COMMUNICATION & MEDICINE SUBMISSION

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Title: Patients and consultations: A rejoinder

Short title (for running head): A rejoinder

Word count (all inclusive): 2,900

Character count (with spaces): 18,522

Bionotes

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Patients and consultations: A rejoinder

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Patients' interest in recording clinic consultations

The paper by Elwyn et al., 'Individuals recording clinical encounters: A review of applicable law in multiple countries', suggests that patients are demonstrating an increasing interest in recording their clinic consultations. Why is this? There are probably at least three reasons: (i) a technology that enables this has become available; (ii) patients anticipate that they may be given complex information or engaged in a technical discussion in their consultation, so that the details may be difficult to recall precisely; and (iii) they may feel a greater sense of their right to record such an interaction with professionals than was usual in the past. Of course, this 'right' may or may not be recognised in law in any particular jurisdiction, but many patients feel that they have at least an ethical right to do this. People will differ in whether or not they feel that professional agreement is required.

Our response to the paper will not address the legal issues raised by Elwyn and colleagues, in which they address the issue of patients recording clinical consultations without the consent of the clinician. We wish to consider an area where patients' perspectives are at the heart of clinical practice – genetic counselling as an aspect of clinical genetics services – and where the outcomes of service delivery are assessed by how they match these perspectives rather than by any centrally- or professionally-set goals. In this setting, the recording of consultations happens from time to time, and usually with the consent of both parties. We discuss the impact of recording clinical encounters in this setting for personal use on the patient and the professional and then consider the application of recording clinical encounters in research.

Possible impact of recording the consultation on the consultation itself: Cognitive burdens and benefits for the patient

Patient led recordings may have effects on how patients engage with the topics raised in the clinic. First, recording an encounter may reduce the immediate cognitive burden on the patient. By recording a conversation, patients give themselves the opportunity to review the clinic conversation at a later stage. This implies that it becomes possible to relive in some sense a conversation taking place in the 'here and now'. Creating this opportunity to return to the conversation that a patient is currently engaged with may shape the conversation as it unfolds. The patient may feel they do not need to engage fully in the immediate conversation as they can go back over its contents later. This might lead them to gloss over some of the technical content, the issues or the consequences that arise in the immediate context of the clinic since they can think more on these topics later. Conversely, because they are recording the clinic, the patient may try to prompt the clinician into providing more definitive answers than they might otherwise seek. They might want the clinician to offer a clearer indication of any diagnosis or prognosis or decisions they may need to make so that they may be certain as to any decision that flows from that conversation.

Possible impact of the recording on the professional

The existence of the recording may prompt a sense of hesitancy on the part of the clinician, particularly if they begin to feel that the recording may be used against them in some way in the future. This may not necessarily affect conversations about the diagnosis and prognosis in the context of current normal treatment but may affect the willingness of the clinician to raise additional factors that may impact prognosis, perhaps in relation to research projects or relevant social or cultural aspects. Such considerations could influence the way a clinician raises the topic of research projects into factors that might shape disease progression.

Applications in research

One potential application of such clinic recordings, in addition to any personal use made of them by the patient or their family, is research. Indeed, while patients will often wish to collect their own data for their own purposes, as outlined above, they could also – where this is legal – be recruited as co-researchers to share their data with a more conventional research project or even collect data primarily for such a project.

This could confer multiple benefits for research. The most immediately obvious might be cost: instead of a researcher needing to be present for a consultation to be recorded, the recording can be made by the participants. Health professionals cannot always be relied upon to record consultations in which they have multiple roles, as they might need to prioritise their clinical role over that of a co-researcher role. In contrast, a patient motivated to record their own consultation might be much more reliable. The time required for transcription and analysis would be no less and might even cost more, if this approach led to the collection of more data.

There might also be disadvantages to this approach, however, as the researcher would no longer need to spend as much time at the research site. This could lead to researchers having less familiarity with the setting within which the data are collected. In some projects, this disadvantage might be of great importance even if the impact of 'less familiarity with the setting' on research quality might be difficult to measure. Another consequence will be the additional risk of vicarious trauma, which is trauma experienced vicariously through an empathetic response to another's experience of trauma[1]. The impact of vicarious trauma may be lessened by being present in clinic when distressing topics are discussed. Once the patient has left the consultation, the researcher will often be able to discuss any issues that arose with the clinician in a mutual 'debrief'. In contrast, if the researcher is sent the audio by the

patient, they are most likely to be listening to/reading it during the working day when colleagues may not be present.

Genetic counselling research project

Thinking beyond the clinic itself, patient-led recording of research data has proved valuable in our ESRC-funded project, 'Framing the trajectories of decision-making in the context of predictive and prenatal genetic and genomic tests'. This has focused attention on what is going on for patients in the 'real world' outside and beyond the clinic, examining the process of making decisions in relation to predictive genetic testing and prenatal genetics. In addition to recording clinic consultations and end-of-the-clinical-process interviews, we asked our research participants to keep diaries during the weeks of their engagement in the research. Patients in effect became co-researchers in this project. These recordings and diaries have proved very informative, providing a sense of how the genetic concern in the family is located in relation to the rest of their lives and giving insight into particular times of stress and anxiety, such as the weeks of waiting for the results of a predictive test. We recommend this co-production approach to research in medical settings: inviting patients to track their own and their family's responses to the situations they are in is highly informative and gives insights available in no other way.

