like intensive care or the pandemic and I feel that only the critical care staff would understand. I have a fear that a counsellor would not understand what I have been through as it is such a traumatic and unique situation. I think the critical care staff should work with counsellors to explain what families have went through.

This comment is specifically related to a bereavement from COVID 19. The absence of in-person communication, the barrier of personal protective equipment and the trauma of the overall experience is evident. They felt that staff from critical care would be in the best position to understand and support them after the death of their loved one from COVID 19.

This project was carried out during unprecedented times. In 2019 when the protocol was being written no one could have predicted what the following two years would bring. COVID 19 has long-reaching implications for both bereaved relatives and critical care staff that are probably yet untold.

Considering the context is important for the analysis of the results of the process evaluation. The complexity of a large critical care department, the influence of organisational and resource barriers, and the social and political context that the programme is set in are all important factors.

5.6 Chapter Summary

Chapter 5 presented the results of the process evaluation. Key information from each data collection strand were outlined along with an overview of the results in Table 8. The results from each data strand were then integrated to answer the questions that related to intervention implementation and acceptability, mechanism of change and context. Chapter 6 discusses these results.

Chapter 6 Discussion

This chapter will discuss the results of the process evaluation. The strengths and weaknesses of the methods are examined followed by a statement of the main findings. The results are discussed in relation to the research questions that were generated from the process evaluation logic model and domains. They are considered along with evidence from the wider literature. Chapter 7 offers conclusions and recommendations for the programme, the critical care community and future research.

6.1 Strengths and Weaknesses of Methodology

The study followed the MRC guidelines for carrying out a process evaluation. Moore et al. (2014) outlined the methods for a process evaluation including the need to examine existing evidence, develop a logic model and research questions, design and conduct the study, and analyse and report findings. Outlining the strengths and weaknesses of the study design in relation to these guidelines helps frame the discussion of the results and guide directions for future research and practice.

Evans et al. (2015) suggested that a systematic review of the evidence base is essential for pragmatic process evaluation of existing interventions. This study started with an integrated literature review that was carried out with systematic rigour. The review highlighted that research specific to bereavement follow-up was limited, with no current studies in the UK. Therefore, a key strength for this project is that it offers an evaluation of a current bereavement follow-up programme in the UK, filling a gap in research and knowledge. The evaluation is important for the development of the current programme and helps inform and guide practice for the wider critical care community.

The examination of the causal assumptions and the development of a logic model were carried out retrospectively. This is not the ideal scenario for intervention design, but the researcher was open about the programme being driven by experience and common sense rather than theory and research. Guidance for this situation states that the development of a logic model is important to define the intervention’s causal assumptions and allow external scrutiny (Moore et al., 2015). Furthermore, Evans et al. (2015) support process evaluations of existing interventions, arguing that they help maintain scientific rigour and support a more cyclical transfer of knowledge between research and practice.

Developing the logic model was an important step and helped form the research questions and data collection methods. The mixed methods design uses quantitative data from existing information, a questionnaire for relatives and qualitative interviews with stakeholders and relatives. A key strength of the study is its success in engaging with bereaved relatives and stakeholders. The integration of the results from the mixed methods design has been particularly important for this study. Quantitative data alone shows low numbers of relatives contacting critical care; but the telephone questionnaire and qualitative interviews with relatives give a deeper understanding of the mechanism of change of the programme and the benefits to recipients.

However, the study has several weaknesses. As a small, single-centre study it has the limitations of similar pilot studies. It has small participant numbers and is arguably contextually bound with limited scope for generalisation. There are limitations in the study design principally based on resources, staffing and the relationship of the researcher with the study. Guidelines for a process evaluation recommend adequate staffing and resources with sufficient expertise and experience. Ideally, staff should be from a range of disciplines with expertise in qualitative and quantitative data methods. This project was carried out by a single researcher rather than a research team. The researcher is a novice and lacks experience in study methods. Moreover, they are part of the bereavement team that implemented the intervention in critical care.

The inexperience of the researcher was mitigated by support from experienced supervisors and research training, outlined in Chapter 4. The study was designed with input from the bereavement team, lead clinicians in critical care and a public engagement representative. However, they are not independent from the intervention team and this increases the possibility of bias. Their pre-existing relationship with stakeholders potentially could have encouraged consultants who are in favour of offering bereavement follow-up to volunteer to participate.

In addition, exclusion criteria for the project meant that the researcher's dual role prevented them inviting all the relatives for interview. This diluted the pool of possible participants and restricted recruitment to the study. The recruitment of participants from surgical high dependency and medical high dependency would have given a better insight into the experience of bereavement follow-up across critical care, allowing better judgements to be made on the influence of clinical context.

The full proposed evaluation was not carried out due to the timeframes. In particular the project was hindered by the COVID 19 pandemic. Applications to the University of Glasgow's ethics committee were stopped between March and June 2020, but more significantly the bereavement follow-up programme was suspended for the same period. The qualitative analysis of meeting notes would have given some insight into the reasons for meetings across the critical care floor, and the staff questionnaire would give an understanding of the staff's process implementation knowledge.

However, the questionnaire and the semi-structured interviews were carried out over a relatively short timeframe between October 2020 and April 2021 as per MRC recommendations. Adaptation to the bereavement follow-up letter was required to reflect restrictions for COVID 19, and routine problems with process were corrected; for example, reminders for staff to ask for contact details have routinely been placed on safety briefs since the programme started. The overall influence of the researcher on the programme at the time of the study was minimal; results from the evaluation as they emerged were not acted upon and did not skew data collection.

Overall, the findings of this process evaluation are conflicting. Moore et al. (2014) stated that interventions may have limited effects due to weaknesses in their design or because they are poorly implemented. Alternatively, positive outcomes can often be achieved even when the intervention is not delivered as planned. This study identified issues relating to process implementation and organisational barriers. Acceptability was good for stakeholders and relatives but possible adaptations to the programme were more difficult to evaluate. The results for mechanisms of change gave a greater depth to the findings of the process implementation data. The following discussion focuses on examining the results in relation to the research questions and existing research.

6.2 Answering the Research Questions

6.2.1 Intervention Implementation and Acceptability Questions

Descriptive quantitative process data aimed to capture fidelity, dose and reach to examine if the intervention was delivered as planned. Overall, the fidelity of the intervention was good but there were issues with implementation relating to the single point of contact, the collection of contact information and the process of giving information at time of death.

There is no reliable way of recording if information, including the condolence card, was given to relatives at time of death. The questionnaire indicated a dose delivered of less than 55 per cent for the bereavement brochure and the condolence card, and highlighted that information usage was low. The low usage of information is comparable to other studies (Santiago et al., 2017; McAdam and Puntillo, 2018). However, feasibility of information giving in other studies is generally much higher at 80–100 per cent, suggesting issues with the process. In particular this may have been significantly affected by the absence of relatives during the pandemic (Santiago et al., 2017; McAdam and Puntillo, 2018; Erikson et al., 2019).

Similarly the process of giving the condolence card either along with the brochure or separately at time of death had an implementation rate of 53 per cent compared to 79 to 100 per cent in the studies where the condolence card is posted to families (Santiago et al., 2017; Erikson et al., 2019). The lower implementation rates are linked to the assumed mechanisms of change for the condolence card in this study, and are discussed further in Section 6.3.2. However, this highlights previous stated difficulties of making comparisons between studies when there is lack of consistency in the design and delivery of interventions (Coombs et al., 2017; Mitchell et al., 2017; Egerod et al., 2019; Fridh and Akerman, 2019).

The implementation of the follow-up letter and card sent after three months relies on information being recorded on the bereavement spreadsheet. The recording of deaths was generally good, with missing data mainly caused by gaps in clerical support. However, incomplete or missing contact information for the nearest/closest friend or relative was a significant issue. This is not unique. Several of the research studies looking at either telephone calls or posting information highlighted issues with incomplete or inaccurate data (Downar et al., 2014; Kentish-Barnes et al., 2015a; McAdam and Puntillo, 2018; Erikson et al., 2019; Cooper et al., 2020). In addition, response information for the telephone questionnaire suggests that the dose received was compromised by factors outwith the organisation’s control relating to the postal service and nearest friends or relatives changing address.

