...you just put up with it for the sake of humanity.': an exploratory qualitative study on causes of stress in palliative care nursing during the COVID-19 pandemic in Germany

Susann May, Kerstin Stahlhut, Matthew Allsop, Martin Heinze, Felix Mühlenariepen

ABSTRACT

Objective To explore and analyse causes of stress among nurses in palliative and inpatient hospice care settings in Germany during the COVID-19 pandemic.

Design Explorative, qualitative study using problem-centred interviews. Interview data were analysed using structured qualitative content analysis.

Setting Telephone interviews with nurses of different settings of palliative and inpatient hospice care.

Participants 16 nurses from inpatient hospice, palliative care units and specialised palliative home care were recruited.

Results COVID-19 infection control measures placed both physical and psychological strain on palliative care nurses. Due to changes in infection control information, workflows were being readjusted on a daily basis, preventing everyday routines and hindering relief from stress. There are reduced and limited opportunities for sharing and reflecting on daily working routines with team colleagues. Specific causes of stress in the individual settings of palliative and inpatient hospice care were identified. Overall, there is a tension between the nurses’ perceptions of proper palliative care nursing, in terms of closeness, psychosocial and emotional support and compliance with infection control measures.

Conclusions Palliative care nurses have been exposed to high levels of both physical and psychological stress during the COVID-19 pandemic. This requires rapid relief and support, with a need to ensure continuity of professional supervision and peer-support, which may be facilitated via digital technologies. The unique role of nurses in inpatient hospice and palliative care during COVID-19 ought to be recognised and valorised.

INTRODUCTION

The COVID-19 pandemic quickly emerged from a regional epidemiological incident to a global concern that is pushing health systems to their limits while challenging their former design and governance. Consequences of COVID-19 are multidimensional and complex, resulting in individual losses and fears as well as ethical and socioeconomic burden. Healthcare professionals during the COVID-19 pandemic are providing care under challenging circumstances with nurses experiencing higher subjective stress than other professional groups.1

Prior to the COVID-19 outbreak, working as a nurse in Germany was attributed to stressful working conditions with salaries perceived as not in line with performance.2 In their daily routines, nurses solve complex problems and are crucial in balancing the holistic needs of patients. In delivering palliative care (PC), nurses serve the psychosocial needs of patients and relatives in desperate life situations and are often the key contact in formal PC.3 PC nurses provide a significant role in supporting the broader healthcare system, with recommendations that they are fully integrated and leveraged in the face of this public health crisis and amid the inevitability of future pandemics.4 Since the beginning of the COVID-19 pandemic, PC nurses are facing new challenges in their daily work: infection control, visitation restrictions,
high documentation requirements, uncertainty among patients and individual infection risk.6–8 Gonçalves et al9 even demonstrated that the prevalence of burnout in PC increased during COVID-19 while differing considerably by setting of PC delivery.

These and further aspects frame the nurses’ role to relieve suffering and pain of the seriously ill and dying. It is essential to understand nurses’ experiences during COVID-19 to guide efforts to ameliorate, where possible, causes of additional burden arising from the pandemic, alongside guiding future pandemic responses.

The present manuscript describes a substudy of a larger research project on stresses and strains of nurses in different settings of PC delivery, which was already planned before the COVID-19 outbreak. Following evidence that causes of stress for nurses differ in various PC settings in Germany,10 11 we strived to identify processual and structural aspects that lead to stresses and strains in everyday nursing care. For a better understanding on structures of PC delivery in Germany, please refer to figure 1. In this work package, we focused on the settings: hospice care, specialised outpatient PC and specialised inpatient PC. Due to the pandemic emergency, we immediately aimed to investigate pandemic-related causes of stress as well.

The aim of this study is to explore causes of stress in the delivery of palliative and inpatient hospice nursing care, to analyse the impact on daily routines and to identify practical implications for improving PC during the COVID-19 pandemic in Germany.

