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Learning from patient feedback: a case-study in NHS culture and practice

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> *'Long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the long term rather than providing single, unconnected 'episodes' of care.'* NHS England[1]
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> *'[We must] enable people to look after themselves through improved health education, information and opportunities to self-care and self-manage long-term conditions.'* Cornwall and the Isles of Scilly: Sustainability and Transformation Plan[2]
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> *'There has been significant progress to how the NHS learns from people's complaints. However, there is still much to do so that people can see how their feedback has made a difference and has helped to change the way services are delivered.'* Healthwatch England[3]
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> *'Whistleblowers have provided convincing evidence that they raised serious concerns which were not only rejected but were met with a response which focused on disciplinary action against them rather than any effective attempt to address the issue they raised. ... I have concluded that there is a culture within many parts of the NHS which deters staff from raising serious and sensitive concerns and which not infrequently has negative consequences for those brave enough to raise them.'* Sir Robert Francis[4]

1. Introduction

The above quotations highlight two present-day pressures for cultural change in the National Health Service. One is a pressure for patients to be much more involved in their own care and for the NHS to work in partnership with them. This would amount to a fundamental shift from a 'treatment' model of care (NHS England describes it as a '"factory" model of care and repair')[5] to one based on 'partnership', with healthcare providers working together with patients, supporting them to manage their health conditions in their own home or community.

The other pressure for cultural change in the NHS is a pressure for better learning, as emphasized by Healthwatch England. Here the treatment of whistleblowers described in Sir Robert Francis's report is relevant. It brings out a crucial aspect of parts of the NHS today: the dominant culture is defensive and *anti*-learning.

Unfortunately these two cultural pressures tend to be addressed in isolation. The notion of partnership between patients and providers barely features in the publications of Healthwatch England, while NHS England scarcely mentioned 'learning' in *Five Year Forward View*. But if the NHS is to adapt to work in partnership with patients, it has much to learn.

In Sections 2 and 3 of this report I relate two stories that have a bearing on this point. Section 2 tells the story of an elderly lady living in Penzance and her experience at the hands of the Cornwall Community Nursing Service, while receiving treatment for a leg ulcer. Section 3 tells the story of my own attempt to find out if and how the feedback 'made a difference'. Sections 4 and 5 deal with two particular issues arising out of the case-study – continuity of care and patient anonymity – while Section 6 shows why, in the interest of both partnership and effective feedback, dialogue between patient and provider should be encouraged.

2. The patient story

The patient in this case – let's call her Mrs P – is in her late nineties and lives in Penzance. She is physically frail but her mind is sharp. She worked as a nurse until her daughter was born. The evidence in this case is provided by her own testimony and that of her daughter, who was formerly a barrister. Mrs P chose to remain anonymous: she wanted to avoid being viewed with hostility or suspicion by community nurses or labelled as a troublemaker. And for the same reasons she has not made a formal complaint.

A note comprising the following numbered paragraphs, dated 22 September 2017, was sent to Healthwatch Cornwall and subsequently to the Cornwall Partnership Foundation Trust, which runs the Community Nursing Service.

1. Mrs P broke her hip (fractured neck of femur) two years ago, and was treated in [the Royal Cornwall Hospital at] Treliske. The hip mended very well, but during the surgery the skin of her lower leg was damaged and the damage developed into an ulcer. This was treated weekly for about six months by community nurses, but there was minimal improvement. It was only after six months that one of the nurses applied a paste which had to be left on for a week. That treatment was administered again for a second week. The ulcer was almost completely healed and rapidly disappeared.

2. Four months ago Mrs P accidentally suffered a scratch on her other leg (from her footstool). Her vascular circulation to her lower limbs is very poor, and this scratch, despite treatment from the Community Nurse Service, turned into an ulcer and gradually grew in size. Mrs P asked for the same treatment, the paste which had been so successful, to be applied again. Despite repeating her request several times this has never been done. She subsequently asked for a pressure bandage and after several times of asking this was supplied. (One week a nurse told Mrs P she needed a pressure bandage; the next week a different nurse told her that she did not.) Since then the ulcer has gradually improved, although the competence with which the bandage is applied has varied. The second or third time the bandage was applied she spent the following night with severe pain in the affected leg. In the morning she called the Community Nursing Service: the nurse arrived and asked her what she wanted her to do about it.

