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Real Talk facilitator manual

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Facilitator Manual

Third Edition - March 2019

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Engaging patients in end of life talk.

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SECTION ONE:

How to Use Real Talk Resources

Welcome to the Real Talk resources. Section One summarises the project's background and the contents of the Real Talk resources, explains things you need to be aware of when using Real Talk, and provides suggestions for how to work with the resources.

All enquiries about Real Talk communication skills resources please email: realtalk@lboro.ac.uk.

For questions relating to the broader topic of Conversation Analysis Research not covered here please email Professor Ruth Parry the VERDIS project leader/Principal Investigator: R.Parry@lboro.ac.uk.

WHAT IS REAL TALK?

Real Talk comprises resources for teaching communication skills relevant to palliative and end of life care. One component of Real Talk is a set of video clips from recordings of real-life practice. These video clips are only to be used in face-to-face training sessions with health and social care staff and trainees. Participants in the video clips used in Real Talk consented to them being played within training only where this is UK-based. Real Talk resources are available free of charge to registered trainers in the NHS, organisations that work with the NHS such as hospices, and HEIs. Trainers do not have to attend training in order to use the resources, but training can be helpful. Real Talk 'train the trainer' events carry a charge, contact the Real Talk team to discuss a bespoke event for your organisation. Real Talk is designed to complement, rather than replace existing forms of training.

Real Talk has been developed as part of a research programme, and aims to enhance the quality and effectiveness of evidence-based communication skills training in the area of end of life care. The research programme is called VERDIS, which refers to video-based research and training on supportive and end of life care interactions. The research approach we use is called Conversation Analysis. VERDIS has been supported by Loughborough University, the University of Nottingham, and grant funding from The Health Foundation and the NIHR.

OVERALL PERSPECTIVE ON COMMUNICATION

Any task that gets done through communication, be it asking for information, or encouraging someone to talk about their own dying and death, can be done in a variety of ways. Each of the different ways will have its pros and cons. This understanding recognises that there is never (or rarely) only one optimal way of doing a healthcare communication task or dealing with a

communication problem. Instead, for any particular set of circumstances, some ways will be more appropriate and effective than others.

Real Talk is designed to help trainees examine various communication tasks and problems, help them consider different ways of handling these, and the various pros and cons of different ways of handling them.

The conversation analytic perspective focuses on what people do, attempt, and accomplish through their communicative actions. It focuses on what is observable and evident in how people communicate, not on under-the-surface matters like intentions and motivations (this does not mean we don't have intentions and motivations, it is just that conversation analysis does not give us access to these). An important assumption in conversation analysis is that people do what they do for good reasons, which may not always be obvious without close analysis. This perspective provides a constructive way of working with recordings.

REAL TALK COMMUNICATION SKILLS RESOURCES

This version of Real Talk is the third. The Real Talk resources are housed in two sections of the www.realtalktraining.co.uk website:

1. An open access section that explains Real Talk, provides details for the case studies and relevant evidence-based learning points and literature. Each case study contains: a synopsis which provides background; a summary of the entire consultation – because the clips only cover small excerpts from it; a transcript of each clip; and learning points for facilitators based on evidence from conversation analytic research. We have provided all these materials into a manual that can be downloaded if required.

2. A secure login section in which the clips can be accessed. Registration for secure access is granted via the Real Talk team at Loughborough University. Application can be made via the online apply form on our website or by emailing realtalk@lboro.ac.uk.

Access is restricted because the video clips are recordings of consultations in which real patients, relatives and doctors are clearly recognisable. All participants gave their permission for their recordings to be used in teaching, but only with certain safeguards. Safeguards include password protection of electronic devices and internet pages containing the recordings and that they will do undertakings that only trainers registered with the project will use and play the recordings, so only for the purpose of preparing and delivering face-to-face training in the UK.

For more information regarding eligibility for access to the clip please look at the FAQ's section or email the team at realtalk@lboro.ac.uk.

WHAT REAL TALK CONTAINS

At its core are video clips from consultations recorded in the outpatient, inpatient and day therapy services of a UK Hospice and is divided into modules of learning.

Module One comprises Cases 1 – 4, which focus on 'broaching dying', i.e., how practitioners encourage talk about patients' own end of life and dying. As you may know, broaching dying is a necessary step towards making plans for the future and provides opportunities to address feelings and fears.

Module Two comprises Cases 5 and 6, which focus on when patients ask, and doctors respond to, a 'How long have I got?' type of question.

At the end of each consultation the patient was asked to complete a Care and Relational Empathy (CARE) questionnaire.

The patient's CARE questionnaire rating is given in the synopsis page for each case; it can be used to incorporate the patient's perspective within the training. A copy of the CARE questionnaire can be viewed/downloaded from the CARE measure website http://www.caremeasure.org/about.php

In each clip, there are other things going on besides 'broaching dying' or talking about life expectancy' – trainers can use clips to focus discussions on other topics including empathy, active listening, body language, expressing compassion, dealing with distress and uncertainty.

MODULE ONE: 'BROACHING DYING' CASES

Each case comprises multiple clips detailing progressive movement from initial hints or opportunities, to more direct talk about dying and about plans for the future.

Case One - Ian

Four clips.

Keywords: broaching dying, euthanasia, pain, mood, resuscitation, returning to something the patient has mentioned earlier, unpacking ambiguity, motor neurone disease, day therapy, advance care planning.

Case Two - Lynn

Four clips.

Keywords: broaching dying, breathlessness, low mood, fear, reluctance to talk about dying, returning to something the patient has said earlier, advance care planning, heart failure, long term cancer survivor, hospice outpatient.

Case Three - Sam

Five clips.

Keywords: broaching illness progression and dying, communication with relative present in the consultation, ventilator, reluctance to talk about dying, neurological condition, out patient.

Case Four - Eashan

Three clips.

Keywords: broaching dying, patient expectations, fear, communication with relative present in the consultation, returning to something patient has said earlier, preferred place of death, patient reluctance to talk about dying, advance care planning, advanced cancer, hospice outpatient, empathy.

MODULE TWO: 'HOW LONG HAVE I GOT?' CASES

Case Five - Lucy

One clip.

Keywords: difficult questions, life expectancy, imminent dying, uncertainty, empathy, pain, distress, desire to die, advanced cancer, hospice inpatient

Case Six - Curtis

One clip.

Keywords: difficult questions, life expectancy, uncertainty, advanced cancer, hospice inpatient

For each case we provide:

- A case synopsis which highlights key words, background details about the patient, and an overview of the consultation. This helps give context to the individual clips. Individual clips focus in on fairly short episodes, the synopsis gives the bigger picture.
- CARE questionnaire rating.
- Clip transcripts - simplified transcripts that can be printed out for use in training or shown via overhead projection.
- A set of teaching and learning points that draw specifically on the conversation analytic perspective to understanding communication. This is the research approach used in the VERDIS research programme from which Real Talk is built. Conversation analysis focuses on what is visible in interactions, and on what people do, attempt, and accomplish through their communicative actions. It assumes people do what they do for good reasons, and that there are various ways to accomplish any communicative task, each of which will have pros and cons. Trainers can use the resources without being trained in conversation analysis.
- A bibliography lists some introductory readings about the conversation analysis perspective, key papers and reports of conversation analytic research findings relevant to palliative care communication; and some background reading about palliative care communication in general. We have included electronic links to publications wherever possible.

Please email the Real Talk team if you want a publication and find you cannot access it realtalk@lboro.ac.uk

Real Talk Safeguards

Real Talk includes clips in which patients, relatives and practitioners are clearly visible and audible. This is because tone of voice, body movement and positioning and so on are all central components of communication. But it means that trainers using clips must be registered, must not play or allow access to the clips to anyone other than their trainees and themselves, and must apply essential safeguards:

SAFEGUARDS

- You must not copy or attempt to copy any video clips from the USB or download/record from the website in any way, in part or whole.
- Real Talk must only be used by trainers registered with the project team via Loughborough University.
- You may only play clips during training preparation and training delivery
- Before playing any clips to trainees you must ensure trainees are aware each of the following six points:
  - These materials include content that can be distressing; feel free to step out of the session if this is the case for you;
  - It is possible in your working or personal life that you could come across people you see in the video clips. Be aware that they are unlikely to know that you have seen them in this way;
  - Both during and after the session, please do not talk about any individual in personal or negative terms, and if you recognise them, please do not refer to them by their real name;
  - No one in the recordings is claiming that their practice is perfect, but the clips do include skills and actions that contribute to good practice;
  - You must not take any photographic images nor make audio or film recordings of the video clips when they are playing;
  - All the people you will see and hear gave their permission for the use of their recordings in training sessions - provided you abide by these safeguards.
- These safeguards are provided as a PowerPoint slide on the website and can be downloaded to embed in your teaching files.

WAYS OF WORKING WITH THE VIDEO CLIPS

Real Talk is designed to fit into and compliment your existing ways of training. You will need to spend some time familiarising yourself with the materials and planning how to use them. You can download all or part of the manual if this helps in your preparations. We have provided broad suggestions for using the clips, rather than detailed lesson plans, because ways the clips can be used are very diverse and flexible. We have provided examples of the ways clips can be used. As we build our evidence we are gaining insight into novel ways of using the clips and we will share this in the 'Blog' section and via twitter.

The following are some suggestions that may be useful in planning training using the resources. Also keep a look out on the 'Blog' section for more ideas and sharing of experiences.

INTRODUCING THE CLIP(S) IN CLASS

Before playing any video clips remember that you must cover the 'Safeguards' listed above. We encourage you to provide the trainees with the context of the clip by drawing on the information we have provided in the case synopses.

Because so much goes on even in small episodes of communication, you may opt to 'prime' trainees in advance about particular practices or skills they are going to see or that you specifically want them to look out for.

Tell trainees that on watching a clip they are likely to feel some practices are good, and some less good, and that you are going to work on unpicking precisely what is going on that leads to such impressions.

In using a conversation analytic perspective, we encourage trainees to focus on what they see and hear, not – in the initial discussion of clips at least – on patients' and doctors' intentions, motivations and feelings.

VIEWING AND DISCUSSING CLIPS

When working with the recordings, perhaps the easiest thing for a group to do is move rapidly into hypotheticals - how things could have been done differently, or into judgements – particularly critical ones regarding what the practitioner did or didn't do. We encourage you to avoid doing this. Instead, to maximise learning from the clips, we suggest you facilitate a "What I saw, what I heard" discussion before moving into discussion of what could be done differently. The suggested teaching and learning points we provide for each case are designed to support "What did you see?" and "What did you hear?" discussions. These points are designed to encourage analytic, descriptive and comparative thinking.

We request that you discourage trainees from making moral evaluations of the practitioners, patients, and their communicative actions – in part because this is unlikely to be pedagogically useful, and in part because any such evaluations would be based on very short clips that can

provide only a very incomplete picture of the whole consultation and practitioner/patient relationship.

Remember: Real Talk is not designed as a tool to criticise a practitioner's skill. Instead we encourage you to facilitate discussion regarding 'why something happened?' 'why that?' and 'why now?'

START AND STOP THE CLIP

A section of the clip can be played, then stopped to promote discussion, before the next part of a clip. This is particularly helpful with the longer clips. A 'stop and discuss' approach can help facilitate discussion or to allow for debate relating to a specific learning point.

MODIFIED ROLE PLAY

This technique involves stopping a clip at a crucial moment (such as just after a patient has mentioned something salient, or asked a particular question) and asking one or more members of the group (in turn) to role play what they would do next. This approach can be less nerve racking than conventional role play, also allowing to follow up role play with examination of what actually happened in the real world.

This technique can demonstrate there are multiple ways of working with difficult conversation topics and can help to allay concerns practitioners may have about 'doing it right or fear of 'getting something wrong'.

TRANSCRIPTS

We have provided transcripts for each clip, these can be printed out for use in training or shown via overhead projection. For example, a transcript can be provided before showing a clip to create discussion in pairs; what do trainees notice about language, turn taking, silences etc. This can help to prompt thought and engagement prior to showing a clip.

SUBTITLES

Video clips can be played with or without subtitles. This will depend on how you are asking trainees to work with the clips.

FACILITATOR NOTES

We have provided a 'facilitator crib sheet' for use with any of the video clips, it can be useful to have pre-pared notes relating to discussion topics, particularly if a group are slow in getting conversations started in class. The notes can be adapted to include your event learning outcomes.

EVALUATION OF TEACHING USING REAL TALK CLIPS

You may want to include feedback on using Real Talk in your training sessions. We have provided a word document with a few evaluation questions. We are happy for you to use/amend these questions as part of your own evaluation of training. We would be happy for to receive any information you collect regarding evaluation of using real talk in your training. This can be emailed to the Real Talk team realtalk@lboro.ac.uk.

Facilitator check list for using Real Talk video clips

Remember, there is no single right way to communicate in difficult situations, these resources may help us when considering the different ways of doing so and their pros and cons. The conversation analytic perspective focuses on what people do, attempt, and accomplish through their communicative actions, people do what they do for good reasons, not always obvious without close analysis. This is the focus for how you will use the video clips with your trainees.

To get the most out of using the video clips we suggest the following:

1. PLAN THE SESSION

Use the learning points for the case you are using to become familiar with how it is linked to evidence.

A transcript can be printed off for use in group work or you can show the transcript via overhead projection.

2. ENSURE SAFEGUARDS ARE EXPLAINED BEFORE SHOWING ANY VIDEO CLIPS

Download the PowerPoint slide we provide to embed in your own slides

3. PROVIDE BACKGROUND TO THE CASE YOU ARE USING

Introduce each clip, provide the trainees with the context of the clip by drawing on the information in the case synopses

You may opt to 'prime' trainees in advance about particular practices or skills they are going to see and hear, also adds authenticity as a way of studying good practice.

Model the Model:
Before showing a video clip, prompt trainees to consider;

- what did you see?
- what did you hear?

This provides the foundation for your discussions.

4. PLAYING THE VIDEO CLIPS

Play video clips with subtitles or without subtitles,

Focus on what did happen, in terms of processes, rather than what did not happen.
Keep focus of discussions on the helpful strategies, avoid negative critique of individuals.
Check focus of discussions is on the process of communication, navigating a way through the conversation. Remember, the conversation analytic perspective focuses on what people do, attempt, and accomplish through their communicative actions.

5. CONSIDER IMPACT OF EACH CLIP AND CHECK TRAINEE WELLBEING

Some trainees may find a clip distressing. This is particularly relevant due to the authentic nature of the video clips.

6. EVALUATION

Do you need to collect any information relating to trainees learning? If so, we have provided some questions that can be included in your evaluation of the session.

Real Talk Evaluation

Please consider the elements of this training event that involved the recordings made of actual consultations between a doctor and patient in a UK hospice, called the 'Real Talk resource'

1. **What did you think about the part/s of the event that involved working with the recordings? Please circle the response that bests fits your views**

   Not at all useful Somewhat useful Very useful

   If you wish, provide further details:

2. **Some people find seeing and hearing the recordings so emotionally difficult that it distracts from their learning. Did you find working with the recordings emotionally difficult?**

   Please circle the response that bests fits your views Yes No

   If yes, do you feel this hampered your learning? Yes No

   If you wish, provide further details:

3. **If you were to attend a similar training event in the future, would you want it to include work with recordings of actual healthcare consultations?**

   Please circle the response that bests fits your views Yes No

4. **If there are things you think could be better about the Real Talk resource please use this space to tell us**

CARE Patient Feedback Measure for

Anonymised code of recording here

Please write today's date here:

D D / M M / Y Y

Please rate the following statements about today's consultation.

