PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	Experiences of preparing children for a death of an important adult during the COVID-19 pandemic: A mixed methods study
AUTHORS	Rapa, Elizabeth; Hanna, Jeffrey; Mayland, C; Mason, Stephen; Moltrecht, Bettina; Dalton, Louise J

VERSION 1 – REVIEW

REVIEWER	Cristina Pinto Centro Hospitalar de Entre o Douro e Vouga EPE, Palliative Care Unit
REVIEW RETURNED	18-Jun-2021

GENERAL COMMENTS	Congratulations on the great work and effort to report how the COVID19 pandemic came to accentuate even deeper previously already fragile healthcare issues as the approach to grieving and loss. The article is overall very easyreading, just wanted to report 2 pivotal questions that were on my mind persistently during the first reading and only got answered later on the article, in case you may want to clarify those earlier for better understanding. 1) does this work concern deaths from COVID19 or any cause of death during the pandemic? 2) the online survey for bereaved families and HSCP was the same? Also on the last paragraph of the "Implications for practice" section, where you read "Additionally, the proportion of grandparents who provideformal or informal ???? chindren..." ; I believe there is a "care" or "support" word missing, please revise. Other than this, let me once again congratulate you for the good work, it was a pleasure o read.

REVIEWER	Liz Lobb University of Technology Sydney, IMPACCT
REVIEW RETURNED	03-Jul-2021

GENERAL COMMENTS	Thank you for the opportunity to review this manuscripts. This group of authors has been prolific during the COViD-19 pandemic and to date have provided valuable early release information for clinicians. I have only minor comments. I feel a flow chart would be appropriate as I found I had to draw my own chart to see where respondents were accessed. It would be easier if when explaining that the data was drawn from a larger survey of 623 participants that 278 were bereaved relatives and 345 were health professionals as I had to calculate this myself. It seems a small response rate from such large numbers to the

	interviews. I am not clear what the protocol amendment was that led to a 2nd round of interviews of an additional 4 relatives and 2 health care professionals. I note that the reference list is incomplete e.g. refs 7,8,19. I also note that the bereaved relatives experienced a death during the first wave of the pandemic and the health care professionals during the first and second waves - through to December. Could this explain the disparity reported between bereaved relatives and HCPs - perhaps the HCPs perceived they got better at communicating with families as the pandemic progressed. Could the authors comment. Otherwise a valuable contribution to communication with children with messages for HCPs both during and outside of a pandemic.

REVIEWER	Jason Boland Hull York Medical School
REVIEW RETURNED	07-Jul-2021

GENERAL COMMENTS	Thank you for the opportunity to review this research study. This research gives further insight into a very important and under-researched area. Exploring experiences of preparing children for death and the role professionals have in supporting them. It is interesting to see the disparity amongst professionals and relatives accounts and something that probably reflects well what is happening in practice both pre and during the pandemic. The research also clearly gives suggestions on the needs of the bereaved and the type of support they require from professionals. There are good use of participant quotes to support the themes. My major comment is that the study appears to focus on children. There are no demographics for the children related to the participant other than relationship with deceased. Does not give age of children that are being discussed. The supplementary file suggests that adult children were also included. This needs to be made clear from the beginning. The abstract and introduction suggests this study focused on preparing children, which I would assume would be 0-18 no information was provided about the children who were relatives of the participants apart from relationship with the deceased. In the supplementary file it appears that children were classed as up to 25 years. So, some of them would be adults which is completely different findings and was not made clear anywhere in the body of the manuscript. Other comments: Abstract, page 3- line 17 typo interviews Page 4- Methods- what was the eligibility criteria for participation? Page 5- line 31- the relatives who completed the survey had experienced the death of a family member, it does not say if the deceased family members all had relationships with children or not. Page 7- line 48, unclear is this their relationship with the deceased family member? What were the participants relationship to the children and how old were the children?

	Line 52- 'most relatives…' does that mean that not all respondents deceased relative had a relationship with a child? If so why were they included? Supplementary file- line 10 children aged 0-25, it was not clear at the beginning of the study that children are considered from age 0-25. There needs to be a statement that explains the ages of children for the purpose of this study and a rationale behind this.

