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“I couldn’t say goodbye”: Thematic analysis of interviews with bereaved relatives who lost their loved ones during the COVID-19 pandemic

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Abstract

Background Delivering serious news is usually challenging for healthcare professionals and the pandemic of COVID-19 and related restrictions brought additional challenges in this process.

Aims To explore the experience of bereaved relatives with receiving serious news from healthcare professionals during the pandemic COVID-19.

Design A qualitative study using thematic analysis and a codebook approach of data collected in semi-structured interviews with bereaved relatives.

Setting/participants Data were collected from July to August 2022 in person/via phone with bereaved relatives who lost their relatives during the pandemic (from March 2020 to March 2022). Participants were recruited using a convenience sample and snowball method through social media and through one university hospital palliative care unit that invited bereaved relatives of deceased patients treated at the unit to participate in this study.

Results A total of 22 participants, consisting of 4 men and 18 women, were interviewed for this study. Most of the participants were sons or daughters of individuals who had died (5 grandchildren, 14 sons/daughters, 2 spouses, 1 great-niece). Six themes were identified: Burden caused by visit ban, Fear of COVID-19, Inappropriate behaviour and communication of healthcare professionals, High need for emotional support, Need for detailed and honest communication, Tendency to make excuses for mistakes and lapses by healthcare professionals.

Conclusions Delivering serious news during a pandemic was negatively influenced by a lack of contact with patients and a lack of support and empathetic communication with staff. Overcoming these circumstances can be achieved by frequent communication using various communication tools (such as videoconferences or phone calls), and maintaining empathy and honesty in the communication process.

Key message

This article describes results from a qualitative study with bereaved relatives focused on their experience with communication with physicians during the COVID-19 pandemic. Relatives lacked empathetic communication,

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they also experienced fear of getting infected and they tended to express understanding for the challenging circumstances faced by the healthcare staff.

Keywords COVID-19 pandemic, End of life, Health communication, Delivering bad news, Family, Qualitative study

Background

Receiving information about the death of a loved one can be one of the most stressful events in human life [1–3]. At the same time, communication about limited prognosis and the end of life is one of the most difficult and stressful tasks in medicine [4]. Doctors repeatedly stated that they were not sufficiently prepared for those situations [5, 6]. They often lack training for leading conversations about serious news and they are afraid of the emotional reaction of patients and relatives [6].

During the COVID-19 pandemic, almost 7 million people died worldwide, over 42 thousand in the Czech Republic [7]. Under exceptionally challenging circumstances, healthcare professionals were compelled to engage in difficult conversations regarding serious health conditions resulting from new serious diseases [8]. These conversations took place while doctors were working in protective equipment in an improvised environment of hospitals that had visitor bans [9]. There was also a greater necessity to conduct these interviews remotely, utilising phone calls or video conferencing which was unfamiliar to many doctors and families [10, 11].

Frustrations from conversations that take place inappropriately lead to a higher number of complaints from families or patients [12]. Lack of or inappropriate communication could also increase anxiety and depression in families and patients. On the other hand, it could also increase the risk of burnout and moral injury in healthcare professionals [8, 13, 14]. During the COVID-19 pandemic, doctors with limited experience in delivering serious news also found themselves communicating serious news to patients with different diagnoses than they usually work with as many clinicians were rotating in COVID-19 wards [15]. Therefore, the already burdened healthcare systems faced additional demands.

The aim of this study is to explore the experience of bereaved relatives with receiving serious news about their loved one's health condition and prognosis from healthcare professionals during the COVID-19 pandemic.

Methods

Design

This study was part of a bigger project called Delivering serious news under pandemic conditions (supported by Czech Health Research Council, project ID NU22-B-100) which aims to create evidence-based recommendations for discussing serious news during pandemic conditions. The present study was qualitative. We conducted semi-structured interviews with bereaved relatives of patients

who died during the COVID-19 pandemic in a hospital setting.

Research team

The research team consisted of professionals with various expertise. M.L. is the principal investigator of this project, psychologist, and researcher in palliative care research. A.H. is a physician who works as a senior physician in the palliative care team in a hospital and a researcher with many experience in palliative care research. K.P. is a PhD candidate in palliative care research and a nurse with experience in qualitative research. M.Z. is a master's student of psychology. K.V. works as a psychologist and researcher in palliative care research and has experience in qualitative and quantitative research.

Ethical approval

This study was approved by the Ethics Committee of the Centre of Palliative Care, reference number 05/2021.

