Dealing with encounters being recorded by patients

Case scenario

Mrs Smith attends the breast clinic alone. During the 30-minute appointment, Mrs Smith and her surgeon discuss the diagnosis of early breast cancer, the treatment options of lumpectomy *vs* mastectomy, probable short- and longer-term outcomes, and the possibility of adjuvant treatment.

At home later, Mrs Smith is upset and anxious. She is also frustrated that she cannot remember much about what had been said. She recalls the diagnosis, and something about an operation. She cannot, however, remember what surgery might involve, how it might affect her appearance, what her prognosis might be or what treatment choices are available. The leaflets provided by the surgeon are fairly useful but do not tell Mrs Smith about her. She looks on the internet. There is too much information and, again, it is not about her.

Mrs Smith is left confused, frightened and unsure what she will tell her family about what is going on.

Introduction

Should doctors advise patients like Mrs Smith to record their clinical encounters? She has received a large amount of complex information at a time of anxiety and upset. This information is needed to help make decisions and prepare for what is to come, but it has long been recognized that patients can later recall little of what has been discussed in encounters. The dogma of patient-centred care is laudable but tailored, personalized health-care information is not yet a universal reality. Why then should patients not create their own records of these encounters?

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Encouraged or not, patients may be doing it anyway (Elwyn, 2014). Personal recording equipment has never been so readily available and patients are legally permitted to use it in encounters (Zack, 2014). The medical profession appears sceptical and guarded, but this may reflect a misunderstanding of patients' intentions. This article explores this controversial issue by considering the potential pros and cons, reviews the legal and professional guidance available to doctors, and finally offers some guidance for the junior doctor.

Using recordings to help with recall and understanding

Studies repeatedly show that people remember little of what is said during encounters. This is compounded in high-stress situations where bad news or complicated treatment decisions are discussed (Kessels, 2003). It is in these cases where high-quality, personalized information is needed to help patients understand complicated treatment options and their implications, but uncertainties remain about how best to deliver such information.

To supplement the information discussed, patients are often provided with written material or directed to websites. While the intentions of these sources may be good, they are often of poor quality, lack evidence-based information, and fail to address subjective information needs (Coulter, 1998; McCartney, 2013). These information adjuncts do, however, have the benefit of allowing patients and their families to consider information in their own time, at their own pace, away from the pressured environment of the hospital clinic (Coulter, 1998). This is important because family members and carers play important roles in the decision-making and coping processes but may not always be present at the encounters in which important information is exchanged (Hubbard et al, 2010).

It is when considering these issues that advising patients to record their encounters becomes an attractive option. Smartphones are almost ubiquitous, and most are equipped with audio recording functions. This means that their use to record should not impede the normal flow of the encounter. Few doctors would object to patients making written notes during encounters, but this is likely to distract the patient, preventing him/her from thinking of questions, and the result may not be an accurate record of what was said. An untampered, contemporaneous audio recording would address these issues.

Had Mrs Smith recorded her encounter with the surgeon, she would have been able to replay the audio in privacy, with her husband present, taking time to consider the information about the disease, treatment options and prognosis. She may have been prompted to seek further information on issues that remain unclear, for example by making contact with the breast cancer nurse specialist. The end result might have been that she made a treatment choice that best suited her, been prepared for what surgery and recovery would be like, and overall more satisfied with her care. But is there evidence to show that this is what happens?

Evidence to support recording encounters

There is relatively little literature on this topic. Most studies have involved recordings initiated by health-care practitioners rather than patients, but with outcomes evaluated from the patient perspective (Tsulukidze et al, 2014). Overall, in a review of 33 studies spanning some 30 years, the majority of patients reported listening to the recordings and sharing them with family or friends. The recordings were often listened to multiple times, and there were beneficial effects on recall or understanding of information. Importantly, when questioned, patients reported hearing 'new' information not heard or remembered. Data showed that patients assigned to control groups later requested information that had already been discussed in encounters. The same patients described a sense of loss and having missed out on an opportunity at not being allowed to hear a recording of their encounters.

Those patients who were older, had some impairment (e.g. deafness), or had been subjected to an emotionally-charged

encounter were found to benefit most. The benefits were not confined to patients. System-level beneficial outcomes included no overall increased encounter time. There was a significant reduction in telephone calls to doctors from patients in the months following the encounters. Health-care practitioners appear to improve the quality of information given when they are aware of being recorded, as measured by patient report. It is not yet known whether this effect is a short-lived response to a new intervention or whether a sustained change in practice results.

