

Conflict in care: Respecting the decision of the individual

KEY WORDS

- ▶ Mental Capacity Act
- ▶ Patient's wishes
- ▶ Pressure ulcer
- ▶ Professional responsibility
- ▶ Vulnerable adult

As the proportion of older people in the UK population grows, clinicians are likely to encounter individuals who, for their own reasons, do not wish to participate in treatment regimens that the clinician deems will protect them from harm. This places the clinician in a difficult position and poses a range of questions: from “How do we provide appropriate care without contravening the wishes of the individual?” to “Does the individual have the mental capacity to make decisions regarding their healthcare needs?”

Protecting patients from pressure damage is a fundamental requirement of nursing and professions allied to medicine. The Nursing and Midwifery Council (NMC) code (NMC, 2008) states that the wishes and preferences of the individual must be considered within their care, while working with others to promote the health and wellbeing of the individual. But what of those circumstances when the wishes of the patient are contra to advice the clinician knows will safeguard them from harm? The case reported here demonstrates such a conflict.

CASE REPORT

Mrs B (who has since died) was a 65-year-old woman who had rheumatoid arthritis and developed severe flexion deformities of all limbs (*Figure 1*). She was completely dependant on carers.

Mrs B was admitted to hospital with sepsis related to dehydration, which had caused both urine and chest infections. On presentation, staff discovered that she was cachectic, unkempt with long, dirty nails on her hands and feet, and her hair

was matted with extensive cradle cap. In addition, she had severe pressure ulceration.

A carer accompanied Mrs B to hospital and explained that Mrs B had no next of kin and was employing a private care agency. Mrs B would inform carers they were not to touch her, wash her, cut her nails, or wash her hair. The accompanying carer was distressed and wanted hospital staff to understand the difficult position that she and colleagues had been placed in. Mrs B's GP saw her frequently and tested her capacity to make decisions regarding her personal hygiene, and had informed the carers were to comply with Mrs B's wishes. The community nursing team were contacted to corroborate the carer's story.

Mrs B's mental capacity was tested before making decisions regarding her care. Mrs B was informed of her need for intravenous cannulation and how her pressure relief needs would be met. However, Mrs B's speech was incoherent, she was febrile, and unable to retain any information or communicate with staff. It was decided that, due to temporary delirium brought on by sepsis, Mrs B lacked the mental capacity to make decisions regarding her care and that the treating clinician should act in her best interests. An intravenous cannula was inserted and fluids and antibiotic therapy commenced.

The hospital's tissue viability service was involved regarding the management of Mrs B's pressure ulcers. She had category III pressure ulcers (European Pressure Ulcer Advisory Panel and National Pressure Ulcer Advisory Panel, 2009) to her right shoulder (*Figure 2a*), bilateral lateral



Figure 1. Mrs B's flexion deformity to her upper limbs.

PAULINE BELDON
Tissue Viability Nurse
Consultant, Epsom &
St Helier University Hospitals
NHS Trust, Epsom

malleoli and plantar edge (Figure 2b), trochanter (Figure 2c), and sacrum (Figure 2d). The decision was made to manage Mrs B on a low-air-loss mattress, with repositioning every 2 hours.

Social services were contacted and informed of the situation. As per local protocol, a Safeguarding Vulnerable Adults Alert was completed and sent to social services and the Trust's safeguarding adults team. Investigation of the circumstances leading to the physical neglect of Mrs B was crucial as such severe neglect could lead to a police prosecution of the carers (Department of Health, 2000), therefore, all local circumstances needed to be uncovered.

A case conference was arranged within 24 hours of Mrs B's admission, and was attended by Mrs B's GP, the manager of the care agency, carers, community nurses, social services, and a safeguarding adults nurse. Social services were satisfied that Mrs B's capacity to make decisions on personal care and repositioning for pressure relief had been tested – by both her GP and the Lead Community Nurse – on separate and numerous occasions and found to be intact. Mrs B had been made aware of the possible outcomes of refusal of care. Her GP had attempted to increase her pain relief, but Mrs B would not take stronger analgesics because she felt they would interfere with her ability to make decisions, nor would she accept a referral to the chronic pain team.

During the following 48 hours, Mrs B remained extremely unwell due to sepsis and continued receiving intravenous antibiotics and fluids. A fine-bore nasogastric tube had been placed to optimise nutritional input and Mrs B was washed, her hair cleansed, and her nails cleaned and cut. In all of these actions she was reported to be passive and compliant, at no time voicing dissent.

On day 3, Mrs B's condition began to improve. She understood she was in hospital, had received treatment for infection, and during this time her personal hygiene needs had been addressed. While she voiced gratitude that this had happened, she quickly began to object when nursing staff approached her with regard to repositioning, they persuaded her – with difficulty – to allow them to change her position.

On day 4 after admission, Mrs B refused to allow nursing staff to deliver any personal care, she remained unwashed, allowing staff only to clean her when she was faecally incontinent. She also refused to be repositioned. Ward staff sought help first from their matron, who was unable to persuade Mrs B, and then from the tissue viability nurse (the author).

On entering the ward, the author found the ward nursing staff to be perturbed that Mrs B would not allow care to be administered. Mrs B explained that she had been disabled for many years; she understood the consequences of not allowing care and, while she disliked being unkempt, felt that the discomfort she suffered during care was untenable. Analgesia was discussed and how this could be improved. Mrs B finally agreed to see a doctor from the palliative care team with regard to her pain management. She agreed to more active care, provided her pain was better controlled, without relinquishing control. Concerned that the patient's refusal of care may stem from her mental state, the author also asked Mrs B if she would see a clinical psychologist, which she agreed to.