Please mark the box like this ☑ with a ball point pen. If you change your mind just cross out your old response and make your new choice. Please answer every statement.

How good was the practitioner at...	Poor	Fair	Good	Very Good	Excellent	Does not apply
1) Making you feel at ease (introducing him/herself, explaining his/her position, being friendly and warm towards you, treating you with respect; not cold or abrupt)	☐	☐	☐	☐	☐	☐
2) Letting you tell your "story" (giving you time to fully describe your condition in your own words; not interrupting, rushing or diverting you)	☐	☐	☐	☐	☐	☐
3) Really listening (paying close attention to what you were saying; not looking at the notes or computer as you were talking)	☐	☐	☐	☐	☐	☐
4) Being interested in you as a whole person (asking/knowing relevant details about your life, your situation; not treating you as "just a number")	☐	☐	☐	☐	☐	☐
5) Fully understanding your concerns (communicating that he/she had accurately understood your concerns and anxieties; not overlooking or dismissing anything)	☐	☐	☐	☐	☐	☐
6) Showing care and compassion (seeming genuinely concerned, connecting with you on a human level; not being indifferent or "detached")	☐	☐	☐	☐	☐	☐
7) Being positive (having a positive approach and a positive attitude; being honest but not negative about your problems)	☐	☐	☐	☐	☐	☐
8) Explaining things clearly (fully answering your questions; explaining clearly, giving you adequate information; not being vague)	☐	☐	☐	☐	☐	☐
9) Helping you to take control (exploring with you what you can do to improve you health yourself; encouraging rather than "lecturing" you)	☐	☐	☐	☐	☐	☐
10) Making a plan of action with you (discussing the options, involving you in decisions as much as you want to be involved; not ignoring your views)	☐	☐	☐	☐	☒	☐

Comments: If you would like to add further comments on this consultation, please do so here.

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© CARE SW Mercer, Scottish Executive 2004: The CARE Measure was orginially developed by Dr Stewart Mercer and colleagues as part of a Health Service Research Fellowship funded by the Chief Scientist Office of the Scottish Executive (2000-2003).

Suggested reading and bibliography

About the conversation analysis approach to understanding communication

POPULAR SCIENCE TYPE BOOKS AND RECORDED TALKS

N J Enfield (2017) How We Talk: The Inner Workings of Conversation. Basic Books, New York

E H Stokoe (2018) Talk: The Science of Conversation. Robinson Little, Brown, UK

E H Stokoe Tedx Bermuda https://www.youtube.com/watch?v=MtOG5PK8xDA

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RESEARCH ABOUT PALLIATIVE CARE COMMUNICATION AND REFERENCES MENTIONED IN REAL TALK LEARNING POINTS

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Lutfey, K. and D. Maynard (1998). “Bad news in Oncology: how physician and patient talk about death and dying without using those words.” Social Psychology Quarterly 61(4): 321-341. http://bit.ly/LutfeyTalkAboutDying

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SECTION TWO:

Learning Modules

Module One - Broaching Dying

Real Talk Case One - Ian

CASE SYNOPSIS (Keywords, Background, Clips, Overview of consultation)

KEYWORDS

broaching dying, euthanasia, pain, mood, resuscitation, returning to something the patient has mentioned earlier, unpacking ambiguity, motor neurone disease, day therapy, advance care planning.

BACKGROUND

The patient, Ian, has motor neurone disease (MND), currently affecting his lower limbs and hands. He does not currently have neck weakness. He is able to walk with a wheeled frame. He attends hospice day therapy weekly. He has asked to see the doctor because of severe pain in his legs the previous night. The pain is mostly not related to his MND per se, but the MND has an impact on it.

The doctor has known the patient for some months, and she has seen him and his partner on several prior occasions.

After the recording, the doctor remarked on some relevant matters. These included that the patient's mood was much, much lower than usual for him, and that she was trying hard to make eye contact with him during the consultation. She commented on the uncomfortableness of the doctor's chair in that particular consultation room, and that whilst its height was suitable for working on the computer, it was higher than optimal for talking to the patient.

The consultation lasted approximately 1 hour and 10 minutes.

After the appointment, the patient rated this doctor as excellent on all ten dimensions of the CARE 'Care and Relational Empathy' questionnaire.

CLIPS

There are four clips: 51 seconds, 44 seconds, 1 minute 36 seconds and 4 minutes 34 seconds.

In the first clip, the patient, in the course of talking about the previous night's episode of severe pain, mentions feeling like 'throwing the towel in'.

In the second clip, the doctor explores what the patient means by this.

In the third clip, the doctor asks the patient a question about his feelings. In response, the patient talks about the recent death of another hospice patient with motor neurone disease. In this context, the doctor opens up opportunities for talk about Ian's own end of life by asking, 'Does it make you think about you?'

In the fourth clip, in the context of having to fill in a mortgage-related form about life expectancy, there is some talk about how long the patient may have left to live. The patient talks about what kind of disability would not be worth living with. He indirectly talks about euthanasia, and the doctor asks questions about this. They then move to talking about circumstances in which the patient would and would not want to be resuscitated.

OVERVIEW OF CONSULTATION

Pseudonyms for people present or referred to in the consultation:

- The patient is Ian.
- Nic is the patient's partner (who is not present at this consultation).
- Bill is a hospice patient with motor neurone disease (MND), who attended day care with Ian; Bill has recently died.

Approximate timings are given as hours:minutes:seconds and rounded up or down for simplicity.

00:00

The doctor discusses with the patient the cameras and his assent to recording. She then says: 'It's good that we can catch up'. Patient talks about his extremely bad night - with leg and heel pain. Doctor mainly listens and acknowledges.

03:50

Clip one (51 seconds) begins: the patient mentions 'throwing in the towel'.

Doctor acknowledges this but at this point does not pursue it further. Patient talks about having good days and bad days, then moves on to further detail his pain and the pills and patches he is on. He starts to talk about another concern - sleeping a lot in the day. The doctor mainly listens, acknowledges, and asks some brief questions.

07:50

The patient returns to the pain problem and reports not telling his partner everything because she has enough stress.

08:02

Clip two (44 seconds) begins: the doctor asks the patient about 'throwing the towel in'.

The patient says he does not know if it worth carrying on taking the pills, and that this is why he wants to see her today. The doctor says: 'You mentioned a feeling of throwing in the towel', and they discuss and clarify what he means. Having done so, the doctor asks about the location of the patient's pain.

08:30

The doctor asks the patient more about his leg pain. The patient gives a detailed description. The doctor mainly listens, acknowledges, and asks clarification questions. There is also some talk about prior abdominal surgery he had.

16:20

In the context of the patient referring to his legs as his main concern, the doctor says: 'Can I ask you about your mood as well?' The patient becomes tearful, and a lengthy discussion follows about loneliness, things getting on top of him, stress and its causes. The doctor asks about his relationship with his partner, he replies things are good, he also talks about his children and grandchildren.

23:30

Clip three (1 minute 36 seconds) begins: a question from the doctor elicits talk about another patient's death.

The doctor asks whether he feels anxious about things. In responding, he mentions the recent, unexpected death of a fellow patient 'Bill', and how that 'brought everything back home'. As the discussion progresses, the doctor asks: 'Did it make you think about you?' Ian confirms it did.

24:20

The patient then talks more about the suddenness and shock of Bill's death. The doctor asks if it has put him off coming to day therapy. The patient reports that the staff, who he likes, successfully encouraged him to keep coming. The patient raises 'happy pills', his and other's experiences of them, and whether if he stopped taking them, his mood would go down.

29:00

The doctor says that pain can be connected with mood, and a discussion of whether this is the case for this patient follows.

30:20

The doctor returns to the issue of mood. They talk about it; the patient says he is down today due to lack of sleep and pain. He talks about not wanting to discuss his mood and difficulties with his partner. The doctor listens, acknowledges, and asks some specific questions about his partner and how both she and the patient are feeling. The patient moves to talk about things he sometimes enjoys.

36:30

The doctor proposes a physical examination of the leg and abdomen, and this proceeds.

47:00

There is a discussion of possible medication side effects, and the doctor proposes talking to the patient's other doctor - who prescribed several of the medications. She says her

gut feeling is that some of the medicines need reducing, as they are not giving enough benefit and he is getting some side effects. The doctor proposes staying on the current medications for the next week, giving her time to discuss with the doctor who prescribed several of them.

48:40

The conversation moves to the patient's difficulties eating, and with bloating. Discussion of related medications follows.

55:00

The doctor writes out and gives the patient an instruction sheet relating to medications, which the patient reads. The doctor says, well, it's good to have time to chat, says 'thanks for sharing that', and 'we'll meet again next week'. The patient says 'Yeah. Sometimes it's nice to just chat to an individual'.

55:50

The doctor asks if there are other people the patient chats with. They talk about the counselling service which the patient has used, but he prefers to see the doctor.

59:20

The patient now raises a new support group he is involved in starting up, and they move on to talk about seeing people more severely affected and how he would feel about this. The patient then says he could get run over by a bus tomorrow, and comments that at least then the insurers would then pay off the mortgage. The doctor mainly listens, acknowledges, and asks brief questions.

1:00:20

The patient says that his insurance will not pay off his mortgage now, because he has answered no to the question on whether he is going to die in the next six months.

1:01:00

Clip four (4 minutes 34 seconds) begins: the conversation moves from life expectancy to euthanasia and resuscitation preferences.

The discussion moves to the patient's likely life expectancy, and he starts to talk about what kind of disability would be bearable, and at what stage it would be time to go. In doing so, he talks about when it would be 'better off having an injection and going to sleep'. Discussion about euthanasia and the patient's thoughts on this ensue. This further develops into discussion of his views and preferences on resuscitation, and to discussions about this with his partner. The patient says he would not want to be resuscitated at the point where

he has lost mobility, but says that if it were a heart attack, this would be different. The doctor goes on to ask questions about this.

1:05:00

The patient says that at the point he has a ventilator, he would not want resuscitation. The doctor asks clarification questions, and the patient then goes on to say he knows the muscles in his lungs are a bit weak. He goes on to talk about the fact he still smokes, his pleasure from doing so, and then moves to talk about a forthcoming holiday. The consultation ends with the doctor noting she will see the patient next week and that this would entail getting him 'set up for a good holiday'. Then patient stands and leaves the room.

IAN CLIP ONE TRANSCRIPT (51 SECONDS)

3 minutes 50 seconds into the consultation. The patient mentions 'throwing the towel in'.

Pat: It didn't seem that I could- couldn't settle my left leg down with the pains
Doc: Mm
Pat: and that and I tried every way of doing it. Now, I'm on all these pills and patches and everything else and you know, it's sometimes um I just feel like throwing the towel in and that
Doc: Mm
Pat: Because um t-t-today, some days I have- I do have me good days and I have me bad days, um but I get cramps in my fingers, and me muscles on me arms.

IAN CLIP TWO TRANSCRIPT (44 SECONDS)

8 minutes into the consultation. The doctor asks the patient about 'throwing the towel in'.

Pat: I d-d I don't know whether it's worth carrying on taking these pills, that's why I wanted to see you
Doc: Mm
Pat: and um
Doc: You mentioned about a feeling of throwing in the towel?
Pat: Yeah
Pat: Stop taking the pills and stuff like that. It's
Doc: Stop taking the pills? That's what you mean by that
Pat: Yeah, yeah
Doc: Okay.
Pat: and that because like I don't know if that'll make me worse
Doc: Mm
Pat: whether it'll make me better,
Doc: Mm
Pat: or feel better
Doc: Mm
Pat: Umm, some days I get so much pains
Doc: Is it always in this left leg or is it in other places?

IAN CLIP THREE TRANSCRIPT (1 MINUTE 36 SECONDS)

32 minutes 30 seconds into the consultation. A question from the doctor elicits talk about another patient's death.

Pat: Believe it or not it [seeing my grandchildren] bucks me up
Doc: Mm hm
Pat: It does buck me up
Doc: Mm
Pat: it um
Doc: Feel anx-
Pat: Yeah I suppose it does
Doc: Mm
Doc: Do you feel anxious about things Ian?
Pat: Erm.... tell you the truth, I never- right, it err, no I suppose I never, not for a while and um I think, when Bill died,
Doc: Mm
Pat: I think that brought everything back home you know?
Doc: Mm
Pat: And.... because it seems so unexpected as well
Doc: Mm
Pat: and that and... don't know....
Doc: Does it make you think about you?
Pat: Yeah it did at the time. A- Before all that I was like I thought well you're going to die one day you know, this that and the other, but now um I think I do think more of it now since Bill died because like I don't know what his situation or whatever that was before like, but he didn't seem poorly. Well to us in the day centre he didn't seem poorly.

IAN CLIP FOUR TRANSCRIPT (4 MINUTES 34 SECONDS)

1 hour and 1 minute into the consultation. The conversation moves from life expectancy to euthanasia and resuscitation preferences.

Pat: But in reality nobody knows how long you've got you know
Doc: Mm
Pat: I could have another two months left or I could have another two years
Doc: Mm
Pat: and nobody knows
Doc: No, it- it's more likely to be nearer the two years than the two months, but
Pat: Yeah well
Pat: Mm
Doc: More likely
Pat: Yeah. As long as I'm still pottering around or if I'm- Alright, I won't be still pottering around, but long as I'm still in the um- Basically I still be using my arms, I might be in- Well I probably will be in a wheelchair by then. And I've still got talk and that, I'll be happy with that. You know? I ain't got a problem with that. But, it's when you're just laying there like a vegetable and you can't do
Doc: Mm
Pat: nowt that is- I think that is the time to go
Doc: Do you?
Pat: Yeah because what good are you?
Doc: Mm
Pat: If you can't do nothing. You can't move
Doc: Mm
Pat: And if you lose your voice
Doc: Mm
Pat: If you're laying there as a vegetable, you've got no life
Doc: Mm
Pat: Better off having an injection and going to sleep
Pat: Whatever
Doc: Do you- are you someone who thinks about that much about euthanasia and
Pat: Erm
Doc: that sort of side of things?
Pat: Um if I get that- if I get really bad
Doc: Mm
Pat: Yeah I suppose. Y' know it um
Doc: Mm
Pat: And
Doc: Do you think about ending it yourself?
Pat: No no no I-
Doc: Mm
Pat: No
Pat: I don't get that- erm

Doc: Don't get that bad
Pat: No
Pat: No No
Doc: Okay
Pat: Um you know
Doc: But in terms of hypothetically if you were-
Pat: Hopefully
Pat: Well I said to Nick [his partner]
Doc: Mm
Pat: 'If I die or whatever, don't um don't resuscitate me'.
Doc: Mm
Pat: Cause if I- If my muscles in my lungs and whatever have packed up
Doc: Mm
Pat: it's a waste of time resuscitating me, you know,
Doc: Mm
Pat: you know it's just... make sure it's all in place.
Doc: And- is it in place?
Pat: Oh well, Nick said she would sort it out.
Doc: Okay.
Pat: Um
Doc: Okay so
Pat: She- she
Doc: So if something out of the blue were to happen and that was your way of going, that's how you'd want it to be.
Pat: Yeah
Pat: Because it's erm... you might only live for a couple of days afterwards
Doc: Mm
Pat: Or if you come back you might be a- vegetable
Doc: Mm, hm
Pat: I mean that's no life is it?
Doc: Mm
Pat: You know?
Doc: Mm
Pat: Yeah, so I said to Nick: 'If I'm just laying there in a bed you know laying there in bed as a vegetable or whatever
Doc: Mm
Pat: if I die I die and that's it. You just leave me.... You know, just put me to p-
Doc: Do you talk about that much with Nick?
Pat: Um, I did at the start
Doc: Mm
Pat: Urm, I said to her, 'Look, you know. This, that and the other.' The question was asked to me am I scared of dying and stuff like that.
Doc: Mm
Pat: Well yes and no really. Um yes I suppose everybody's scared of dying. I don't know. But, the way I look at it now. Everybody dies sometime or another. Right? Um, I would like to go in my sleep. I don't want to be laying there choking or in agony or whatever trying to breathe and then die. I would

rather like to go in my sleep. And, but I haven't spoken to Nick for a long while and then I think the subject come up a few weeks ago. When Bill died I think it come back up, and I said to her, 'Look, when I've gone, I've gone,'

Doc: Mm

Pat: 'That's it you know?'

