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Different Experiences and Goals in Different Advanced Diseases

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Original Article

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Abstract

Context. Quality care for people living with life-limiting illnesses is a global priority. A detailed understanding of the varied experiences of people living and dying with different conditions and their family and professional caregivers should help policymakers and clinicians design and deliver more appropriate and person-centered care.

Objectives. To understand how patients with different advanced conditions and their family and professional caregivers perceive their deteriorating health and the services they need.

Methods. We used a narrative framework to synthesize eight methodologically comparable, longitudinal, multi-perspective, interview studies. We compared the end-of-life experiences of people dying from cancer (lung, glioma and colorectal cancer), organ failure (heart failure, chronic obstructive pulmonary disease and liver failure) and physical frailty and those of their family and professional caregivers in socioeconomically and ethnically diverse populations in Scotland.

Results. The dataset comprised 828 in-depth interviews with 156 patients, 114 family caregivers and 170 health professionals. Narratives about cancer typically had a clear beginning, middle and an anticipated end. Cancer patients gave a well-rehearsed account of their illness, hoping for recovery alongside fear of dying. In contrast, people with organ failure and their family caregivers struggled to pinpoint when their illness began, or to speak openly about death, hoping instead to avoid further deterioration. Frail older people tended to be frustrated by their progressive loss of independence, fearing dementia or nursing home admission more than dying.

Conclusion. These contrasting illness narratives affect and shape the experiences, thoughts and fears of patients and their carers in the last months of life. 'Palliative care' offered

by generalists or specialists should be provided more flexibly and equitably, responding to the varied concerns and needs of people with different advanced conditions.

Key Words: cancer, organ failure, frailty, serial interviews, qualitative longitudinal research, palliative care, end-of-life care, illness trajectories

Running head: Different Experiences with Different Advanced Diseases

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AU: DO YOU NEED PERMISSION FOR FIGURE 1?

Introduction

Quality care for people living with life-limiting illnesses is a global priority. Extending a palliative care approach to people with all advanced chronic conditions is a major challenge, particularly to those with non-cancer illnesses who are relatively under-served (1). Although early specialist palliative care can improve patient experiences and outcomes in parallel with oncology treatments (2), palliative care is still strongly associated with cancer and “preparing to die” in the minds of patients, family caregivers and professionals. A detailed understanding of the varied experiences of people dying with different conditions and their family and professional caregivers can help policymakers and clinicians design and deliver appropriate and person-centred services (3, 4). This is particularly important at a time when new specialist and generalist models for sustainable palliative care are being developed and reviewed globally in response to increasing demographic needs (2, 5, 6).

Many people formulate personalized narrative accounts in the face of life-threatening conditions in order to help them make sense of events and reconstruct their identity or sense of self (7). It is important for clinicians to gain “narrative competence,” so as to be able to hear and respond to patients’ histories (8). It can be helpful to draw on narrative methods to understand the biographical disruption that can accompany advanced illness from beginning to end (9-11). Over the last decade, three typical patterns of functional decline in the last phase of life have been described and widely accepted (12). These trajectories include acute decline (typically aggressive cancers), fluctuating deterioration (typically organ failure) and gradual decline (usually frailty or dementia), as illustrated in Fig. 1 (13). Physical changes are usually accompanied by psychological, social and existential fluctuations in the well-being of patients themselves, and also in their family caregivers (14, 15). We expected that experiences might

differ significantly among these proposed patient groups. We thus sought to compare and contrast how patients with different advanced conditions, and their family and professional caregivers, perceived their deteriorating health, to gain insights into how best to provide effective, person-centred care for people living with these three different patterns of decline.

