We are not human beings in medicine any more

A study of creative writing in the general practitioner consultation

Patricia Ferguson
Novelist

William House
GP researcher

Penny Nettelfield
Research nurse

Summary

This research was born of frustration at the loss of the quirky, colourful character that lurks within both the patient and the doctor. By unconventionally recruiting a novelist to write word portraits, we showed the GPs how they saw their patients – opening an unfamiliar or perhaps forgotten window on their work. Revealing in a different way was the reaction of the patients to the novelist's words about them.

I trained as a nurse and midwife long ago, and have published six novels and a collection of short stories. Some of my stories have also been broadcast on Radio 4. My latest book, *The Midwife's Daughter*, will be out at the end of September.

Patricia Ferguson

I am now a recently retired GP and vice-chair of the British Holistic Medical Association. I have been interested in the interface of medicine and the arts for many years, and more recently ways in which the arts, action research and complexity can be used to build communities.

William House

I have worked on health-related research projects since 1995. I currently work as a practice nurse and for nine years combined that role with that of research nurse working with William House. I am particularly interested in literature and the stories we tell about ourselves and others.

Penny Nettelfield

Introduction

When the GP looks at the next patient's electronic patient record (EPR) on her computer screen she will see one or two recent consultation notes (usually very brief), a summary of past and present medical problems, investigation results, medications, allergies and suchlike markers of health and disease. But is there no space to tell her who is this person she is about to see? Space is found for telling her whether the practice is earning the maximum revenue from this registered patient through the 'QOF' or Quality and Outcomes Framework linking certain health and chronic illness markers to practice income. The QOF matters for health too but what kind of portrait do they paint of the person who is about to come in? They are part of a public health agenda treating the individual as a specimen of the species and the GP as a rational economic actor. That is the implied relationship.[1] Yet a deeper understanding of the nature of the unique individual's gifts and sufferings surely becomes more vital with pressure to conform socially.[2] Attempts to produce a fully comprehensive patient-centred EPR are unwieldy[3] and in any case, a person is unknowable in their entirety, as expressed in poetry by MacNeice and in prose by Cassell.[4, 5] Given that knowledge will always be partial, what part could the EPR play in projecting the *patient as a person*? Attempts to

engage patients in recording their own narratives in a personal EPR have not thrived.[6] There is little published data on the recording of clinicians' subjective impressions and narratives about their patients in the EPR.[7]

Summary of research

Electronic patient records are used throughout primary care in the NHS. They are heavily oriented to scientific and public medicine and give no indication of what sort of person the patient is. What if the GP's computer screen included a couple of lines of free text – an impression of that patient from a previous consultation? What could a GP write that might evoke the *person* in a helpful way? What would the person–patient think about this? These are the research questions underlying this study. First, we asked patient-participants their views on recording a 'word-portrait' in their record. Secondly, we arranged for a novelist (PF) to sit through 55 consultations with eight different GPs. She wrote a vignette about every patient as if they were a character in their own story. We then discussed this process including a selection of the vignettes with the participating GPs in two focus groups. Thirdly, we showed some of these patients the vignette that was written about them. The results were very revealing and offer lessons for holistic care.

Methods

Phase 1

Individual interviews (2002 to 2004)

Fourteen patients were recruited by letter from one GP practice near Bath. Selection was for maximum variation according to educational background, illness experience, frequency of attendance, marital status and current occupational status. Age range was 27–75 years. Interviews were by PN using a semi-structured interview guide to elicit views about what is and could be written in their EPR (Box 1). Audio tapes were fully transcribed and analysed using Miller and Crabtree's five phases of data interpretation. 8

BOX 1: Phase 1 interview guide

1 What importance do you attach to how much the clinician you consult knows about you?
2 What do you currently believe is recorded in your medical records?
3 What sort of personal information do you believe would be useful for a clinician in order to provide good quality primary medical care?
4 Do you think your personal values and preferences are relevant?
5 What are your beliefs and views concerning the storage of personal information on computer?
6 What safeguards would you like concerning access to that information?

