What’s the Story?

Dr. Marilyn Kendall, Primary Palliative Care Research Group
University of Edinburgh.

Cicely Saunders Institute, seminar series
22nd June 2016
The importance of stories

When you are in the middle of a story, it isn’t a story at all, but only a confusion; a dark roaring, a blindness. A wreckage of shattered glass and splintered wood; like a house in a whirlwind or a boat crushed by icebergs or swept over the rapids, and all aboard powerless to stop it. It’s only afterwards that it becomes anything like a story at all, when you are telling it, to yourself, or to someone else.

Margaret Attwood, Alias Grace 1999
Clinical Medicine

Storytelling is a fundamental part of clinical practice. It provides the mechanism by which doctors and patients communicate and understand the meaning of illness and possible ways of dealing with it.

Professor Sir Kenneth Calman

Stories and lives

Stories are what make our lives worth living....providing coherence amidst fragmentation and fracture
Richard Kearney On Stories 2002

We tell ourselves stories in order to live
Joan Didion 2006

I keep telling this story...always this story, because a story is a tightrope between two worlds
Jeanette Winterson, The Powerbook 2001

Hermes, messenger of the gods. Athenian red figure vase 5th Century BC
Three key features of narratives

• **Chronological**
  Life Course work since 1970s, importance of temporal qualities of social life, longitudinal studies
  Beginning, middle and end, linked by plot and change in circumstances, sense of causality, characters, arouses emotions

• **Meaningful**
  Key events picked out and arranged from perspective of those involved, provokes empathy

• **Social**
  Role of interviewer in shaping data, importance of audience for which data produced, draw on larger cultural narratives and values

**Narratives do things-shaped for a purpose**

• Jane Elliott 2005 Using Narrative in Social Research, Sage
Illness and stories

Narrative accounts expected in research into illness experience

Bury’s work (1982) on the “biographical disruption” of chronic illness

Charmaz’s (1983) work on the loss of self identity

Gareth Willam’s (1984) work on the need for “narrative reconstruction”

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)

Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social psychological and spiritual decline towards the end of life in lung cancer *J Pain Sympt Man* 2007; 34: 393-402

*His old friends won’t even take a cup of tea with me now I’ve got cancer”* Mrs LR.
“living with uncertainty”

“It was like a black hole”

“It’s much worse the second time round”

“You don’t know what is going to happen to you, fear is the worst thing”

“great nurses and departments they are so caring”
Multidimensional Trajectory of Organ failure

Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social psychological and spiritual decline towards the end of life in lung cancer J Pain Sympt Man 2007; 34: 393-402
Multidimensional trajectories in frail older persons

Well being

Distress

Change over time - years

Existential
Psychological
Social
Physical

Anna Lloyd PhD – Exploring the changing multidimensional experiences of frail older people towards the end of life, University of Edinburgh 2015
Fig 2 Trajectory for severe acute brain injury—patients present with a crisis that may result in early death (often after a decision to withdraw life sustaining treatments) or survival with a high degree of disability.
The patients’ story
Illness narratives from people living with severe COPD
Listening to the patients’ story of COPD

- 20 people with severe COPD
- In-depth interviews
- Every six months for 18 months

- Patient, family and professional carers

Listening to the patients’ story of COPD

The first COPD interview...

Marilyn’s field note

How can I do narrative research with people with no stories??

Listening to the patients’ story of COPD

Can you tell me how your illness started, and what has happened since then?

Must have been the beginning of the 80s I’d say, yes

Oh, it’s been a long time then?

Aye, I was in the hospital, then transferred to Glasgow for 4 months, and they didn’t know what it was, they thought it was pneumonia and och they didn’t know what it was but actually my wife was sent for twice, you know

Really, it was that bad?

I was in there for 4 months

Can you tell me how your illness started, and what has happened since then?

“Well, what happened was that I had been, I retired last February and, em, after a few months, I thought I’m losing an awful lot of weight but I thought, oh, well, it must be because I was sitting at a computer all day and I thought, oh well, it’s maybe because I’m getting more exercise and doing more out in the garden and doing different things and walking more and everything and I thought, oh well, I’m losing weight and I was quite happy about that and I, in actual fact, I was a bit overweight, I was 12 ½ stone at the time. But then, as the months went on, the weight started to melt off me and it was my friends and not so much my family because they were seeing quite a lot of me, so you don’t notice the same but the girls I’m still very friendly with from the office, em, they go out maybe every three months for dinner - they couldn’t get over how much weight I’d lost and then I saw a very good friend I hadn’t seen for a long time and she could... she got an awful shock, she said, when she saw me she said, you’re losing far too much weight.”

Listening to the patients’ story of COPD

What is a narrative?

Once upon a time…

… and then… and then...

