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This is a pre-copyedited, author-produced PDF of an article published in *Clinical Ethics*. The definitive publisher-authenticated version [Newson, A.J. (2010) "Clinical Ethics Case Study 10: For the record: Should our patient's relatives be able to record her treatment?" *Clinical Ethics*, 5(2): 57-62.] is available online at <http://cet.sagepub.com/content/5/2/57.full>

Clinical Ethics Committee Case 10:

For the record: Should our patient's relatives be able to record her treatment?

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Introduction

This is the 10th in a series of cases provided and discussed by UK Clinical Ethics Committees (CECs). All CECs registered with the UK Clinical Ethics Network may submit a case, which is then discussed by another committee. To safeguard confidentiality, if a case is based on an actual clinical scenario, consent from all parties is obtained. To the same end, the committee referring a case is not identified (as this would provide a geographical indicator of identity), but we do name the committee discussing the case. A member of the editorial committee attends the discussion of the case and writes the summary to be published in *Clinical Ethics*, once the discussing committee and the journal editors have approved it.

The Gloucestershire Hospitals NHS Foundation Trust CEC agreed to discuss the following case. The CEC was established in 2005 and serves two large acute district general hospitals in the South West of England. Group membership comprises representatives from senior medical staff, nursing, nurse consultants, allied health-care professionals and lay persons, as well as a clergyman. Legal advice is available on request, but a lawyer does not sit on the committee. The CEC provides a consultation service, education for hospital staff and, while not in its terms of reference, will review hospital policies if requested. The group meets approximately every six weeks and there are around 20 members, with six to 10 meeting each time. Members are also available at times in between to receive referrals and give advice, but to date this has usually comprised an invitation to the referrer to attend the next meeting so the group as a whole can discuss the issue. The cases reviewed and issues discussed have varied. Cases are anonymized and made available to hospital staff on the hospital intranet. Minutes of the meetings are recorded, within which the group discussion is summarized.

A referral to the CEC from the manager of the Accident and Emergency Department

F, a 67-year-old woman, was brought in to the Accident and Emergency (A&E) Department by ambulance on a busy Friday night with acute chest pain. Her family (husband and adult daughter) arrived soon afterwards. F was not in good general health: she had diabetes and severe asthma, although these were well managed and F was compliant with ongoing treatment. She was also obese and involved in a weight loss programme through her local health centre.

Soon after her arrival in the A&E Department, F went into cardiac arrest and stopped breathing. A resuscitation trolley arrived in good time and a team began to work to try and resuscitate F.

At this point, F's adult daughter H entered the treatment area. She retrieved her mobile phone from her bag and began to film the resuscitation attempt. This behaviour alarmed the multidisciplinary team treating F and H was asked to cease recording. The reasons for their request for H to stop were: that the team were becoming distracted and concerned that this intervention could disrupt the care they were providing to F; the effect H's filming may have on other patients and visitors; and how such footage might be interpreted in the future.

Nevertheless, H was determined to continue filming. She claimed that: 'It's our right to film our mother. If she dies, this will help the rest of our family to say goodbye. Plus, if we're worried she hasn't received the best possible treatment, this will help us later on'. H was, however, asked again to stop filming and reluctantly did so. F's resuscitation was successful and she was moved from A&E to the cardiac care ward, where she remains unconscious but slowly improving.

Three days later, I (the manager of the A&E Department) received a written complaint from H and F's husband T, saying that they should have been allowed to continue filming the A&E staff resuscitating F. Through some background investigation, H had established that there was no Trust policy on relatives filming patients, or indeed any policy about patients themselves recording consultations and treatment. H claimed that: 'several of my friends record their medical consultations to help them remember everything, and what we wanted to do is no different from that'. She also stated that 'this is no different to family members taking photos of their loved ones to remember them by'.

On behalf of the A&E Department, I am therefore approaching the CEC for assistance before responding to H's complaint. We are worried that while some people may seek to record or film consultations as an aide memoire in times of stress or for personal reassurance, others may do so for more litigious or unusual purposes (such as making the material available on the Internet). We are also concerned about how such material may be interpreted by an inexperienced audience. Further, we worry about patient consent to this filming and the disruptive nature of the practice.