Using recordings to promote patient-centred care

Patient-centred health care is policy in many countries (United States Government Publishing Office, 2010; Department of Health, 2012). Shared decision-making, the collaborative deliberation about treatment options between doctor and patient, is a key part of patient-centred care (Edwards and Elwyn, 2009). It has the potential to reduce overuse of health-care resources, and ultimately deliver more effective, safer care. But none of this can happen without high-quality, evidence-based information. Awareness of being recorded may encourage doctors to adopt a more patient-centred, evidence-based approach to encounters (Elwyn and Buckman, 2015). Patients will subsequently have access to this audio-recorded information to help them work through treatment decisions alongside a decision aid, for example.

The idea that patients' records are the preserve of the medical establishment is no longer relevant. Recent developments include allowing patients to contribute to their records, adding questions of importance to them, and even having the final 'sign off'. Audio recordings of encounters could be a valuable addition to systems like this which are designed to promote patient-centred care (Open Notes, 2015).

Policy, the law and professional guidance

Doctors are well aware of the requirement to gain patients' consent before making recordings of encounters for training or research. It appears that many assume that the same rules apply to patients seeking to record their own encounters (Zack, 2014). This is not the case. Patients have no obligation to gain the doctor's consent to record the encounter, whether covertly or openly. The key distinction is that information discussed and disclosed during the encounter 'belongs' to the patient. The data are the patient's to store, process and share. If particularly sensitive or private topics are discussed and captured on tape, it may be prudent to advise the patient to carefully consider who he/she allows to hear it. It is known that patients discuss information with their doctors that they later withhold from family members.

Doctors may question why a patient chooses to make a covert recording. It may reflect an underlying problem with the relationship, indicating a lack of trust perhaps. Realizing that a patient is covertly recording is not justification for terminating the encounter but should instead open a discussion. Advice from medical defence organizations is that an open, honest approach should be adopted. If a doctor suspects a patient is making a covert recording, the advice is to invite the patient to do so openly, and not to assume that the patient's intentions are malicious or litigious (Zack, 2014).

Guidance from professional bodies is also helpful here. The General Medical Council (2013) states that patients should be provided with 'information they want or need in a way they can understand'. The National Institute for Health and Clinical Excellence (2012) is more explicit and advises that doctors should 'ask patients whether they want to take notes or make an audio recording of the encounter'. It is not unusual to see posters in GP and hospital waiting rooms advising patients that they can request copies of their clinic letters. Maybe these posters should also prompt patients to record their encounters?

The overall message from professional organizations appears to be that, if a doctor practices medicine ethically, professionally and with courtesy, he or she has little to fear from patients recording encounters. It is worth pointing out that the General Medical Council has allowed covert recordings of encounters as admissible evidence in conduct hearings. It is likely that this will become more common, but it should be remembered that such data could act in defence of the doctor by proving good practice.

Are there potential pitfalls?

It appears that patients like to have recordings of encounters and there are likely to be benefits when they do. However, there are potential negative aspects to consider. Awareness of being recorded may result in defensive practice whereby doctors order more investigations, write more prescriptions or refer for more specialist opinions (Elwyn and Buckman, 2015). Further study data are needed to show if this happens and, if so, whether it is sustained. Encounters may take longer (Elwyn and Buckman, 2015) but this may be offset by fewer follow-up encounters if the patient is more satisfied with the information he/she received in the first place.

Easy access to digital recording equipment has been accompanied by ready means of sharing data. This has potential advantages. The doctor, for example, could request a copy of the recording to accompany the medical record. The potential for misuse here must also be acknowledged. Broadcasting the recording on social media or online fora, particularly when there is a dispute between the doctor and patient, may cause distress, upset or embarrassment to one or both parties (Elwyn, 2014). Where others who attend the visit, such as family members, undertake the recording without the patient's knowledge, and without permission, complex questions arise. If these situations occur, the authors suggest that the doctor seeks advice from his/her defence organization (Care Quality Commission, 2015).

It should be emphasized again that it is unlikely that most patients record their encounters seeking to exploit the data in this way. It is more probable that they simply want an enduring, personalized record of what has been said. To illustrate, let us revisit the scenario described above, this time imagining that Mrs Smith had recorded the encounter.

Case scenario revisited

Mrs Smith attends the breast clinic alone. During the encounter, her surgeon discusses the diagnosis of early breast cancer before going on to outline some treatment options. Noticing that Mrs Smith is upset and probably not hearing much of what is being said, the surgeon suggests she uses her phone to record the remainder of the encounter so that she can listen back to it

later. Mrs Smith agrees and, over the next 20 minutes, the treatment options are described and information discussed about outcomes and prognosis.

