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ORIGINAL ARTICLE

Enacting open disclosure in the UK National Health Service: A qualitative exploration

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Abstract

Background Open and honest discussion between healthcare providers and patients and families affected by error is considered to be a central feature of high quality and safer patient care, evidenced by the implementation of open disclosure policies and guidance internationally. This paper discusses the perceived enablers that UK doctors and nurses report as facilitating the enactment of open disclosure.

Methods Semistructured interviews with 13 doctors and 22 nurses from a range of levels and specialities from 5 national health service hospitals and primary care trusts in the UK were conducted and analysed using a framework approach.

Results Five themes were identified which appear to capture the factors that are critical in supporting open disclosure: open disclosure as a moral and professional duty, positive past experiences, perceptions of reduced litigation, role models and guidance, and clarity.

Conclusion Greater openness in relation to adverse events requires health professionals to recognise candour as a professional and moral duty, exemplified in the behaviour of senior clinicians and that seems more likely to occur in a nonpunitive, learning environment. Recognising incident disclosure as part of ongoing respectful and open communication with patients throughout their care is critical.

KEYWORDS

adverse events, being open, hospitals, incident disclosure, medical error, open disclosure

1 | INTRODUCTION

Open and honest discussion between healthcare providers and the patients and families affected by adverse patient safety events is considered to be a central feature of high quality and safer patient care.¹⁻³ Open disclosure policies require healthcare providers to inform the patient and/or representative that an incident has occurred, give an apology or expression of regret, a factual explanation of what happened, some indication of potential consequences for the patient and discuss the changes being made to prevent recurrence.^{2,3} Advocates of open disclosure propose that failing to communicate effectively with patients following adverse events may have negative repercussions for all stakeholders, including distress amongst patients and

health professionals, loss of trust in healthcare providers, and the increased pursuit of litigation by patients in a quest for information.⁴

Despite policy advancement and implementation around open disclosure, as few as 30% of harmful events may currently be disclosed to patients.⁵ Recent high profile cases, such as the events occurring at the Mid-Staffordshire Hospital Trust in the UK demonstrate that the practice of open disclosure continues to fall short of patient and family expectations.⁶ Fears of litigation, a health service culture of secrecy, lack of confidence amongst health professionals, fear of exacerbating patient's distress, and doubts regarding the effectiveness of open disclosure in meeting patients' needs relating to adverse events (AEs) are identified in the literature as the main reasons for nondisclosure.⁷

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Since June 2015, new guidance on a professional duty of candour in the UK has aimed to support doctors, nurses, and midwives to fulfil their professional duty to be open and honest about mistakes and adverse events.^{8,9} Individuals must offer information on what has happened, make a meaningful apology, report these incidents to prevent them from happening again, and, for clinical leaders, encourage a culture of reporting and learning. Additionally, a new statutory duty has been in place for all providers in England since April 2015.⁸ The duty sets out how and when a patient must be informed of a “notifiable safety incident.” It requires organisations to inform patients verbally and in writing of any “unintended or unexpected incident” causing at least moderate harm or prolonged physical and/or psychological harm.⁸ The addition of psychological harm is new but the statutory duty is similar to a previous contractual requirement on national health service (NHS) organisations in England. Similar statutory duties for organisations are being actively considered in other parts of the UK.^{8,10}

Although greater openness is being promoted in policy, uptake in practice requires greater understanding of the factors that support effective open disclosure. Our systematic review identified several gaps in the literature. Original research evidence only constitutes a small part of the many publications and grey literature that discuss incident disclosure. The evidence available generally focuses on patients' experiences of disclosure (or the lack of it) and their views of what constitutes “good” disclosure and on health professionals' perceptions of what is required. These are all important, but internationally there is a need to identify the individual, local and organisational factors within each health system that support or discourage clinicians' honesty when things go wrong. Most evidence to date originates from the US, with a particular absence of UK data regarding experiences of incident disclosure practices. Given the unique model of healthcare provision in the UK, principally provided for by the National Health Service (free at the point of delivery), and related policy development process, it is likely that some of the factors influencing disclosure will be unique to this setting.

This study aimed to address this significant gap through a qualitative study of doctors and nurses in the UK. The study will facilitate the translation of policy into practice, with implications for multiple stakeholders including clinicians, patients, families, healthcare managers, and organisational leaders. These data are critical to guide efforts to improving the information sharing process that patients experience following an adverse event.