On contacting the Trust's communications department, we have established that there seems to be a gap in hospital policy regarding this kind of recording activity, as the only relevant policy is one relating to requests from the press to film on site – with requests for filming or photographs needing to be approved by the Trust's director of communications. The communications department has received requests for clarification as to whether this policy would cover the use of phones or other hand-held devices for recording. From speaking to colleagues in other departments I have also heard anecdotal reports that such attempts at recording are on the increase – from both relatives and patients themselves. Some patients have also apparently attempted to take photographs of other patients with whom they have shared a ward, with claims that this has taken place with verbal consent.

We are approaching the ethics committee with the following questions in mind:

1. Should H have been allowed to continue filming?
2. Is H's claim that filming resuscitation is akin to recording other more routine consultations defensible?

3. If a patient is unconscious, should a family member be able to record them, or should recording only be possible if a patient consents in advance? What should happen if a patient specifically requested such filming? Or, should recording not be permitted at all? (This is also interesting in relation to giving birth.)
4. Is Trust policy on this issue, to cover and protect both patients and staff, needed? If so, how might such a policy be structured? How could it be implemented in the hospital?

Response from the Gloucestershire Hospitals NHS Foundation Trust CEC

Thank you for your referral, which we considered at our meeting on 22 January 2010. This case prompted a lot of discussion in our group, as it raises a range of issues that go beyond the core scope of the referral. We spent some time discussing the presence of family members during resuscitations, current practices towards filming or photographing procedures in different hospital departments and what impact our deliberations about this case may have if they were applied more widely.

Background

It is interesting to note that guidance on patients' witnessing resuscitation attempts, issued by the Resuscitation Council (UK), has been in place for over 10 years.¹ Rather than focusing on the potential for the presence of a patient's relatives to disrupt the care being given, these guidelines emphasize that having relatives present can actually help them to understand the process. This attendance should only take place, however, if the relative is accompanied by a senior staff member. However, this guidance does not encompass advice that applies to H's behaviour – that is whether relatives can film resuscitation attempts.

Filming of medical procedures is certainly not unknown within a hospital setting. Apart from the press gaining access to a Trust site to obtain relevant footage, surgical procedures are often filmed to help with continuing education. In an obstetrics environment, expectant fathers are often allowed to film some or all of the safe arrival of their baby. In the case of caesarean births cameras are often permitted in theatre in order to photograph the baby shortly after birth, although filming of the operative site is not usually permitted.

We return to these examples below; but also pertinent to this discussion is the practice in a paediatric setting in which a dying child's parents, who have been involved in decision-making for their child, are able to take pictures of their child during the dying process. Parents who have also experienced a stillbirth or intrauterine death are also encouraged to take pictures to assist with grieving and moving on. However, these examples tend to be from contexts where active intervention is not being pursued and the filming or photography is therefore not of ongoing active treatment. We did wonder what (if anything) might be different if F's case involved a child.

There is also the practice (common in North America and emerging in the United Kingdom) of having a fixed camera in the roof of a designated bay within an A&E unit. This is installed for the purpose of filming resuscitation attempts. All staff members working in the department know about the camera's presence, although patients will not if they are unconscious on arrival into hospital. Resuscitation attempts that have been filmed will be reviewed by the care team within one or two days, for the

purposes of audit and teaching. The tapes are then erased. Therefore, recordings of resuscitation attempts do already take place in a professional setting, but this is something that is controlled by the responsible department and this material is not retained.

The question, therefore, is what it is that is different about H's request to film in the manner that she did, and how such a distinction could be sustained within any Trust or other policy on this issue?

What are the issues that arise with respect to H's complaint?

Our discussion continued with a more in-depth exploration of current filming practices within a hospital setting. In an obstetric environment, for example, filming is relatively common. Expectant fathers can take pictures or video recordings, often including the use of a mobile phone. This can also take place during surgical procedures such as caesarean sections, although screening is used to obscure the operating site and the pregnant woman must give consent to the recording.

We wondered about the motivation for such kinds of filming. Usually it would be to record a happy event, but there may also be an element of control if complications arose. We also considered what might happen if a patient was unconscious in this kind of situation, as family members are not usually able to be present during a general anaesthetic for caesarean section. We did discuss whether a staff member could undertake the filming instead, but this may fall outside his or her core job description.

