

Sitting with you in uncertainty: a reflective essay on the contribution of social work to end-of-life care

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Abstract: Death may be the only certainty in life, but for palliative care patients and their carers, it is anything but. How long is there left? Will a hospice bed be available? What new loss (big or small), will tomorrow bring? Research suggests that the poor management of uncertainty in palliative care can significantly impact patient outcomes as well as the experience of bereaved families. Social workers cannot mitigate this uncertainty, but they can support individuals to recognise and engage with it. Often, this can create tensions with their personal instinct to remove distress, as well as their professional drive to ‘fix things’. By overcoming these challenges and embracing their ability to find ways forward ‘in the midst of the messy stuff’, they model a constructive mode of behaviour that patients and other multidisciplinary professionals can then mirror.

Keywords: hospice care, live discharge, palliative care, social work, uncertainty

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Foreword

In the following essay, we speak about ‘discharge’ from hospice. For those who are not familiar with this concept, or who are under the impression that all patients admitted to a hospice stay there to die, we felt that it would be useful to add a few words of clarification at the outset. Live discharge is a common process in UK hospices; it is estimated that around one-third of patients admitted are moved to an alternative care setting prior to death.¹ Whilst the authors note that discharge rates and processes may be different in other countries,² we hope that the themes of loss and change discussed in this reflective essay, alongside the feelings and emotions that they illicit, will be relevant and recognisable to all those working in palliative care settings.

For those interested in reading more around live hospice discharge, we recommend the work of Stephanie Wladkowski.³ Focusing on the United States, she highlights the difficulties that live discharge can create in terms of interrupting the physical and psychosocial care that a patient has been receiving in the holistic hospice

environment. Based on our own experiences, we agree with her call for further research into the impact of the live discharge process, as well as the need for more formal national guidelines to support patients, families and palliative care professionals.⁴

Introduction

This reflective essay was co-written by two social workers at very different points in their career paths. At the time of writing, [Rebecca] was newly qualified and embarking on her first role in palliative care. [Sarah], with 10 years of post-qualification experience, had just taken on a new and challenging role at the hospice: Head of the In-Patient Unit (IPU). In that sense, we were both viewing the social work role through fresh eyes. After only a few weeks of working together, the hospice received an official complaint relating to a patient’s discharge. In true social work style, this provided an opportunity to reflect, and re-reflect, on our practice and values. In the months that followed, we developed our thinking, seeking out a theoretical model that could aid our

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journey. This led to an internal focus group with other social workers, as well the creation of a poster for the Hospice UK 2023 conference.⁵ We did not know it at the outset, but one of the most useful outcomes of our reflections turned out to be a new perspective on the unique contribution that social workers can make in end-of-life care. The following essay outlines how we arrived at this point, and why we believe our framework could help other practitioners who may be struggling to ‘clarify, describe, and justify their role on the interdisciplinary team’.⁶

A newly qualified social worker gets a shock

When I ([Rebecca]) started this role, I believed that one of the main contributions I could make as a social worker was to provide patients and families with reassurance: this was one of my personal values that I thought could also be a professional one. Though I was aware from the outset of the need to make individuals aware that the hospice was a short-stay facility, I often softened this blow with phrases such as ‘But we don’t need to worry about that for now’ or ‘In all likelihood you’ll be staying here’. I soon learnt the hard way that such platitudes were not only ineffective, but potentially dangerous. Whilst they may have made some conversations more comfortable for me personally, they did not serve me well professionally. When the time came to actually have a concrete conversation around discharge, there was more work to do to bring patients and their families round to the perspectives of the Multidisciplinary Team. Furthermore, those reassuring comments risked bringing a level of dishonesty to the conversation that could end up undermining meaningful relationships.

