

## **A comparative study of the impact of the COVID-19 crisis on the communication practices of end-of-life care workers**

MARGO TURNBULL, XIAOYAN IVY WU AND BERNADETTE WATSON

*Hong Kong Polytechnic University*

### **Abstract**

*Previous research has identified that effective and high-quality communication between patients, families and professionals is a key contributing factor to end-of-life (EOL) care and recovery after bereavement. Increasingly, this communication work is being done by non-clinical staff in places such as homes and community settings. These additional care providers offer important pre- and post-bereavement support that can improve the quality of EOL care as well as promote healthy grieving for families, friends and communities. Despite this contribution, though, little is known about how these non-clinical workers use communication in their daily practices. This paper reports on the analysis of a set of nine in-depth interviews conducted in Hong Kong and in one region of Australia that examined in detail relational aspects of communication that shape interactions between non-clinical workers and service users. Data were collected during the COVID-19 health crisis, when the workers experienced exceptional restrictions on communication. The findings of this study highlight the fundamental importance of both verbal and non-verbal communication to the relationships established between non-clinical workers and service users. Specifically, greater support for the development of communication skills in non-clinical EOL workers will promote improvements in the quality of EOL care.*

*Keywords: Australia, communication, community services, crisis, end-of-life, Hong Kong, workers*

## 1 Introduction

The provision of high-quality end-of-life (EOL) care is both a public health concern and a key element of ethical health care practice (Chan *et al.* 2020). Public health and ethical imperatives are derived from the importance of the experience for the individual (Scholz *et al.* 2020) as well as the support and recovery needs of bereaved families and friends (Chow *et al.* 2019) as well as service workers (Gjerberg *et al.* 2015). Communication between individuals, families and care workers has been consistently shown to be a key factor in the provision of care that is perceived both to be effective in the management of the end stage of life as well as conducive to grieving and recovery (Keeley and Generous 2017). However, the majority of research conducted on EOL communication has focused on the experiences and perspectives of clinical workers (Scholz *et al.* 2020). Our study, in contrast, aimed to extend this body of work by addressing the following research question: *How do non-clinical workers communicate with service users during the EOL stage?*

To address this research question, this paper presents the detailed analysis of nine in-depth, semi-structured interviews conducted with EOL workers in Hong Kong and in one region of New South Wales (NSW), Australia, during the COVID-19 health crisis in 2020. These interviews were gathered as part of a broader mixed-methods study that aimed to examine the impact of the exceptional infection control regulations associated with responses to COVID-19 on non-clinical workers in education and social care.

We first provide a brief review of literature concerning the study of EOL communication, with particular reference to non-clinical workers. We then outline the methods used for data collection and analysis and conclude the paper by highlighting specific dimensions of communication that were viewed as *essential* by these EOL workers. In our

discussion we highlight the dimensions of EOL communication in non-clinical contexts that warrant further investigation and support.

## **2. Literature review**

Communication in the EOL setting incorporates a broad range of people and interactions across clinical and non-clinical sites. Effective communication during the EOL period has been consistently linked with understanding and respect associated with ‘good death’ (Aldridge and Barton 2007; Anderson *et al.* 2019; Curtis *et al.* 2018). Research into strategies and practices that constitute effective communication at EOL has grown in recent years but there remains limited consensus on how practice improvements can be achieved (Curtis *et al.* 2013; Brighton *et al.* 2017).

Death in the modern world is most often associated with clinical settings, and thus the majority of research focused on EOL communication has drawn on data from hospitals, hospices and palliative care settings (Banerjee and Rewegan 2017; Keeley and Generous 2017; Scholz *et al.* 2020). This research has focused on various areas of interest including the emotional challenges faced by clinical workers as well as the multiplicity of skills required for careful management of emotional and medical needs (Kozłowska and Doboszynska 2012; Tse *et al.* 2016; Chan *et al.* 2020; Omori *et al.* 2020; Scholz *et al.* 2020). These competencies can be optimised through various approaches to communication training (Selman *et al.* 2017; Brighton *et al.* 2019) that often take up a skills-based perspective (Banerjee and Rewegan 2017). The experiences of individuals and families are fundamental to this relationship-based work, and the importance of patient-centred care and communication in the EOL setting has been reiterated in studies across regions and cultures (Keeley and Generous 2017; Brighton *et al.* 2019; Beaunoyer *et al.* 2020; Golightley and Holloway 2020; Wong *et al.* 2020).

However, communication that contributes to high quality EOL and bereavement care is often done by non-clinical staff in places such as homes, community services and religious settings, as well as care or residential homes run by non-government organisations (Chung *et al.* 2020). Demographic changes associated with ageing populations as well as greater choice in the location of care means that increasing numbers of deaths in some regions are occurring in these non-clinical community sites (Finucane *et al.* 2019). Despite these shifts, non-clinical EOL workforces remain relatively fragmented, as these workers are often employed on casual and part-time contracts and may work across multiple sites (Hussein 2018) or take on duties as volunteers. Underinvestment in services and workers in this sector has been identified in some developed countries (Chung *et al.* 2020) and this has impacted upon the provision of training and skills development for individuals.

