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Title: Duty of candour and the disclosure of adverse events to patients and families

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Abstract

The disclosure of adverse events to patients or their families who have been affected is considered to be a central feature of high quality and safer patient care, but despite this, as few as 30% of harmful errors may currently be disclosed to patients. Advocates of open disclosure propose that failing to communicate effectively with patients following adverse events may have negative repercussions for all stakeholders. The disclosure of adverse events and errors to patients and their families is part fulfilling the duty of candour advocated in the numerous recent reports into the quality and safety within the NHS. This paper considers why disclosure remains challenging for organisations and professionals alike, despite guidance and in a clear moral imperative and commitment from stakeholders to transparency in healthcare.

"……..there are no easy answers when it comes to making mistakes. That needs to be said outright lest someone, especially someone in training who is less experienced, think that admitting a mistake stops at quality control or sharing responsibility, and that there is then some way around the difficult task of actually taking responsibility for the mistake. Within the culture of medicine and even more broadly in modern society there seems to be a drive for finding the easy way out. In this case there is none, and it needs to be made very clear that this is a defining moment in the life of a physician with regard to integrity and professionalism" page 570.[1]

In the UK, the National Patient Safety Agency (NPSA) re-launched their Being Open framework in November 2009 [2]. The framework describes Being Open as being about the way in which healthcare organisations and their staff should communicate with patients and/or their carers following a patient safety incident and sets out 10 key principles that underpin the successful facilitation of this process. These include providing a genuine and timely apology for what has happened, keeping patients and/or their carers informed about the progress made with the incident investigation, reassuring patients and/or carers that the incident is being taken seriously and ensuring measures are taken to prevent it from happening again. Disclosure of adverse events to patients is a specific, highly emotive and often poorly executed professional duty and as such is worthy of some consideration in any discussion of duty of candour.

The picture of disclosure and non-disclosure

The failure to disclose errors to patients takes place at scale, on an international level with estimates as low as 2.7% [3], and is based on over-dependence of the severity or obvious nature of harm as a motivator to disclosure [4]. Health professionals still hesitate in their reports of errors or adverse events unless serious harm occurs. The little we know about any epidemiology of disclosure suggests that patients who

experience error are less likely to report disclosure if they are older than 50 years, have poor general health, experienced preventable events, or continue to be affected by the event [5]. This suggests that disclosure occurs when individuals and organisations feel compelled to do so because the error is more visible [6]. Although there is little work directly addressing attitudes to and rates of disclosure in the UK estimates around of 30% of events not being disclosed have been cited and reasons for non-disclosure listed as, negligible perception of patient harm, fear of litigation, fear of organisational or professional reprisal, and that the patient moved, died or remained unconscious [7]. While supportive environments seem to encourage staff to disclose errors to colleagues, disclosure to patients lags behind [8]. This picture highlights the need for further training for clinical staff with relation to both current duty of candour but also medico-legal aspects of care.

The disclosure gap

The enthusiasm for what is seen by many as the moral imperative may not be reflected in practice. Disclosure still remains an elusive concept for some and despite a clear message from patients that they require an honest conversation about poor outcomes, mistakes and errors, what clinicians, (doctors in particular) say they would provide is unlikely to meet patient expectation [9 10]. This discrepancy has been referred to as the "disclosure gap" [11]. Reasons for the disclosure gap are not difficult to fathom. For healthcare professionals, admitting that they have harmed a patient is psychologically difficult. As well trained and compassionate individuals they have a professional and often personal commitment to helping patients. The challenge to this identity posed by unanticipated outcomes and errors is uncomfortable. While clinicians often received training in 'breaking bad news' this rarely extends to

conducting the challenging conversations that are required for disclosure of errors or mistakes. Historically it seems likely that healthcare organisations and the individuals who work within them may not fully appreciate how important full disclosure is to patients and thus make well intentioned interpretations about what is important to disclose. In fact many clinicians would argue they are protecting patients from difficult information. Finally, the fear of litigation looms large despite attempts to reassure clinicians that an apology does not constitute admission of liability and the increasing attention received by claims that disclosure actually reduces litigation costs. So the disclosure gap persists despite the codes of a number of UK health professional and indemnifying bodies advocating openness as a professional obligation. However in response to a persisting lack of consistency in openness over mistakes, there have been calls to introduce a statutory duty of candour in the UK.