Doc: Mm

Pat: I said unless it's a heart attack or something like that you know? It's different but I- you know, if, if I stop breathing and it's my lungs or if I'm there a vegetable, just leave me I said, because it's a waste of time you know, to me.' You know?

Doc: What do you mean by: 'if it's a heart attack it's different'?

Pat: If I got up now and had a heart attack

Doc: Mm

Pat: I know me lungs are still working, that's entirely different

Doc: Okay, so if you were to ha- it to happen now, you would want us to

Pat: Well if possible

Doc: see what we could do?

Pat: Yeah yeah

Doc: Okay

Pat: Um but if it was MND related, like once I'm on the machine. Well I haven't got one anyway.

Doc: Do you mean a breathing machine.

IAN - LEARNING POINTS FROM A CONVERSATION ANALYSIS PERSPECTIVE

There are four clips. In the first, within the course of talking about the previous night's episode of severe pain, Ian mentions feeling like 'throwing the towel in'. In the second clip, the doctor explores what he means by this. In the third, the doctor asks the patient a question about his feelings, and in response, the patient talks about the recent death of another hospice patient with motor neurone disease who has recently died, in this context, the doctor opens up opportunities for talk about Ian's own end of life by asking: 'Does it make you think about you?' In the fourth clip, in the context of having to fill in an insurance and mortgage form where there is a question about life expectancy, there is talk about how long Ian may have left to live. He talks about what kind of disability would not be worth living with. He indirectly talks about euthanasia, and the doctor asks questions about this. The talk evolves to discussion of circumstances in which Ian would not, and would, want to be resuscitated.

Small words can do important things. The doctor's 'Mm's' are what conversation analysts call 'continuers'. When we use them whilst another person is talking, continuers such as 'yes', 'mm hm', and 'uh huh' can tell that other person we are not going to come in (or 'take the floor'), so they encourage the other person to continue[1,2]. Continuers are supportive or 'aligning' actions by a person who is the recipient of another person's extended talk[3].

In clip two, we can notice that the doctor waits for a lull in the patient's talk before investigating what he might mean by 'throwing in the towel'. If she had immediately 'pounced on' what he said, the doctor could have been heard as more judgmental - treating what he said as something so problematic or serious that it needed very immediate investigation.

In clip three, as is commonly the case in the recordings from the VERDIS research upon which Real Talk is built, the doctor's question about the patient's feelings provides an opportunity space in which the patient moves towards talk that is more closely relevant to his own death than what he has been talking about before. We can see how, with the doctor's support: 'Does it make you think about you?' Ian gradually unpacks his allusive references (e.g. 'I think that brought everything home you know?') to more directly talking about his own dying. The VERDIS research team have written about ways healthcare practitioners can sensitively move towards talk about end of life[4,5].

In clip four, the doctor unpacks the patient's allusive or indirect reference 'Better off having an injection' in a particular way. She asks him if he is 'someone who thinks that much about euthanasia and that sort of side of things?' We can notice at least three things about what she asks and how she asks it;

1. By asking if he is someone who thinks about it, she implies that there are people who do think about this, and doing so to a degree normalises it. This helps neutralise the negative moral or personal evaluation that a question about euthanasia could carry.

2. By adding 'that sort of side of things', the doctor softens the starkness of the reference to euthanasia.

3. Her tone of voice implies an interested but not negative judgemental attitude – the doctors in the VERDIS recordings often use this tone of voice when asking or talking about contentious, and/or highly sensitive matters (see also, for instance, the Eashan Real Talk case).

The case illustrates that practitioners do a lot of 'active listening' – acknowledging what the patient says, encouraging them to continue talking, and waiting until the patient seems to come to the end of their topic or story before coming in and asking questions, raising new topics, or returning to earlier topics.

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Real Talk Case Two - Lynn

CASE SYNOPSIS (Keywords, Background, Clips, Overview of consultation)

KEYWORDS

broaching dying, breathlessness, low mood, fear, reluctance to talk about dying, returning to something the patient has said earlier, advance care planning, heart failure, long term cancer survivor, hospice outpatient.

BACKGROUND

The patient, Lynn, has various problems secondary to radiotherapy for lymphoma which first occurred fifty years previously. She has osteoporosis, bronchiectasis, heart failure, and a few months ago a fracture in her cervical spine left her unable to swallow. She has a portable oxygenator, and this is audible within the consultation. The doctor has seen the patient twice before, at home and at the clinic. Since he last saw her, she has had a severe infection, was admitted to hospital, and had a near death experience.

After the recording, the doctor remarked on some relevant matters: that within previous consultation with her, he had described the nature of an emergency care plan and had discussed some aspects of that with her.

The consultation lasted approximately 34 minutes.

After the consultation, the patient rated this doctor as excellent on all ten dimensions of the CARE 'Care and Relational Empathy' questionnaire.

CLIPS

There are four clips. The earlier ones involve initial questions from the doctor which the patient answers in ways that the doctor can then draw upon to get dying and advance care planning onto the surface of the conversation. In the later ones, the patient talks about some of the difficulties of talking about her imminent death, the doctor and patient do talk about end of life, and some planning is done.

OVERVIEW OF CONSULTATION

Pseudonyms for people present or referred to in the consultation:

- The patient is Lynn.
- Her husband is Michael.
- Her daughter is Nina.

- An observing medical student and a nurse are also present but take little or no part in the consultation itself.

Approximate timings are given as minutes:seconds and have been rounded or down for simplicity.

00:00

The patient talks to the doctor about when her lymphoma first occurred - she is 70 now, and lymphoma first started at 19.

00:15

The doctor mentions the cameras are up and running, then opens the consultation saying: 'It's been quite a while since we last met, what have you been up to?'

01:00

The patient reports she is experiencing more and more problems, slowly and insidiously getting worse. She talks about her breathing being the worst, and about a recent associated hospital admission. She says her biggest problem is her mobility. She talks further about her heart and lung problems and treatments. The doctor mainly listens and acknowledges, with the effect of inviting her to continue, he also asks a few clarifying questions. The patient says she still can't do what she'd like to do. The doctor asks what, in an ideal world, and within reason, she would like to be doing, and her reply is about being able to walk more.

03:30

Clip one (1 minute 45 seconds) begins: the patient reports low mood, doctor asks about this, the patient reports fear. In the clip, the patient talks about her mood, responding to a question, the doctor asks about her views on what it is about. The patient responds that it is fear. The doctor listens to and acknowledges this, then mentions 'an interesting comment' in the letter from her recent hospital admission. In this letter, the 'heart doctor' reports an understanding that Lynn had been given the opportunity to talk about end of life issues by hospice staff, though had not felt ready to do so. The doctor says this does not sound like the patient, and the patient says she cannot remember the episode. The patient asks the doctor if he can find the letter in question, and he turns to his computer and searches for the report from the heart doctor.

07:20

Clip two (1 minute 37 seconds) begins: the patient talks about her perspective on the imminence of her dying before returning to the topic of low mood – this time as depression. In this clip, in the context of the doctor having introduced the topic of discussing end of life issues, the patient conveys her awareness of the imminence of her dying, she emphasises uncertainty 'this could be a very open-ended situation for me', and

goes on to suggest that engaging with dying/end of life issues could be a waste of time – she draws parallels with being depressed being a waste of time.

09:00

The patient talks of how once she spent a whole winter depressed, assuming she would not see the Spring, but she was still alive in the Spring, and this led her to realise it was a waste of time to have been depressed. The doctor comments: 'So, you've almost learnt from experience not to worry too much about what you can't be sure of', the patient responds 'exactly'. She then moves to talk about how difficult it is to 'say something' to relatives because they get upset, the doctor listens, acknowledges, and the patient then speaks particularly of talking to her husband Michael.

09:35

Clip three (2 minute 4 seconds) begins: the doctor returns to something the patient mentioned earlier - 'the fear'. This moves the conversation to talk around fear of dying, of sometimes wanting to die, of how it is not what ordinary people think about, and that others might think it is morbid and a bad thing for her to think about. The doctor talks about how it can be understandable to think of it, and to feel the way she reports. The doctor distinguishes between wanting to die and accepting it if it came. The patient then starts a new topic – relating to not being able to eat food and have a drink (since surgery some months ago).

11:30

The doctor comments on how 'miserable' this is, and the patient talks a bit more about it. The patient seems to bring this topic to an end, saying: 'so all in all, what can we say?'. The doctor proposes coming back to talking about her mood, and he begins to talk about options to try – talking and listening, or antidepressants. The patient says she does not want medication, talks about how she has had them in the past, but says that over the years she has not relied on them, she has relied on herself.

13:30

Clip four (4 minutes 52 seconds) begins: the patient mentions, and the doctor picks up on, a metaphor - 'falling off a cliff', the conversation moves to talking about the future, preferred place of death, and emergency care planning. Towards its end, besides talking of preferred place of death, the doctor asks about who she would want with her. She mentions her husband, then her daughter. She then moves on to talking about the most recent time her daughter looked after, and that this involved her daughter showering her for the first time.

18:15

The patient then goes on to say that it is important that the doctor remembers the patient is a brain as well as a body, even if the body is a load of rubbish. She talks of the importance

of not forgetting there is a human being there, that this does not take much: just a touch or a reassurance. When the patient seems to be ending this topic, the doctor thanks her for sharing this.

19:30

The doctor slowly moves towards detailing what he will do arising from the consultation, including updating the emergency care plan, and taking a watch and wait approach to her mood. The patient raises a new concern about excessive saliva secretions and their management, they talk at some length about this.

23:30

They talk about oral morphine and its use and dosage.

24:50

The patient reports that she now needs help to shower, from her husband. She describes this in terms of them having overcome the problem together. The patient talks about how much her husband does, doing up a flat they own, keeping the garden, looking after her, and she proposes he is not unduly stressed.

27:30

The doctor hands the patient his handwritten notes about prescriptions and plans, and both joke about the (poor) quality of his handwriting. They talk further about medications.

29:00

The patient raises the fact that when she moved to the hospice's care she stopped seeing the heart failure community nurse specialist, suggesting this was a mistake on her part, but also implying the hospice should have some mechanisms for maintaining communications with such nurses. The doctor asks about who she is seeing now, and acknowledges that the hospice needs to pursue this.

30:00

There is an exchange of thanks, they discuss booking a next appointment and agree the doctor will arrange one. The nurse helps the patient out of the room.

LYNN CLIP ONE TRANSCRIPT (1 MINUTE 45 SECONDS)

3 minutes 30 seconds into the consultation. The patient reports low mood, doctor asks about this, the patient reports fear.

Pat: Um I have been a wee touch... I wouldn't say depressed, but I've been aware of a mood-swing down.
Doc: Mm. Right.
Pat: And I said to Michael, that I would mention it to you
Doc: Okay
Pat: Obviously with having had so much experience of ill-health, I know when this can come on
Doc: Yeah
Pat: And I know I shouldn't ignore it
Doc: Right. Okay
Pat: And I n- I know I need to tell you
Doc: Okay
Pat: It's not um a desperate problem or anything like that
Doc: No
Pat: But we don't want it to get that way, do we?
Doc: Okay
Pat: So I'm just telling you that uh my mood has dri- dropping.
Doc: Do you think that's re- that's around your breathing getting worse or something else?
Pat: If you want- if you ask me (?) I think it's just fear
Doc: Fear?
Pat: Just fear. Just the reality of knowing what's happening
Doc: Right
Pat: and not being able to anything about it
Doc: I saw an interesting comment in the letter from the heart doctor saying that they were wondering about talking about what we'd talked in the day therapy about end of life issues or something and you hadn't felt ready for it. Does that ring a bell? or had she got the wrong end of the stick? But... Because I thought we'd kind of talked a little bit about that a long time ago.
Pat: Are you sure you got- me? I don't know whether it's me. I can't remember.
Doc: Doesn't sound, doesn't sound like you.
Pat: No
Doc: But that's what they're written, that, that um people will talk about end of life issues but that you hadn't felt ready for it.

LYNN CLIP TWO TRANSCRIPT (1 MINUTE 37 SECONDS)

7 minutes 20 seconds into the consultation. The patient talks about her perspective on the imminence of her dying.

Doc: '...Mrs. Hill tells me they offered to discuss end of life issues but she does not feel ready for this as yet.'
Pat: Oh yes. Well I did say...
Doc: Oh yeah.
Pat: That um I felt that I was um... Uh I know I'm terminally ill. I know I'm not going to get better.
Doc: Of course.
Pat: But I felt that um I wasn't in imminent danger of dying.
Doc: Okay
Pat: Such as I- if I'd got cancer
Doc: Okay
Pat: But I haven't got cancer. So I'm not in imminent danger of passing away because of that
Doc: Right
Pat: But the- Um I could die if I got an infection
Doc: Right
Pat: And that uh or my heart packed up
Doc: Yeah
Pat: That's what I said to her, I said that-
Doc: Yeah
Pat: That that's how I saw myself, that this could be a very open-ended situation f or me
Doc: Yes
Pat: That we're in a s- I'm a very long-term survivor of lymphoma for fifty years
Doc: You are
Pat: I mean, you'd never- You're not going to meet anybody like me again in a hurry
Doc: No
Pat: So you don't know what's going to happen and I certainly don't.
Doc: No.
Pat: And it doesn't matter. This is why I said to you about the depression
Doc: Yes
Pat: You can waste what time you've got being depressed and I'd hate that

LYNN CLIP THREE TRANSCRIPT (2 MINUTES 4 SECONDS)

9 minutes 30 seconds into the consultation. The doctor returns to something the patient mentioned earlier - 'the fear', this moves the conversation to talk about her feelings about dying.