An emerging interest in the implications of the non-clinical EOL sector has been reflected in recent publications focused on groups such as social workers and volunteers (Wang *et al.* 2020), generalist palliative care providers (Brighton *et al.* 2019) and carers of older adults in residential settings (Omori *et al.* 2020). The findings of these studies often emphasise the importance of relational care and communication as individuals and families are brought together at the end of life and offered psychosocial support from a variety of workers (Banerjee and Rewegan 2017; Brighton *et al.* 2019; Omori *et al.* 2020). Relational care in this context refers to practices or behaviours of workers that promote safety, trust and open communication (Banerjee and Rewegan 2017). The dimensions of communication that facilitate relational care include taking time to interact, directing personal attention towards individuals and families and supporting open discussion about various topics related to death and grief (Jonsdottir *et al.* 2004). Manusov and Keeley (2015) reported that effective communication at this stage contributed to what people described as *companionship*, with key influences including physical proximity (proxemics) and time (chronemics). It is also of

note that research has identified that the *type* rather than quantity of communication contributes to positive post-loss outcomes for families and friends (Metzger and Gray 2008). The links between relational care and communication and worker resilience are yet to be examined in detail for non-clinical EOL workers, although research in other sectors has consistently identified positive communication as an important variable in job satisfaction and stress management for workers in jobs with such intense emotional demands (Ablett and Jones 2007; Aiello and Tesi 2017; Brighton *et al.* 2019).

Since the emergence of COVID-19 in 2020, governments and institutions have introduced a range of policies to attempt to control the spread of the virus and protect vulnerable communities. These regulations have placed exceptional restrictions on the work of non-clinical staff through limiting visits to residential settings, funeral services and face-to-face counselling (Wallace *et al.* 2020). Considering how communication has been limited as well as how staff have adapted during this period provides an opportunity to reflect on those dimensions of communication considered essential within non-clinical EOL services.

### **3 Data and methods**

#### **3.1. Data**

This paper draws on data collected through nine interviews as part of a broader two-stage mixed-methods study undertaken in Hong Kong and in one region of Australia. These two locations were selected to reflect the global nature of the pandemic and to consider the feasibility of cross-cultural studies of EOL communication. Ethics approval for this study was granted by the relevant body at The Hong Kong Polytechnic University<sup>1</sup>. Stage one of this study involved completion of an online survey for demographic data collection and an option for respondents to volunteer to participate in follow-up interviews (stage two). All

researchers and authors were located in Hong Kong and the research participants gave informed, written consent to participate in the study.

The interviewees were issued with a research ID code to ensure anonymity, and the interviews were audio recorded and transcribed verbatim by either the interviewer or another member of the research team. The transcripts were then checked for accuracy by another team member. No personal or identifiable details were collected or stored during this research. The research participants provided informed and written consent prior to the interview. All personal identifiers have been removed so that the person(s) described cannot be identified through the details of the story. The research participants did not receive any incentives or rewards for participation.

### **3.2. *Participants and procedure***

The research participants were recruited through a convenience sampling approach (Meltzer *et al.* 2012) via existing research and social networks. The research participants were adult workers (over 18 years of age) and the inclusion criteria for participation were as follows:

1. currently employed as a paid worker in EOL services offered by government, private and not-for-profit (non-government) organisations including those offering funeral, religious and/or community services; and
2. personally involved in delivering pre- and/or post- bereavement care during the current global health crisis.

### **3.3. *Methods***

Twenty people completed the survey and nine volunteered to participate in the interviews. These volunteers were contacted directly by the research team and the interviews were

conducted in September and October 2020. The interviewees were aged over 35 except for one Hong Kong interviewee, who indicated they were aged between 20 and 35 years. The interviewees reported they had between four and 22 years of experience in the sector. In terms of reported gender, five interviewees were female (two in Hong Kong, three in Australia) and four were male (one in Hong Kong, three in Australia). The three Hong Kong interviewees indicated that they were employed in community services. All six Australian interviewees were employed in religious organisations and were additionally involved in funeral services. The interviewees were not directly asked to provide details about professional qualifications, but some participants indicated they had trained as nurses, social workers and counsellors.

