

Everybody matters 3: engaging patients and relatives in decision making to promote dignity

Patients and their families must never become passive receivers of impersonalised care. Dignity is promoted by ensuring patients are involved in treatment decisions

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ABSTRACT Nicholson C et al (2010) *Everybody matters 3: engaging patients and relatives in decision making to promote dignity*. *Nursing Times*; 106: 22, 10-12. The Dignity in Care Project (DCP) aims to develop practical interventions to promote dignified care in hospitals. It is a nurse led research collaboration between Royal Free Hampstead and Barnet and Chase Farm Trusts and City University.

Practical interventions are presented around three main themes in this three part series. This third part explores “shared decision making – involve me” (Bridges et al, 2009). This recognises the importance of engaging patients, family and staff in decisions about care and treatment. The article offers a range of interventions to hear the voices of patients, staff and relatives.

INVOLVING PEOPLE

In this project, the term “involvement” means engaging with people and the issues that are important to them. This is broader than the principle of giving information and gaining informed consent – it is an ongoing intention to value different perspectives and needs and to ensure that “everybody matters” (a project slogan) in the delivery of dignified care.

Research shows that *how* we deliver hospital care is as important to the patient/

family experience as *what* we do to or for them (Bridges et al, 2010).

“Living out” the practice of involving patients with different needs is complex. Not all choose to be involved (Millard et al, 2006; Florin et al, 2006) and, for some, non-involvement is an active, informed choice. One patient in our study said:

“It’s about trust, I trust them to do the best for me. I don’t need to know what they are doing or be a part of it, that’s what they train for.”

This relationship between the patient and those caring for him was underpinned by his active non-involvement.

The literature shows nurses who connect personally and socially with patients “set the scene” for them to be on an equal footing. Millard et al (2006) said: “By concentrating on the social dimension, the nurse continually reaffirmed to the patient their importance as a person and not a task or condition.”

Patient centred communication “invites and encourages the patient to participate and negotiate in decision making regarding their own care” (Langewitz et al, 1998).

However, looking only at the individual nurse-patient relationship misses the organisational context. Hospital culture, leadership and organisational priorities can enhance or diminish patient, nurse and family capacity to relate and be involved.

For this reason, relationship centred care (Nolan et al, 2006), rather than patient centred care, underpins the interventions that we have developed with hospital staff.

Below is a list of suggestions to help other nurses and hospitals enhance shared decision making between patients, relatives and staff. These are considered under the following headings and summarised in Table 1:

- Enhancing shared decision making in everyday care;
- Engaging patients whose condition or context challenges involvement;
- Valuing and collecting different perspectives on being in hospital.

Enhancing shared decision making in everyday care

Pressure of work encourages nurses to focus on tasks, so patients and their families can become passive receivers of impersonalised clinical activities, some of which they may neither understand nor desire.

There is an established emphasis on intentionally gaining involvement in procedures that affect safety, such as surgery. Sometimes it is easy to forget that everyday care activities require the same thought to engage and assist patients and families to participate to the level they wish.

● **Putting the “personal” back into personal care:** washing, using the bathroom, deciding what clothes to wear and food to eat are highly personal activities.

Patients and families recognise that routines are necessary, and part of the DCP is to think with staff about “good enough” dignity when it is not possible for personal needs to be met in the way in which patients most desire. For example, staff need to respect drawn curtains and closed doors as a sign that personal care is in progress. Behavioural prompts such as signs with “stop, wait and ask” pinned to curtains/doors can be helpful reminders.

How staff offer personal care is important. We have been reflecting with nurses about this and why some patients may feel uncomfortable or even refuse help with activities. Some feel embarrassed at having to ask for help and become angry with nurses who remind them of their dependence. Others find that nurses assume that because they are in hospital they cannot do anything:

“They [the nurses] came and said: ‘I’ll be over to give you a wash in a minute.’ I said: ‘No you bloody well won’t.’ Then they said: ‘Can you get to the toilet?’ Of course I can bloody well get to the toilet” (patient interview).