Pat: You know, and I'm thinking- and I'm saying to Michael 'Oh please don't get upset. I'm just telling you this is how it is.'
Doc: Yes.
Pat: 'This- is- nothing you can do about it.'
Doc: Okay.
Pat: 'You just live with it and...'
Doc: But you think- So coming back to what you were saying before for a second, Lynn. Part of it is the fear of what might happen
Pat: I'm- I'll be honest
Doc: Right
Pat: I've never been frightened of dying
Doc: No
Pat: Until just lately
Doc: mm. Right
Pat: But I think you-when you know that, you know, it is on the cards, it is an experience that you t- you just think, 'How- how is it going to happen? Am I going to choke to death?' I think the breathing's probably scared me
Doc: Yeah
Pat: Trying to gasp for breath and I'm thinking, 'I just want it to be quick' and all that. You know
Doc: Yeah. Yeah
Pat: It's the silly things that-
Doc: Yeah
Pat: -ordinary people don't even discuss in their own minds
Doc: No no
Pat: because they're not in that zone
Doc: No
Pat: But-
Doc: It's very real for you isn't it?
Pat: Yes
Doc: That you feel your breathing and you wonder...
Pat: Yes
Doc: Mm
Pat: And I think, 'Will I be on my own?' You know, and all this..... things- it's morbid like they think. it's bad for me to think of it, but I do
Doc: I think it's understandable to think of it when you're feeling so ill really?
Pat: Yeah
Doc: Um...
Pat: And I said to Michael the other day that I wanted to go, I wanted to die because I'd had enough and-

Doc: Right
Pat: He got ever so upset about that
Doc: Yes
Pat: and then I said, 'Listen to me.
Doc: Right
Pat: 'I didn't really', but I said, 'It wouldn't worry me.'
Doc: Right.
Pat: It's funny isn't it how your mind...?
Doc: Well I think again sometimes- sometimes people get to that point where they feel almost they've s- they've suffered enough?
Pat: Yes
Doc: And actually dying That would make dying okay?
Pat: Yes
Doc: That's not to say you want to die
Pat: No. I don't
Doc: But you'd accept it if it came
Pat: I know. I don't
Doc: Mm
Pat: But that's it and it's...
Doc: Mm
Pat: Those things. I think one of the hardest things for me is not being able to be- be fed food and have a drink.

LYNN CLIP FOUR TRANSCRIPT (4 MINUTES 52 SECONDS)

13 minutes 30 seconds into the consultation. The patient mentions, and the doctor picks up on, a metaphor - 'falling off a cliff', the conversation moves to talking about the future, preferred place of death, and emergency care planning.

Pat: But over the years I haven't relied on them [antidepressants taken from time to time]
Doc: No
Pat: I rely on me
Doc: Mm. Well you're pretty tough aren't you?
Pat: Usually
Doc: Usually. Not quite so at the moment
Pat: Well... I'll be alright
Doc: Okay
Pat: I should recover
Doc: Okay. So the hospital are thinking about is it your lungs, is it the heart? The day therapy ladies were wondering whether it might come- whether you might die soon. But you think probably not because it's not cancer where you can kind of know that?
Pat: No. I don't think so
Doc: But you're quite- you sound quite realistic that an infection or your heart stopping might be enough to...
Pat: Yeah. It-
Doc: Die from, really.
Pat: Because
Doc: Yeah
Pat: I- a few weeks ago I had to go back into hospital because it was May. The Bank Holiday, May Bank Holiday this year
Doc: Yeah
Pat: And Michael went to the football, to the away match. And he left me in the morning and I was alright. My daughter looked after me
Doc: Yeah
Pat: Then he came home at night I was gasping for breath. And I ended up in the hospital at midnight
Doc: Right
Pat: And the doctors in there said, 'You're a woman standing on the edge of a cliff and you just fell over'.
Doc: Right
Pat: And they gave me antibiotics
Doc: Yeah
Pat: And I was back out in four days
Doc: Okay
Pat: But I just needed them very quickly.
Doc: You did
Pat: So now I've got them at home. So that- Had it not been a Bank Holiday, I'd

have rang the GP
Doc: Yes. But you went in. I mean I suppose that's what I see partly Lynn is...
Pat: Yeah
Doc: That you're managing as much as you can day-to-day...
Pat: Yes
Doc: But it wouldn't take much to push you off the cliff
Pat: Not at all. Nothing much
Doc: And a bit like with cancer, sometimes you kind of see the cliff. You see the cliff and over you go
Pat: Yeah.
Doc: I think with the illnesses you've got you're kind of on the edge
Pat: Yeah
Doc: And then you're just waiting for the breeze almost
Pat: Yeah
Doc: And who knows when the wind will blow
Pat: That's right. That's it
Doc: Um...
Pat: Yeah
Doc: I- And I suppose that's the difficult thing sometimes is you- It's you know it
Pat: I keep with that
Doc: it could be a few weeks
Pat: Yeah
Doc: It could be many months
Pat: Yeah. That's right
Doc: And it's hard to work with that sometimes
Pat: That's right. You've just got to be very tough
Doc: Yeah. Okay. I know when we were chatting a while ago about um, you know, when it became clearer that you might be dying shortly
Pat: Yeah.
Doc: You know, you had thought about that a little bit
Pat: Yes
Doc: Where you'd want to be, how you'd want it to be
Pat: Yes
Doc: And you were saying, you know, I got the impression you didn't want to be alone?
Pat: No
Doc: You don't want to be feeling that you're choking?
Pat: No
Doc: No. Um...Di- Have you made any - have you made any changes to what you'd want in terms of.... of whether you'd want to be- Where you'd want to be and so forth? Now you've had a bit longer?
Pat: I just don't want to be in a hospital. I'd rather be here [at the hospice]
Doc: Yeah
Pat: Or at home
Doc: Okay
Pat: I really don't want to be in hospital
Doc: Okay

Pat: It's um... not the right environment
Doc: No
Pat: I think that's one of the things that does bother you. Where am I going to end up? Am I going to go in as an emergency and it's all going to go wrong in the hospital
Doc: So if it was Bank Holiday Monday again back in May and your chest was really bad, I suppose you're right. There's a risk that if you go into hospital and it doesn't get better...
Pat: Yeah
Doc: You end up stuck there
Pat: Yeah. We can all wish
Doc: Yeah
Pat: For things. But you can't do anything about it if it happens
Doc: So if you were in hospital and it was getting worse
Pat: Yeah
Doc: I mean we could try and have a plan where you'd either come here or go home
Pat: Yeah
Doc: Right at the end
Pat: Yes
Doc: Would you want that?
Pat: Yes
Doc: Okay
Pat: Definitely
Doc: Okay
Pat: Absolutely. Definitely. One hundred per cent
Doc: Well why don't I- I can have a- Do you remember we did an emergency healthcare plan a while ago?
Pat: Yeah
Doc: Why don't I look at updating that?
Pat: Yeah
Doc: Put that in, that even if you went to hospital to try and get better...
Pat: Yeah
Doc: If that wasn't working out
Pat: Yeah
Doc: You'd want to make sure you weren't there at the end?
Pat: Yes please
Doc: And as much- You know, we'll let Michael know that
Pat: Yes
Doc: And as much as is possible we'll work with that
Pat: Yeah
Doc: And also you don't want to feel like you're choking
Pat: I don't
Doc: And you want someone with you?
Pat: Yes please
Doc: Anyone in particular?
Pat: Um well Michael would be the one

Doc: Yeah
Pat: He would be the one
Doc: If possible with Michael
Pat: And uh...
Doc: Yeah
Pat: Nina [her daughter] there for Michael
Doc: Yeah
Pat: my daughter
Doc: Yeah
Pat: She's good
Doc: Yeah
Pat: She is good. She does this for a living. So...
Doc: Yeah.... It's different when it's your mum, but
Pat: But- Well that's what we said on Saturday because he went to a football match

LYNN - SOME LEARNING POINTS FROM A CONVERSATION ANALYSIS PERSPECTIVE

There are four clips. The earlier ones involve initial 'openings' in which the doctor asks questions that create opportunities for the patient to raise things that can then be drawn upon to get dying and advance care planning onto the surface of the conversation. In the later ones, despite Lynn conveying some reasons not to talk about her imminent death, the topic does reach the surface, and she and the doctor collaboratively make plans for end of life. Within consultations, moving towards talking about end of life is often a lengthy, cautious, stepwise process spread across several parts of the consultation, with both parties using euphemisms and indirectness, sometimes as here, they talk about dying in more explicit terms as the conversation progresses1. As is common amongst people in her position, Lynn implies (in clip two), and then later directly refers to the fact that talking about dying is depressing, morbid and so on. Concerns like these can push against any move towards talking about end of life and associated plans. The doctor listens to and acknowledges these concerns, and then begins to add a slightly different perspective. In clip three states 'It's very real for you isn't it' treating the concerns and feelings Lynn has been talking about as a real and present concern for her, and then he moves on to say that it is understandable to 'think of it'. In the set of recordings upon which Real Talk is based, it is common for patients to talk about how strange, depressing, morbid etc. it is to engage in talk talking about their end of life and dying. In response, the clinicians convey through both what they say, and how they say it, that thinking and talking about it is understandable and acceptable in the patient's situation, and they work to convey the consultation as a place where it is a useful, normal, and understandable to talk about, and by extension make plans for dying. The doctor here – and elsewhere in our recordings - often uses a rather neutral but curious/interested tone, this contrasts with the distress Lynn reports her husband expresses when she talks with him about dying. The doctor's 'That's not to say you want to die … But you'd accept it if it came' in clip three also conveys to Lynn an accepting (and what we might call morally neutral) understanding of dying that contrasts with what she says others have said to her (e.g. admonishing her for being morbid).

In clip one, the doctor asks a question about what Lynn thinks underlies her reported drop in mood. When practitioners ask patients about their views and feelings, this often results in them mentioning something the practitioner can pick up on as part of moving towards talk about the patient's end of life[1]. You can see this in all the cases of broaching dying in Real Talk. In this particular case, the doctor does not pick up on the patient's report of 'fear' straight away, but he comes back to it soon after - in clip three. Notice that in clip one, Lynn says: "Just fear. Just the reality of knowing what's happening and not being able to do anything about it." This is ambiguous – Lynn might mean fear of breathlessness itself, or fear of the future and, in particular, dying. In clip three, when the doctor returns to the fear, he says: "So coming back to what you were saying before for a second, Lynn. Part of it is the fear of what might happen" – his small change to her wording shifts the meaning more clearly towards the future and thus further towards end of life. Lynn's response moves rapidly into talk about dying. To get the patient's dying onto the conversational surface, practitioners can ask questions about feelings and thoughts, and then can pick up on things the patient says in response (either right away, or a bit later in the conversation). This clip shows they can also refer to what the patient has said in a way that more clearly points towards talk of end of life.

In the set of recordings on which Real Talk is based, all patients and all doctors start out talking about dying in euphemistic, allusive, indirect ways. They then 'unpack' towards more direct talk, and do so at varying speeds. In Clip three we can see that Lynn quite quickly unpacks the doctor's relatively vague reference: 'fear of what might happen' by referring to dying. In responding, the doctor uses the same 'dying' term later in clip three, and also in clip four. Indirect talk can have its place in a stepwise movement towards talking about the patient's dying[2,3,4]. As seen in other cases, when a patient uses a more direct word, here 'dying', the practitioner then uses the same term that the patient has used (see the Curtis Real Talk case for a further example). In several other cases, neither the doctor or patient to directly use the terms death and dying, but nevertheless, the patient and the doctor clearly understand exactly what each of them is talking about. It may be that for some people, it is too painful to use those direct terms. People can still make themselves clear by using euphemistic but terms and phrases[5].

REFERENCES AND FURTHER READING

More reading suggestions are given on the Real Talk references list .

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2. Lutfey, K. and D. Maynard (1998). Bad news in Oncology: how physician and patient talk about death and dying without using those words. Social Psychology Quarterly 61(4): 321-341. Download: http://bit.ly/LutfeyTalkAboutDying

3. Del Vento, A., J. Bavelas, S Healing et al. (2009). An experimental investigation of the dilemma of delivering bad news. Patient Education and Counseling 77: 443-449. http://bit.ly/DelVentoBavelasBadNewsEquivocalLang

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5. Pino, M. and Parry, R. (2019) Talking about death and dying: Findings and insights from five conversation analytic studies. Patient Education and Counseling 102(2) 185-187. Email realtalk@lboro.ac.uk for a copy

Real Talk Case Three - Sam

CASE SYNOPSIS (Keywords, Background, Clips, Overview of consultation)

KEYWORDS

broaching illness progression and dying, communication with relative present in the consultation, ventilator, reluctance to talk about dying, neurological condition, out patient

BACKGROUND

The patient, Sam, has a rare degenerative neurological syndrome. She attends with her husband Michael. This is a routine updating outpatient appointment, rather than an urgently arranged one. The doctor has met Sam several times before at the hospice. After the recording, the doctor told us that a few weeks later, Sam attended again without her husband and that at that consultation, Sam and she talked about her fears for the future and her wishes with regards advance care planning.

The consultation lasted approximately 50 minutes.

After the consultation, the patient rated this doctor as excellent on all ten dimensions of the CARE 'Care and Relational Empathy' questionnaire.

CLIPS

There are five clips. In the first, Michael, the patient's husband, raises a concern about the top limit which Sam's ventilator pressures can reach (she uses non-invasive ventilation (NIV) at night). Sam, the patient, suggests this is not something to be worried about.

In the second, the doctor returns the conversation to Michael's concern about ventilator pressures, asking about his biggest worry in this regard. Michael responds in terms of 'the dependency thing', and the conversation evolves to talking about how what can happen is using the ventilator for an increasing amount of time.

The third clip comes soon after; in it the doctor raises the matter of 'dependency' and says that she hears Michael raising 'worries for the future' – that is, she makes a step towards unpacking the concern Michael has couched in terms of ventilator pressures and their top limits. In responding, Michael mentions that 'What the next stage is' is a worry. At this point, Sam rapidly moves the conversation to a current symptom (wind), and this has the effect of moving talk away from the future.

In the fourth clip, the doctor is explicit that people do die when NIV is no longer able to support respiratory function. This is noticeably phrased in terms of 'people' – i.e. in general terms as opposed to referring to Sam, her future and her death specifically and personally. The

conversation moves to talking about other respiratory options and the need to clarify options with the respiratory/ventilator team.

To follow what goes on in the fifth clip, it is important to know what has gone on in the minutes beforehand. A few minutes before the clip, Sam has allusively touched upon her illness trajectory and life expectancy in terms of 'how quickly things are going to move.' She then implies she does not want to talk about the end of her life - saying she just wants to live life as she can and not be filled with depressing thoughts. At this point, Michael talks about his concerns at seeing the deterioration in terms of her being less able to get out and about, including into the garden. In this context, the doctor comments on not knowing whether or not they wish to talk about the future with her. Sam implies she does not want to 'go into it' much. The doctor notes they have lots on their minds now (a forthcoming family wedding and associated stresses have been discussed), but that it can be helpful to do 'a bit of rainy day planning' and that this does not need to be 'all doom and gloom'. Referring to how Sam's ventilation needs are increasing, and noting that Michael is seeing this too, she suggests – or encourages - talking about plans in the future.

OVERVIEW OF CONSULTATION

Pseudonyms for people present or referred to in the consultation:

- Patient is Sam. Patient's Companion is her husband Michael.
- NIV = Non-invasive ventilation – ventilator support delivered via a mask or similar device.

Approximate timings are given as minutes:seconds and have been rounded or down for simplicity.

00:00

The doctor greets Sam and her husband, then briefly checks their agreement about recording and about a medical student sitting in. She asks: 'How are you?' In replying, Sam talks about getting very cold, they talk about how she and Michael are managing this.

03:00

Sam reports being exhausted last week and not sleeping well, and that she asked Michael to raise the levels of her ventilator (NIV, used at night) and that she is now feeling a bit better. She also mentions a 'funny stomach turn', saying this happens every few weeks. The doctor listens and acknowledges.

03:30

Clip one (38 seconds) begins: the patient's husband raises a concern about the top limit to which the patient's ventilator can go.