VERSION 1 – AUTHOR RESPONSE

Reviewer One	
Congratulations on the great work and effort to report how the COVID19 pandemic came to accentuate even deeper previously already fragile healthcare issues as the approach to grieving and loss. The article is overall very easy reading, just wanted to report 2 pivotal questions that were on my mind persistently during the first reading and only got answered later on the article, in case you may want to clarify those earlier for better understanding.	Thank you for this supportive comment.
Does this work concern deaths from COVID19 or any cause of death during the pandemic?	Thank you for this comment. We have provided further clarity surrounding the circumstances of the cause of death during the pandemic: **"Participants** *Bereaved relatives* The survey was completed by individuals (≥18 years old) who experienced the death of a family member or close friend during the first wave of the COVID-19 pandemic (March – June 2020) in the United Kingdom. There were no inclusion or exclusion criteria relating to the cause of the death. Of the 48 respondents that expressed an interest to be involved in follow-up research, a total of 19 relatives were interviewed; 28 potential participants did not respond to the interview invitation, and one declined." In the survey, bereaved relatives were asked: 'Was the person who died infected with Coronavirus?'. This has been added to the results and reflected in Table 2: "Of the 278 bereaved relatives, 110 reported their

	relative/friend 'definitely' or 'probably' had coronavirus." Text added to Table 2 **Was the person who died infected with Coronavirus?** Yes, certainly (82) Yes, probably (28) No, probably not (54) No, certainly not (92) Missing (22)
the online survey for bereaved families and HSCP was the same?	Two separate questionnaires were used. These are reflected in the supplementary file. Additional text has been added to the methods to reflect this: "The survey included questions about support for families in relation to preparing children for a death during the COVID-19 pandemic; questions were developed by the research team and were different for relatives and professionals (see supplementary file)."
Also on the last paragraph of the "Implications for practice" section, where you read "Additionally, the proportion of grandparents who provideformal or informal ???? chindren..." ; I believe there is a "care" or "support" word missing, please revise	Thank you for this. We have amended, and now reads as follows: "Additionally, the proportion of grandparents who provide formal or informal childcare for working parents means this population are significantly involved in the lives of children.[20]"
Reviewer Two	
Thank you for the opportunity to review this manuscripts. This group of authors has been prolific during the COViD-19 pandemic and to date have provided valuable early release information for clinicians.	Thank you for your supportive comment to our work.
I feel a flow chart would be appropriate as I found I had to draw my own chart to see where	Thank you for this. We agree with this author that it would be appropriate to include a figure to make

respondents were accessed. It would be easier if when explaining that the data was drawn from a larger survey of 623 participants that 278 were bereaved relatives and 345 were health professionals as I had to calculate this myself.	it clear how and when participants were involved in this study. This is reflected in Figure 1.
It seems a small response rate from such large numbers to the interviews.	Thank you for this comment. Within our survey, we did not use the 'forced response' option, and therefore not all professionals or relatives answered the questions. We felt this was appropriate to promote participant autonomy. This has been reflected in the ethical considerations section: "Participants were not forced to answer questions within the survey and each question was optional." We conducted 35 interviews and purposeful sampling was completed and when no further categories were identified.
I am not clear what the protocol amendment was that led to a 2nd round of interviews of an additional 4 relatives and 2 health care professionals.	Thank you for this comment. Follow-up interviews were conducted to provide clarity on experiences as these were not clear from the initial recording. This has been reflected in the methods section: "Preliminary analysis identified some of the categories developed from the transcript data required further clarification. Following discussion as a research team and a protocol/ethical amendment, JRH invited eight participants via email to take part in a second interview to provide clarity on their experiences. Four bereaved relatives and two HSCPs agreed to another interview."
I note that the reference list is incomplete e.g. refs 7,8,19	Thank you for highlighting these incomplete references. We have now amended these references. Just to note, reference 19 is now reference 20 due to the inclusion of another reference in the manuscript: [7] McCaughan E, Semple CJ, Hanna JR. 'Don't forget the children': a qualitative study when a parent is at end of life from cancer. Supportive Care in Cancer. 2021 Jun 18:1-8. https://doi.org/10.1007/s00520-021-06341-3 [8] Dalton LJ, McNivan A, Hanna JR, Stein A, Rapa E. Family centred communication when an