At home later, Mrs Smith is upset. Her husband has lots of questions about what happened at the hospital. Mrs Smith can't recall much but does remember making a recording of what was said. The couple are able to listen to the encounter several times. They identify some issues that they want to ask more questions about. Mrs Smith is able to call the clinical nurse specialist and ask those questions before she is admitted for surgery.

Conclusions

Patients have a right to expect high-quality, accessible, personalized health-care information. Encounters are increasingly complex but should guide the patient through the intricacies of the decision-making process. Actively encouraging patients to make audio recordings of encounters could be seen as a way of enhancing the doctor–patient relationship, improving patients' ability to understand this complex information and potentially improving outcomes. The law is clear in stating that patients are free to do this. Doctors are perhaps understandably nervous about what recordings may be used for, but how can you be sure that your patients are not recording anyway? An approach of openness and transparency from both parties is advised. Analogous to the 'universal precautions' principles of infection control, an awareness that patients may be making recordings should promote universally high-quality, patient-centred communication at all times. **BJHM**

Conflict of interest: Mr B Main: none; Dr G Elwyn initiated and developed the Option Grid Collaborative, which produces tools to support shared decision making. He is part of a research team that has developed the CollaboRATE, a patient-reported measure of shared decision making. He acts as an adviser to Emmi Solutions, a producer of patient decision support interventions in the US.

KEY POINTS

- Health-care information is increasingly complex but patients often have difficulty remembering what has been discussed in clinics.
- Audio recording encounters on smart phones is one way of providing patients with a reliable source of information.
- The law permits patients to record these encounters without seeking the doctor's consent, and the General Medical Council allows un-edited recordings as admissible evidence.
- Professional bodies and defence organizations recommend an open, honest approach whereby doctors are not hostile to, or feel threatened by, these recordings.
- Better doctor–patient communication, better resource use and better outcomes could result from allowing patients to record encounters but more evidence is needed to support these claims.
- Clearer guidance from regulatory and defence organizations is needed to help doctors deal with this issue, particularly where there is potential for conflict or misuse of recordings.

Care Quality Commission (2015) Thinking about using a hidden camera or other equipment to monitor someone's care? www.cqc.org.uk/sites/default/files/20150212_public_surveillance_leaflet_final.pdf (accessed 27 March 2015)
Coulter A (1998) Evidence based patient information is important, so there needs to be a strategy to ensure it. *BMJ* **317**: 225–6
Department of Health (2012) The NHS Constitution. www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf (accessed 3 February 2015)
Edwards A, Elwyn G, eds (2009) *Shared decision-making in health care: Achieving evidence-based patient choice.* 2nd edn. Oxford University Press, Oxford: 3–9
Elwyn G (2014) "Patientgate" – digital recordings change everything. *BMJ* **346**: g2078 (doi: 10/1136/bmj.g2078)
Elwyn G, Buckman L (2015) Should doctors encourage patients to record consultations? *BMJ* **349**: g7645 (doi: 10/1136/bmj.g7645)
General Medical Council (2013) Good Medical Practice. www.gmc-uk.org/guidance (accessed 3 February 2015)
Hubbard G, Illingworth N, Rowa-Dewar N, Forbat L, Kearney N (2010) Treatment decision- making in cancer care: the role of the carer. *J Clin Nurs* **19**: 2023–31 (doi: 10.1111/j.1365-2702.2009.03062.x)
Kessels RPC (2003) Patients' memory for medical information. *J R Soc Med* **96**: 219–22
McCartney M (2013) Patient information leaflets: "a stupid system". *BMJ* **347**: f4748 (doi: 10.1136/bmj.f4748)
Open Notes (2015) mobihealthnews: Beth Israel pilot to let patients add notes to medical records. www.myopennotes.org/mobihealthnews-beth-israel-pilot-to-let-patients-add-notes-to-medical-records/. (accessed 2 February 2015)
National Institute for Health and Clinical Excellence (2012) Patient Experience in Adult NHS Services: Improving the Experience of Care for People Using Adult NHS Services. www.nice.org.uk/guidance/cg138/resources/guidance-patient-experience-in-adult-nhs-services-improving-the-experience-of-care-for-people-using-adult-nhs-services-pdf (accessed 3 February 2015)
Tsulukidze M, Durand M-A, Barr PJ, Mead T, Elwyn G (2014) Providing recording of clinical consultation to patients – a highly valued but underutilized intervention: A scoping review. *Patient Educ Couns* **95**: 297–304 (doi: 10.1016/j.pec.2014.02.007)
United States Government Publishing Office (2010) The Patient Protection and Affordable Care Act. United States Government Office, Washington DC (www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf accessed 3 February 2015)
Zack P (2014) Patients recording consultations. *The Medical Defence Union: Good Practice* **5**: 18–19