Duty of candour and communication during an infection control incident in a paediatric ward of a Scottish hospital: how can we do better?

Teresa Inkster,[1] John Cuddihy[2]

[1]Microbiology, Queen Elizabeth University Hospital Campus, Glasgow, UK
[2]Parent and family representative on Communication & Engagement Sub-Group, Family representative on Oversight Board convened in furtherance of Escalation to Stage 4 by Scottish Government, Coventry University, Glasgow, UK

Correspondence to
Dr Teresa Inkster, Microbiology, Queen Elizabeth University Hospital Campus, Glasgow G51 4TF, UK; teresaink@hotmail.com

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ABSTRACT

Duty of candour legislation was introduced in Scotland in 2018. However, literature and experience of duty of candour when applied to infection control incidents/outbreaks is scarce. We describe clinician and parental perspectives with regard to duty of candour and communication during a significant infection control incident in a haemato-oncology ward of a children's hospital. Based on the learning from this incident, we make recommendations for duty of candour and communication to patients and families during future infection control incidents. These include the need to consider a crisis management approach, the importance of not underestimating psychological harm in incidents of a prolonged duration and embedding the existing legislation pertaining to the rights of the child.

INTRODUCTION

Duty of candour legislation was introduced as a statutory requirement in England in 2014.[1] Issues with openness and transparency were highlighted in the 2013 Francis Inquiry report which examined failings in care at Mid Staffordshire National Health Service (NHS) trust.[2] One of the many recommendations from this report was to implement duty of candour legislation. Scotland followed suit with duty of candour becoming a legal, statutory requirement in April 2018.[3]

Duty of candour refers to the ethical responsibility for healthcare professionals to inform patients or their families when mistakes have been made and they may have suffered harm or death as a result. It involves apologising, acknowledging and explaining what has happened to patients. Duty of candour is applied where moderate or severe harm has been determined to take place. Box 1 illustrates the levels of harm where duty of candour should be triggered if the event was unintended or unexpected and related to the patient safety incident rather than the patient's natural disease course.[4]

Organisations have a responsibility to support staff reporting adverse incidents and systems must be in place in order for them to do so.[5] Professional bodies such as the General Medical Council have guidance and examples available to guide healthcare workers.[5] However, hospital-acquired infection control outbreaks/incidents do not feature, and guidance for this area is lacking. What constitutes a duty of candour event and what is the definition of harm in relation to an infection control incident? We describe our experience of duty of candour in relation to an infection control incident occurring in a children's hospital, from the perspective of both a clinician and a parent.

The infection control incident

In February 2018, following a rare and unusual bloodstream infection in a paediatric haemato-oncology patient, water testing revealed widespread contamination of the hospital water and drainage system. Further cases were detected and investigations evolved over a prolonged period lasting from early February to the end of September 2018. Due to a failure to control the ongoing source and to enable implementation of more aggressive infection control measures, the children's' ward was closed, and patients and families were relocated to a ward in the neighbouring adult hospital. Initially, this was planned to be a temporary decant with plans to move the children back into their original ward by Christmas 2018. However, investigations revealed further evidence of environmental risk and remedial work remains ongoing. The situation was further complicated by the development of more infections in children in the new and perceived safe ward setting in June 2019 with further environmental risk factors being identified. Risk mitigation measures were implemented and infection rates in 2020 remain low.

CLINICIAN PERSPECTIVE

This clinician perspective is written by an infection control doctor who was the chair of the Incident Management Team (IMT).

Hospital-acquired infections are more often than not sporadic cases and typically communicated by the patient's clinical team. For the most common hospital-acquired infections, for example, Methicillin-resistant *Staphylococcus aureus*, *Clostridium difficile* infection, there are well-established patient information leaflets available. In many NHS boards, a single case of preventable *S. aureus* bacteraemia will initiate a serious clinical incident review. Single episodes of hospital-acquired infections might also be classified as a duty of candour event if related to a preventable source and harm ensued, for example, bloodstream infection secondary to a contaminated infusate. Postoperative surgical site infections are highlighted as a risk during the consent procedure but might constitute a duty of candour event if there was clear organisational failing such as failure to sterilise equipment or suboptimal operating theatre ventilation, leading to harm.

Box 1 Examples of moderate and severe harm

Death of patient

Severe harm—permanent lessening of bodily, sensory, motor, physiological or intellectual functions

Harm which results in:

1. Shortened life expectancy.
2. Increased treatment.
3. Changes to the structure of the patient's body.
4. Impairment of sensory, motor or intellectual functions of the patient which has lasted (or is likely to last) for at least 28 days continuously.
5. Pain or psychological harm that has lasted (or is likely to last) at least 28 days continuously.