Methods

Study Design

In-depth analysis of data from comparable studies can generate unique insights into complex issues that are important in developing patient-centred health care (16). We synthesized data from eight qualitative, longitudinal studies carried out by the authors over the past ten years. The studies were all with patients nearing the end of life, their family caregivers and key professionals, and were conducted using the same methodology, namely serial in-depth interviews using a narrative approach (17, 18). Three studies explored experiences of cancer – lung, glioma and colorectal.(19-21) Three were with people with organ failure – heart failure, chronic obstructive pulmonary disease (COPD) and liver failure (22-24). One study was of older people with frailty (unpublished PhD thesis) and one with South Asian participants representing all three trajectories (25). In each study, we had used purposive sampling to gain a broad range of perspectives encompassing age, gender, deprivation and social diversity, as well as clinical indicators of advanced illness in each patient group. All the patients were considered to be at risk of dying within the next 12 months by the clinicians who helped enroll them into the studies. We had used qualitative, longitudinal multi-perspective interviews to explore the complex and dynamic experiences in the last years of life (17, 18). The patients had been interviewed up to four times over 12-18 months; they had nominated their key family caregivers and, in some

cases, the professionals who knew them best, for interview. The interview transcripts generated in all the studies were previously analyzed with the support of NVivo and were available for secondary analysis. Ethical and institutional approvals had been gained for each study.

Analysis

We used Riessman's model of thematic narrative analysis, which focuses on what is said by participants, rather than how it is said (26). While maintaining the integrity of the narratives, we explored the themes emerging from the multiple illness accounts in order to understand the evolution of attitudes to death and dying among the participants. Using a series of inductive and deductive steps, we used insights from the existing studies to initially develop an analysis framework based on three phases of an illness narrative – becoming ill, living with advanced illness, and dying – and the three archetypal trajectories of physical decline; namely cancer, organ failure and frailty (27, 28). A researcher involved in each study used the framework to review the data from their own study, and generated key themes, with illustrative quotations and a narrative summary. Data from patients with the different conditions in the South Asian study contributed to the relevant disease trajectory analysis, also offering an opportunity to explore potential cultural differences. Participants' narratives were initially synthesized by illness trajectory (i.e., cancer, organ failure or frailty) and we then compared the three phases of the illness narrative (i.e., becoming ill, living with advanced illness, and dying) across the three trajectories. The findings were iteratively discussed in dedicated analysis workshops and with the wider research teams. While the archetypal narratives described in each trajectory served as a potentially useful heuristic device enabling a general understanding of the type of narrative account being employed, we also searched for contrasting perspectives and individual variations in order to develop a nuanced appreciation of the data and the potential implications for services.

Results

The dataset comprised 828 in-depth interviews, with 156 patients, 114 family caregivers and 170 health professionals (Table 1). Patients ranged in age from 21 to 95 years. Many had multiple conditions. The findings are presented first by illness trajectory and then synthesized by phase of illness across the trajectories.

Cancer: “Am I Going to Die?”

The narratives related by patients with progressive cancer had a clear beginning, middle and end. The patients, their family caregivers, and professionals largely held a similar, shared account of the illness, cancer treatments, and likely progression, although this was less apparent in the South Asian study. (Table 2)

Becoming Ill. Patients and carers identified a clear start to their illness. Many remembered the exact date they realized they had cancer, although for some reaching a diagnosis was distressingly slow. The news shocked most people, as they were suddenly confronted with the possibility of dying. This fear was balanced with hope and an impetus to fight for recovery.

Living with Advanced Illness. People quickly moved into a “cancer world” dominated by hospital treatment regimens and clinic visits. Managing treatments and the difficulties of adjusting to life as a “cancer patient” caused uncertainty and often low mood. Some interpreted any symptoms as implying relapse. Patients and family caregivers valued ongoing support and continued to relate a dual narrative encompassing hope for recovery alongside fear of dying.

Dying. Relapse and further symptoms usually brought realization that dying was inevitable. This normally triggered increased input from primary care teams and referral for

specialist palliative care. Many people talked frankly about dying and were preparing for it emotionally and practically, although some found such openness too difficult and used disavowal to help them cope. Death was anticipated and well-managed for those able to discuss what was happening and plan ahead. Most patients expressed concerns about the family members they would leave behind.

Organ Failure: “I Know I Won’t Get Better but I Hope I Won’t Get Worse...”