The interviews were semi-structured and followed an interview guide developed by the research team (see interview guide in the Appendix). One of the research team (MT) conducted interviews in English with the six Australian interviewees and another member (XW) conducted interviews in Cantonese Chinese with the three participants in Hong Kong. The interview aims were to collect data on the workers' perceptions and experiences of communication with individuals and families during the COVID-19 crisis, and were based around the following introductory question: *How have the infection control regulations associated with COVID-19 affected the way you do your work and interact with your service users?* The interviewees were also invited to provide feedback on the structure and content of the survey. All interviews were conducted remotely over the phone or using an internet service (e.g. Skype, Zoom) and lasted between 15 and 25 minutes, with an average of 19 minutes. Four of the Australian interviewees used video connections and the five other interviewees used audio services only.

The verified interview transcripts were analysed using an inductive approach (Braun and Clarke 2006) and conventional content analysis (Hsieh and Shannon 2005; Lundgren *et*

*al.* 2015) in the original source language. The Chinese data has been translated into English for publication. The utterance (i.e. the smallest unit of speech with cohesive semantic meaning) was the unit of analysis and the context of the utterance was considered while coding (Bryman 2001). The free version of Atlasti 8 software (<https://atlasti.com/>) was used for data management. Two research team members (MT and XW) read each transcript several times as a whole text, extracted utterances for coding and independently generated initial codes. Across the data, 208 utterances were initially extracted and 40 codes were originally generated through independent coding. These were then revised by the research team using a constant comparative method. After revision, 19 individual codes were agreed and the researchers then grouped these into two overarching themes and five associated subthemes (see Table 1, below). These codes were then used to code all transcripts and a total of 140 utterances (72 English and 68 Chinese) were recoded with one or more of the agreed codes by two research team members (MT and XW). There was a high rate of agreement after the initial round of recoding and any discrepancies were reviewed and discussed until consensus was reached.

#### **4. Findings**

The analysis of the interview transcripts focuses on how the infection control regulations impacted upon communication between workers and service users and families. As reflected in the high level of emotional demands in these jobs reported in the literature review, the interviewees noted that interpersonal interaction made up a significant proportion of their daily work. The changes associated with the health crisis affected how the care workers were able to fulfil job tasks related to communication and, in turn, attend to the emotional needs of others during a time of significant personal and familial crisis. Changes in communication, particularly the loss of nonverbal and interactional dimensions of communication, were



linked in the interview discussion with increased levels of stress and anxiety and decreased levels of job satisfaction. Two themes and five associated subthemes were identified in the analysis of the interview data (Table 1) and are discussed in detail below.

<Insert table 1 here>

#### **4.1. *Altered communication and interaction***

Thirty-six percent of coded utterances referred to changes in interpersonal communication. These comments were usually related to the loss of *nonverbal communication* dimensions as a result of social distancing regulations and limitations on personal contact and gatherings. These limitations were linked specifically to *losses*, which are discussed under the following subthemes: (1) loss of time and opportunity to communicate; and (2) loss of tactile interaction practices such as hand holding, hugging and shaking hands, and minimisation of facial expressions such as smiling and eye contact due to face masks or other coverings.

##### **4.1.1. *Loss of time and opportunity to communicate***

The participants commented on the loss of time and opportunity to be present physically with service users at the end of their life due to restrictions on access to settings such as hospitals, hospices and community venues such as residential homes. The participants involved in both religious and community support work reported that being able to visit people, often at short notice, at the end of their life was a key element of their work and often reflected the culmination of a relationship that had been built up over a period of time. The Australian interviewees said that clinical settings had at times been able to facilitate such visits but that generally this service had been significantly restricted during the health crisis. This loss of time and opportunity to communicate with service users was discussed in terms of limiting

the care workers' ability to fulfil EOL wishes and provide support for families and carers.

This is evident in Extract 1, which is taken from an interview with an Australia priest.

### **Extract 1**

And I think it really will change the nature of people at their...in their end-of-life care, not just logistically, but sort of spiritually. Like there's a whole cultural thing about, you know, getting the family around, gathering the family around. (Aust. priest \_01)

Time and physical presence at EOL was also linked with social and cultural expectations for some people, and this loss was described as a disruption to those established ritual practices. The loss here was also connected to broader changes in the grieving experience. For example, time and presence at memorial services and funerals was noted as being of value to communities as well as being a reflection of the significance of the person who had died. The significance of time and opportunity for communication are reflect in Extracts 2, 3 and 4.

### **Extract 2**

And in terms of funerals, I just think like if we have to live with continued restrictions on numbers at funerals then it will ultimately change the nature of funerals from being like a big thing where everyone in the world who knew 'Joe' turns up to be there for 'Joe'. (Aust. priest\_01)

### **Extract 3**

Now the gentleman whose funeral I took at [city], now he was a key figure in the community and we were allowed to have 20 people at his funeral. [...] So the

community missed out on the opportunity to honour his life. And there was an intention to have a memorial service after things settle down. But I think by the time things settle down, it's going to be too late. (Aust. priest\_05)

Similarly, the Hong Kong interviewees talked about the loss of personal contact with their service users and how that made it difficult to build a picture of people's needs and to connect with them at the end of their life. Online or phone contact was not an adequate substitute.

