

The psychological impact on family members of a patient experiencing pressure ulcers — a reflective account

KEY WORDS

- » Caregiver
- » Duty of Candour
- » Family
- » Pressure ulcer
- » Psychological impact

Verbal communication is considered the most effective way in which humans communicate feelings, experiences and views (Parahoo, 1997). This article captures the story of the family of a 95-year old patient who had been admitted to an acute trust, where he developed a pressure ulcer on the heel, alongside some moisture-related damage on the buttocks. After being transferred to a local care home, he was re-admitted to the Emergency Department with sepsis and two unstageable pressure ulcers on his heel and sacrum, which he subsequently died from. The article outlines the impact and emotions family members felt during that time, which were recorded using open, unstructured, *ad hoc* interviews. The author allowed the family members to voice their feelings without prompting, collecting the information in a way that was comfortable to the family over several meetings. What follows is a reflective piece on the experiences and emotions felt about 'a pressure ulcer in the family' to help healthcare professionals gain a holistic view on the impact on family and caregivers.

The impact of pressure ulcers on patients has been well documented (Langemo et al, 2000; Spilsbury et al, 2006) and the cost to quality of life includes changes to body image, loss of productive time as well as pain and suffering (Repic and Ivanovic, 2014; McGinnis et al, 2015). Experiences described in qualitative studies have been likened to the stages of the grieving process (Langemo et al, 2000) and patients report a lack of understanding or acknowledgement from healthcare professionals regarding the impact of pain and loss of independence (Spilsbury et al, 2006). Hopkins et al's study of patient stories identified that alongside the personal impact of sustaining a pressure ulcer, some patients also reported their concerns for the impact on their families and their worries about the extra burden for family members having to become caregivers (Hopkins et al, 2006).

Very little has been written regarding the emotional impact of pressure ulcers on the family or caregiver of the affected person. One small qualitative study by Rodrigues et al (2015) considered the impact on caregivers, where participants expressed fear of the person they were caring for dying, but it predominantly focused on practical issues around changes of lifestyle, adaptations to the

property and changes of role from being the relative to becoming the caregiver. Reflection on recent experiences suggests that there is a need to recognise and document the impact on the family and/or caregiver to help healthcare professionals to gain a holistic oversight.

In a busy acute trust, nursing staff often report that they find too little time to talk in-depth with family members. Recently, concern was raised in the author's local trust when a family member voiced a lack of communication with ward staff as the main factor that led to misunderstandings in care of a patient and frustration of the family concerned.

Specialist nurses often have a unique position in that they have more focused time to holistically assess and plan care for patients with a specific problem, such as in tissue viability and patients with wounds. Repeat visits often result in the building of a relationship with patients and their family.

DUTY OF CANDOUR

The author is an experienced Lead Tissue Viability Nurse Specialist who has been involved in the care and investigation of pressure ulcers for over 20 years. More recently, the author attended an HM Coroner

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Inquest as a witness, after a patient had died as the result of a pressure ulcer. While caring for this patient during his two in-patient stays, the investigation into the cause of the pressure ulceration, Duty of Candour meetings and inquest preparation, the author met the relatives and friends of the patient several times. Hearing their perspectives and experiences of caring and using past experiences of discussing care and pressure ulcer investigations with relatives of other patients has allowed the author to reflect on the wider context of the impact of pressure ulcers on those around the person immediately affected.

The advent of ensuring Duty of Candour — the legal duty to be open and honest when things go wrong — as part of the investigation of the incident process gives opportunities for healthcare professionals to not only have open and transparent conversations but also to listen to those involved with the person affected (Health and Social Care Act, 2014). There is an opportunity for family and friends to express how an incident has affected them as well as the patient.

METHOD

A factual patient story was documented to give clinical context to the occurrence of the pressure ulcer. Information was gathered as part of the investigation and inquest report process, using a standardised information gathering template and summarised for this paper. The patient details were anonymised and family members consented to the use of their story for educational purposes and have actively contributed to the writing of this account for publication.

Interviews and discussions were transcribed as quotes at the time of the discussion so that details were not lost. Themes emerged, allowing the author to catalogue and reflect on the pre-perceived impact and the actual voiced impact from the family.

THE PATIENT

Fred died when he was 95 years old, having lived a mainly healthy life. He developed Type 2 diabetes in his 80s and had shown a recent decline in memory function. He was admitted to an acute trust following a fall and proceeded to decline rapidly in his mobility and cognition. During his admission, he developed a category 2 pressure ulcer on his heel, alongside some moisture-associated skin damage on his buttocks. A

full investigation took place to establish if any lapses in care led to these wounds and the trust complied with the full Duty of Candour with his next of kin, a nephew who met face to face with the Lead Consultant and the Lead TVN.