In this group, patients, family caregivers, and professionals often held different views about how the illness would progress. Many patients struggled to say when their illness had started or to make meaningful connections between acute episodes of illness and their condition as a whole. (Table 3)

Becoming Ill. Patients and family caregivers looked back, often over decades, to find a beginning for their illness. Lack of understanding about the illness, its cause(s) or likely outcomes made explaining their condition to others difficult. Professional language, such as heart or liver failure or COPD, was rarely used. People described symptoms, but struggled to make connections with failing organ systems. Exceptions were people with advanced alcohol-related liver disease whose hospital specialists had told them unequivocally that they would die unless they stopped drinking, and an unusual and knowledgeable patient with COPD related to alpha-1-antitrypsin deficiency.

Living with Advanced Illness. Living with progressive organ failure was uncertain, chaotic and characterized by seemingly unrelated events. People experienced fluctuations in their health, uncertainties and setbacks, and most had to manage multiple medications and comorbidities. For many this was compounded by frustration, isolation and hopelessness as they

and their family caregivers coped with growing restrictions on daily activities, loss of family and/or societal roles, increasing dependence, and the emotional demands of a contracting world. Patients with heart failure struggled with changes in body image, and fears of choking to death. In alcohol-related liver disease, some battled with behavior change while others continued an inexorable decline. Many patients and family caregivers in this group were reluctant to contemplate death, preferring to “think positively about living with their condition” and resetting their “norm” to accommodate progressively disabling symptoms. Health professionals also expressed frustration as they watched patients deteriorate with increasing problems for which they had few therapeutic options and limited access to resources that could meet social and emotional needs.

Dying. Unlike health professionals, most patients with heart or respiratory failure and their family caregivers did not view the condition as fatal. Patients with all types of organ failure described severe, life-threatening exacerbations from which they had recovered. Between exacerbations, many people, especially those with advanced lung disease, considered themselves as just getting older or being “back to normal.” Few volunteered concerns about dying and this was not distinguished from normal, societal expectations of death.

Frailty: “This Isn’t the Real Me...”

Frail, older people, and their family caregivers and service providers all struggled to recall exactly when their health began to deteriorate. Patients focused on staying as well as possible and maintaining autonomy in the face of increasing dependence. They expressed frustration at their declining capacities. The inevitability of death was recognized only in abstract terms such that it did not feature strongly in these accounts until death was imminent. (Table 4)

Becoming Ill. Some patients and family carers did cite a fall or a specific illness, but for many there was no obvious diagnostic process or event. Apart from a patient with arthritis, most people lacked satisfactory explanations for their frailty. They spoke of their old age yet did not always perceive this as the sole cause of their declining health.

Living with Advanced Illness. Living with frailty was about coping and adapting, while trying to retain one's identity. Parameters changed, but were linked to past abilities or interests, such as becoming a person who now watches, rather than plays, tennis. People mostly experienced a gradual decline, although an acute event or illness could lead to a rapid final deterioration more typical of the cancer trajectory. Frail people expressed fears of being ignored, or of being imprisoned by loss of physical capacity. Many were more concerned about dementia or admission to a nursing care home than about dying.

Dying. People with frailty spoke of dying in terms of getting their affairs in order. Very few talked openly about their own death or expressed fears about the process. They had witnessed death among family and friends and viewed it as a normal aspect of aging. Professionals found it difficult to plan for something that could happen tomorrow or in the next year or two.

Phases of Illness Across Trajectories

Comparing the three sets of illness narratives, we found marked contrasts in the experiences and perceptions of the participants in terms of these three phases. These are summarized in Table 5.

Discussion

Summary

There were marked differences in the ways patients and family and professional carers experienced progressive cancer, organ failure and frailty. Through exploring the “beginnings, middles and ends” of their narratives, distinct patterns emerged from a large dataset. Patients with progressive cancer generally followed a well-understood and predictable trajectory, and shared understanding of this with their family and professionals. Most of these patients eventually reached an open acceptance that they were dying, which facilitated hospice and palliative care involvement with its explicit goal of achieving a planned, “good” death. Patients with organ failure and those with frailty and their family caregivers were much less aware of the causes and likely progression of their condition and seldom shared the same perspectives as their health professionals. Theirs were less coherent stories as they focused on maintaining “normality” through coping and adapting in the present. Death was a character in all these narratives, but the immediacy of his presence varied over the course of each illness and there were marked differences between conditions. Hospice and other specialist palliative care services were involved rarely, or late in the illness, and had little resonance for people with organ failure or frailty.

