How do patients respond to end-of-life status?

In this article...

- Review of open and closed contexts of palliative care
- Patients' perceptions of end-of-life prognosis
- Multidisciplinary approach to end-of-life communication

Although health professionals may tell patients when they are nearing the end of their lives, patients do not always absorb or want this information.

A side from close companions and friends, nurses have the closest and most sustained contact with dying people. In the UK, Field's (1989) study of nurses' experiences of caring for dying patients showed that, by the 1980s, attitudes to telling patients about their terminal prognoses had changed.

"Open awareness", as it became known, is now promoted (Department of Health, 2008), in the main because it is thought to help with planning and making patient-centred decisions about treatment and care at the end of life, before crises arise.

Literature review
Glaser and Strauss' (1965) landmark text described how hospital patients could move in any direction between a context of "closed" awareness, where staff withheld information about their prognosis, to one of open awareness, where all parties - patient and family included - acknowledged that the patient was dying.

The basis for not telling patients of their prognosis was to preserve their hope of a recovery but, as the discipline of
palliative care developed in the 1970s, a clear link emerged between encouraging people to talk about their experiences of dying and an improvement in that dying experience (Field, 1996).

One of the ongoing barriers to entering a context of open awareness is the difficulty in giving an accurate prognosis, particularly for conditions other than cancer (Murray and Sheikh, 2008).

In addition, clinicians responsible for breaking bad news continue to find doing so difficult and so avoid it (Gott et al, 2013; Barclay and Maher, 2010), while the way that people interpret or absorb bad news when they are given it is not straightforward. There is often a difference between the information professionals perceive they have given and the message received by the patient (Fried et al, 2003).

Aim and method
This qualitative interview study was conducted in 2010-11 as part of a large multi-method Department of Health-funded project about transitions to palliative care in UK hospitals (Gott et al, 2013). The aim was to explore whether and how information about a transition to a palliative care approach was communicated to patients, and to what extent they felt involved in decision-making. Ethical approval was provided by the Nottingham 1 Research Ethics Committee.

Participants were recruited during a comprehensive survey of patients at two hospitals in England (Gardiner et al, 2012). Hospital case notes of consenting participants were examined to identify those who met the Gold Standards Framework (2012) prognostic indicator criteria. The GSF is an assessment tool for identifying people with advanced progressive, eventually fatal illnesses who are likely to be in the last year of life and may benefit from palliative care. In total, 131 people agreed to be contacted (by letter) inviting them to interview; of these, 15 agreed to be interviewed 3–6 months after discharge. Three participants asked for a live-in family carer to be present during the interview.

Semi-structured interviews were conducted in participants’ own homes (n=12) or by telephone (n=3). The interviews lasted approximately one hour and were tape recorded and transcribed verbatim. In the analysis phase, two researchers read and re-read the interview transcripts independently to identify themes. The themes of “communication of prognosis” and “thoughts about the future” were selected as of particular interest and a loose typology of awareness was developed.

Results
All but one of participant was aware of his or her diagnosis, but knowledge of prognosis was far less complete. None of the participants mentioned palliative care and only one alluded to non-curative treatment (which they called “remedial care”).

“I don’t want no shilly shallying” – open awareness
Some participants fully aware of their prognosis and acknowledged they might be approaching the end of life. For one, Beverley (all names are pseudonyms), the experience of developing cancer 40 years earlier and recovering from it had the effect of reducing her fear of dying from her present illness. This influenced her approach when asking for information from her doctor:

“I’d rather they just said to me ‘we don’t know how long you’ve got, but...’. And I would say ‘well, can you give me what normally is the length of time, you know, I know you haven’t got a crystal ball.’”

Beverley was actively trying to open up a conversation with her doctors about her future without looking for false certainty (the elusive “crystal ball”). Another participant, Paul, a 64-year-old man with heart disease and severe chronic obstructive pulmonary disease, was similarly aware of his limited life expectancy and had signed a do not attempt resuscitation order – evidence that some discussion of future deterioration had occurred.

To indicate to his doctor that he preferred a situation of open awareness, Paul told his doctor that he didn’t want “no shilly shallying”:

[The doctor] says to me, ‘I’m glad you’re up front about it’, so I said ‘well, it’s daft lying isn’t it.’ I said, ‘well, I want you to do the same, if you think I’ve got about six months to live, don’t hang back’.

Here, we infer that Paul is giving his doctor permission to engage in open and honest communication. Both Paul and his son (his live-in carer) openly acknowledged that his disease is life limiting: Paul: “[The doctor] said ‘it can’t be cured, you know that don’t you?’ and I said ‘well, aye.’”

Son: “They’ve not gone into details, like [that the attacks] are going to get more frequent or they’re going to get worse, but they’ve said, you know, it’s terminal. He’s come to terms with that, he does know, he’s not shirking, he knows what’s what.”