3. There is no regular schedule of appointments, which means Mrs P can never be sure on which day she should expect the community nurse to call. (This was also the situation during treatment for the first ulcer.)

4. A different nurse attends almost every week. Very rarely does Mrs P see the same nurse two weeks running. (Again, this was also the situation during treatment for the first ulcer.)

5. Each nurse decides for herself what treatment to give to the leg ulcer. (Once again, this was also the situation during treatment for the first ulcer.) Mrs P has experienced one nurse applying an ointment, only for a different nurse the following week to say that the ointment was not appropriate and 'scrubbing' it off.

6. Some nurses appear not to have read the notes on the patient before they visit. One arrived expecting to treat a cut on Mrs P's arm. She is frequently asked what treatment she has been having.

7. Recently Mrs P had to attend Treliske for eye surgery (laser treatment) as a day patient. She told the community nurse on three occasions about her forthcoming appointment and that she would be out of the house that day. However a nurse did turn up while she was out, and was not best pleased to find that she was not in.

8. Recently Mrs P suffered another fall, and was taken to Treliske by ambulance. A break of her other hip was diagnosed. Her daughter spent the evening with her (getting home at 12.30am) and called the Service the next day, leaving an answerphone message informing them of Mrs P's situation and saying that she would not require a community nurse to visit until further notice. However, a nurse did call in the week beginning Monday, September 18th (leaving a note, undated).

9. It is apparent that the constant changes in treatment waste money. Mrs P has at least three tubes of various ointments and different dressings ordered by different nurses, used once and then never again. And nurses turning up after Mrs P or her daughter has specifically told them that she won't be in amounts to a further misuse of scarce resources.

10. While this vital service is doubtless under huge stress, there is clearly scope for making it more efficient. There would seem to be a great need for staff training and firmer leadership. Potentially the Community Nursing Service is a great service, and it is badly needed in this part of the world with so many of its population elderly and housebound.

3. The follow-up story: Seeking a response to feedback

This is the story of my own attempt to see whether the feedback contained in the above Note 'made a difference'. It takes the form of a 'trail' of emails, reproduced here shorn of greetings etc. but otherwise unedited.

30 September 2017 *Email from PL to Communications Manager, Healthwatch Cornwall*

> Is this [i.e. the patient story] of interest? Have you any suggestion as to how we might progress the matter?

10 October 2017 *Email from Communications Manager, Healthwatch Cornwall to PL*

> We can of course add this information to our patient feedback and we may be able to use as a case study.

13 October 2017 *Email from Secretary-Coordinator, West Cornwall HealthWatch to Locality Support Manager, NHS Kernow*

> One of our members sent the attached patient experience story to Healthwatch Cornwall last month but was disappointed by the response. He is concerned because he wants to see improvements in care in community nursing, and thought that highlighting this story might help focus minds. I would be glad if this can be investigated in some way, and will look forward to hearing from you.

1 November 2017 *Email from Communications Manager, Healthwatch Cornwall to PL*

> If you would like me to use this as a case study, it would be best if I can also contact the person sharing the issue to seek permission to do so. Or perhaps you would like to ask them to call me?

9 November 2017 *Email from PL to Head of Patient Experience, Cornwall Partnership Foundation Trust (CPFT), following a telephone conversation.*

> Good to talk to you just now.
>
> As I said, while Mrs P and her daughter do not wish to register a formal complaint, or indeed to find themselves labelled as troublemakers, they are keen that other patients do not receive the same treatment as Mrs P sometimes did, so I was pleased to receive your assurance that you will pass this information on to the key members of the Service to look into community nursing practices, and will let me know the outcome.

15 November 2017 *Email from Head of Patient Experience, CPFT to PL*

> Thank you for your time last week. I will develop a plan around this and will get back to you with feedback about how this information has been used to improve services.