The above may seem simple process problems but they affect the fidelity of the intervention by compromising dose and reach. Process issues require careful consideration when looking at ways to improve both information gathering and alternative methods of contact. Interestingly, during COVID 19, due to the restrictions in place for visiting and changes to the process for death certification, there was greater focus on collecting telephone numbers and email addresses. The adaptations in communicating with families were unrelated to bereavement follow-up but may provide solutions to improving the fidelity of the intervention through using alternative contact methods.

For those relatives that did engage with the programme, the process worked well. The bereavement team returned calls and replied to emails, and where necessary arranged meetings. The programme naturally adapted to accommodate virtual meetings and the nursing staff offering support over the telephone. This is in conjunction with more referral to bereavement support organisations and to the hospital chaplaincy service. At departmental level, bereavement follow-up has become more established with stakeholders referring relatives for support. Adaptations were partly in response to COVID 19 but were also due to the increased experience and confidence of the nursing staff. Fidelity in this part of the process is important as dissatisfaction with the condolence letter in the RCT by Kentish-Barnes (2017a and 2017b) was associated with offers of support being unmet.

Overall, the acceptability of the bereavement follow-up is high, with 94 per cent of respondents from the telephone questionnaire stating that they thought critical care should contact bereaved relatives. The method and timing of the contact was acceptable with limited variations suggested. In general, this is in keeping with the research which shows that relatives appreciate contact (Kock et al., 2014; Kentish-Barnes et al., 2015a; Santiago et al., 2017; McAdam and Puntillo, 2018; Erikson et al., 2019; Laurent et al., 2019).

The suggested adaptation of a telephone call was met with a mixed response similar to that found in the study by Erikson et al. (2019). Both studies are opinion based and highlight that respondents were uncertain about the timing of a one-off telephone call and unsure how a call would be helpful. However, this could be seen as contradictory when considering the research project. The questionnaire was carried out on the telephone and, beyond answering questions, relatives were generally keen to talk about their bereavement.

The larger research studies by Kentish-Barnes et al. (2015) and Laurent et al. (2019) looking at the use of telephone calls in bereavement research showed a more positive outcome with relatives suggesting that it was a desirable method of support. However, as stated in the literature review, it is difficult to compare the larger research studies with opinion-based research. The larger studies were carried out over a period of time, and participants had agreed to take part and were expecting the call. The conflicting results suggest a need to better understand the optimum process for a bereavement follow-up telephone call including the intended aims and outcomes.

The process of arranging and carrying out a meeting was acceptable to stakeholders. The consultant group commented that the additional support, structure and governance were helpful when compared to their experience of other ad hoc meetings. Acceptability and willingness to support bereavement follow-up among the stakeholders were high. However, the lack of resources and formal support for the programme meant that balancing with clinical time pressures was difficult. In addition, there was an emotional burden associated with offering bereavement support that was compounded by a lack of time to debrief.

The study by Downar et al. (2014) found that there was a desire among clinicians to support bereaved relatives and the study by Kock et al. (2014) showed that the presence of a clinician to answer clinical questions is important. However, the results of this study suggest a more complex relationship between the participants in a meeting. Often there is disparity between what consultants perceive the needs of relatives to be and what relatives want. The in-depth interviews show that families gain significant benefits from meetings and yet engagement with bereavement follow-up is low, indicating shortcomings in the process, resourcing and organisational structure of the programme. Examination of the change mechanisms gives a deeper understanding when evaluating the complexity of these results.

6.2.2 Mechanisms of Change

The contrasting results make it difficult to pick apart the mechanisms of change of bereavement follow-up. The key mechanisms of change outlined in the logic model were recognition of significant loss, non-abandonment by signposting and offering ongoing support, and providing an opportunity to have questions answered and events clarified.

Overall, the results from the telephone questionnaire with relatives identified that bereavement follow-up was important regardless of whether the information is used or recipients contact the clinical team. The results support the change mechanism of recognition of significant loss and non-abandonment, similar to those identified from research studies in the literature review (Kentish-Barnes et al., 2017b; Santiago et al., 2017; Erikson et al., 2019; Kentish-Barnes, 2019). Relatives reported that they wanted contact from critical care, that they found it meaningful and that they felt they had not been forgotten.

The condolence card was rated as meaningful with recipients happy to receive it. However, the condolence card differs from those described in the pilot studies and the RCT in France (Kentish-Barnes et al., 2017a). The condolence card in this study was given along with an information brochure, was not handwritten or signed by staff and had the practical aim of providing contact details and informing families that they would be contacted again in three months.

Limitations with the implementation process discussed earlier are interlinked with the aim and assumed mechanism of change for the condolence card. There was poor recall among participants that the condolence card stated they would be contacted again in three months. From a mechanism of change perspective, the condolence card was less successful as an information tool.

The analysis from the qualitative interviews with bereaved relatives indicated that they had poor retention of information and recall of events at time of death. This difficulty in remembering events is supported by a small number of respondents from the telephone questionnaire who were unsure if they had received information at time of death.

Problems with information giving are not unique to this study. McAdam and Puntillo (2018) achieved better implementation rates but identified that the information was poorly used. However, the studies by Santiago et al. (2017) and Hewison et al. (2020) suggest that information giving is an important element of support for relatives; and those respondents that did not receive information at time of death in this study stated that it would have been useful.

For some families in this study the condolence card given at time of death was a trigger to engage with the bereavement follow-up programme. Information giving at time of death has a mixed response and is perhaps questionable beyond a source of reference, but this will depend on the way the information is given, the individual receiving it and the needs of wider family and friends.

The letter and card sent out after three months differ to the condolence letter used in the RCT (Kentish-Barnes et al., 2017a). It is sent much later and although offering condolences its primary aim is to provide ongoing bereavement support information and offer an explicit invite to contact critical care. However, a key question for the process evaluation is why the uptake is so low.

Over 50 per cent of respondents reported keeping the letter and card, supporting the simple change mechanism of non-abandonment and signposting.

However, consideration needs to be given to possible gaps in how the offer of support is made and the mechanisms of change for bereavement follow-up. Respondents from the telephone questionnaire suggest that they were unsure of what they would want from critical care, and there was evidence that families are supported within their own community. However, there is possibly unmet need created either by the medium of a letter or the way the letter offers the support.

The suggested adaptation of a telephone call was met with a mixed response. Downar et al. (2014) and Santiago et al. (2017) both highlighted the need for diversity in bereavement follow-up to meet the needs of the individual. The mixed and often conflicting results for the methods of bereavement follow-up in this study indicate that a range of tools would be beneficial to meet different needs.

Earlier researchers suggested that screening for those at high risk of complicated grief symptoms and psychiatric disorders is needed to target interventions (Anderson et al., 2008; Siegel et al., 2008). Erikson et al. (2019) state that a risk assessment screening tool would help target the implementation of telephone calls. However, there are common themes identified from this study and from the research of a simple desire for support and to not feel forgotten. The mechanisms of change highlighted from this study are complex and targeting intervention delivery with the use of screening tools may risk missing the simpler benefits identified.

Bereavement follow-up research in critical care is criticised for being culturally and contextually bound, and Efstathiou et al. (2019) argued that studies are small with limited scope for generalisation. They suggested that the RCT by Kentish-Barnes et al. (2017a) is the only study with the potential for generalisation but even this is questionable based on cultural limitations (Efstathiou et al., 2019). Yet, Kentish-Barnes (2019) admitted that the RCT was perhaps flawed; she argued that the wrong outcome measures were used and suggested looking at the broader experience of families as opposed to grief outcome measures.

Examining the broader experiences of families is supported by the results of this study. Significant benefits are identified from the qualitative interviews with relatives who had attended a bereavement follow-up meeting. Although not everyone will want or need to contact critical care, attempting to close the engagement gap could potentially support more bereaved families.

