**The service user and carer perspective**

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**Introduction**

There is increased commitment to patient and public involvement in healthcare, with healthcare providers seeking service users’ (patients and families) perspectives through various means, for example, through patient experience surveys, which are now well embedded in the United Kingdom’s (UK) National Health Service (NHS). There is a requirement to have service user involvement in healthcare services, with representation on NHS governing boards, service development teams and on health and social care inspection teams. Narratives from users of health services, patients and carers, are another way of facilitating patient and carer involvement. The aim is that through capturing and sharing these stories, health service providers can gain the patient and carer perspective, which will lead on to improvement in care quality. In particular, narratives can do much to illuminate human experiences of dignity in healthcare. However, how narratives are captured and used is an important consideration and we must ensure that their use is beneficial to all involved and impacts positively on the quality of care.

We first set out the background to patient and public involvement in healthcare and explain associated key concepts. We then introduce patient and carer stories and critically review how these are being used within healthcare. A narrative from a carer’s perspective is then presented, followed by an analysis using a model of dignity (Nordenfelt and Edgar 2005) and drawing on research about dignity in healthcare. Finally we draw conclusions about the use of narratives for improving quality of care.

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| **Learning outcomes**This chapter will enable you to:* Appreciate the background to patient and public involvement in healthcare and key related concepts
* Critically review the use of patient and carer stories within healthcare from a range of perspectives
* Analyse a narrative of healthcare experience in the context of a theoretical model of dignity and service user involvement
* Draw conclusions about the use of narratives in healthcare and potential to improve quality of care
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**Patient and public involvement**

The term ‘patient involvement’ is a complex concept, and the term is sometimes used interchangeably with ‘partnership’ and ‘participation’ although these similar terms are slightly different. In general terms, patient involvement can be described as:

‘*approaches which engage individual patients in the management of their health and healthcare, and in the decisions that are made in the course of it’.* (National Voices 2012).

A qualitative study undertaken in fifteen countries across Europe in 2012 for the European Commission, found that patient involvement was not clearly understood by either patients or practitioners and often meant different things to different people (TNS Qual+ 2012). The same study found that patient involvement, in the sense of having patients at the heart of the healthcare process, seems poorly understood by many professionals and patients across the EU, with only limited concrete ideas and activities which substantiate the concept in real healthcare practices.

**Historical perspective to patient and public involvement in healthcare**

It was during the late 1990s that a distinct positive shift to patient and public involvement (PPI) in health care in the UK was recognised. This was partly driven by the Modernisation Agenda under the Labour Government at that time, but also because of high-profile inquiries into serious clinical and service failings such as in Bristol, England (Department of Health 2001). The Bristol enquiry identified the need to place PPI at the centre of developing a patient safety culture, and as a consequence, the early 2000s saw a number of publications from the Department of Health on PPI, such as *Strengthening Accountability: Involving Patients and the Public* (2003), *A Stronger Local Voice: A Framework for Creating a Stronger Local Voice in the Development of Health and Social Care Services* (2006) and *Real Involvement: Working with People to Improve Services* (2008). It also became a legal duty in 2006 to involve patients and the public in the planning of, and changes made, to healthcare services (NHS Act, 2006).

More recently there have been other attempts to embed PPI across NHS services in England, such as *Equity and Excellence: Liberating the NHS* (2010), where the Government’s vision was for an NHS that puts patients and the public first, and where ‘*no decision about me, without me*’ would become the norm. It included proposals to give everyone more say over their care and treatment with more opportunity to make informed choices, as a means of securing better care and better outcomes. The Health and Social Care Act in 2012 made clear the duties on the NHS Commissioning Board and clinical commissioning groups (CCGs) to promote the involvement of patients and carers in decisions about their care and treatment, and to enable patient choice.

In summary, patient and public involvement is concerned with contributing to decisions about healthcare policy and care services, and representing the views of patients and the public, but also about individuals being involved in their care.

**Patient and public involvement programmes**

Recent Care Quality Commission (CQC) in England patient surveys have shown that 48% of inpatients and 30% of outpatients want more involvement in decisions about their care (CQC 2011). It is important to note of course, that not everyone, whether patient or carer, wants to be involved in their healthcare: the extent to which involvement is desired can depend on the contexts of type and seriousness of illness, various personal characteristics and patients' relationships with professionals (Thompson 2007).

