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## **Emotional labour in palliative and end-of-life care communication: a qualitative study with generalist palliative care providers**

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## **Abstract**

**Objective:** To explore generalist palliative care providers' experiences of emotional labour when undertaking conversations around palliative and end-of-life care with patients and families, to inform supportive strategies.

**Methods:** Semi-structured interviews conducted with generalist staff (those providing 'primary' or 'general' palliative care, not palliative care specialists) who had attended a communication workshop. Sampling was purposive (by gender, profession, experience). Data were analysed using a framework approach; a sample of transcripts were double-coded for rigour. Data collection and analysis were informed by theories of emotional labour, coping, and communication.

**Results:** Four ambulance staff, three nurses, two speech and language therapists, and one therapy assistant were interviewed. Five themes emerged: emotions experienced; emotion 'display rules'; emotion management; support needs; and perceived impact of emotional labour. Participants reported balancing 'human' and 'professional' expressions of emotion. Support needs included time for emotion management, workplace cultures that normalise emotional experiences, formal emotional support, and palliative and end-of-life care skills training.

**Conclusion:** Diverse strategies to support the emotional needs of generalist staff are crucial to ensure high-quality end-of-life care and communication, and to support staff wellbeing.

**Practice implications:** Both formal and informal support is required, alongside skills training, to enable a supportive workplace culture and individual development.

**Key words:** Emotions; Communication; Education; Terminal Care; Palliative Care; Qualitative Research.

**Highlights:**

- Emotional labour is required by generalist palliative care providers during communication
- This emotional labour is driven by a desire to put patients' needs first
- To foster good communication, clinicians' emotional needs must be supported at both an individual and organisational level
- Support must be both pro-active and reactive to clinicians' emotional needs

## 1. Introduction

Palliative care seeks to improve quality of life by addressing the physical, psychological, social and spiritual needs of people facing life-threatening illness, and their families[1]. With a growing ageing population, most care for people with life-threatening illness and those nearing the end of life is provided by 'generalist' palliative care providers[2]. Although subject to multiple interpretations[3], we refer to 'generalist staff' as those delivering a 'palliative care approach' or 'primary palliative care' as part of their role when working with people with life-threatening illness and their families (e.g. community nurses, ambulance staff). This is in contrast to specialist palliative care staff where this forms the majority of their role and involves working with patients with the most complex needs[2, 4]. Generalist staff across a variety of professional backgrounds are exposed to the complex and emotive aspects of death and dying[5, 6], including conversations around diagnoses, disease progression, and bereavement. These conversations with patients and families are frequently conducted poorly,[7-9] resulting in multiple adverse outcomes[10-12]. It is therefore a priority that generalist staff are supported to develop skills in end-of-life care communication[13-15].

Many health and social care staff describe conversations around deterioration and end-of-life care as challenging[16-21], emotionally draining and demanding[22]. Communicating with clarity and compassion requires the ability to navigate complex clinical circumstances and powerful emotions[23]. Efforts to improve communication have largely focused on behavioural aspects, for example using mnemonic-based frameworks (e.g. SPIKES[24], SCARS[25]) and opportunities for practice[26]. The emotional experiences and needs of staff, and how or if these should be addressed, are often overlooked[27, 28].

Lazarus and Folkman's transactional model[29] defines emotions as a response to person-environment relationships[29]. These have causal antecedents (e.g. self-esteem) and mediating processes (appraisal and coping), with immediate effects (e.g. emotions experienced during an encounter) and long-term effects (e.g. wellbeing)[29]. As detailed in Heaven and Maguire's

model[30], professionals' fears and perceived support influence their ability to communicate with patients and families. Indeed, evidence suggests that staff who are not emotionally supported struggle to provide emotional support[31-34]. These relationships may be further compounded by population and organisational pressures within services, resulting in greater numbers of emotional experiences, but less capacity to manage them[35]. Being concerned with staff members' emotional experiences is therefore essential to sustaining a healthy and effective workforce[36].

Inducing or suppressing emotional expressions to benefit others, particularly in a professional capacity, has been defined as 'emotional labour'[35]. Emotional labour theory is relevant to health and social care staff[37-39], who are often required to manage their own emotions when caring for patients and families. It is suggested that emotional labour is conducted in line with perceived 'display rules': expectations around what emotions should and should not be expressed during an encounter. As a mismatch between felt and expressed emotion (known as emotional dissonance) is proposed to have implications for staff outcomes (e.g. burnout[40, 41]), this framework can aid understanding of emotional aspects of communication about palliative and end-of-life care. This will help to develop theoretically grounded complex interventions for supporting staff and improving care for patients and families[42, 43].

We therefore aimed to explore the experiences and impact of emotional labour among generalist staff when undertaking conversations about palliative and end-of-life care issues with patients and families, in order to inform future supportive strategies.

## **2. Methods**

### **2.1. Study design**

This qualitative interview study used a critical realist perspective: acknowledging that while phenomena exist outside of our perceptions, we can only understand them through our perceptions[44, 45]. The COREQ checklist[46] guided reporting (Appendix A).

### **2.2. Theoretical model**

This study is underpinned by emotional labour theory[35] to explore how and why emotions may be manipulated within the workplace. The transactional model[29] was also drawn upon as a broader model of how emotions and coping techniques arise. To supplement this, Heaven and Maguire's model[30] was used to understand factors that may specifically affect these processes in the context of communication. Together these theories informed data collection and analysis.

### **2.3. Setting**

Participants were sampled from communication skills workshops run in London, UK, for people that worked in hospital and community settings. Most self-selected to attend the workshops, however sometimes staff attended within larger training programmes or at the request of their manager.

### **2.4. Participants and Sampling**

Participants were eligible if they attended a specific end-of-life care communication skills workshop between September 2016 and February 2017 and were generalists in palliative care[4]. Participants were purposively sampled[47] to represent a range of occupations, years of experience, and genders, for the following reasons. First, generalist palliative care providers encompass a heterogeneous group of occupations with differing responsibilities, which may expose them to different types of challenges around communication[48]. Second, literature around coping and emotional labour in the workplace suggests years of experience may influence these processes[49, 50]. Finally, considering well documented gender differences in emotional interpretation and

expression[51, 52], we anticipated associated variations in perceptions and experiences of emotional labour.

### **2.5. Recruitment**

Eligible staff were invited to participate via email, based on the purposive sampling criteria.