Pattison et al. (2020) stated that options such as family meetings are generally focused on event review. The more targeted study by Kock et al. (2014) found that the majority of respondents wanted meetings to continue and that the presence of the physician was important. However, the results of this study show that a meeting with bereaved relatives goes beyond simple event review. This is a key finding of the process evaluation especially when compared to other pilot studies that mainly capture feasibility, acceptability and opinion-based evidence. The qualitative interviews with relatives showed significant benefit from engaging with the intervention that went beyond the proposed mechanisms of change of answering questions and clarifying events.

The qualitative interviews with relatives identified the deeper experiences of having a meeting with the clinical team. Relatives had poor or absent recall and the outcomes of attending a meeting included closure and having their own feelings of guilt assuaged. Significantly, and despite event clarification, there was a general need to talk, reconnect with the clinical team, be listened to and tell their story.

Moreover, after a meeting, relatives were able to share the experience with their family. Relatives described being able to move on in their grief journey. The meetings alleviated the experience of trauma, and relatives expressed that the experience was both life changing and possibly lifesaving. These findings are more in keeping with therapeutic targeted studies such as the storytelling interventions by Schencker et al. (2015) and Barnato et al. (2017), which were feasible and acceptable, and alleviated grief symptoms.

The results from interviews with stakeholders who had attended a meeting highlighted that the experience for the clinical team was complex. Stakeholders reported unexpected reasons for a meeting, while their concerns about complaints or the apportioning of blame were largely unsupported by the study.

Alternatively, participating in bereavement support had benefits for the clinical team through feedback and learning from the experience. Relatives wanted to thank the clinical team, but also provide constructive feedback to help improve others' experience.

Stakeholders identified the different roles of professionals in a meeting. The role of the nurse as a listener was important in identifying the subtle needs of families. Alternatively, the chaplain viewed bereavement support as integral to their role; their lack of clinical involvement allowed them to provide more emotional support for bereaved relatives. Downar et al. (2014) suggested that the presence of different professionals and their different roles can be helpful to support different needs. This study highlighted a gap in what the clinical team perceive the needs of relatives to be and what relatives actually want. Identifying this gap helps inform practice and validate the role of other professionals in bereavement follow-up

Understanding the impact of context on the study is necessary to answer the research questions fully. The context of the intervention will influence and be influenced by the intervention, and is necessary when considering the complexity of the process evaluation results. The organisational, social and political context that this process evaluation is set in has significant influence on the intervention delivery and impact.

6.2.3 Context

This study differs contextually from other bereavement follow-up research as it is based in a large critical care department, with data drawn from high dependency and intensive care. This could be considered both a strength and a weakness of the study. The search strategy for the literature review used criteria to include critical care and high dependency but the identified research was based in intensive care. This could make comparison with other studies more difficult.

There is an argument that the generic nature of the intervention does not meet the needs of relatives from different units, but this is not understood through a relatively small study. Certainly, gaps in the process evaluation have already been outlined that, if filled, would have facilitated a better understanding of the context of a large department.

Conversely, the context of a large critical care department gives a broader perspective to the study. The acceptability of critical care maintaining contact was high, with respondents to the telephone questionnaire coming from all units. Additionally, there have been meetings with relatives from surgical and medical high dependency. From my experience as a member of the bereavement team, I know that even relatives who experience death in a medical or surgical high dependency unit have similar needs to those from intensive care. The bereavement team have supported relatives in these circumstances, but due to limitations of the study they were unable to be included in the research. Recommendations for future research to capture these experiences are made in Chapter 7.

Organisational barriers to bereavement support transcend the otherwise contextually bound research. Lack of time, resources and policy guidance were identified as barriers in the national surveys and mirrored in the results from the stakeholder interviews (Mitchell et al., 2017; Egerod, et al., 2019). The bereavement follow-up programme was led from the bottom up. This is not uncommon but compounds resource issues. More importantly the results identified concerns about the emotional burden on the clinical stakeholders and burnout among the bereavement team.

Recommendations on bereavement support from the Faculty of Intensive Care Medicine do not include an outline for bereavement service provision. At a national level, services are fragmented and shared between the acute sector, charity sector, and community and third sector services (Hewison et al., 2020; Pattison et al., 2020). These services are fragmented and have a lack of understanding of the needs of critical care families.

This is even more so in the global context of the COVID 19 pandemic. At a local level the impact of the pandemic is significant with major disruption to the critical care department and the bereavement follow-up programme. The ongoing ability to run a service largely built on the good will of the staff is increasingly questionable when they are tired and stretched. Yet, the interviews with stakeholders suggest that staff were acutely aware of the impact that the pandemic had on relatives' experience of grief. They worried about families after they left the hospital and had a desire to continue to offer them support.

In a global context this study suggests that research from other cultures can still be relevant. Despite cultural differences, certain elements of bereavement support such as information giving, condolence letters and ongoing contact from the clinical team are common. Storytelling for surrogates in the US was a successful intervention (Barnato et al., 2017). Although surrogacy decision-making is not relevant for the UK, relatives interviewed in this study appeared to have a need to tell their story and generalisable benefits of the storytelling interventions are apparent. Similarly, lessons can be learned from bereavement support research from other clinical areas such as the emergency department and palliative care. Perhaps an important stance is to accept that there are common themes that cross clinical settings and cultures.

6.3 Chapter Summary

This chapter discussed the results of the process evaluation with consideration given to previous research. The strengths and weaknesses of the study design were initially outlined. The main strengths of the study lay in the integration of results from a variety of data sources, and the success of the project in engaging with bereaved families. The influence of the researcher, their relationship with the clinical team and potential for bias were identified as significant weaknesses. Lack of time and resources to carry out the full evaluation limited the results.

The results were discussed with reference to answering the research questions aligned to the core elements of the process evaluation. Implementation issues were identified. Acceptability was good and simple mechanisms of change of non-abandonment and offering ongoing support were in keeping with the logic model and previous research. The most significant results came from the qualitative interviews with bereaved families and stakeholders. They demonstrated that mechanisms of change went beyond event clarification and had far-reaching benefits for families. For stakeholders, they identified gaps in knowledge and understanding, and were important to inform future practice.

Chapter 7 Conclusion and Recommendations

7.1 Conclusions

This study offers valuable insight into a current bereavement follow-up programme in critical care in Scotland. The mixed methods process evaluation allowed the integration of results from different data strands to answer a variety of research questions relating to process implementation, acceptability, mechanism of change and context.

The bereavement follow-up intervention was generally implemented as planned although, not surprisingly, overall fidelity was higher pre-pandemic. The most significant implementation findings are that the dose and reach of the programme were mainly affected by the reliance on collecting complete nearest/closest friends' or relatives' contact details, and by inadequacies of information giving at time of death. Additionally, the reach of the programme is limited by using a single point of contact. Despite this, there was some evidence that bereavement follow-up information was shared beyond the single contact.

Overall, acceptability of the intervention was high, with non-abandonment and recognition of significant loss valid mechanisms of change. Beyond this the results were conflicting. Although relatives wanted contact from critical care and found it meaningful, information was poorly used and the number of relatives making contact with the clinical team was low.

There was mixed feeling about adaptations such as telephone calls and generally there was uncertainty among relatives about what they would want from critical care. In contrast, there are significant and often life-changing benefits from contacting the clinical team. This is an important research finding and helps support the need for bereavement follow-up and guide direction for future research.

Among the stakeholders, acceptability of the programme was good regardless of whether they had participated in a bereavement follow-up meeting. Findings from the study help inform practice. Analysis of relatives' and stakeholders' data highlights both the stakeholders' anticipation surrounding the reasons for a meeting and the relatives' actual needs. Stakeholders' concerns around complaints are unfounded and relatives' feelings of personal guilt and a general need to tell their story are among the unexpected reasons for a meeting. Participation in bereavement support is a learning experience for the clinical team and the role of different professionals in supporting bereaved families is highlighted.