Learning that there had been a formal complaint so soon after starting at the hospice was definitely a shock. Though the complaint was not specifically directed at me, I felt a high level of responsibility as I had been working closely with the patient and her family. Whilst I was reassured that the complaint had most likely arisen due to complex family dynamics and general hospice processes rather than something I had specifically said or done, I did not distance myself from the issues that had been raised. Though this was uncomfortable at the time, it was also a pivotal moment in my development as a reflective practitioner.

Looking back now, I recognise that there had been times when I could have been less ambiguous with

the patient and her family about the hospice processes and the need for her to be discharged. I have now questioned what I originally felt was best for the people who draw on care and support at the hospice. I had been providing them with what I thought they wanted or needed, without first reflecting on the consequences on this approach. It is possible that some element of personal bias was also at play here, as my own mother died of cancer at the end of 2019. I wonder if I was trying to provide comfort because that was something I was still seeking myself.

An experienced social worker provides support

When [Rebecca] spoke to me ([Sarah]) about her above realisations, I gave her a wry smile. I said that I was glad that she had reached these conclusions, but they were ones that she had needed to arrive at by herself. I agreed that it is natural to want to remove people’s distress and ‘fix things’, especially when they are in a heightened emotional state, but the key to progressing as a palliative care social worker is to be both empathetic and explicit. We can tell individuals that the future cannot be perfectly mapped out, but that we will be there to support them whatever path it may take. The interesting thing about this approach is that it still allows us to provide some form of comfort and reassurance, but by embracing uncertainty rather than mitigating it.

I reassured [Rebecca] that complaints of this nature were not uncommon, and that every Social Worker experiences a difficult situation early in their career that causes them to question their practice. I shared some of my own early experiences, including discharging a patient home who died within hours of getting back there – suddenly, and unexpectedly. I had planned and planned, but I could not plan for that. I felt sad, confused and questioned myself constantly: ‘Was it right for him to go. . .and what did I miss in planning his return home?’. Now I know that ‘holding’ that uncertainty is such an integral part of our role, but it has taken time and experience to get there. I always say to patients ‘This is your show. . .’ and it truly is, they will live (and die) their way. We are just supporters; listening, advocating and sitting alongside them in what can sometimes feel like chaos.

Turning to the literature for guidance

Following our peer reflections, we decided to look further for theories and research that could

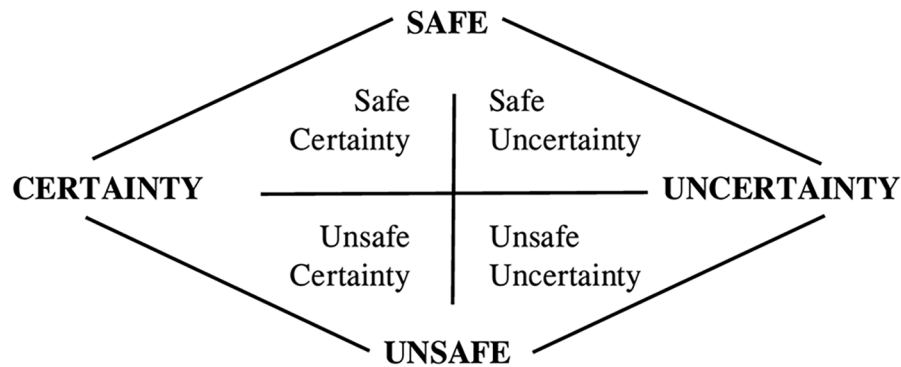


Figure 1. Towards positions of safe uncertainty.¹⁰

support our thoughts. We were not surprised to find that the poor management of uncertainty in palliative care can significantly impact patient outcomes as well as the experience of bereaved families.^{7,8} This is significant, as there are so many areas of uncertainty to contend with. There is the ‘When’ (How long is there left?), the ‘Where’ (Will I stay and die here?) and the ‘How’ (What version of myself or my loved one will I be met with in the morning?). Since professionals do not have certain answers to these questions, it seems there is a place for care and support that helps people learn how to sit *with* uncertainty rather than try to resolve it.