METHODS
Study design
To explore daily work routines during the COVID-19 pandemic, we conducted an exploratory qualitative study among PC nurses in different settings of adult palliative and inpatient hospice care. Guided problem-centred interviews12 were analysed using inductive qualitative content analysis to derive replicable and valid conclusions overall and also setting specific causes of stress including team and patient communication, information needs and sharing as well as adaptation to infection prevention measures. The study includes an exploratory study design in order to capture and examine new and lasting pandemic-related causes of stress, by allowing nurses to speak openly and to reflect on their day-to-day work situation in times of a pandemic emergency. This approach allows us a deeper understanding of the stress factors by covering and differentiating working routines in different PC settings.

Participants
Participants were selected using purposive expert sampling.13 Inclusion criteria were working in one of the relevant settings, continuous employment as a nurse throughout the COVID-19 pandemic and willingness to participate in the study. Participants were recruited from healthcare institutions which are clinical partners of the Center for Health System Research of Brandenburg Medical School. Initially, the head nurses were informed about the study. They provided information to the team and asked whether there was interest. The interested persons then contacted the interviewers by telephone. The participants did not receive incentives. At the time of recruitment, centres from which recruitment occurred were not managing patients with COVID-19 but instead PC patients with conditions other than COVID-19.

Data collection
A preliminary interview guide was drafted by a professional advisory board for the project, comprising professionals from each PC setting included in the study. A hospice nurse, a PC physician (KS) and a consultant psychiatrist (MH) as part of a quality improvement initiative focused on working conditions in regional care settings were chosen to represent individual
settings. The preliminary interview guide included items developed to explore changes in daily routines due to COVID-19 that releases stress and to identify causes of stress. The guide was reviewed by hospice nurse, KS and MH to ensure clarity and relevance of questions. Prompts were developed for specific items to ensure consistency in probing by the interviewer. The interview guide was developed in two rounds, in individual face to face meetings or via video conferencing. In the first round, relevant questions were collected, in the second round the questions were reviewed and sorted until no further amendments were necessary. The main topic areas explored were:

► How does COVID-19 affect daily work routines in palliative nursing?
► What causes of stress do PC nurses experience physically and psychologically? How do these affect every day care?
► What practical implications can be derived to improve PC during the COVID-19 pandemic?

In addition, sociodemographic data were collected, including gender, age and training. In order to reduce the risk of infection, the interviews were conducted via telephone. The phone interviews took place from May to December 2020. The interviews were recorded and transcribed verbatim.

Data analysis
Data collection and analysis were conducted simultaneously by two researchers (SM, FM), based on Kuckartz’s structured qualitative content analysis14 using MAXQDA software. Categories were developed both inductively and deductively by setting, describing the material based on the transcripts. Deductive categories derived from the literature available at the start of COVID-196, 15 were considered in the analysis were: control, visitation restrictions, high documentation requirements, uncertainty among patients and individual infection risk. The aim was to develop an exhaustive category system. Next, the category system was applied to the entire interview material. At this stage, data collection had already been completed. To ensure traceability, application of the category system was validated by a member check, where findings were shared and consolidated with the participants in an informal setting. This manuscript has been compiled in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ)15 (please refer to online supplemental material 1). For the presentation of the results, representative quotes of the discussion transcript were selected, translated into English and included in the text.

Ethical considerations
After receiving a study information pack, potential informants were invited to provide a written informed consent prior to participating in the study.

Patient and public involvement
Patients were not involved in this study. However, participants were involved in designing the interview guide and interpreting the results.

RESULTS
A total of 16 female nurses of inpatient hospice (n=5), specialised palliative home care (n=6) and PC units (n=5) participated in the study. The average age was 46.4±10.82 years (table 1). The interviews lasted between 42 and 77 min in duration. The mean duration of interviews was 55 min.

Causes of stress across PC settings
Nurses from all palliative and hospice care settings reported that their daily work was particularly demanding during the COVID-19 pandemic, with multiple causes of stress identified (please see figure 2).