However, the department has over 300 nursing staff, 22 permanent consultants, and rotational medical and allied health care workers. Implementing and maintaining a bereavement follow-up programme with limited resources in a department of this size is a challenge. Education, communication and the different needs between medical and surgical high dependency and intensive care are important aspects relevant to context that affect the delivery of the programme. The commitment of the staff and the bereavement team is commendable but the lack of organisational support makes the sustainability of the programme questionable.

In addition the emergence of a global pandemic in March 2020 has hampered, influenced and changed the bereavement programme, the professionals offering it and the bereaved relatives that are the recipients of the intervention. The COVID 19 pandemic and its overall impact on staff, the organisation and society were common threads throughout the study and the most significant consideration in terms of context.

Perhaps all death is sudden and unexpected. No matter how prepared the dying and their loved ones are, the finality of death and the difficulty in accepting our mortality makes it so. With death comes the unpredictable journey through grief with its unexpected twists and turns. Ultimately, what matters most is the relatives' perspective of the situation rather than our judgement of the clinical context of the death. Every close friend or relative of the deceased will have their own journey and their own story. It is those stories that are important.

The process evaluation highlighted issues with the local implementation of the intervention, considered adaptations and helped inform gaps in our knowledge about the mechanisms of change for bereavement follow-up. Picking apart the mixed results is difficult and poses questions that cannot be fully answered by this study. Section 7.2 outlines recommendations for the current intervention, the wider critical care community and the direction of future research.

7.2 Recommendations

7.2.1 Queen Elizabeth University Hospital Bereavement Follow-Up

The implementation process results indicate that there are shortfalls in recording nearest/closest friends' and relatives' data. and the process of giving the information brochure and condolence card at time of death. The information brochure and condolence cards are stored centrally and also on individual units. A simple review of the process of storing and accessing this information would improve delivery.

There are often multiple professionals involved with families at time of death and re-education across the floor would help improve the overall fidelity of the intervention. Evidence from the study shows poor recall of events at time of death. Using the results to educate staff would encourage them to take time to explain the brochure and condolence card to relatives to enable them to better process the information they are being given.

The ability to audit the bereavement follow-up intervention is important for future evaluation and development of the programme. There is a tick box on the end-of-life pathway on the electronic patient-record system but it is not reliably used. A consistent method of recording if the bereavement brochure and condolence card are given to families would help prompt staff, and support collection of data for future research.

There is the option to implement a process to send information to families that did not receive it at time of death. Since the pandemic in 2020, email addresses are more consistently collected than postal addresses. Consideration should be given to using email as an alternative method of communicating with bereaved relatives. Potentially information at time of death and the three-month follow-up letter and card could be sent to families via email, improving the overall fidelity of the programme.

There is potential for adaptation to the current programme that could improve the reach beyond the single point of point of contact, for example, sharing bereavement follow-up information through an online medium such as social media or a critical care website. There is scope to offer more varied methods of contact through a trial of a telephone call. There are multiple options for a telephone call at different points in the process that might improve engagement with support:

1. A telephone call within the first week to make sure that there is no immediate support or information required and that all administration duties are carried out
2. A telephone call at six weeks, prior to letter and card at three months; this would reach those who do not engage with written information
3. A third option would be to trial a telephone call after the letter and card are sent out. This would support relatives who did not engage with written information or find making contact difficult.

Due to limited resources, the current letter caveats what cannot be offered and this may put relatives off getting in touch. A review of what the bereavement team can offer and more positive wording of the letter may increase engagement. Offering more services would require critical care to forge links with local community groups, charity organisations and bereavement support organisations to build a network of support for onward referral. This would include increasing links with the multi-disciplinary team in the hospital such as the chaplains and psychology services.

There is evidence that families want to talk and share their story. A trial of a peer group for bereaved relatives facilitated by the bereavement team could meet relatives' desire to share their experience with others without the need to attend a formal meeting with the clinical team.

A regrouping of the link nurse team in each unit with the possibility of increased involvement to manage their own bereavement case load would improve buy-in of individual units. Allocated slots for bereavement meetings along with a core team of consultants who have an interest in bereavement support would help facilitate meetings and build experience among the clinical team.

All of the above would require buy-in at an organisational level, with a commitment to fund and resource bereavement follow-up. The current programme is run by a group of nurses with a passion for bereavement support. While their hard work and compassion are to be commended, it is not sustainable if improvements are to be implemented. A general increase in resources, particularly administrative and allocated non-clinical time, would be necessary. This should include ongoing education and support for the clinical staff caring for families at end-of-life, and for those offering bereavement support. For the critical care community, it has implications for both policy development and further research.

7.2.2 Recommendations for Wider Critical Care Community and Future Directions for Research

To the researcher's knowledge this is the first study of a bereavement follow-up programme in the UK. Other bereavement follow-up initiatives similar to this one exist but, with no published research or evaluation, collaborative work in Scotland is difficult. Sharing the results of this research with the wider critical care community will increase awareness of the topic, inform practice and encourage more research.

However, bereavement support in critical care needs more policy and guidance from national bodies. Clearer policy guidance from the critical care professional bodies such as the Faculty of Intensive Care Medicine, Intensive Care Society and Scottish Intensive Care Society would support the development of bereavement follow-up services. This should involve cross-working between professional bodies, organisations and policy-makers. There is potential for the development of a critical care bereavement charter to set standard principles to work towards. This would be in keeping with the Bereavement Charter for Children and Adults in Scotland (Support Around Death, 2020).

The development of evidence-based services would require further research. This process evaluation is a small step in beginning to fill the research gap in the UK. Moore et al. (2014) stated that quantitative data may identify challenges not answerable by qualitative data, and qualitative data may generate new hypotheses that require further research. Therefore, a good quality process evaluation while offering partial insights should also highlight priorities for future research (Moore et al., 2014).

Further research studies are required to guide the implementation and adaptation of interventions. Research should focus on the broader experiences of bereavement follow-up while trying to build in adequate variation to cater for different needs. Larger research studies with cross-collaboration in critical care would offer more generalisable results. This study shows that it is possible and ethical to carry out research with bereaved families and that they are willing to participate. Future research should aim to engage with stakeholders and relatives to help guide both the research and the interventions.

7.3 Chapter Summary

Chapter 7 offered a conclusion of the process evaluation, recommendations for practice and directions for future research. The evaluation offers valuable insight into a current bereavement follow-up programme in critical care. The study draws conclusions on all the domains of process evaluation. By far, the results from relatives' data sources offer the most valuable insight into the acceptability and mechanisms of change for the intervention. Recommendations are made but more guidance and funding are required. Directions for future research should involve collaborative working and include engagement with bereaved families.

Appendices

Appendix1 Bereavement follow-up letter and cards

Critical Care Bereavement Support
Critical Care Unit
Level 1
Queen Elizabeth University Hospital
1345 Govan Road
Glasgow
G51 4TF

Telephone – 0141 452 3047
Email – ggc-uhb.bereavement.qecc@nhs.scot

Dear

The Critical Care team would like to offer our sincere condolences after the recent death of your loved one in critical care. We appreciate that this is a difficult time and that everyone copes in different ways. We would like to offer our ongoing support. Enclosed is a card which provides details of organisations who offer specialist advice and support around bereavement.

We are unable to offer counselling services but if you or close family member have any unanswered questions, then please get in touch using the contact details above. Depending on restrictions in place due to Coronavirus we may be unable to offer face-to-face meetings. However, we can speak to you on the telephone and, if needed we can arrange a virtual meeting. Equally if you have any other ideas on how we can support you, please let us know and we will try our best to achieve this.

You can contact us by phone, email, or in writing using the contact details at the top of this letter. When contacting us, please include your details and your relative’s name. One of the staff from the Bereavement Team will then contact you as soon as possible.

If you would prefer to have your details removed from our file and receive no further contact, then please let us know by using the contact information above.

Kind Regards

Bereavement Team
Critical Care Unit
Queen Elizabeth University Hospital

Enc

NHS
Greater Glasgow
and Clyde

Bereavement Support Critical Care

Queen Elizabeth University Hospital

Contact Telephone Number: **0141 452 3047**

Email: **ggc.bereavement.qecc@nhs.scot**

Chaplaincy Telephone Number: **0141 452 3221**

We wish to offer our ongoing support to you and your family at this difficult time following your recent bereavement.