The husband then says: 'I must admit I've been concerned about that ventilator because I mean there must be a top limit to where we can go up to?' Sam seems to take a different position regarding whether raising the pressures is permitted by the ventilator specialist team. The doctor asks about recent and forthcoming contacts with the respiratory and ventilator specialists. Sam says she has a forthcoming appointment.

05:10

Clip two (50 seconds) begins: the doctor returns the conversation to Michael's concerns about the ventilator.

She asks Michael about his biggest worry regarding this, he talks about dependency, and says he presumes there is a top limit. The doctor then talks about ventilator use, and how besides raising pressures, it can also be used for more of the time.

06:30

Clip three (56 seconds) begins: the patient's husband returns to his concern with high setting, the doctor refers to 'your worries for the future', and the patient moves the conversation to her recurrent abdominal symptoms.

Michael raises again his concern that there must be a limit, and that different specialists have suggested different top levels. After responding to this second concern, the doctor proposes that 'What is difficult is that people do become dependent' and then that 'I guess what I'm hearing is you're worried for the future.' Michael replies suggesting 'where it's going', and 'what's the next stage' are worries. Immediately, Sam raises the symptom of abdominal wind, and as a result, the conversation immediately shifts from the future, to talk about the nature and possible causes of the current wind symptom.

09:30

The doctor encourages them to discuss the issue of the abdominal wind at Sam's next consultation with the ventilator and respiratory specialists. She also encourages Michael to share his concerns for the future with them. Sam and Michael talk about the clinic they go to being very busy, and about communication difficulties they have experienced there.

12:40

Clip four (50 seconds) begins: the doctor explicitly talks about people dying when the NIV is no longer effective. The doctor has talked about her experience of NIV use by people with motor neurone disease. She says that NIV becomes less effective in supporting people's respiratory function, and she goes on to say: 'You are not stupid you know what that means, it means that actually people then die.' Sam briefly acknowledges this, and the doctor immediately moves on to talking about not knowing whether the respiratory team would contemplate any other respiratory support and asks them if they know what she means by that.

13:20

The doctor moves on to cautiously explain tracheostomy and ventilation, and that this is 'not a light undertaking'. Michael says this has not been mentioned, and Sam shifts the conversation towards current breathing symptoms.

15:00

The doctor says it would be helpful to ask the respiratory team 'those questions about what happens' and offers to write to the team on this matter. Michael returns to his concerns about the pressures going up and up and that there 'must be a limit'. There is talk about his worries, how Sam wants him to be happy, and about problems of getting the pressure right to avoid wind but to ensure ventilator is effective in preventing her exhaustion.

17:00

Sam then talks some more about tiredness and neck weakness, and they talk about their causes and management. The doctor raises the possibility that increasing CO_2 levels underlie the tiredness.

19:45

Sam says that worrying about things is also tiring, they talk at length about family issues and worries of a forthcoming family wedding.

23:00

The doctor recaps, noting the anxiety, muscle weakness and CO_2 levels all going up. She proposes talking to Sam's specialist nurse and writing to the ventilator team 'in the hope that they give you the chance to share some of your concerns'. They talk at some length about ventilation options - including tracheostomy - the doctor makes it clear she does not know if this would be offered. The doctor reiterates the importance of finding out more from the ventilation and respiratory team.

27:00

In a lull in the conversation, the doctor notes cautiously that 'you don't appear as on top of things as you did the last time'. Sam laughs softly and talks of various things 'taking it out of me a bit'. She raises that winter is coming and this is 'one of the worst things'. She implies she is thinking about how she will occupy her day, and mentions that reading is difficult because of eyesight problems.

28:30

Michael says Sam does not always go out, but that going out is good for anyone, and he raises her reluctance to have a wheelchair. Sam says she is 'teetering' on it, but that it seems

a big step. She asks the doctor what she thinks. The doctor acknowledges it as a hard thing to consider, then mentions positive reasons for having one. She asks if Sam is using a walking frame. She is not.

29:30

The doctor and medical student gently encourage wheelchair use – as an 'enabler' and not for all the time. Sam expresses some agreement, and the husband gives several reasons in favour of her having a wheelchair. The doctor suggests a physiotherapy referral regarding obtaining a wheelchair, but also for work on strategies for energy conservation. Sam accepts this offer, they discuss arrangements for this. They move on to talk about getting a disabled 'blue badge'.

36:00

The doctor raises medications and these are discussed at some length. The doctor moves the conversation in the direction of closing it – by raising arrangements for the next appointment and what will be done before then. The doctor again refers to speaking to the ventilator team as important in terms of 'asking where we might go next, and beginning to get our heads around the future.'

38:30

At this point, Sam says "I've no idea and I don't suppose you have either really of how quickly things are going to move." In replying the doctor makes reference to a previous conversation with Sam about her getting in touch with people with the same (rare) disorder via the internet and asks about what Sam had found out from talking to people over the internet. It seems likely that the doctor asks about the internet group in order to see what Sam knows about 'how quickly things move' with her condition. Sam however comes in to say she has stopped looking at this matter on the internet because it was so depressing. She mentions some useful things she discovered through these channels, e.g. about acupuncture.

40:00

When Sam seems to be bringing this topic to an end, the doctor says: "So I guess that's difficult and I've always been aware that you wanted to remain fairly upbeat." Sam says that in a way she does not really want to know, but then in practical terms in terms of putting things into place, she does, but that she does not want to depress Michael. Michael says that his perspective is that in the past Sam had some episodes of abrupt deteriorations, but that it is now just a very slow deterioration. He then says that what does concern him is that Sam is going out less and less, and the talk turns to this, and to how even going out into the garden to sit is not easy. Sam says the numerous medications and nutritional supplements she needs to take mean it is difficult for her to get out into the garden. They talk about how Michael likes to be out in the garden all day.

43:30

Clip five (1 minute 38 seconds) begins: the doctor encourages 'rainy day planning', and suggest doing so in the future, after the family wedding and Sam's forthcoming respiratory clinic appointment.

As the conversation lulls, the doctor says 'I don't know how much you want me to say. You've kind of raised the future, and it's backtracked a little now.' Sam agrees, says it is tricky, and that she does not know how she feels about going into great detail now – that is, she implies not wanting to talk about the future now. The doctor suggests it would be helpful to talk about things, and about rainy-day planning. She says she understands that they see things as steadily changing but that she is concerned by the need for the ventilator pressures to go up, and where this is going, and implies this is a shared concern – not just something she is seeing, but that they are seeing too. She says it would be good to talk, but proposes doing so after the wedding, and after seeing the respiratory team.

After the clip ends, the doctor talks more about the importance of planning, of having a back-up 'rainy day' plan, that doing so is not about giving up.

45:00

The doctor then lists the various actions she will take, and proposes a date to see the couple again, after the wedding.

46:00

Michael says he is sorry it has 'all been doom and gloom today' and that he 'must admit I've found it a bit awkward recently because I feel like the Summer's come and gone and not much has happened'. The doctor and patient talk about how Winter can be difficult. Michael mentions a holiday trip he will shortly go on, and which he is looking forward to. The talk then moves to the wedding again, and how he is not looking forward to it.

47:00

Their talk moves on to arrangements and things the doctor will do, and about the next routine appointment. The doctor says they can get in touch sooner if need be. With final goodbyes, and thank yous, the consultation ends.

SAM CLIP ONE TRANSCRIPT (38 SECONDS)

3 minutes 30 seconds into the consultation. The patient's husband raises a concern about the top limit to which the patient's ventilator can go

Hus: I must admit I've been conc- concerned about that ventilator because I mean there must be a top limit to where we can go up to?
Pat: Well they said not to worry didn't they?
Doc: Right.
Hus: Given that when Sam started with it which was on- two years ago down to - whatever the numbers mean - about twelve.
Doc: Yeah.
Hus: Whereas it's now up on twenty-eight I think. Which is...
Doc: Right.
Pat: But they said not to bother the last time we went. Said don't worry about that.
Hus: Well they d- No, they said there was a top limit not to go above.
Pat: Yeah but that was before. Anyway, yeah

SAM CLIP TWO TRANSCRIPT (50 SECONDS)

5 minutes into the consultation. The doctor returns the conversation to Michael's concerns about the ventilator.

Doc: When you say you worry about the levels going- the pressures going up, what's the biggest worry?

Hus: Well... Well I suppose it's coming back to this dependency thing. I mean, the fact that it's just going higher and higher.

Doc: Mm.

Hus: Presumably there is a top limit as to what it can go up to and it...

Doc: Well I guess- I guess two things tend to happen. It tends to be that the pressures go up. Um the other thing that tends to happen is that you tend to need it more.

Hus: Mm.

Doc: So you're right. There is a limit to how high the pressures can go. Um but the way of getting around that is that you use it more.

SAM CLIP THREE TRANSCRIPT (56 SECONDS)

6 minutes 30 seconds into the consultation. The patient's husband returns to his concern with high setting, the doctor refers to 'your worries for the future', and the patient moves the conversation to her recurrent abdominal symptoms.

Hus: And now we're well above what they regarded as a very high setting so it's...
Doc: Yeah. Right
Pat: Mm.
Doc: Okay.
Hus: I just don't think things can keep going up, and up and up [laughs] you know there must be a limit somewhere
Pat: They seem to vary, though
Doc: Yeah
Pat: They seem to vary very much in the way they talk about it.
Doc: Yeah. I think there are. I think different members of the team are more relaxed with different aspects
Pat: Mm.
Hus: Yeah.
Doc: I mean I guess what is difficult is that people do become dependent.
Hus: Mm
Pat: Mm
Doc: Um and increasingly dependent.
Pat: Mm
Doc: Um but I guess what I'm hearing is your worries for the future
Hus: Oh yeah. It's where it's going because it can't- obviously it can't keep going up, and up, and up.
Doc: No. No.
Pat: What worries me a bit-
Hus: And so it's what's the next stage after that I suppose is uh what the worry is.
Doc: Okay. Okay.
Pat: You know this wind that I get

SAM CLIP FOUR TRANSCRIPT (50 SECONDS)

12 minutes 40 seconds into the consultation. The doctor explicitly talks about people dying when the NIV is no longer effective.

Doc: And I guess kind of drawing parallels from things like motor neuron disease, what normally happens is that the lungs do get weaker and weaker
Pat: Mm
Doc: And the N. I. V. becomes less effective in supporting people's respiratory function
Pat: Mm
Hus: Mm
Doc: Um and you're not stupid. You know what that means
Hus: Mm
Pat: Mm
Doc: You know, it means that- that-
Pat: Mm
Doc: Actually people then die
Pat: Yeah
Doc: What I'm not clear about is whether they would contemplate any other respiratory support and I don't know whether they've ever talked to you about that
Pat: No
Doc: I don't know if you know what I mean by that
Pat: Means of oxygen or anything?
Doc: Um no
Pat: No?
Doc: I mean....

SAM CLIP FIVE TRANSCRIPT (1 MINUTE 38 SECONDS)

43 minutes 30 seconds into the consultation. The doctor encourages 'rainy day planning', and suggest doing so in the future, after the family wedding and Sam's forthcoming respiratory clinic appointment.

Doc: Okay. I guess it's- I don't know how much you want me to say. Um, you know, you've kind of raised the future.
Pat: Yeah.
Doc: And you've backtracked a little bit now. Um
Pat: Yeah. Mm it's tricky.....
Pat: Umm, I- I don't know to be honest how I feel about...
Doc: Okay.
Pat: Going into great detail at the moment.
Doc: Okay. Okay. Um I'm mindful that you've got this wedding and things like that. So you've got quite a lot think-
Pat: Yes. I feel I've got enough to... yeah.
Doc: I think it would be helpful to talk about things
Pat: Mm
Doc: And sometimes a bit of rainy day planning...
Pat: Mm. Yeah
Doc: Isn't all doom and gloom but it is having your kind of plans in place just in case
Pat: Mm. Yeah. Yeah
Doc: I hear what you're saying, that it feels that things are just steadily changing
Pat: Mm
Doc: I guess the thing that concerns me most is the business with ventil-, the N.I.V.
Hus: Mm
Doc: You know, the needing to go up with the pressures
Pat: Mm
Doc: Um and where that's going. And I'm hearing that you're seeing that too
Hus: Mm.
Pat: Mm.
Doc: So I think if you can manage it, I think it would be good for us to talk about it.
Pat: Yes. Yes. Talk about it.
Doc: But maybe talk about it after your wedding and after you've been to see the Respiratory Team.
Pat: Mm. Yes, yes.
Hus: Mm.
Doc: And see whether they give you any answers.
Pat: Yes

SAM - SOME LEARNING POINTS FROM A CONVERSATION ANALYSIS PERSPECTIVE

There are five clips.

In the first, Michael, Sam's husband, raises a concern about the top limit which Sam's ventilator pressures can reach (she uses Non-Invasive Ventilation at night). Sam, the patient, suggests this is not something to be worried about.

In the second, the doctor returns the conversation to Michael's concern about ventilator pressures, asking about his biggest worry in this regard. Michael responds in terms of 'the dependency thing', and the conversation evolves to talking about the fact that the ventilator can be used for an increasing amount of time.

The third clip comes soon after; the doctor raises the matter of 'dependency' again and says that she hears Michael raising 'worries for the future' – that is, she takes a relatively large step towards unpacking the concern Michael has raised, and in this way she moves the conversation towards illness progression - and by implication end of life. In responding, Michael mentions: 'what the next stage is' as a worry. At this point, Sam rapidly shifts the conversation to a current symptom ('wind'), and this has the effect of moving talk well away from talk of, and concerns about, the future.

In the fourth clip, the doctor is explicit that people do die when NIV is no longer able to support respiratory function. This is phrased in terms of 'people' – i.e. in general terms as opposed to referring directly to Sam, her future, and her death in a way that is specific and personal. The conversation moves to talking about other respiratory options and the need to clarify options with the respiratory/ventilator team.

To understand what goes on in the fifth clip, it is important to know what has gone on in the minutes beforehand. A few minutes beforehand, Sam has allusively touched upon her illness trajectory and life expectancy in that she says she does not know 'how quickly things are going to move.' After some probing by the doctor, she implies she does not want to talk about the end of her life - saying she just wants to live life as she can and not be filled with depressing thoughts. At this point, Michael talks about his concerns at seeing her deterioration – Sam being less able to get out and about, including into the garden. In this context the doctor comments that she does not know whether they (or perhaps particularly Sam) wish to talk about the future with her. Sam implies she does not want to 'go into it' much. In response, the doctor notes they currently have lots on their minds (a forthcoming family wedding and associated stresses have been discussed), but emphasises that it can be helpful to do 'a bit of rainy day planning' (again, this is somewhat allusive, although it clearly means advance care planning) and says that this does not need to be 'all doom and gloom'. Referring to how Sam's ventilation needs are increasing, and noting that Michael is seeing this too, she suggests – or encourages - talking about plans in the future the next time they meet.

- One way that patients and relatives often respond when talk moves towards the future and the patient's end of life, and planning for this, is by changing the topic towards current symptoms and interventions. Of course, it is important that practitioners respond to

concerns about current symptoms and interventions, but skilled practice also entails being able to steer the conversation back towards the (perhaps more difficult to discuss) future matters, to retrieve them from earlier parts of the conversation as it were, and to ascertain if the patient is ready to do so without undue distress. Here, one of the ways the doctor does so is to pick up on Michael's concern about ventilator pressures. In clip two, she 'retrieves' the concern he has expressed and asks him about his biggest worry in relation to this. He responds in rather vague and allusive terms - 'this dependency thing'. In clip three, instead of asking a question that encourages Michael himself to take the lead in this unpacking, the doctor does some unpacking herself: 'I guess what I'm hearing is your worries for the future'. This meets with some success in relation to getting the difficult future onto the surface of the conversation – in that Michael now talks about 'what's the next stage after that [the ventilation pressures reaching their top level] is what the worry is'.

