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Telling the truth to young children: ethical reasons for information disclosure in paediatrics

Abstract

When parents ask doctors not to disclose certain information to a child, doctors are challenged to articulate ethical reasons for giving information to children. This paper maps out the professional and legal landscape in which information-giving to children is taking place and identifies the key ethical arguments that have been made for disclosure of information to the child patient. We focus on pre-adolescent children, who have not reached a developmental stage that would see them regarded as "mature minors". While doctors can be relatively certain that professional and legal requirements will endorse their disclosure of information to the "mature minor", guidelines are not clear on information-giving to pre-adolescents ("immature minors"). We identify six ethical reasons for telling the truth to younger children. It is noteworthy that there are good reasons to tell the truth to children which are independent of any question of the child's capacity to be involved in decision-making.

Key words: child; communication; truth; disclosure; paediatrics; bioethics

Key points

1. There is a paucity of specific reference to younger children in position statements and guidelines of major paediatric organisations in Australia, the United Kingdom and the United States that deal with disclosure of information to children. Doctors can be relatively certain that professional and legal requirements will endorse their truthful disclosure to the "mature minor" but there is no clear mandate for "immature minors".

2. Key ethical reasons for telling the truth to young children are: improving well-being; demonstrating respect for the child as a person; promoting involvement in the therapeutic relationship and promoting some degree of involvement in decision-making.

3. There are good reasons to tell the truth to children which are independent of any question of children’s capacity to be involved in decision-making.

Multiple Choice Questions

1. The Bluebond-Langner study demonstrated terminally ill children were aware of their diagnosis and prognosis, despite no adult having told them, as young as…

a) 3 years

b) 5 years

c) 6 years

d) 8 years

e) 10 years

Correct answer - a) 3 years of age – see the relevant page of the review

2. Which of the following ethical reasons stated in this paper for telling the truth to younger children clearly relates directly to children's involvement in decision-making?

a) Disclosure respects and promotes some degree of involvement in decision-making

b) Disclosure and open communication promotes involvement in the therapeutic relationship

c) Disclosure demonstrates respect for the child as a person

d) Disclosure improves well-being

e) Disclosure instantiates truthfulness and fidelity

Correct answer – a) clearly relates to decision-making

Although b) and c) mention control and involvement, these are not totally connected with decision-making per se.

d) Clearly not related to decision-making *e) Does not even mention decision-making. The focus is on interests.*

3. **The most accurate definition of the term "immature minor" as used in this paper refers to:**

a) Poorly behaved teenagers

b) Pre-adolescent patients, not competent to make their own decisions.

c) Gillick-competent minors.

d) Children with minor intellectual disability.

e) Children under 5 years old.

Correct answer – b) is the most accurate definition of "immature minor",

c) is clearly not, a) d) and e) could be immature minors but that is not the whole of the definition.

Introduction

How should doctors respond when parents ask them not to disclose certain information to a child? It is now accepted practice in paediatrics to give children developmentally appropriate information, so this request puts doctors in an uncomfortable situation. It challenges doctors and ethicists to articulate the ethical reasons for giving information to children, in order to understand how to respond to this request for non-standard practice. Despite evidence that direct communication between doctor and child improves health outcomes,[1] and that young children have been shown to be more able to engage with medical and health concepts than was previously thought,[2] communication in paediatrics is made more ethically complex by the number of stakeholders involved in the child's care and their potentially conflicting views of what information should be conveyed. Paediatric practice no longer endorses the doctor as unilateral decision-maker, and there is a recognised role of parents to organize flow of information and systems of emotional support for the patient. While parents are sometimes regarded as "moral agents for their children", parental authority is not seen as absolute.[3, 4, 5]

This paper will map out the professional and legal landscape in which information-giving is taking place and identify the key ethical arguments that have been made for disclosure of information to the child patient. We will focus on pre-adolescent children, who have not reached a developmental stage that would see them regarded as mature minors.

Guidelines and the professional landscape for truth-telling

A paradigm shift has taken place in Western medicine from paternalistic practice to endorsing enhanced patient autonomy since the mid-20th century.[6] The shift has been tempered in its application to children by questions around the relative capacity of children, and the literal paternalism of family influence. Deliberations in paediatric practice are now seen to involve three stake-holders: doctor, patient and parent, with the roles and rights of these parties not clearly defined. The principle of autonomy is central to the issue of what information the patient should receive and how they are involved in their care. A review of the position statements and guidelines of major paediatric organisations demonstrates an emphasis on autonomy. Even where young children are concerned, “choice” and “decision-making” are the rationales for disclosure of information to children. While we acknowledge that differences in medical culture may be found in other care settings, we will focus our discussion on the respective peak paediatric bodies of Australia, the United Kingdom and the United States, as these are presumed to be the most relevant to practice in the Australian context.

