Patients and consultations: A rejoinder

ANGUS CLARKE¹, LISA BALLARD² AND SHANE DOHENY¹

(1) Cardiff University, UK (2) University of Southampton, UK

1. Patients’ interest in recording clinic consultations

The paper by Elwyn and co-authors, ‘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: (1) many people now have the technology for this to hand at all times; (2) patients anticipate that they may be given complex information or be engaged in a technical discussion in their consultation, so that the details may be difficult to recall precisely; and (3) patients 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 as to 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 and where the outcomes of service delivery are assessed by how they match these perspectives rather than by any centrally or professionally set goals. The setting is genetic counselling as an aspect of clinical genetics services; here, 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.

2. 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 in clinic, patients give themselves the opportunity to review it at a later stage. This implies that it becomes possible in some sense to relive 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 can feel more sure about what they should do following on from that conversation.

3. 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.

4. 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. It should be noted, however, that the time required for transcription and analysis would be no less and might even be greater, raising costs, if this approach led to the collection of more data.

There might be additional 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 through an empathetic response to another’s experience (Branson et al. 2018). In a clinical environment, the researcher will often be able to discuss any issues that arose from distressing topics with the clinician in a mutual ‘debrief’ once the patient has left; however, if the researcher is sent the audio by the patient, they are most likely to be listening to / reading it alone, without any readily available support from colleagues.

5. 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 where 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
Angus Clarke

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.

6. 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 (Kavanagh and Broom 1998). 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, referred to by the ethnographer Van Gennep (1960 [1909]) as ‘liminal rites’. The ‘suspended life’ of patients caught between two states has been studied in a number of contexts, e.g. in relation to breast cancer (Koutri and Avdi 2016), and comparable states exist for those who are currently unaffected but aware of a high familial risk of inherited conditions, as in the case of Huntington’s disease (HD), one of the contexts for the current study.

7. 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 were 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 laden with emotion and induced painful experiences for the researcher also.

We identified three 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). Although, as discussed above, this is ‘in-between space’ for patients, it is briefer than the wait from an adverse predictive test result to the onset of symptoms that may not appear for 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 condition 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.

8. Audio recordings: Monologues and conversations

Some of the ‘diary entries’ in the project were not written, but instead recorded as audio monologues. In both cases, however, they 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: specifically, family conversations. One of these recordings was of a very open conversation in a prenatal genetics context. This was a conversation in which the pregnant woman, her partner and her mother discussed their thoughts and feelings about the foetus, which 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, that then led into discussion of how to manage the situation.

9. 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, it 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, and 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.

10. 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 in our research project – at least in terms of data gathering – has shown 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.

Note


References


A rejoinder

Angus Clarke received his DM in clinical and molecular genetics from Oxford University and is currently Professor in Clinical Genetics at Cardiff University, Wales, UK. His research interests include Rett syndrome, ectodermal dysplasia, genetic counselling and the social and ethical issues that arise in human genetics. His most recent book-length publication is the eighth edition of Harper’s Practical Genetic Counselling (2020, CRC Press, Taylor & Francis). Address for correspondence: Institute of Medical Genetics, University Hospital of Wales, Heath Park, Cardiff CF14 XN, Wales, UK. Email: clarkeaj@cardiff.ac.uk

Lisa Ballard received her Professional Doctorate in health psychology from the University of the West of England in 2017 and is currently a Senior Research Fellow at the University of Southampton, UK. Her research interests include the communication of genetic results within families, meaningful engagement with underserved groups in genomics and the ethical, legal and (psycho)social aspects of technological development in health. Her most recent publication is ‘Ethical preparedness in health research and care: The role of behavioural approaches’ (2022, BMC Medical Ethics). Address for correspondence: Clinical Ethics, Law and Society at Southampton (CELS), University of Southampton, University Road, Southampton SO17 1BJ, UK. Email: l.ballard@soton.ac.uk

Shane Doheny received a PhD in the sociology of welfare from the University of Luton in 2004 and is currently a Research Associate at the Centre for Innovation Policy Research, Cardiff University. His research interests include the ethical and social aspects of genetic testing, but he has also developed research interests in gerontology and in critical theory. His most recent publication is ‘Recontacting in medical genetics: The implications of a broadening knowledge base’ (2021, Human Genetics). Address for correspondence: Cardiff Capital Region Challenge Fund, Cardiff Business School, CF10 3EU, Wales, UK. Email: dohenys1@cardiff.ac.uk