SUMMARY POINTS OF PAPER

Whilst benefits of participating in research are well known, therapeutic benefits of participating in qualitative research interviews have been more generally described. To date, there has been little exploration on the nature of therapeutic benefits specifically for participants in end of life and bereavement research.

Secondary analysis was undertaken using three existing end of life and bereavement datasets on research conducted in the United Kingdom and New Zealand to identify whether therapeutic benefit for participants occurred during qualitative research interviews. Using existing literature on therapeutic benefit of QRI, an analytical frame was used to direct content analysis.

Emotional, cognitive and social therapeutic benefits for participants were present. Emotional therapeutic benefit, specifically emotional healing and having someone to listen and to talk to, was particularly identified.
Qualitative research interviews can have positive therapeutic benefits for participants, although researchers must have the skillset to safeguard participants and themselves when researching populations who are bereaved or at end of life.
Introduction
Qualitative research interviews (QRI) are commonly used to gather information to answer questions about specific social phenomena. Whilst this clearly helps the researcher, therapeutic benefits for participants in QRI have also been recognised, in particular the emotional effects following a recounting of experiences and life events. However, inviting participants to an interview where emotional release can occur requires careful consideration. A population often perceived as vulnerable in this way are the bereaved and those at end of life. It is therefore important to consider whether therapeutic benefits can occur when undertaking QRI with this population. This can bring a more balanced perspective in considering not just risks, but also potential benefits for QRI in this population.

This paper presents an exploration of therapeutic benefits of QRI for the bereaved and those at end of life. We define ‘therapeutic’ as a ‘process by which an individual understands previous experiences in different—sometimes more positive ways’. Findings are presented that highlight potential therapeutic benefits of QRI from secondary analysis of existing end of life and bereavement research datasets.

Methods
Secondary analysis was performed on three end of life and bereavement datasets that all utilised QRI. We set out to explore whether there was evidence of therapeutic benefit occurring during QRI. The existing literature on therapeutic benefit of QRI was categorised to develop an analytical frame that was used to direct content analysis of the data.

Developing the analytic frame for directed content analysis
A structured narrative review of the literature was conducted. Web of Knowledge and Scopus databases were searched for the terms ‘therapeutic benefit’, ‘qualitative interview’, and ‘qualitative research interview’. No date restrictions were used. Only papers published in English were included. Papers were filtered for inclusion by reading of the title and the abstract for suitability for inclusion. Drawing on the main findings of the 23 identified papers, key concepts relating to therapeutic benefits of QRI were identified, collated and categorised. The agreed developed subcategories and categories informed the analytic frame (Table 1).

Identifying the primary datasets
Three datasets exploring aspects of end of life and bereavement care utilising a range of qualitative approaches (ethnography, interpretive, and phenomenology) were used. There was broad alignment of: research aims across the studies; general characteristics of the study populations: and conduct of the QRI in each study. Written consent for all studies included a request for secondary use of the data. All interviews were audio recorded and transcribed. Researcher field notes and supplemental documentation e.g. follow-up letters from participants, were available.

Dataset 1: Experiences of family members bereaved in intensive care
MC undertook in-depth QRI with family members bereaved in a United Kingdom Intensive Care Unit (ICU) in the previous 6-12 months. The study was conducted in 2012 and explored experiences during treatment withdrawal and events on the ICU after the family member had died. National Health Research Ethics Service approval was given (08/H0501/65).

Dataset 2: Transitions in care in the last year of life
RP conducted semi-structured interviews with participants who had advanced and progressive disease, identified by healthcare professionals to be in their last year of life. This study was
conducted in New Zealand in 2015 across acute care hospital and rest home settings. Ethical approval was received from the study site’s Regional Advisory Group – Maori (Ref. no. RAG-M 2014/346), the Health and Disability Ethics Committee (Southern Health Region) (14/STH/180) and Victoria University of Wellington Human Ethics Committee (RM 21627).

Dataset 3: Experience of family dementia care givers at end of life
KdV explored experiences of preparedness and support for dementia caregivers, before, during and following the death of the person with dementia in New Zealand. Ethical approval was given by the Human Disability Ethics Committee (Central Region) New Zealand (NZ CEN/12/EXP/029).