This brought us to Fook, who says that social workers must develop an ‘ability to tolerate ambiguity and uncertainty’.⁹ By recognising and accepting that situations might have contradiction and conflict and that outcomes cannot be guaranteed, they can avoid being defeated by daily dilemmas and instead regard them as opportunities for ongoing challenges. Thinking of the hospice discharge process, this led us to reflect further on the specific contribution that social workers can make to palliative care. If, as Fook⁸ says, the tolerance of ambiguity and uncertainty are key to our role, then can they help define what we actually *do* on a day-to-day basis? And could they serve as a framework for us to engage in direct work with patients and families?

We then discovered a model (Figure 1) that a therapist has previously used with clinical patients, and which we felt was particularly relevant to our reflections. Conceptualised by Mason,¹⁰ the model of ‘safe uncertainty’ is not considered to be a technique or skill, but ‘an always evolving state of being’.¹⁰ In brief, it explains that there are two ‘unsafe’ positions that patients or families may

feel they are in when they first access services: ‘unsafe uncertainty’ (having a problem and feeling hopeless there is no solution) and ‘unsafe certainty’ (having a problem but being clear what is causing it and what will solve it). Professionals can then lead patients or families to positions of ‘safety’: ‘Safe certainty’ (believing that the problem can be solved is solvable, that risk can be eradicated) and ‘Safe uncertainty’ (multiple explanations for the problem and solution, a constant state of flow and exploration). Mason¹⁰ believes that it is the latter, the position of ‘safe uncertainty’, which should be the goal. Reading this, it felt like something clicked! Though it is not a model specific to social work, it seemed to be consistent with our professional values of ‘never understanding too quickly’, ‘respectful curiosity’ and the recognition that good social work is a mutually influencing process. Unlike ‘safe certainty’, ‘safe *uncertainty*’ does not assume that a problem can be solved or is solvable, opening up space for other views to be stated and heard.

Exploring our ideas with peers

In a focus group of In-Patient and Community Social Workers, we discussed the ways the concept of ‘safe uncertainty’ could help frame our professional practice. Although the discharge process had been the springboard for our initial reflections, we found that the concept had relevance to all elements of palliative care social work.

A way to start the necessary conversations

‘Safe uncertainty’ is a phrase that people may not have heard before, but as a phrase it can be effective at starting a dialogue. As we explain the concept, we can start to gently probe into an

individual's situation. As Egan¹¹ highlights, 'Probes, used judiciously, help clients name, take notice of, explore, clarify, or further define any issue at any stage of the helping process'. 'Safe uncertainty' introduces a number of conversation starters. What is making you feel unsafe at the moment? What knowledge or information could make you feel safer? What is currently uncertain about the future? What might each of these future possibilities mean to you and your family?

A way to normalise uncertainty

The ability to tolerate uncertainty will naturally vary across the population of patients and families that access palliative care. Without overgeneralising, it could be hypothesised that older generations find it more difficult to face unpredictable situations, especially if their lives to date have been characterised by controlled choices. For example, unlike their younger counterparts, they may have faced more certainty in their chosen careers or the expected trajectories of their romantic relationships. There are many exceptions to this rule of course, but as one of the social workers in our focus group said – 'It is always worth considering how certain generational tendencies may differ from our own and impact the end-of-life experience in different ways'. In addition, there are other groups of individuals who may find uncertainty particular difficult to tolerate, including those who struggle to regulate their emotions.¹² The concept of 'safe uncertainty' could be particularly relevant for those who are unfamiliar or uncomfortable with the feeling of not knowing what's around the bend. Telling people 'It's ok not to know' will not eradicate worry or doubt, but it might add a sprinkling of much needed support.