The use of the term “shirking” suggests a moral imperative to take responsibility for one’s own awareness. In spite of Paul’s request for straight talking, his son’s comment about a lack of details reveals they still lacked information about what to expect from the disease trajectory.

“I’ll bounce back” – reluctance to face the future
Other participants displayed more reluctance in accepting the life-limiting nature of their condition. While some acknowledged conversations with health professionals about their prognosis, they appeared not to have fully internalised the information communicated to them.

John, reflecting on being told of his prognosis by his surgeon, said: “I don’t think he held back, he just told me how it was and that’s accepting it. It’s just how it’s got to be.” John, who had lung cancer, said he “could have done with talking to somebody” because he felt he was going through it alone: “[I could have benefited from] a bit more info, a bit more care.” He clearly wanted more opportunities to talk through his fears.

Later in the interview, John signalled that he was still hopeful of a recovery.
Although his doctor “hadn’t held back”, John did not want to abandon a residual hope that he would recover: “It were a close shave, a couple of close shaves for me […] but I’ll bounce back.”

“As long as I can cope, I’m not interested” – closed awareness

Some participants did not seem aware of their prognosis at all in that they did not mention any discussions with health professionals about expected future deterioration, and reported no desire for information. These patients were all over 85.

As Cynthia, aged 90, said: “I’m not bothered, I don’t care. As long as they know what’s wrong with me […] they can tell you all these things and frighten the living daylights but if you don’t know what’s wrong and you’re just quite happy to lay there and let them do their worst. That’s all you can do really, isn’t it?”

If a patient is reluctant to ask questions or to hear bad news, this begs the question of how far practitioners should persist in giving this information.

Liz, aged 96 and living with various comorbidities, revealed her lack of awareness in her comment that she thought she had been cured for now: “They’re going to operate if it gets desperate but not otherwise […] the surgeon said if they operated I should probably be besotted so it was up to me so I turned it down and said I’d wait […] THEY put it all down to old age [laughing].”

Liz’s comments suggest it was presented as her choice whether to opt for more surgery; she declined because she valued mobility over longevity. However, the disclaimer – “if it gets desperate” – indicates a reluctance to let go altogether of the possibility of further medical interventions. Her reference to her age suggests that, in her mind, it was a factor influencing the doctors’ diagnosis and advice against opting for further treatment, rather than one influencing her own decision to turn down further medical and nursing interventions.

In general terms, while these participants showed awareness of the influence of old age on decisions about treatment, this did not signal an awareness of the way their own old age was affecting their health, bringing them closer to death.

Discussion

Evidence suggests that individuals’ lack of awareness of their disease stage is likely to result in unnecessary and often unwanted hospital admissions (Benyon et al, 2011), leading to an increased likelihood of dying in hospital (Aabom et al, 2005; Seale et al, 1997), a lower likelihood of referral to specialist palliative care services (Johnson et al, 2011) and less end-of-life planning, which would enable them to use time left consciously to achieve personal goals (The et al, 2000).

Such evidence has been combined with culturally informed assumptions about a desire for self-determination to offer a cue to policymakers to create guidance supporting the sharing of information (Nursing and Midwifery Council, 2008) and the active promotion of an open awareness context as patients approach death (General Medical Council, 2010; Department of Health, 2008).

The 15 participants were all identified as potentially in need of palliative care according to standardised diagnostic criteria (GSE). Despite indications that they might be nearing the end of their lives, most were unaware of their prognosis and showed little insight into what they could expect from the trajectory of their disease.

None reported having discussed goals of care during their hospital admission, while some expressed an understandable ambivalence towards fully accepting the life-limiting nature of their condition, preferring to live “day by day”.

Conclusion

Overall, our study shows that communication between health professionals, patients and their families is not easily mapped onto ideal-type scenarios.

A significant amount of communication literature in palliative care relates to doctor-patient communication, yet nurses are the constant presence across many settings and often spend critical time with people at the end of life, helping them to interpret bad news and clarify medical information about the likely trajectory of their disease.

Nurses are the “practical managers” of events after disclosure of prognosis (May, 1993), so must be involved in the multidisciplinary effort to come up with “novel ways of delivering palliative care” (Zimmermann and Rodin, 2004) rather than relying on the ideologically based assumption that awareness can and should be encouraged in all cases. NT


Funding: this project was commissioned by the NIHR Service Delivery and Organisation programme under the management of the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre, based at the University of Southampton. In January 2012, the NIHR SDO programme merged with the NIHR Health Services Research programme to establish the new NIHR Health Services and Delivery Research programme. The views and opinions expressed here are those of the authors and do not necessarily reflect those of the NIHR HS&DR programme, NIHR, NHS or the Department of Health.

References


Benyon T et al (2011) How common are palliative care needs among older people who die in the emergency department? BMJ Supportive and Palliative Care; 1, 184–188.