Recruitment was continued until theoretical saturation was reached[53, 54], determined by preliminary analysis of detailed reflective interview notes and constant comparison of new data with existing findings[55].

### **2.6. Topic guide development**

The interviews followed a semi-structured topic guide (Appendix B), informed by the underpinning theories. This encompassed questions about: difficult conversations with patients and families, the emotions associated with these experiences, how they managed these emotions, perceived support needs, and their experiences of the workshop (not reported here). The topic guide was reviewed by a multi-professional team of academics, healthcare staff, and patient and carer representatives. A revised topic guide was tested in practice interviews with two staff representatives.

### **2.7. Interviewer details**

The interviews were conducted by a female research assistant [LB] with a background in psychology (BSc). The researcher had previous experience and training in qualitative research and interviewing techniques, including previous qualitative work around end of life care and communication. They had briefly met some participants previously during other data collection for the larger project but was otherwise not known to them. The reasons for conducting the work were made clear to participants in study information materials and at the start of the interviews.

### **2.8. Data collection**

One interview was conducted per participant in-person or by phone; there were no repeat interviews. The interview setting was often meeting rooms in their work setting; some were



conducted over the phone when participants were at home. The interviews were audio-recorded and transcribed verbatim. Transcripts were not returned to participants for comment. Reflective field notes were written by the researcher [LB] immediately after each interview and integrated in the analysis, to maintain transparency and encourage reflexivity[54]. Participants' demographic information and confidence in communication were obtained through questionnaires they completed as part of a larger study[56].

### **2.9. Data analysis**

Data was analysed using the framework approach[57]; following six stages (Table 1).

[INSERT TABLE 1]

### **2.10 Ethical considerations**

Ethical approval was obtained from the Health Research Authority Research Ethics Committee (Ref. 16/LO/1571). All participants provided written informed consent prior to their interview.

## **3. Results:**

### **3.1 Participants**

Targeted emails were sent to 66 of 109 eligible participants between February 2017 and April 2017. Theoretical saturation was reached following interviews with 10 participants. During this time one participant declined to participate, and 55 did not respond. Interview duration ranged from 51 to 80 minutes (median 65 minutes). Seven participated face-to-face, three participated by telephone. In all but one interview there was no one else present; in one interview, a colleague was present intermittently.

Participants' demographic details are shown in Table 2. Three were in nursing (two community nurses, one student nurse), three were therapists (two speech and language therapists, one therapy assistant), and four worked for the ambulance service (two clinical team leaders, one paramedic,

and one trainee ambulance crew). Eight identified as White British, one as White Croatian, and one as Asian Indian. Most were female (n=7), and ages ranged from 26 to 52 years (median 39 years). Time spent in their current role ranged from two months to 23 years (median 3 years). Time since the communication workshop ranged from three to eight months (mean 5.5 months). Participants had varying levels of self-rated confidence in conversations about life-limiting illness and end-of-life care: two 'very confident', three 'confident', and five 'not very confident'. A table showing the characteristics of the final sample in comparison to the full sampling frame is shown in Appendix C. Non-participants were more likely to be GPs and care home staff.

[INSERT TABLE 2]

### 3.2. Themes

Five themes emerged: emotions experienced; emotion 'display rules'; emotion management; support needs; and perceived impact of emotional labour (Table 3). A meta-theme of 'putting the patient and family first' ran across these themes. A full coding frame is shown in Appendix D.

[INSERT TABLE 3]

#### 3.2.1. Emotions experienced

Participants described two types of emotions experienced around conversations about life-threatening illness and end-of-life care: skills-focused emotions, and situation-focused emotions, and how these can "build up" or accumulate.

**Skills-focused emotions:** Emotional responses to individuals' own perceived abilities, rather than the situation at hand, were most commonly described. These included: frustration with not having the skills or information required, guilt that an interaction could have gone better, and satisfaction with an interaction they felt had gone well [Q1.1]. Participants frequently spoke of feelings of anxiety,

particularly around not knowing the best way to communicate something, or anticipating an emotionally charged reaction [Q1.2].

**Situation-focused emotions:** Emotional responses to the situation based on their own appraisal of the situation, and emotions reflecting what others were feeling or potentially feeling were also described. The most common emotions here included frustration (e.g. with poor care), and feeling humbled by situations that felt 'bigger than them', or where it could have happened to anyone [Q1.3]. Often empathic emotions included sadness and distress that reflected the nature of the conversations participants had with patients and families. In some cases, this represented intentional efforts to empathise with patients or families [Q1.4]. In other cases, perceived similarities between themselves or someone they knew, and the people they were working with, led to an almost unintentional or instinctual empathic reaction.

**“Having that build up”:** Across these emotional experiences, participants discussed the potential for an accumulation or 'build up' of emotional experiences. This was often described as a growing pressure that required a vent, or else it might burst [Q1.5]. This phenomenon was mentioned particularly by the ambulance service staff, and staff with more years of experience.

### **3.2.2. Emotion 'display rules'**

Participants described the different 'display rules' governing which, and how much, emotion they displayed during an interaction with patients and families. Professional or workplace expectations tended to focus on limiting emotional expression. This included, for example, not crying in front of patients [Q2.1]. Although most participants described professional expectations as unspoken rules, one participant recalled being explicitly told at university *“if you are going to cry, go and cry somewhere else”* (S8, Student nurse).

This more 'professional', non-emotional style was balanced with more 'human' (i.e. emotional) expressions, which were perceived as more personally exposing but potentially more authentic

[Q2.2]. These styles were often seen as mutually exclusive, requiring a choice between the two. This balance of emotional expressions was tailored to the individuals they were working with and what they felt would benefit the service user: most often ensuring displays of empathy, or refraining from projecting unwanted emotional expressions [Q2.3-2.4].

### **3.2.3. Emotion management**

Participants used multiple strategies to manage their emotions before, during, and after interactions with patients and families. In some instances, participants described preparing in advance for an interaction that they expected to be emotional. Examples included adopting a 'persona' to draw strength from, or conducting more background work beforehand [Q3.1]. Another strategy was to avoid emotional experiences altogether by becoming 'robotic'. Participants described avoiding eye contact, changing topic to something less emotional, or focusing on clinical tasks and protocols instead [Q3.2] – and acknowledged this to be a potentially self-protecting emotion management strategy [Q3.3].