The Patient Participation team at NHS England are working on a number of programmes which support patients to be more actively involved in their own care, such as enabling people to have more confidence to talk to health care professionals; taking steps to manage health and care and being able to access and understand information to help make decisions. Programmes of work include:

* Patient activation: patients having the right skills, knowledge and confidence to play an active role in their own care
* Patient information and health literacy
* Personalised care and support planning
* Shared decision-making and patient decision aids

Yet despite policy drivers and momentum to involve patients and the public, it has been contested that involvement is still not a mainstream activity that sits alongside other policy and performance requirements in the NHS (Ocloo and Fulop 2011).

**Different degrees of patient and public involvement**

There are many different ways in which people might participate in health depending upon their personal circumstances and interest. The ‘Ladder of Engagement and Participation’ (Arnstein 1969) is a widely recognised model for understanding different forms and degrees of patient and public involvement. Figure1 (adapted from Arnstein) shows one way in which practitioners can evaluate their involvement practices, by asking themselves where on the ladder they believe their interactions with service users to be.



**Figure 1: The Engagement Ladder (adapted from Arnstein 1969)**

Patient and public engagement becomes increasingly valuable as the steps of the ladder are climbed, although participation becomes more meaningful at the top of the ladder. For example there has been increasing debate about shared decision-making (sharing power) in recent years, and this has been defined as a process by which “clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient’s informed preferences” (Coulter and Collins 2011). Shared-decision making (SDM) is important for patients because of potential benefits such as improved physiological parameters through self-management programmes and increased patient satisfaction (Coulter 2009).

**Use of patient and carer narratives for improving healthcare**

Increasing, healthcare organisations are being encouraged to involve patients in improving care. Berwick (2013) asserts that *“patients and their carers should be present, powerful and involved at all levels of healthcare organisations”* and that they should:

*“advise leaders and managers by offering their expert advice on how things are going, on ways to improve, and on how systems work best to meet the needs of patients”.*

Barello et al.’s (2012) review of the literature observes that recent focus has been on engaging patients in order to manage their own physical health and suggests a lack of empirical research into the components of patient engagement at individual, relational, and organisational levels. Despite this, patient stories have gained acceptance as empowerment strategy perhaps, as Rose and Gidman (2010) contend, because stories provides an alternative form of knowledge. There is, however, little clarity about how to use their stories and they risk becoming a token response to the patient engagement agenda. One might go so far as to say it is unethical to ask a patient or relative to endure the stress of presenting their experience without a clear intended outcome.

There are a number of different purposes that may be served by the storytelling. Stories connect with people at an emotional level and storytelling at the start of a meeting can encourage a patient sensitive, reflective stance to the consideration of the subsequent discussions. For many patients, though, there is a desire for their story to have a tangible specific impact and to ensure that no one else has the same experience that they had. Where there has been a safety failure or poor experience, patients are often frustrated by the impersonal nature of the investigations that are undertaken and they want the audience to understand the nature of the impact on the patient, their family and friends that goes well beyond clinical outcomes.

Organisations may have a different purpose and wish to hear patient stories at meetings as a way of helping them understand how effective their policies are in practice and how their strategic plans have influenced patients’ experiences. They may also use patient stories to help set priorities in their business planning.

Whatever the purpose for the telling of patient stories, it is important that they are well handled. The audience needs to understand how the storyteller has been selected, are they considered to be representative of a group of service users or is their experience an extreme example? Is there evidence that might support their interpretation or contest it and does the audience need to hear any other viewpoints of the experience (particularly if there are allegations of poor conduct)?

There appears to be little or no evidence about the extent to which patients and their relatives universally welcome the opportunity to tell their story in person and it should not be assumed that they want to share intimate experiences beyond the care team with whom they have established a relationship. Their willingness to do so may in part be influenced by the choice of media through which the story can be conveyed. The patient may nominate someone else to tell the story on their behalf, either an advocate or a trusted member of staff. They may prefer to be video or audio recorded rather than attend a meeting where they might feel overwhelmed. It is important that no assumptions are made about their intentions and that a range of options are offered.