Being open, what is the problem?

The recent catalogue of events, investigations and reports in the NHS has highlighted lack of transparency in healthcare as a problem again and again and it is easy to blame clinicians and managers for withholding information from patients, to hold them up as arrogant and self-preserving. From the public perspective it is hard to understand why a group of professionals whose code of conduct and day to day practice is concerned with protecting and caring for patients find this so difficult to achieve.

If we examine the area carefully, for both NHS trusts and those employed within them, there are a number of interlinked and persistent issues which may lead to

variation and inconsistent practice if not for the broader area of openness at least in relation to the disclosure of errors and adverse events. The simple ethical question of 'is it the right thing to do', to disclose error, is easily answered. The answer is almost always likely to be yes. But any exploration of its enactment highlights the numerous challenges associated with action. It is both emotionally and legally sensitive and takes considerable skill which is not captured well by current guidance which is unlikely to be able to address the complexity of decision-making which underpins disclosure of an adverse event, whether serious or one associated with less or no apparent harm.

Defining harm

There is a pervasive problem around definitions of error and harm which are defined solely by one side (the provider) and are driven by definitions of events which are classed as moderate or severe. The naming of harm, beyond so-called 'never events' (or those that the organisation judges to have harmed the patient) appears to be open to interpretation and as such some subjective judgement is inevitable applied. Patients and clinicians appear to define error differently [12]. From the patient perspective, the distinctions between the terms error, adverse event and unexpected outcome seem relatively unimportant. Such definitions are largely constructed from the safety systems perspective and may be at odds with the way in which patients interpret harm. If the patient perceives harm, then regardless of how organisations, professionals and lawyers wish to classify this harm, patients who perceive they have suffered will feel they deserve a timely, supportive and informative conversation

about their concerns. Unless definitions are transparent, and applied and seen to be used consistently, then patients will be frustrated by such inconsistencies

The aspiration of zero-harm

Open disclosure could be linked to the valued commitment to learn from previous safety problems in preventing future errors and harms. Careful analysis of events is important but will not predict how things might happen in the future. Analysis of events should be viewed as an opportunity for sensitive discussion and planning for how to avoid the situation, or more realistically, how to handle a situation if it happens again. In most cases such discussions omit the perspective of patients and families. While the aspiration of the NHS may be zero harm, in the journey to this aspiration, the usefulness of the approach of handling how to disclose error must not be forgotten. Broader literature on quality and safety will need to address how the aspiration of zero harm can be made to sit more comfortably with values and behaviour in relation to open disclosure where the very aspiration of a service has been challenged by the occurrence of error. Failure to address this as part of on-going support and development is unlikely to result in changes in action.

Implementation of change

The importance of engaging physicians and their indemnity and professional bodies in any system change in the NHS has been identified. The issue of who makes decisions about disclosure and how it is done seem largely to fall in the domain of doctors, although others, specifically nurses and risk managers, may also play important and sometimes leading roles. Transformative initiatives such as improving transparency in

care are often championed by nurses or non-clinical mangers (who have less power) but their attempts are often frustrated by blocks from medical colleagues. The medical collegial regulatory framework is self-policed and geared towards detecting extreme examples of poor practice or unethical behaviour to protect the profession rather than monitoring quality. That gives them a great deal of power in responding to transformative events and professional regulatory guidance usually has most influence on the moral perspective articulated in practice. The influence of professional regulation was apparent during the duty of candour debate with the medical profession objecting to a legal duty of candour on the grounds that their professional regulatory framework already meant they had a duty to be open with patients. Nurses and patient organisations on the other hand were supportive of regulation around openness in care which went beyond a statutory duty. Since doctors often have a power of veto when other groups are keen to adopt a new normative stance the engagement of the medical profession in making in-roads into transparency in healthcare is fundamental. Coordinating and disseminating consistent messages from all stakeholders from the NHS Litigation Agency, medical indemnifiers, and professional bodies from all disciplines will be key.