#### **Extract 4**

其實真係大家平時就真係有啲服務真係講感情。佢哋要係實體……咁佢見到你哋、即係見到一啲同事、工作人員，佢哋會好開心啦。

[In fact, some of our services are really about rapport. They (the service users) would want something tangible... When they meet us, like some colleagues and other staff, they will be very delighted.] (HK community services worker\_03)

The interviewees consistently commented on the impact of this loss of physical proximity and presence and discussed how this had altered communication. This loss impacted upon the reinforcement of support relationships as well as important opportunities to talk about and prepare for post-bereavement tasks such as funeral planning and fulfilling the wishes of the deceased. As shown in Extract 5, other modes of communication (such as phone calls) were used for some tasks, but the nature of interaction and presence were fundamentally altered and the interviewees observed that they had lost the ability to collect holistic information about their service users through observation.

### **Extract 5**

我同佢面對面見嘅時候，我睇到佢嘅眼神、表情、動作、佢嘅活動能力、佢家居嘅環境……但係呢因為我哋啲老人家有陣時都真係八、九十歲，佢哋都唔係用 smartphone 嘅人嚟嘅。

[When I meet them in person, I could observe their eyes and facial expressions, gestures, physical mobility, and their living environment... But some of our service users are in their eighties or nineties and they are not smartphone users.] (HK community services worker\_01)

#### *4.1.2. Loss of nonverbal and tactile interaction and communication*

Dimensions such as hand holding, hugging and shaking hands were also noted as a significant loss in communication. These dimensions were not related to conveying information but rather to signifying comfort and company and, as with time and opportunity to communicate, were also linked to grieving and recovery for bereaved families. The importance of these dimensions is evident in Extracts 6, 7 and 8.

### **Extract 6**

I was thinking of those hospital visits where, you know, normally you sit beside a bed and hold someone's hand and look at them. (Aust. priest\_02)

### **Extract 7**

家訪都好緊要所以，即係對我地嚟講，同埋即係成個氣氛係親切呀，嗰啲咁樣㗎嘛。我地係想做到呢個感覺。

[Therefore, home visits are really important. For us, a welcoming and comfortable atmosphere or alike is what we want to provide.] (HK community services worker\_01)

The loss of these dimensions of communication also impacted on the expression of grieving at funerals.

### **Extract 8**

I think the lack of physical contact was huge, like at the end of the funeral, usually you shake hands and you stand with the people and say, if you need if need, contact I'm here that sort of thing. And they're able to mingle with the people who have come, but they're not supposed to hang around. [They're] supposed to leave. (Aust. priest\_02)

Wearing face masks limited facial expression and, in combination with required social distancing, even eye-contact was reported as being difficult at times. This made a particular difference to people with poor eyesight or hearing loss. The respondents in Hong Kong and Australia commented that limited facial expressions and eye contact made it more difficult to communicate with people who had dementia or hearing loss and their comprehension of what was being explained to them was reduced. A Hong Kong participant remarked that it was nearly impossible to communicate with these people and assess an emergency online (Extract 9).

### **Extract 9**

即係喺一個危急嘅情況，因為有啲譬如我哋都接觸過就係佢個老人家即係一係就唔識用嗰啲視像啦，一係呢就佢聾嘅或者佢認知障礙嘅咁樣。咁你隔住個 mon 真係同佢完全 sense 唔到呀，即係佢又唔覺得你存在。咁你又即係 assess 唔到一啲嘅狀況。

[Just like when we are under an emergency, some of our elderly service users either have no idea how to use video calls or they are suffering from hearing loss or dementia. You cannot recreate the in-person feeling, nor can they sense your presence via the monitor. You simply cannot assess the situation at the other end.] (HK community services worker\_01)

#### **4.2. *Impact of changes in communication on care workers***

Sixty-four percent of coded utterances directly linked changes in communication to significant impact on the care workers' roles and job functions. This, in turn, increased the care workers' own perceptions of stress and anxiety. This theme incorporated three subthemes: (1) inability to fulfil role; (2) changes in roles and responsibilities; (3) and increased workload.

##### **4.2.1. *Inability to fulfil role***

All interviewees repeatedly commented on the impact of infection control regulations as affecting their ability to fulfil their role as expected by families and service users. The interviewees commented on the expectations and plans people had for bereavement and grieving that had to be suddenly altered. The interviewees linked this sense of disappointment with increased personal stress levels, as shown in Extracts 10 and 11.