Frank A.
The Wounded Storyteller: body, illness and ethics.
Chicago: University of Chicago Press, 1995

‘Restitution’; ‘Quest’; ‘Chaos’
A story with no beginning…

“I’ve had it forever”

How it started is anybody’s guess; there is no way of knowing. … so it has always been my belief that something happened in my younger years that started the damage

“I can’t find a beginning, so I’ll pick on a milestone”

About 18 months ago. It started off as a chest infection which I couldn’t get rid of.

“I can’t say ‘when’, so I’ll tell you ‘how’”

They blame smoking but … I spent years down in the mines so I swallowed a lot of stoor that doesn’t help any of us

I had a major op in the Infirmary in, 1985 was it? No, no, 94, 93. I had an abscess on the bowel. They thought I had cancer. I was worried eh.

… a middle that’s a way of life…

“It’s just old age…”

“I’m all right if I sit still. It’s all just part of getting older I suppose” [T03.1]

“I’m only ill with exacerbations…”

“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 Feb to shake it off. But no, I’m fine again now. Back to normal” [T01.1]

People like Mr X who doesn’t really bother us that much, we really only see him when he’s not well. [F08:GP]

... an end that is unpredictable...

“They’ don’t know when I’m going to die”

“It wouldn’t have surprised me if she had maybe died before now but on the other hand it is very difficult to know how long she might carry on”

[LO5 GP]

“They’ don’t know when I’m going to die”

“...he has been knocking on death’s door a few times now. I think the last time he came into the Royal we really didn’t think he was going to make it through the night, never mind go home”

[L06.1 Hospital doctor]

“I don’t know when I’m going to die”

“So, I’ll come and see you again in about 6m time, see if anything has changed, what’s going on [LO5.1] “If I am still alive in 6 months’ time”

“I don’t know when I’m going to die”

“I hope you will be, do you think you might not be?”

[L05.1] “I don’t know”

“...we are all going to die aren’t we? But it is a case of picking the time and place [to discuss it]”

[LO6.1 Hospital doctor]

“Very occasionally I’ll bring it [death] up but no...I don’t think generally they think they are going to die of that, of COPD”

[LO5 nurse]

... and unlooked for...

COPD: a lifelong story… losing the plot?

“I’m all right if I sit still. It’s all just part of getting older I suppose” [T03.1]
“The Gay Gordon” (by Scotland’s Ceilidh Band)
DVORAK – “Two Waltzes, Op. 54” (by Musicians from Marlboro)
Cancer – Am I going to die?

Beginning
• Diagnosis often rapid although sometimes distressingly slow
• People suddenly confronted with the possibility of dying

Middle
• People moving into a cancer world
• Managing treatments and difficulties adjusting to life
• Sometimes dual narratives encompassing hope for recovery alongside fear of dying

End
• Dying inevitable
• Triggering input from primary care
Organ Failure – “I know I won’t get better but I hope I won’t get worse”

Beginning
• Patients, family caregivers and professionals often held different views about how their illness would progress
• Many patients struggle to say when their illnesses started or to make meaningful connections between acute episodes and their condition as a whole

Middle
• Chaotic seemingly unrelated events
• Frustration, isolation, hopelessness

End
• Few concerned about dying
• Described previous exacerbations
Frailty – “This isn’t the real me”

Beginning
• Patients, carers and service providers all struggled to recall when their health began to deteriorate

Middle
• People focussing on staying well and maintaining autonomy
• Frustrated as decline capacitated

End
• Viewed death as normal aspect of ageing
## Box 4: Typical features of the three phases by illness trajectory

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<td>Often no clear event, just functional decline</td>
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<td>Busy with treatment, then dual narrative of hope for ‘normality’ or even cure while fearing relapse</td>
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<td>Slow or rapid final decline; hospice &amp; palliative care rarely involved</td>
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Box 4: Typical features of the three phases by illness trajectory and patient perception of death

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<td>Death rarely considered</td>
<td>Death not a concern</td>
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<td><strong>Death</strong></td>
<td>Death backstage with occasional appearances</td>
<td>Brushes with death during exacerbations</td>
<td>Worries about “fates worse than death”</td>
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<td><strong>Death</strong></td>
<td>Death centre stage</td>
<td>Might die, but might not, so why discuss it?</td>
<td>Death will happen in due course</td>
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End of life care should help you to live as well as possible until you die, and to die with dignity. The people providing your care should ask you about your wishes and preferences, and take these into account as they work with you to plan your care. They should also support your family, carers or other people who are important to you.

People who are approaching the end of their life are entitled to high-quality care, wherever they're being cared for. Good end of life care is tailored to the person who needs it. You and the people close to you should be at the centre of decisions about your care. NHS Choices
Dancing to a different tune: living and dying with cancer, organ failure and physical frailty

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Paper currently in press with the Journal of Pain and Symptom Management

Website of the Primary Palliative Care Research Group: http://www.ed.ac.uk/usher/primary-palliative-care
Edinburgh!

death on fringe