Complexity of judgements

The role of situated judgement in making decisions about what to disclose, to whom and when may be more complicated than it first appears. While the moral and ethical stance in relation to being open with patients seems clear cut as with any safety practice there needs to be clarity about both theory and [13] and this could equally apply to the broader but related value of openness in healthcare. Defining the events to be

disclosed without due care and attention to the multiple values inherent in decisions about disclosure behaviour fails to address contextual issues and thus the effectiveness of guidance such as Being Open.

Providing care for individual patients and organisation of care for populations are related but different endeavours and this may lead to tensions [14]. Healthcare professionals and healthcare organisations aspire to provide the best possible care for individuals but the reality of a system such as the NHS is that this is achieved through providing shared resources at a population level. Thus there is an inherent challenge in managing a shared resource in an ethical way which often differs from managing a resource for an individual. So managing the reputation of an organisation to maintain the trust of the larger population may conflict with disclosing information about an individual error.

Doing the right thing in the right way

The importance of doing the right thing in the right way is also important and this point is particularly salient in disclosure conversations [14]. To put it bluntly clinicians may be afraid of getting it wrong. Training, where it exists, focuses on raising awareness of the moral and legal imperative but occasionally also on how to have a challenging conversation. A doctor or any other professional who wishes to tell a patient that an error in their care has occurred is ethically correct but blurted out, in the wrong circumstances, in the wrong way, could cause even further damage. So the skill involved in doing the moral thing in the right way is important. Finding the right place, having all the information, and rehearsing this takes time and underpins all

efforts to train people to do this well, if the ethical course of action is to be done in a morally appropriate way. Preferences of the family or patient need to be taken into account thus the person disclosing should have good knowledge of the individual being dealt with and this has implications for who discloses. Moral communication requires skills and these skills need to be practiced and experienced and there is currently little opportunity to do this. The degree of emotional intelligence required in such situations is important in relation to managing difficult conversations; being able to express empathy, manage anger and distress (their own and that of the patient) are all important in making the communication with the patient or family sensitive. Forgiveness may not be forth coming from the patient and family and dealing with this response when an individual and an organisation feel they have acted with integrity can be hard to accept.

Taking the risk

There is an inherent sense of risk for organisations in relation to disclosure and the wider principle of candour., In order to achieve an open culture they must be prepared to give up some control. Patient safety initiatives are, for the most part, aimed at exerting as much control over processes as possible, limiting the points where initiative or opinion come into play, checking the process at as many identified points as possible to reduce the likelihood of mistakes. However, disclosure requires a degree of resilience and the ability to manage uncertainty if organisations and individuals are to deal with errors and disclosure effectively. The process linking the monitoring of quality and safety is unlikely to be able measure or quantify a sea change in openness which may be imperceptible even to those using healthcare

services and so cannot be conceptualised in the same way as the majority of safety interventions. Disclosure of adverse events should be focused around informing future practice and improving quality and safety but it has wider implications for the staff and patients involved. For these reasons sitting disclosure entirely within the current patient safety theoretical models is unlikely to fully address its challenges and models which are able to address the complexity of values within healthcare and emotional intelligence in practice are also likely to be useful.

Overall, while we should continue to aspire to attain transparency; and accepting that in a small number of cases information is deliberately withheld; a representation of healthcare organisations and those that work within them as deliberately avoiding disclosure conversations is overly simplistic. A more accurate reflection where multiple but defensible values are apparent and may be in conflict at times may be a better reflection of what currently exists. We know little about how to best disclose error or indeed whether there may be any adverse outcomes as a consequence and these are all areas which need to be explored moving forward.

Healthcare reforms are often difficult to enact and the changes that all stakeholders in the NHS aspire to may not translate into practice or change may take longer because working practices are institutionalised. This is apparent in a policy of open disclosure and is complicated by the levels at which the policy needs to be delivered on. Being Open is, in fact, a clear set of guidance but short pieces of advice run the risk of being used unthinkingly. It is intended to act as a simple reminder of what to do, but unless it is coupled with attitude change, education and efforts to remove barriers to actually disclosing, it will continue to have limited impact.

2476 words

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