A controlled expression of some of their own emotion, but not all, was a strategy all participants spoke about. This was often used alongside the perceived display rule of tailoring emotional expression to the individual, at a level intended to benefit patients and families [Q3.4]. Sometimes, however, participants found it challenging to limit expression of strong emotions.

Whilst with the patient or family, many put emotions on hold altogether with the intention of processing them afterwards. Participants did this when they felt their emotional expression would not benefit the service user or situation [Q3.5]. Two ambulance service staff, however, noted that there was not always time to work through their own emotions afterwards [Q3.6], which related to the potential for a 'build up' of emotions.

All participants spoke about the importance of revisiting and reappraising emotional experiences, alone or with others, as a way of managing their emotions. This was typically described as reflection and discussion of their experiences [Q3.7]. In some cases, this was a formal team process, while for others, particularly in the ambulance service, this included more informal discussions with crewmates [Q3.8]. One of the ambulance team leaders shared that these informal discussions used to take place organically in the 'mess room' back at the ambulance station between jobs. However, due to the increasing service demands, there were fewer opportunities for this to happen.

Three participants also talked about participating in cathartic activities after interactions to release a 'build up' of emotion. This included crying, but also un-related activities such as cooking, or sport.

#### **3.2.4. Support needs**

Participants expressed three key components of support required:

**“Not having that expectation of everyone to be okay”:** The most salient aspect of participants' support needs was their request for a workplace culture that acknowledges and normalises emotional experiences and management. This was at an organisational level through provision and signposting of formal services, but also at a team level in how colleagues and supervisors react and role model [Q4.1]. Where cultures within teams were more accepting of discussing emotional experiences participants reported more opportunities for reflection about challenging encounters.

**“Time to reflect”:** Participants stressed the importance of having time to reflect on and manage emotional experiences, particularly following an emotionally charged interaction. Participants valued time and space for informal support including talking to colleagues, although one participant preferred time alone to group discussions. Participants also discussed the need for more formal mechanisms such as scheduled team reflections or debriefs, despite the resource implications [Q4.2]. Ambulance service participants most often referred to having little time to reflect [Q4.3].

**“Confidence and experience”:** Participants described a relationship between their confidence and experience, and their emotional wellbeing. For example, one participant described being begged to resuscitate a patient by the patient’s wife, a situation he described as “horrible”. However, his confidence that he was doing the right thing reassured him [Q4.4]. As such, participants saw a role for training in supporting emotional aspects of their work, by changing how they appraise situations and therefore how they respond emotionally [Q4.5]. Ambulance service staff most commonly expressed a need for more training in palliative and end-of-life care skills, due to a perceived increase in frequency of these cases.

### **3.2.5. Perceived impact of emotional labour**

Skilled and supported emotional labour was seen as important for maintaining meaningful relationships with services users. Without this, participants could foresee challenges in forming trusting relationships, which may in turn make patients and families less communicative [Q5.1]. Being able to manage emotional expression was also perceived as important in participants’ ability to provide the care required during clinical encounters. This included having effective communication, but also the ability to put emotions on hold when appropriate [Q5.2]. However, despite the utility of emotional labour when building relationships and providing care, two ambulance staff and two therapists also considered the potentially detrimental impact of emotional labour on staff members’ mental health. They suggested that a lack of support around this element of their role could be detrimental in the long-term [Q5.3-5.4].

### **3.3. Relationships between themes: the emotional labour triangle**

Across the five themes above, ‘Putting the patient first’ emerged as a central tenet of the emotional labour triangle: emotions experienced, emotion ‘display rules’, and emotion management (see figure 1). Surrounding this, there is an important role for organisational considerations in supporting staff across these three areas. This includes: (1) increasing ‘confidence and experience’ to alter the

emotions experienced in the first instance and potentially address perceived display rules; (2) providing both informal and formal 'time to reflect' to support emotion management and respond to long-term emotions experienced; and (3) changing workplace cultures to 'not having that expectation of everyone to be okay', to alter the perceived display rules and the potential pressures of these on emotion management. Without these organisational considerations of support generalist staff can become unable to put the patient first: affecting relationship-building, communication with patients and families, and in some cases staff mental wellbeing.

[INSERT FIGURE 1]

## **4. Discussion & Conclusions**

### **4.1. Discussion**

Our findings demonstrate the varied and often emotionally demanding conversations experienced by generalist staff around life-threatening illness and end-of-life care, and how they manage them. For the first time, understood through the lens of emotional labour and coping, we found that generalist staff prioritise the needs of patients and families, and in doing so utilise high levels of emotional intelligence, monitoring their own and others' emotions to guide their communication behaviours[58]. Previous models of communication behaviour have proposed the importance of skills, knowledge, self-efficacy, outcome expectancies, and perceived support[23, 30]. Our findings go further by describing how each of these factors interact with generalist staff's emotional experiences, contributing to their communication behaviours and emotion management, and demonstrating the types of support that are required.

Previous studies of emotions experienced during clinical encounters have primarily focused on empathic emotions[39, 59]. Whilst these were present, our findings also show the importance of skills-focused emotions, for example anxiety and frustration. This type of emotion was referred to the most but is considered far less in existing literature. These different categories of emotional

experience and how they arise suggest a need for multiple strands of support: more pro-active strategies for skills-focused emotions, and more reactive strategies for situation-based emotions (Figure 2). This may be pivotal in avoiding what participants described as a 'build up' of emotions over time, reported particularly by participants with more years of experience and from the ambulance service. The latter may relate to ambulance staff members' reports of having little time to reflect alongside their increased service demands.

[INSERT FIGURE 2]

Participants expressed the importance of 'time to reflect', both in terms of informal support strategies, and formal mechanisms such as debriefing. However, they also noted the perceived relationship between skills-building interventions and emotional resilience. Previous work has suggested training in emotion management and self-care[28, 60]. Whilst this may help, our participants suggested that improving their clinical skills in palliative and end-of-life care might itself reduce stress-responses. This is because training specifically tackles skills-focused emotions that were common in our generalist sample, whereas traditional emotional support mechanisms address more situation-focused emotions. This highlights a cross-over between aspects of support (traditionally split into psychosocial interventions for emotional support, and training to build skills[23, 36]) that is not acknowledged: psychosocial support may improve clinical communication skills (e.g. by reducing avoidance), and training may bolster emotional wellbeing (e.g. through changing appraisals of clinical situations). If so, ensuring generalist palliative care providers have access to both types of support may be crucial.