Comparison with Other Studies

Most previous serial studies have explored the experiences of patients following a specific trajectory, such as cancer or organ failure (29, 30). This study brings together data from a number of different archetypal trajectories to highlight differences and lessons for patient- and carer-centred care. We confirmed that between exacerbations, the gradually increasing disability of organ failure or frailty often becomes a way of life and a new “normal” (31) and that little

support is accessed from specialist palliative care services (32). By innovatively looking at people's perceptions of their journey from becoming ill to death and bereavement, we could understand more about the crucial difference in their attitudes to approaching death and palliative care.

Strengths and Limitations

Extensive data from our own studies were analyzed by the researchers involved in the original data collection, who thus brought their in-depth understanding of key themes and perspectives to the data synthesis, a methodological strength in qualitative analysis (16). We collated eight substantial studies using a theoretically informed analysis framework to explore and synthesize equivalent data from each study. This allowed us to hear the subtle nuances of patients' accounts and detect hidden narratives, such as that of cancer patients whose private fears of dying ran alongside hopes of survival. Attention was paid to ensuring the validity and trustworthiness of the study throughout the research process by strategies such as the research team consistently ensuring the methods and sampling were appropriate. The researchers were experienced, responsive, and well supported, and the original analysis was concurrent with data generation and theoretically aware (33).

Our studies were all from central Scotland. The majority of patients were white Scottish with a small number from the Scottish South Asian Sikh and Muslim populations. The findings may not be fully generalizable to other populations and cultures; however, the three trajectories described here are widely recognised internationally. Many of the patients had comorbidities, which may have affected the archetypal trajectories, but a dominant trajectory appeared to prevail in each patient group.

Conclusions

Sustainable services for all patients with advanced illnesses require integrated models where hospital specialists and primary care clinicians address supportive and palliative care needs, referring more complex situations for specialist palliative care (5, 34). Regardless of their diagnosis, patients and family caregivers wanted support to avoid crises and enable them to manage the ongoing uncertainties and restrictions of advancing illness or physical frailty while retaining as much “normality” as possible (35). The services provided by palliative care and hospice care are generally associated with imminent expected death, making their introduction difficult or even unacceptable for some patients, carers and professionals. The challenge for health systems is to learn from the experiences of delivering effective palliative care for patients dying with cancer, and develop new integrated approaches more appropriate to providing person-centred, supportive care for people living with the unpredictability of long-term conditions and general frailty associated with advancing age. If health care providers focus on reducing mortality rather than quality of life, patients’ goals may not be addressed towards the end of life (36).

Implications for Practice and Policy

Recognizing which people with advanced conditions are at risk of deteriorating and potentially dying and assessing their physical, psychological, social and spiritual needs is the first step in good end-of-life care. Anticipatory care planning, to avoid whatever crises that threaten independence and the retention of meaningful roles in family or society may be more relevant and acceptable for patients with nonmalignant illnesses than routine “advance care planning” for how they wish to die in the future (23). The fact that many people with organ

failure do not consider their condition as fatal is a “modifiable factor” that can be addressed when discussing goals of care. Increasing emphasis on community-based health care professionals providing personalized integrated, holistic care can make an important contribution to addressing the needs of people living with advanced conditions (37).

All professionals caring for people with life-limiting conditions need core generic skills to enable them to assess supportive care needs and judge the readiness of individual patients and families to participate in discussions about the future. In addition, promoting public narratives that encourage talking about end-of-life choices as a positive and helpful aspect of care for people with long-term conditions would prevent much unnecessary distress (<http://www.ihl.org/engage/initiatives/conversationproject/pages/conversationready.aspx>). This could facilitate clinicians, patients and family caregivers to engage with thinking about loss of capacity, nomination of a proxy decision maker or specific, individual concerns about future care goals, living arrangements or treatment and care options as their health deteriorates.

