Series Title: The Power of Stories

Articles in the series:

Part 1: Narratives and Nurse Education

Part 2: Metaphors and Narratives

Part 3: Advocacy and Narratives

Part 4: The Practitioner's Narrative

Part 5: Narrative Inquiry: where do we go from here?

Part 3: Advocacy and Narratives

Keywords: narrative inquiry, advocacy, nurse education

Standfirst: This article entitled 'Advocacy and Narratives' is the third of five in our series and explores the concept of advocacy and narrative work.

Headline: The power of stories: advocacy and narratives

Key points

- Narratives have the power to inform thinking.
- Understanding the narrative threads of an individual's lived experience can support the health and social care professional in their role as an advocate.
- Advocacy is complex and challenging, but only through engagement with people's stories can the professional realise advocacy as a duty of care.

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Abstract

This article defines the concept of advocacy in the context of health and social care practice. Questions will be posed as to the content and utility of narratives and how they can support the role of the professional as an advocate. Challenges to the role will be explored in the context of professional practice.

[Main article]

Understanding the concept of advocacy in the context of professional practice is inherently complex. The etymology of 'advocacy' arises from the Latin '*advocare*': to 'add' a 'voice', or to '*call, summon, invite',* with the noun *'advocate'* recognised as 'a *person who supports, recommends, or speaks in favour of something, a proposal or doctrine* (Oxford English Dictionary, 2023). Whilst it is acknowledged that advocacy is a role fundamental to the relationship between the healthcare professional and the patient and recognised in professional codes of conduct, formal definitions remain ambiguous and elusive (Sorensen & Ledema, 2007*).* Advocacy is understood to involve acting on behalf of another in the absence or presence of mental capacity, supporting individuals in their decision making by respecting an individual's autonomy and self-determination, and safeguarding or furthering one's best interests (Baldwin, 2003; Heck, *et al.*, 2022; Kalaitzidis and Jewell, 2015; Mallik, 1997; Vaartio and Leino-Kilpi, 2005; Water, *et al.,* 2016).

With respect to The Code (Nursing and Midwifery Council [NMC], 2018) whilst advocacy is not explicitly cited, statements within The Code (NMC, 2018) reflect aspects of the advocacy role. For example: 1.5: Respect and uphold people's human rights; 2: Listen to people and respond to their preferences and concerns; 4: Act in the best interests of people at all times: 16: Act without delay if you believe that there is a risk to patient safety or public protection and 17: Raise concerns immediately if you believe a person is vulnerable or at risk and needs extra support and protection.

Reflection Point
How would you define the concept of 'advocacy'?
Can you describe an occasion when you believe you acted as a person's advocate?

As early as 1979, Curtin supported the view that, in defining nursing's philosophical foundations that uphold the welfare and primacy of others, it is only through the adoption of a philosophy which furthers concern for a shared humanity, that advocacy is realised. Gadow (1980, p. 84) developed the concept by defining it as '*existential advocacy*', whereby the nurse is positioned to *'assist'* in furthering the '*principle that freedom of self-determination is the most valuable human right'*.

The statutory interpretation of advocacy allows for a clearer definition whereby the individual is positioned to 'plead the cause of another' through legal representation (Care Act 2014; Mental Health

Act 1983 / 2007; Mental Capacity Act 2005). In the absence of autonomy, the legal role of the advocate is to protect and further legitimate best interests. Examples include the appointment of the Lasting Power of Attorney (Mental Capacity Act, 2005), which authorises court-appointed deputies, registered with the Office of the Public Guardian, to make decisions with respect to health and welfare, and property and financial affairs.

Models of advocacy

Fry and Johnstone (2008) discussed three models of advocacy namely; The *Rights-Protection Model* (the nurse acts as defender of a person's rights and ensures these rights are understood), *Values-Based Decision Model* (the nurse engages and assists the person to establish desires, choices, interests and needs) and the *Respect-for-Person's Model* (the nurse focuses on respecting privacy, dignity, welfare of another). Whilst these models collectively reflect the fundamental premise of the nurse-patient relationship identified within The Code (NMC, 2018), it remains inherently challenging for the health and social care professional, as there are many factors which influence our role as advocates. This may include occasions when an individual decides about a particular treatment regime and as professionals we support that decision, however due to economic or resource limitations, the individual's expectations cannot be realised. Also, in the absence of an individual's capacity, it can be difficult to accurately establish what their autonomous wishes would be, and we risk misrepresenting them.

Advocacy and Narratives

From the discussion above, it is clear that to be an authentic advocate and truly represent the person we must understand their perspective. We propose that to do this, professionals need to have a readiness to listen and hear the narrative threads which comprise a person's story. This gives a *script* to work from that allows the professional, as an advocate, to feel confident that there is an accurate portrayal of the reality of the *storyline*. If we fail to engage with the *script*, which is not the professionals to own, then the default position is that as professionals, we become the author of the script. It could be argued that this then becomes a biographical account and not an autobiography.