A way to empower patients and families

Unintentionally or not, the holistic, multi-professional approach to hospice care can be disempowering to patients and families.¹³ On admission, individuals are introduced to a multitude of professionals – nurses, doctors, social workers, chaplains, physiotherapists – which can give the impression that dying is a complex process that requires a team of experts to 'fix'. Without minimising the skill and compassion that each of these professionals bring to the table, it is important not to forget the expertise of those with lived experience. We believe that helping patients and families to face uncertainty can be one way to readdress

this imbalance. By suggesting tools and techniques that can guide them through the perceived chaos, we can provide them with the tools to build their own resilience and to come up with creative pathways rather than focusing on rigid solutions.

A way to facilitate advance care planning and manage expectations

The concept of safe uncertainty can also be applied to the way we manage one of the most challenging aspects of palliative care – that of prognostication. For patients and their families, it often feels like the most important question to be answered, the one that will provide some solid ground from which they can start to accept, discuss and plan. However, prognostication in palliative care is a famously inexact science and disclosing prognosis can cause fear, uncertainty and emotional distress.¹⁴ As a multidisciplinary team, we often 'look back' to look forward, which involves considering a person's rate of deterioration to try and understand when they are entering the final phase of their life. As a method, this is fairly reliable. However, it is far from certain. This is where Social Work comes in! Our presence in discussions around prognostication and advance care planning can help manage expectations and facilitate dialogue between patients, family members and other professionals. By thinking in terms of 'safe uncertainty', we can help remove some of the fear of getting it wrong, for example when we are considering discharging someone whose condition is very variable or unpredictable. We can help the patient and the team acknowledge that although we do not *expect* someone to die within days of discharge, the *reality* is that this can sometimes happen. We can talk through the various 'what if' scenarios, providing a safe space to explore distressing topics. Of course, all of this pre-emptive work does not mean we feel comfortable when things do 'go wrong'. Finding out that someone who has just been discharged has died will always provoke big feelings for us and the multidisciplinary team; learning to accept these feelings takes time and reflection.

A way to promote team communication and gain insights

When things do not go according to plan, it is essential that the multidisciplinary team has an opportunity to regroup, reflect and debrief. Once

again, ‘safe uncertainty’ can be used as a way to frame these conversations and to provide some comfort when professionals are questioning their own decision-making and practice. At our hospice, we have formal multidisciplinary team meetings throughout the discharge process, allowing all members to share their opinions and discuss what is the *safest* course of action in the midst of much *uncertainty*. This is particularly important with a ‘challenging’ live discharge, as we need to ensure that the whole team is behind a decision so that patients and their families hear a consistent and clear message. We also conduct regular ‘Schwartz rounds’⁴ to reflect on our learning and growth as well as the triggers we can experience when faced with a lack of certainty. Schwartz rounds are safe spaces provided for clinical and non-clinical teams to explore the emotional impact of our work and to recognise the support we need to provide compassionate care that results in positive patient experiences.⁴ They are not a space for problem solving but for learned experience and reflection. These are brave and unpredictable conversations that encourage us to sit in a space of ‘safe uncertainty’ as a team.

A way to quantify the contribution of palliative care social workers

By far our favourite definition of the social work profession is the one provided by Ruth Allen, Chief Executive of the British Association of Social Workers. Her quote is worth reading in full, but most pertinent to our current reflections is the claim that as social workers, ‘We are always in the midst of the messy stuff, finding ways forward’.¹⁵ Uncertainty is our currency! This is unsurprising, given our professional training. All social workers study human development across the lifespan, learning how trauma, loss, ageing and end-of-life issues can impact physical, cognitive and emotional development.¹⁶ In addition, we should not forget the core competencies of palliative care social work that should be embraced and communicated to level the playing field with other health care disciplines. In the United States, the Educating Social Workers in Palliative and End-of-Life Care (ESPEC) curriculum highlights our specific skills around biopsychosocial-spiritual assessment, advance care planning, family meetings, interprofessional communication and professional development,¹⁷ whilst a 2018 Delphi study reached a consensus that one of our 41 core competencies is ‘to help patients and families anticipate needs and achieve smooth transition

between settings’.¹⁸ In Europe, two white papers by the European Association of Palliative Care^{19,20} and a framework by the Irish Health Service Executive²¹ all outline similar sets of core competencies – demonstrating that there is substantial international overlap regarding the ways that Social Work contributes to end-of-life care. It is likely that COVID-19 will further crystallise these shared experiences, as Palliative Care Social Workers across the world were required not only to upskill themselves in the midst of a crisis, leading to moral suffering but also opportunities to recognise their resilience, their creativity and the meaning of their work.²²