Below are some useful contact details for advice and support.

NHSGGC Bereavement webpage
www.nhsggc.org.uk/your-health/health-services/bereavement-services/bereavement/

Cruse Bereavement Care Scotland
0845 600 2227
www.crusescotland.org.uk/

Winston's Wish for support with bereaved children
08088 020 021
www.winstonswish.org.uk/

WAY Widowed and Young
www.widowedandyoung.org.uk/

Review Date: August 2024

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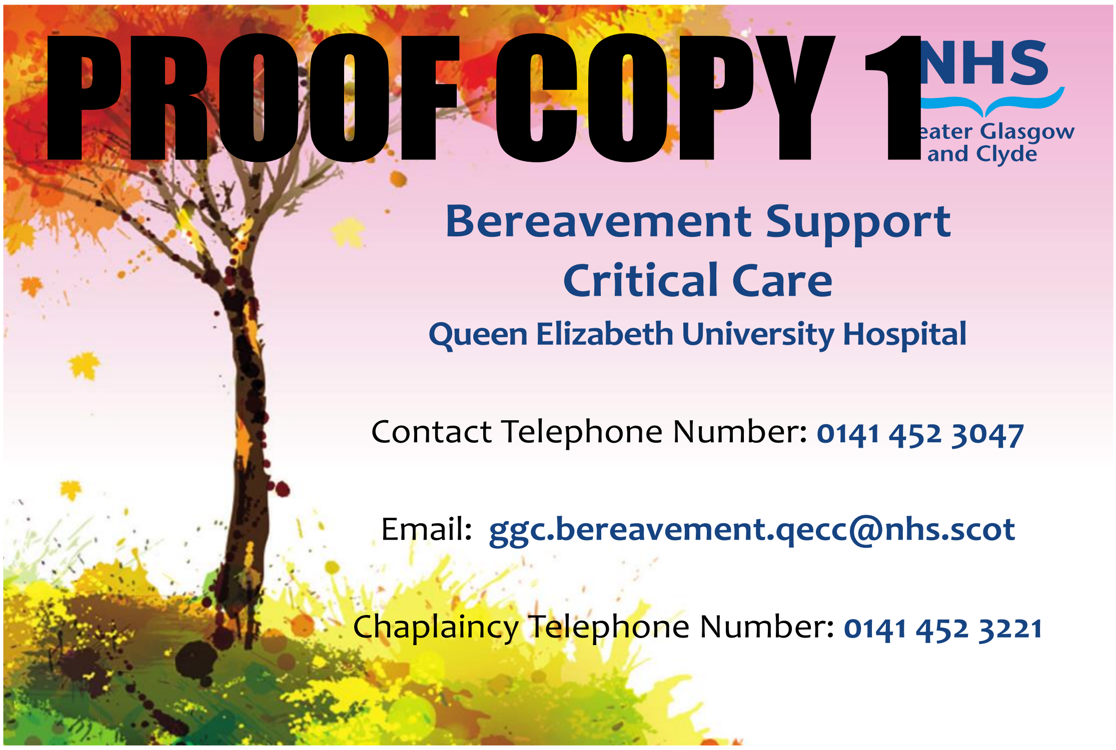

NHS
eater Glasgow
and Clyde

Bereavement Support Critical Care

Queen Elizabeth University Hospital

Contact Telephone Number: **0141 452 3047**

Email: **ggc.bereavement.qecc@nhs.scot**

Chaplaincy Telephone Number: **0141 452 3221**

The staff at the QEUH [illegible] care [illegible] express their sincere condolences to you and your family.

You will have been given a booklet entitled **"What to do after Someone has died"** which gives practical advice that may be of use to you in the weeks ahead.

At the QEUH critical care unit we offer a bereavement follow up service. As part of this service we will contact you by post in 3 months.

If you need further help and advice in the mean time, please contact us on the number provided on the front of your **"What to do after someone has died booklet"** or using the contact details on the front of this card.

We will keep your details for three months to allow us to send out bereavement support information. If you do not want us to keep your details, please let us know using the contact information on this card.

Review Date: January 2023

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Appendix 2 Participant information sheets

Participant information Sheet-Relative Questionnaire

1. Introduction

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. There will be an opportunity to ask questions when the researcher contacts you or please feel free to get in touch using the e-mail address or telephone number at the bottom of the information sheet.

2. Project title

An evaluation of the Bereavement Follow Up Programme in Critical Care at the Queen Elizabeth University Hospital (QEUH), Glasgow

3. The purpose of this project

The loss of a loved one is difficult to cope with and that loss can be more difficult if it is unexpected and happens in an acute hospital. The bereavement team at the QEUH, Critical Care Unit introduced a bereavement follow up programme to improve the support we offer bereaved families.

The purpose of this study is to evaluate how well the bereavement follow up programme is working, and if it helps support loved one's at this difficult time. As part of this evaluation we would like to ask relatives who have lost a loved one in critical care and received bereavement support information to complete a questionnaire. Asking relatives questions to get their feedback about the information they received is vital to the evaluation of the service.

4. Why have I been asked to take part?

You have been invited to take part in this study because you are the Next of Kin of a loved one who died in Critical Care at the QEUH and have received our bereavement follow up letter and card.

You can only be in this study if you are over 18 years of age, live in the UK and speak English.

5. Do I have to take part?

No, it is up to you to decide to take part. This information sheet is for you to keep. The researcher from the bereavement follow-up team will call you within a month to ask if you would like to complete the questionnaire.

You will be offered the option of answering the questionnaire on the telephone with the researcher. By agreeing to answer the questions on the telephone you will be consenting to take part in the project on the basis that the answers you provide will be anonymous. If you would like to take part but prefer to answer the questionnaire in your own time, then we can send you the questionnaire by post or provide a web link either on the telephone or by email. It will then be up to you whether you want to complete it.

6. What will happen to me if I take part? What will I have to do?

The researcher from the bereavement team will call you to ask if you would like to take part. Answering the questionnaire will take up to 15 minutes on the telephone. If you would like to take part but it is not a good time, then we can arrange to a call you back at another time. If you would prefer to answer the questionnaire by yourself then we can arrange to have it sent to you by post or e-mail.

Once you have answered the questions there is nothing else to do.

7. What are the possible disadvantages and risks of taking part?

Taking part in this study will involve a small amount of your time. We do not expect there to be any risks or disadvantages to you taking part. However, losing a loved one is difficult and if you are upset once you start to talk to the researcher then you can stop at any time. if you express any need for more support then we can offer information on organisations that may help.

8. What are the possible benefits of taking part?

Taking part in this study is voluntary and we cannot offer any incentive. However, answering the questionnaire will give us a better understanding of how well our bereavement support is working and help us to improve the support we offer relatives in the future.

9. Will my taking part in the project be kept confidential?

All information which is collected about you, or responses that you provide, during this project will be kept strictly confidential. For administration purposes we use a contact form that will have your details on it along with a unique identifier (a number made up by the researcher that relates only to you). The questionnaire when completed will be anonymous and will not have your name, address or the unique identifier on it. The contact form will be destroyed once we have completed any communication with you.

10. What will happen to my Data?

Data refers to the information you provide us with when answering a questionnaire.

All data will be held in accordance with the General Data Protection Regulation (2018).

If you answer the on-line version of the questionnaire the web-link will be given to you on the telephone or sent to an e-mail address provide by you. The information you enter will be stored in secure password protected questionnaire handling software. Results will be anonymous and will not have identifiable information such as name and address. If you return the questionnaire by post the paper copy will be destroyed once the information has been entered onto the electronic system.

All data in electronic form will be stored on secure password-protected computers and will be anonymous. Paperwork used by the researcher to keep track of the study will be destroyed once contact is completed. The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, data from the questionnaire will be securely destroyed in accordance with the relevant standard procedures.