The interviewees reported additional physical strain due to infection control measures, such as the obligation to wear a face mask as well as additional dressing and undressing of sterile work clothing:

‘The eight and a half hours of wearing a mask - sweating, headaches, shortness of breath and lack of oxygen - were really bad… like: ‘I’m going to dump it all and go home.’’ (BASAL_07_inpatient hospice, pos. 54)

Nurses described a conflict between infection control and, in their words, humanness. This particularly related to wearing a face mask, protective clothing or contact prohibitions. Continually, nurses had to make decisions in situations that were described as morally stressful. Nurses reported an incompatibility to maintain infection protection when these measures did not correspond with their own convictions of PC.

‘Thank God we are at ground level, so I said: ‘Enter through the patio and not through the house. That way you won’t infect us’. [relatives are addressed here]. As a result, we have turned a blind eye many times. But you know that you’re breaking the law right now, and if the manager sees that, there’ll be a big fuss. Happened a few times. You always have the feeling that you’re acting on behalf of the guest, the patient, the relatives, but you’re doing something wrong. So that was always… you knew you were making a mistake. But you just put up with it for the sake of humanity.’’ (BASAL_07_inpatient hospice, pos. 56)

All participants described the constantly changing information on infection regulations as very disruptive:

‘Then this fuss about infection control. New decisions are made every day: will this be done, will that be done? There is always new information, and sometimes I simply can’t process it any more. It’s too much for me. I just don’t want it any more. And I can’t even hear the word ‘COVID’ anymore either.’ (BASAL_02_inpatient hospice, pos.82)
Processing a permanent flood of information and deriving decisions from it were described as another cause of stress:

‘We as an inpatient hospice are left behind by all means. The regulation for B. (federal state) is then for nursing homes, similar facilities, paragraph so and so does not apply to the care of dying and seriously ill people. So I can choose for myself how to deal with it. Yes, exactly, and you are told from all sides what you could and should do, but in the end I have to decide, and there is always someone who is not happy with it, and for me it is difficult to be absolutely constant.’

(BASAL_16_inpatient hospice, pos. 86)

The interviewees expressed that patient communication was severely limited due to the infection control regulations. This was perceived to be a burden because communication is a vital part of PC, again, expresses the contradiction between infection control regulations and humanness.

‘So I carry my face mask around with me. That is sometimes very exhausting. Palliative care is also a lot about facial expressions and gestures. What do I symbolise? A single touch can sometimes express more than a thousand words. A look is worth a thousand words, as the expression goes. And that makes it difficult.’

(BASAL_10_specialised palliative home care, pos. 64)

Team communication with peers was also affected, becoming very limited during the COVID-19 pandemic. PC nurses reported that intercollegial exchange is particularly essential in PC and to cope with death and dying. Due to an absence of personal contact, communication, which is the basis of mutual cohesion was at times unavailable.

‘[…] we are communicating less and less. Well, everything is falling behind because there is only one person on duty. Team communication has decreased considerably. You only see each other at handover, you only write notes, you are alone during the break. It affects you somewhat.’

(BASAL_03_inpatient, pos. 94)
In addition, there were barriers in the exchange of information, which also resulted in the loss of appointment information.

‘No, at some point, when we saw each other in front of the office, at a distance of one and a half meters, that was already. Distressing would be an exaggeration […]. And you also really noticed that the office staff. Well, that didn’t last any longer, they were exhausted. You could tell. There were no serious mistakes, for God’s sake. But information really got lost and you found yourself standing in front of the door of a client who had cancelled earlier.’ (BASAL_09_specialised palliative home care, pos. 95)

In the interview situations and also in the analysis, it became apparent that the timing of the interview (and currently applicable safety measures) was related to the stress experienced.

‘Fortunately, it’s not quite so dramatic now, not at the moment (September 2021, after the first Lockdown in Germany). And what we really wish for is that at some point it will be normal in the inpatient hospice. Where the door is open and everyone can go in and out. But that’s certainly not going to happen in the foreseeable future. Let’s see what the winter brings.’ (BASAL_08_inpatient hospice, pos. 82)

Alongside common factors, there were specific sources of stress derived from each of the PC settings under investigation (please refer to figure 2).