19 November 2017 *Email from PL to Communications Manager, Healthwatch Cornwall*

> Just to bring you up to date: [*Head of Patient Experience, CPFT]* is looking into this matter, and has promised to let me know the outcome. So as a case-study it is incomplete at the moment: I'll be in touch when we have reached some sort of a conclusion - or if we don't!

12 January 2018 *Email from Head of Patient Experience, CPFT to PL*

> I am still working on this. I will update you in due course.

15 February 2018 *Email from PL to Head of Patient Experience, CPFT*

> As you see, it is now three months since I contacted you about this matter. You told me a month ago that you were 'still working on this' and would update me 'in due course', but as yet you have told me nothing at all about the plan you said you would develop, nor have you got back to me with your promised 'feedback about how this information has been used to improve services'.
>
> I have to say bluntly that I do not find this satisfactory. As you will appreciate, In the absence of a response from you I have no alternative but to seek other avenues to bring

about some improvement in the community nursing service. To judge by the evidence I provided, such improvement is badly needed.

16 February 2018 *Email from Head of Patient Experience, CPFT to PL*

Please be assured that I am ensuring that all colleagues who need to be aware of this feedback/patient experience are being made aware of it, and I will certainly pass back to you any changes in service delivery/design made as a consequence of this.

Apologies for the delay in getting back to you.

1 March 2018 *Email from Head of Patient Experience, CPFT to PL*

Just a quick note to assure you that I am still following up the feedback further to you sharing an anonymous patient story with us before Christmas. I will get back to you asap.

17 April 2018 *Email from PL to Head of Patient Experience, CPFT*

Just to say that I am still looking forward to hearing from you.

No further communication has been received from CPFT since the email dated 1 March 2018.

4. Continuity of care

As the patient story relates, during both episodes of treatment almost every week a different nurse attended Mrs P. Very rarely did she see the same nurse two weeks running. This would have been less upsetting for Mrs P were it not that different nurses had different ideas about what was appropriate treatment for a leg ulcer, and often refused to continue a treatment that another nurse was giving.

So not only was there no continuity of personnel: because of that failure there was no continuity of treatment either. Mrs P's consequent distress, aggravated in the case of the second ulcer by the withholding of the treatment which had dealt successfully with the first, seems to have had no impact on the treatment that she received.

The lack of continuity of care was further aggravated by the evident failure of some nurses to have read the notes on the patient before they visited.

So we see that while the consequences of the lack of continuity of care might have been mitigated by discussions among the nurses involved to agree the appropriate treatment, and by simply reading the case notes before visiting, these opportunities were not taken advantage of.

What seems to be missing from the treatment of Mrs P is any understanding of the impact of the absence of continuity of care on her state of mind. Given also the lack of a regular schedule of appointments, which meant that Mrs P could never know on which day or at what time she should expect the nurse to call, or who would walk in through the door, the situation could hardly be more stressful and anxiety-producing for an unwell elderly person.

5. The anonymity issue

It may be that the Cornwall Partnership Foundation Trust (CPFT) has a problem to do with identifying patients who offer feedback. From their point of view, knowing the identity of a patient who does this enables the staff concerned to be identified and questioned about any treatment given or incidents that took place. But for the patient, different considerations may apply, depending on whether treatment has concluded, e.g. where the patient has fully recovered from an injury or illness, or the patient is continuing to receive treatment.

Where treatment has concluded, the patient will generally have no incentive to conceal any details of the treatment received, or to soften any judgments made. For patients continuing to receive treatment, however, the situation may be very different. Vulnerable patients, like Mrs P, will invariably be reluctant to give their details for fear of being picked on and subjected to 'worse' treatment. This is not uncommon: Healthwatch England reported in 2014 that a recent survey found that over half of people who had problems with health and social care, did not make a complaint. Similarly, 3 in 5 who had experienced or witnessed a problem with health or social care services in the last two years had not made a complaint.[6]

The fact that the Cornwall Partnership Foundation Trust has gone quiet on Mrs P's case leads me to suspect that the fact that she did not register a complaint, which would have involved identifying herself, has been used as an excuse for shelving her case and not responding to emails.

