Issues in prognostication for hospital specialist palliative care doctors and nurses: a qualitative inquiry

Dr David Pontin - Dept. of Nursing & Midwifery, University of the West of England, Bristol, UK
David.Pontin@uwe.ac.uk

Nikki Jordan – North Bristol NHS Trust, Bristol, UK
Background

• Patients with advanced life-limiting diseases have high information needs about prognosis (Steinhauser et al 2000, Lamont & Christakis 2001)

• Discussions between patients & health care professionals about prognosis are avoided/inaccurate: systematic over optimism (Higginson & Costantini 2002)

• Prognostic models: lack of independent validation & a cancer specific focus, a heavy reliance on physician survival estimates (Stone et al 2008)
Background

• Limited research literature about prognostication experience & hospital specialist palliative care (HSPC) team members

• Literature - HSPC professionals frequently asked to prognosticate, although prognostication experience unknown, understated in everyday work & is a complex, emotive subject (Innes & Payne 2009, Barnett 2002)
Research Questions

• ‘How do specialist palliative care team members prognosticate? ’

• ‘How do they view prognostication?’
Research Design

• Qualitative interpretative design
• NJ = HSPC clinical nurse specialist: explore HSPC team members’ experiences of prognostication from insider perspective
• Local NHS Research Ethics Committee approval for 4 focus groups with HSPC teams in four English hospitals
• Permission sought to conduct research from each relevant research governance committee. 5 month response delay from 4\textsuperscript{th} hospital. Removed from frame due to timing issues.
Sampling Strategy

• Purposive sampling
• Focused on HSPC team members (nurses & doctors) - relevant knowledge & experience of prognostication: transferability
• HSPC teams invited via lead hospital palliative medicine consultant/senior doctor (invitation letters, participant information sheets, consent forms & interview schedules)
• 1 focus group in each hospital, maximum of 8 members
• Focus group timing & venue based on HSPC team preferences
• All teams chose to meet in their respective hospitals & they booked a room for the focus group. Ensured teams were comfortable with the choice of room & privacy was maintained.
Conducting the Focus Groups

• Took place February-May 2009: NJ = facilitator
• Lasted from 68-74 minutes
• Study purpose, format & assurances about confidentiality reiterated before focus group started
• Written consent from participants for audio-recording. Notes taken during the interviews capture non-verbal interactions within the group
• Field notes capturing emergent topics used as aide memoirs for data analysis
• Recordings transcribed following each interview.
• During transcription, analytical memos generated to support data analysis process
Data Analysis

• Iterative process used to develop themes and carry out progressive focusing

• Data analysis began concurrently with data generation & data synthesis

• NVIVO 8 used to assist in the management & analysis of the data
Ethical Considerations

• Characteristics of focus group interviews
• Use of quotations
• Practitioner research with colleagues intensify ethical considerations
• Transcripts transcribed by NJ to maintain confidentiality
• Data anonymised during the transcription: numeric codes assigned to individual teams & participants
• We followed local university & NHS Trust guidance on data management
Focus Group Composition & Characteristics

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All participants work in HSPC teams caring for people with malignant & non-malignant disease with varying levels of experience.

The lead hospital specialist palliative medicine consultants have 04 to 14 years role experience.

Nurse palliative care experience 1-15 years; some were acquiring specialist palliative care qualifications, others had specialist palliative qualifications at Bachelor or Masters level.
Benefits of prognostication

Services accessing funding & services planning patient care

Difficulties of prognostication

Non-malignant disease

Communicating uncertainty

Seeking a definitive prognosis

Dealing with reaction of prognosis

Participants’ feelings

Confidence in prognostication

Communicating prognosis

Estimating prognosis

Prognostic error

Revising prognosis

Living past prognosis

Dying before prognosis

Estimating prognosis

Accuracy of prognosis estimates

Factors considered

Prognostic scores

Patient informed decision making to prioritise needs & care

Family-prioritising commitments

Services accessing funding & services planning patient care
Benefits of Prognostication