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References

1. Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: a consensus report from the Center to Advance Palliative Care. *J Palliat Med* 2011;14:17-23.
2. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363:733-742.
3. Kleinman A. Caregiving as moral experience. *Lancet* 2012;380:1550-1551.
4. Kleinman A. From illness as culture to caregiving as moral experience. *N Engl J Med* 2013;368:1376-1377.
5. Quill TE, Abernethy AP. Generalist plus specialist palliative care -- creating a more sustainable model. *N Engl J Med* 2013;368:1173-1175.
6. Department of Health. End of life care strategy: promoting high quality care for all adults at the end of life. London: Department of Health, 2008. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277.
7. Williams G. The genesis of chronic illness: narrative re-construction. *Sociol Health Illn.* 1984;6:175-200.

8. Charon R. Narrative medicine: Honoring the stories of illness. New York: Oxford University Press, 2008.
9. Kleinman A. The illness narratives: Suffering, healing & the human condition. New York: Basic Books, 1988.
10. Frank A. The wounded storyteller: Body, illness and ethics. Chicago, IL: University of Chicago Press, 1995.
11. Bury M. Chronic illness as biographical disruption. *Sociol Health Illn* 1982;4:167-82.
12. Lunney J, Lynn J, Foley D, Lipson S, Guralnik J. Patterns of functional decline at the end of life. *JAMA* 2003;289:2387-2392.
13. Murray SA, Sheikh A. Care for all at the end of life. *BMJ* 2008;336:958-959.
14. Murray SA, Kendall M, Grant E, et al. Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. *J Pain Symptom Manage* 2007;34:393-402.
15. Murray SA, Kendall M, Boyd K, et al. Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: secondary analysis of serial qualitative interviews. *BMJ* 2010;340:c2581.
16. Heaton J. Reworking qualitative data. London: Sage, 2004.
17. Kendall M, Murray SA, Carduff E, et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ* 2009;339:b4122.
18. Murray SA, Kendall M, Carduff E, et al. Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ* 2009;339:b3702.

19. Murray SA, Boyd K, Kendall M, et al. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002;325:929.
20. Cavers D, Hacking B, Erridge SE, et al. Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *CMAJ* 2012;184:E373-382.
21. Carduff E. Realising the potential: developing qualitative longitudinal methods for understanding the experience of metastatic colorectal cancer. Edinburgh: University of Edinburgh, 2012.
22. Boyd KJ, Murray SA, Kendall M, et al. Living with advanced heart failure: a prospective, community based study of patients and their carers. *Eur J Heart Fail* 2004;6:585-591.
23. Pinnock H, Kendall M, Murray SA, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ* 2011;342:d142.
24. Kimbell B, Kendall M, Boyd K, Murray SA. Living and dying with liver failure: a serial interview study. [abstract]. *BMJ Support Palliat Care* 2013;3:124.
25. Worth A, Irshad T, Bhopal R, et al. Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *BMJ* 2009;338:b183.
26. Riessman CK. Narrative methods for the human sciences. Thousand Oaks, CA: Sage Publications, Inc., 2008.
27. Irwin S, Winterton M. Qualitative secondary analysis in practice: an extended guide (with reference to concepts, contexts and knowledge claims). Swindon, UK: Economic & Social Research Council, 2011. Available at:

http://www.timescapes.leeds.ac.uk/assets/files/secondary_analysis/working%20papers/WP7-Nov-2011.pdf.