Given that stories can evoke strong emotions in both the teller and the listener, the session has to be well facilitated in order to ensure that all voices are heard and respected and to manage sensitively any criticism of individuals or organisations in the same way that staff stories need to be well facilitated (Lown et al. 2010). The story teller needs to be supported and understand how the session will run. The audience also needs to be briefed on how questions and comments will be handled and how to question appropriately, particularly if there is a potential to breach confidences.

It is important that issues raised in the story are not left hanging at the end and that the issues are named. The facilitator must ensure there is clarity about how these will be taken forward. This might be investigation of unresolved issues, it may be celebrating good experiences but perhaps the most useful aspect of patient stories for service improvement is the development of questions or themes, taking the story from the concrete to the abstract, the operational to the strategic in order to review organisational strategy and to guide quality monitoring. For organisation’s Boards, it might be a case of joining the dots to see which of its routine data reporting might be used as a proxy indicator for the issues raised in the story and what the gaps in routine assurance data are.

A further step is needed in the management of patient stories: an evaluation of the session. Most importantly, there should be a chance for the story teller to give feedback on the telling of the story. Both the storyteller and the audience might reflect on whether sufficient time was allocated to the story, especially if it is the opening item on a meeting agenda. It is also useful to reflect on the type of presentation of the story and whether it might have been done differently. Finally, the story might involve strong emotions in the audience hearing it and it is important to ensure that there are opportunities to talk these through and provide more formal support if required.

**A family carer’s narrative**

In this section, one of this chapter’s authors, Elaine Maxwell, presents a narrative of her experience after her father was admitted to hospital following a rapid deterioration in his health. The narrative raises many issues of involvement of patients and families in decision-making and ends with Elaine’s experience of telling her story to staff at the NHS Trust and being asked if her story could be used. The narrative is analysed using Nordenfelt and Edgar’s (2005) dignity model and research about dignity and illustrates how patient and carer involvement influences dignity.

**Seeing the diagnosis but not the person: written by Elaine Maxwell**

My father, Delwyn, was an active man who suffered neck pain which he put down to arthritis. At 80 he cycled around Jersey. Then one day, he started to experience tingling in his hands. He was admitted to the local hospital and as I had previously been Director of Nursing there, I was confident that he would be well treated.

I kept ringing the ward but they were unable to tell me anything. I eventually discovered that he had been clerked by a junior doctor but had not been reviewed by anyone senior. However, I was reassured that he was comfortable and stable and there was no need for me to come to the hospital immediately. The next day he was seen by the on call Consultant and a CT scan was performed.

When I arrived at the hospital that evening, Dad had been transferred to an orthopaedic ward and I was shocked by his condition. He was now unable to hold a cup, fasten buttons or stand. When I pointed out this deterioration I was told that his Early Warning Score (EWS)[[1]](#footnote-1) was fine. The EWS only looks at cardiac and respiratory function and his loss of independence, mental state and a host of other functions seemed to be invisible to the team who only seemed to be concerned with preventing cardiac arrests.

No one knew what the scan showed, I naively thought it must be OK or Radiology would have told someone but as my father deteriorated over the weekend I kept asking to see a doctor. No medical team doctors would come to speak to me on the orthopaedic ward and of course Delwyn wasn’t the patient of the orthopaedic doctors. The Ward Sister studiously ignored me each time I went to the nurses’ station to enquire.

At 5pm on the following Monday, a Consultant examined my father then asked to speak to me. The scan had shown a massive malignant spinal cord compression but he could not explain to me why this had not been discussed with a senior doctor on the Friday or why they had not put a collar on Dad nor referred him to neurosurgeons. It did however explain why none of the junior doctors would come to see me over the weekend. The irony of sitting on a ward proudly displaying the NICE[[2]](#footnote-2) guidelines for metastatic spinal cord compression on the wall was not lost on me at this point.