#### **Extract 10**

They (infection control regulations) have impacted pretty significantly on families that we are helping, you know, farewell their loved one. And they're not able to do that in the way they would wish so that it's difficult for them at an already difficult time. And it's also difficult for us and the funeral directors who just want to be able to give them what they want and we can't. (Aust. priest\_01)

#### **Extract 11**

即係以往探訪我哋會去同佢傾一啲 advanced care planning 啦，或者係會有啲即係有啲叫 wish fulfillment 嘅活動，又或者係希望有多啲嘅譬如一啲佢哋 enjoy 嘅活動係可以離開嗰個病人嘅身份，或者係等佢就算係喺個 end stage 呢都可以有啲 quality of life 咁樣。咁而家出街嗰啲就梗係做唔到啦。係呀，譬如以往佢哋想去酒店食飯咁樣，又或者係去 museum 睇嘢咁樣，而家呢啲就真係做唔到啦。

[In our past visits, we would discuss advanced care planning with them (service users) or have some activity called wish fulfilment and we hope that there could be more activities that they enjoy, which can help them draw out from their roles as patients so that they could also have some quality of life even at the end-stage. Now, of course, we can't have outdoor activities. That is, for example, in the past, they would want to dine in hotels or visit museums but can't do any of those now.] (HK community services worker\_02)

#### *4.2.2. Changes in roles and responsibilities*

Another key change concerned new responsibilities in terms of implementing infection control regulations. This was particularly evident in comments from Australian interviewees who were involved in church and funeral services and who had to take on roles as enforcers of rules. Extract 12 is an example.

### **Extract 12**

You've got to be a bit more authoritarian with that. So having to remind people and even with things like hand sanitising and yeah that sort of thing, like don't forget ... And it's sort of almost like mum. (Aust. priest\_05)

Some comments indicated that care workers recognised and accepted the need for these rules but also highlighted the difficulty of enforcing such regulations in sites such as churches and cemeteries. The need to devise and enforce these rules was stressful and, as shown in Extract 13, sometimes led to conflict and negative interaction with bereaved families.

### **Extract 13**

Then we did have another (funeral) here at [town name] and I did the service. But the strange thing is we were trying to limit it to the 25 and make sure it was only family and a couple of people lied as they went in and said they were family and we sort of just got to look at them and say, well I can't start an argument here. (Aust. priest\_06)

#### *4.2.2. Increased workload*

The interviewees commented on increased workloads associated with infection control regulations. Close analysis of these comments suggests that this perceived stress may have been related to increased and new tasks (such as devising restrictions for cemeteries and funerals, developing video-based resources to replace face-to-face contact) *as well as* the loss of relationships and interactions with service users and families around the time of bereavement. As illustrated in Extract 14, the care workers invested additional time and effort



into trying to find high-quality ways of compensating for the loss of communication, but these often fell short of expectations.

#### **Extract 14**

其實個工作量呢係大咗好多好多。同埋嗰啲嘢唔係我地熟手。正如你拍片嗰啲呢，我地坦白講我地唔係嗰啲網紅。即係唔識拍㗎……我地又唔可以拍得太簡陋啦，都要保住機構少少嘅名聲呀。

[In fact, our workload has increased tremendously and those things are not familiar to us. Take filming as an example. Honestly, we are not online celebrities. We don't know how to film stuff... But we can't make it too simple or crude. We have to maintain the reputation of the organization somehow.] (HK community services worker\_03)

### **5. Discussion**

The analysis of this interview data highlights the multidimensional nature of communication that these non-clinical EOL workers engage in. The alterations in communication practices and perceptions of 'losses' emphasise the fundamental importance of time and physical presence as well as nonverbal and tactile dimensions of interpersonal interaction. Unlike descriptions of communication that focus on information transmission, these care workers highlighted what can be described as paralinguistic and relational features of communication (Rogers 2008), with an emphasis on the proxemic and chronemics aspects of communication that have been identified in other EOL research (Manusov and Keeley 2015). These features were foregrounded through discussion of aspects of communication that were 'lost' as a result of the infection control regulations.

In addition to identifying these changes in communication practices, the interviewees also discussed some of the consequences from both a personal and professional perspective. The interviewees reported being unable to fulfil their job roles and described the emotional consequences in terms of disappointment and stress. Previous research has emphasised the consistently high emotional demands associated with clinical EOL work (Ablett and Jones 2007; Brighton *et al.* 2019) and it is likely that non-clinical workers experience similar levels of emotional involvement. The nature of communication for non-clinical workers may involve a greater proportion of interpersonal and relational work, as they are less involved with managing clinical details and more committed to communication practices involved in providing company, empathy and support. Thus communication may play an even greater part in their resilience.

