Life or death medical decisions involving a child – new study asks questions about current process

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How parents and clinicians make life or death medical decisions involving very young children is the focus of a new study published in the *Archives of Disease in Childhood*. The findings may offer insight into how the 'best interests' of a child are decided, when consensus between parents and clinicians can't be reached.

Cases where doctors and families disagree are exceptionally difficult for everyone involved. They can be desperately distressing for both the child's parents, who might think that any possible treatments should be given, and the child's doctors, who might believe that further intensive care is not in a child's best interests. Current practice is based on agreement between parents and doctors on children's best interests, with the courts making the final decision if consensus is not reached. High profile cases may give the impression that the courts are called upon frequently to resolve these sorts of cases. The reality is that few disagreements come to court, and little is known about how they are resolved at the bedside.

The Wellcome Trust-funded research was privileged to be able to discuss these issues with parents and clinicians who had gone through difficult situations in which they had tried to agree what the best interests of very sick children were. A total of 39 interviews took place with parents of children who had been patients on Paediatric Intensive Care Units, doctors and nurses working on Paediatric Intensive Care

Units, and members of clinical ethics advisory committees who are consulted in very difficult cases. The study focused on decisions about children who do not take part in decision-making because they are too young, too sick, or have a pre-existing disability.

Dr Giles Birchley, the study's lead author and Senior Research Associate in Surgical Innovation and Bioethics in the School of Social and Community Medicine at the University of Bristol, found that parents and clinicians viewed children's interests differently in decision-making. Doctors and nurses tended to think that parental interests sometimes carried more weight than those of the child. When a decision about treatment needed to be made, doctors encouraged parents to consider medical opinion. Sometimes parents could not agree with their doctor until their child began to show physical signs of decline in their condition. This situation was likely to increase the suffering of the child.

The study highlighted that in life and death situations, where consensus could not be reached, several aspects might be considered:

- Since bereavement itself is harmful parents, it might be appropriate to take the interests of parents into account as well as those of the child
- Doctors and nurses are reluctant to use the Courts, and place an emphasis on reaching consensus with parents.
- The current manner in which decisions are made tends to emphasise the interests of parents, to an extent that it is sometimes difficult to ensure children's interests are not overlooked.

Dr Giles Birchley, a former nurse with ten years' experience of working in Paediatric Intensive Care, said: "Making medical decisions on behalf of children requires the collaboration of many groups of people who work hard to reach consensus. While disagreements in end-of-life

decisions are rare, there is considerable reluctance to use the courts as the decision makers of last resort. This creates a situation where children's interests are less important than the process of consensus.

"While this study recommends that the way decisions are made could be changed, more research is needed to respond to the complexity of decision-making in such cases."

More information: Giles Birchley et al. 'Best interests' in paediatric intensive care: an empirical ethics study, *Archives of Disease in Childhood* (2017). DOI: 10.1136/archdischild-2016-312076

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