Fred was discharged to a local care home, where he resided for 19 days before being re-admitted with sepsis. On arrival to the Emergency Department, he was found to have a large unstageable necrotic pressure ulcer on his sacrum, incorporated in his buttocks in a saddle shape, which would manifest as a category 4 pressure ulcer during his in-patient stay and a necrotic unstageable pressure ulcer to his heel at the site of the previous category 2 pressure ulcer. Fred ultimately died as a result of these pressure ulcers in August 2019. The inquest took place over three days and involved the hearing of several statements from healthcare professionals from the acute hospital and two care homes; the family had the opportunity to also speak about their relative and their perspectives on the care he had received.

Fred's nephew is a formal carer and had been instrumental in caring for his uncle before his initial fall and first admission, he had altered living arrangements as his health declined and ensured he received good care with hygiene, nutrition and company. Fred's nephew is passionate about helping others to learn from his experience and has expressed how this personal experience has impacted the way he continues in his professional caring role.

EMERGING THEMES

Initial conversations followed the timeline of events, from reminiscing about Fred's pre-admission life, through the events of his first admission, his first care home stay, his re-admission and end-of-life decisions leading to his second care home stay and ultimately death and the inquest that followed. Other themes emerged, which aligned with the grieving process, including anger and blame as well as sadness and depression, supporting findings from previous quality-of-life studies regarding the impact of pressure ulcers (Langemo et al, 2000). Like the caregivers in Rodrigues et al (2015) study, there was an acceptance that the pressure ulcer may not heal, that it was a sign of increasing frailty and an indicator that life was nearing its end.

Based on previous family meetings involving other patients, the author had a perception that

ACKNOWLEDGEMENT

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anger and blame would be the over-riding theme of the discussions. So there was surprise when the majority of the conversations involved reminiscing and remembering the person rather than the events leading to his death, although these formed significant themes also.

REMEMBERING FRED

Fred’s nephew and other family members were keen to ensure that healthcare professionals and the Coroner knew the person and that Fred was not just a patient or a deceased body. Having a good knowledge of the person before a health change can enable healthcare professionals to engage with a patient during the assessment, planning and implementation of care. Complaints from families often include the feeling of not having been listened to, of not understanding the person being cared for.

Fred’s family spent time telling his story from growing up, meeting his wife, sadly learning they would not have children of their own and the joy they found in caring for their nieces, nephews, extended family and friends. There were memories of a house full of happiness, that Fred was *“the kindest gentleman, non-judgemental, I would go to him rather than my own father for advice, he always gave good advice.”*

He was described as always open and honest *“telling it as it is”* and his nephew related this characteristic to the open and honest discussions he had with the hospital team regarding his pressure ulcer and medical condition: *“He would have appreciated that honest conversation.”*

As his health declined in later years, family roles changed from being cared for by Fred to caring for him, a dynamic described by others as a change in a family relationship (Rodrigues et al, 2015): *“We worried about him going out, collecting his pension. Was he washing properly, was he eating? We arranged for him to come to us for dinners. I helped him shower.”* *“It was hard seeing him lose his choice, independence and control. I had to speak for him, act for him and even now he is gone, I still must speak for him.”*

Fred’s nephew spoke of using his own experience as a professional carer to plan and implement the changing care needs for Fred, alongside the family’s desire to allow him as much independence as possible. There was a recognition that the fall, hospital admission and development of pressure ulcer were possible indicators that Fred’s life was nearing

its end. *“It was only a matter of time before something serious happened, I didn’t want him to break a hip, I know people with dementia don’t get better from that.”* *“The Doctor was so good, he explained how Fred was on a path of decline, and we could see it but it’s hard to see it.”*

These conversations led to themes aligning to the stages of the grieving process of sadness and depression at their loss and, as the author anticipated, anger and blame regarding the development of the pressure ulcers.

ANGER AND BLAME

In alignment with a similar stage of grieving, families involved in Duty of Candour conversations often express anger and blame towards healthcare professionals about their loved ones developing pressure ulcers.