Setting

This study took place in Prague, the Czech Republic, in the Centre for Palliative Care which is a non-profit organisation focused on research and education in palliative care. University Hospital Kralovske Vinohrady is a large tertiary academic medical centre in Prague which was involved as the data collection site.

Participant recruitment

Eligible criteria for participation in this study were: death of relatives which occurred between the 1st of March, 2020 and the 1st of March 2022, age 18+, and Czech language as a mother tongue. The exclusion criteria was the death of a patient out of the hospital. Participants in the study were recruited using convenience sampling in two ways. Firstly, we recruited participants through various social media channels of the Centre for Palliative Care and using a snowball technique. Twelve participants were recruited using this way, however, 2 of them did not fulfil the eligible criteria and they were not interviewed. Secondly, we recruited participants from two departments at the University Hospital Kralovske Vinohrady – the internal medicine department and the anaesthesiology and resuscitation department. During the pandemic, there were 1966 deaths of patients in these two departments, and we approached 121 bereaved relatives via text message with the offer to participate in the study. Eligible criteria for family members were that their relatives had been in care for at least a week, had been communicating

a diagnosis or prognosis and had died in hospital. Twenty-four out of 121 replied, 12 negatively, and 12 replied positively and participated in the study. Negative responses meant that respondents were not interested in participating, did not have time or did not give a reason.

Data collection

Eligible participants were contacted by researchers (K.V. and K.P.) and informed about the research goal and offered whether they wanted to meet in person in the office of the Center for Palliative Care, via phone or using videoconference. Researchers did not have any previous relationship with participants. Semi-structured interviews were conducted from July to August 2022 using an interview guide which was developed based on a review of existing literature considering our research aim by the research team and (M.L., K.P., K.V., A.H.). The guide contained questions regarding how they found out about the disease, their experience in communication with a physician during the treatment of their relatives, experience with remote communication with physicians a experience with communication with protective equipment.

Table 1 Coding tree

Themes	Sub-themes
1. Burden caused by visit ban	1) need for information about health condition 2) visiting restrictions 3) visits allowed for dying patients 4) patient could not use phone due worse health condition 5) laying out the death body was restricted 6) helpfulness
2. Fear of COVID-19	1) fear of being infected 2) fear of infecting loved one
3. Inappropriate behaviour and communication of healthcare professionals	1) insufficient communication 2) not showing interest about patient 3) not offering support to bereaved relatives 4) the undignified handing over of the estate 5) rudeness
4. High level need for emotional support	1) empathy 2) understanding 3) humanity 4) showing interest about patient 5) support for bereaved relatives 6) flexibility in using protective equipment
5. Need for detailed and honest communication	1) honest communication 2) information about future 3) organization of communication 4) understandable speech 5) dedicated physician 6) staff initiated communication 7) warning shot in phone call 8) invitation for laying out the death body
6. Tendency to make excuses and lapses by healthcare professionals	1) lack of physicians 2) strict epidemiological conditions 3) psychological exhaustion 4) protective equipment 5) temporary conditions

They were also asked whether they had any guidance for communication in the pandemic. The guide was tested with the first two participants. After 22 participants and preliminary analysis data collection was stopped due to data saturation. Data saturation was considered to be reached as no new codes or topics were added to the codebook which is an admissible approach in our type of analysis [16]. After an initial reading of themes and codes, the research team also agreed on sufficient information power of our data which supported the decision on end data collection [17]. The interview guide is in Supplement 2. Researchers (K.V., K.P.) also wrote field notes after each interview. All interviews were audio recorded and transcribed verbatim with the use of NVivo Transcription software (QRS International Inc, Doncaster, Victoria, Australia) and reviewed by K.V.

Data analysis

The data were analysed using thematic analysis and codebook approach which combines deductive and inductive approaches [18, 19]. The coding process was guided by a established codebook developed by K.V. and K.P. which was created after an initial familiarisation with data and review of existing literature [16, 20]. The coding process was carried out by M.Z. and K.V. and it was triangulated by K.P. Initial codes were applied to each transcript and grouped to form potential themes. Codes which were not in line with the study objectives were removed from the final coding matrix. Preliminary themes were reviewed through discussion by the research team (M.L., A.H., M.Z., K.P., K.V.). Through this iterative process, the final set of themes was defined. Coding of data was conducted on transcripts in the Czech language; illustrative quotes were subsequently single-translated into English (K.V., M.Z.) The coding tree is in Table 1.