28. Punch KF. Introduction to social research - Quantitative & qualitative approaches. London: Sage, 2005.
29. Murtagh FE, Sheerin NS, Addington-Hall J, Higginson IJ. Trajectories of illness in stage 5 chronic kidney disease: a longitudinal study of patient symptoms and concerns in the last year of life. *Clin J Am Soc Nephrol* 2011;6:1580-1590.
30. Hansen L, Rosenkranz SJ, Vaccaro GM, Chang MF. Patients with hepatocellular carcinoma near the end of life: a longitudinal qualitative study of their illness experiences. *Cancer Nurs* 2014 Aug 13. [Epub ahead of print].
31. Giacomini M, DeJean D, Simeonov D, Smith A. Experiences of living and dying with COPD: a systematic review and synthesis of the qualitative empirical literature. *Ont Health Technol Assess Ser* 2012;12:1-47.
32. Dy S, Lynn J. Getting services right for those sick enough to die. *BMJ* 2007;334:511-513.
33. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. *Int J Qual Method* 2008;1:13-22.
34. Royal College of Physicians of London. Improving end-of-life care: professional development for physicians. London:Royal College of Physicians, 2012.
35. Buckingham S, Kendall M, Ferguson S, et al. HELPing older people with very severe chronic obstructive pulmonary disease (HELP-COPD): mixed-method feasibility pilot randomised controlled trial of a novel intervention. *NPJ Prim Care Respir Med*, in press. **AU: ANY UPDATE?**

36. Gawande A. Being mortal: Illness, medicine and what matters in the end. London, UK: Profile Books Ltd., 2014.
37. Kirschner N, Barr MS. Specialists/subspecialists and the patient-centered medical home. Chest 2010;137:200-204.

ACCEPTED MANUSCRIPT

Table 1. Summary of Study Participants and Interviews Included in the Synthesis of the Eight Studies

Study	Inclusion Criteria	No. of Patients Interviewed (who died)	Age of Patients (yrs)	No. of FC Interviewed	No. of HP Interviewed	No. of Patient Interviews	No. of FC Interviews (bereaved) ^a	No of HP Interviews	Total No. of Interviews	Data Capture Period (months)
Lung Cancer ¹⁹	Advanced disease	20 (8)	48-87	15	28	43	24(4)	40	107	12
Glioma ²⁰	From diagnosis	26 (14)	21-76	24	67	56	55(9)	67	178	12
Bowel cancer ²¹	Duke's stage D	16 (8)	48-80	8	0	36	19(3)	0	55	12
Heart failure ²²	Breathless at rest	20 (6)	57-92	12	18	50	29(3)	33	112	12
COPD ²³	MRC4-5	21 (11)	50-83	13	18	52	28(2)	35	115	18
Liver failure ²⁴ (Kimbell PhD, unpublished)	Advanced disease	15 (9)	34-84	11	11	32	21(3)	11	64	12
Frailty (Lloyd PhD, unpublished)	Frailty Scale – (Rockwood et al.)	13 (5)	75-91	13	8	33	35(3)	8	76	18-24
South Asian participants ²⁵	Life-limiting illness (Sikh or Muslim)	25 (6)	30-90	18	20	53	38 (4)	30	(92) 121	76-12
Eight studies		156 (67)	21-91	114	170	355	249 (31)	224	828	6-24

FC = family caregivers; HP = health professionals; COPD = chronic obstructive pulmonary disease.

^aThe number of caregiver interviews where the carer was bereaved is given in brackets

Table 2. Cancer Narratives***Becoming Ill***

Well what happened was I had retired in the February and after a few months I thought I'm losing an awful lot of weight... and I went to see the GP.... Ms. A, Lung cancer

It was on the 19th December. I was at work and my wife had a seizure, sitting there.... Husband of Ms. B, Glioma

I was scared when they told me when they said there was a tumour. It knocked me for six. I thought, O my God, I am going to die...Mr. C, Glioma

It really started just over 3, well eh 4 years ago, well with my bowel, passing blood (OK) Eh that turned out to be, the test was done eh various tests that they took, samples of the bowel they turned out to be cancerous...Mr. D, Colorectal cancer

Living with Advanced Illness

I honestly sometimes think there's nothing wrong with me.... Mr. E, Lung cancer

Well I think what we're trying to do is try and get back to a normal life as soon as possible... Mr. F, Glioma

Well I said to them 'don't tell him how long,' but they said if he asks any questions, they'll have to tell him. He never asked. Wife of Muslim patient Mr. G, Cancer

There's no point on dwelling on it. I mean you've basically been told there's nothing they can do at the moment (yeah) ... but my feeling is as long as it's controlled (yeah) if they can control it then I'm quite comfortable... Mr H., Colorectal cancer