- Questioning patients (and relatives) in healthcare is often thought of in terms of whether the question is open or closed. It is useful to consider question design in a bit more detail. For instance, consider just how narrowly an open question focuses in upon - and thus encourages - a particular response. In some clinical circumstances, a narrower question can be helpful by encouraging particular responses from patients[1, 2]. The doctor's question to the husband 'What's your biggest worry?' is a relatively narrow question. It works to encourage him towards more specificity, and in other cases we have[3], this results in the patient or their companion articulating something clearly relating to end of life – thus it helps get this matter on the table. There has been a lot of CA research on how questions work in healthcare[4].

- There seems to be some mismatch between Michael and Sam in their willingness to move towards talking about Sam's illness progression and dying. This is seen most starkly at the end of clip three, where – at the point where Michael seems to be getting closer to talking about her illness progression and thus, by implication – dying, Sam immediately makes a move to change the topic to a current symptom. It would not be right for a practitioner to just ignore such current concerns – and indeed this doctor then pays attention to Sam's current 'wind' problem. However, as in the other broaching dying cases, the doctor later works on moving the conversation back towards the topic of illness progression again.

- There is not much detailed research on the skills practitioners use to manage the differing communication and differing needs of patients and friends/relatives simultaneously attending a consultation. Some preliminary observations include the fact that gaze[5] is very important. Gazing at someone can be used to show you are encouraging them to talk; gazing away can discourage them from talking, or starting to talk again. Another strategy for managing communication in this circumstance is to directly talk about the fact that there are differences in needs. Sometimes this is called 'meta talk' – wherein we comment on what we are talking about. We see this phenomenon here, where the doctor to some degree surfaces the communication problems in relation to differences between Sam and Michael in their willingness to talk about illness progression at the start of clip five. In doing so, the doctor provides an opportunity for Sam to take a position on this – and she does: implying that she is not currently keen to discuss the future. We also see that this difficult situation is then managed by the doctor by offering to talk about these issues next time. The doctor subsequently told the research team that at her next appointment, Sam did indeed talk

much more about her feelings and plans for the end of her life (perhaps relevantly, Michael was not there).

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Real Talk Case Four - Eashan

CASE SYNOPSIS (Keywords, Background, Clips, Overview of consultation)

KEYWORDS

broaching dying, patient expectations, fear, communication with relative present in the consultation, returning to something patient has said earlier, preferred place of death, patient reluctance to talk about dying, advance care planning, advanced cancer, hospice outpatient, empathy.

BACKGROUND

The patient, Eashan, has advanced cancer affecting his neck, with metastases in his lungs. He has a close family, including a thirteen-year-old child. He attends the outpatient clinic of the hospice with his brother Rajesh. The doctor has met the patient at clinic before, but he has not met the patient's brother.

After the recording, the doctor remarked on how much more ill the patient was compared to when he saw him a few weeks previously.

The consultation lasted approximately 40 minutes.

After the consultation, the patient rated this doctor as excellent on all ten dimensions of the CARE 'Care and Relational Empathy' questionnaire.

CLIPS

There are three clips. In the first one the doctor asks the patient about his thoughts and feelings in relation to his symptoms and this works to provide opportunities that can be drawn upon to get dying and advance care planning onto the surface of the conversation.

The second clip shows the doctor asking a question that could open up these opportunities – he asks the patient if he has thought through what might be coming next, but at this point, this does not work to move the conversation to talk about dying and advance planning.

In the third clip, the doctor returns to asking the patient about the future, and to a 'death relevant' matter raised in the first clip – the patient's admission that he sometimes wonders if 'this is it'. The conversation now moves to a good deal of talk about dying, about not wanting to die and wanting to fight. The doctor demonstrated empathic assessment and works to raise 'worst

case scenario' planning, and the talk moves (though not straightforwardly) towards talk about preferred place of death.

OVERVIEW OF CONSULTATION

Pseudonyms for people present or referred to in the consultation:

- The patient is Eashan, his Companion is his brother is Rajesh.
- The patient talks of being in touch with a hospital in an effort to join an experimental cancer drug trial, our pseudonym for this centre is 'The Royal'. The patient refers to a doctor who he recently saw and who prescribed him a single dose of radiotherapy.

Approximate timings are given as minutes:seconds and have been rounded up or down for simplicity.

00:00

After checking the patient and his brother know about and agree to recording, the doctor asks how the patient has been since they last caught up. The patient immediately says it has gone downhill. He reports worsening cough, antibiotics not having an effect, coughing up blood, and that he has seen an oncologist, and has been given a single high dose of radiotherapy to his chest. Doctor listens, and mainly acknowledges and asks clarification questions. The patient rounds this off saying 'That's how it is'.

03:20

The patient then says: 'And I'm still waiting for the trial, I'm meant to go to a trial', and he talks about a centre where experimental trials on new cancer drugs are run. The patient says he has been to this centre for assessment, and he talks at some length about correspondence between the trial centre and the local oncology department. The patient complains about the slowness of the process. Rajesh says this is making Eashan frustrated and irritable. Eashan says he is frustrated, and that now he is going downhill.

05:00

Eashan says he has gone downhill over the last four weeks, they talk about deterioration in mobility. The doctor asks whether if the trial centre were to phone tomorrow, Eashan would feel well enough to go. He says he feels fit enough, qualifying with 'well mentally I am.'

05:50

The doctor clarifies that the centre is both waiting for information from the oncologist, and waiting until the patient is several weeks post-radiotherapy. The patient says the trial centre has told him they will call him within a week of getting information from the oncologist, and that they will take samples even if though they cannot yet start the trial because of the radiotherapy.

06:20

The doctor asks the patient 'What are they thinking they might offer you in terms of treatment? The patient responds about three possible trials, and gives some details about randomization processes.

07:15

The doctor asks about 'the practicalities' – they talk about this – the trial centre is almost two hours away. The talk moves onto how the patient has become more ill over the last three or four weeks. The doctor talks with the patient about symptoms, and about medications. The doctor goes on to ask about the location and character of the pain. There is lengthy discussion about pain and pain medications.

13:00

Rajesh, Eashan's brother, raises the fact patient is not eating. The patient says he does not feel like it, and talks about his PEG, night feeds, and oral supplements.

13:45

The doctor summarises, noting that the need to think about the pain, coughing, appetite. There is more talk about symptoms and medications.

14:45

Rajesh talks about how, when the pain is bad the patient's breathing and everything 'goes' and he panics. The patient joins in and says that when he calms down and has medicine it is fine.

15:00

Clip one (1 minute 8 seconds) begins: in replying to the doctor's questions about what goes through his mind, the patient talks about sometimes thinking 'this is it'.

The doctor asks the patient what goes through his mind when he panics. In responding, the patient says that sometimes he feels like 'that's it', the doctor comments that this must be frightening. The brother raises the fact that sometimes Eashan asks if he is going to hospital when such episodes occur, but that he is scared of going in and afraid he will not come out again, and that this is a reason to 'stay on top of things'. The patient then moves to talking about how a bad breathlessness episode led to his requesting and receiving a recent appointment with the oncologist, and about the radiotherapy that was given, saying 'So probably that might help.'

The doctor suggests if Eashan is experiencing bad symptoms, he could ring him (at the hospice). This moves on to talk about where the patient would and would not go in an

acute episode – the GP surgery, and A and E. This evolves into the patient talking about an episode that led to an admission months ago, in which the cancer spread to his lungs was diagnosed. He mentions 'all this chemo', how the oncologist 'hasn't got anything else' and how they are now waiting for the trial and the letter to the trial centre.

18:40

The doctor offers to write today to the oncologist, to see if there is anything that can be done to speed things up. The patient accepts the offer then says the trial centre is very eager to help him, but that they need the information.

19:46

The doctor summarises, and asks if whether if he is well enough he wants to be able to go straight into a trial. The patient says: 'Oh definitely'. The doctor now proposes moving to the examination room for examination of breathing and pain.

21:50

When the patient and doctor return to the consultation room, the doctor says that there is 'not quite as much air going into the right side of the lungs' and that there is no sound of infection. He proposes changes to pain medications. There is more talk about mobility problems and feeling weak and tired. The patient now says he does not do anything; that he fights to get himself better, but that the lack of breathing stops him.

23:50

Prescriptions of medications are discussed and written.

27:20

The doctor asks patient what the oncologist said about the X-ray he had recently. The brother's and patient's response refer to 'a rough cough'. The patient again mentions the radiotherapy, and that the oncologist said it would help with the cough and the blood. The patient seems to wind down this topic by saying 'that's what I mean, so far I'm good'.

28:00

Clip two (42 seconds) begins: the doctor gives a summary, including the fact that the patient has been much less well, then asks the patient if he has had a chance to think about what might be coming next.

The patient's response focuses on follow up after his recent radiotherapy, and the fact that he doesn't have an appointment with the Oncologist unless he becomes more ill or gets worse. Talk then returns to the issue of the experimental drug trials.

29:30

Clip three (4 minutes 27 seconds) begins: the doctor asks the patient a question about 'what will happen....', and also returns to the patient's earlier comment that sometimes he thinks 'this is it'. The patient talks about recognising that his time might be up, but also wanting to live. The doctor raises the issue of plans for the future, the patient resists in some ways, but they do move to talk on preferred place of dying.

They talk about what the patient would want were he admitted to hospital, but not getting better, and the pros but also the cons of hospitals and, by implication, the cons of dying in a busy, noisy hospital.

33:45

The doctor raises the option of coming to the hospice, as somewhere peaceful. They talk about this a little. The doctor notes that the patient does not have to decide today, but says that talking it through is useful. Eashan says he does not mind, that he has thought about it, but not in a lot of detail.

35:30

The patient talks about the hospice, asks the doctor how many beds there are, and says he has friends who are familiar with the hospice and that it is a good place.

36:00

The patient now asks 'is there anything for me like treatment? Or do you reckon that's it now, I'm just counting days, or well months or, you know', adding 'I don't mind you being honest.' The doctor responds, over a number of cautious turns, that trial treatments have a very small chance of helping, and he talks about the burden of travelling to the trial centre versus the small chance of benefit. He says he knows the patient has people to live for, and the patient says he is still keen on the trial.

37:30

The doctor says: 'hopefully you will feel well enough to try it'. He raises the fact that even if he starts, at some point he will stop the trial. He says that at some point the patient will feel weaker. He says that given how quickly things have changed in the last month, it is not going to be years, it is going to be a matter of some months, a few months, and implies it will not be more than six. Then he says: 'I don't know what you think about that'.

38:30

Eashan says he has heard this many times before. He talks about the need to try to keep strong, and to be better for his family. The doctor notes the uncertainty of the future, and counsels spending time with family, trying to enjoy what there is to enjoy. Eashan says

OK, and they move into making arrangements for future appointments and organising prescriptions.

39:30

The brother asks: 'So next time he is in pain we can call you?' and the doctor confirms this. The doctor raises Macmillan nurses, the patient says he has not been in touch with them for a while, the doctor proposes getting in touch with them to ask them to be in touch with the patient.

40:45

They arrange a next hospice appointment, the doctor assures him he can come earlier if he needs. He types prescription and appointment letters. As the consultation draws to a close, the patient says 'It does help to come here' and that 'it clears questions in my mind, it is just if you see somebody you feel good.', and 'Makes you feel looked after'. The consultation ends with goodbyes.

EASHAN CLIP 1 TRANSCRIPT (1 MINUTE 8 SECONDS)

15 minutes into the consultation. In replying to the doctor's questions about what goes through his mind, the patient talks about sometimes thinking 'this is it'.

Doc: And when the pain's bad and you're f- start to feel a bit panicky, can you can you remember what's going through your mind at that time?
Pat: It's just cough. One af- It's terrible
Doc: So cough, cough, cough
Pat: Cough, cough, cough. And...
Doc: And what do you- what- what do you-
Pat: My eyes goes funny and I just- I w-
Doc: What do you think's going to happen? What's- What are you thinking? It's difficult to answer
Pat: A very rough tough time. Sometimes I feel like, 'Oh this is it now'
Doc: Right. Okay
Pat: Yeah. I mean I shouldn't be saying- but I mean sometimes I do feel it-
Doc: Sometimes you wonder if this is it
Pat: Yeah. Just wondering yeah
Doc: Mm
Pat: I feel like it's coming now, it's coming
Bro: Mm
Doc: Right. That must be frightening
Pat: Then u- Makes me frightened. Yeah it does
Doc: Mm
Pat: So yeah
Bro: Sometimes he says that, 'That's it. Are we going to hospital?'
Doc: Right.
Bro: And then- I think he's scared of that
Doc: Yes
Bro: That, you know, 'Once I've gone in, he's not going to come out.' So...
Doc: Is that right?
Pat: Yeah
Doc: Yeah
Bro: So he does feel that. So he does. That's why he really try to stay on top of
Doc: Mm
Bro: it, you know. That he doesn't he doesn't want to go back there
Doc: No
Pat: I mean when the doctor saw me, I felt frustrated.
Bro: Yeah
Pat: And I thought, 'I'm bad. I need somebody'

EASHAN CLIP TWO (42 SECONDS)

28 minutes into the consultation. The doctor gives a summary, including the fact that the patient has been much less well, then asks the patient if he has had a chance to think about what might be coming next.

Pat: That's what I mean, so far I'm good
Doc: Okay
Pat: With the radiotherapy
Doc: Okay. Um um so what- so what I'm hearing is that you've been much less well the last month. You've had the radiotherapy. Waiting for the Royal
Pat: Yeah
Doc: Um I don't know what you think might be coming next. Have you had a chance to to think that through?
Pat: No
Doc: Mm
Pat: Probably- when I'm in for radiotherapy
Doc: Mm.
Pat: The nurses- the nurse asked me, 'Oh-'
Doc: Mm
Pat: 'Have you got after...' What was it? You know, after you have radiotherapy you see a doctor. I said 'no'. She said 'let me go and look at my notes'

EASHAN CLIP THREE (4 MINUTES 27 SECONDS)

29 minutes 30 seconds into the consultation. The doctor asks Eashan a question about 'what will happen....', and also returns to Eashan's earlier comment that sometimes he thinks 'this is it'. Eashan talks about recognising that his time might be up, but also wanting to live. The doctor raises the issue of plans for the future, Eashan resists in some ways, but they do move to talk on preferred place of dying.