Outbreak situations can be more complex and may involve multiple patients and families requiring an apology if harm has ensued. No one outbreak or incident is the same and bespoke decisions about duty of candour will be required for each circumstance. Often outbreaks in the hospital setting are short lived, however occasionally they can become protracted lasting >28 days.

Following the issue of the Scottish guidance in 2018, the lead author, an infection control doctor, introduced duty of candour as an agenda item for all infection control incidents/outbreaks within the organisation. This was first tested during the aforementioned prolonged incident related to a contaminated water system involving paediatric haemato-oncology patients who developed hospital-acquired infections. Where patients met the outbreak case definition, the infection control doctor accompanied the patient's clinician to apologise to families, answer questions and provide assurances.

Cause and effect may be clearly identifiable for most duty of candour situations, however infection control incidents are characterised by less certainty. Some outbreaks, such as the aforementioned, require multiple hypotheses to be investigated with a subsequent need to evaluate the control measures. Incidents may be multifactorial requiring a multimodal strategy to prevent further cases. Duty of candour in such a situation becomes more complex due to an evolving situation, a lack of definitive cause and effect early on and an inability to determine the weight of any particular intervention. As a result, the initial conversation with families can be a source of frustration for both parties, with patients and families seeking definitive answers which clinicians are unable to commit to.

As the outbreak in this haemato-oncology unit evolved, duty of candour and effective communication became more challenging. While families whose children met the outbreak case definition were spoken to, others, whose children did not develop infections, received communication in the form of written statements. As part of the outbreak communication strategy, press statements were issued to the public and on occasion were released before parents had been communicated with, causing considerable distress.

The psychological harm associated with such a prolonged incident was underestimated. Haemato-oncology patients are more susceptible to hospital-acquired infections due to both the underlying disease itself and also the treatment and presence of central lines. As such, patients and families are very aware of infection risk and will practice infection control in the home environment. They require assurances that the hospital environment is safe and that all measures have been taken to mitigate risk. Parents of children who had infections were concerned regarding repeat episodes, those whose children had not developed infections were concerned regarding the ongoing risk to their child and those of children who were outpatients were concerned about the safety of day care and clinic attendance. The need for duty of candour and effective communication becomes more crucial in such a situation. Various strategies were employed; written information continued to be provided with all inpatients being spoken to by the infection control doctor, the patients' clinicians and a hospital manager. Outpatients were spoken to in groups and some were contacted by telephone. Later in the incident social media was used establishing a closed Facebook group. Adequate assurances regarding the environment were not sufficient and information was not considered to be open, transparent and timely. The situation was compounded with the closure of the paediatric ward and the relocation of patients into a ward within the adult hospital, one not designed with a paediatric patient and their families in mind. Further anxiety and mistrust developed following the development of further infections in this new ward setting in June 2019. Subsequently, oversight was provided by the Scottish Government and the closed Facebook site was used, with answers to parent questions publicised.

The significant learning from this incident is that patients and families should be communicated to in a timely, open, transparent fashion, with frequent updates. Information should be released ahead of and containing the media lines to avoid the anxiety of finding out via this route. Every effort should be made to provide families with assurances that control measures have been implemented and that the risk has been mitigated. Where risk remains, it must be explained along with the proposed strategy to mitigate. Duty of candour remains an underdeveloped area with respect to hospital-acquired infection incidents and further thought is required with future policy development. With respect to duty of candour, consideration must be given to what constitutes harm for the particular patient group and this should be continually reassessed during an evolving situation. Psychological harm should not be underestimated. While there may be reticence by an organisation to discuss ongoing investigations and unconfirmed hypotheses, from the experience of the lead author and IMT chair, families valued honesty and assurances that everything was being done that could be done, over any withholding of information. IMTs must develop clear communications and duty of candour strategy particularly where an incident is likely to be of a prolonged nature. Significant resource may be required and consideration should be given to a communications subgroup of the IMT.

Parent perspective

This parent perspective is written by a patient's father whose child developed an infection while on the ward.

My first duty as a parent is the care, safety and well-being of my child; to protect her from the various threats, risk and harm that may expose and exploit her known or, as yet unknown vulnerabilities as she progresses through her young impressionable life.

Such protection is influenced by information, both from my own experience and the experience of other, trusted sources and as such, informed decision-making is critical in identifying, managing and mitigating the various risks that are prevalent during my child's lifetime, including those impacting her health.

However, when my child was diagnosed with cancer, I realised that I had neither the knowledge, experience or expertise required to adequately identify, respond, manage or

communicate on behalf of my child, the complexities and impact of her medical condition. Decisions made during such prolonged treatment may have a profound impact now and in the future.