**Causes of stress across the settings**

- Infection control regulations
- Conflict between infection control and human behavior
- Permanent flood of information
- Limited communication with patients
- Limited communication with team member

**Figure 2** Category system after analysing the interviews.

**Causes of stress in PC units**

Internal hospital reorganisation and resulting staff shortages were experienced as burdensome. Due to reorganisation, nurses often had to help on other wards or wards were merged, resulting in an intensification of work.

‘And of course, we are occasionally filling gaps on other wards. And the workload, I mean over the last few weeks, is getting heavier and heavier, because everyday life is returning. In our situation, the COVID really put a strain on us in the sense that we had to take three neurological beds because the neurology ward was restructured, so we were saddled with three neurology beds and six palliative care beds. So we had to cover neurological patients as well. And then the management said: ‘We still have six palliative patients and three neuro patients, so one nurse on early duty is enough for the six palliative patients.’’ (BASAL_03_inpatient, pos. 90)

Nurses on the PC unit highlighted the issue of dealing with relatives in terms of visitation bans as particularly challenging and stressful.

‘That was a big problem dealing with the relatives. So the visiting ban put a lot of strain on us.’ (BASAL_05_inpatient, pos. 74)

**Causes of stress in inpatient hospice care**

An issue resulting from the visitation ban which was reflected in the inpatient hospice setting was the additional workload of informing, communicating with and counselling relatives. Besides questions about current
visitation regulations, inpatient hospice nurses had to address concerns and fears of relatives.

Nurses reported a higher need for psycho-social care for patients, which had to be met in addition to their daily routines.

‘There is a greater need for conversation and a significantly higher ringing frequency [patient bell call button]. Well, it’s true that when relatives are there, they take care of a lot of little things for us, too, I must admit. And that all fell away, you could feel that quite clearly. That was already an additional burden in many respects. (...) You had to do a lot more legwork, I would say, to work through the bells, to fulfill wishes. Simply because they were also alone so much, and you don’t always want to be alone. The wishes differ, depending on the presence of the relatives, but many like to have someone sitting with them. And if that is no longer the case [visit of relatives], then it was also our task, in a sense, to try to fulfill this need. That’s when it often got really difficult. Exactly. That was unpleasant for many weeks.’ (BASAL_08_inpatient hospice, pos. 84)

In inpatient hospice care, nurses described the additional effort for administration and documentation as straining. Increased reporting requirements relating to infection control, including documentation of visitors, regular fever measurement and keeping a symptom diary, were described as necessary but burdensome and diverting away from other work:

‘A lot of it really revolved around that. Maybe there was no room for other conversations at that point, which was a pity, because other things might have got lost, because people were always talking about this Corona. And we had to keep records of everything, we had to take each other’s temperature, we still have to do that, then write down the symptoms and so on, that takes an incredible amount of time. As assistant head of nursing, I also have to print out the lists so that all sorts of people who come in make their ticks, and still, a lot of bureaucracy. We have files of addresses of relatives and so on, which is of course that is completely lacking in nursing, or also among ourselves, because you are very busy with filing, documenting, making ticks and measuring temperature.’ (BASAL_07_inpatient hospice, pos. 58)

Participants described limited, patient-centred care in their everyday routines at the inpatient hospice. Due to various sources of distress, the nurses were often unable to respond to the individual needs of each patient.

‘But at the beginning, I have to say, it was really hard to please everybody. But of course, that’s not possible.’ (BASAL_06_inpatient hospice, pos. 92)

Nurses in inpatient hospice settings highlighted that wider, external changes also heighten stress during COVID-19:

‘You can already notice the mood is more tense, of course it also changes something for each family member. Spouses are still at home due to short-time work, and the children are suddenly at home again as well. That means that family life has also changed for everyone. And it has also become more strenuous, I would say.’ (BASAL_01_inpatient hospice, pos. 122)

Causes of stress in specialised palliative home care

Nurses in specialised palliative home care described reorganising various procedures in order to keep contacts in office premises as low as possible. For this purpose, nurses’ home visits were rescheduled to avoid nurses meeting each other on the office premises.