This discussion also led us to briefly discuss the wider issue of aggressive or disruptive family members in the hospital environment and how staff should respond to them. It can be very difficult to remove a family member in this situation, as if they refuse to leave, physical handling may be required and this will not always be available. Some assistance may be provided by The Criminal Justice and Immigration Act 2008 (England and Wales): section 119 of this Act provides a new offence of causing nuisance or disturbance on NHS premises, which could perhaps be used to expunge disruptive family members from scenarios like these.

With regards to regular filming with a fixed camera in a designated bay, we would want to ensure that this was something that was explained carefully to, and accepted by, all involved staff and that filming was undertaken with their consent. Such filming should have a non-accusatory purpose with the goal of improving practice.

We then turned to discuss this particular referral in more detail. One of the problems in this case is that patient consent is not obtainable, which distinguishes this scenario from some of those we have already discussed. This filming is also unlikely to inform and improve future practice. We return to this point below.

Our discussion of this case was structured first around the actual or presumed interests of key stakeholders and then the specific questions posed in the referral. We first discussed the patient, F. Then we considered H and other family members before turning to hospital staff.

The patient: F

As F could not (and still cannot) speak for herself, we have a responsibility to consider what might lie in her best interests – both in providing her medical treatment and also her wider interests as a patient

under our care. We should of course consult her family about this but ultimately the decision lies with us, assuming that no other legal powers are in place.

As to F's best interests, our major concern was that filming did not appear to offer any benefit to F. We also worried about how F might feel if she were to view the footage afterwards? Resuscitation attempts are by their nature very busy and can at times appear chaotic. Although utmost care is being provided to patients, the process can also appear a little undignified.

Determining F's exact best interests will be difficult, particularly in an emergency context. As F recovers, would she later want to know that everything possible was done? If she had not survived, would she have wanted her wider family to know about her care? We do view H's request as somewhat odd and we wonder, like the referrer does, about her motivation, but it is still possible to imagine a scenario in which a person could conceivably want to know that everything possible was done to help them.

One possible course of action would be to ask H why she wanted to do this filming. She may think that it may later help F to adjust to her situation, that it could help the family come to terms with her (possible) death or that the act of filming could itself help ensure that she received the highest standards of care. It could, therefore, increase F's trust and confidence in the medical system. However, these possible motives are conjecture and we have no way of determining F's thoughts at this stage.

If F had considered this scenario and given her consent in advance, then some of us may have been persuaded in favour of filming going ahead. However, we consider that such consent would have to be in writing in advance of her becoming unwell – just as patient consent is required for other forms of clinical photography. However, many of us were concerned about the prospect of every patient making such a request 'just in case' for every operation they undergo.

We did recognize that lots of medical procedures are now routinely recorded for training purposes, often without explicit consent. But most of this footage is non-identifiable, is produced in a controlled manner for audit and training purposes and is not kept in the longer term. The difference here is that F's dignity is at stake, the purpose of filming has not been made clear and the technology being used is not within the control of the care team. We also noted that there could be Data Protection issues with this footage, given that it is identifying of F and would be likely to be treated as sensitive patient data.

Therefore, without F's consent we did not feel her resuscitation should be filmed. There is little that can be said to support it being in F's best interests. Further, this filming could actually harm F given that it appears to have been done without consent, in a situation where F may not have much dignity, and the footage may give rise to psychological disturbance or damage to family relationships if viewed afterwards. H's comments about this being 'what F would have wanted' are not enough (assuming she is not vested with the necessary legal authority to act as F's lasting power of attorney) to provide legal compulsion for filming to go ahead. We would have wanted to have a longer discussion with H and F's husband T prior to filming, which was simply not possible in this emergency context.

However, our position is perhaps qualified by one caveat – whether there are any cultural factors relevant to this scenario. We do not have any information about F's cultural or ethnic background, but we did note that in some cultures, family members are very involved in the dying process, at least those which are planned. In some cultures it is common for family members to sit with a dying relative and to take photos. It may therefore be 'normal' to be present when a family member is facing a life-threatening situation in hospital, and filming might be considered an 'extension' of this. If this behaviour

is enshrined in the culture of the patient (and perhaps his or her extended family), then this may influence our view on the acceptability of filming. However, we would emphasize that this should form part of a discussion about filming in advance and should not lead to an adversarial encounter such as happened here.