Doc: Okay. So that's one h- so that's one thing, is hoping that the Royal will have treatment that'll work.
Pat: Yeah
Bro: Yeah
Doc: Do you ever wonder what'll happen if they don't have treatment that works?
Pat: No.
Doc: Because you've said-
Pat: It's a long wait, isn't it? Eh?
Doc: Yeah.
Pat: There's nothing else.
Doc: No. And you were saying some-
Pat: They have been very honest, there's nothing else.
Doc: No.
Pat: Because you guys gave me all chemo and there is nothing el- more chemo you guys can give me.
Doc: No. No.
Pat: Radiotherapy, last time he said, 'I won't give you any more', but he- luckily he gave me one more.
Doc: Mm
Pat: Just to...
Doc: Mm
Pat: Yeah, it's a long wait now.
Doc: It's a long wait
Pat: I've got no idea what...
Doc: Mm
Pat: The worst thing is I'm getting worse
Doc: Yes
Pat: So my mind plays up a little bit
Doc: Mm.
Pat: And I hope it's not my time yet. Heh
Doc: Yeah..because-
Pat: Being very honest.
Doc: Because you said when the coughing was bad, sometimes you wonder if it might be then.
Pat: Oh yeah, yeah, oh yeah. When the coughing is really bad, it's/it just-
Doc: Mm
Pat: I think about it

Doc: Mm
Pat: Sometimes you don't want to think about it but it just comes
Doc: Mm. It's not easy to think about
Pat: It's not easy
Doc: But-
Pat: And now I'm in bed twenty four seven, you know
Doc: Mm
Pat: I've got a family. I've got brilliant family.
Doc: Mm.
Pat: Got really good support from my brothers
Doc: Mm
Pat: my wife, my dad, the hospital, every-... But then when I'm sleeping on my own, I'm fighting a battle on my own now
Doc: Right
Pat: And there's no- nothing there telling me, 'Oh, you're going to treatment.' mentally you feel if there is anything coming
Doc: Yes
Pat: Any treatment or anything, you think, 'Hm...'
Bro: It's something to look through for (?)
Pat: Then there's- there's something happening
Doc: Yeah
Pat: But now they say, 'Oh, everything is stopped.'
Doc: Yeah
Pat: So yeah it worries me
Doc: Yeah
Pat: It scares me, not worries me
Doc: Scares you
Pat: That probably my time's up
Doc: Mm
Pat: If it's up, it's up. I can't- There's nothing nobody can do but-
Doc: No. No. But it's...
Pat: We- It's just that I've got a daughter she's only- she's only thirteen. You know, I feel like, 'I wish I can get couple of years.'
Doc: Mm.
Pat: 'Just fighting all this.'
Doc: Yes.
Pat: And...
Doc: You want to be there for them
Pat: I don't mind really(?) but I'm thinking only when she's fifteen I might think, 'Oh I need a couple more years' Just being greedy I would say
Doc: Well it-
Pat: I think the thing- bottom line, I think I just want to live
Doc: Yes
Pat: Heh heh
Doc: Yes
Pat: That's what it is
Doc: That's understandable

Pat: That's what the bottom line is
Doc: Yes. Do you s- Do you... When you think about the kind of, you know, if the- if time's getting short, worst case scenario, almost, do you have things that are important for you then or plans you want to make for that?
Pat: No, I won't plan anything
Doc: Mm
Pat: I'm happy as it is. I'm...
Doc: Mm.
Pat: I'm supported by a good family
Doc: You've got a good family, yeah
Pat: And a good wife and I'm happy
Doc: Mm. Um- And if you were very unwell for example would you stay at home and be s- looked after at home?
Pat: No
Doc: What would you do?
Pat: Well, that's one thing I've not decided but, yeah, if I'm going to be very ill-
Doc: Yes.
Pat: If they're going to... because I had a care plan. My GP gave to m- made me a care plan.
Doc: Yes
Pat: So she put all this in that
Doc: Yes
Pat: You know she asked me the same question
Doc: Yes
Pat: And I said, 'Look. If I'm really ill-'
Doc: Mm
Pat: 'I'd rather be in the hospital and they try and look after me and see if I can get less pain and maybe they can treat me.'
Doc: Mm
Pat: I don't want to just die at home.
Doc: You-
Pat: And not treated me.
Doc: No.
Pat: I'd rather they treat me, and then if die, I die.
Doc: Right.
Pat: I rather would go in the hospital or where they would look after me.
Doc: Mm-hm. Would you come here, as opposed to hospital? Or would you want to go into hospital?
Pat: That's one thing I'm not sure sure of. Heh heh
Doc: No.
Pat: No. I mean I don't mind here.
Doc: Mm.
Pat: And I heard this been looked after well, but...
Doc: Mm.
Pat: I think and down here it's like the dead-end
Doc: Mm-hm
Pat: After here there's nowhere else

Doc: Mm-hm
Pat: You know
Doc: Mm-hm
Pat: So I'm a bit scared. But if I have to, I have to
Doc: Mm
Pat: I don't mind
Doc: It's difficult isn't it? Because I hear what you're saying. It's im- it's helpful to have hope and treatment might work. Sometimes you come to a point where people know treatment won't work
Pat: Yeah. I know
Bro: Mm
Pat: Yeah
Doc: And then... it feels- is it helpful then to go to the hospital where it's busy and noisy and...
Pat: Oh it's ridiculous yeah, hah
Bro: I think-
Doc: All that- you've-
Bro: I think-
Doc: Mm
Bro: I've seen him a couple of times in hospital
Doc: Yes
Bro: He is not very happy
Doc: No.
Bro: It's a busy hospital, you know, nurses are good things, you know. And
Doc: Yes, that's the reality isn't it it's busy and
Pat: It is
Doc: Yes.
Pat: It's the best in the world, but still at the end of the day, I'm a number.
Doc: Mm.
Pat: To them I'm just one number.
Doc: Mm.
Pat: And they're very busy.
Doc: Mm.
Pat: I would like to die peacefully somewhere like this place, yeah.
Doc: Right right

EASHAN - SOME LEARNING POINTS FROM A CONVERSATION ANALYSIS PERSPECTIVE

In the first clip the doctor asks the patient about his thoughts and feelings in relation to his symptoms. Eashan's responses include "Sometimes I think: 'Oh this is it now.' This we could describe a 'cue' that the doctor can then pick up on in a movement towards talking about end of life and advance care planning. In the second clip, the doctor asks a question that could open up these opportunities, asking Eashan if he has thought through what might be coming next. But at this point, the conversation does not work towards talk about dying and advance planning. In the third clip, the doctor returns to asking about the future, and to the 'end of life relevant' matter raised in the first clip – that Eashan sometimes wonders if 'this is it'. The conversation now moves to a good deal of talk about dying, about not wanting to die and wanting to fight. The doctor raises 'worst case scenario' planning, and the talk moves gradually towards talk about preferred place of death.

- This case can be used to prompt discussion about how practitioners sometimes have to balance attention to hope and optimism and to a patient's current focus on these, with input that will provide the patient with opportunities to consider or recognise that they may die soon, and that allows them opportunities to consider and influence their care at the very end. Several times Eashan suggests he does not want to engage with the topic, but several times, he does in fact go on to engage with the topic (and, as the case synopsis describes, at the end of the consultation, the patient remarks to the doctor how helpful it has been to talk things over with him). This is a helpful case for (1) thinking about how people can be 'in two minds' about whether or not they wish to engage in talk about dying and end of life care, and (2) that what patients and relatives end up talking about is very much influenced by the healthcare professional's questions and also their responses to what patients and relatives say. Some consideration of how what people say relates to their inner thinking can be found in the first chapters of two books listed below[1, 2]

- You may notice that the doctor tends not to make proposals about what the patient may be thinking and feeling in relation to dying. Instead he asks questions that strongly encourage the patient himself to report on his feelings and thoughts. Notice that the questions he asks do not presume knowledge of what the patient is feeling and thinking[3]. In this case, whilst the doctor in some ways takes the lead in getting dying and end of life care planning onto the conversational surface, he does so in a way that results in Eashan actually making the most direct references to it: from "Sometimes I think: 'Oh this is it now." through to clip three in which he notes that "probably my time's up" and then later: "I would like to die peacefully somewhere like this place, yeah." Doctors in the set of recordings upon which Real Talk is based by and large make the running in terms of getting the topic of dying and end of life care onto the conversational surface. But they often do so in ways that mean it is the patient who makes the crucial moves in doing so. (As an analogy, envisage a cycle race in which the doctor is the pace maker, but peels off at just the right moment for the patient to take the lead). A number of communication practices used by practitioners can allow a patient to make the crucial moves[4]. One is asking questions about the patient's thoughts and feelings. Another is to encourage discussion of what the patient has already been thinking about in relation to their dying. We see this in clip two when the doctor

says: “I don’t know what you think might be coming next. Have you had a chance to think that through?” At first, this meets with little success in that the patient moves to talk about practical arrangements that are coming next. But in clip three the doctor’s: “Do you ever wonder what’ll happen if they don’t have treatment that works?” meets with some success in moving the topic forward. Encouraging patients to talk about what they have already been thinking about helps create a sense that dying and advance care planning are not matters that are solely on the health professional’s agenda, but rather are things already on the patient’s agenda.

- Like other examples, for instance in the Lynn Real Talk case, we see the doctor asking a feeling/thinking question (in clip one) that results in the patient saying something that implies dying, (‘this is it’), and the doctor later returning to what the patient has said in order to move talk towards dying and end of life plans.

- In the third clip, we hear Eashan telling the doctor that, if he is honest, he just wants to live. Throughout the consultation, Eashan very clearly expresses his efforts and desire to live longer. It seems clear that the doctor is concerned that in fact Eashan might die soon (the doctor is particularly keenly pursuing talk about dying, and Eashan has reported being in bed 24/7). Eashan’s ‘I just want to live’ presents a communicative dilemma for the doctor, which he deals with through displaying empathy ‘That’s understandable’ and through conveying advance care planning in a softened form which conveys it as just in case rather than vital because the end is near – he refers to ‘worst case scenario planning’ (this is similar to the ‘rainy day planning’ phrase we hear in the Sam case). Joe Ford and colleagues have written about how practitioners in palliative care display empathy in certain difficult situations[4]. They note: “our paper on empathy shows that it doesn’t simply work to help with rapport-building or helping the patient ‘feel good.’ Instead, it can be integrated into healthcare tasks, softening and adding a human dimension to what could otherwise be a detached, rationalistic process. While this integration is of particular benefit in palliative care (where patients’ emotions are likely to be especially strong and practitioners’ tasks particularly difficult), it could also be important in any context where experience and expertise somehow come into conflict.”

- As a final point, healthcare professionals need to decide in any individual situation whether and how hard to encourage talk about end of life. Some communication practices make it particularly easy for a patient to opt not to move towards this topic, others push harder towards it[5, 6]. In the case, the d
- octor opted to repeatedly encourage end of life talk with a patient who had been deteriorating rapidly, it seems the doctor here decided it was in the patient’s best interests to encourage end of life talk fairly strongly.

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Module Two – How long have I got?

Real Talk Case Five - Lucy

CASE SYNOPSIS (Keywords, Background, Clips, Overview of consultation)

KEYWORDS

difficult questions, life expectancy, imminent dying, uncertainty, empathy, pain, distress, desire to die, advanced cancer, hospice inpatient.

BACKGROUND

The patient, Lucy, has peritoneal cancer. The doctor has known her for some months and has seen her on several prior occasions. Another doctor saw Lucy when she was admitted the previous Sunday with symptoms suggesting obstruction. The patient had had a previous episode of bowel obstruction from which she recovered, and she had a few weeks at home. The doctor is seeing the patient within her ward round.

The consultation lasted approximately 17 minutes.

After the consultation, the patient rated this doctor as excellent on all ten dimensions of the CARE 'Care and Relational Empathy' questionnaire.

CLIPS

There is just one clip, taken from towards the end of the consultation – the foregoing talk has been mainly about Lucy's acute abdominal symptoms and their management. As the clip begins, the doctor asks Lucy if there is anything she wants to ask her. This provides an 'opportunity space' in which Lucy asks a question about how much time she has left. In the way Lucy asks her question, she makes some reference to knowing that it is difficult to be precise or certain about this. In the collection of recordings from which this case comes, patients often indicate this understanding. Lucy conveys that she is asking this 'how long' question in a context where it feels to her that death is taking too long to come – using a metaphor: the grim reaper. In this, the patient indicates some readiness for death. The doctor now starts to respond. First, she ascertains what the patient already knows, understands, and has been told about her life expectancy, also about her feelings in relation to this. In talk about life expectancy in our recordings, doctors and patients recurrently talk about what the patient knows, understands, has been told, and feels. The next part of the doctor's response – in which she refers to an estimated time frame - comes in a context where she has ascertained the patient's understanding and emotional perspective, so she can fit what she says to what the patient has revealed. The doctor gives an estimate by

indicating she agrees with that given by another doctor to Lucy a few days earlier. The doctor then emphasises the difficulty of being precise and also returns to emotional responses to being given a (short) prognosis. She raises this in general terms – by talking of what 'some people' find difficult to 'get their heads'. The patient responds in terms of her own feelings.

OVERVIEW OF CONSULTATION

Pseudonyms for people present or referred to in the consultation:

- The patient is Lucy.
- A member of nursing staff and a registrar are also present in the room.

Approximate timings are given as minutes:seconds and have been rounded up or down for simplicity.

00:00

The doctor greets Lucy, and checks her awareness of and her agreement to recording. There is a conversation about Lucy's symptoms: pain, discomfort, stomach distension and lack of appetite. They talk about these symptoms and their management. The doctor remarks that last time Lucy came into the hospice, this was due to a blockage, and how the current episode is very similar. Lucy agrees. There is more talk about the pain and the effects of current medications.

04:00

After asking her permission, the doctor examines Lucy, and as she does so, she asks Lucy various questions about sensations and their locations.

05:00

The doctor washes her hands, and remarks that it is all a bit disappointing. Lucy agrees. They talk about how she 'bounced back' last time. The patient raises eating as an issue, the doctor asks questions about this, and about vomiting and they talk about this for a while.

06:30

There is lengthy talk about medications, how these should be taken (i.e. by injection). The doctor summarises the medications proposed, and some reasons for these. Lucy softly moans towards the end of this. The doctor asks if she needs a pain killer now, Lucy agrees, and becomes distressed. She is crying, says she has had enough. Lucy apologises for crying the doctor says 'It's alright', and comments: 'you're usually so active, it is really hard, must be really hard for you'. In a sotto voce voice, the doctor asks the nurse to go and organise a pain relief medication.

10:00

Lucy says that she is in so much pain that she is 'getting where I don't want to be here anymore, just, alive'. The doctor says 'I know', as Lucy ends her talk, the asks if she thinks 'about dying a lot?'. Lucy says she feels like it's coming to the end. She remarks on her the way her body is acting now and contrasts this with how she has always had a healthy appetite. The doctor asks: 'Are you happy to stay here for the moment' [meaning at the hospice], and Lucy says, 'Yes, I feel safe.' The doctor says: 'Well we're happy to have you' and says they are trying to get her more comfortable.

11:15

After further brief talk about medications and symptoms, the doctor says how sorry she is to see Lucy so uncomfortable. She proposes going through the medication chart outside the room, and that they might increase some dosages. Lucy agrees. The doctor says: 'Hopefully with the changes we make, things will settle, but we'll keep everything under review for you.'

12:20

Clip one (2 minutes 38 seconds) begins: the patient conveys her interest in 'how long', and the doctor responds.

The doctor asks Lucy if there is anything she wants to ask. In response, Lucy moves into talking about how long she has to live. Lucy has already referred to asking other doctors. In the first part of her response to Lucy, the doctor first checks what she knows/thinks/understands by asking what the other doctor said. When Lucy says 'a month or so', the doctor asks Lucy how she feels about that. They talk a little about these feelings, and about how it is understandable that she might feel she wants to die. The doctor offers hope that they will 'get on top of things', agrees with the 'about a month' estimate, and mentions the difficulty of being exact. Lucy says she is 'fine with it', then remarks on how strange it is: 'when you start to get quite poorly and you realise it's not going to be that much longer'. The topic ends when the nurse comes into the room with the analgesia injection.