Another key finding was how organisational culture influenced participants' experiences, and the importance of workplaces 'not having that expectation of everyone to be okay'. Organisational culture influenced perceived display rules around maintaining 'a professional air', often increasing pressures to suppress emotional expression with both service users and colleagues. Gray[61] described how this restraint can result in emotions becoming 'invisible' in a professional context:



this is also seen in our participants' reports of emotions being disenfranchised by their workplace. A culture that normalises emotional experiences and expression, and provides time and space for this, allows participants to make the most of informal and formal support structures and avoid instances of emotional build up. As some participants suggested, integrating these structures within routine practice may help ensure staff have time to access support as well as normalising an emotionally healthy workplace.

This study is strengthened by use of established underpinning theories to ensure it builds on well-developed constructs around emotions and coping. Involvement of multiple stakeholders throughout the project adds credibility to the overall findings by ensuring interpretations are not limited to those of one researcher[54]. Similarly, analytical rigour was increased by the process of double coding by a second researcher[54]. Purposive sampling also resulted in a diverse final participant group in terms of relevant characteristics (e.g. gender, profession), increasing the breadth and depth of the data and theoretical generalisability[47, 54].

However, there are limitations to consider. Social desirability biases with this potentially sensitive topic may have affected some participants' responses. More women than men participated and there was a slight bias toward people who were more confident in their communication skills at baseline. This is may be due to a high number of non-responders and the original setting from which the sample was recruited[55]. Moreover, recent participation in a communication workshop may have changed participants' attitudes towards and experiences of conversations around end of life care. Generalists who did not respond to the invitation to participate, and those who did not attend the communication skills workshop from which participants were recruited, may also differ in unknown ways to those who did participate. Some important groups of generalists are not represented in this sample (e.g. care home staff, general practitioners, medics). Experiences of staff in these groups might be different, and this should be acknowledged when considering the applicability of our findings. Future research should test the findings of this study in ways that

address these sampling biases. Following this, our findings can inform development and testing of supportive interventions for generalist palliative care providers, in line with existing MRC and MORECARE guidance[42, 43]. Finally, this study was conducted within the UK National Health Service, where care is available free at the point of delivery. It is unclear how transferrable these results are to international cultures, and contexts with different healthcare funding models.

#### **4.2. Conclusions**

The experiences of generalist staff suggest multiple strategies for support are needed to pro-actively and reactively address the emotional aspects of their' work. Whilst these include time and space for informal supportive processes, formal emotional support and palliative and end-of-life care skills training are also required. This training and support needs to occur within a workplace culture that normalises emotional experiences and supports emotion management. To not address these needs has implications not only for the wellbeing of generalist staff, but also their communication with, and care for, patients and families.

#### **4.3. Practice Implications**

This work highlights the emotional labour conducted by generalist palliative care providers that is often overlooked. A first step in supporting generalist staff in this work is acknowledging the challenging nature of some of the conversations they engage in, and the emotional labour required. All staff have a role to play in normalising the need for emotional support. This might include facilitating and/or participating in experience sharing and reflection activities, such as Schwartz rounds, which evidence suggests support communication and compassion[62, 63].

Senior clinical leads need to consider the range of support that is currently available, including initiatives that can proactively address skills-focused emotions and reactively address situation-focused emotions. Where gaps exist, sharing learning and capitalising on existing initiatives may

help, as provision of training and support varies widely across organisations and professions. Teams also need to ensure staff have protected time to access support, including more organically-occurring reflective practice, and be aware of how increasing pressures inhibit these processes. Endorsement of the need for both training and supportive strategies at a policy level could support this. Together, these actions may contribute to an organisational culture that does not simply expect 'everyone to be okay', and addresses the risk of emotional 'build up' and its impact on staff, patients, and families.

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**Conflict of interest statement:**

The Authors declare that there is no conflict of interest.

**Data Sharing:**

Requests for access to anonymised data should be directed to the corresponding author.

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Figure 1: Diagrammatic depiction of emotional labour and support needs