Employing the concept of ‘safe uncertainty’ can help us maintain ownership of all of this rich and valuable expertise. As palliative care social workers, we are professionals who are not afraid of the unknown. We have sat with patients and families in the messy world of uncertainty before, and we have helped them safely reach the other side. By saying – ‘I know it’s uncertain, but I can talk to you about my experience, what may happen’, we can be seen as a safe pair of hands – somebody who has seen this before, is open to it, and is not worried.

Putting the concept of ‘safe uncertainty’ into practice

More and more over the past few months, we have found ourselves using the concept of ‘safe uncertainty’ in direct work with patients and families. For Newly Qualified Social Worker [Rebecca], this happened most frequently during discharge conversations. She found that patients responded positively when she directly acknowledged the amount of uncertainty in a situation. Often, patients would respond with comments such as ‘Yes! That’s it, that’s the toughest part’. They were appreciative of the opportunity to discuss the unknown, and as a practitioner, [Rebecca] did not find it as scary as she first thought to remove the unnecessarily reassuring comments from her vernacular. Even though many discharge conversations started with the same initial distress and upset, once it was confirmed as a possibility and they were talked through the process, many felt a lot calmer once they had been given all the facts.

As a more experienced Social Worker in a leadership position on the IPU, [Sarah] has chosen to illustrate her learnings around sitting with

uncertainty through the following two case studies. These explore the concept of safe uncertainty in a more general way, demonstrating its relevance beyond the topic of live discharge.

Case study 1: Uncertainty and holding risk

'Sitting' alongside our patients and families in 'safe uncertainty' means holding risk and feeling comfortable with managing risk positively. This can often involve promoting a person with lived experience's independence and rights – a position Social Workers often feel secure in as our training is rooted in law and our values are embedded in human rights and ethics. Part of my social work practice has been supporting other professionals along the way who may feel less comfortable with risk. After all, as Mr Justice Munby notoriously said in a family court judgement '*. . . What good is it making someone safer if it merely makes them miserable?*'²³ Holding this uncertainty can take my own courage and faith; as a patient said to me once early in my career when we were exploring their discharge home: 'I have trusted you, you have to trust me now'. When someone is coming to the end of their life, their goals, wishes and physical condition are constantly changing. As Mason states '*. . . A position of safe uncertainty is never fixed. It is always evolving. It is a place where doubt, uncertainty, unhelpful difference, can be safely, if at times uncomfortably explored.*'²⁴ As Social Workers we can (hopefully!) aid these conversations with professionals and those important to the dying. Using our communication skills and professional curiosity, we can manage risk and more smoothly navigate the emotional landscape of death and dying.

Case study 2: Uncertainty and leadership

As world events and the echoes of the COVID pandemic leave us heart-sore, the impact of the increasing complexities of our patients ensures that mounting uncertainty is a day-to-day experience. As Head of a Hospice IPU, how can I lead my team through a time of change and increasing pressures when they already feel overwhelmed? In a recent Harvard Review Business Article on how to lead through uncertainty,²⁵ one of the six named strategies was 'Let Go of Perfectionism'. This approach enables us to create a culture of learning and reflection, makes allowances for mistakes and encourages us to foster the abilities and skills needed to grow and develop. This can be challenging in a hospice environment where the ethos