As such there was a requirement to place my faith, trust and honesty in those who will care for my child. There was a requirement to have implicit trust in 'strangers', relinquishing that first duty to protect and care for the most precious of commodities, my child. To hand over such control, is the hardest of things, a decision that will influence the physical, emotional and psychological effect now and in the future of both my child and my family.

There results a tremendous sense of helplessness, fear, anguish and guilt; guilt that I have failed to protect my child; guilt that I have devolved responsibility for my child's care to people I know nothing about; fear that I have placed my trust in individuals and an organisation that I hope will make decisions in the best interest of my child.

It is for the above reasons that I am required to have confidence in the health service, believing that there will be processes and procedures in place, governed by experienced and knowledgeable professionals. I had to believe that during the hardest times they will respect, protect and fulfil their statutory requirement to ensure that the best interests of my child would be a primary consideration in all actions concerning her.

The treatment of cancer, especially in children, is distressing for all concerned not least of all the child. There is an absolute requirement for open and honest discussion between the clinicians and my child and myself as her parent. The risks associated with the treatment of the cancer are laid bare, however nothing prepared me for the heartache of watching the 'treatment' take effect; the physical, emotional and psychological trauma that develops with the many identified side effects articulated by those I have developed relationships and built trust. Understanding the likelihood of infection, including hospital-acquired infections as a result of being immunocompromised is part of the learning curve and an acceptable risk that is managed and mitigated with increased awareness and implementation of necessary and proportionate control measures.

One such control measure, that enables the impact and implications of 'harm' or the potential increase in harm caused or likely to be caused to my daughter by an unintended or unexpected incident or series of incidents, is the duty of candour. However, the implementation of this control measure is depending on the understanding of its use by those who seek to implement it. The effective implementation of such statutory responsibility serves to build and indeed enhance trust between the clinicians, my daughter and our family. As such, when my daughter contracted a bacterial infection it was crucial that openness and honesty were exercised through the exchange of information, not least of all to enable all of us to understand how this occurred within those existing control measures. It is not necessary for us to know the source of the infection, although if it was known, should have been disclosed. However, when unknown this should be articulated in a timely and transparent fashion, enabling informed decisions to be made that can influence future protection measures and minimise further physical, emotional and psychological trauma. Indeed, if such infections are identified as hospital-acquired infections, this should be identified and disclosed immediately.

However, when one considers theenvironment and the extremely close relationships of patients and theirrespective families within a paediatric haemato-oncology ward, multiple hospital-acquired infections aresoon exposed increasing our individual and collective fear and alarm as to theenvironment in which our children aretreated.

DISCRETION

An important aspect within duty of candour should be the continual evaluation by those discharging their duty of the impact and implications for the patient and those acting on behalf of the patient while having an ability to apply discretion in making decisions through the use of reasoning and professional judgement. However, discretion, when applied, should be recorded to reflect such decision-making, ensuring that the risks of doing against the risks of not doing, are clearly documented with due regard to likely harm, then and in the future.

It is the case that during complex cases, the aggregated impact of physical, emotional and psychological harm may result in the patient and or family being considered too vulnerable for further information or that their emotional state renders them temporarily vulnerable. In such circumstances, it is considered prudent to consider discretionary decision-making within their statutory duty as this may alleviate further harm. This is in essence a reciprocal duty of candour, proactively protecting the patient and family until such times as they have suitably recovered, to receive the information.

If discretion has been exercised by the statutory body, with proper recording of such decision-making, including rationale for doing so, there should be further written acknowledgement of the fact that patient care was not adversely impacted and that as soon as is reasonably practicable the patient and/or their family should be advised accordingly. This will have the further safeguard of ensuring corporate knowledge among clinicians resulting in the development of corporate memory and resultant corporate approach to duty of candour, with due regard to the respect for their patient and their rights.

DISCUSSION

Since 2018, the Queen Elizabeth University Hospital and Royal Hospital for Children in Glasgow have been ensconced in a developing crisis, attracting media and political attention, ward closures, and numerous independent and internal investigations as to the cause of numerous outbreaks. Indeed, public anxiety has increased resulting in Crown and Procurator Fiscal Service initiating inquiries into deaths within a healthcare setting, a public inquiry under the Inquiries Act 2005 with wide-reaching terms of reference and an independent case note review of 85 patients from the haemato-oncology ward will be undertaken. A documentary on national television exposed identified risks. Lack of management and oversight and internal conflict have impacted on the levels of public confidence and increased anxiety. The aggregated impact on an already vulnerable patient group is enormous, impacting further on their emotional, physical and psychological well-being. Trust between the patients/families and the health board is further eroded making the need for more effective use of duty of candour and effective communication even more crucial.