The Neurosurgeons were contacted and felt the tumour was too large to operate on. No one asked Delwyn or me what he would like to do but the medical team insisted on speaking to the oncologist about radiotherapy. The oncologist was keen despite my reservations and my father’s concern that it would mean a transfer to another hospital. In the meantime, I tried to get the junior medical staff to speak to my father about his resuscitation wishes. The junior doctors preferred not do so until they had the Consultant’s blessing but the Consultant was busy and I did wonder why they hadn’t thought about these things when they were on the ward with my father themselves.

My father was transferred to another hospital and started radiotherapy which he found extremely painful. After 3 days the tumour had grown significantly so it was decided that radiotherapy should stop. I will never forget the oncology registrar who told my totally paralysed father that he would have to leave as this was an acute ward and if there were no beds in the hospice he would have to go to a community hospital 40 miles from his home but he couldn’t stay in ‘her’ beds. Dad was distraught and in tears and it was obvious to me that he was dying and in pain. I told the nurses this but they showed me that the doctor had written in Dad’s notes that he had a life expectancy of 6 – 9 months. He died 5 days later.

At this point I decided I could not leave him alone so I moved into his room to care for him myself. The Sister told me I could not stay for ‘infection control’ reasons; I told her she would have to get the police to remove me but I do not know how tenacious other relatives would have been in such circumstances.

Once I was resident on the ward, the nurses kept coming to tell me how busy and stressed they were, and how much pressure they were under to free up beds so that the hospital did not breach the 4 hour waiting target for Emergency department admissions.

I decided not to use the official complaints procedures as I know how demanding that is of bereaved relatives. I did write to the Chair of the NHS Trust who asked to see me. She asked if I wanted the staff present but I did not feel able to discuss his care with them at that stage. She listened to me then asked if I would present Delwyn’s story at the Board. I told her that it was not my responsibility to manage her hospital. What I wanted to do was to pass the story to someone I trusted to act on it. I wanted to grieve my father and not have his memory tainted by continued meetings with the hospital.

I didn’t think any of staff were bad people and I didn’t want to sue or for anyone to be sacked. I think they lacked awareness of the seriousness of Delwyn’s condition and were unable to manage their own stress, let alone Delwyn’s or mine.

Dad’s experience illustrates that point described by Marianne Rigge of the College of Health that the problem with evidence based medicine is that many patients don’t have evidence based problems. Without a diagnostic label, staff were apparently unable to understand his needs and unable to see the deterioration that was painfully obvious to me.

**Analysis of the narrative**

Elaine’s narrative reveals the impact on her and her father of not being informed about his diagnosis in a timely nor sensitive way and a lack of any involvement in decision-making, whilst also raising a number of dignity-related issues. In particular, there was a failure to consider Delwyn and his daughter as valued human beings who should have been involved in decisions about care. The focus on diagnosis and treatment led to Delwyn being viewed as a medical problem that could not be solved rather than a person who was in pain and in need of care, comfort and dignity.

Nordenfelt and Edgar’s (2005) theoretical model of dignity comprises four notions of dignity: *Menschenwürde*, dignity as merit, dignity of moral stature and dignity of personal identity; each of these will be further explored. *Menschenwürde* is a German word referring to the universal dignity that is inherent in all human beings and cannot be lost, reflecting the Universal Declaration of Human Rights (United Nations 1948) perspective that all human beings have equal dignity and rights. This notion of human dignity is well supported within healthcare literature, both primary research studies based in healthcare (Matiti 2002; Jacelon 2003) and concept analyses of dignity (Jacelon *et al.* 2004; Griffin-Heslin 2005, Jacobson, 2007). This notion of universal dignity applies to each person in what ever circumstances they are in and thus applies to both Delwyn and Elaine.

