**The road to clinical fantasy: a UK perspective**

Commentary on "From “Longshot” to “Fantasy”: Obligations to Patients and Families When Last-Ditch Medical Efforts Fail" by Elliot Weiss and Autumn Fiester

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The ambition of Weiss and Fiester (2017) to articulate clinical and associated steps for communication in the management of treating the sickest children is admirable. We argue however, that such stages are in themselves an illusion and are therefore likely to offer false hope. Moreover, we think that using the term ‘fantasy’ in discussions with parents and children, where there is little or no hope of benefit from treatment, is unlikely to improve communication.

The four staged process proposed aims to assist healthcare professionals (HCPs) in managing the progression from treatment options which are ‘longshot’ – those treatments where “*there is a medical possibility of success”,* even though this may be extremely low – to those which fall into the realm of ‘clinical fantasy’ – those treatments where there is no chance of success. Weiss and Fiester argue that recognising such a change in circumstances when treating very sick children, and having a clear idea of what actions to take as this happens, can help to improve communication between families and HCPs, and avoid the harms associated with such scenarios including distress to family and staff, wasted resources and potential for deception. However, the notion that longshot or clinical fantasy treatments, or indeed the distinction between them, might in themselves be clear cut is, in itself, problematic. When treating the sickest children where there is limited chance of success, decisions regarding management are contextual in nature and case-specific. This is similar to other areas of medicine, as we have argued elsewhere (see for example Fenwick 2010; Lucassen and Fenwick 2012). What constitutes ‘success’– or indeed fantasy – in the context of treating very sick children, is unlikely to be universally agreed upon by clinicians. Moreover, the cases that are most challenging are precisely those where there is disagreement between the different parties involved, whether it is between HCPs or between HCPs and families. For example, ‘success’ after a longshot treatment, for some, might simply be indicated by a child still being alive, with minimum functional ability, yet involving intensive medical interventions; whereas others might be concerned that the burdens of continuing the treatment are outweighed by the painful nature of the treatment itself. Moreover such disagreements take place often in emotionally charged circumstances.

In the UK, the recent Charlie Gard case illustrates the difficulties surrounding ‘longshot’ treatment options and the differences in opinion surrounding what constitutes ‘success’ and best interests. Charlie Gard was born in September 2016 with encephalomyopathic mitochondrial DNA depletion syndrome (MDDS). He was hospitalised at a month of age and soon after intubated and ventilated. The multidisciplinary team caring for him – and those who gave an independent second opinion - agreed that there were no available treatment options which could improve his health outcomes and alleviate his suffering and it was therefore in his best interests to receive palliative treatment. Adopting Weiss and Fiester’s four stages, the team were in agreement that there was no chance of ‘cure’ given the available scientific evidence, and so were at Stage 4. His parents, however, were determined that they wanted him to receive a novel ‘longshot’ experimental treatment only available in the US - nucleoside replacement therapy – and sourced crowd funding to pay for it. Thereafter ensued a protracted legal battle, played out in the UK courts from January 2017 and only ending in July 2017, when his parents agreed to end their fight to take him to the US for the treatment. Professor Hirano, based in the US, who developed the therapy, offered to provide the treatment despite no medical evaluation of Charlie Gard’s particular circumstances and only making an assessment with pertinent information of the case, in person, in July 2017. So, it would seem that Professor Hirano and the parents were still at Stage 1 - wanting to try a longshot treatment despite success being ‘unlikely’.

It was broadly agreed within the medical community, in subsequent reporting, that the offer of nucleoside replacement therapy provided the parents with false hope; the treatment offered such limited chance of success, quantified by any means, and, additionally, would have been a significant burden to the child in terms of travel (whilst being ventilated), suffering risk to life. The case was widely discussed and commented upon, with ‘pro-life’ – including the Pope – and parental rights lobbyists weighing into the debate. Emotive headlines abounded in both the UK and the US spurring public opinion on the subject and providing a wider context which HCPs caring for Charlie Gard could not ignore. A large number of supporters of the parents formed ‘Charlie’s Army’ using social media raising money, and protesting outside the hospital and the courts for him to be allowed to go to the US for the treatment, using slogans like ‘Give Charlie a Chance’ (Lusher 2017). This adds a relatively new complexity and difficulty to the circumstances in which HCPs attempt to make management decisions for very sick children in conjunction with parents.

The arguments surrounding the case have been debated elsewhere (see for example Savulescue 2017; Wilkinson 2017) but here we refer to it to provide insight into the clinical utility of Weiss and Fiester’s proposed four stages. The process, from attempting longshot treatments to recognising that the point of ‘clinical fantasy’ has been reached, does not take into account the wider contextual factors such as those played out in the Charlie Gard case, nor how to manage the stalemate of different parties believing the case is clearly at one stage or another. The clinical utility of the stages is therefore limited, largely because in any case where treatment has an extremely low chance of success the disagreements and inherent uncertainties surrounding predicting outcomes mean that different parties may vary significantly in determining what is in the child’s best interests. They may only serve to further identify the disparity and difficulty in translating a stance in such difficult situations, rather than to move a case forwards.

Weiss and Fiester acknowledge some of the difficulties in their discussion about the problematic use of the term ‘futile’ and suggest that their use of the term ‘fantasy’ is better employed to reflect the fact that families need to be informed about the impossibility of achieving their goals for their child in order to overcome any factual misunderstandings or deception. They argue that this is crucial so that families themselves “are empowered to make educated decisions about life-sustaining treatments that conform to *their* beliefs and values”. Whilst we agree with this general aim in principle – although in the UK the welfare of the child is always central to the decision making process - we cannot agree that adopting the term ‘fantasy’ in family scenarios like Charlie Gard’s would have been useful. Our view is that the term fantasy in this context is less clear than futile and as open to being misunderstood or inflaming already difficult and heightened emotional situations.

**References**

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