Phase 2

Consultations (2005 to 2006)

Fictitious vignettes were piloted with groups of patients and local practitioners. Then a local novelist, creative writing tutor and erstwhile nurse (PF) was provided with basic instruction in the principles of qualitative research. Eight GPs (5 female, 3 male; age 32–55) from seven practices in and around Bath were recruited, self-selected from open email invitation to all Bath clinical area practices. PF's brief was to sit in the room during consultations, take notes and later write a short vignette about the patient as if they were a character in their own story and in a way that could be shown to the patient. The consultations were recorded (for PF use only) and the GP computer entry was copied. Patient participants were given full information about the study and at least 24 hours to consider participation. Local research ethics permission was obtained.

Focus groups

All participating GPs were then invited to two focus groups. The first was run as a creative writing group with discussion facilitated by PF. They were invited to try writing vignettes on their patients before the second focus group four weeks later. Each participant was sent their own patient's research vignettes ahead of the second focus group. Selected vignettes were used in the second group with a semi-structured discussion (Box 2). The group was facilitated by WH, notes taken by PN, and PF was a group member. Both focus groups were recorded for full transcription. All eight GPs attended the first focus group and seven attended the second. Focus group analysis used the Crabtree and Miller method above.

BOX 2: Phase 2: Focus group 2: discussion guide

- How do you feel about writing your subjective impressions – which inevitably reflect your own feelings?
  - What is lost if you don't?
  - Why do you feel the way you do?
  - What is at stake?
  - How much of this is for patient care, how much for yourself?
  - Medico-legal worries?
- What do you feel about Pat's vignettes?
  - What about writing these sorts of entries yourself?
  - How true are they – how do they relate to the patient?
  - Who would you want to write vignettes about?
  - How do you imagine the patient feeling if they read this?
  - How helpful would this entry be to read – if another doctor in the practice had entered it in the record?

Phase 3

(2006 to 2009)

All patient participants involved in phase 2 were invited to take part in a one-to-one semi-structured interview with PN, at a venue of their choice. An interview guide included showing the participant their vignette written by PF (Box 3). The interviews were recorded for full transcription. Interview analysis was undertaken using the Crabtree and Miller method.

BOX 3: Phase 3 interview guide

1 Remind participant of the consultation with their GP that was subject of the vignette and that the vignette is based on how things were on that occasion only. (This will have taken place at least 12 months previously.)
2 Show participant the vignette written about them and note initial non-verbal reaction. Ask for their verbal reactions to the vignette.
3 Ask them to enlarge on their reactions – positive or negative.
   – What elements do they react to?
   – How much difference is made whether the reference is to their character, appearance, social circumstances?
4 How do they feel about someone else writing an impression of them?
   – How does it compare with a portrait or photograph?
   – How do they feel about the 'word portrait' being flattering?
   – If not flattering, what should it be?
5 If their GP had written the vignette, how would it affect what they think of him or her?
6 How do they feel about a vignette written by the GP becoming part of their patient record?
   – What effect would they like the vignette to have on the next doctor or nurse who sees them?
7 Administer simple demographic questionnaire for completion of maximum variation matrix.

Version 1; 09/08/2006

Results

Phase 1

The numbers after each quotation denote patient–participant identifier.

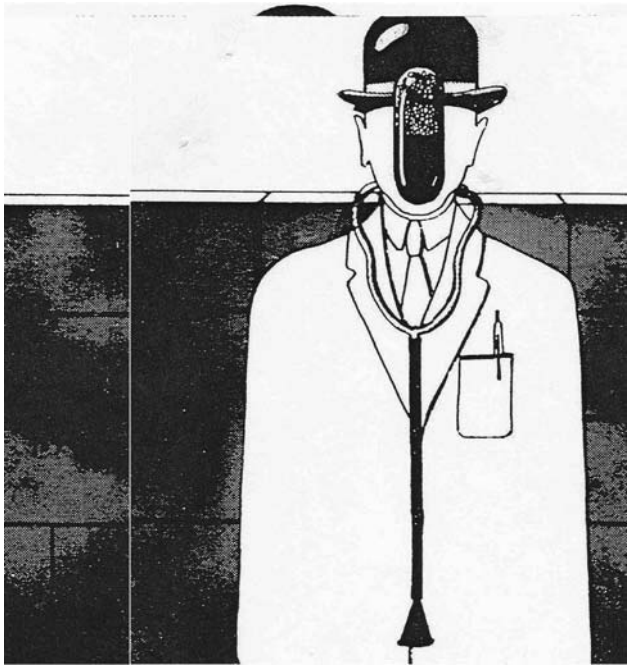
All 14 phase 1 patient participants attended for interview.