11. What will happen to the results of this project?

The results from the questionnaire will be analysed using data analysis software. Any comments you make in open questions will be transcribed word for word into the questionnaire software. The data will be analysed by the researcher who will use the information as part of an overall evaluation of our service. The results will be produced in a thesis for the award of MScR at the University of Glasgow and will be reported to the management team at the QEUH, Critical Care Department. We may later submit the finding of the project to academic journals or present them at an academic conference. Again, we can ensure that at all stages of this project, your data will be kept strictly confidential, and you will not be identified.

12. Who is organising and funding the project?

The project is organised by Aileen Labram, Charge Nurse at the QEUH, Critical Care Unit, Glasgow under the supervision of Professor Bridget Johnston at the University of Glasgow. The project is being carried out for a MScR at the University of Glasgow and is funded by NHS Greater Glasgow and Clyde WRVS endowment fund.

13. Who has reviewed the project?

The project has been reviewed by the Clinical Director of Critical Care at the QEUH and by the College of Medical, Veterinary & Life Sciences Ethics Committee.

14. Contact for further information

If you have any questions or require further information, please contact Aileen Labram (MScR Student) at 2507983@student.ac.uk or on 07952412340

The research team and staff at the QEUH, Critical Care Unit would like to take this opportunity to thank you for considering participating in this project.

Participant information Sheet-Relative Interview.

1. Introduction

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. This participant information sheet is yours to keep along with a copy of a signed consent form if you decide to take part.

2. Project title

An evaluation of the Bereavement Follow Up Programme in Critical Care at the Queen Elizabeth University Hospital, Glasgow

3. The purpose of this project

The loss of a loved one is difficult to cope with and that loss can be more difficult if it is unexpected and happens in an acute hospital. The bereavement team at the QEUH, Critical Care Unit introduced bereavement follow up to improve the support we offer bereaved families.

The purpose of this study is to evaluate how well the bereavement follow up programme is working, and if it helps support relatives at this difficult time. As part of this evaluation we would like to interview relatives that have attended for a bereavement follow up meeting. The purpose of the interview is to gather your opinion and experiences of attending for a bereavement meeting.

4. Why have I been asked to take part?

You have been invited to take part in this study because you attended for a meeting after receiving our follow up letter and card. You can only be in this study if you are over 18 years of age, live in the UK and speak English.

5. Do I have to take part?

No, it is up to you to decide to take part. This information sheet is for you to keep. The researcher from the bereavement follow-up team will call you in about two weeks' time to ask if you would like to take part. If you do decide to participate the researcher will arrange for you to sign a consent form and date and time that is suitable to yourself will be made to take part in the interview. Due to coronavirus restrictions we may ask if you would be willing to be interviewed over the telephone or by videocall. This can be discussed when the researcher calls. You will have a further opportunity to ask any questions before the interview takes place.

6. What will happen to me if I take part? What will I have to do?

The interview will take place at a date and time arranged with you and the researcher. Face to face interviews are preferred but due to restriction in place for coronavirus it may be more suitable to arrange either a telephone or video conferencing interview. The researcher will discuss this when they call. The interview will be audio recorded and involve the researcher asking some questions about your experience of attending for a follow up meeting. The interview will take up to one hour, depending on how much you want to discuss.

7. What are the possible disadvantages and risks of taking part?

Taking part in this study will involve your time. We do not expect there to be any risks or disadvantages to you raking part. However, losing a loved one is difficult and if you should express any need for more support then we can offer information on organisations that may help. If you become upset by the interview, then we may stop and then you can decide whether to carry on or not.

8. What are the possible benefits of taking part?

Taking part in this study is voluntary and we cannot offer any incentive. However, answering the questionnaire will give us a better understanding of the experience of relatives attending for follow up meetings and help us to improve the service in the future.

9. Will my taking part in the project be kept confidential?

All information which is collected about you, or responses that you provide, during this project will be kept strictly confidential. You will be identified by a pseudonym (made up name), and any information about you will have your real name removed so that you cannot be recognised from it. Please note that confidentiality will be strictly adhered to unless evidence of serious harm is uncovered, in such cases, the researcher may be obliged to contact relevant agencies.

10. What will happen to my Data?

“Data” refers to the information you provide us with during interviews, in the form of recorded conversation, or handwritten notes taken by the researcher.

All data will be held in accordance with The General Data Protection Regulation (2018).

Any data in paper form will be stored in locked cabinets in rooms with restricted access at the Queen Elizabeth University Hospital, Glasgow. All data in electronic format will be stored on secure password– protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you. The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.

If you decide to withdraw from this project, we will keep the data you have given us up to that point. Your rights to access, change or move the information we store may be limited, as we need to manage your information in specific ways for the research to be reliable and accurate. As stated in the previous section, we will use a pseudonym in any written report we produce, and you will not be able to be identified from your data.

11. What will happen to the results of this project?

The recordings from the interviews will be transcribed verbatim. This means they will be made into an exact document of what was said in the interview. We will then delete the recording. This document will be analysed by the researcher, to look at the themes that were discussed in the interview.

The results will be produced in a thesis for the award of MScR at the University of Glasgow. The results will be reported to the management team at the QEUH, Critical Care Department. We may later submit the finding of the project in academic journal or present them at an academic conference. Again, we can ensure that at all stages of this project, your data will be kept strictly confidential, and you will not be able to be identified.

12. Who is organising and funding the project?

The project is organised by Aileen Labram, Charge Nurse at the QEUH, Critical Care Unit, Glasgow under the supervision of Professor Bridget Johnston at the University of Glasgow. The project is being carried out for a MScR at the University of Glasgow and is funded by NHS Greater Glasgow and Clyde WRVS endowment fund.

13. Who has reviewed the project?

The project has been reviewed by the Clinical Director of Critical Care at the QEUH and by the College of Medical, Veterinary & Life Sciences Ethics Committee.

14. Contact for further information
If you have any questions or require further information, please contact Aileen Labram (MScR Student) at 2507983@student.ac.uk or telephone 07952412340.

The research team and staff at the Critical Care Unit in the QEUH would like to take this opportunity to thank you for considering participating in this project.

Participant information Sheet-Stakeholder Interview

1. Introduction

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If you have further questions, please get in touch with Aileen Labram on the e-mail address provided at the bottom of this information sheet.

2. Project title

An evaluation of the Bereavement Follow Up Programme in Critical Care at the Queen Elizabeth University Hospital (QEUH), Glasgow

3. The purpose of this project

The purpose of this study is to evaluate the bereavement follow up programme introduced at the QEUH, Critical Care Unit in 2018. The overall aim is to assess the effectiveness of the intervention in supporting bereaved relatives. As part of the evaluation we would like to interview key staff that are vital to the bereavement follow programme to gather more information about your opinions and experiences.

4. Why have I been asked to take part?

The opinions and experiences of staff directly involved in supporting bereaved relatives through bereavement follow up are vital to this project. You have been asked to take part because you belong to one of the groups of key stakeholders outlined below:

- ☐ **Intensive Care Consultant:** as a consultant in Critical Care you will have been, or potentially will be involved in attending meetings with families.
- ☐ **Chaplain:** as the hospital chaplain you may be involved in supporting our bereaved relatives as we offer your services in our information and at follow up meetings.
- ☐ **Visiting Specialist:** as a visiting specialist to Critical Care you have been asked to be involved with a family requesting bereavement follow up.
- ☐ **Bereavement Team:** you are directly involved in running the bereavement follow up programme and supporting bereaved families at meetings.

4. Do I have to take part?

No, it is up to you to decide to participate. The researcher will get in touch with you again in two weeks to ask if you would like to take. If you have decided to participate before then you can e-mail them with your decision using the contact details at the bottom of this sheet.

5. What will I have to do?

You are being asked to take part in an interview that will take place on a date and time arranged with you by the researcher. The interview will be audio recorded and involve the researcher asking some questions about your opinions and experience of the bereavement follow up programme. The interview will take up to one hour, depending on how much you want to discuss.