‘We also went into the office earlier and had different starting times and had to leave the office at different times. So the tours were rescheduled and we couldn’t sit in the office as a couple and plan the nursing care.’ (BASAL_09_specialised palliative home care, pos. 91)

Fear of infection also led to patients cancelling nurse appointments, limiting participants’ ability to provide in-person care.

‘When this lockdown started, some of the patients cancelled many appointments, put visits on hold for 3 months. They just got back. They were really panicked by the media.’ (BASAL_14_specialised palliative home care, pos. 44)

In specialised palliative home care, nurses described how the stress from their daily work routine is carried over into their personal lives.

‘And then they start the meeting at 7 pm because the management staff are on the phone. And they’re done at 9 pm. Child is hungry, husband is hungry too, no one has made anything to eat, it sucks too. And that was a time when I was very dissatisfied. At which point you also say: well, that’s really the end of it.’ (BASAL_10_specialised palliative home care, pos. 68)

DISCUSSION

COVID-19 places both physical and emotional strain on PC nurses. We identified both setting-specific and setting-agnostic causes of stress, including the fulfillment of infection control regulations and their physical and organisational consequences (eg, wearing a face mask, and additional administrative and documentation work), tracking changing information on infection control regulations, tension between execution of infection control measures and nurses’ own professional demands in PC and limited communication with patients and peers. The causes of stress highlighted by participants are without relief during COVID-19. Team meetings are dispensed and collegial exchange is omitted, corresponding to previous research results from paediatric PC. Furthermore, there is limited diversion in nurses’ private lives. Nurses reported tensions due to COVID-19 pandemic as childcare is not arranged and partners are affected by short-time work. Due to ever-changing information on infection control and also setting-specific
structural changes, working routines do not evolve during COVID-19 pandemic, causing psychological distress and unhappiness.

Our results correspond to other healthcare domains, where COVID-19 and infection control measures lead to increased stress and workloads in nursing. Some identified causes of stress (eg, service reorganisation and staff shortages) may have existed prior to the pandemic but have been exacerbated over the last year. For example, frequency of redeployment of nurses has increased during COVID-19 and staff shortages have been further aggravated. Other identified causes of stress may have now been mitigated or become part of routine practice, including infection measures. Organisational change may lead to both gains and risks in the reorganisation of responsibilities and roles, with adaptation and adjustment possible for some measures introduced during the initial phase of the pandemic response. Other causes of stress endure: visitation restrictions in inpatient settings remain in place in Germany. Patients still need to be tested for COVID-19 and nursing care requires more extensive preparation than before the pandemic, which results in persistently higher workloads overall. Nurses’ communication with the patients continues to be restricted due to mask and distance requirements, further hindering the psychosocial support of patients.

Psychosocial care is a major part of PC. Contact and visitation restrictions have the effect of reducing the informal support provided by relatives and also volunteers, especially in PC units and inpatient hospice care. Traditionally, caregivers and volunteers are available to patients for conversation and personal contact. In addition, they communicate needs and wishes when patients are not able to. With COVID-19, this informal support is not available. Palliative nurses have to compensate for this, which ties up additional resources. Similar impacts to the impairment of communication due to COVID-19 have also been reported in other healthcare domains too.

A salient characteristic of PC is satisfying the physical, emotional and spiritual needs of patients and family members. Due to the isolating situation caused by contact restrictions, the situation is particularly challenging for nurses in PC.

During the interviews, all nurses described their personal ethos and high professional demands towards themselves, to provide the best possible care for patients. Important resources of palliative nursing care include social interaction, psychological and physical closeness, or as interview partners put it: humanity. Reconciling this understanding of humanity with infection control regulations (eg, wearing a face mask, keeping distance and so on) is difficult. Nurses have to balance their professional duties and competences with the decisions that must be made in practice. This creates constant tension between the nurses’ own requirements in terms of ‘proper palliative nursing care’ and humanity versus current infection control regulations. As a result, the nurses experience psychological stress, which is further amplified when patients demand physical closeness or personal contact. Finally, nurses reported that they do not always act in compliance with infection control regulations, endangering their own health in order to care for patients—in line with their own professional ethos. This may not be specific to PC because this phenomenon has also been reported in nursing homes. Nevertheless, these tensions should be addressed in the team.