Building a trusting relationship was a very strong theme:

> *If you can establish a relationship it's so much the better.* 8

The interviews also revealed that patients (most of the time) wanted their GP to know something about them:

> *I think possibly what kind of person you are, sort of how easily you cope with stress.* 4



However, participants recognised how challenging it would be to describe what kind of a person the patient is and yet retain the patient's trust.

> *I don't know…how one could keep a record of that because it's more how people feel isn't it, rather than something written down about, and it's a subjective thing and if somebody else is going to objectively write something down about… I don't know that that's the sort of thing they would be able to pick up & write objectively.* 7

The most common worry was about being prejudged on the basis of an entry.

> *We're all guilty, can judge people by appearances and I suspect it'd be easy for something to end up in the notes that might not be relevant or might even be the wrong end of the stick, and whether that would then bias a view in the future or lead to a differing type of conclusion, perhaps, I don't know.* 1

There were also comments about the ephemeral nature of the brief encounters. They are at a particular time, day and place. Patient–participants recognised that both GP and patient are human and fallible and might misrepresent themselves or the other person.

Phase 2

Doctor as person

The numbers after each quotation denote GP identifier and gender.

Fifty-five GP consultations were included in phase 2 with a vignette written for each one.

In the first of the two GP focus groups (a creative writing class) two participants chose to write about their palliative care patients. To their surprise both became

emotionally choked up when talking about their writing. Subsequently, the question of dealing with their emotions in their work came up again and again in both focus groups. This is a sequence of conversation:

> *And if we're human beings we're going to have feelings and impressions and things about them, just as they do about us, we can't help that.* 9M

> *You often hear patients talk about their old doctors, they often like talking about their quirks and odd things they've say.* 4F

> *He told me to take my hands out of my pockets and told me to stand up straight. I loved him.* 6F

Patient as person: The vignettes

The bulk of the second focus group was structured through six of the 55 vignettes – selected as likely to stimulate discussion. An indication of the GP's EPR entry is given (not available to the group during the session; summary only).

Well coiffed M1

Accompanied by smart well-coiffed daughter using first person plural; but able to speak for himself. 'I paid for this in 1940!'

[GP EPR entry: concerning recovery from recent surgery]

The relevant GP was not present but his partner instantly recognised this couple. There ensued a long (three pages in transcript) discussion on the interpretation of those two lines of text. The group was animated and interested. At least some of the interest emerged from the desire to interpret this enigmatic fragment. At the end, this was said:

> *Imagine if we had a series of consultations for everyone who'd done that sort of thing* [write a vignette] f*or that patient on particular visits, it would give a very different view wouldn't it – a lovely sort of mosaic.* 4F

Artistic F2

Dr: 'So, you're artistic'. She couldn't agree: too clear, too simple, and too much like praise, for her to accept that it might fit any of the chaos she knows is inside her.

[GP EPR entry: blood pressure recording]

PF said the GP uttered this in a 'kindly and encouraging way'. After a while her GP recalled her…

> *It's a really good description of that person because really I think what I was trying to do was to lead her out of the chaos into something and she couldn't go could she, couldn't go anywhere. Yes. Very…Yes, good…But I don't know how that* [vignette] *would help anyone else.* 7F

Another GP's reply:

> *It makes me think she's interesting, so I would actually be sort of quite interested to see what she's like, so it would make me actually want to consult with her I think.* 5F

Both of the above vignettes bring out another recurring theme: that the GPs want to be interested in their patients.

> *…I think part of this is to get us to maintain interest or even rekindle interest in our patients, and one of the points of this was to see if we can handle our heartsink patients better…and help us to maintain relationships in the hope we can improve on them.* 2M

Self-neglect M3

Not as old as his bearing, his manner, his clothes, the worn trousers, ancient shoes, bright new anorak of extreme old age. A preliminary fragility: on the brink of dignified self-neglect. Not used to looking after himself?'