• 3 sub-themes emerged during group discussions

• They relate to patient, family & care centred prognostication

• Supports findings of Steinhauser et al, & Lamont & Christakis
Benefits of Prognostication: patients - informed decision making

• Participants talked about patients benefiting from knowing their prognosis in terms of
  – informed decision making about potential treatment
  – enabling prioritisation - what they wanted to do, who they wanted to see & where they wanted to die
Benefits of Prognostication: patients - informed decision making

• ‘It can just help patients with their forward planning to have an idea of how long they’ve got to achieve their goals. So they can set realistic goals in terms of what they want to do before they die and plan for the future in terms of place of care and seeing distant relatives’ (cons200338)
Benefits of Prognostication: family – prioritising commitments

• ‘I think it’s nice for families sometimes to sort of be there, because sometimes people are still going to work and so if they know time scales are a bit shorter they would maybe make those choices so that they are home more with their loved one’. (cns300259)
Benefits of Prognostication: HCP - access & planning

• ‘So they may stop and think well the prognosis is short and maybe just change the way that investigations are booked or follow up and what they do or don’t do’. (spr00339)

• ‘The home support service like a prognosis for whether or not they will accept a patient onto their service’. (cns300337)
Difficulties of Prognostication:

• Estimating Prognosis
  – factors considered when estimating a prognosis
  – prognostic models
  – accuracy in estimating prognosis
Difficulties of Prognostication: Estimating Prognosis - factors

- Scientific and measurable
- Rate of patient deterioration
- Time is problematic due to the pressure to discharge patients or difficulties in meeting the wishes of rapidly deteriorating patients whose priority is to die at home
Difficulties of Prognostication: Estimating Prognosis - factors

• ‘And to see somebody over consecutive days as well. Not just make it [prognosis] on that one day because I think then you don’t know about a pattern. Sometimes you don’t have time. Sometimes you have to make a bit more of a snap decision if you want to get someone home’ (cns1001229)
Difficulties of Prognostication: Estimating Prognosis - factors

- Experience, pattern recognition & intuition

- They experience particular difficulties estimating a prognosis when patients’ investigation results oppose their instincts
Difficulties of Prognostication: Estimating Prognosis - factors

• ‘When the evidence is contrary to gut instincts those are the really difficult ones. You know I can think of a couple of patients where they were just supposed to have localised disease and yet the patient looked like someone with widespread metastatic malignancy. And the ones where the oncologists will say, you know they’re deteriorating, “But their CA125 is falling and their tumour markers are improving on chemo”. But they’re getting worse and worse....you can tell that they have got progressive disease but they haven’t found it yet, or imaged it yet’ (cons1001245)
Difficulties of Prognostication: Estimating Prognosis - factors

• Asking colleagues to give a 2nd opinion about a prognosis is commonplace

• Several participants talked about having to see a patient in order to prognosticate
Difficulties of Prognostication: Estimating Prognosis - factors

• ‘You can’t offer a prognosis over the phone you HAVE to be able to see a patient. .....It’s so much easier if you have seen them, as you all know, so I think we under estimate how important it is to physically see a patient and see what they look like. .....that’s the minimum and then ideally you need to see them over a different time period and that will give you even more information’ (spr002343)
Difficulties of Prognostication: Estimating Prognosis - prognostic models

• Groups asked if they use models in practice to estimate prognoses. Claimed not because models rely on physician estimation

• Poor sensitivity & specificity & reliance on physician estimation echoed by Vigano et al 2000 & Maltoni et al 2005

• Major problem with physician estimation is non-reproducibility
Difficulties of Prognostication:
Estimating Prognosis-prognostic models

• ‘I mean it’s fascinating if you look at the literature on prognostic outcome scales you know you can look at such and such a white count or such and such a biochemical parameter but the recent ones all build in physician hunch which is just you know, counter intuitive really. I just think it’s fascinating that they can’t get rid of physician hunch. So I’m afraid it just seems easier to stick with physician hunch really until someone comes up with a fabulous score’ (cons003293)
Difficulties of Prognostication: Estimating Prognosis- accurate prognosticators