The other notions of dignity in Nordenfelt and Edgar’s (2005) model can fluctuate between and within individuals. Dignity as merit is based on rank or status in society, either conferred at birth (as in royalty) or due to later accomplishments, and is closely linked with the original Latin word *dignitas*, which was used to describe high ranking individuals in the Roman empire (Nordenfelt and Edgar 2005). Elaine’s previous senior position in the NHS Trust, infers her dignity of merit accomplished through her nursing career. Dignity as moral stature concerns self-respect and relates to the character of an individual, moral virtue and behaving according to one’s own principles and values. Baillie (2009) argued that dignity of merit and dignity of moral stature have less relevance to healthcare as nurses (and other healthcare professionals) have an ethical and professional obligation to preserve dignity of all healthcare users. For example, healthcare professionals often care for people who would not be considered to hold dignity of moral stature within society (e.g. a convicted sex offender) but they must nevertheless recognise their human dignity and provide care in a way that preserves dignity. However, dignity of moral stature is relevant to the dignity of healthcare professionals’ own behaviour, for example, raising concerns about quality of care could be considered dignity of moral stature. Staff who raise concerns are acting in accordance with their duty of care (Jackson et al. 2011) and maintaining the ethics of truth telling, the promotion of justice and the redressing of wrong (Berry 2004). From a carer’s perspective, Elaine’s insistence about staying with Delwyn reflected her own values of doing what she believed was right for her father, portraying a dignity of moral stature. Staying with her father would have helped him to feel cared about as a valued person, which is important for a person’s dignity (Chochinov *et al*., 2002; Jacelon, 2003; Matiti, 2002; Baillie 2009). Furthermore, in Slettebø et al’s (2009) study, patients specifically referred to support from family and friends as a factor that preserved their dignity.

Dignity of personal identity is closely linked with a person’s self-image and concerns the integrity of a person’s body and mind and is affected by the behaviour of other people, as well as changes within the person, such as illness and disability (Nordenfelt and Edgar 2005). Elaine’s narrative starts by highlighting Delwyn’s personal identity as a man who, at the age of 80 years, was still active and was fit enough to be able to cycle around Jersey. The narrative illustrates how dignity of identity is threatened by deteriorating health and that the behaviour of the hospital staff compounded the undignifying effects of Delwyn’s health condition. Jacobsen (2007) refers to the notion of ‘social dignity’, which is experienced through the interactions of ourselves and others and comprises two linked elements: 'dignity-of-self' (includes self confidence, self-respect) which is created through interaction, and 'dignity-in-relation', which concerns the conveyance of worth to others. In her further work, Jacobsen (2009) details ways in which dignity can be violated; almost all result from other people’s behaviour and some of these were illustrated in Elaine’s narrative, as discussed later.

Elaine’s recognition of her father’s rapid deterioration when she visited him in the orthopaedic ward was all the more alarming because it seemed the staff did not recognise how ill he was; they appeared to focus only on measurable aspects of Delwyn’s condition rather than focusing on him as a person. The loss of independence that Delwyn experienced, such as being unable to hold a cup or do up his buttons, should have been recognised as a significant physical deterioration that needed urgent investigation. Loss of independence has also been associated with diminished dignity (Matiti, 2002; Woolhead *et al*., 2005; Baillie 2009) and will affect the personal identity of an individual who had been as active as Delwyn.

Baillie (2009) found that a serious illness, or uncertainty about diagnosis, led to feelings of being out of control, which diminished dignity. In the narrative, Elaine feared that her father’s diagnosis was serious and she struggled to gain information. Explanations and information-giving help people to feel in control and promote their dignity (Bayer *et al*., 2005; Enes, 2003; Jacelon, 2003; Matiti, 2002; Baillie 2009). In addition, information is essential for patients and families if they are to make informed choices and be involved in their care and decision-making. Involvement of patients and families requires staff to be willing and able to engage with them but Elaine experienced a lack of engagement from the ward sister and junior doctors. She described how the ward sister ignored her; both indifference and disregard (portrayed through ignoring) are behaviours that violate dignity (Jacobsen 2009) as well as posing barriers to involvement in care. Elaine perceived that the junior medical staff refused to engage with her and provide information about her father’s diagnosis or involve either her or Delwyn in decisions about resuscitation. The result of their lack of confidence, influenced by hospital procedures and hierarchy, led to further uncertainty for Elaine and Delwyn and a lack of involvement in important care decisions. Facilitating choice, for example in decision making, has also been found to promote dignity (Widäng and Fridlund, 2003; Woolhead *et al*., 2005) but there was no evidence in the narrative of any choices in care decisions.