[GP EPR entry: review of blood pressure control and medications]

His own GP's response:

> *That's really my patient. Actually I read that and I went back to his notes and thought gosh! Is he only as old as that! So I* [had] *added sort of five or ten years to his age!* 4F

Another GP:

> *That would be really useful for the next person. I don't think he would be offended….because you are forearmed the next time a little bit to sort of think, why is he in trouble, why is he like this, what's going on at home?* 8F

Black F4

Why is she in unrelieved black, is she not even worthy of a necklace or a ring? Why are her clothes all so tight? Straight sad hair.

[GP EPR entry: assessment and advice for benign lump in arm]

After two pages (in transcript) of mostly female discussion about what might be going on for this woman and her hair and her tight, black clothes , one of the male GPs said:

> *I think if we we're looking at one- or two-liners on a very medical history we would just be in a discussion about the eventual diagnosis. We wouldn't be talking about people at all really, whereas these are actually stimulating a debate on what the person is like and got nothing to do with medicine.* 2M

This statement stood out as a sort of 'eureka' moment. One of the female GPs responded:

> *Well it must have something to do with medicine as well! People aren't above pressure are they, there's all these other things that – how they react to their illness or whether they take their tablets or not. I can't separate the two in my head.* 5F

Welsh F5

Well-groomed exclamatory Welsh lady, with a certain relish in the drama of illness: 'It's better on my back than on my side, interestingly enough!'

[GP EPR entry: detailed history and examination for neuralgic leg pains and rash]

The first response:

It's a really good description, I can just see her now. 3F

Then a lively discussion (4F is her own GP):

The bit about the relishing drama of it all… I'm not sure how she would take that because it could just mean that she's nicely dramatic, that's just how she is, it's a flavour of her personality or it could mean…' 4F

I saw this as a slightly more subtle way of writing 'enjoys being ill'. 2M

Interesting! She's not like that to see at all, she's not... a difficult patient. 4F

I didn't feel she was at all enjoying being ill. (PF)

Interestingly enough she's actually a drama teacher so… 4F
Is she! Is she! (several)
In that case she'd take that very well then! 8F

The key points here are that the group were intrigued about the patient, nervous about inadvertently causing upset and that PF had picked up her demeanour but the vignette could easily be misinterpreted. This patient–participant reappears (angrily) in Phase 3.

Hair F6

A daughter all her life: dependent parents? Hair limp with depression. 'Too tired to notice other feelings.'
[GP EPR entry: assessment of anaemia, gynaecological issues]

Patient's own GP said:

Actually this lady is very like that [unexplained symptoms] and I think you have spotted something because I don't see her like that, I see her as quite fat and jolly. But this is actually what's going on underneath and I don't see it any more, you know, or maybe I never did. 7F

I did have a very, very strong impression of melancholy. (PF)

The ensuing discussion revealed that the patient's parents were indeed increasingly dependent.

* * *

Constraints of the computer

There were varying degrees of frustration over the limitations of computer programmes for holistic records, especially from the female GPs. They had particular problems with being obliged to 'code' entries to make them searchable. For example, to enter 'carer' is easy but…

…you can't put in the heading 'reluctant carer' which tells you a hundred times more … it comes down to the very bare bones but it doesn't give you any of the edge which tells you far more. 3F

The screen was also an unwanted presence:

I mean I'm not anti-technology but I think because that computer is there, the patient keeps looking at it, and it's bright and it's colourful and it's distracting and it hums… 3F

…Like having a TV in the room. 8F

Worries about upsetting patients, litigation, and doctor as person (again)

This recurring theme in both focus groups has been touched on with vignette F5. The effect we saw was to inhibit writing anything 'subjective'. 'Objective' writing is seen to be 'safer' and this seems to have seeped deeply into the system. Here are two male GPs:

I've just come up from …a mentoring course today and an aspect of that was talking about cases in a very different way with someone and it's a shame that is being crushed out. 1M