Studies were discussed to ensure methodological suitability and agreement on inclusion. A quality assessment was undertaken on the primary datasets to determine whether there was sufficient in-depth data available, and which interviews were suitability for use. Interviews were sorted and included if participants made an observation about perceived therapeutic benefits related to QRI. From a total of 75 interviews across the three datasets, 23 interviews were suitable for secondary analysis: Dataset 1 n=5, Dataset 2 n=7, Dataset 3 n=11.

Data analysis
All data from the studies were systematically read and coded using directed content analysis. The predetermined categories and subcategories from the literature were used as a coding frame. All data excerpts were coded and analysed separately by each author and then compared, discussed and verified collectively.

Findings
There was evidence of emotional, cognitive and social therapeutic benefits when participating in QRI about end of life and bereavement with 53 data examples of therapeutic benefit across the 23 interviews (emotional n=23, cognitive n=17, social n=13). These are now explored in more depth together with illustrative data excerpts.

Emotional benefits
The importance of having someone to talk to was clearly identified in the interviews. In Dataset 2, one participant had recently moved into a rest home. Throughout the interview, he expressed emotional turmoil at the realisation that his wife was now a visitor, that he was probably not going to see his home again and that he was probably going to die in a rest home. He admits: “I probably wouldn’t say these things to [wife’s name]... This is helping me talking to you.”

The importance of having someone to listen was further evidenced in an interview with a son whose father had died in ICU (Dataset 1). The son spoke in detail about the last time he saw his father. Field notes documented that after the interview, the son revealed that this was the first time he had spoken to anyone about his father, and how glad he was to talk about him.

For some participants, QRI provided opportunity to share and explore experiences which had not been previously discussed. In this excerpt from Dataset 2, the participant used language which suggests emotional release through the interview:

“Researcher: Just as we draw the interview to a close, is there anything that you’ve thought about that you would want opportunity to say before I turn the tape off?
Participant: No I don’t think so.... no I think I’ve unburdened my soul, thank you.”

Cognitive benefits
There was often an exchange of information in QRI that helped participants make sense of situations, especially during transition points. In the following quote, the participant lamented the
rules he had to live by since moving into the rest home (Dataset 2). However, as his internalised problems became externalised during the QRI, he realised a new perspective:

“Participant: When you come to a place like this suddenly there’s all the rules and regulations for the good of everybody, you have to adhere to.
Researcher: What sort of rules?
Participant: Rules.
Researcher: Can you think of any examples?
Participant: It’s hard, things like you know you’ve got to eat at a certain time, breakfast certain I used to do that at home anyway all the same what I do here I used to do them at home. I mean you can’t play music as loud as you want to, I didn’t do that at home. Really rules and regulations I’ve lived by all my life.”

The death of the person with dementia was a relief for many family members in Dataset 3, and this brought feelings of guilt. Verbalising events enabled some participants to cognitively process their experiences and come to a new understanding:

“I feel bad for how I treated my Mum when I was a teenager... but I think she will forgive me. It’s just things that I didn’t know and I shouldn’t really feel guilty for it because I didn’t know at the time. So it’s not my fault. So yeah I shouldn’t really.”

Some QRI brought greater understanding of the events at end of life, as in this quote from a follow-up letter received from one participant in Dataset 1:

“I have found that following our conversation, after the interview, I do feel a bit better informed about my [name of family member] death and do feel that I have taken a big step on the grieving path.”

Social benefits
The final category concerned social benefits of participating in QRI. This included two key areas of how participating in QRI could meet participants’ need for human interaction (social needs), and be used for the greater good to help others (an altruistic act). In an interview from Dataset 2, the available social events and gatherings were explored. The participant suggested that the interview had actually helped by relieving some of his social isolation:

“Participant: Well they organise things where you can get together and listen to some music or do a little bit of drawing. I don’t think there’s anything more they could do. I mean this is helping me, talking to you.”