- RNs & health care assistants working on wards considered most accurate prognosticators
- Attributed to the amount of time spent with patients
- Close involvement in essential care delivery
Difficulties of Prognostication: Estimating Prognosis- accurate prognosticators

• ‘You only see a patient once a day perhaps, you know for ten or fifteen or twenty minutes and that is very different to the nurses who are going in and out looking after that patient every day, constantly through the day. So I think that is why nurses are much better at prognosticating than doctors, because we are seeing an absolute snap shot and sometimes that is useful because you can come back and say that’s a really dramatic change in 24 hours. And maybe that isn’t apparent to the nurses who just, just keep doing things but often it is the nurse who says “well actually the last time they could mobilise to the bathroom and now they can’t’ (spr001319)
Difficulties of Prognostication: Confidence in Prognostication

• Participants’ self-confidence in estimating & conveying a prognosis

• Confidence patients & families place in professionals’ ability to prognosticate
Difficulties of Prognostication: Confidence in Prognostication

• Self-confidence in prognostication is greater when:
  – patients’ test results are available
  – patients are in the last days of life
  – there is a cancer diagnosis
  – a 2\textsuperscript{nd} opinion is available
  – patients are seen over a period of time
  – the prognostic uncertainty is shared with patients
Difficulties of Prognostication: Confidence in Prognostication

• ‘I feel confident in why I think the things I think. Confident as in the basis of my opinion, but I don’t feel confident as to whether my opinion is correct. Which is definitely different. And that’s why it’s always labelled with uncertainty, yes, it has to be’ (spr001289)
Difficulties of Prognostication: Confidence in Prognostication

• Compared to estimating a prognosis, participants report feeling more comfortable communicating prognoses to patients or families
Difficulties of Prognostication: Confidence in Prognostication

‘I think the thing we haven’t talked about which contributes to confidence in prognostication is actually what the patient thinks, and what the family thinks. So when you are talking to the patient or the patient is asking you, most of us will actually ask them back. You know, what they are thinking about, how are they thinking about it, or sometimes I mean they give you the answer themselves don’t they? And if they say “well I think it’s not long” you are much more confident in saying yes then aren’t you? Or if you ask the family to describe what they have seen in the changes [of the patient] it becomes clear. Then that kind of helps people’s confidence, the professional’s confidence’ (cons001296)
Difficulties of Prognostication: Seeking a Definitive Prognosis

• When patients’ & families’ seem to expect HSPC team members to offer definitive prognoses

• Although a definitive prognosis isn’t conveyed it may be perceived as such
Difficulties of Prognostication: Seeking a Definitive Prognosis

• ‘But I have also stood outside the curtain during a ward round waiting to see a patient and I heard the conversation that happened and the chest physician very, very carefully talking to the woman about prognosis and expectations. And maybe this time she was more poorly than she had been in the past and in between episodes she wasn’t recovering quite, you know, all the very gentle moving towards giving some information and finally you know she did ask something more blunt “Am I going to get better this time?” He did say “I don’t think so, I think time is getting shorter now and I don’t think you have got so much time”. And then I went to see her afterwards and she said, “He has just told me I’ve got six months”. And I had heard all the conversation, time was never mentioned, six was never mentioned, months were certainly never mentioned because we weren’t talking months. So I just find it very interesting, I wish I could have tape recorded that whole process of how a very careful conversation had happened, giving her warning shots, not giving her specific times, turned into a concrete six months which was totally incorrect. She had days to weeks left, which was what he was trying to tell her’ (cons00227)
Difficulties of Prognostication: Seeking a Definitive Prognosis

• When prognosticating with patients & families, participants claim to avoid specific timescales but talk in terms of hours, days, weeks or months