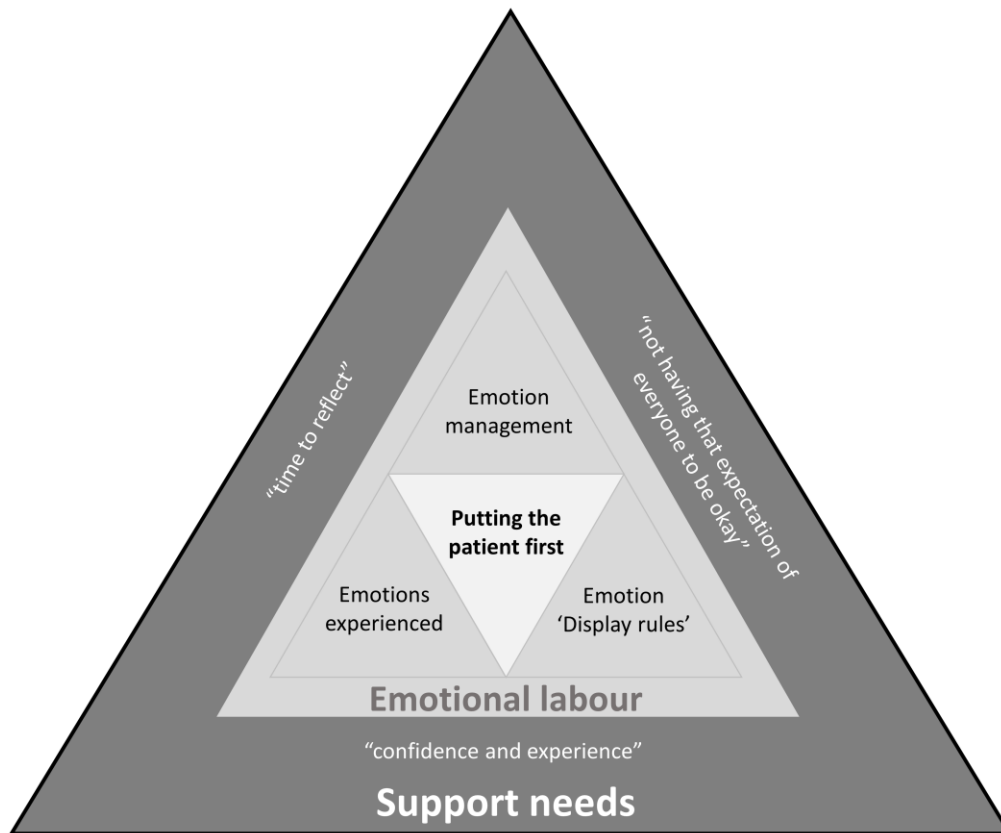


Figure 2: Provision of staff support in line with emotional experiences

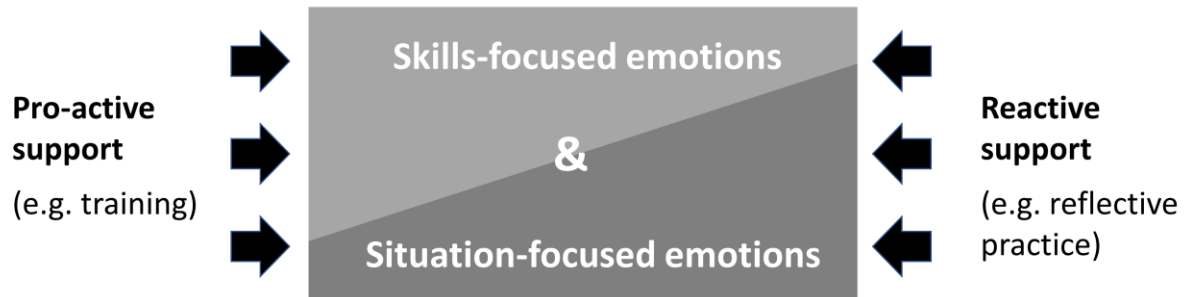


Table 1: Analysis using the framework approach

| <b>Stage</b>                               | <b>Process</b>   |
|--|--|
| <i>Familiarisation:</i>                    | The researcher familiarised themselves with the interviews through reading and re-reading the transcripts and reflective notes.  |
| <i>Coding:</i>                             | Line by line codes were then applied by one researcher to describe key concepts, and potential themes arising in the data. These were generated inductively, although some of the language used (e.g. 'display rules') was drawn from the underpinning theories.   |
| <i>Creating an analytical framework:</i>   | Codes were reviewed, reorganised and grouped in line with the data. Together these formed the analytical framework containing themes and codes. Where possible, 'in-vivo' were used[64]. Throughout this stage the researcher was cognisant of structures from the underpinning theories that may aid interpretation and form part of the analytical framework, but was not limited to deductive interpretations.  |
| <i>Applying the analytical framework:</i>  | The analytical framework was then applied to the data using NVivo Qualitative Data Analysis Software[65], with attention to capturing divergent views. <u>To address issues of rigour and trustworthiness, a second researcher double coded a sample of transcripts (30%).</u> Both sets of coding were compared and discrepancies were discussed until consensus was reached. Where consensus could not be reached, a third researcher was consulted.   |
| <i>Charting into the framework matrix:</i> | Following application of the analytic framework, the data was abstracted and charted into a framework matrix.  |
| <i>Interpretation:</i>                     | The final framework matrix was explored to interpret the study findings. Connections were mapped between categories, and hypotheses were explored. (e.g. potential relationships between participant characteristics and their experiences). Throughout this process the researcher considered areas of convergence with the underpinning theories, but also paid attention to areas of divergence and/or additional complexity[66]. Final interpretation of findings was presented using a narrative approach. Participants did not provide feedback on the findings. |

Table 2: Sample demographic characteristics

| <b>Characteristic</b>      | <b>n / mean</b> | <b>% / SD</b> |
|----------------------------|-----------------|---------------|
| Age in Years               | 39.2            | 10.12         |
| Gender                     |                 |               |
| Female                     | 7               | 70            |
| Male                       | 3               | 30            |
| Ethnicity                  |                 |               |
| Asian                      | 1               | 10            |
| White                      | 9               | 80            |
| Role                       |                 |               |
| Allied health professional | 3               | 30            |
| Ambulance service staff    | 4               | 40            |
| Community nurses           | 2               | 20            |
| Student nurse              | 1               | 10            |
| Years in Role              | 8.56            | 9.38          |
| Perceived Confidence*      |                 |               |
| Not confident              | 0               | 0             |
| Not very confident         | 5               | 50            |
| Confident                  | 3               | 30            |
| Very confident             | 2               | 20            |