is very much 'we have one chance to get this right'. Kinman and Grant²⁶ discussed the concept of 'Socially prescribed perfectionism' and the expectations of others in relation to our practice including 'the public at large'. As a social worker, I have felt the weight of this responsibility from those I support, from myself, and also from the community we serve. There are often heavy expectations of what a hospice 'should' be and 'should' provide. As a leader, I also have to manage any perceived 'perfectionism' that may be projected from managers or even those in my team who expect me to make the 'right' decisions because of my position. The reality is, as a human being myself, I think, feel and undergo all of the negative emotions that come with wanting to provide the best possible experience for all who are dying, and I sometimes feel limited by external factors. In the literature, they refer to this debilitating phenomenon as 'moral distress', which occurs 'when individuals feel constrained from acting in accordance with moral choice, or act against moral judgement, generating painful, unresolved emotions and problems that continue long after an event'.²⁷ I know this has personally contributed towards burnout and feelings of reduced personal accomplishment. I cannot express how many times I have supported my team, paralysed by guilt and shame over errors that were entirely 'human'. Expecting perfection in a complex environment is impossible, and I feel often we have to be as kind to ourselves as we always try to be to those we care for. As a leader, I have to hold that safe uncertainty of 'less than perfection is ok'.

Recently, we experienced a challenging few weeks on the IPU. A person with a degenerative brain disease was dying with us, completely vulnerable and only able to communicate using one finger to type. The patient's young family were bruised and battered by several years of watching their loved one lose so much of their identity. The patient was physically hard to care for and emotional distress was high in interactions between their partner and the team. It was like an electric current running through the IPU, ready to spark at any time – when I met with them, I knew they were on the edge – if I pushed or was 'too kind' I knew they would break down and may never stop.

On the other side of the IPU, there was a patient who was regularly bleeding from a neck tumour and laryngectomy site. The constant risk that they may have a catastrophic bleed met the electric current and emotion on the other side of the IPU

and created a perfect, terrible storm. By week 3, my team were trying (and struggling) so hard to 'hold on' whilst these two patients were on the edge of living, teetering with very complex needs that made us all feel fearful and unsafe. Drawing on my resilience and skills as a Social Worker to lead the team through this felt more important than ever. In my years working in palliative care, I have gained expertise in managing distress and holding a position of 'authoritative doubt'. My training and experience have allowed me to support people to thrive and learn even whilst in an 'unsafe' position. I think that my biggest learning was how important it was to listen, *really listen*, to be curious about what the team were feeling and ultimately, to provide reassurance that this situation was 'just for now'. It was also powerful to remind the team of why we are here: to absolutely provide specialist care when people need it most. Delivering this message was not always easy, being present, open and unafraid to have the hard conversations is ingrained in my practice and experience as a Social Worker. I have never needed these skills more to encourage the team to 'hold on' until the storm passed.

Final thoughts

At one point, we were so enthralled with the concept of 'safe uncertainty' that we thought we should change our job title from 'Social Worker' to 'Uncertainty Supporter'. We soon dismissed the idea, mostly due to the pride we take in our profession. But internally, we do believe that feeling 'comfortable' in facing uncertainty is a gift we can give those we work with, so they can feel safe at a time that is arguably the hardest they may face.

To finish this essay, we could not resist including a quote from one of our favourite authors, whose writing and research has much relevance to social work. We think that it sums up a lot of what we are trying to express in this piece, and we hope it provides you with a little bit of inspiration too. So, for the last word, over to Brené: 'The foundation of courage is vulnerability – the ability to navigate uncertainty, risk and emotional exposure'.²⁸

Declarations

Ethics approval and consent to participate

Ethics approval was not needed for this study. The social workers taking part in the focus group gave their consent to participate.

Consent for publication

Case studies have been fully anonymised and therefore consent for participation/publication was not obtained.

Author contributions

Sarah Dowd: Conceptualisation; Methodology; Writing – original draft; Writing – review & editing.

Rebecca Salama: Conceptualisation; Methodology; Writing – original draft; Writing – review & editing.

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Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials

The focus group was held at the hospice and recorded on Zoom. A link to this recording is available from the corresponding author on request.

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