In studying narrative inquiry, students were invited to share their stories of occasions when they believed they acted as advocates.

Ellie, a third-year adult student nurse, provides an example in which the nurse composes a backstory to the person they are working with. This may be either helpful or unhelpful in understanding the reality of the situation for that person.

Ellie Warren

During a module entitled '*Learning from the Lived Experience*', there were several inspiring conversations around patient advocacy and storytelling. A patient described his early childhood experiences and behaviours that resulted in a custodial sentence. He reported how his outlook on life had changed following an encounter with a nurse who showed an interest in his story, asking questions to understand how his experiences had led to his behaviours. The patient recognised that if professionals had listened to his story at the time, and been prepared to act as his advocate, then he may not have pursued the life choices that he did. Such questions ultimately challenged his accountability for his actions and empowered personal change.

This is why I decided nursing was for me - hearing peoples' struggles and knowing I can and will help them is something I will never take for granted. I remember feeling helpless as a child and young adult, wishing somebody would help me. People have helped me, many of them. Now, I can be the person that someone trusts with their worries. This will always be a privilege to me.

However, as nurses on busy wards, we know that making time to ask patients to tell their story is often a luxury we can't afford. We are pressured to prioritise and complete tasks, and the management of acute physical deterioration frequently takes precedence over holistic conversations, even though we know how beneficial and important these are. It is for this reason that when I find myself in situations where there is no time to talk to ask '*why*', I make a story up in my head, on behalf of the patient. This may seem controversial, as under The Code (NMC, 2018), nurses must avoid making assumptions. However, this is coming from a place of care, support and empathy, which drives me to advocate for the patients I am working with. I am not there to judge. I am there to empower patients to make informed decisions about their care. In situations when there is no time to ask, I create a '*why*' to better understand the person's background and what might have led to their admission. Patients may be going through adverse life experiences, and it is not my place to make it worse. I only want to make things better. I would love to sit and have conversations with everyone about their lives, but on an Intensive Care Unit for example, this is not possible. I put myself into their shoes and imagine what kind of life they live, and this allows me to better advocate on their behalf.

Although I come from a place of care, there are times when this perspective could be taken advantage of. When used inappropriately, the nurse may believe they know what is best for the patient without asking them. This goes against my morals and values as a nurse, as where possible, patients should be supported in making their own informed decisions. What is right for one, is wrong for another. I will never impose my beliefs onto another, but in times when I can't talk to the patient, I find it helpful to imagine their life outside of the hospital, so I can be an advocate they never knew they had.

What Ellie highlights is the realities of being a nurse advocate, particularly when we have no knowledge of what a person would deem to be in their best interests. Ellie recognises that creating a back story risks the production of a fictional account, where she may make judgements and reposition the narrative. However, in these circumstances her intentions and motivations are inherently supportive. This account reflects the *Respect-for-Persons Model* of advocacy (Fry and Johnstone, 2008). Through narrative construction Ellie was able to empathise with those in her care in the absence of them being able to inform her of their wishes. In this respect, Ellie is furthering the best interests and welfare of the person.

Reflection point

Can you think of occasions when you may have interpreted a person's behaviour?

Were assumptions made about the person because of the behaviour that they demonstrated?

How did this impact on your ability to advocate for that person?

Within the following discussion Fredrika May, a third-year mental health student questions the role of the nurse as an advocate and how it can be operationalised in practice.

Fredrika May

Patient advocacy is often spoken about in healthcare - indeed it is seen as an integral part of the Holy Grail that is person-centredness - an approach which underpins mental health nursing care. Health Education England, Skills for Health and Skills for Care (2017, p. 55) defined advocacy as follows:

'Advocacy supports and enables people who have difficulty representing their interests, to exercise their rights, express their views, explore and make informed choices. In doing so, people can make informed decisions, have a voice, express choices and take control of situations in their life.'

This definition appears to impose conditions on patient's advocacy…shouldn't we advocate for all patients in our care? What does it mean to be a true advocate? Is it possible to disagree with a patient's values and still advocate for them? Is it possible to advocate for a patient when you have no idea what their home life is like? Is it possible to advocate for a patient with psychosis?

Meeting a patient on placement who had lived through a traumatic experience helped me fully understand advocacy in practice. This patient was admitted to an acute mental health inpatient unit due to persistent suicidal thoughts and feelings and an attempt to take their own life. I met them after they had spent a year on an acute ward and completed an episode of care with them. During our initial meeting, they disclosed that there was no point in telling their story to yet another healthcare

professional. I curiously and gently asked '*why*' and was saddened by their response: "*...because no-one listens anyway…"*. I would like to think that they felt that I did listen to their story. However, I am not naive enough to believe that I could make a huge difference in such a short space of time.

Perhaps true advocacy begins with simply listening - really listening - to a patient's story. Alongside that, removing the healthcare professional lens and the assumption that one knows what is best for a patient on account of a plan of care, which tells the world that "we" (the healthcare professional) are sane, and "you" (the patient) are most definitely not.