*\*Self-rated confidence in end-of-life care communication*

Table 3: Illustrative quotes

| Theme                   | Quotes  |
|-------------------------|---|
| Emotions experienced    | <p>1.1 - <i>"I felt like for once in my life I had left that really horrible situation actually in a really positive thing"</i> (S1, Speech &amp; Language Therapist)</p> <p>1.2 - <i>"As I say I felt somewhat hesitant because I felt all of a sudden a little bit, possibly, nervous of where the conversations might go"</i> (S10, Ambulance Crew)</p> <p>1.3 - <i>"for me, it's the ones that you call quite humbling. People get run over on the roads, people get stabbed all the time and all sorts. I went to two ladies. A woman had a hypo while driving, went unconscious, and basically rolled her car over these two people walking down the street. That could have been anyone - you, me, your family, my family, anyone. It's just those sorts of things."</i> (S6, Paramedic).</p> <p>1.4 - <i>"in a sense, trying to involve feelings - not necessarily in the session, in the meeting, but I just try and think, well, what that could feel like."</i> (S5, Therapy Assistant)</p> <p>1.5 - <i>"But I think we are in danger of having that build up in people and not having a proper vent for it. I'm not sure how we're going to change that."</i> (S7, Ambulance Team Leader)</p>   |
| Emotion 'display rules' | <p>2.1 - <i>"I would give her a hug and cry with her, but that's not professional and you can't do it every time. You're expected to be very strong"</i> (S4, Community Nurse)</p> <p>2.2 - <i>"This doesn't look professional, the last thing you want to do is be sobbing going, 'I'm so sorry.' Then again, part of me thinks that actually I'm human and there's nothing wrong with showing your human side"</i> (S3, Ambulance Team Leader)</p> <p>2.3 - <i>"I gave him a hug, because we had that kind of relationship. Although we were patient and clinician, we were friendly as well, so yes, I gave him a hug."... "You knew that was probably what he wanted. That's probably why he came to tell me"</i> (S8, Student nurse)</p> <p>2.4 - <i>"I tailor back, because no, there are some people that don't want you touching them, or being emotional at all. They want facts and figures, and that's all they want. You have to just, basically, adjust your communication skills based on the way they behave"</i> (S1, Speech &amp; Language Therapist)</p>  |
| Emotion Management      | <p>3.1 - <i>"ones that cause me a bit of anxiety or I'm quite worried about, I do tend to do a bit more planning"</i> (S2, Speech &amp; Language Therapist)</p> <p>3.2 - <i>"I just couldn't even look at the mother straight. It was in a way like I was trying to avoid eye contact because I felt she's going to come and ask me"</i> (S4, Community Nurse)</p> <p>3.3 - <i>"She just looked stressed and extremely tired"..."So I found myself being quite, almost hesitant in terms of asking more specifically other than, you know, do you have local family? Are they able to come round and help you out? How's your sleep? And that sort of thing."..."That's our normal operating procedure so again is that our safety net making us feel comfortable?"</i> (S10, Ambulance Crew)</p> <p>3.4 - <i>"I suppose when I talk to people like that, I allow myself to show emotion to a certain extent. I do it for their gain, as opposed to for me."</i> (S1, Speech &amp; Language Therapist)</p> <p>3.5 - <i>"I would say that I block a certain amount of emotion, especially when I'm finding it quite difficult, because it's not your time to be upset. It's not your mum."</i> (S1, Speech &amp; Language Therapist)</p> <p>3.6 - <i>"Sometimes though, it depends what it is, I don't have time because I'm trying to cope with everybody else. Say it's a member of staff feeling what I would be feeling, I have to go and deal with them and chat with them and stuff. Sometimes it's a case of putting your own emotions on hold for somebody else."</i> (S3, Ambulance Team Leader)</p> <p>3.7 - <i>"Reflective practice is very important, so you see where you're at yourself in this piece of work that you're doing with a particular person. That's when it comes to maybe considering are there parallel processes there or are you transferring something that is irrelevant to your work onto the person."..."Yes, we have that reflective practices in here. That works"</i> (S5, Therapy Assistant)</p> <p>3.8 - <i>"if any emotional venting needs to happen then normally just a bit of a chat with your crewmate that you've just done the job with, is enough, in that situation."</i> (S10, Ambulance Crew)</p> |

## Emotional labour in palliative and end of life care communication

|                                      |   |
|--------------------------------------|---|
| Support Needs                        | <p>4.1 - <i>"I suppose if someone is willing to share their story, to sit down in front of them and to say, 'Do you know what, I had this one patient who reminded me so much of my mum, and I had to come off the case because it was doing this, this and this. I had to go and speak to someone and actually it's okay. It's okay to feel like this. It's okay to do this, because the job we do is really emotionally demanding, and we need to look after ourselves'..." "I think just not having that expectation of everyone to be okay with doing stuff like this all the time, or not having emotions involved." (S1, Speech &amp; Language Therapist)</i></p> <p>4.2 - <i>"A debriefing - I haven't had anybody do that. I think that's really important, but how would they manage with this situation with the resources and staff. They've got to take out time. I think it should be a mandatory part of, you know like we do team meetings." (S4, Community Nurse)</i></p> <p>4.3 - <i>"So from the moment we get in - say if I'm on a 12-hour shift, 7am until 7pm - I'm on a vehicle. I come in, I check my vehicle and I go out and I will be out all day. Job, after job, after job. So there is no time to reflect on that. If something quite serious has happened, you can be stood down. You know, have a cup of tea and a debrief with your colleague or whatever. But that's not the norm. And we don't really understand yet...the effect that way of working is having on our staff." (S7, Ambulance Team Leader)</i></p> <p>4.4 - <i>"I think that's it: knowing that was the right thing to do is the thing. I suppose it was in the back of the mind, "Well, should I resuscitate? Is there any chance..?" That, I think, is 'confidence', and only going to these sorts of things [training workshops] and understanding the process of dying in end-of-life care [will provide that]" (S6, Paramedic)</i></p> <p>4.5 - <i>"When you are having the training you are thinking, 'Oh I am doing it right. I should do this. I shouldn't have hesitated doing that. Now I know I'll be fine.' ... it is reassuring" (S4, Community Nurse)</i></p> |
| Perceived impact of emotional labour | <p>5.1 - <i>"so they've, like, taught themselves to be too far the other way. But unfortunately that then sort of comes across in their care towards the patients, they're quite reserved, they're quite, like - there is a wall between them and the patients." (S9, Community Nurse)</i></p> <p>5.2 - <i>"Because you can't be seen to be panicking, although probably in your head you are. I think it's self-taught actually. Trying to maintain a level of professionalism, I guess. You have to get people to believe in you I think. You can do stuff, you can get things sorted." (S7, Ambulance Team Leader)</i></p> <p>5.3 - <i>"I don't think there's enough emphasis on that emotional support, which is probably why people go off with stress and everything so much, or are ill. I think that's an area which we don't have enough of." (S1, Speech &amp; Language Therapist)</i></p> <p>5.4 - <i>"When I started we'd come back from a job and we'd sit in the mess room and we'd talk about it. We don't do any of that anymore because we're not- we don't see each other. So it's difficult to tell whether that is going to have an impact or our mental health in the long term, because we don't really get a chance to debrief and let out all of that emotional stress." (S7, Ambulance Team Leader)</i></p>  |

## Online Appendix: Emotional labour in palliative and end-of-life care communication: a qualitative study with generalist palliative care providers

Authors: Lisa Jane Brighton, Lucy Ellen Selman, Katherine Bristowe, Beth Edwards, Jonathan Koffman, Catherine J. Evans