The Royal Australian College of Physicians, which oversees Australian paediatric practice, does not make explicit standards or recommendations around information-giving, but does make recommendations around the patient’s involvement in decision-making processes: “consideration must be given to the rights of all children and adolescents to be involved in decision-making about their own health. In particular, cognitively mature adolescents have the right to make decisions relating to their own health and to maintain their privacy, including in respect to their parents/carers”.[7] Precisely how the college envisages consideration and respect of the minor is a matter of interpretation, but it is significant that it is expected that the child should have a presence or at least representation in clinical matters, and that this is not reduced to input from the parents only.

The American Academy of Pediatrics’ policy statement on family-centred care makes more explicit reference to a child’s right to medical information, again contextualised in decision-making: “pediatricians should share information with and promote the active participation of all children, including children with disabilities, if capable, in the management and direction of their own health care. The adolescent’s and young adult’s capacity for independent decision-making and right to privacy should be respected … Pediatricians should share medical information with children and families in ways that are useful and affirming. This information should be complete, honest, and unbiased”.[8] It is worth noting that while these recommendations are firmer in regards to adolescents and young adults, they do specify both participation and the giving of medical information for all children. It is also worth noting their specification that medical information should be "honest and unbiased".

In their 0-18 years guidance, the UK's General Medical Council recommends clinicians "should involve children and young people in discussions about their care, be honest and open with them and their parents, … give them opportunities to ask questions, and answer these honestly and to the best of your ability" and, interestingly, "give them the same time and respect you would give to adult patients".[9] With regards to decision-making, they recommend "you should involve children and young people as much as possible in decisions about their care, even when they are not able to make decisions on their own".[10] These recommendations are the only one to offer an account of how the interests of all stakeholders interact in paediatric decision-making, under the guiding principle of serving the child's "best interests". The best interests principle is that in making decisions around paediatric care, doctors must include consideration of what is clinically indicated, the views of the young person, the views of the parents and others close to the young person, the views of the health-care professionals involved in their care, and which choice will be least restrictive of the person's "future options".[4]

While these position statements and guidelines make allusions to the arguments in favour of open communication and involvement of children in clinical decisions, they are not prescriptive in terms of what information children should receive. The paucity of specific reference to younger children (who are not mature minors) and their informational rights is telling for how little is established in the practice of telling the truth to children.

Beyond the "mature minor": a new information-giving frontier

The professional guidelines described above refer largely to information-giving as a facet of involvement of the child in decision-making. That is, of the value of information-disclosure being in how the child can apply it to clinical decision-making. In order to understand the assumptions of how information relates to decision-making in these statements, we are required to unpack terms such as “maturity” and “competence” that arise in their discourse. Competence can be described as a threshold above which a minor is able to understand their situation and make decisions relating to their health care.[11] A person is deemed competent if they are able to assimilate information and apply it personally to make a decision. This distinction has arisen through historical cases where medical practice has interacted with the law. The Gillick ruling in 1985 deemed that a minor could be competent to consent to treatment, [12] but subsequent judgments have questioned whether they can refuse it, with the power to overrule maintained by parents or doctors.[13] However, as we have seen reflected in the relative dearth of legislation and guidelines that have arisen around the informational rights of the “mature minor”, with the acceptance that a minor can possess sufficiently full capacity for decision-making, the point of contention shifts to younger children, in whom these capabilities may only be partially developed.[14] Doctors can be relatively certain that professional and legal requirements will endorse their disclosure of information to the mature minor, shifting the frontier of unguided information-giving to younger, pre-adolescent patients, or, for want of a better term, “immature minors”.

Ethical arguments for disclosing medical information to the immature minor

Irrespective of the lack of clear guidance around the information requirements of the immature minor, the literature presents several arguments in favour of disclosure for this cohort:

(1) Disclosure respects and promotes some degree of involvement in decision-making

The disparity between the right to accept and decline treatment results from what is seen as limitations of the applicability of the concept of informed consent to the minor, due to their indeterminate level of capacity and legal power. An alternative or complementary concept is of child assent, which asks that the paediatrician involve the child to the extent of their capacity, assisting them to participate as best they can rather than applying an arbitrary threshold beyond which children are considered competent.[15] Kohrman and Clayton[16] suggest that “if physicians recognise the importance of assent, they empower children to the extent of their capacity”, arguing that “pediatricians should not necessarily treat children as rational, autonomous decision makers, but they should give serious consideration to each patient’s developing capacities for participating in decision-making, including rationality and autonomy”. The Committee on Bioethics led by Levetown recommends open disclosure to young patients: “involving children in communication about their health and in decisions regarding their health care shows respect for their capacities, will enhance their skill in the process of making future health decisions, and enables their essential input into decisions where there is no ‘right answer’ other than the 1 that best meets the needs of the individual child”.[2] The significance of this concept for our discussion is that even the child who is not deemed competent is still owed the information requisite for involvement in their care proportional to their developing capabilities.