I agree I think it's been drummed out of us… a lot of education in consultation styles and consulting generally is to try and reduce making value judgements about our patients and I think anything that has a subjective label is by default a kind of value judgement. There is this sort of subliminal pressure on us to be objective, to write notes as if they are being read out in court…and I tell my registrars to think that as well. 2M

Even using verbatim quotations (as in vignettes 1, 5 and 6) is suspect:

…why choose that particular thing to quote, so you're all still giving a judgement about that person. 2M

The fear of a complaint deeply affects the way medicine is practised. Here is an unedited exchange with three GPs near the end of the second focus group:

Yes, the prospect of getting a complaint is so horrible and such a long drawn out business that you go to huge ends not to get anywhere near it so... 3F

Yes! 2M

… so you necessarily err on the side of being neutral and boring. I think we do and I mean, kind of, I mean I feel myself that this is somewhat soulless medicine. 3F

Yes, and I agree with your comment earlier that there is a sense that you know we are not human beings in medicine any more. A very sad comment but you know, it's just changed so much, it's not what I was expecting. 8F

But in focus group 1 shortly after the creative writing session when several participants became emotional there was more willingness to be 'human':

Isn't it because we're human beings that the patients want to come and see us and they don't

mind us being human beings do they? I mean, most of them? 9M

There's that saying isn't there that we all get the patients we deserve which must kind of say something about the way patients see us in terms of our personality. So perhaps we are a bit too paranoid about it all. 2M

Phase 3

Illusive truth

The numbers in grey denote patient–participant gender and identifier. Participants are different to those in phase 1.

Fifteen patients, who all had a vignette written about them, participated in phase 3.

In line with phase 1 most interviewees wanted a 'profile' of themselves as a person available to their GP.

Yeah, yeah one glance [at the vignette] *and anyone would know that you know I was…I'd pretty much ran out of steam* **F10**

I'd be fine about it [vignette in EPR] *because I think that is true to me. That is me. That is how I was at the time.* **F9**

But this raises the key issue of truth. This clearly relates to the concern about 'prejudgement' that worried patient–participants in phase 1. Both of the phase 2 participants quoted above recognised themselves in their vignette but neither of these vignettes were risqué. In contrast, the vignette of participant M3 self-neglect (phase 2 above) could have caused upset:

I suppose…I suppose it's a fair comment…That's how others see you, not as I see myself but as others see me. **M3**

He is able to stand back and view himself through an 'artist's' eyes. He goes on to compare the vignette with Rolf Harris' controversial portrait of the Queen. Three more participants with risqué vignettes were able to stand back in this way. However, some were not:

I am very irritated! [flushed with anger as she spoke] **F5**

This participant's vignette is Welsh F5 in phase 2 above. She felt (as several GP-participants predicted) the vignette made her out to be 'enjoying illness'. She believed it would be 'dangerous' if written in her notes. She was the only angry participant but two other vignettes were problematic:

Christian name: F7

A mass of information eagerly relayed. Pleased to use the doctor's Christian name. 'Am I allowed to say what I want?'

Plaintive M8

Talking in plaintive detail only his doctor will listen to: home alone. Indignant. 'I need to lie down after lunch!'

F7 was defensive of her special relationship with her GP and had no insight into the possibility of a controlling conspiracy of silence. Regarding M8, the description of the interview from PN corresponds closely with a re-enactment of the 'plaintive detail' and indignation in the vignette, again with no self-awareness.

Found (or lost) in translation

Pink and black F9

Wife of sick husband, in brave pink and black.

'I'm coping fine at the moment…can't leave him for long.'

So you've really got to read into that…yeah and I think the pink and black as well (laughs) it just makes me laugh, it makes me look…oh yeah, it makes me look like I'm trying to liven myself up with the pink…perhaps that's how it was I don't know…yeah, I do tend to do that….brighten myself up! F9

However, there was a failure to understand metaphor and literary allusions among patient-participants. Four of the 15 vignettes in phase 3 contained one or more of these devices (including M8 and M3) and none were understood even with attempted explanation.

Discussion

The scientific paper is not just about science, it's about telling a good story.[9] Here we squeeze a story of hope and disappointment, of anger and bewilderment, of laughter and sorrow into the IMRAD (Introduction, Methods, Results And Discussion) format. This constraining structure is a fractal of the constraints of the heavily ritualised format of 21st century GP consultations in the NHS.