There are likely to be many patients who may not have been given the opportunity to tell their story, or even have anyone ask them for it. This is an oversight that precludes successful treatment: akin to treating someone for a fractured leg when in fact it is the arm.

Within traditional hierarchies of evidence, the opinion of '*experts by experience*' and anecdotal evidence are seen as the weakest form of evidence. Reflecting on this, it could be argued that patient narratives threaten the status quo: they are not viewed as "real" evidence. Why is this? Do healthcare professionals regard patient narratives as an inferior, subjective form of evidence and fail to see the benefits of their inclusion in nurse education?

Patient narratives are definitely not inferior, they provide valuable insights into the human side of healthcare. Surely this is the reason why we chose the healthcare profession? If we chose this profession purely for the kudos and a skewed power dynamic - perhaps we should reconsider our career.

For me - mental health nursing ought to be **all** about the person, **all** of the time.

Fredrika's reflection demonstrates that in the absence of the patient's narrative, it is difficult to establish their understanding of the personal meaning and impact of their illness and hospitalisation. She challenges her peers to truly listen and see the person within the illness, not as someone with symptoms to be managed but rather understand how their back story has influenced their decisions and perspectives on life. Fredrika clearly recognised her role as an advocate, reflective of the *Rights-Protection Model and* the '*Values-Based Decision*' Models (Fry and Johnstone, 2008).

Adele Taylor is a third-year adult student who also offered an account of an occasion when she reflected on her understanding of advocacy.

Adele Taylor

In our module '*Learning from the Lived Experience*', we were fortunate to have a guest speaker, Danny Wolstencroft from '*Lads Like Us'*, who experienced harrowing, adverse childhood trauma. Danny really highlighted the power of advocacy through his storytelling and the impact of not having anyone advocate on his behalf. Danny spoke so candidly about his life journey, and how

the abuse he was subjected to as a child was never discovered until much later in his life. The poignant part of Danny's story for me, was when he described his time at both primary and secondary school as turbulent. His behaviours, by his own admission, included aggressive outbursts and tipping tables over in the classroom. He went on to say that he was dubbed '*the naughty kid*' and he remarked that nobody ever asked him '*why'*. If somebody had seen beyond his challenging and disruptive behaviours, and asked him why he was behaving that way, his life from then on could have taken a path of healing and recovery instead of an adult life laced with drugs and prison.

As a student nurse, I am grateful for the opportunities that my various placements have afforded me. Not least because I feel that having placements across the different sectors has enabled me to become a better advocate for my patients. In one placement I had on a medical ward in an NHS hospital, one of my patients had been admitted with community acquired pneumonia [CAP]. They were also admitted with an advanced chronic pressure ulcer to their heel, in which the calcaneus bone was exposed when the dressing was removed. I felt I had advocated for my patient, as I have an affinity for medicine and wound care, so in my time in the hospital, I ensured that the patient got the right treatment, including a referral to the Tissue Viability Team, who then commenced larvae therapy. On my next placement I was fortunate to work with the district nursing team, and I met the same patient whilst on a home visit to redress their wound. When in the patients' home, it gave me a better picture of how they lived and explained why the wound had deteriorated so much due to their living conditions at home.

On the surface, advocacy is easy. However, it is only by reflecting on these two care episodes with the same patient, that I now appreciate how difficult it is. Advocacy is multifaceted and influenced by so many factors, there is no one size fits all as to how you act as an advocate. This example of care for the one patient enabled me to see the patient in another light and from their perspective how their environment impacted their health. It is so easy to overlook this when a patient is in the hospital environment, and perhaps as a result, advocacy through a biographical lens can be harder. It has challenged me to think about the patient beyond the four walls of hospital and advocate for them to live well at home and beyond discharge.

Adele reflects honestly about her role as an advocate and recognises how the context of care can adversely impact an individual's recovery and wellbeing. Meeting her patient in their own home enabled her to truly appreciate how their lifestyle had resulted in a deteriorating wound. This correlates with the *Values-Based Decision Model* by recognising that we sometimes either expect or ask people to take responsibility for their own health and fail to recognise that their life outside of

hospital may affect their ability to do this. Because Adele had both the hospital-based and home-based narratives, she was more able to advocate for the person with staff who were more senior to her.

Summary

This article has explored the concept of advocacy and by providing student reflections shows the challenges that can be faced. Whilst the professional's role as an advocate is frequently cited as integral to person-centred care, it is only by truly listening to narrative accounts that advocacy is better understood in the context of health and social care. If we fail to listen and hear the 'narrative threads' which comprise the rich tapestry of an individual's experience then we risk composing a fictional account, authored by the professional, in the person's absence. Working with narratives as an educational tool can support the learner to respect the meaning of health and illness for individuals and understand more fully their responsibilities as a professional, authentic advocate.

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