6. What are the possible disadvantages and risks of taking part?

Taking part in this study will involve a small amount of your time. We do not expect there to be any risks or disadvantages to you taking part.

7. What are the possible benefits of taking part?

Participation in this study is voluntary and we cannot offer any incentive. However, taking part will provide us with important information on the opinions and experiences of key staff involved in supporting bereaved relatives through our follow-up programme. This is important to allow us to evaluate our service and improve how we support bereaved families.

8. Will my taking part in the project be kept confidential?

All information which is collected about you, or responses that you provide, during this project will be kept strictly confidential. You will be identified by your professional title and interview number. Any information used will have your real name removed so that you cannot be recognised from it. Please note that confidentiality will always be strictly adhered to.

9. What will happen to my Data?

Data refers to the information you provide us with during interviews, in the form of recorded conversations, or handwritten notes taken by the researcher.

All data will be held in accordance with The General Data Protection Regulation (2018).

Any data in paper form will be stored in a locked cabinet in rooms with restricted access at the QEUH, Glasgow. All data in electronic format will be stored on secure password-protected computers. No one outside the research team or appropriate governance staff will be able to find out your name, or any other information that could identify you. The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, your data will be securely destroyed in accordance with the relevant standard procedures.

If you decide to withdraw from this project, we will keep the data you have given us up to that point. Your rights to access, change or move the information we store may be limited as we need to organise your information in specific ways for the research to be reliable and accurate. As stated in the previous section, we will use your professional title and interview number in any written report, and you will not be able to be identified form your data.

10. What will happen to the results of this project?

The recordings from the interviews will be transcribed verbatim. This means they will be made into an exact document of what was said in the interview. We will then delete the recording. This document will be analysed by the researcher, to look at the themes that were discussed in the interview.

The results will be produced in a thesis for the award of MScR at the University of Glasgow. The results will be reported to the management team at the QEUH, Critical Care department. We may later submit the finding of the project in academic journal or present them at an academic conference. Again, we can ensure that at all stages of this project, your data will be kept strictly confidential, and you will not be able to be identified.

11. Who is organising and funding the project?

The project is organised by Aileen Labram, Charge Nurse at QEUH, Critical Care Unit, Glasgow under the supervision of Professor Bridget Johnston at the University of Glasgow. The project is funded by WRVS endowment fund.

12. Who has reviewed the project?
The project has been reviewed by Dr Alexander Binning, Clinical Director of Critical Care at the QEUH and by the College of Medical, Veterinary & Life Sciences Ethics Committee.
13. Contact for further information
If you have any questions or require further information, please contact Aileen Labram
(MScR Student) by e-mail

The researcher would like to take this opportunity to thank you for considering participating in this project.

Appendix 3 Relatives questionnaire

Queen Elizabeth University Hospital, Glasgow.
Critical Care Bereavement Follow Up Programme.
Relative Questionnaire.

The first two questions have been completed from our records as this may be information that you find difficult to remember.

1. Please State the unit that your loved one died in.

- ○ Unit 1
- ○ Unit 2
- ○ Unit 3
- ○ Unit 4
- ○ unit 5
- ○ Unit 6

2. Please state how long your loved one was in the unit

- ○ <24 hours
- ○ 24-72 hours
- ○ >72 hours and up to one week.
- ○ 8-13 days
- ○ 14-20 days
- ○ 21-27 days
- ○ >27 days (Please State) ________________

3. What was your relationship to your loved one?

○ Spouse
○ Partner
○ Brother or Sister
○ Friend
○ Parent
○ Son/Daughter
○ Other ☐

The following questions are about information you received when your loved one died in Critical Care. Please tick one option. If there is a box provided next to the option, please give some more information. Depending on your answer, you may be directed to the next relevant question to answer. Where questions have boxes for free text please give as much of an explanation as possible.

4. At the time of your loved one's death did you receive an information pack containing the booklet "when someone has died-information for you"?

○ Yes (Please go to Q5)
○ No (Please go to Q7)
○ Unsure (Please go to 7)

5. Did you find the information helpful?

○ Very helpful (Please go to Q7)
○ Helpful (Please go to Q7)
○ Not helpful (Please go to Q6)
○ I did not look at the booklet.

6. Could you briefly explain why you did not find the information helpful?

☐

7. At the time your loved one died, did you receive a Critical Care Bereavement Follow up card. The card had a message of condolence and some contact details?

- ○ Yes (Please go to Q8)
- ○ No (Please go to Q13)
- ○ Unsure (Please go to Q13)

8. Did the message of condolence on the card have meaning for you?

- ○ Very meaningful
- ○ Meaningful
- ○ Somewhat meaningful
- ○ Not meaningful

9. Do you remember the card advised you that we would contact you in three months?

- ○ Yes
- ○ No
- ○ Unsure

10. Did you use any of the contact details on the condolence card?

○ Yes, (please state) ____________________

○ No

○ Unsure

11. Would you rather NOT have received the condolence card?

○ Yes (Please go to Q12)

○ No (Please go to Q13)

○ I have no preference (Please go to Q13)

12. If you would rather NOT have received the condolence card, can you briefly explain why?

13. At the time of your loved one's death is there any other information that you would have found useful?

The following questions are about the bereavement follow up information that we sent to you 3 months after your loved one died.

14. Please rate the timing of the follow up letter

○ I have no opinion on the timing (Please go to Q16)

○ The right time (Please go to Q16)

○ Not the right time (Please go to Q15)

15. When would you have preferred to receive the follow up information?

16. Did you use any of the bereavement support information on the card?

○ Yes (Please State)

○ No, I will not use the information

○ No, but I have kept it.

17. Overall, please rate your opinion of the bereavement follow up letter and card

○ Very Helpful (Please go to Q19)

○ helpful (Please go to Q19)

○ Not helpful at all (Please go to Q18)

18. Can you briefly explain why you did not find the letter and card helpful.

19. The letter offers the opportunity to contact critical care. Can you choose an option that best describes your response to this invitation?

- ○ I have made contact
- ○ I plan to make contact
- ○ I am still thinking about it
- ○ I would not find a visit helpful but may keep the details for the future.
- ○ I would not find a visit helpful
- ○ Other ______________________

20. Is there something that might stop you contacting the Critical Care Bereavement Team? You can pick more than one option.

- ☐ I find it difficult to make initial contact.
- ☐ I have a disability
- ☐ No.
- ☐ I am unsure of what I would want
- ☐ I find travelling to the hospital difficult
- ☐ I do not think it would be helpful
- ☐ I live too far away

21. Is there something else, not mentioned above, that would stop you contacting the bereavement team?

22. Did you share the support information with family or friends?

○ Yes
○ No
○ No, but I would consider it.

23. Would you have preferred to receive a telephone call to offer you support?

○ Yes (Please go to Q 24)
○ No (Please go to Q25)
○ Unsure (Please go to Q25)

24. When would you have liked to receive a telephone call?

○ One month
○ Two months
○ Three Months
○ Four Months
○ Five Months
○ Six months
○ Other (Please state) ____________________

25. Do you think critical care should contact families after their loved one has died?

○ Yes
○ No
○ Unsure

26. Have you looked for bereavement support from any other source? You can choose more than one option.

☐ General Practitioner
☐ Local Community Groups
☐ Private Counselling
☐ Bereavement Support Organisations
☐ Online support groups
☐ No
☐ Other (Please state)

27. Is there anything else that you think the critical care team could offer to help support bereaved family/friends?

28. Are you

○ Male
○ Female
○ Prefer not to say
○ Other

29. What age are you

○ 18-25
○ 26-35
○ 36-45
○ 46-55
○ 56-65
○ 66-75
○ >75

30. Questionnaire completed by, please tick which method you used to complete the questionnaire.

○ Telephone
○ weblink
○ Post

Appendix 4 Relatives questionnaire guide, and interview guide

Process Evaluation of Bereavement Follow up

Relative Telephone Questionnaire Guide for administration purposes only.