This quote exemplifies the need to ask and involve those people being cared for, rather than assume a level of capacity or incapacity.

Nurses need to connect with patients and form a relationship from which shared decision making can flow.

● **Working in a way that affirms personhood:** a central theme of the project is appreciative inquiry (Cooperrider and Whitney, 1999). This means that, to understand a situation or person, an open, curious and inquiring attitude is needed. The underlying beliefs are that each person's voice and experience is important and that seeking to involve people will enhance current and future possibilities. This underpins our project slogan "everybody matters".

Nurses may want to think about how they involve patients in their care. Giving them information is important and can be as simple as letting patients know who is caring for them. Some units have a whiteboard in each bay giving the name of the nurse; in others, nurses make a point of introducing themselves at the start of a shift.

Other units have involved patients and their families on ward rounds. Engagement with the multidisciplinary team has been important in addressing the challenges of timely rounds, which allow patients to be involved in decisions about their own care.

Our observations suggest that involvement is particularly difficult when nurses are unable to give precise information, such as the time of a scan. It seems difficult for them to say "I do not know" or to acknowledge the anxiety that not knowing can cause patients, carers or, indeed, nurses themselves. Instead, needs for information are ignored or not followed through:

"They are all very kind and so busy... but I still want someone to help me find out about my appointment. They are all well meaning and say they will find out but nobody ever gets back to me."

This patient comment came in the middle of an interview praising staff kindness and the good job they did. The patient was at pains not to be seen as complaining, yet she was clear that her need for information had not been met.

"Getting back" to people means holding them and their need in mind as well as all the other things nurses do. This is not easy. Part of finding a way to work that affirms personhood involves acknowledging there is an emotional cost to caring.

Furthermore, staff need to be supported if they are to remain involved with patients (Menzies Lyth, 1988). One of the most important ways to enhance patients' and

TABLE 1. WAYS TO INVOLVE PATIENTS IN DECISION MAKING

Enhancing shared decision making in "everyday" care	Putting the personal back into personal care
	Working in a way that affirms personhood, such as keeping people informed, involvement in ward rounds
Engaging patients whose condition/context challenges involvement	Involving older people
	Involving people nursed in a side room, for example. The importance of answering call bells, being mindful
Valuing, collecting and acting on the different perspectives of being in hospital	Engaging with stories of care from patients/families/staff by using pocket postcards and emotional touchpoints
	Introducing listening posts to hear and celebrate good care, and collect ideas for development

families' dignity may be to provide structures to support staff, for example ensuring staff meetings are open to discussion of care issues as well as providing managerial information and group/individual clinical supervision.

Engaging patients whose condition/context challenges involvement

People with particular needs, such as communication difficulties, are at greater risk of non-involvement in hospital.

We worked with nurses to develop attitudes and behaviours to enhance involvement for such patients. We were also mindful of keeping a balance between the focused needs of a particular patient group and the need for a ward culture that invites involvement from all patients, staff and relatives.

● **Involving older people:** people over 65 account for two thirds of hospital admissions (Department of Health, 2000), so all nurses working in adult services will care for older people. Yet the literature suggests that involvement of older people in decisions about care is a common challenge (Bridges et al, 2010; Flatley and Bridges, 2008).

A number of factors are involved in this – not least ageist attitudes. Valuing the expertise of this group and their capacity is important when an ageing body may suggest deficit. This is the case even when someone is acutely confused or has cognitive deficits.

The following extract from field notes illustrates something of the complexity associated with negotiating care with a woman diagnosed with dementia: "Yvonne* was very frail. She was sat in bed, constantly plucking at her bed sheet. I went to introduce myself, she clutched at my hand, whispered something unintelligible to me and then began plucking at my sleeve. I spoke again asking if I could take her blood pressure and she clearly said: "Who will talk to me?" I replied (surprised) I would, and she said something incoherent, moved her

hand away from my arm and began to pluck at the sheet. I hesitated as to whether to take her blood pressure and kept looking at her but she didn't return my gaze and spoke incoherently for a moment then closed her eyes, I talked to her about my day, the ward, anything that came to my mind. She stopped plucking at the sheets and fell asleep." (*The patient's name has been changed.)