2 | METHOD

2.1 | Ethics

Ethical approvals were granted from the University of York and the Bradford NHS Research Ethics Committees. Research governance approvals were granted for each of the 5 hospital trusts included.

2.2 | Setting

Five UK trusts were invited to participate including 2 large hospital trusts, 2 smaller hospital trusts, and 1 primary care trust in a range of geographic locations that serve urban and rural communities with patients from a range of socio-demographic backgrounds.

2.3 | Recruitment

Health professionals were eligible to take part if they were doctors or registered nurses or midwives in a clinical or managerial role and had been involved in open disclosure. Potential participants were identified by the trust management and were invited to take part via direct email from the research team to avoid coercion. Participants were purposively sampled to ensure perspectives were captured from a range of grades, clinical specialities, and degrees of experience of open disclosure. A total of 35 interviews were conducted between March and November 2012. The sample comprised 13 doctors (10 senior doctors including 4 general practitioners and 3 registrars) and 22 nurses (12 senior nurses [band 8 and above, 10 nurses from bands 5-7]).

2.4 | Interview schedule

An interview schedule was developed and refined based on pilot work. Interview questions focused around the following topics: participants' understanding of the term “open disclosure,” experiences of participating in open disclosure, the training received or available to them, and their feelings about the factors that enable or pose challenges to disclosure.

2.5 | Procedure

All interviews were face to face and held in a private meeting room in the participating trusts and audio-recorded. After obtaining consent, a topic guide was used to guide discussion with participants who were also given the opportunity to shape the discussion and develop their own narratives. Interviews lasted approximately 60 minutes. Confidentiality was maintained by anonymising audio tapes and the direct quotations.

3 | ANALYSIS

Data were collected and analysed in an ongoing process until no new information emerged. Transcripts were analysed thematically using an established interpretive approach.¹¹ Framework analysis was selected for several reasons. Firstly, it is especially well suited to applied qualitative research, in which the objectives of the investigation are typically set a priori, and shaped by the information requirements of the funding body, rather than wholly emerging from a reflexive research process. Secondly, framework analysis provides a visible method which can be scrutinised, carried out, and discussed and operated by individuals in a team. Lastly, the approach lends itself to reconsidering and reworking ideas because the analysis follows a well-defined procedure, which can be documented and accessed by several members of a research team. Following initial familiarisation with interview transcripts, the research team developed a thematic coding framework based on discussions about a priori questions and issues that had been identified from the research questions and as emerging from the interview data. Initial codes from this framework (including codes relating to communication with health professionals) were then systematically applied to the transcript data. NVivo 8 text management software was used to mark specific pieces of interview data that were identified as corresponding to the thematic index

codes. More generally, NVivo 8 was also used to help organise the data to facilitate further analytic consideration and interpretation.

4 | FINDINGS

We identified 5 themes that described factors that support open disclosure to take place: (1) open disclosure as a moral and professional duty, (2) positive past experiences, (3) understanding the repercussions, (4) role models and guidance, and (5) clarity.

1. Open disclosure as a moral and professional duty

Health professionals who felt comfortable understanding when disclosure should occur, and to go to the patient and disclose an incident, appeared to accept that openness was a professional and moral duty regardless of the repercussions.

"I think there are going to be times where I might meet with a family... who would you know take this opportunity with both arms made a process...but that is their right at the end of the day and it shouldn't in principle put me off being honest and upfront with my patients."(Nurse, 1)

Respondents were consistent in the belief that the lead doctor has a professional duty to disclose an incident to a patient, but the remit of nurses was less clear, with some suggesting that the nature of the incident would determine who should have a role in the disclosure.

"For me, I think if there's been an event or if somebody's died unexpectedly, then I think there should be some involvement from the consultant at the outset...if there's something that's happened around a nursing issue, then we may very well involve the nurse, or certainly, we would involve the nurse's manager, ward manager."(Nurse, 2)

Those nurses who considered disclosure as a professional and moral duty were more confident that disclosure was not primarily the doctor's responsibility. Feelings of personal morality and accountability were in some cases seen as outweighing legal risk. In disclosing an event, nurses in particular, attributed blame to themselves even when this may not have been warranted.

"If I'd made a mistake I've got to go and see that person and say look I am sorry it was my fault, I am not saying it was right, you know it was me that did it and I did it and it was an error and I apologise. And if they then want to take that further well that is their prerogative." (Nurse, 3)

2. Positive past experiences

Many of the participants described positive experiences of being upfront and honest with patients, reinforcing their belief that open disclosure was the best approach. Contrary to their expectations, disclosures had enhanced the patient-professional relationship and were therefore considered a valuable opportunity.