• Participants were asked to clarify what they meant by ‘days, weeks or months’, & their use of ‘short’ or ‘long’ before days, weeks or months
Difficulties of Prognostication: Seeking a Definitive Prognosis

• ‘It’s a funny one, but I use short weeks, which I think a lot of and I have discussed this with colleagues they say “Well what does short mean?” But I think if you are talking in terms of weeks rather than months, then my understanding of short weeks is less than one month. So one’s looking at sort of, I think less than six weeks. But I still won’t mention numbers and I still will talk about short weeks, or long weeks, or and a I just won’t let them tie me down to numbers because I know what happens they circle it on the calendar’ (cns100172)
Difficulties of Prognostication: Seeking a Definitive Prognosis

- Participants are expected to convey a definitive prognosis for patients to access various community services.

- They experience difficulties having to offer definitive prognoses to service providers while being less definitive with patients.
Difficulties of Prognostication: Seeking a Definitive Prognosis

• ‘It feels wrong to be telling, to be sitting with family and patients and to be vague about time when you’re ringing up agencies being absolutely clear, it feels unjust I guess to be giving specifics to others even if they’re not, the kindness is in being vague for patients and you know that, that feels right and all the rest of it but if they want to know and you are then ringing up an agency saying “Yes six weeks” it feels wrong sometimes. And it seems that it is a bit, almost parental to not be giving a number to a patient if they specifically ask for it’ (cns001397)
Difficulties of Prognostication: Seeking a Definitive Prognosis

• Important re: patient outcomes & social policy

• HSPC not usually formally trained in prognostication but perception/expectation that they offer definitive prognoses
Difficulties of Prognostication: Seeking a Definitive Prognosis

• Problems:
  – Definitive prognoses likely to be inaccurate, so patients die before /beyond the prediction
  – HSPC staff talk of short/long days, weeks or months, open to interpretation by patients because ambiguous or inconsistencies between HSPC staff
  – Undermines partnership working & may compromise moral trust
  – Other agencies seek definitive prognoses due to inflexible referral criteria
Difficulties of Prognostication: Seeking a Definitive Prognosis

• Problems:
  – Literature demonstrates consistent trend to overestimate survival (63% in Christakis & Lamont’s 2000 study)
  – Patient referrals for end-of-life care & other benefits may be delayed leading to late/missed referrals likelihood of poor patient outcomes
  – Referral criteria based on flexible approach to patient/family need & likely benefit may be more useful
Difficulties of Prognostication: Prognostic Error

• Acknowledgement that prognostication can never always be right
• But seeking, conveying & perceiving definitive prognoses may lead to their revision, or patients dying before or living past their prognosis
• Participants talked about the difficulties of responding to and revising erroneous prognoses
Difficulties of Prognostication: Prognostic Error

- ‘I had a similar experience of lady, it was a while ago. She was on ward x, was dying and was told that she had, and the family, she had twenty four hours to live. And she actually lived seven days and that was really hard for the family. And every day you would go up and they would want to know an exact timescale. The same as SPR said you can’t so, they found that really difficult having been given a time and that time had passed, and kept passing it was really difficult for the family because they were sleeping, you know twenty four hours a day on a rota and they were just finding it really difficult’ (cns300320)
Difficulties of Prognostication: Communicating Uncertainty

• When prognosis discussed with patients it is common practice to communicate prognosis uncertainty to buffer the consequences of prognostication & to maintain patients’ hope
Difficulties of Prognostication: Communicating Uncertainty

• ‘But we still have to qualify it [prognosis] very strongly with the uncertainties that go with that because we all know of incorrect prognostications that we have all made, and I mean majorly incorrect. And they have to kind of acknowledge that, so that hopefully people can factor that in when they are making their decisions’ (cons00195)

• ‘I often do that [convey prognosis with uncertainty] but I’ve never known who I’m protecting, myself or them. But I’d like to think it’s a lot of protecting them from having something and then it not occurring and preparing them for the doubt. But some of it I must admit is probably because I want to protect myself in terms of the honesty of what I say and just from that defence against “Well you were completely wrong’ (spr003246)
Difficulties of Prognostication: Dealing with the Reaction of Prognostication