Participating in QRI was often seen as a way to help others. Participants often prepared notes prior to interview to ensure the detail of many (sometimes distressing) situations encountered was not forgotten, so as to help others. The participant (Dataset 1) below prepared written notes in advance of an interview, the purpose for this is clearly stated in the initial sentence of this quote:

“Participant: I am very much of the view that if this can help other people and their experiences... I’m very happy for you to take this, just something I wrote.... so if it would help at all.”

In the quote below, a participant (Dataset 2) commented that she was speaking for the benefit of others, suggesting an altruistic benefit. She perceived the interview as providing her with a voice. Where she was not physically able to ‘walk along the street and wave a flag’, the interview enabled to her be heard:

“Participant: I think I’ve got enough care but every chance I get I feel I must point out that somehow they should be able to find someone that they can trust to be a designated shopper. I want to emphasise it every time I come in contact [with someone] because... I do know that people die alone without anything in the cupboard because they’re just too weak
to manage themselves…. that is something that if I could walk along the street and wave a flag I would about this. So that’s something I just want to say.”

Discussion
What we have set out to do in this paper is to bring synthesis to existing literature on therapeutic benefit of QRI as used to direct the content analysis, and explore potential for therapeutic benefit of QRI specifically for participants in end of life and bereavement research. In acknowledging debates on the ethics of undertaking research on those considered to be vulnerable at end of life, it is important to be able to hold a balanced understanding of risks and benefits when considering QRI in this population. This paper proposes that whilst the primary purpose of QRI is, and should always be to collect data, there is potential for therapeutic benefit for this group.

With literature demonstrating emotional, cognitive and social benefits of QRI, there was evidence of all these benefits across datasets used in this secondary analysis study. The emotional benefits of QRI were most prominent in our study and, concurring with the literature, highlighted benefit in the cathartic process of talking to another person about experiences previously unspoken. Given the circumstances of end of life per se, and particularly end of life within intensive care (Dataset 1) and dementia care (Dataset 3), it is perhaps unsurprising that emotional benefit was most strongly identified here by participants.

Cognitive benefits of QRI were present and appeared related to increased understanding of processes and events, especially during transition points towards the end of the family member’s life. In common with the literature, this appeared to help participants make sense of events thereby enabling new perspectives to be attained. Further work is required to determine whether the nature of specific end of life trajectories or the quality of information given to families at end of life impact on this area. There was evidence of participating in QRI as relieving social isolation and of helping others through sharing of experiences. This may have been present here as participants were generally older, and those who experienced distressing episodes of care particularly wanted to improve care for others.

Given the potential for such therapeutic benefits, especially resultant from emotional catharsis, safeguards must be in place to protect participants and researchers. Firstly, researchers should hold in mind that the primary purpose of QRI is to collect research data and should reflexively consider the impact of their interview style on the participant’s emotional vulnerability. To ensure participants are kept safe, the researcher should be skilled in QRI techniques and be prepared for any practical or emotional support that may be required. This may include building in sufficient time for participants to talk ‘off-tape’ as well as ‘on-tape’ and identify support agencies so that participants are not left vulnerable.

Study limitations
Participants in the primary research were not specifically asked about any perceived therapeutic benefit from involvement in QRI. Whilst this is a limitation, we would argue that based on data gathered, participants were aware of benefits and made reference to these as evidenced in the data excerpts. This is an area requiring further exploration, including within different end of life contexts.

When considering therapeutic benefit, one must also acknowledge risk. Whilst we did not set out to explore this concept, we noted little evidence of risk across the datasets. We postulate that participants who judged risk to be excessive did not proceed to interview. Field notes identified some conversations (n=3) with potential participants who expressed concerns about the potential
for emotional distress. None of these participants continued through to QRI and counselling was offered. The issue of risk is a separate issue requiring more focussed investigation.

Conclusion
In this paper, we have posited that QRI can hold emotional, cognitive and social benefits for participants in end of life and bereavement research. Cleary recognising the primary focus of QRI as collecting data, and maintaining a safe research environment by use of skilled QRI researchers are important areas. However in considering the potential therapeutic benefit of QRI, an alternative view is offered to balance concerns about risks of QRI in this particular research population.

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Declaration of conflicting interests
The authors declare there is no conflict of interests.
References