We've accepted the fact that yeah that it's there and it won't go away em and I think that's the hardest hurdle is acceptance of that don't dwell on it, try and get on with your life as best you can round about it. Sister and carer of Mr. H, Colorectal cancer

It is nice to have a bit of a relationship before they are coming to the terminal stage of their illness. District nurse of Mr. I, Glioblastoma

Their contact with the hospital may go down to once every few months. So it is important that people in the community have a good idea as to what the current problems are, the current management, so they can continue with that. Consultant oncologist of Mr. J, Glioblastoma

Dying

The main thing is, how long am I going to live? Ms. K, Lung cancer

I've kind of made up my mind that it's better to be going than to live like this...Mr. L, Glioma

One of the great concerns I have is housecalls, where the only person who is able to speak English is the patient who is dying...the input to support the rest of the family is much more restricted. GP of Mr. M, Muslim patient with cancer

Well obviously if it becomes terminal, we'll obviously be in a position to help, you know, we really would become involved. We would normally get the local palliative team. GP of Mr. N, Glioblastoma

I had to get the doctor in a couple of times the next again week, more so for reassurance than anything else. Husband and carer of Ms. O, Colorectal cancer

ACCEPTED MANUSCRIPT

Table 3. Organ Failure Narratives

<p><i>Becoming Ill</i></p> <p><i>It's something to do with the fluid that's floating round my body...it's all connected somehow I think...Ms. P, Heart failure</i></p> <p><i>It's hard to say when it started. Maybe a couple of years ago. I mean this is the third time I have been jaundiced...Mr. Q, Liver failure</i></p> <p><i>It was quite a few years ago we first heard that he had slight damage to his liver. And obviously it was really worrying, but I think like [patient] I kind of sort of blocked it out, just, that it's not going to be that bad. And you never think it's going to get really serious. Partner and carer of Mr. Q, Liver failure</i></p> <p><i>How it started is anybody's guess...Mr. R, COPD</i></p> <p><i>He fell off a ladder about four years ago and broke his ribs, and then he got a chest infection... Daughter and carer of Mr. S, COPD</i></p> <p><i>Living with Advanced Illness</i></p> <p><i>It's one day on top and the next day back under again...Mr T., Heart failure</i></p> <p><i>It feels like I'm kind of stuck in limbo. I don't really know from one day to the next how I'm gonna feel, I can't go back to work because I don't know how I'm going to feel, and I don't really know what I'm supposed to be doing...Mrs. U, Liver failure</i></p> <p><i>I'm now thinking about my work side of things that if [patient]'s well, great, if she's not will we need care packages? Financially, how does that affect me? When does it affect me?(...) Do I work for another few months? Do I need to stop and sell and move into something smaller and so I can afford to get support? What finances are out there? Husband of Mrs. U, Liver failure</i></p> <p><i>Now I'm fine, but I had a bad time over Christmas. I got a chest infection at the beginning of December and it took me till February to shake it off. But no, I'm fine again now. Back to normal...Mr. V, COPD</i></p> <p><i>We are paddling downstream to Niagara. GP of Ms. W, Heart failure</i></p> <p><i>There isn't an obvious, you know, move-on place from us, you know? There are patients that we are confident are not going to get better and get out of hospital, but because we've known them so well and there isn't really another facility, you know hospice facility we've occasionally been able to access but not frequently, they tend to die with us, (...) but it is an acute busy medical hospital and it's not always the best place for these people to be looked after. Consultant hepatologist of Mr. X, Liver failure</i></p>

Dying

I know it won't get better, but I hope it won't get any worse... Ms. Y, Heart failure

As long as the damn thing just keeps working the way it is working I'll be quite happy...Mr. Z, Liver failure

He has been knocking on death's door a few times now...we really didn't think he would make it through the night, never mind go home. Hospital doctor of Mr. AA, COPD

Even the doctor said that it won't get any better. What I thought was actually I could stay on that same sort of level...Mr. BB, COPD

*I'm not a defeatist. I don't crack up. I might have a few tears sometimes with worry, but at the end of the day you've just got to face it and get on with it and hope for the best.
Mother and carer of Ms. CC, Liver failure*