- Participants’ experience difficulties dealing with some patients’ reactions to being told their prognosis

- They interpret patients’ reactions as unpreparedness for devastating news & movement from a state of uncertainty to absoluteness
Difficulties of Prognostication: Dealing with the Reaction of Prognostication

• ‘I would share SPR’s experiences that it’s horrid when you feel or a patient has said to you “Yes I do want to know” and you tell them and there is a complete change in their personality therein, you just feel, you know, you want to turn the clocks back. You know, you have made very sure that they’ve actually said they want the information but then when you’ve have given it to them that’s hard’ (cns1001158)
Difficulties of Prognostication: Non-malignant Disease

• Prognosticating in non-malignant disease, specifically heart failure & chronic obstructive pulmonary disease (COPD) is difficult

• Difficulties for non- HSPC staff prognosticating with this patient group
Difficulties of Prognostication: Non-malignant Disease

• ‘I got asked to do a lecture for a COPD meeting and talked about advance care planning and an awful lot of people were saying “But when should we do it, because every time they look as if they’re going to die and they just keep bouncing back and we don’t know, which one, which episode they’re going to deteriorate in?” So I said “Well perhaps you need to do it every time” They didn’t like that, not at all. And the reason that, I think one of the reasons that it is so difficult to judge prognosis in patients with heart failure and COPD, at the point you are asked to do it they are always at their very worse. But if you saw in five days time, post their course of antibiotics ready to go home you, your judgement would be very different. And that is what the respiratory physicians are up against. But they don’t want to have the conversation, because they look better. They didn’t want to do it too early for some reasons because they were worried about upsetting people’ (cons003214)
Difficulties of Prognostication: Participants’ Feelings

• Insight into the everyday dilemmas faced by palliative care staff who are called on to prognosticate

• Provides pointers for potential areas to be addressed in training, support & supervision
Difficulties of Prognostication: Participants’ Feelings

• ‘I would say that of all the challenges there have been for me being fairly new in post is that [prognostication] is probably the biggest one. Especially with the form that you are talking about. And the only thing I really, well I sometimes come and say “Cons001 come to me with a patient because I don’t know.” Or I will try and ask somebody much more senior because I feel really concerned that I just don’t know and that there seems to be so much pinned on it, particularly about is it relevant for this service to which I am referring. It’s really challenging’ (cns200114)
Difficulties of Prognostication: Participants’ Feelings

• ‘I think some of the patients that it can be hard to prognosticate on are patients who could die in a number of ways. So for example a head and neck patient who is at risk of a carotid blow out and they’re asking you “Have long have I got?” And you know, “If things remain as they are and you just die without a blow out, you know it could be a matter of months but you could actually die at any moment”. Is really difficult I think to, I think as a professional it’s really difficult to talk about and I would imagine that it’s awful for the patient because they are not getting any kind of guide then because it’s huge’ (cons2-003287)
Conclusion

• Strength of study:
  – rich data generated from the interviews
  – insights into participants’ experiences, views & feelings around prognostication
  – highlights lack of evidence to support practice

• Complexity & emotional labour involved in prognostication by HSPC team
Conclusion

• Weakness of study:
  – Small scale qualitative study employing a purposive sample from 3 HSPC teams.
  – Not possible to determine whether participants’ experiences & feelings are common amongst the wider population of HSPC team members
  – Not possible to determine whether other HSPC teams practice in the same way
Further Work

– Accurate prognostication & timely communication improve decision-making & outcomes for palliative patients at the end-of-life?
– Impact of prognostic information on patient outcomes?
– How and why are specific prognostic factors used?
– Inter-relationship between scientific & non-scientific factors?
– What factors enhance HSPC team members’ self-confidence & patients confidence?
Acknowledgements

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