Embracing inherent uncertainty in advanced illness

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Embracing inherent uncertainty in advanced illness

Hoping, coping and planning 'just in case'

"Medicine is a science of uncertainty and an art of probability' Osler

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Key messages

- Uncertainty characterises most advanced illnesses, so how to deal with it is an important challenge for patients, families, professionals and health services.
- We should stop searching for more accurate mortality risk assessment tools to trigger palliative care. Let's talk about what we do know, enable people to live with uncertainty, and plan for what might happen as a person's health declines.
- Uncertainty is an opportunity to improve care. Acknowledging and addressing it supports people living with advanced conditions in person-centred ways and is the basis of effective shared decision-making about treatment and care options.

Everyone dies, but uncertainty about how and when is inevitable.[1] Advances in science and technology are challenging that view.[2] Uncertainty may even be seen as an 'enemy' to be constrained by medical science. Tools providing a reliable 'prognosis' for people with specific health conditions abound and assert that meaningful choices are based on robust evidence of mortality risk. However, evidence of reliability and validity at an individual level is lacking.[3] Uncertainty is a powerful driving force behind fears of future debility, loss of control, and either inadequate or excessive health care.[1 4 5] The perception that uncertainty is an insurmountable challenge and a barrier to appropriate person-centred care towards the end of life is questionable. Uncertainty may in fact be more 'friend than foe'. An unpredictable but evident risk of deteriorating and dying constitutes a key trigger for care planning. It offers a prime opportunity to accept and manage the inherent uncertainties of living and dying with progressive, advanced conditions.

Uncertainty as a challenge for people living with diverse advanced conditions

Uncertainty is complex, multidimensional and variable. It may relate to ambiguity about changing circumstances and roles associated with declining health, loss of control and autonomy, and difficulties navigating the complexities of treatments or care systems. People have a poor understanding of the underlying causes, severity and future course of many long-term conditions. Many struggle to make sense of events and experiences, to anticipate likely outcomes, and have difficulty summoning the resources they need to cope with them. This reduces their capacity for self-management and puts them at risk of anxiety and depression.

Professionals need to manage uncertainty actively, coordinate care and help people to sustain their identity as a 'person'.[6 7] When the experiences of people with different advanced conditions were compared, contrasting illness narratives and perceptions of uncertainty emerged among patients, carers and professionals.[8]

People with progressive cancer had a widely-understood and anticipated illness trajectory starting with hope for recovery alongside fear of dying, followed by adapting to life with treatment, and then a final phase of planning for death.[9 10] However, people with advanced heart or respiratory disease focused on coping and adapting to the limitations and frustrations of daily life between unpredictable exacerbations, while hoping not to get worse and not contemplating dying.[11-13] Living, dying and caring in advanced liver disease was dominated by persistent and universally shared uncertainty that left people struggling to adjust or plan ahead and meant that most of them died in hospital with illness-related, acute complications.[14] Having a life-limiting, neurological illness or dementia meant that people faced an overwhelming diagnosis followed by a long and variable illness journey complicated by progressive disability, cognitive impairment, personality changes and communication problems.[15 16] People's experiences of sudden, severe acute brain injury (for example in stroke disease or after trauma) were a roller-coaster of uncertain outcomes, complex treatment decisions and fears of imminent death or prolonged, devastating disability.[9 17] Frail older people were more afraid of developing dementia and further loss of independence than death itself. They had a protracted but unpredictable journey of neither living a normal life nor imminently dying.[8 18] Some had a relatively sudden and 'unexpected' final deterioration.[19] Increasing numbers of people are living with not one but multiple advanced illnesses causing them to have a highly unpredictable pattern of declining health.[20] Many of these people saw themselves as 'getting older' rather than being seriously ill, purposely chose not to think too far ahead, and saw no role for 'palliative and end-of-life' care in helping them manage daily life.[21 22]