Studies about dignity in healthcare have illuminated how behaviour of staff affects the dignity of patients, positively or negatively (Widäng and Fridlund 2003; Baillie 2009). Baillie’s (2009) research illustrated how staff behaviour can either promote or threaten dignity of patients, who are already vulnerable to indignity due to their health conditions. The oncology registrar’s words implied a focus on systems (’her’ beds) with a resulting failure to see Delwyn as an individual human being, who was near the end of his life. Her stance signified a dismissal of concerns, which is a behaviour identified as a dignity violation (Jacobsen 2009). Furthermore, the discussion about a move to another healthcare facility implied no involvement of either Delwyn or Elaine.

Elaine’s perspective was that staff focused on Delwyn’s medical diagnosis without seeing him as an individual and the failure to recognise and manage Delwyn’s pain certainly added to his distress and that of Elaine too. From a nursing perspective the narrative contrasts sharply with the International Council of Nurses’ Code of Ethics (2012) view that ‘*inherent in nursing is respect for human rights, including the right to life, to dignity and to be treated with respect’*. The narrative indicated little regard for Delwyn’s dignity, nor that of his daughter. From a legal perspective, leaving Delwyn in pain is inhumane and degrading and therefore possibly breaches the UK’s Human Rights Act too (Article 3). Much of Elaine’s narrative about the ward sister and nurses implies that hospital systems (e.g. infection control policy, bed management pressures) posed barriers to caring in a way that considers individual needs of patients and their families. Baillie’s (2009) research highlighted how hospital systems threaten dignity and in a UK-wide survey, many nurses identified hospital systems, in particular bed management , prevented them from providing dignified care (Baillie *et al.* 2008). As Elaine recognised, the staff were not ‘bad’; it seemed however that their priorities had become target driven (4 hour A&E target) and policy-bound (infection control) rather being focused on the person and family. The culture of an organisation influences the systems put in place and will affect whether staff feel supported to prioritise individual needs over organisational priorities and systems (Baillie and Black 2014).

From Elaine’s narrative, the Chair of the NHS Trust was concerned and interested in listening to her experience and she also offered the opportunity to directly speak to staff and to present the experience to the Trust’s Board. Elaine’s response to these opportunities, that she only wanted to tell her story to the Chair at this stage, illustrates that we must make no assumptions about how patients and families may wish to share their experiences with healthcare staff. Providing choices and options gives back some control, which is an important factor influencing dignity (Matiti and Baillie 2011). Another learning point from the narrative is that Elaine was only prepared to share her story with someone she trusted. For healthcare professionals who wish to learn from the stories of patients and families, a crucial first step is building a trusting relationship; furthermore building relationships with patients and families promotes dignity (Baillie and Gallagher 2011). If, as in Elaine’s experience, the healthcare provider has not engendered trust with the family, we must not underestimate the task in building the trust necessary for a family member to share their story. We need to recognise the exposing nature for patients and families of sharing personal information about themselves. Maintaining privacy of information promotes dignity (Calnan et al. 2005; Matiti 2002) and relates to dignity as personal identity from a personal integrity perspective. Therefore organisations that wish to use patient and family narratives for learning purposes must start with this factor in mind. It would be a travesty if the act of sharing patient or family narratives with the intention of learning and improving care, leads instead to diminishing of dignity and a further breakdown of trust.

**Conclusion**

In this chapter we explained the background to patient and public involvement in healthcare, with particular reference to UK health policy. Within England’s NHS services, involvement of service users is a requirement and there is a growing interest in using patient or carer narratives or stories as the basis for learning and healthcare improvement. Narratives can provide a more personal and holistic insight into the experiences of patients and carers than routine surveys, helping healthcare providers to contextualise experiences and appreciate service user perspectives. The analysis of a narrative for this chapter illuminated the patient and carer experiences of dignity as well as the importance of developing trust and adopting a sensitive approach when stories are obtained from patients or carers. Insights from narratives have potential to lead to quality improvement but as we have discussed, the way in which healthcare providers gather and use narratives needs careful consideration, with clarity about their purpose and how they will be used in practice.

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1. The Early Warning Score is calculated using vital signs measurements. The scoring system prompts actions with the aiming of early intervention to prevent deterioration and cardiac arrest. [↑](#footnote-ref-1)
2. NICE (National Institute for Health and Clinical Excellence) produces evidence-based guidelines for healthcare in England. [↑](#footnote-ref-2)