It seems obvious that Mrs P's story should have prompted a review of how nurses work together and decide on treatment, and of what steps might be taken to minimize the stress that patients are under. One would expect a manager who has an interest in providing the best possible care to be perfectly happy to use feedback from patients in this way, irrespective of whether it is anonymous or not.

6. Conclusion: The need for partnership and dialogue between providers and patients

As we saw in the Introduction, there are currently two significant pressures for cultural change in the National Health Service. One is a pressure for patients to be much more involved in their own care and for the NHS to work in partnership with them. This would amount to a fundamental shift from a 'treatment' model of care to one based on 'partnership' between healthcare providers and patients. The other pressure is for better learning, a need emphasized by Healthwatch England.

The story of Mrs P illustrates the resistance that these pressures will have to overcome if they are to make an impact. In no sense did the behaviour of most of the community nurses who visited Mrs P even hint at any kind of partnership between them and her. And the refusal of the Cornwall Partnership Foundation Trust to engage in any dialogue on the subject of her treatment is a clear demonstration of the defensive, anti-learning culture identified by Sir Robert Francis in his report on whistleblowing in the NHS.

Patients' responses to the care that they receive and to consultation and explanation constitute what is widely known as 'feedback'. It may be provided on an individual basis by patients, as in Mrs P's case, or in aggregate form, as in responses to surveys. As we have seen, Healthwatch England is keen to see how learning from feedback is improving care. It also emphasizes the need for people to be able to 'see how their feedback has made a difference and has helped to change the way services are delivered.' *So feedback on its own is not enough: there has to be a response as well. Two-way communication – dialogue – is called for.*

There are several reasons why dialogue between providers and patients should be encouraged:

(1) The provider can use dialogue to 'play back' what he or she thinks they have heard, and check whether they have drawn the correct inferences from the feedback.

(2) A provider's response to feedback can take the form of explaining why a certain action has been taken. This both acknowledges the patient's entitlement to an explanation, and can provide a basis for negotiating a compromise. For example, in the case of home visits by a community nurse, a phone call beforehand could avoid the 'surprise' visit for which the patient is not prepared.

(3) Paying attention to feedback and responding to it shows respect for the patient, it acknowledges their right to have a say, while ignoring it shows disrespect, and discourages future attempts to give feedback. Failure to respond conveys a stark message: 'We are not interested in what you have to say.' Patients will be discouraged from continuing to provide feedback if they cannot see any positive response to the effort they have made.

(4) Dialogue is a necessity if partnership is to be genuine. It positively encourages patients to take an active part in looking after their health.

(5) In formulating a response to feedback, providers have to talk to one another. It is not merely a matter of partnership between provider and patient: partnership between providers is called for. This could help to redress the situation where a community nurse visits a patient unaware of the patient's treatment history.

Finally, it is worth reminding ourselves of Healthwatch England's emphasis on seeing how learning from feedback is improving care:

> [There] is still much to do so that people can see how their feedback has made a difference and has helped to change the way services are delivered.[7]

Amen to that!

Notes and references. All websites last accessed on May 20th, 2018.

[1] NHS England, *Five Year Forward View*, October 2014, p.17
https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

[2] *Cornwall and the Isles of Scilly: Sustainability and Transformation Plan: Draft Outline Business Case.* October 2016, p.12
https://www.cornwall.gov.uk/media/22984634/cornwall-ios-stp-draft-outline-business-case.pdf

[3] Healthwatch England, *Six areas we want NHS England to focus on in 2018*, 10 January 2018
https://www.healthwatch.co.uk/news/six-areas-we-want-nhs-england-focus-2018

[4] Sir Robert Francis, *Freedom to Speak Up*, February 2015, p.8
http://freedomtospeakup.org.uk/the-report

[5] As [1], p.10

[6] Healthwatch England, *Suffering in Silence: Listening to consumer experiences of the health and social care complaints system*, October 2014. pp.2, 10
https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/hwe-complaints-report.pdf

[7] As [3].