Reporting guidelines

The process of reporting the study follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [21], checklist is attached as Supplement 1.

Results

Characteristics of participants

Interviews were conducted with 22 participants, 4 men and 18 women. The majority of participants were sons or daughters of individuals who died grandchildren, 14 sons/daughters, 2 spouses, and 1 great-niece), detailed description in Table 2. The shortest interview lasted 15 min, the longest 62 min. The average length of interviews was 25 min. Five interviews took place in person in the office of the Center for Palliative Care, and 17 interviews were conducted using videoconference or phone.

The analysis identified 6 themes (see Figure 1):

Table 2 Characteristics of participants

Participant	Gender	Relationship to patient	Mode of interview
1	W	Grand-daughter	Remote
2	W	Daughter	In person
3	W	Niece	Remote
4	W	Daughter	Remote
5	W	Grand-daughter	Remote
6	M	Son	Remote
7	W	Grand-daughter	Remote
8	W	Daughter	In person
9	W	Mother	Remote
10	W	Daughter	Remote
11	W	Spouse	Remote
12	M	Son	Remote
13	M	Son	In person
14	W	Daughter	Remote
15	W	Grand-daughter	Remote
16	W	Grand-daughter	Remote
17	M	Son	In person
18	W	Daughter	Remote
19	W	Daughter	Remote
20	W	Wife	Remote
21	W	Daughter	In person
22	W	Daughter	Remote

W=woman, M=man

Burden caused by visit ban, Fear of COVID-19, Inappropriate behaviour and communication of healthcare professionals, High need for emotional support, Need for detailed and honest communication, Tendency to make excuses for mistakes and lapses by healthcare professionals, Burden caused by visit ban.

Burden caused by visit ban

During the COVID-19 pandemic, it became significantly complicated to visit or to stay personally in touch with relatives who were in hospitals. In some cases, visits were banned completely, in others, they were allowed only during the terminal phase of a patient’s illness. In some cases, visits were allowed, but the hospital staff did not inform of this possibility, and due to the pandemic restrictions participants did not even expect this

possibility. At the same time, the patient’s condition often made it difficult to communicate with their families remotely. The lack of contact between relatives was very difficult and burdensome both for patients and their families. Visiting restrictions persisted after the death of patients and families could not say goodbye to the body of their deceased loved one.

“We did not know anything at all and even the announcement of the death was actually terrible, they didn’t inform me of my rights, like that we could go to see her, which I was very sad about after her death.” (Bereaved participant 4, daughter of death patient, phone call).

Fear of COVID-19

Participants were also often afraid of COVID-19 themselves. This fear manifested in two ways: Firstly, there was fear of potentially infecting their loved ones, which led participants to refrain from visiting them in the hospital. Secondly, some participants expressed fear of visiting the hospital due to their underlying medical conditions and their fear of being infected.

“I: And could you or couldn’t you visit your mom during this period?”

R: Not at this time, I don’t think, because my mom was in the ICU a lot and basically there was restricted access. I didn’t even want to take too many chances, mom was weak from the chemo, so if I was sick with something... I didn’t want to put her at risk.” (Bereaved participant 12, son of death patient, phone call).

Inappropriate behaviour and communication of healthcare professionals

Very often communication was perceived as inadequate during the pandemic. Communication with physicians was mostly done remotely by a telephone call. As these conversations were usually very brief, the most common struggle the families faced was a lack of information. Families had trouble reaching the hospital and also



Fig. 1 Thematic map

reaching the right person who could tell them the information they needed, as the nurses who usually responded to phone calls had only limited competence in sharing the information about patients' status. Participants reported that they felt like the staff was not honest with them and, in some cases, received incorrect or incomplete information. It was perceived negatively by the families as if the hospital staff did not show interest in patients or when they used inappropriate and offensive language. Not using a designated place where the families had privacy was seen as problematic. Participants also lacked support after the death of a patient, and they also mentioned an important issue of undignified handing over the belongings that were left after the death of their relative. Commonly, these belongings were handed to the families in a non-sensitive manner, in a black bag with a warning about the possibility of infection.

"Yes, that was the only doctor that I personally had a problem with because I was fixated on my grandma and I just knew that she<the doctor>was lying to my face because we could see what the health condition really is." (Bereaved participant 5, granddaughter, phone call).