The benefits of access to communication training for clinical workers in relation to pre- and post-bereavement periods are well known (Scholz *et al.* 2020), and similar provision needs to be developed for non-clinical community-based workers. Communication for these workers is complex and requires advanced skills and awareness in relation to offering psychosocial supports to families and individuals. The challenges faced by these care workers during the COVID-19 pandemic have highlighted those dimensions of communication that are valuable and influential in shaping relational care. Aspects of nonverbal communication such as facial expression, time, physical presence as well as tactile contact like hand holding were described as significant losses during this crisis period. As has been identified in previous research (Aiello and Tesi 2017; Chow *et al.* 2019), EOL workers often draw on positive relationships with service users to help manage their own emotions and stress levels. Changes to these relationships and communication opportunities are likely to have significant impact on stress and anxiety levels for community-based workers.

Research into workers' resilience in other EOL sectors highlights the importance of training and support for non-clinical EOL workers. Care workers themselves need to understand more about the integral and complex nature of communication and its role in the management of personal and work-related stress as well as the provision of high-quality care. As noted by one interviewee, there is a risk that some of the changes established during the period of this crisis may have a long-lasting impact on the nature of community-based service provision, especially if services remain fragmented and with limited investment. Changes such as the increase in online or virtual services may help to manage costs but some of the unique benefits of interpersonal communication will be lost. It is, therefore, important that managers and care workers understand more about the dimensions of communication that need to be restored and further developed. Additionally, some of the service adaptations devised during this period provide important insights into how communication practices can be improved across the sector in the longer term.

## **6. Conclusion**

Our findings foreground the importance of nonverbal and interpersonal aspects of communication during the EOL stage. Studies of communication during EOL have focused on both verbal and nonverbal communication but with little elaboration on the latter, particularly from the perspective of community-based service providers. The nature of the COVID-19 global pandemic and the strategies introduced to mitigate the spread of the virus raise the likelihood that there are numerous care workers, families and communities who have not been able to experience bereavement and begin recovery in an optimal fashion. This has implications for public health and the wellbeing of community-based workers. It also provides a valuable opportunity to learn more about the communication 'losses' that have been experienced, in order to help to strengthen future service development. Similarly, some

of the service developments and adaptations that care workers have devised provide insight into how communication practices can be improved in the future.

The limitations of this study include the small sample size, which means that the findings cannot be generalised to broader groups. Only three Chinese interviews were conducted, so a systematic comparison of the subthemes between the two interviewee cohorts was not feasible. However, the findings of this research suggest similarities across the two locations in the communication needs of both care workers and service users during this life stage. Future research that explores intercultural communication at EOL would provide valuable insights for services supporting multicultural communities.

It is of note that although data were collected during the period of the health crisis, the insights generated have relevance beyond the current context. Attending to care workers' experiences and descriptions of how communication practices were adapted and changed during this intense time offers unique insights into the broader topic of communication at EOL.

## **Acknowledgements**

We would like to acknowledge and thank Ms Ching Wai Ho and Dr Amos Yung for their support with translation and analysis of the Chinese language data.

## **Funding**

This work was supported by a grant from the Departmental General Research Fund, Department of English, The Hong Kong Polytechnic University.

## **Note**

1. The ethical approval reference is HSEARS20200805002-01.

## References

- Ablett, Janice R. and Robert S. P. Jones (2007) Resilience and well-being in palliative care staff: A qualitative study of hospice nurses' experience of work. *Psychooncology* 16 (8): 733–740.
- Aiello, Antonio and Alessio Tesi (2017) Emotional job demands within helping professions: Psychometric properties of a version of the Emotional Job Demands scale. *TPM-Testing, Psychometrics, Methodology in Applied Psychology* 24 (2): 167–183.
- Aldridge, Matthew and Ellen Barton (2007) Establishing terminal status in end-of-life discussions. *Qualitative Health Research* 17 (7): 908–918.
- Anderson, Rebecca, J., Steven Block, Megan Armstrong, Patrick C. Stone and Joseph Ts Low (2019) Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative Medicine* 33 (8): 926–941.
- Banerjee, Albert and Alex Rewegan (2017) Intensifying relational care: The challenge of dying in long-term residential care. *Journal of Canadian Studies* 50 (2): 396–421.
- Beaunoyer, Elisabeth, Lisandro H. Torres, Lenn Maessen and Matthieu J. Guitton (2020) Grieving in the digital era: Mapping online support for grief and bereavement. *Patient Education and Counseling* 103 (12): 2515–2524.
- Braun, Virginia and Victoria Clarke (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3 (2): 77–101.
- Brighton, Lisa J., Jonathan Koffman, Amy Hawkins, Christine McDonald, Suzanne O'Brien, Vicky Robinson, Shaheen A. Khan, Rob George *et al.* (2017) A systematic review of end-of-life care communication skills training for generalist palliative care