"Part of me was telling me you shouldn't do this, why ask for trouble, this is going to just lead to litigation or complaints ... But you know every time I've done this has been a positive and rewarding experience, I've not regretted it." (Nurse, 4)

"Through the course of my career, so many times I've seen very bad things have happened and patients have in the end not taken any kind of legal action and not taken grievance with the doctors when they've immediately said: 'Look, I'm very sorry, this went wrong and this is why it went wrong and this is what we're going to do to try and fix it.'" (Doctor 1)

3. Understanding the repercussions

Professionals who had observed instances in which events have been covered up often observed that a lack of openness may lead to more negative repercussions for the health professionals involved.

"I've learned that it's [being open] also quite a self-preserving thing to do... the worst thing...is if they [patients] get it into their heads that there's some sort of cover up going on, then they get the bit between their teeth and solicitors get involved and it's all very difficult." (Doctor 1)

"If you are very honest and straight forward and treat the patients right then often they feel that, they take a generous view towards the mistake as opposed to getting very litigious about it, which I think they are more inclined to do if there's a big cover up and people aren't honest." (Doctor 2)

Experienced health professionals rarely reported experiencing negative repercussions such as legal action. Yet the perception that punitive action may result from openness was highlighted as a barrier to openness and one critical to address.

"Sometimes there's a culture of well if I admit I am wrong...my employer would sack me because I've been open and honest and if I don't say anything they can't sack me." (Nurse, 3)

"I think there's still a fear of the action that might be taken against you, but I think people are much more aware of, and responsible really about the failure to disclose a mistake that they've made...[but] there's still a concern I guess for everyone that there will be a whole weight of something coming on them." (Nurse, 5)

4. Role models and guidance

When asked about training around disclosure, most doctors talked about opportunities to witness others success, both formally and informally. Rather than observing 1 instance, respondents described role models who consistently conducted care in a transparent and upfront

manner. Respondents considered this modelling behaviour to be a part of the role of a senior clinician.

"To be honest, it's people who've led by example. So, consultants who've shown that actually they're open and honest and they're still practicing, they haven't been struck off... it's partly leadership by example ... And juniors pass through lots of consultants, so if they pick up good things off each consultant." (Doctor 3)

"Sometimes they'll ... the junior doctors they'll come with me so they can see how I do it and I used to do that as a junior doctor." (Doctor 4)

The value of guidance around disclosure was reinforced by the instances in which a need for training that is specific to the disclosure of an adverse event (as opposed to general training such as breaking bad news) was identified as important; most commonly identified by the nurses in our sample. Very few interviewees were able to cite any formal training provided by either their professional body or their trust.

"I haven't had any personal training. Certainly, the trust offers a sort of day if you like around breaking bad news, however, I think that tends to be more related to breaking, you know, cancers and diagnoses type thing, rather than adverse events that happened." (Nurse, 2)

5. Clarity

Health professionals who felt confident that an apology was not an acceptance of liability and had no professional or legal implications appeared more ready to offer an apology or expression of regret immediately in the context of an incident. Yet not all respondents were clear as to the implications of apologising, and the existence of a culture that at 1 time did not encourage apology was referred to by many.

"I think there was a culture a number of years ago that apologising was accepting sort of liability and responsibility. But it's not, it is an apology and if somebody has made an error or I've made an error then I am going to apologise." (Nurse, 6)

The need for informal discussion between patients and professionals prior to formal open disclosure meetings was considered important as part of an open and honest dialogue with patients and for both parties to feel informed and supported. Informal discussions rely upon health professionals' ability to recognise when patients or families are in a position to talk about the events that have occurred.

"You are told not to discuss things between yourselves and not to discuss it with the family and not to approach the family but it seems to me that actually it is better if you do because you feel more supported if you can speak to your colleagues. And maybe having more dialogue with relatives or people who are affected is going to stop this feeling of dread you get before these meetings." (Nurse, 6)

Most participants discussed their own experiences of engaging in open disclosure although those in managerial positions also commented on broader perceptions amongst their staff. The key themes were consistent across participants, but some differences were evident between the professions. Doctors generally assumed responsibility for undertaking disclosure in relation to a broader range of events compared to nurses who focused on disclosing their own mistakes. Doctors spoke more of role models, receiving support after mistakes and good guidance about how to disclose. Nurses were generally more fearful of punitive action, discussing the culture around incident disclosure and indicating a greater lack of clarity regarding what to disclose and who would be responsible for this.