### Appendix A: Completed COREQ checklist

| No.  | Item                                     | Guide questions/description  | Page # |
|--|--|--|--------|
| <b>Domain 1: Research team and reflexivity</b> |  |  |        |
| <i>Personal Characteristics</i>                |  |  |        |
| 1.   | Inter viewer/facilitator                 | Which author/s conducted the interview or focus group?   | 6      |
| 2.   | Credentials                              | What were the researcher's credentials?<br>E.g. PhD, MD  | 6      |
| 3.   | Occupation                               | What was their occupation at the time of the study?  | 6      |
| 4.   | Gender                                   | Was the researcher male or female?   | 6      |
| 5.   | Experience and training                  | What experience or training did the researcher have?   | 6      |
| <i>Relationship with participants</i>          |  |  |        |
| 6.   | Relationship established                 | Was a relationship established prior to study commencement?  | 6      |
| 7.   | Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research   | 6      |
| 8.   | Interviewer characteristics              | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic               | 6      |
| <b>Domain 2: study design</b>                  |  |  |        |
| <i>Theoretical framework</i>                   |  |  |        |
| 9.   | Methodological orientation and Theory    | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 5      |
| <i>Participant selection</i>                   |  |  |        |
| 10.  | Sampling                                 | How were participants selected? e.g. purposive, convenience, consecutive, snowball   | 5      |
| 11.  | Method of approach                       | How were participants approached? e.g. face-to-face, telephone, mail, email  | 6      |
| 12.  | Sample size                              | How many participants were in the study?   | 7      |



|  |   |               |
|--|---|---------------|
| 13. Non-participation                  | How many people refused to participate or dropped out? Reasons?   | 7             |
| <i>Setting</i>                         |   |               |
| 14. Setting of data collection         | Where was the data collected? e.g. home, clinic, workplace  | 7             |
| 15. Presence of non-participants       | Was anyone else present besides the participants and researchers?   | 7             |
| 16. Description of sample              | What are the important characteristics of the sample? e.g. demographic data, date   | 7-8, Table 2  |
| <i>Data collection</i>                 |   |               |
| 17. Interview guide                    | Were questions, prompts, guides provided by the authors? Was it pilot tested?   | 6, Appendix B |
| 18. Repeat interviews                  | Were repeat interviews carried out? If yes, how many?   | 6             |
| 19. Audio/visual recording             | Did the research use audio or visual recording to collect the data?   | 7             |
| 20. Field notes                        | Were field notes made during and/or after the interview or focus group?   | 7             |
| 21. Duration                           | What was the duration of the interviews or focus group?   | 7             |
| 22. Data saturation                    | Was data saturation discussed?  | 6, 7          |
| 23. Transcripts returned               | Were transcripts returned to participants for comment and/or correction?  | 7             |
| <b>Domain 3: analysis and findings</b> |   |               |
| <i>Data analysis</i>                   |   |               |
| 24. Number of data coders              | How many data coders coded the data?  | Table 1       |
| 25. Description of the coding tree     | Did authors provide a description of the coding tree?   | Appendix D    |
| 26. Derivation of themes               | Were themes identified in advance or derived from the data?   | Table 1       |
| 27. Software                           | What software, if applicable, was used to manage the data?  | Table 1       |
| 28. Participant checking               | Did participants provide feedback on the findings?  | Table 1       |
| <i>Reporting</i>                       |   |               |
| 29. Quotations presented               | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | Table 3       |
| 30. Data and findings consistent       | Was there consistency between the data presented and the findings?  | 8-13, Table 3 |
| 31. Clarity of major themes            | Were major themes clearly presented in the findings?  | 8-13          |
| 32. Clarity of minor themes            | Is there a description of diverse cases or discussion of minor themes?  | 8-13          |

## **Appendix B: Topic guide**

### **Background information**

- To start, could you please tell me about your role? How often do you care for people with life-threatening illness or in the last year of life, and their carers?
- What sorts of things make conversations with these patients / carers more difficult?
- What sorts of things make conversations with these patients / carers less difficult?

*[Questions evaluating the difficult conversation workshop, not shown here]*

### **Experiences**

- To begin, could you think back to a difficult conversation you've had with a patient with a life-threatening illness or in the last year of life, or with their carer? Can you talk be through that conversation, from start to finish?
- In this scenario, you've mentioned feeling [emotion] and [emotion]. How often do experience emotions like these in difficult conversations?
- Are there any other emotions that you have experienced during a difficult conversation?

### **Expectations**

- Do you think there are any expectations around which emotions you should or shouldn't show, during these conversations?
- If so, can you tell me more about this? Where do these expectations come from about what emotions you could share and those that might be less acceptable?

### **Managing emotions**

- You talked about feeling [emotion]. How do you manage that?
  - How easy or difficult is that to do?
  - What can make this easier?
  - What can make it more difficult?

[Repeat for other emotions, make sure to explore positive and negative emotions]
- How important do you think it is to be able to manage your emotions during a difficult conversation?

### **Support**

- To what extent was the emotional side of your work covered during your training?
- What type of support do you draw on for the more emotional side of your work?
- What else could support you in this part of difficult conversations?

Is there anything else you would like to mention before we finish?

**Appendix C: Table C1****Table A1 - Characteristics of sampling frame and final sample**

| Characteristic              | Sampling frame (n=109) |        | Sample (n=10) |        |
|-----------------------------|------------------------|--------|---------------|--------|
|                             | n / mean               | % / SD | n / mean      | % / SD |
| Age in Years (missing n=6)  | 36.6                   | 11.46  | 39.2          | 10.12  |
| Gender                      |                        |        |               |        |
| Female                      | 83                     | 76.1   | 7             | 70     |
| Male                        | 24                     | 22.0   | 3             | 30     |
| Missing                     | 2                      | 1.8    | -             | -      |
| Ethnicity                   |                        |        |               |        |
| Asian                       | 14                     | 12.8   | 1             | 10     |
| Black                       | 11                     | 10.1   | -             | -      |
| Mixed                       | 6                      | 5.5    | -             | -      |
| White                       | 74                     | 67.9   | 9             | 80     |
| Other                       | 2                      | 1.8    | -             | -      |
| Missing                     | 2                      | 1.8    | -             | -      |
| Role                        |                        |        |               |        |
| Allied health professional  | 5                      | 4.6    | 3             | 30     |
| Ambulance service staff     | 41                     | 37.6   | 4             | 40     |
| Care home staff             | 8                      | 7.3    | -             | -      |
| Community nurses            | 23                     | 21.1   | 2             | 20     |
| General practice            | 13                     | 11.9   | -             | -      |
| Specialist nurses           | 8                      | 7.3    | -             | -      |
| Other                       | 9                      | 8.3    | 1             | 10     |
| Missing                     | 2                      | 1.8    | -             | -      |
| Years in Role (missing n=8) | 7.1                    | 8.3    | 8.56          | 9.38   |
| Perceived Confidence        |                        |        |               |        |
| Not confident               | 10                     | 9.2    | -             | -      |
| Not very confident          | 47                     | 43.1   | 5             | 50     |
| Confident                   | 44                     | 40.4   | 3             | 30     |
| Very confident              | 2                      | 1.8    | 2             | 20     |
| Missing                     | 6                      | 5.5    | -             | -      |