Living with embodied risk: a liminal space

The experience of living at high risk of an inherited condition – an embodied risk – has been conceptualised as an in-between state, a liminal or ambiguous space between health and illness[2]. Liminality – the term 'limen' in Latin means threshold – describes the process of transition from one state to another, and such transitions are often recognised in social life by

rites of transition, also referred to as liminal rites by van Gennep[3]. The 'suspended life' of patients caught between two states has been studied in a number of contexts, e.g. for breast cancer[4] and comparable states exist in those who are unaffected but aware of their high familial risk of inherited conditions, such as Huntington's disease (HD).

Diaries as a way of examining the space between clinic consultations

Six patients deliberating the decision to undergo predictive testing for HD became co-researchers in the ESRC research project by recording data in a diary style regarding their thoughts and feelings. We used these diaries as a way of examining the space between genetic counselling sessions. Data was also collected from clinic consultations and interviews at the end of the testing process. By comparing what was in these diaries with recordings of clinic consultations, we identified aspects of the 'real world' that did not appear in the clinic consultations. The overarching difference between the diary content and the clinic data was its emotional quality. The diary data was at times ladened with emotion and induced painful experience for the researcher also (see https://www.youtube.com/watch?v=u8DGEW16GZ4&t=92s for more detail).

More specifically we identified the following themes:

1. Life is on hold. The participants described not being able to move on with other aspects of their lives as they waited for the result of their predictive test. The uncomfortableness of the waiting was palpable in their diary entries: '*I am afraid that results will change my life. If I find out that I am affected my world will break; I will feel as if I received some kind of judgement'* (Kayleigh). The diary data indicate that the period between deciding to have a predictive test for HD and then receiving the results is an 'in-between space' for patients,

although usually briefer than the wait from an adverse predictive test result to the onset of symptoms that may last years or even decades. The wait for results magnifies the uncertainty that was already there, because the counselling process has shone a spotlight on it. The uncertainty becomes more uncomfortable to live in once a decision has been made to have the test, so that the time between contacting clinical genetics and getting the result may be harder to 'cope' with than the period before a decision to proceed with predictive testing had been made. Van Gennep describes 'rituals' that move a person through this 'in-between space', from one state or place to another.[3] To what extent does genetic counselling function as the ritual that moves a patient from the status of uncertainty to the status of knowing?

2. The repetition – the echoing – of family experiences. All participants had at least one relative with HD symptoms. Their diary entries looked with sadness at the parallel between the current experiences of their relative and their own reflections on what the future may have in store for them, if they have a positive result: '*Got upset (in private) about potentially caring for Dad as becomes more symptomatic/end of life whilst potentially having to go through symptoms and treatment* [myself]' (Rosie).

3. Forecasting of emotions: Whilst looking into the future, the participants were also predicting how they would feel in the different possible futures ahead of them: "*I'll be nothing. I'll be a pain, a burden*" (Leah). The participants were 'trying out' these futures as if they were the present, essentially experiencing these forecasted emotions in advance.

Audio recordings: monologues and conversations

Some of the 'diary entries' in the project were not written but recorded as audio monologues. Whether written or recorded, the diaries gave vivid insights into the lives and concerns of the

participants. Furthermore, on two occasions, the research participants recorded not only their own voices but also those of others: they recorded family conversations. One of these recordings was of a very open conversation in a prenatal genetics context. This was a conversation in which the couple and the woman's mother discussed their thoughts and feelings about their fetus, who was affected by a chromosome anomaly and a serious congenital cardiac defect. The conversation showed great frankness and courage. The other was a descriptive account – a report – of a predictive clinic consultation that the patient's partner had not been able to attend.

Clinical genetics

In clinical genetics, it has for decades been commonplace – indeed usual, at least in the UK – for clinicians to dictate a letter to their patients after any consultation as a clinic summary. There may be other reasons and uses for this, such as to ease communication and explanation to other members of the family, or to prompt the patient to make specified practical arrangements. Primarily, however, this is motivated by the desire to ensure that the patient should understand and be able to remember the information provided and discussed in the consultation.

It is said that clinical genetics and genetic counselling deal in information and considerations based on that information; information may be said to play as central a role in genetics as drug prescriptions do in general (internal) medicine. Recording a consultation is only a small step beyond this. It does not require the work of synthesis that a summary letter requires, that can rephrase or repackage information in a way that the patient may find helpful. On the other hand, however, it does not give the clinician the opportunity to provide supplementary information or to correct any errors that they discover after the consultation. Of course,

clinicians may still write letters if they wish, to rephrase information, prompt actions or correct errors, even if a recording is made: that does not preclude these other activities. The real disadvantage of a recording for the professional (such as the patient's referrer or general practitioner) is that it takes so much longer to listen to than to read a letter, but this need not be a disadvantage for the patient.

Where next?

Our genetic counselling project has been a salutary exercise in making clear what we already know but too often put to the back of our minds. Diaries (and recorded monologues and conversations) show that patients often have a much more sophisticated understanding of interactions in the clinic than may be apparent from their behaviour within that setting, where they may feel at a disadvantage in terms of status and therefore of voice. This limitation, of course, may also apply to post-clinic interviews as data. Recruiting patients to act as co-researchers – at least in terms of data gathering – in our research project has a great potential to open up the making of decisions by patients in the sensitive, delicate area of genetic counselling. We need to understand how these difficult decisions are made as genetics continues to grow in importance within medicine and society at large.

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