"The only thing that bothered me was that when they transferred Dad from one ward to a different one, they didn't tell us, so when I called someplace where Dad used to be originally, they told me he wasn't there. So, there was the initial shock obviously, that he had died." (Bereaved participant 10, daughter of death patient, phone call).

High level need for emotional support

Participants appreciated the emotional support offered by hospital staff who showed their empathy and understanding for their difficult situation by giving them space to talk or ask questions. Interviews indicated that it helped families to see the real interest of staff for the patient. Seeing humanity, empathy, and expressions of understanding was important to family caregivers. Staff also offered emotional support by informing the families about further support after the patient's death. Some participants perceived it as emotional support and a 'demonstration of humanity' when hospital staff showed flexibility regarding the use of protective equipment. This flexibility involved allowing patients to remove their masks when feeling unwell or granting permission to remove masks during the delivery of serious news which was considered a sign of humanity and empathy of healthcare professionals.

"they accommodated us. They really were very nice to us, they stood with us at the bedside and the doc-

tors were crying, they were about the same age as my son and immediately some psychologist was there, and you are in such shock that you don't even know what happened at all. She came to us and said if we needed help with anything, to let her know anytime." (Bereaved participant 9, spouse of death patient, phone call).

Need for honest and detailed communication

Respondents Participants needed honesty in communication. If the information was delivered to them honestly and was straightforward, they were able to psychologically prepare for the following events. The organisation of communication also played a large role in the comfort of families. Families were comfortable when they always spoke to the same doctor who had information about their loved one and when the frequency of communication was agreed upon in advance. The family caregivers wanted to be informed that their loved one was dying and it was important to them to have information on what to expect next. A warning shot phone call was often used by hospital staff to invite the family for an in-person meeting. Upon hearing this, families could psychologically prepare themselves for serious news before it was actually announced.

"The doctor used to work in the oncology ward before and she told me - this was in early November - she told me that it could take a month. "Prepare yourselves, it will be very hard, prepare for hospice care if that is what you want" and she was the only one who spoke to me like very honestly, completely straight up and didn't sugar coat it and that really helped me and I knew what to expect." (Bereaved participant 4, daughter of death patient, phone call).

"I have to say that when someone talked to me they were open and I always felt good about it, I felt like they were telling me the truth and that was important to me and I got the feeling from people that they did everything they could." (Bereaved participant 4, daughter of death patient, phone call).

Tendency to make excuses for mistakes and lapses by healthcare professionals

There was a tendency in participants to express sympathy for the difficult situation in which the hospital staff had to operate, including protective equipment regulations, even at times when health care and communication were not perceived by them as ideal. In cases where families were not satisfied with the care, they often sought explanations in the challenging conditions as they were aware

(through media) of the lack of doctors and the high workload they had to endure.

“If we could have been there with the grandfather and the doctor would come and talked about it in front of him, it would have been like better, that was missing there. But on the other hand, I don’t know if that was like possible for the doctor to...if he had the time capacity to put on the suit and go visit the patient with us and to run back, the talk I had with him in his office it lasted a while.” (Bereaved participant 1, granddaughter of death patient, phone call).
“So sure, we got the suits, the masks, the check for vaccination, but that allowed us to say goodbye to him. Personally, I was glad.” (Bereaved participant 11, spouse of death patient, phone call).

Discussion

Main findings

We identified those themes: The people had to face burden due to reduced contact with their loved ones, their fear of COVID-19, struggled with the inappropriate behaviour and communication of healthcare professionals and lack of emotional support. Participants also reported the need for detailed and honest communication, while simultaneously exhibiting a tendency to make excuses and lapses in healthcare professionals.

What this study adds

Our findings are in line with similar studies which revealed that in situations where direct contact was restricted, family caregivers experienced a higher level of burden [22] and had an increased need for clear and comprehensive information regarding the health condition of their loved ones [23, 24]. They also need more empathy, however balancing the duty to respect safety measures and providing empathy could be challenging and could be seen as a moral dilemma (for example taking off the masks that were appreciated by participants in our sample). Reduced contact could be replaced by using videoconference [23, 25, 26]. However, it seems that this was not used in Czech hospitals very much as none of our participants had experience or even recalled an offer of that, probably due to technical requirements and unavailable equipment which was the reason for less utilization of technology-assisted communication identified in other settings [25]. Opinions on its usefulness also vary [27]. The capacity of staff for communication was reduced by the shortage of personnel or restrictions related to reducing the spread of COVID-19 which additionally complicated the situation and increased the workload and the stress at work [28–30]. Those circumstances may explain

some inappropriate behaviour or lack of communication of healthcare professionals.