A degree of uncertainty can have benefits too and may indeed provide a way for people to live as well as possible with advanced illnesses. Disavowal (choosing to live in the present) provides a distinct coping strategy where people understand the threat to their life situations but seek hope through positively reconstructing this threat so as to avoid keeping it at the forefront of their minds.[23]

Uncertainty as a challenge for healthcare professionals and policy makers

For professionals everywhere, uncertainty has long been cited as a major barrier to identifying when treatment goals should be reviewed and the focus of care shifted towards prioritising quality of life and a comfortable death.[24-26] Treatment advances, public expectations, fear of litigation, and a plethora of evidence-based guidelines combine with established beliefs about professional roles responsibilities and values, to make 'changing gear' and accepting the reality of death and dying challenging for professionals.[27] Primary care teams face uncertainty due to perceived limitations in disease-specific expertise, difficulties with judging prognosis if people do not have cancer, a lack of clarity about role boundaries across care settings, and conflicting information about the benefits of further treatments.[28-33] In addition, the relatively predictable illness trajectory associated with progressive cancer retains its influence on policy and practice even though it does not transfer well to people with other illnesses.[34-36] The evident diversity and variability of people's experiences of deteriorating health and dying belie attempts to specify what constitutes a 'good' death. We can clarify some core principles but need to adapt our goals and expectations in line with people's changing circumstances and evolving priorities.

A widely adopted strategy for addressing prognostic uncertainty in advancing illness involves making predictions about when a person is likely to die so that 'end-of-life' care can be started. However, clinician estimates of prognosis are notoriously unreliable in the months before death.[37] Despite this, more recent iterations of the well-known 'Surprise question' instruct clinicians to identify people who might die within a year instead of using it, as originally intended, to support broader judgments about a risk of deteriorating and dying.[35 38 39] Strenuous efforts to develop more robust mortality risk scores and tools have not achieved this goal either.[1] Formulating temporal prognostic judgments for individuals remains an inexact science in all diseases and is nigh on impossible when people have multiple advanced conditions.[3 40 41] Professionals and policy-makers continue to differ in their interpretation and definition of 'end-of-life' and the time period it signifies. Most have adopted the last year of life as a working definition, although the recent NHS England action plan acknowledged that for some people 'end-of-life' care refers to the last few years of life, whereas for others this could be a matter of months, weeks, days or hours.[38 42-44] This is consistent with the World Health Organisation definition of palliative care which focuses on improving the quality of life of people living with life-threatening illnesses and their families at all stages of their illness journey.[45]

In the USA, advance care planning had its roots in an imperative to reduce medicalisation of dying and promote individual autonomy. Advance care planning does not control inherent uncertainty and is more effective when the main focus is preparing people for shared decision-making in the future.[46 47] Respect for autonomy and preservation of personal choice when dying have become established professional and service responsibilities in some countries. However, emphasising choice above other considerations can be inequitable or cause unintended harm if we do not listen to people's evolving ideas and personal stories and then regularly review the available options as their health, situation and priorities change.[2 5 48 49] People do welcome opportunities to have conversations with professionals about their health and care in the future, but will struggle if they are expected to participate in making explicit advance care plans for situations they cannot relate to or about unknown future circumstances.[50] Some patients became more distressed when given clear prognostic information about limited disease reversibility when their fears about how to handle an uncertain future were not addressed.[51] People living with cancer had difficulty reconciling hope and realism when faced with unequivocal prognostic information that made them focus too explicitly on their death.[52 53] Calls for more 'realistic' medicine aim to reduce costly and burdensome interventions that are of low value and not in line with people's preferences.[54] This depends on professionals, people living with advanced illnesses and the wider community developing new ways of exchanging knowledge, perspectives and information and embracing a degree of uncertainty.[55-57]