The dilemma between compliance with infection control measures and nurses’ professional requirements is also likely to persist. In PC units, team meetings are reinstated under high precautionary measures. Nevertheless, this is associated with a latent risk of infection. In specialised palliative home care, face-to-face team meetings remain cancelled. The physically close collegial interaction which has been described as a source of relief by the interviewees remains limited.

**Practical implications for improving palliative care across the settings and setting-specific**

Several approaches could contribute to target stress and improve the situation of PC nursing. Consistent with previous findings, our data point to the high relevance and need for transparent information and communication during COVID-19. This includes provision of information on the current infection situation, regulations on procedures, responsibilities, measures to manage the infection situation and their immediate consequences for nurses. To increase acceptance and practicability, specifications have to be presented transparently and could be adapted participatively. Despite COVID-19, team interaction—the central source of relief and information on current infection control measures—may need to be reinstated. While physical face-to-face team meetings are associated with a risk of infection, digitally enabled meetings could be a sufficient alternative for professional-to-professional contact. They might also serve as a tool to offer supervision, peer-support and self-care recommendations. As demonstrated in many other healthcare domains, information and communication technologies possess considerable potential to contribute to augmentation and adaptation of palliative nursing care during COVID-19. Furthermore, the role of telehealth in the provision of patient care during the pandemic has broad acceptance from health professionals, becoming part of routine use in Germany. If implemented meaningfully, telehealth also provides a potential means of overcoming stressful challenges to nursing care for establishing contact between patients and relatives despite lockdowns and visitation restrictions.

In summary, based on our results,
practical implications for future pandemic situations can be assigned to the different settings (please see figure 3). Further evidence-based recommendations were consolidated in PallPan, which the authors highly support.

**Strengths and limitations**

Palliative nursing care is a critical component in the response to the COVID-19 pandemic. Yet, the role and experiences of nurses in this situation are rarely described in the research literature. To the best of our knowledge, we have performed the first study on PC nurses’ burden during COVID-19 pandemic in multiple settings of palliative and inpatient hospice care in Germany. The qualitative study design allowed for an in-depth understanding of the impact of the COVID-19 pandemic on day-to-day working routines of palliative nurses. Due to the open and explorative approach, interview partners were able to consider the narrative accounts they provided. The study directly informed quality improvements across PC sites in one region in Germany and further research is needed to explore its relevance within other regions in Germany and other national health systems. Furthermore, settings including outpatient and volunteer hospice service, which to our knowledge is currently very limited in Germany, were not represented. Due to the relevance and urgency of the topic and defined settings and providers, no specific recruitment strategy (eg, maximum variation sampling) was pursued which may have led to self-selection bias as our sample is exclusively female and middle-aged. The experience of stress has changed again and again over time and the waves of infection. However, to capture this, a qualitative approach is unsuitable; instead, a quantitative approach would have been necessary.

**CONCLUSION**

PC nurses have been exposed to high levels of physical and psychological stress across specialised palliative home care, PC units and inpatient hospice settings during COVID-19. These causes of stress are both transverse and setting-specific. There is a tension between nurses’ own professional and compliance with infection control measures. This tension has to be jointly addressed to ameliorate known causes of stress and to balance individual health and infection risk. Professional supervision and peer-support are key sources of relief for PC nurses and should be prioritised during the pandemic with self-care encouraged. Digital technologies may provide a means of facilitating elements of PC nursing during COVID-19, both organisationally and in the actual care of patients, but approaches to guide meaningful implementation are needed. Nurses are essential in both the global response to the COVID-19 pandemic and care of the seriously ill and dying. Developing approaches to identify and address stressors in their delivery of care during the pandemic should be explored to support their role in the PC workforce.

**Author affiliations**

1. Center for Health Services Research, Brandenburg Medical School Theodor Fontane, Neuruppin, Germany
REFERENCES