Involving people in care decisions is not always possible but it is always feasible for nurses to connect with other staff to support them and help promote involvement.

What this project has facilitated, through action learning teaching across departments and networking between wards, is the capacity of nurses in different areas to share expertise. Involvement needs to be an organisational as well as an individual value. ● **Involving people nursed in a side room:** in some ways, being in a side room can be said to enhance patient privacy and dignity. Yet our observations and data suggest it is often those in side rooms who are most at risk of non-involvement.

Our interpretations suggest this is in part due to the nature of being in a side room, for reasons of infection control. Being "in isolation" can be distancing and, although nurses are rightly vigilant in carrying out procedures, technical requirements can sometimes undermine patient involvement.

The other main factor is reliance on the call bell to get attention. Our data suggests that many people are reluctant to ring the bell and it is not always easy for nurses to respond in a timely fashion. One development from this finding is intentionally carrying out rounds to ensure that all side rooms are visited every half hour.

Valuing, collecting and acting on the different perspectives of being in hospital

Involving people at different levels of the trust requires a range of tools and languages.

practice changing practice

It is not always easy for staff or patients/families to communicate their experience.

Feedback therefore tends to be when an experience has been outstanding, either positive or negative. Below are three interventions used to help people to engage with the experience of being in hospital.

● **Pocket postcards to engage with patient/family/staff stories of care:** postcards with phrases or pictures can act as a support for a conversation that is different from recounting a clinical history. We collected some images for staff to keep in their pockets or nearby, to use to start conversations about aspects of dignity and involvement in care.

● **Emotional touchpoints:** use feelings at key points (touchpoints) of a story as a way of understanding experience. The patient/family or staff member is asked to select from a range of emotional words those that best describe their experience and are then invited to explain why they felt this way.

In some projects (such as the Leadership in Compassionate Care Project, see tinyurl.com/emotional-touchpoints), these stories are transcribed and given back to the storyteller to check for accuracy before being used with permission for staff development. Dewar et al (2010) used this method with great success in moving to a deeper level of dialogue and understanding between patients/families and staff.

In our project, that level of depth has been reached through using emotional touchpoints with staff. It seems a valuable tool in connecting with the emotional impact of a particular case and the strength and possibilities that clinicians were able to access in that situation.

● **Listening posts to hear and celebrate good care, and collect areas for development:** listening posts were devised to facilitate staff and lay stories of dignity in real time. Postcards inviting responses to the statements “Tell us what we do well” and

“Tell us what we could do better” were given to patients, staff and carers.

Responses were posted in boxes in the hospital concourse. The project team were present to facilitate and listen to stories and act on them immediately if appropriate. Additional listening posts were given to wards; postcards with the statement “I feel valued at work when...” were given to all wards and staff groups.

The high staff response rate highlights the value of an appreciative stance. Posters summarising the responses to the “I feel valued” postcards were placed on all wards to help sustain discussion. Patients, relatives and staff seem to value being asked to talk, write and gain feedback about their experiences in a simple and immediate way.

CONCLUSION

We have suggested that dignity in hospitals requires engagement by patients, carers, nurses, multidisciplinary teams and the

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wider organisational leadership. There is a complexity of meeting individual needs with dignity within vast hospital organisations driven by political initiatives.

Our project suggests that many people are practising and experiencing dignified care. Some have questioned the emphasis on small acts of dignity, suggesting that highlighting smallness can denigrate their value.

We would like to end with an alternative perspective. It is the very “smallness” of the dignity interventions highlighted in this project that enable them to be owned by individual nurses, who can make a real difference and therein lies the power. Small changes give time for our current working practices and support structures to grow with us and thus make the change sustainable.

So to end this series with a challenge: what is the *smallest* change you can make to enhance dignity in your place of work?” ●

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