Before beginning the telephone, call have questionnaire ready. Have available bereavement support information and useful telephone numbers (Cruse, Samaritans etc)

Unique identifier	
NOK Name	
Address	
Telephone Number	
Unit	
Length of Stay	

Hello, my name is……..I am a researcher and nurse working in QEUH, critical care. Can I speak to (**as above?)**

If the person is correct, then proceed.

How are you? Do you have a few minutes to let me explain the reason for my call?

I am calling about the bereavement follow up letter and card you should have received from the QEUH, critical care department. **Establish if they received it.**

If No

Would you like us to send the information out today Yes/No?

If yes, check name and address correct as at top of sheet, if different record below.

Unique identifier	
Name	
Address	
Telephone Number	

I will include an information sheet on the questionnaire that we are carrying out.

Can we call you in about a months' time to get your view on the information **yes/no.?**

If Yes file to call back in one Month ________________________________

If No: send information and destroy form.

If they did receive the information.

There was an information sheet about a research study included along with the letter and card

Ask if they read the participant information sheet? If not or cannot remember, then explain the study.

Do they have any questions about the questionnaire and what it would involve?

Would they like to take part **Yes/No?**

If Yes, would they like to answer the questionnaire by

Telephone/post/web link e-mailed to them.

<u>If by telephone.</u>

Would they like to complete **now/later date?**

If now proceed to questionnaire.

If later: date and time to call back ____

<u>If by post</u>

Check name and address and send out questionnaire with first two questions completed.

<u>If web link provided by e-mail.</u>

E-mail address____

Send web link and inform the participants of the information to complete for the first two questions.

Thank the relative for talking and offer any support that they may require.

Process Evaluation of Bereavement Follow up

Relative Interview Guide.

Questions/Statements in bold, reminders in plain text.

This is an audio recording of an interview for the bereavement follow up process evaluation. On

Date_______/_________/_________Time________.

Face to face/video-conference/telephone.

Carried out by____________________________________

With____

For the purpose of the recording would you mind stating your name.

Thank you for agreeing to take part in this interview your opinions and experiences will really help with our project.

How are you today?

The interview is related to you experience of attending for a bereavement follow up meeting, but before we discuss this I wondered if you could tell me a bit about yourself and your loved one that died.

If spouse partner/how long had they been together

Relationship

Were you the Next of Kin? If not, did the information get passed on to you?

Could you tell me a little bit about your loved one's time in critical care?

Was it a sudden admission or had they been in hospital?

How did you find visiting critical care? Did you feel supported and understood by staff?

How long were they a patient?

Were they in HDU/ICU/Both?

Did they deteriorate suddenly or over time?

Could you tell me a bit about contacting the bereavement team for follow up?

How long did they wait before they made contact?

Did you discuss it with other members of their family?

Do you think you would have made contact if you did not get a letter?

Did you have specific questions in mind when you attended for the meeting?

What were your expectation of a meeting?

How long it would last?

Who you would meet with?

Did you expect to be offered other support?

What do you think about the way a meeting was arranged?

Length of time it took, the consultant that you met with, the venue.

I wondered about how helpful you found the meeting.

Can you explain.

Staff carrying out the meeting.

Were your questions answered?

How did you feel after it?

Did the meeting prompt you to seek other sources of bereavement support?

What about after the meeting-did you speak to other family members?

Is there anything else that you think the team could offer to help with your bereavement?

That's all that I really wanted to ask you today. Is there anything else that you wanted to talk about, or I can help you with today?

Thank you very much for your time. Interview ended, time______________________

After the interview is complete offer any further support or information. Researcher should have leaflets and useful telephone numbers with them.

Appendix 5 Stakeholders interview guide

Key Stakeholder-Interview Guide

Questions are in bold and prompts in normal text

Thank you for taking part. This is a key stakeholder interview for the bereavement follow up process evaluation.

Date -----/-----/----- start time---------. For the purpose of the audio recording can you tell me your name and job title.

Thank you for taking part in this interview. The purpose of the interview is to explore your opinions and experience of the critical care bereavement follow up programme. You have agreed to take part as a professional who has attended/or could be asked to attend a bereavement follow up meeting.

Can you tell me a bit about your professional capacity?

What is your professional role, how long have you worked here, did you always work at the QEUH or at another ICU/HDU/hospital, what length of experience do you have? If Chaplain/speciality-a bit about their professional background.

What do you think about offering bereavement support to relatives?

Have you had any training in supporting bereaved relatives?

Can you tell me what you think about the bereavement follow up programme at the QEUH?

Have you taken part in a bereavement follow up meeting?

Questions for yes.

Can you tell me a bit about the meeting/s you attended?

Did you lead the meeting?

In terms of preparation, what did it involve?

If there was anyone else there did you feel that they were a support to you?

Did you feel you were the right person to carry out the meeting?

How did you feel about attending a meeting?

What were your expectations before you went to the meeting?

How did you feel during the meeting?

Do you think the family benefitted from the meeting?

How did you feel after it?

Did you learn anything from the meeting?

What about the process involved in meeting the relative? Organisation, environment, availability of background information?

Is there anything that you think could improve the service?

Is there anything that would help you meet bereaved relatives: further training. Support

(Have you carried out meetings with bereaved relatives prior to this?

If yes, how did they differ?)

Questions for No.

Have you met with families after a bereavement, but not via the follow up programme?

If you did, can you tell me a bit more about that. What was it for? How did they get in touch?

-How did you feel during and after the meeting?

-Do you think the family benefitted from it?

-Did you learn anything from the meeting?

How do you think you would feel about being asked to meet with a family for bereavement follow up?

What kind of reasons do you think families would want to attend a meeting for?

That's about all I wanted to talk about is there anything else that you would like to add.

Thank you for taking the time to take part.

Interview ended time ______________________

Appendix 6 Relatives informed consent form

Title of Project: Evaluation of the Critical Care Bereavement Follow-Up Programme at Queen Elizabeth University Hospital, Glasgow. Relative Interview.

Name of Researcher: Aileen Labram

CONSENT FORM

	Initial
I confirm that I have read and understood the Participant Information Sheet 1 version 1.0 dated 23/07/2020.	☐
I have had the opportunity to think about the information and ask questions and understand the answers I have been given.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.	☐
I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers.	☐
I agree that my name, contact details and data described in the information sheet will be kept for the purposes of this research project.	☐
I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.	☐
I agree to my interview being audio-recorded.	☐
I understand that the recorded interview will be transcribed word by word And the transcription stored for up to 10 years in the University archiving Facilities in accordance with the Data protection policies and regulations.	☐
I understand that things I say in an interview may be quoted in reports And articles that are publishes about the study, but my name or anything else that tell people who I am will not be revealed	☐

Consent form 1 Relative Interview Version 1 23/07/2020

I agree that should significant concerns regarding my mental or physical health arise during my participation in the study that I will be offered support by the researcher to contact appropriate services. ☐

I agree to take part in the study.

Name of participant	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

(1 copy for participant; 1 copy for researcher)

Appendix 7 Stakeholders informed consent form

Title of Project: Evaluation of the Critical Care Bereavement Follow-Up Programme at Queen Elizabeth University Hospital, Glasgow. Stakeholder Interview.

Name of Researcher: Aileen Labram

CONSENT FORM

	Initial
I confirm that I have read and understood the Participant Information Sheet 3, version 1.0 dated 23/07/2020.	☐
I have had the opportunity to think about the information and ask questions and understand the answers I have been given.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.	☐
I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers.	☐
I agree that my name, contact details and data described in the information sheet will be kept for the purposes of this research project.	☐
I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.	☐
I agree to my interview being audio-recorded.	☐
I understand that the recorded interview will be transcribed word by word And the transcription stored for up to 10 years in the University archiving Facilities in accordance with the Data protection policies and regulations.	☐
I understand that things I say in an interview may be quoted in reports And articles that are publishes about the study, but my name or anything else that tell people who I am will not be revealed	☐

Consent form 2: Stakeholder Interview Version 1 23/07/2020

I agree to take part in the study.

Name of participant	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

(1 copy for participant; 1 copy for researcher)

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