F's wider family, including her husband T and daughter H

In considering this request from the perspective of F's wider family, we were again struck by its unusual nature. That said, the use of hand-held recording devices is increasing, and people are becoming accustomed to having instantaneous information available. The family may well feel strongly about this, but in our view filming should only take place with permission from the Trust. We are also concerned to ensure that the Trust should be able to exert some control over the footage to try and ensure it does not end up in the public domain, yet we recognize that this would be resource-intensive and difficult to enforce in practice.

Increasing Trust control would also have implications in other domains where family member filming is already common, such as obstetrics. The difference between these two contexts could be that birth is a natural process, while resuscitation is highly interventional. Birth is also a happy event the majority of the time, whereas success rates for resuscitation are low and there is some discomfort around death, albeit with sensitivity to culture as we have recognized above.

As for F, we found it difficult to provide a positive justification for H to film her resuscitation, but we also recognize that H has correctly pointed out that there is little policy on this issue. We do worry about H's intention; would this be to aid in dealing with a possible bereavement, or to aid in later litigious activity? An important aspect of this footage is that it will in no way reflect or convey the clinical decision-making that occurred around F's resuscitation. If video footage were to be used for later legal action, this would be an important omission.

It might also be claimed that witnessing a resuscitation attempt can help in a bereavement, and H's filming may have allowed F's wider family to share this benefit had she not survived. This could allow access to a powerful form of closure for family members who could not be present, but there is no strong evidence for this either way and the desire to view such footage may differ depending on the filial relationship involved.

Filming may also give rise to harm to F's wider family. The family may not share a consensus view about H's actions, which could cause disagreement. Some may have concerns with coercion and voyeurism or the availability of this material outside the hospital.

The hospital staff

In any resuscitation, hospital staff work to the best of their ability in the patient's best interest. They do, however, need to think and act quickly, and witnessing this kind of team working can be upsetting for the uninitiated. It is also arguably unfair on staff for them to be subjected to an unscheduled and unannounced filming event when they are in the process of dealing with an acute situation.

The intention of the family members is also something that may cause concern to hospital staff. It may have been possible for H to reassure the staff that her purpose for filming was merely to show close family members; however, this would be difficult to control in practice and discussion would not have

been possible in this acute situation. The care that F receives should of course be transparent to all parties, but H filming in the way that she did would not guarantee this and consideration must also be given to staff and patient privacy.

Some may claim that allowing filming of staff could (even if the material were to be taken outside of the Trust) cause staff to perform better, knowing that their work will be subjected to external scrutiny. But to commence this with no prior warning or consent can cause stress, as was observed in F's case. More importantly, the disruption could have affected the standard of care provided to F. Staff are also themselves potentially subject to adverse events and footage which contained such an instance would have to be carefully controlled.

Therefore, our view from the perspective of staff is that they should have the right to either consent or refuse filming, particularly when the recording is going to be taken out of the hospital environment. Filming staff within a Trust is likely to be a useful aid for learning and audit, but this material should also be strictly controlled.

Addressing the questions posed by the committee

Should H have been allowed to continue filming?

In this particular case, virtually all members of our committee believed that H should not have continued filming. Our reasons for this position have been discussed above and include aspects of control, use of the footage (which contains sensitive personal data), the impact on staff members, the lack of benefit to F, the absence of prior discussion, concerns about lack of consent and concerns over privacy and confidentiality. An informal consultation with Gloucestershire Local Involvement Network also indicated a desire not to have family members filmed in this way.

One counter-point to our majority view was that if the filming would not interfere with the management of F's case, then weighing the potential benefit to other family members who may have the opportunity to view the footage later may mean that filming could go ahead. This may occur, for example, if staff had stopped actively treating F.

However, in claiming that H should have stopped filming, we are also mindful that a consideration of this issue more generally may also mean that we need to consider factors such as consistency across different specialist areas. How might filming in this example differ from filming in an obstetric environment, or a child dying? Some Trusts allow resuscitations to be filmed in a fixed bay, not always with patient consent – does this set a precedent?

We are also mindful that cultural and ethnic factors often inform attitudes to death and dying, and that what may appear unusual in one culture may be standard practice in another – such as taking photographs of recently deceased relatives. New technology may simply extend these existing customs and practices.