	adult patient is diagnosed with a life-threatening condition. In Prep. 2021 [20] Buchanan A, Rotkirch A. 'Twenty-first century grandparents: global perspectives on changing roles and consequences.' Contemporary Social Science. 2018; 13(2), 131-144. https://doi.org/10.1080/21582041.2018.1467034.
I also note that the bereaved relatives experienced a death during the first wave of the pandemic and the health care professionals during the first and second waves - through to December. Could this explain the disparity reported between bereaved relatives and HCPs - perhaps the HCPs perceived they got better at communicating with families as the pandemic progressed. Could the authors comment.	Thank you for this reflective insight. In terms of the quantitative data, the surveys for HSCPs and bereaved relatives ran concurrently so any disparity should not reflect the timings of the experiences being reported. The qualitative data collection was staggered, with the HSCP interviews taking place after those with bereaved relatives. However, the professional interviews did not include any reflections about how their practice had changed over the course of the pandemic. What seems more pertinent from the data is how professionals reflected on **not** having these conversations pre-pandemic.
Reviewer Three	
Thank you for the opportunity to review this research study. This research gives further insight into a very important and under-researched area. Exploring experiences of preparing children for death and the role professionals have in supporting them. It is interesting to see the disparity amongst professionals and relatives accounts and something that probably reflects well what is happening in practice both pre and during the pandemic. The research also clearly gives suggestions on the needs of the bereaved and the type of support they require from professionals. There are good use of participant quotes to support the themes.	Thank you for your kind and reflective comments towards our work.
My major comment is that the study appears to focus on children. There are no demographics for the children related to the participant other than relationship with deceased. Does not give age of children that are being discussed. The supplementary file suggests that adult children were also included. This needs to be made clear	Clarification has been provided to Table 3 in relation to the age of the children in the qualitative study with bereaved relatives. All children were less than 18 years old in the study.

from the beginning.	
Abstract, page 3- line 17 typo interviews	Thank you. This has been amended: “A total of 623 participants completed the survey and interviews were conducted with 19 bereaved relatives and 16 professionals**.”**
Page 4- Methods- what was the eligibility criteria for participation?	Clarification has been provided about the eligibility criteria for participation: “Participants were considered eligible to complete the survey if they were ≥18 years old, experienced the death of a family member or close friend during the first wave of the COVID-19 pandemic (March – June 2020), and resided in the United Kingdom. There were no inclusion or exclusion criteria relating to the cause of the death.” “HSCPs were considered eligible to take part in the survey if they provided end of life care during the first and second waves (March – December 2020) of the COVID-19 pandemic in the United Kingdom”
Page 5- line 31- the relatives who completed the survey had experienced the death of a family member, it does not say if the deceased family members all had relationships with children or not.	Thank you for this comment. The survey was embedded in a larger study about end of life experiences during the COVID-19 pandemic. Consequently, it is possible some took part in the survey that did not have important relationships with children. As part of this, this is why the questions about the children were not forced response, as this question may not be applicable for them. We have added a statement that reflects this: “It is possible that bereaved relatives did not answer the survey questions about the children as this may not have been reflective of their family composition.”
Page 7- line 48, unclear is this their relationship with the deceased family member? What were the participants relationship to the children and how old were the children?	Thank you for this comment. Clarification has been provided to this section: “The participant’s relationship with their family member varied, including spouse/partner (n = 4); son/daughter in-law (n = 2); adult child (n = 11); grandchild (n = 1); and niece (n = 1). Most relatives reported the deceased had significant relationships with children (<18 years old), including parent (n = 2), grandparent (n = 14), and aunt/uncle (n = 3).”

Line 52- 'most relatives…' does that mean that not all respondents deceased relative had a relationship with a child? If so why were they included?	This study was embedded in a larger study exploring bereaved relatives' experiences of end of life care during the COVID-19 pandemic. Therefore, some of the participants who were interviewed did report they did not have important relationships with the children. However, from an ethical perspective, we consider it appropriate to acknowledge the total number of interviews conducted in this study. Clarification has been provided as to how many bereaved relatives reported important relationships with children: "Most relatives (n = 16) reported the deceased had significant relationships with children (<18 years old), including parent (n = 2), grandparent (n = 14), and aunt/uncle (n = 3)." We have also reflected this with a statement in the strengths and limitations section: "This research was embedded in a national survey of end of life experiences during the COVID-19 pandemic and some of the bereaved relatives interviewed did not have important relationships with children; however it was considered ethically appropriate in the method section to report the total number of interviews conducted."

VERSION 2 – REVIEW

REVIEWER	Liz Lobb University of Technology Sydney, IMPACCT
REVIEW RETURNED	26-Jul-2021

GENERAL COMMENTS	Thank you for the revision of this manuscript. I am satisfied that my comments and those of the other reviewers have been addressed.

REVIEWER	Jason Boland Hull York Medical School
REVIEW RETURNED	26-Jul-2021

GENERAL COMMENTS	thank you for addressing our queries