Table 4. Frailty Narratives***Becoming Ill***

It was all due to an accident [story of a fall] but I've never really been the same you see...
Mr. DD

Well, they haven't got an answer for it, neither have I... Mr. EE

I said, "It's just old age" I said "and your heart's not working properly" Daughter and carer of Mrs. FF

Living with Advanced Illness

It's just a gradual deterioration, you can't expect anything else... Mr. GG

You get annoyed at yourself for not being able to do it. Ms. HH

Otherwise you get around it some way or another, you know?... Mr. II

Well I mean my mum before used to be able to just walk out the door or go and see people or go and see her friends, but now her life is really here sitting in the house and people coming in, you know, to see her. Daughter and carer of Mrs. JJ

Dying

I said "I'm going home" I said "you're no putting me into any [nursing] home." Mrs. KK

If you had no mind and a good body what would you do, you'd just go shuffling around wondering where you were, mind you you'd be quite happy doing that, but I wouldn't be happy doing that, I would rather be away than have that. Ms. LL

I want to be here [alive] for as long as possible. Ms. MM

I find, em preparing people for something that could happen tomorrow, but actually might not happen for a year or two you know so, it's quite difficult. GP of Mr. EE

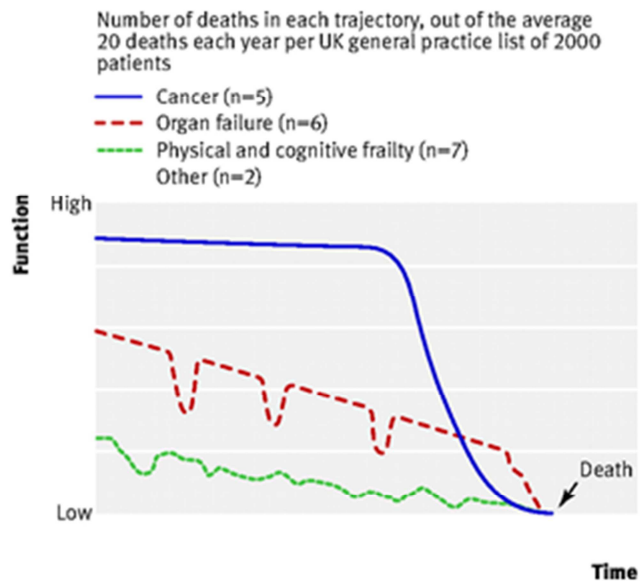
I think that a lot of [the people that I visit] that's what they're finding difficult, it's they don't know when it's going to end. I mean, that's....as well, it's an unexpected thing, they could go on...they could go on for years and years and years being as ill as they are, being, you know....just gradually getting worse, but it could last forever. Care assistant of Mrs. NN

He's always said oh don't put me into a nursing home, shoot me first. Daughter and carer of Mr. OO

Table 5. Typical Features of the Three Phases by Illness Trajectory and Patient Perception of Death

	Cancer	Organ Failure	Frailty
Becoming Ill	Usually a sudden, memorable event	Often no clear event, sometimes an illness episode	Often no clear event, just functional decline
<i>Death</i>	<i>Death as a real threat</i>	<i>Death rarely considered</i>	<i>Death not a concern</i>
Living with Advanced Illness	Busy with treatment, then dual narrative of hope for “normality” or even cure while fearing relapse	Uncertainty between exacerbations; trying to live “normally” with frustrating limitations	Normalizing and adapting; fear of dementia or nursing home admission
<i>Death</i>	<i>Death backstage with occasional appearances</i>	<i>Brushes with death during exacerbations</i>	<i>Worries about “fates worse than death”</i>
Dying	Hospice & palliative care involved; focus on a “good death”	Keeping going; hospice & palliative care limited and late	Slow or rapid final decline; hospice & palliative care rarely involved
<i>Death</i>	<i>Death center stage</i>	<i>Might die, but might not, so why discuss it?</i>	<i>Death will happen in due course</i>

Figure 1: The three main trajectories of decline at the end of life.



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