Duty of candour in relation to infection control incidents is new and evolving, and we were unable to find any published literature in this area. However, much can be learnt and applied from other areas of medicine and there are similarities to our

experience. One such example is the cervical check audit in Southern Ireland whereby 208 women with cervical cancer had original smear tests that were inaccurately reported as 'all clear'.[6] Initially these audit results were used for education and training purposes until the Health and Safety Executive requested that audit results should be passed to the women involved. Much debate took place as to whose responsibility it was to inform the affected women, with eventually letters being sent to relevant clinicians looking after the patients. What ensued was a chaotic and hurried approach influenced by politics and media. Some women were in the unfortunate position of finding out via the media, others described insensitive conversations with clinicians and a lack of confidence arose between women and the clinicians involved in their treatment. This incident highlights the counterproductive effects of inadequate communication and transparency, and demonstrates how these can lead to erosion of confidence and a breakdown in trust.

In 2020, an NHS trust in England became the first to be fined for failed duty of candour in relation to an elderly patient who died following a perforated oesophagus during endoscopy.[7] A lengthy time to respond and a poorly worded apology transpired between family members and the organisation.

In our incident, there was significant impact on patients and families having been, displaced from the bespoke wards, created to cater for their complex clinical care, deprived of the support of peer group relations such as those provided through the likes of Teenage Cancer Trust. How has the impact on those vulnerable children been measured and how could the duty of candour have more effectively been discharged through recognising the unique circumstances of this outbreak?

It is the right of every young person to have assurance that proper consideration has been given to the impact that a policy/measure will have on children and young people up to the age of 18 years. Indeed, it is important to ensure that any measures adopt a human rights-based approach. Making this clear within any effective governance structure and resultant policy or procedure would be in line with the Scottish Government's commitment to incorporate the United Nations Convention on the Rights of the Child (UNCRC) into Scots law and to embed human rights within the work of the government.[8]

In taking such an approach it is important to recall that human rights are interdependent, indivisible and inter-related. This means that respect and fulfilment of the right to the highest attainable standard of health (Art 24 UNCRC) depends on other rights being similarly respected.[9] In particular, Article 13 of the UNCRC provides the right to receive and impart information, while Article 12 requires children to be able to participate in decisions made about and for them.[9]

The WHO has identified that participation and inclusion are key to taking a human rights-based approach in a health setting. As the WHO notes, 'Participation increases ownership and helps ensure that policies and programmes are responsive to the needs of the people they are intended to benefit. Information sharing is a critical component of participatory processes.'[10]

The Scottish Government Child Rights and Well-being Impact Assessment (CRWIA) Guidance was originally produced for Scottish Government officials but is also suitable for use by public authorities such as health boards.[11] The guidance sets out steps for governance groups that will enable them to gather and produce evidence as to the impact and implications of a policy/measure, such as duty of candour, has on children and young people. The CRWIA follows current impact assessment practice and uses two identified frameworks: the UNCRC[8] which the Scottish Government, along with other duty bearers, is required to respect, protect and fulfil; and child well-being indicators developed as part of the Get It Right For Every Child approach to children's services provision in Scotland. CRWIAs will help clinicians and health board officials cater for the needs of children and young people impacted on by such crisis management. It will also ensure issues with openness and transparency and their statutory responsibility under the 2018 Act relative to duty of candour are satisfied together with ministerial duties in part 1 of the Children and Young People (Scotland) Act 2014.[12] This includes the duty to report progress on the implementation of the UNCRC to the Scottish Parliament every 3 years.

CONCLUSION

While there is a lack of literature pertaining to duty of candour and infection control incidents, there are parallels between other duty of candour incidents and the incident we describe. There was a hurried and chaotic approach influenced by media and political oversight. It is critical that effective governance and proactive communication is delivered regardless as to the identified source(s) of the outbreak(s), in a consistent, open and honest manner that seeks to reassure and enable patients and their families with opportunities to engage in dialogue, make informed decisions and seek assurances. If this is not managed from the outset, an outbreak can quickly become a crisis, which consumes the governance structure charged with managing and mitigating the outbreak. It is the case that distinction must be drawn between the role of an IMT and Crisis Management Team required to manage the critical incident supported by more prominent and transparent strategic leadership, coordination, governance, resilience, business continuity and public engagement. This would enable a focus on communications and duty of candour leaving the IMT to concentrate on investigating and implementing control measures. It would ensure timely, responsive, reassuring and accessible communication with the patients and families involved in order with a view to minimising the anxiety and distress experienced during similar incidents.

Twitter Teresa Inkster @teresaink

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