Fred’s nephew was able to use his experience as a carer to compare what care he felt should have been in place but wasn’t. Regarding the first admission to hospital: *“My knowledge as a carer means I know what he should have had. At first, I told staff he needed an air mattress, I could not understand why he did not have one.”* *“I thought if only he had his heels lifted up, he might not have got that first pressure ulcer.”*

Fred’s nephew was also able to use his professional experience, expressing an understanding of the complexities of caring for someone with dementia and agitation: *“Could it have been prevented, I don’t know, he was so fidgety, would he have kept the heel boots on, I don’t know, but they didn’t give him the chance.”*

During the Duty of Candour meeting, these statements made the hospital team realise that an opportunity to explain the function of different types of mattresses in the trust compared with what was used at home had been missed. This may have reassured his nephew that an appropriate mattress was in place and that any attempt to offload heels was impeded by Fred’s confusion, which had caused him to be agitated and fidget in bed.

The majority of the expressions of anger and blame were directed towards the first care home and were voiced as feelings of shock and disbelief of what had occurred: *“We were shocked, he looked like he was in his last hours, he was ashen, grey.”* *“When they (the hospital) showed me his bottom, I could not believe it, it was nothing like the last time I’d seen when he left hospital last time.”* *“I was shocked at some of the notes,*

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I questioned what care was he getting, what had I been told, did they do any of it? It wasn't written down so now I'm disbelieving of whether it (washes, care) got done.” “The manager tried to pass the responsibility on to others, it was like ‘I wasn't there so it wasn't me’ she did not take accountability.” “I've lost trust in care homes.” “Frustrated as a professional carer that others don't do what I do.”

When reflecting on care in the first care home, Fred's nephew also expressed guilt and anger at himself, feeling he had not prevented the development of the pressure ulcers and subsequent medical events that ultimately led to Fred's death. These feelings filtered into the following theme of depression and sadness. *“I kick myself that I didn't do more, say more, I left him in their care.”*

DEPRESSION AND SADNESS

Inevitably, with the loss of a loved one, Fred's family expressed emotions of sadness and depression through the conversations; particularly during reminiscing, the feeling of loss extended beyond just the loss of Fred: *“He was the last sibling on my mother's side to die, until then I always had a bit of mum still with me, now I have nothing, he was the last link, I've had to grieve for him and mum, I didn't expect that, she died so many years ago.”*

The feelings of depression were directly related to Fred's death rather than the pressure ulcer, but there was a sense of sadness that he had developed a pressure ulcer and a wish for him not to have been in pain: *“I prayed for someone up there to take him that night, I said oh please let him go, let him have peace.” “When we were told he would not heal, we knew, but it was hard, I didn't want him to suffer anymore, we all agreed us, the doctors and tissue viability that we had to keep him comfortable, no more tests, scans.”*

APPRECIATION

During the investigation and inquest, the family were vocal in wanting to show appreciation for positive aspects of Fred's care and the processes that followed: *“Really grateful for the phone calls and meetings, thankful we were kept in the loop, that the hospital was honest.” “If the hospital hadn't worked so hard, gave him everything they could, he would have gone that night, I'm sure.” “The care at the (second) care home was faultless, they did everything we would expect, I'm so grateful they gave him a comfortable end.”*

REFLECTIONS

Fred's nephew concluded the conversations with his own reflections and learning from experiencing a family member developing a pressure ulcer and declining at the end of their life. *“Being a carer, this has made me stronger in my job than ever, now I have seen what can happen, I work even harder to keep someone in their own home wherever possible to avoid them ending up in the same situation as Fred.”*

The author's reflections on her experience as a specialist nurse, investigator and witness echoed Fred's nephews learning. Learning of lapses in care identified during the investigation and inquest has given a renewed feeling of wanting to influence and change practice. As a TVN, there is constant pressure from trusts to find ways to reduce the development of pressure ulcers; developing new and innovative ways of teaching others to achieve this has driven the writing of patient stories and case scenarios. By including the voices of patient's families and caregivers within these stories and scenarios, the author hopes to impart the human emotional impact pressure ulcers have on those around the person affected to influence a change in practice amongst healthcare professionals.

CONCLUSION

The advent of the Duty-of-Candour approach during investigations of incidents offers an opportunity for healthcare professionals to listen and hear perspectives not previously considered. Family members can express the impact of quality of life on their selves, as well as be an advocate for their relative who is experiencing a pressure ulcer. All family discussions should be documented so the impact on the quality of life can be used as part of the post-incident learning.

During pressure ulcer investigations and while partaking in the inquest process, it is important to recognise the impact a deceased patient has on the emotions of healthcare professionals. Opportunities to reflect and de-brief with others involved should be made available. More often than not, de-briefing sessions are formal and involve only the healthcare professionals; having the opportunity to hear and converse with a deceased patients family has given the author a unique period of reflection and a different insight than could be achieved through discussion with clinicians alone.

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