Is H's claim that filming resuscitation is akin to recording other more routine consultations defensible?

We do not believe H's claim is defensible. This is an emergency context and so is very different from recording a routine consultation. In a non-emergency context, recording (of any kind) is done with the advance consent of all parties. The purpose of this is usually directed by the patient and is often to aid in

his or her recall of treatment. The law is unlikely to support H's filming without prior consent and there is little public interest in this footage.

If a patient is unconscious, should a family member be able to record them, or should recording only be possible if a patient consents in advance? What should happen if a patient specifically requested such filming? Or, should recording not be permitted at all? (This is also interesting in relation to giving birth.)

As we have already stated, we believe that filming of unconscious patients, particularly in an emergency context, should only take place if a patient has made their wishes about this known in advance.

We would think that it would be unusual for a patient to make such a request in advance (this could be seen as a form of advance directive), but if such a statement is made and documented, then we do not have an in-principle objection to filming patients' treatment. Filming should only, however, take place with consent from all staff, which may be difficult to obtain in F's case. We do not feel that a Trust should (or could) consent on behalf of its staff. Ideally it would also be carried out with proper equipment and control over the material to produce, as we remain concerned about the uses to which any footage may be put.

Is Trust policy on this issue, to cover and protect both patients and staff, needed? If so, how might such a policy be structured? How could it be implemented in the hospital?

There is a draft policy on the use of mobile phones within our Trust, which does cover the use of photography with mobile devices, but not filming. However, the focus of this policy is on concerns over electronic interference and not on how the material obtained could be used. Additionally, this policy has remained at draft stage, likely because of difficulties in how it could be enforced in practice.

It does therefore seem that there is a policy gap. Our view is that filming on a mobile phone is inappropriate (subject to the above caveats), but a policy focus is perhaps required to look at filming in general. However, if we are to develop policy, we need to be sure that it can be justified. Will it help staff with their work? Can a policy possibly account for the spread of filming activities within a Trust and the possible relevance of cultural factors? A policy may be warranted if broad agreement can be reached on filming in the various contexts we highlighted in our discussion. Any policy would need to be consistent and would need to provide the Trust with some control.

The most significant problems with any policy of this kind will be implementation and ensuring compliance. It would be logistically impossible and resource-intensive to check the mobile devices of every person leaving the hospital. It will also be impossible to ensure that only those who have consented are included in any footage. Ultimately, what is required is Trust-wide discussion and education, involving the CEC.

Conclusion

As hand-held technologies increase in uptake and further decrease in size, there is a challenge for both policy-making and education, for Trust staff, patients and their relatives.

We have observed that there is already a fairly diverse range of attitudes and practices towards filming in our Trust. The key challenge is whether this diversity is defensible and how practices may be brought together in a policy to protect staff and vulnerable patients, but also to facilitate filming or photography

when it may be beneficial to patients and their families. The greatest challenge posed by this case is that it occurs within an emergency context, as gaining the necessary permissions is always going to be difficult.

In this particular case, we feel that filming should not have continued and the care team was right to ask H to stop. But the case highlights a need both within and beyond the Trust to determine whether patient- or family-led filming or photography of treatment is appropriate, and if so, under what conditions. In attempting to reach consensus on this issue, it will be important to work with national bodies such as the Resuscitation Council (UK) as well as patient-led organizations.

Members of Gloucestershire Hospitals NHS Foundation Trust CEC who discussed this case

Carole Butler-Williams, Consultant Nurse – Critical Care Outreach Team (CEC Vice Chair); Dr W F (Bill) Casey, Lay Member; Debra Clark, Specialist Palliative Care – Clinical Nurse Manager; Maureen Dore, Lay Member; Dr D A (David) Gabbott, Consultant Anaesthetist and Chair of the GRHNHSFT Resuscitation Committee; Gillian Thistlewood, Lead Occupational Therapist; Alex Townsend, CEC Administrator; Sharon Wade, Consultant Nurse – Orthopaedics; Mr Mark Whyman, Consultant General and Vascular Surgeon (CEC Chair).

Article Notes

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Reference

Resuscitation Council. Should Relatives Witness Resuscitation? London: Resuscitation Council (UK), 1996. Available at: <http://www.resus.org.uk/pages/witness.pdf> (last checked 27 January 2010).