- providers: Research quality and reporting guidance. *Journal of Pain and Symptom Management* 54 (3): 417–425.
- Brighton, Lisa J., Lucy E. Selman, Katherine Bristowe, Beth Edwards, Jonathan Koffman and Catherine J. Evans (2019) Emotional labour in palliative and end-of-life care communication: A qualitative study with generalist palliative care providers. *Patient Education and Counseling* 102 (3): 494–502.
- Bryman, Alan (2001) *Social Research Methods*. Oxford: Oxford University Press.
- Chan, Carmen W. H., Meyrick C. M. Chow, Sally Chan, Robert Sanson-Fisher, Amy Waller, Theresa T. K. Lai and Cecilia W. M. Kwan (2020) Nurses' perceptions of and barriers to the optimal end-of-life care in hospitals: A cross-sectional study. *Journal of Clinical Nursing* 29 (7–8): 1209–1219.
- Chow, Amy Y. M., Michael Caserta, Dale Lund, Margaret H. P. Suen, Daiming Xiu, Iris K. N. Chan and Kurtee S. M. Chu (2019) Dual-process bereavement group intervention (DPBGI) for widowed older adults. *The Gerontologist* 59 (5): 983–994.
- Chung, Roger Y.-N., Dong Dong, Nancy N. S. Chau, Patsy Y.-K. Chau, Eng K. Yeoh and Eliza L.-Y. Wong (2020) Examining the gaps and issues of end-of-life care among older population through the lens of socioecological model – A multi-method qualitative study of Hong Kong. *International Journal of Environmental Research and Public Health* 17 (14): Article 5072.
- Curtis, J. Randall, Anthony L. Back, Dee W. Ford, Lois Downey, Sarah E. Shannon, Ardith Z. Doorenbos, Erin K. Kross, Lynn F. Reinke *et al.* (2013) Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: A randomized control trial. *Journal of the American Medical Association* 310 (21): 2271–2281.

- Curtis, J. Randall, Lois Downey, Anthony L. Back, Elizabeth L. Nielsen, Sudiptho Paul, Alexandria Z. Lahdya, Patsy D. Treece, Priscilla Armstrong, Ronald Peck and Ruth A. Engelberg (2018) Effect of a patient and clinician communication-priming intervention on patient-reported goals-of-care discussions between patients with serious illness and clinicians: A randomized clinical trial. *JAMA Internal Medicine* 178 (7): 930–940.
- Finucane, Anne M., Anna E. Bone, Catherine J. Evans, Barbara Gomes, Richard Meade, Irene J. Higginson and Scott A. Murray (2019) The impact of population ageing on end-of-life care in Scotland: Projections of place of death and recommendations for future service provision. *BMC Palliative Care* 18 (1): Article 112.
- Gjerberg, Elisabeth, Lillian Lillemoen, Reidun Førde and Reidar Pedersen (2015) End-of-life care communications and shared decision-making in Norwegian nursing homes – Experiences and perspectives of patients and relatives. *BMC Geriatrics* 15 (1): Article 103.
- Golightley, Malcolm and Margaret Holloway (2020) Editorial: Unprecedented times? Social work and society post-Covid-19. *British Journal of Social Work* 50 (5): 1297–1303.
- Hsieh, Hsiu-Fang and Sarah E. Shannon (2005) Three approaches to qualitative content analysis. *Qualitative Health Research* 15 (9): 1277–1288.
- Hussein, Shereen (2018) Job demand, control and unresolved stress within the emotional work of long term care in England. *International Journal of Care and Caring* 2 (1): 89–107.
- Jonsdottir, Helga, Merian Litchfield and Margaret Dexheimer Pharris (2004) The relational core of nursing practice as partnership. *Journal of Advanced Nursing* 47 (3): 241–248.

- Keeley, Maureen P. and Mark A. Generous (2017) Final conversations: Overview and practical implications for patients, families, and healthcare workers. *Behavioral Sciences* 7 (2): 17–25.
- Kozłowska, Lena and Anna Doboszynska (2012) Nurses' nonverbal methods of communicating with patients in the terminal phase. *International Journal of Palliative Nursing* 18 (1): 140–146.
- Lundgren, Johan, Gerhard Andersson, Örjan Dahlström, Tiny Jaarsma, Anita K. Köhler and Peter Johansson (2015) Internet-based cognitive behavior therapy for patients with heart failure and depressive symptoms: A proof of concept study. *Patient Education and Counseling* 98 (8): 935–942.
- Manusov, Valerie and Maureen P. Keeley (2015) When family talk is difficult: Making sense of nonverbal communication at the end-of-life. *Journal of Family Communication* 15 (4): 387–409.
- Meltzer, Christine E., Thorsten Naab and Gregor Daschmann (2012) All student samples differ: On participant selection in communication science. *Communication Methods and Measures* 6 (4): 251–262.
- Metzger, Patricia, L. and Matt J. Gray (2008) End-of-life communication and adjustment: Pre-loss communication as a predictor of bereavement-related outcomes. *Death Studies* 32 (4): 301–325.
- Omori, Maho, Jude Jayasuriya, Sam Scherer, Briony Dow, Marie Vaughan and Steven Savvas (2020) The language of dying: Communication about end-of-life residential aged care. *Death Studies* 13: 1–11.
- Rogers, L. Edna (2008) Relational communication theory: A systemic-interactional approach to interpersonal relationships. In Leslie Baxter and Dawn Braithwaite (eds)



*Engaging Theories in Interpersonal Communication: Multiple Perspectives*, 335–348. Thousand Oaks: SAGE Publications.