At its core a consultation consists of two or three people meeting in a room in the hope of tackling a problem that has something to do with health. The patients in phase 1 told us they wanted a trusting relationship with their GP, to be seen as a unique person, to have a true human profile in their records. The GPs told us they wanted to be more interested in their patients; to have an 'edge', perhaps some human mystery to spark curiosity, to be able to tell the truth as they saw it; and to be human. Some GPs, particularly the males, found some consolation in the computer or other interests. Most in our sample did not and the 'neutral and boring' epithet for what is left behind on the computer screen is unlikely to inspire the next clinician or be a basis for healing. There has to be a better way.

The different light we shone onto the meeting-in-a-room was creative art. Currently, this meeting is dominated by the factual products of science, political correctness (PC), possible complaints (PC) and the computer (PC). Both science and art are engaged in a process of discovery but they celebrate different things: for science it is objectivity and sameness; for art it is subjectivity, paradox and uniqueness. The scientist collects information about a subject and formulates it into a theory through an analytic process. Truth is tested by experiment – perhaps blood tests or X-rays. The artist engages with the subject, in our

case by looking, listening and imagining, and an interpretation emerges from the sharing of a dynamic space – called 'public space'[10] or 'sacred time'[11] – a moment of order within dynamic opposing forces. The truth of the interpretation is tested by the recognition of common humanity, and this was seen in this study, as well as the accompanying interest and emotional release – the feeding of an impoverished soul for GPs who find medicine 'soulless' – and the comfort of validation or the challenge of an unfamiliar view for patients. Here interpretation replaces prediction and probability replaces certainty[12] and the impact of PC might be reduced. The light we shone onto patient records gave us a glimpse into the complexity, rewards and risks of professional relationships.

Of course, this was not new, just forgotten! In 1883 Oliver Wendell Holmes delivered a speech to open a new building at Harvard Medical School.[13] He suggested that a doctor should always be accompanied by his quick-witted wife who 'would recognise the love-lorn maiden by an ill-adjusted ribbon… a droop in the attitude – a tone in the voice – which mean nothing to him.' But, of course, neither doctor nor wife is good on their own.

Acknowledgements

Gratitude to GP and patient participants, Dr Jenny Ingram, Mary Reed, Gill Underhill, Bath Research and Development, Royal College of General Practitioners Scientific Foundation Board.

Address for correspondence: thehouses@phonecoop.coop

References

1 Edgecumb D (2010) But there are no QOF points for Balint work! *BJGP* Nov, 858–859.

2 Leopold N, Cooper J, Clancy C (1996) Sustained partnership in primary care. *J Fam Pract* 42 (2) 129–137.

3 Donnelly WJ (2005) Patient-centered medical care requires a patient-centered medical record. *Academic Medicine* 80 (1) 33–38.

4 MacNeice L (2002) Entirely. In: *Staying alive – real poems for unreal times*. Tarset, Northumberland: Bloodaxe Books, p60.

5 Cassell EJ (1991) *The nature of suffering and the goals of medicine*. New York: Oxford University Press, p30–64 and p211–212.

6 Greenhalgh T, Hinder S, Stramer, K, Bratan T, Russell J (2010) Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. *BMJ* 341: c5814.

7 Risdale L, Hudd S (1997) What do patients want and not want to see about themselves on the computer screen: a qualitative study. *Scand J Prim Health Care* 15, 180–3.

8 Crabtree BF, Miller WL (eds) (1999) *Doing qualitative research*. London: Sage, p127–143.

9 Albert T (2000) *Winning the publication game*. Oxford: Radcliffe.

10 Taylor C (1985) *Human agency and language, philosophical papers 1.* Cambridge: Cambridge University Press, p259.

11 Eeynik Van JR (1997) *Archetypes and strange attractors: the chaotic world of symbols.* Toronto: Inner City Books, p161.

12 Doll WE, Trueit D (2010) Complexity and the health care professions. *Journal of Evaluation in Clinical Practice* 16, 841–848.

13 Leader D, Corfield D (1996) W*hy do people get ill?* London: Penguin, p47.