“Crowded” paediatrics

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It is a simplification, but the traditional ethical model of the doctor-patient relationship begins and ends at the door of the clinic. After parents enter, and the paediatrician closes the door, they engage together in a confidential, private space. The paediatrician offers expert assessment and advice while parents share in decision-making.

But as Delany and colleagues point out in their timely paper in this issue (1), in our digital world the walls of the contemporary consultation seem dangerously thin. A ‘crowd of voices’ potentially push into that hitherto private space offering novel opinions and options and sometimes making serious disagreements between health professionals and parents more likely or more difficult to manage. Or else families may choose to reach beyond the paediatrician’s office by sharing their child’s story, (including potentially their experiences and views of the health professionals) with an online crowd.

Delany et al provide a valuable framework and helpful questions for thinking through the ethical questions arising from the influence of the ‘crowd’ in paediatrics. In this editorial we emphasise the importance of explicitly acknowledging and engaging with the online extension of the consultation.

The recent case of Indi Gregory, an eight-month-old with a rare mitochondrial disorder who died after her family lost a legal battle to continue life-sustaining treatment, is the latest UK example of a family’s personal dilemma being acted out on a public stage. Indi was even granted Italian citizenship in a last-minute attempt to allow her to be transferred to a hospital in Rome for ongoing care. The case received widespread media attention, some of which was highly critical of the approach taken by professionals.

As highlighted in the recent Nuffield Council report on disagreements in the care of critically ill children, the influence of the crowd has profound effects on paediatric health professionals, creating emotional, psychological and moral distress and a sense of fear and unease amongst the profession as a whole (2).

Crowdsourcing opinions and treatment is potentially threatening and undermining to healthcare professionals in its challenge to the traditional model of medical expertise. The democratisation and proliferation of easily accessible medical information on a global scale means that paediatricians may feel they have to compete with Dr Google, Dr X (Twitter) or Dr Facebook, etc. Furthermore, those offering opinions may come from different ethical and legal frameworks than the UK (for example, countries in which life-support is rarely withdrawn, or in which parental autonomy over their children’s medical treatment is absolute). The attention surrounding these cases has the potential to be threatening in a very real way, and many doctors will avoid speaking out because of professional obligations of confidentiality or from fear of personal attack (either online, or even in person). But if professional voices or the healthcare organisations they work for (3) do not contribute to these societal debates, it is not surprising if the wider discussion is both unbalanced and riven with misunderstanding. So there is an ethical obligation for senior paediatricians and organisations like the Royal College to sensitively but openly engage in public discussions.

In the more routine day-to-day of paediatric practice, many professionals will have experience of parents who choose to share their child’s story online. Our personal experience is that this is often not openly acknowledged. There may be hushed rumours amongst the clinical team about a post someone has seen on social media from a parent (“did you see what they wrote last night?”), but this is rarely directly discussed with the family. But this then creates a virtual elephant in the room.

These scenarios raise interesting questions about whether it is ethical for health professionals to look up their patients or families online. One reason that parents' posts are not discussed is a fear that admitting to looking at them might lead to criticism or even sanction (4). It is not an obvious violation of parents' privacy to read information that the parents themselves have placed in the public domain. But that information may not be something that they planned to share with their paediatrician. They might consider it a breach of trust, or contrary to normal personal/professional boundaries. In situations where a professional has reason to believe that online information would be directly important to the care of the child it may be ethical to seek out this information. Where paediatricians are aware that parents are writing about their child's care online, it could be helpful to open up a discussion, expressing a non-judgemental curiosity and a desire to learn more. They could ask if parents would be happy for the health care team to read those posts, or if they'd like to talk about what they are writing.

What should paediatricians do if or when there are challenges or conflict with families? Delany et al propose a practical approach. Their list of questions will act as useful aid for professionals when attempting to tease out the competing the ethical considerations at play in any given clinical scenario. However, it may also be helpful to seek additional support – for example Clinical Ethics Committees offer an opportunity for those who are not directly involved in the clinical case help clarify the central ethical tensions and identify possible forms of compromise. Professional mediation services can also offer a highly valuable way forward in situations where relationships and communication have broken down. It would be important to seek institutional support in cases like the one that Delany and colleagues cite (1) where parents are recording staff without consent or naming clinicians online.

Where paediatricians might feel uneasy about engaging with the online crowd outside our consultation room, it may be helpful to start with an approach which is grounded in ethical humility (5). Being open to learning from new evidence and new approaches will support an approach where the child remains at the centre of all discussions and ultimately receives the best care available. By being receptive to the proliferation of knowledge in the digital space we might be able to approach our deliberations with patients and parents on a more even footing. And perhaps paradoxically, when we acknowledge what we don't know, we might have less to fear when we share what we do know in the societal debates about how to care for our most vulnerable patients.

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