After meeting with Mrs B, the clinical psychologist ascertained that she was not suffering from a depressive illness and agreed she had the mental capacity to make decisions regarding her care. The author continued to provide a ward presence to support both Mrs B and ward staff. It was possible that Mrs B's feelings

**Practice development notes:
A safeguarding adults team**

All NHS organisations are required to have a recognised Safeguarding Adults Lead, whose function it is to both guide internal staff regarding the identification and protection of vulnerable adults and to liaise with external NHS Trusts, social services, learning disabilities teams and, where necessary the police.



Figure 2. Pressure ulcer on Mrs B's (a) right shoulder; (b) bilateral lateral malleoli and plantar edge; (c) trochanter; and (d) sacrum.

Additional resource

If you would like to learn more on this topic, visit the below link and watch the video presentation:
<http://bit.ly/M8GZZ3>
(free registration)

“For clinicians – accustomed to patients who wish to return to good health and are largely compliant with care – being faced with an individual who does not want to participate in care, can be difficult.”

towards her care could change and staff had to be prepared to become more engaged if that situation arose.

Mrs B agreed to remain in hospital until a suitable nursing home placement could be found. Two weeks later, Mrs B began to bleed via the vagina. An ultrasound scan was not possible due to her flexion deformities. A gynaecological opinion was sought, but Mrs B declined any further investigations.

During the course of her inpatient stay, little progress was made in healing Mrs B pressure ulcers. She removed the nasogastric tube and her oral intake of food and fluids remained poor. She refused to have another cannula inserted for intravenous fluids. Mrs B made clear that, were she to develop another chest or bladder infection, she was not to be treated with antibiotics.

A nursing home placement was found, where the matron was experienced in caring for those with progressive life-shortening illnesses. Mrs B was assured that her wishes would be respected.

Mrs B died 4 weeks after taking up residence in the nursing home due to a chest infection.

DISCUSSION

Mrs B's case raises a number of questions for the clinician. Primarily, questions around the ability of clinically unwell, vulnerable patients to possess the mental capacity to make sound decisions about their care. And further, the willingness of clinical staff to carry out the wishes of a patient when those wishes are contra to their own opinions as to what is in the patient's best interest.

The Department of Health (1997) defines a vulnerable adult as: “A person who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is unable to take care of themselves or unable to protect themselves from significant harm or exploitation.” Mrs B was undoubtedly a vulnerable adult based on this definition, due to her complete reliance on others for her daily needs.

Mental capacity is the ability to make a reasoned decision (Department for Constitutional Affairs, 2005). This ranges from the ability to decide what to have for breakfast, to whether to go to the doctors when feeling unwell; in other words, to have the insight into one's own physical, mental,

or healthcare needs and act appropriately. Mental capacity also refers to a person's ability to make a decision that may have legal consequences for themselves or others, such as making a will or agreeing to have medical treatment.

The Mental Capacity Act (Department for Constitutional Affairs, 2005) states that a person lacks mental capacity when they have an impairment or disturbance that affects the way their brain works and, furthermore, the impairment means they are unable to make a decision at the time it needs to be made.

It should be remembered that a lack of mental capacity can be temporary. Temporary loss of capacity may be due to acute illness, during which the clinician who is acting without prior knowledge of the individual's long-term wishes, must act in their best interests.

Patients with progressive diseases – like Mrs B's rheumatoid arthritis – that render them unable to lead independent lives may feel that the only means of exercising any control in their lives is to decline care or treatment. However, it is important to explore whether the individual concerned is exhibiting signs of depressive illness (NMC, 2009).

Nursing and medical staff found Mrs B's decisions to decline care difficult to accept and needed regular support and guidance through her admission. The emphasis was placed on being available to deliver care on Mrs B's terms, which she appreciated. It was important that Mrs B could see that staff only wanted to provide good care, but that her decisions regarding her care would be respected.

CONCLUSION

All individuals have the right to have their wishes regarding their care heard and respected. For clinicians – accustomed to patients who wish to return to good health and are largely compliant with care – being faced with an individual who does not want to participate in care can be difficult. Therefore, it is important that the mental capacity of the individual is tested by clinicians who have the relevant skills and that assumptions are not made regarding the patient's capacity. In such situations, it is vital that both the patient, and all clinicians involved in providing care, are fully supported.

WUK

REFERENCES

- Department for Constitutional Affairs (1997) *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults. A Consultation Paper*. Available at: <http://bit.ly/1obimu2> (accessed 10.02.2014)
- Department for Constitutional Affairs (2005) *Mental Capacity Act 2005: Code of Practice*. Available at: <http://bit.ly/1bNXovS> (accessed 10.02.2014)
- Department of Health (2000) *No Secrets: Guidance on Protecting Vulnerable Adults in Care*. Available at: <http://bit.ly/18wPgAs> (accessed 11.02.2014)
- European Pressure Ulcer Advisory Panel and National Pressure Ulcer Advisory Panel (2009) *Treatment of Pressure Ulcers: Quick Reference Guide*. Available at: <http://bit.ly/1kGFRfh> (accessed 11.02.2014)
- Nursing and Midwifery Council (2008) *The Code: Standards of Practice, Performance and Ethics for Nurses and Midwives*. Available at: <http://bit.ly/1h6ufzG> (accessed 10.02.2014)
- Nursing and Midwifery Council (2009) *Guidance for the Care of Older People*. Available at: <http://bit.ly/M8QqbA> (accessed 11.02.2014)