5 | DISCUSSION

Clarity in relation to consequences of and roles in disclosure, support, exemplars and professionalism were perceived as key contributors to open disclosure. Health professionals who have strong role models and understand disclosure as part of a professional and moral duty appear more likely to be open and respectful with patients. These professionals may be more willing to engage in ongoing open discussions with patients and carers throughout their care, which facilitates openness in circumstance where things go wrong.

Our findings map to existing literature from the UK, USA, and Australia regarding perceived barriers to open disclosure. This work has discussed a number of areas that challenges a culture of openness: the lack of clarity among clinicians about what requires disclosure in relation to categories of events and definitions of harm, concerns about how to disclose incident information to patients and family members, the challenge of communicating with colleagues about incidents and uncertainty about the legal, and insurance implications of disclosure have all been identified.^{5,7}

In the shift from incident disclosure guidance to Duty of Candour, understanding of disclosure and apology has changed at a policy level. Talking about adverse events arising in care is part of a professional responsibility and respect for patients that should be evident from the start to end of every instance of care. Yet our findings indicate that concerns about legal implications, professional implications, and specific aspects of actually undertaking incident disclosure discussions impede health professionals from recognising open disclosure as part of an overall respectful and transparent approach to care provision.

5.1 | Implications

Effective open disclosure relies on a clinician's nontechnical skill and knowledge; the cognitive, social, and personal resource skills that complement technical skills and contribute to safe and efficient task performance.¹² Nontechnical performance has only been recognised as a critical component of clinician training relatively recently, central to enhancing quality of health care and patient's safety. In 2007, the Accreditation Council for Graduate Medical Education (ACGME) published the following 6 core patient safety

competencies: patient care, medical knowledge, interpersonal and communication skills, professionalism, practise-based learning and improvement, and systems-based practice.¹² These competencies are reflected in clinician training and as part of professional registration internationally.^{13–18}

While preclinical training in nontechnical skills is essential to increase uptake and improve the quality of open disclosure, clinicians often experience “cultural resistance” to the adoption of the skills learnt in training when entering practice.¹⁹ Fear of repercussions from the employing organization and professional bodies was evident in the narratives produced in this study. This creates substantial barriers to putting policy and theoretical learning into practice. It is therefore critical that strong role models in the workplace reinforce what it is to be open and honest about problems arising in care, in addition to modelling correct technical performance.²⁰ To date, formal approaches to incident disclosure training in the UK have inconsistent uptake between trusts and have been delivered as standalone workshop sessions. These sessions lack integration into the workplace and do not identify incident disclosure as part of a broader patient-centred approach to care provision. The use of mentorship models to promote open and honest discussion in the context of adverse events may increase uptake and be more effective.

5.2 | Limitations

Doctors and nurses are the key actors in enacting open disclosure, but by focusing on only these professions, the study may not reflect the experiences of other professional groups. In addition, our sample does provide insight into the practices of those in primary care, community care, and mental health organisations in which reporting systems and events themselves may be less clearly defined. As a multisite study that included urban and regional hospitals, the findings are likely to be relevant to other parts of the UK. Differences between health systems mean that not all findings are relevant to other health systems internationally. This evidence presents the experiences of clinicians and not that of patients; the patient perspective may identify enablers and barriers to good disclosure that clinicians do not recognise.

6 | CONCLUSION

Greater openness in relation to adverse events requires health professionals to apply nontechnical skills and knowledge: to recognise candour as a professional and moral duty, and to communicate with patients and families effectively throughout the care process as well as when things go wrong. We cannot rely solely on clinician training to develop the necessary skills and knowledge that underpin candour in health care. Evidenced in this data, once clinicians enter the working environment, the culture they are surrounded by inhibits their willingness to speak openly with patients. Senior clinicians and healthcare managers, as opinion leaders and role models, have a significant role in developing a genuinely nonpunitive, learning environment to encourage and sustain uptake of the incident

disclosure policy and the duty of candour in practice. Peer support between health professionals is also critical. Current models that provide one-off training in incident disclosure or communication are not sufficient to drive the cultural change required. A model of training and supervision that integrates these nontechnical knowledge and skills in an ongoing process throughout a clinician's career is essential.

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