(2) Disclosure and open communication promotes involvement in the therapeutic relationship

Lewis,[17] an American research psychologist, argues that the prevailing paediatric communication practices which favour gathering of information from children while excluding them from receiving information enforces a passive role for children, at odds with efforts to promote a sense of participation and control over health. Her research in communication in paediatrics demonstrates that patients have a superior buy-in to the therapeutic relationship when inclusive communication is practiced.

(3) Disclosure avoids restriction of future autonomy

Hébert,[18] a Canadian bioethicist, argues for disclosure as a means of avoiding restriction of future autonomy, as well as a means of cultivating the young child's decision-making capabilities: "while very young children might be unable to appreciate their medical conditions, they often grow to become more able to grasp complex data and participate in decision making. The important fact is not the child's chronological age, but his or her ability to understand the consequences of giving or withholding consent". He specifies that the patient who is incompetent due to immaturity must regardless have any information required to understand the consequences of giving or withholding consent, and stipulates that any decision to withhold important information from a minor must incorporate strategies for disclosure as they grow older. This is crucial ethically to ensure that the child is not inadvertently locked out or left behind as their capacity for decision-making increases.

This argument may be limited in its application to patients with a greatly reduced life-expectancy, but may favour disclosure when survival is highly probably or even indeterminate.

(4) Disclosure demonstrates respect for the child as a person

Kunin[19] argues that it is not necessary to treat children as fully autonomous, rational decision-makers in order to act respectfully towards them. The grounds for this is that their capacity to think and feel is not contingent on full autonomy of action. Kunin gives the example that the decision to give a child an injection can be made independently of the child's input, but that the importance of administering the drug must be explained in appropriate language, and the experience of pain and anxiety that might accompany the procedure acknowledged. This approach, he argues, allows for recognition and validation of the child's experiences and a sense of control irrespective of their age. He does not elaborate on how this approach would apply to more abstract information such as prognosis.

(5) Disclosure improves well-being

A further argument for telling the truth to young patients is for their psychological, emotional and physical well-being.[20] The Bluebond-Langner study of the experiences of terminally ill children demonstrated those as young as 3 years of age were aware of their diagnosis and prognosis despite no adult having told them. Avoidance of giving this information and adult's denial of seriousness led to the patients feeling unloved and abandoned.[21] In a publication on consent and the rights of minors, the British Medical Association warns that secrecy and dishonesty not only contribute to a child patient's fear and anxiety but also undermine trust in the therapeutic relationship.[22] As well as the potential for causing emotional harm, withholding information from a patient on grounds of their apparent cognitive immaturity may be ill-founded. This is endorsed by work in psychology which suggests that "cognitive capacity and emotional understanding do not develop at the same rate" in children and "there is huge individual variation in both the time taken to reach particular mental levels and the ultimate levels attained".[11]

The well-being argument is not limited to the detriments of withholding information: open communication has been shown to improve adherence to treatment when the child is involved in treatment discussions.[23] One study entailed a randomized controlled trial of communication practices, modelling to young patients the role of a health partner, encouraging them to raise concerns and ask questions. Parents and physicians were simultaneously educated about how to encourage the child's participation. Children in the consultations where doctors had been encouraged to communicate more information and where children were coached to ask more questions recalled more information about their medications than controls, reported better rapport with the physician and greater satisfaction.[2, 17]

(6) Disclosure instantiates truthfulness and Fidelity

Harrison[24] argues that disclosure of medical information to the minor should be guided by the principle of fidelity, which she describes as requiring “that we act towards others in such a way that we fulfil the commitments made and the promises implicit in the relationship we have with them”. She states that truthful disclosure is expected in the doctor-patient relationship, creating a duty for doctors to fulfil this requisite of care and describes fidelity in information giving to the child, as: “placing the patient’s interests ahead of others’ interests, including those of members of the patient’s family, society, and oneself.” Her description is reminiscent of the best interest principle found in British paediatric guidelines.

Conclusion

The concept of the mature minor has been established, endorsed and assimilated into paediatric care, creating a clear requirement for truthful disclosure to mature paediatric patients. This has narrowed the paediatric population for which there is not a clear mandate to disclose medical information to patients who are not yet mature enough to make significant treatment decisions. For these patients, there is a paucity of specific reference in paediatric guidelines for how they should be involved in communication of medical information. Reasons in favour of telling the truth to these patients can be found in the ethical and psychosocial literature. This paper has clearly articulated these reasons and brought them together in one place. It is noteworthy that there are good reasons to tell the truth which are independent of any question of a child’s capacity to be involved in decision-making.

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