The pandemic situation was also associated with a lot of stress and led to an increase in mental health problems in the general society [31], and a lot of people suffered from a severe fear of the disease (called coronaphobia) [32] especially at the beginning of pandemic resulting in COVID-stress syndrome [33]. Our data also reflected a similar trend, as contact with dying patients was significantly reduced among relatives due to the fear of COVID-19. They were afraid of getting infected as well as infecting their loved ones. Those feelings were accompanied by emotions of guilt or shame [34] and this aspect is likely connected to their need for emotional support from healthcare professionals, as identified in our data. This is in line with the UK study which showed that bereaved relatives need extra emotional support [24]. Some of our findings extend beyond the context of the pandemic, as they highlight the universal need of relatives and patients for honest and detailed information, as well as the necessity for emotional support [e.g. 35, 36]. Not providing concrete and detailed information is seen as harmful [37] and usually, it is recommended to tailor the amount the information and assess the preferences and the extent of information that patients and relatives want to hear [37, 38]. Therefore, this is in line with previous findings in this field which stated that most patients do want to know complete and detailed information [39, 40], but probably this is even more stressed when the contact with patients and staff is limited. Patients and relatives also emphasise the importance of showing empathy to physicians while delivering serious news [41, 42].

We also identified in our data that some relatives of dying patients can understand the situation of healthcare staff and they also tended to express understanding for their inappropriate behaviour. Due to their understanding, they also did not question protective equipment and they did not mention it as a barrier for communication in our data. The understanding of healthcare staff might be caused by the fact that the media repeatedly reported the difficult situation of healthcare professionals during the pandemic and also highlighted their service, often by calling them heroes [43, 44]. The high level of personal emotional engagement of people during the COVID-19 pandemic is also documented by the fact that some people in the general public even suffered from vicarious trauma after the pandemic [45].

Implication for practice and future research

This study has shown that the COVID-19 pandemic has increased the demands on health professionals to communicate with patients and families. Showing empathy and supporting other people becomes challenging in remote communication scenarios [10], but still, health

professionals should know and use it. Further research should focus on the impact of the pandemic on health workers, as well as exploring the most appropriate support tools for affected relatives. Further attention should also be paid to the perceptions of men who were not well represented in our study.

Strengths and weaknesses

This study was conducted in the Czech Republic which makes the generalizability of the finding challenging although possible as the COVID-19 pandemic brought similar challenges to all countries [46]. Part of the sample was reached by physicians from the hospital which could cause only relatives who were very satisfied or not satisfied with care in return to participate in the study. However, this was probably limited as the presented experiences of participants were both positive and negative. The data collection was done retrospectively, therefore the participants' recollection of the events could be biased. Also, most of the participants were female, the male perspective should be further explored. Despite that, our data brings important insight into bereaved relatives' experience. Rigour was maintained in our study by following a prepared script for interviewing and using a co-designed dataset for data analysis. Data analysis was performed by 2 persons, with a third person supervising the analysis to ensure that rigor was maintained. The codes and themes developed were also discussed repeatedly throughout the team to maintain reflexivity. Illustrative quotes for publication were also selected by the team.

Conclusion

The pandemic situation brings a lot of challenges for delivering serious news. Family caregivers have reduced contact with their loved ones and although they can understand the challenging working conditions of health-care professionals, they need both information and emotional support from hospital staff [24]. The experience of bereaved relatives who lost their loved ones during the COVID-19 pandemic showed that reduced contact should be compensated by detailed and honest communication provided by staff, using videoconferencing when possible, or taking enough time for phone calls when possible. Using trained volunteers might also help to provide support to families when clinicians are overwhelmed [47]. Good training in basic communication skills is required as many of them can be used in pandemic conditions.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12904-024-01551-y>.

Supplementary Material 1

Supplementary Material 2

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Author contributions

KV contributed to the data collection, investigation, data analysis and overall writing of the manuscript. KP contributed to the data collection, investigation, data analysis and overall writing of the manuscript. AH contributed to data collection and editing of the manuscript. MZ contributed to data analysis and editing of the manuscript. ML contributed to conceptualization, funding acquisition, data collection and editing of the manuscript. All authors have read and reviewed the manuscript.

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Data availability

Data from this study are available upon reasonable request.

Declarations

Conflict of interest

The authors declare that there is no conflict of interest.

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