15:30

The doctor says they are doing everything they can to get rid of this pain, and she encourages Lucy to use her call buzzer. Lucy asks the doctor if she should have 'drainage'. The doctor says she thinks the pain is being caused by air rather than fluid, Lucy indicates her understanding of this, and they further discuss the symptoms.

17:00

The doctor says she is sorry Lucy is in so much discomfort, and that she hopes things will settle down. In Lucy's hearing, the doctor asks the registrar, who is also in the room, to come back and see Lucy later.

17:15

The doctor thanks Lucy for seeing her. They exchange thanks and goodbyes.

LUCY TRANSCRIPT (2 MINUTES 38 SECONDS)

There is one clip. 12 minutes 20 seconds into the consultation. The patient asks a 'how long' question, and the doctor responds.

Doc: Hopefully with the changes we make, things will settle down, but we'll keep everything under review for you
Pat: Okay
Doc: Is there anything else I can do for you today?
Pat: No
Doc: Anything you'd like to ask me?
Pat: I think I've asked the other doctors. About... the... You can't tell, I know you can't say how much time I've got left. But I do- I feel- I feel like I'm waiting for the Grim Reaper but I don't know when he's coming. And I do feel a bit like he's too long
Doc: What did the other doctor say?
Pat: On Sunday the doctor said he probably thought I'd got a month or so
Doc: Mm, ok,
Pat: Because of the way my stomach is filling with fluid
Doc: Mm
Pat: and the cancer's reacting
Doc: Mm. What did you feel about that?
Pat: Well I know- I don't mind because I know I'm going to die. It just feels like you wish you knew when really. When you're in pain it is
Doc: Mm
Pat: Because it's so horrible
Doc: As you are at the moment, I guess it can't come too soon
Pat: No
Doc: Um hopefully we'll get on top of things, you'll feel calmer about things. Um I think what he said is probably about right. Unfortunately we can't be exact because we get it wrong
Pat: Yeah, of course you can't
Doc: Everybody's different. So we can only give people if you like our best guess
Pat: Yeah
Doc: Which some people do find quite difficult to get their heads around
Pat: No, I'm fine with it because I knew it was coming any- I've been fine with it a long while
Doc: Mm
Pat: But I just think it's very strange when it- when you start to get quite poorly and you realise it's not going to be that much longer. While I'm in this much pain it feels like it's more like weeks than a month
Doc: Right, right
Doc: Here she is [nurse arrives with an injection to help manage Lucy's pain]

LUCY - SOME LEARNING POINTS FROM A CONVERSATION ANALYSIS PERSPECTIVE

There is just one clip, it comes towards the end of the consultation – the foregoing talk has focused mostly on Lucy's acute abdominal symptoms and their management. As the clip begins, the doctor asks Lucy if there is anything she wants to ask her. This provides an 'opportunity space' in which Lucy asks a question about how much time she has left. In most of the episodes of talk about life expectancy in our recordings, the patient raises life expectancy, 'how long', after the doctor gives the patient opportunities to raise things[1].

- In the way Lucy asks her question, she makes some reference to knowing that it is difficult to be precise or certain about this. In the collection of recordings from which this case comes, patients often indicate this understanding[1]. It seems important for both doctors and patients to establish an understanding that precision is not possible.

- At the start of the clip, notice the doctor asks Lucy two distinct questions, one about things she might be able to do for her, a second about things Lucy might like to ask. This works well in that although Lucy responds no to the first question, she takes the second question as an opportunity to ask about something that is a concern to her.

- Each 'How long have I got' case in the Real Talk materials is different in terms of the context in which the patient asks the question. Here, Lucy implies her question comes in a circumstance where she feels read to die – having mentioned the Grim Reaper, she says "I do feel a bit like he's too long". In other cases, patients convey they want more time and/or want to know so as to plan what they do in the time remaining to them. However, whatever the context in which the question is asked, there seem to be common features in how the doctors we recorded respond. We see these here. First, if the patient has not already volunteered it, they try to ascertain what the patient already knows and understands – in this case, the doctor does this by asking Lucy what she has already been told. This means that when the doctor gets to the point of giving some estimated time frame, they can do so in a context where they have already ascertained something of the patient's understanding and emotional perspective. This allows them to fit what they say to the individual patient's understandings and needs. Turning to giving difficult and bad news more broadly, when doing so a practitioners can seek the patient's perspective first before actually delivering the news. Getting the patient's perspective first means the practitioner can fit what they say appropriately to the patient's understanding and emotional state, and convey the news both sensitively and effectively bringing the patient towards a realisation of their situation[2,3].

- The patient is clearly distressed during much of the recording and we can see within this clip the doctor responding to this emotional context in several ways – noticeably her posture and positioning, and the softness of her voice. During the clip she also (1) asks Lucy about her feelings, and (2) conveys she has some understanding of how Lucy may be feeling – she responds empathically. When we respond empathically, we convey that we in some degree apprehend or comprehend the other person's emotional state or condition – what they are feeling, or would be expected to feel[4]. We see the doctor here doing so very specifically with regards Lucy's current circumstances: "As you are at

the moment, I guess it can't come too soon", and then by referring more broadly to the fact that 'some people' find it hard to 'get their heads around' end of life estimates. Lucy's response to each of these bits of talk by the doctor suggest that she has said the right thing for Lucy and her circumstances. (Further reading on empathy from a conversation analysis or interactional perspective: Ruusuvuori 2005, Hepburn & Potter 2007, Ruusuvuori 2007, Heritage 2011).

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Real Talk Case Six - Curtis

CASE SYNOPSIS (Keywords, Background, Clips, Overview of consultation)

KEYWORDS

difficult questions, life expectancy, uncertainty, advanced cancer, hospice inpatient

BACKGROUND

The patient has been admitted with severe pain and vomiting, this has settled by the time of the conversation that we recorded. He has cancer of the bowel with extensive metastatic disease, and a stent inserted for nephrosis. Scans have shown his cancer is growing. He has recently had radiotherapy to treat pain from nerve root compression in his lumbar spine. The doctor has known the patient for some months.

The consultation lasted approximately 15 minutes.

After the consultation, the patient rated this doctor as very good on all ten dimensions of the CARE 'Care and Relational Empathy' questionnaire.

CLIPS

There is one clip. In it, the patient asks a how long question, the doctor responds first clarifying what he is asking, then subsequently giving a figure: 'we're looking at months' as well as talking about the kinds of things one uses to judge 'how long', these being his recent deterioration, the fact he is not having treatment for the cancer, and the expectation that the cancer will carry on growing. It is relevant to note that the doctor subsequently returns to the patient's 'what kills you question' and responds to it – this is described in synopsis below, at 10 minutes.

OVERVIEW OF CONSULTATION

Pseudonyms for people present or referred to in the consultation:

- Patient's name is Curtis.
- There are two other people in the room: a nurse who helps the patient from the garden and into his side-room at the start of the consultation and back out again at the end, and one of the hospice registrars.

Approximate timings are given as minutes:seconds and have been rounded up or down for simplicity.

00:00

The patient makes his way into the room. The doctor greets Curtis, checks he knows the registrar and nurse who are present, and checks he knows about and agrees to the recording. She then asks him how he is. They discuss his pain and abdominal symptoms and their treatments, Curtis reports there has been considerable improvement. They discuss the fact that he is going home this afternoon, and who will be looking after him.

04:30

There is a discussion about a consultation with another doctor who provides nerve blocks, this ends with agreement that a block is not needed at the moment as he has no pain.

05:30

The patient asks what his scans said, and the doctor says that unfortunately it shows his disease has progressed, she talks about where there is cancer, and how this connects with his symptoms, the patient asks about radiotherapy and where it has treated him.

06:20

Clip one (2 minutes 22 seconds) begins: the patient asks 'how long do you reckon it'll all take?', the doctor responds first clarifying what he is asking, and then she gives a figure: 'we're looking at months' as well as talking about the kinds of things one uses to judge 'how long': his recent deterioration, the fact he is not having treatment for the cancer, and the expectation that the cancer will carry on growing.

08:45

They move to discussing what radiotherapy does. The doctor mentions that last time they had talked, he had said he did not want chemotherapy again, they discuss chemo and decision making about it (weighing up possible benefits versus being unwell), and the patient is clear that he 'does not fancy being on chemo again'.

10:00

Curtis seems to wind down the chemotherapy topic. Then he returns to the issue of what one dies from: 'What actually does- Do you just fall asleep in the night or nobody knows or?'. The doctor responds that the usual pattern is becoming more and more frail and sleeping more. She mentions that kidney problems can affect how you die, and liver problems too – that jaundice can be a sign of things speeding up. She discusses how it is not possible to be exact about what is going to happen. She tells him they will 'keep an eye on him and deal with things as they develop.'

12:00

Curtis mentions a forthcoming oncology appointment. They talk again about chemotherapy, and he talks about how he did not have good outcomes last time he had it, and that he thinks that if he had chemo again, it would probably 'knock him for six', doctor says it could do.

12:30

The patient now says: 'It's a terrible thing though isn't it, I thought I'd rather just go' but that it 'has to wind its way around your body first doesn't it, make you feel bad?'. The doctor says yes, and she suggests his body is quite strong, so it can take time. They then move into making arrangements for a hospice clinic appointment, and for a specialist nurse to get in touch with him at home. The doctor tells the patient he can phone the hospice in the meantime. She does a bit of 'managing expectations' – saying that it may be that the hospice would then say he needs to contact his GP.

14:30

As the consultation seems to be drawing to an end, the doctor asks the patient 'Has anything I've said surprised you particularly?'. Curtis replies 'No not really. Just the way it's affecting, you know, it's come on.... But if it's there, that's it now.' The doctor listens, says she is sorry.

15:00

Curtis raises the issue of his syringe driver, implying that it is troublesome to carry around. They discuss the pros and cons of having it, and that removing it would risk a worsening of his symptoms, Curtis agrees to the proposal not to remove it at present.

15:40

The doctor talks about what she will write in the discharge letter to the GP and specialist community nurse. She asks Curtis if he has any questions, he says no, together, they start to bring the consultation to a close. The doctor tells the patient he can call the hospice if there is anything else. The patient gets up off the bed and the nurse helps him back outside into the garden.

CURTIS TRANSCRIPT (2 MINUTES 22 SECONDS)

There is one clip. 6 minutes 20 seconds into the consultation. The patient asks a 'how long' question, and the doctor responds.

Pat: So it's growing? [his cancer]
Doc: Mmm
Pat: Blimey. So how long do you reckon it'll all take? Do you reckon it takes years before or weeks or months or what do you reckon?
Doc: When you say it all takes, what do you mean by that?
Pat: Well gets a hold of you properly and kills you? What kills you? Because you know what I mean? It's-
Doc: Yeah I mean, that's an interesting question because some people just have a little bit of cancer and they're really unwell with it and other people can have it wide-spread
Pat: Yeah
Doc: and are remarkably well with it
Pat: Yeah
Doc: So what kills you is a difficult thing to answer because it depends where it is and what it does
Pat: Yeah
Doc: Um how long is it going to take to s-... to kill you? Is that what you're asking me?
Pat: Yeah Roughly
Doc: Roughly I think if we go by how things have changed in the last few months then probably we're looking at months
Pat: Yeah
Doc: Yeah
Pat: Right
Doc: So one looks at the speed at which it's growing but also at which you're changing
Pat: Yeah
Doc: You look remarkably well today
Pat: Yeah
Doc: And that's great, but I've seen you not so well, and when I compare you to how you have been in the past
Pat: Yeah
Doc: Um you're frailer
Pat: Yeah
Doc: I'd say
Pat: Yeah Yeah Yeah I am, my build....
Doc: Yeah
Pat: My build and my body and everything isn't it?
Doc: Yeah
Pat: t's all frailer. Yeah. Arms, everything
Doc: Yeah

Pat: Yeah. So that's it then. It just- it'll just keep growing now then?
Doc: Um-hum. Well we're not giving you any treatment to actually treat the cancer per se
Pat: Yeah Right
Doc: So one would expect that it will carry on growing
Pat: Right. So there's nothing to stop it now then really?[the patient's phone rings]
Doc: No
Pat: No Okay So the radiotherapy won't stop it no more, no? [phone still ringing]
Doc: The radiotherapy treats- Do you want to just turn that off..... or do you need to answer it?
Pat: I don't know how to turn it off
Doc: Oh, you did it Well done [Laughs]
Pat: I think so, yeah
Doc: Um the radiotherapy treats specific areas. So it doesn't treat the cancer as a whole
Pat: Right

CURTIS - SOME LEARNING POINTS FROM A CONVERSATION ANALYSIS PERSPECTIVE

The patient asks a how long question, the doctor responds first by clarifying what he is asking, then subsequently giving a figure 'we're looking at months' as well as talking about the kinds of things one uses to judge 'how long': his recent deterioration, the fact he is not having treatment for the cancer, and the expectation that the cancer will carry on growing. It is relevant to note that the doctor subsequently returns to his 'what kills you question' and responds to it – this is described in synopsis.

- The doctor's task of providing a patient with a prognosis in a sensitive but realistic manner seems especially complicated and challenging here for a number of reasons. As detailed below – the patient's question rather sharply switches the direction of the conversation they have been having. Also, the patient appears to have limited awareness of his terminal situation and the fact that he is not receiving any treatments that will inhibit the progression of his cancer

- Up until just before the start of the clip, their conversation has been very focused on the good news that following an acute episode of abdominal pain and discomfort he is now feeling substantially better and is about to go home. This means that her explanation that she estimates 'months' on the basis of the speed of his deterioration involves shifting from upbeat talk about recent marked improvement, to talk about long term deterioration. One way to sensitively make such shifts in conversation is to provide some context. This doctor does so by noting that 'some people just have a little bit of cancer and they're really unwell with it and other people can have it widespread [as he has] and are remarkably well with it [as he currently is].

- As in other recordings from the research on which Real Talk is based, the doctor first clarifies what the patient is asking. This leads to something of a complication in that at this point he also raises a different question: 'what kills you?'. The doctor responds to this question later in the consultation. Here, the doctor opts to stick to answering the question he first put as 'how long do you reckon it'll all take?' after first clarifying: 'how long is it going to take to s- to kill you? Is that what you're asking me?'. One element of skilled practice involves the practitioner being able to hold in their head, then come back to matters a patient has mentioned earlier.

- Sometimes, as here, it is not clear if a patient recognises their terminal diagnosis, and that no curative treatment is occurring – even if this has been discussed before. We see the doctor gently but clearly clarifying this with Curtis. This is done in a gradual, stepwise manner, moving from 'You look remarkably well today, and that's great' to 'when I compare you to how you have been ... you're frailer', to we're not giving you any treatment to actually treat the cancer.... So one would expect it to carry on growing'. At each step, she gives the patient an opportunity to respond, which he generally does, agreeing and confirming what she says with yeah's and 'I'm frailer yeah' and so on. This is a form of stepwise building of agreement and understanding, step by step, gradual and cautious movement towards a topic is an important practice in healthcare communication, particularly when difficult

delicate issues are discussed, and when helping patients to come to understandings[1, 2].

- As the clip ends, in response to his questions the doctor moves to build understanding about the nature and purpose (i.e. palliative) of the radiotherapy he has recently received.

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