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, questioning patients, 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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