**Appendix D: Final analytical framework**

| <b>Theme / Definition</b>   | <b>Code</b>   | <b>Definition</b>  | <b>Illustrative quotes</b>   |
|---|---|--|--|
| <b>Emotions experienced</b><br><i>Emotional responses experienced by staff in clinical practice</i>                       | "Having that build up"  | An accumulation of emotional experiences   | "But I think we are in danger of having that build up in people and not having a proper vent for it. I'm not sure how we're going to change that." (S7, Ambulance Team Leader)   |
|   | Skilled-focused emotions  | Emotional responses to their own skills (e.g. anxiety about handling a situation)                                    | "As I say I felt somewhat hesitant because I felt all of a sudden a little bit, possibly, nervous of where the conversations might go" (S10, Ambulance Crew)   |
|   | Situation-empathic emotions   | Emotional response to the situation reflecting emotions felt (or potentially felt) by others (e.g. empathic sadness) | "I went through this with this patient and everything else buried deep inside of me has been coming out because this one person reminds me of my granddad who died" (S1 Speech & Language Therapist)   |
|   | Situation-judgement emotions  | Emotional response to the situation based on their own judgement (e.g. frustration)                                  | "I've had to do a few safeguarding, and you just think, 'What on earth are you thinking?' Yes, you can sometimes get, not angry as in, 'I am going to scream and shout.' You're just upset." (S8 Student Nurse)                                |
| <b>Emotion 'display rules'</b><br><i>Perceived rules or expectations around what emotions can and cannot be expressed</i> | "You are the person that they need you to be at that point in time" | Matching emotional expression to benefit the patient and/or family   | "it doesn't necessarily mean that you need to start crying yourself to show empathy in that way, but there are different forms that you can use in how to show that you're appreciative of their experiences" (S5, Therapy Assistant)          |
|   | "As a human as opposed to a clinician"                              | Balancing 'human' or emotional expressions with 'professional' or non-emotional expressions                          | "This doesn't look professional.' The last thing you want to do is be sobbing going, 'I'm so sorry.' Then again, part of me thinks that actually I'm human and there's nothing wrong with showing your human side" (S3, Ambulance Team Leader) |
|   | "you are expected to maintain a professional air"                   | Professional or workplace expectations around emotional expression   | "That is one of many not very nice cultures amongst nurses" ... "Like, you can't get attached, that is the word, and you can't be upset when someone dies." (S9, Community Nurse)  |
| <b>Emotion management</b><br><i>Strategies for responding to own emotions or anticipated emotions</i>                     | "You become a little bit robotic"                                   | Avoiding emotional experiences e.g. by changing topic, focusing on clinical tasks                                    | "I just couldn't even look at the mother straight. It was in a way like I was trying to avoid eye contact because I felt she's going to come and ask me" (S4, Community Nurse)   |
|   | "Anything that I feel will be therapeutic"                          | Participating in cathartic activities perceived to release a 'build up' of emotion                                   | "because I commute by bike or motorbike, I can get my frustrations out there" (S8, Student Nurse)  |
|   | "I allow myself to show emotion to a certain extent"                | Expressing some emotion but not all  | "I suppose when I talk to people like that, I allow myself to show emotion to a certain extent. I do it for their gain, as opposed to for me." (S1, Speech & Language Therapist)   |
|   | "Sometimes you have to steel yourself"                              | Tasks to prepare for a perceived emotional encounter (e.g. planning, emotional preparation)                          | "ones that cause me a bit of anxiety or I'm quite worried about, I do tend to do a bit more planning" (S2, Speech & Language Therapist)  |

## Emotional labour in palliative and end of life care communication

|  |   |   |   |
|--|---|---|---|
| <b>Emotion management (cont.)</b>  | "Your emotions are really on hold"                        | Not expressing felt emotion   | <i>"if you're sobbing your heart out when someone is... Yes, so it's not really practical, but you can show feeling and understanding without... You can go outside afterwards and get emotional whatever"</i> (S6, Paramedic)  |
|  | "Reflective practice is very important"                   | Importance of revisiting and reappraising emotional experiences (alone or with others)              | <i>"We then need to think what was felt in the team or what your feelings were in the team about the case in general. Yes, we have that reflective practices in here. That works"</i> (S5, Therapy Assistant)   |
| <b>Support needs</b><br><i>Support needs around emotional labour</i>                       | "Confidence and experience"                               | The role of skills building in emotional wellbeing  | <i>"When you are having the training you are thinking, 'Oh I am doing it right. I should do this. I shouldn't have hesitated doing that. Now I know I'll be fine.' Even though you're never fine but it is reassuring"</i> (S4, Community Nurse)  |
|  | "time to reflect"   | Needing time to manage emotional experiences (formally and informally)                              | <i>"I'm very introvert so I'll have to go and sit in the ambulance and just be on my own to recharge my batteries"</i> (S3, Ambulance Team Leader)  |
|  | "Not having that expectation of everyone to be okay"      | A workplace culture that acknowledges and normalises emotional experiences and management           | <i>"station managers now and team leaders - are very good. You can always, generally, talk to them. I think when it starts getting up to the Directorate and senior managers, I don't think they're interested."</i> (S6, Paramedic)  |
| <b>Perceived impact of emotional labour</b><br><i>Perceived impact of emotional labour</i> | "It's crucial, yes, from a mental health point of view"   | Impact of emotional labour on their wellbeing, including their ability to keep working              | <i>"I just don't know how much people access [support]. You might be able to pick that up in looking at trends of sickness and things like that but a lot of it is probably still, hidden is the wrong word, not seen."</i> (S3, Ambulance Team Leader)   |
|  | "Then you wouldn't be very good at your job"              | Impact of emotional labour on their ability to provide the care required during clinical encounters | <i>"Because you can't be seen to be panicking, although probably in your head you are. I think it's self-taught actually. Trying to maintain a level of professionalism, I guess. You have to get people to believe in you I think. You can do stuff, you can get things sorted."</i> (S7, Ambulance Team Leader) |
|  | "Can affect your emotional connectivity with the patient" | Impact of emotional labour on relationships with patients and/or families                           | <i>"so they've, like, taught themselves to be too far the other way. But unfortunately that then sort of comes across in their care towards the patients, they're quite reserved, they're quite, like - there is a wall between them and the patients."</i> (S9, Community Nurse)                                 |