Scholz, Brett, Liza Goncharov, Nathan Emmerich, Vinh N. Lu, Michael Chapman, Shannon J. Clark, Tracey Wilson, Diana Slade and Imogen Mitchell (2020) Clinicians' accounts of communication with patients in end-of-life care contexts: A systematic review. *Patient Education and Counseling* 103 (10): 1913–1921.

Selman, Lucy Ellen, Lisa J. Brighton, Amy Hawkins, Christine McDonald, Suzanne O'Brien, Vicky Robinson, Shaheen A. Khan, Rob George *et al.* (2017) The effect of communication skills training for generalist palliative care providers on patient-reported outcomes and clinician behaviors: A systematic review and meta-analysis. *Journal of Pain and Symptom Management* 54 (3): 404–416.

Tse, Johnson W. K., Maria S. Y. Hung and Samantha M. C. Pang (2016) Emergency nurses' perceptions of providing end-of-life care in a Hong Kong emergency department: A qualitative study. *Journal of Emergency Nursing* 42 (3): 224–232.

Wallace, Cara L., Stephanie P. Wladkowski, Allison Gibson and Patrick White (2020) Grief during the Covid-19 pandemic: Considerations for palliative care providers. *Journal of Pain and Symptom Management* 60 (1): e70–e76.

Wang, Qianrong, Iris K. W. Chan and Vivian W. Q. Lou (2020) Effectiveness of a holistic capacity-building program for volunteers in community-based end-of-life care. *Research on Social Work Practice* 30 (4): 408–421.

Wong, Eliza L. Y., Nicole Kiang, Roger Y. N. Chung, Janice Lau, Patsy Y. K. Chau, Samuel Y. S. Wong, Jean Woo, Emily Y. Y. Chan and Eng-Kiong Yeoh (2020) Quality of palliative and end-of-life care in Hong Kong: Perspectives of healthcare providers. *International Journal of Environmental Research and Public Health* 17 (14): Article 5130.

**Margo Turnbull** received her PhD in primary health care from the University of Technology, Sydney. She is currently research assistant professor at The Hong Kong Polytechnic University. Her research interests include health and wellbeing, communication, group interaction and community recovery after trauma. Address for correspondence: International Research Centre for the Advancement of Health Communication, The Hong Kong Polytechnic University, Yuk Choi Road, Hung Hom, Hong Kong SAR, China. Email: [margo.turnbull@polyu.edu.hk](mailto:margo.turnbull@polyu.edu.hk)

**Xiaoyan Ivy Wu** is a communication researcher with a particular interest in barriers and facilitators to patient care in Hong Kong public hospitals and community-based services. She is also interested in intercultural communication and crosscultural adaptation positioned at the intersection of crosscultural psychology and the social psychology of language. Address for correspondence: International Research Centre for the Advancement of Health Communication, The Hong Kong Polytechnic University, Yuk Choi Road, Hung Hom, Hong Kong SAR, China. Email: [ivyxywu@gmail.com](mailto:ivyxywu@gmail.com)

**Bernadette Watson** is a health psychologist who studies intergroup communication in the health context. She researches how patients and health professionals communicate interpersonally and in groups as well as interactions across multidisciplinary and multicultural healthcare teams. Address for correspondence: International Research Centre for the Advancement of Health Communication, The Hong Kong Polytechnic University, Yuk Choi Road, Hung Hom, Hong Kong SAR, China. Email: [bernadette.watson@polyu.edu.hk](mailto:bernadette.watson@polyu.edu.hk)

Table 1. *Themes and subthemes from interview data analysis*

Theme	Subtheme
Altered communication	<ol style="list-style-type: none"> <li>1. time and opportunity to communicate</li> <li>2. nonverbal and tactile interaction and communication (e.g. hand holding, hugging, eye contact and facial expression)</li> </ol>
Impact of changes in communication	<ol style="list-style-type: none"> <li>1. inability to fulfil role</li> <li>2. changes in roles and responsibilities</li> <li>3. increased workload</li> </ol>

## Appendix

### Interview guide.

1. Do you have any comments or feedback about the survey you completed?
2. How have the infection control regulations associated with COVID-19 affected the way you do your work and interact with your service users?
3. Is there anything else that you'd like to comment on in relation to the topic or the research or your own experiences?