Delivering patient-centred care in the context of uncertainty

Uncertainty presents major challenges for people living with advanced illnesses and for the professionals who are caring for them. If signs of deteriorating health are identified in timely ways, uncertainty actually offers valuable opportunities for the kind of care planning conversations that explore people's concerns, wishes and goals in the short and longer term. Effective and sensitive ways of broaching unpredictable decline and a risk of dying should be adopted by professionals alongside public campaigns that promote more open dialogue about what matters to people whose health is deteriorating. A gradual approach to increasing prognostic awareness is of proven benefit in advanced cancer.[53] Observational evidence of doctor-patient communication shows that hypothetical talk about what might happen 'if the person were less well' is particularly effective in engaging people in discussions about challenging topics. Likewise, linking hopes with concerns about possible deterioration helps to open a supportive dialogue about the future.[58 59] Promoting the idea of 'hoping for the best, but preparing just in case' can enable people to become active and informed decision-makers in their ongoing care but without causing undue distress.[60 61] Smith suggests talking about what people would find helpful as they manage the effects of uncertainty on their lives and begin to think about what might happen in future.[40] Responding directly to people's individual needs and priorities fosters a positive approach to care. This lets us integrate supportive and palliative care with appropriate disease-modifying treatments while also making plans with patients and carers for managing changing situations that are shared among professionals and services. Glare defined 'prognostication' broadly as encompassing science and clinician judgement in a person-centred way.[62] It is time to make that a reality in the way we approach care planning about the future.[63]

Conclusion

We should be supporting people to live as well as they can with advanced illnesses, rather than seeking to identify with certainty when a person has entered their dying phase.[45] Uncertainty offers a timely trigger for initiating dynamic conversations with people that explore their concerns, values and priorities and inform shared decision-making about their current and future care. People with a new diagnosis of any life-limiting condition or who have deteriorating health due to multiple illnesses and indicators like an unplanned hospital admission or increasing care needs can all benefit. These conversations should not focus exclusively on breaking bad news about approaching the 'end of life' or only be about clinically driven priorities such as cardiopulmonary resuscitation status. They could relate to diverse individual worries about hospital or care home admission, what to do if a carer becomes ill, support for family members, important future events or potential loss of capacity.[64] (see Box 1) Ultimately, care planning about the future must help people play active and informed roles in determining the quantity and quality of their remaining time. Widespread adoption of person-centred care planning discussions requires professionals and policy-makers to concentrate on promoting and engaging in conversations about the inherent uncertainties of deteriorating health and dying as a normal aspect of people's lives.

CONTRIBUTORS AND SOURCES: We have drawn on a synthesis of over 1000 in-depth serial interviews with people who had diverse life-limiting conditions and their carers from studies carried out in the last 15 years by our research group. We have integrated these data with a review of the wider literature concerning uncertainty and care planning in advanced illness, and recent policy documents and reports about palliative and end-of-life care. The authors comprise a carer with extensive experience of representing service users, a social scientist, a general practitioner and a palliative medicine consultant. We wish to challenge the common perception that uncertainty in progressive disease is an unsurmountable challenge for patients, carers and professionals and reframe it as an opportunity to offer person-centred care.

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Box 1: Talking about deteriorating health and uncertainty

- Ask about what the person knows, expects and wants to know; involve people who are close to them.
  - *When someone comes into/ out of hospital, we make a time to talk about what is happening and what might happen next…*
    Is there a family member or a friend we should speak to as well?
  - *Can you tell me what you know about your health problems….?*
  - *Do you have any thoughts or worries about what might happen that we can talk about?*
- Talk about the illnesses; explain what the symptoms mean; and share information about what might happen linked to their understanding.
  - *If you did get more unwell again, it is possible that you might need treatment with….*
  - *I hope you will not need to go to hospital, but I am worried that at some point… It might be a good idea to talk about that now…*
- Ask about the things that matter to this person now and in the future.
  - *What things are important to you that we should know about?*
- Talk about what they think would help with these things; then discuss possible options and make plans for the future.
  - *What would be the best way for us to help you stay at home?*
  - *Can we talk about how we might cope with not knowing exactly what will happen or when?*
  - *It is good to talk about what to do and how to get help if you are more unwell …*
- Seek advice or a second opinion if the person or their situation is complex.
- Most conversations about care in the future happen over time and need revisited if things change.