

## Handling Request for Non-Disclosure of Clinical Information in Paediatrics

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### Abstract

**Non-disclosure in Paediatric Practice is a controversial issue. There was a time when the care of children was solely the responsibility of parents and any decision with respect to treatment or non-treatment would have been the joint responsibility of the parents and of the attending medical professionals. This practice, viewed as adopting a more paternalistic approach, has been challenged in many parts of the world. In essence what is being challenged is the notion that the sole responsibility of decision-making rests with parents.**

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**Key words:** Decision-making capacity, Gillick competence, Minor's rights

### Introduction

Over the past 3 decades, there has been a growing recognition that most neurologically normal adolescents have the capacity to make decisions about their healthcare needs. Furthermore, there is an increasing willingness by physicians and parents to affirm them in doing so.<sup>1,2</sup> The professional literature indicates that “adolescents, with some exceptions, are capable of making major health decisions and giving informed consent. An increasing number of professionals in developmental psychology, paediatrics, biomedical ethics, and health law agree that fundamental reorientation toward adolescents is necessary to increase adult acceptance of the important decisions that many adolescents now seem capable of making for themselves.”<sup>3</sup>

In the paediatric literature, Leikin<sup>4</sup> surveyed the findings of developmental psychologists, mainly those of Jean Piaget, and applied them to the issue of minors' assent or dissent to medical treatments. He observed that while cognitive development cannot always be equated with chronological age, good evidence exists “that, by age of 14 years, many minors attain the cognitive developmental stage associated with the psychological elements of rational

consent. Minors between 11 and 14 years of age appear to be in a transition period.”

Grisso and Vierling<sup>5</sup> concur with Leikin's views, “There appear to be no psychological grounds for the general assumption that minors 15 years of age or older cannot provide competent consent.”

### Minor's Rights in Medical Decision-Making

It is generally acknowledged that as children grow from infancy to young adulthood, parents and guardians gradually relinquish responsibilities and decision-making to them, while remaining as a safety net for them. This is true for medical decision-making as well. This understanding is echoed in the words of Lord Denning: “Parental rights, while not ceasing till the age of majority, are dwindling rights; it starts with the right of control and ends with little more than advice”.

In England, an under 16-year-old child's legal capacity to consent to medical treatment is determined by fulfilling the criteria as set out in the Gillick judgement.<sup>6</sup>

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**Background To Gillick Competency<sup>6</sup>**

Prompted by a memorandum by the (British) Department of Health and Social Services to all health service doctors to make contraceptives available to all people, including the young, Mrs Gillick, a mother of 4 daughters, wrote to the local health authorities, for a written assurance that her daughters would not be given contraceptive treatment without her knowledge and consent whilst they were under 16. The authority refused to grant the assurance. Mrs Gillick commenced proceedings seeking a declaration that the memorandum was unlawful on several grounds inter alia it adversely affected parental rights and duties. The case went to the House of Lords. Mrs Gillick was declined the declaration she sought. The Court of Appeal reversed the decision and unanimously granted Mrs Gillick her declaration. The House of Lords, however, refused to grant her the declaration by a majority of three-to-two.

A child who meets them is ‘Gillick Competent’.<sup>7</sup> The principles affirmed by Gillick have been highly relevant to the issue of non-disclosure in paediatric practice.

However, Gillick principle has yet to be challenged in Singapore. A survey of the literature showed that, unlike Singapore, the USA, UK and Canada have the concept of emancipated minor and mature minor in the area of minor’s rights in decision-making.

In Singapore, the Termination of Pregnancy Act (Singapore, 1974) provides no lower age limit to giving consent but following condition must be satisfied.

- Acting on the request of pregnant female with her written consent.
- Procedure carried out by a registered practitioner.
- Must be a citizen of Singapore or spouse of a citizen of Singapore.
- Or a holder or wife of holder of permanent residence for more than 4 months immediately preceding date of termination.

**Respectful Involvement of Children**

An important and practical aspect to explore is, how to respectfully involve children in medical decision-making. This involves not only legal and ethical perspective but also cultural, social and family perspectives. It is indeed multifaceted. The Cambridge Textbook of Bioethics (2008) notes that “Respectful involvement of children in medical decision-making requires respect for parental authority and family context as well as careful attention to the communicative and developing decisional needs and abilities of the child”.<sup>8</sup> It is more than just decisional autonomy of the child. In the involvement of children in medical decision-making, it is important to be cognizant of the following:

- Information-sharing should be distinguished from ascribing decisional authority.

- Children from infancy to teens have dramatically differing levels of capacity for decision-making and should not be treated similarly. It is, therefore, important to be sensitive to the particular capacity of each child.

There are 4 categories of children. On the basis of the differing developing capacities of each child, they may be grouped as seen in Table 1.

Table 1. Evolving Capacity of Children<sup>9,10</sup>

| Type of Children                                                                             | Decision-making Capacity | Role of Parents                                                            |
|----------------------------------------------------------------------------------------------|--------------------------|----------------------------------------------------------------------------|
| With no communication (e.g. neonate and young children)                                      | NIL                      | Full decision<br>Comfort child                                             |
| With some communication but no decisional maturity (e.g. younger school-aged children)       | NIL                      | Full decision<br>Comfort and explain in simple terms to child              |
| With some communication and developing decisional maturity (e.g. Older school-aged children) | NIL                      | Full decision with assent from child                                       |
| With decisional maturity (e.g. Mature minors and emancipated minors)                         | Full decision (possible) | Encourage to keep parents informed if appropriate (professional to decide) |

The degree of appropriate involvement of the child therefore depends upon assessment of:<sup>10,11</sup>

- Child’s decision-making capacity
- What the child can understand
- What the child can benefit from being told (even if not capable of making a decision)
- What a child wants to know
- What a child needs to know in order to participate appropriately

Respectful involvement of the child, therefore, involves attention to the communicative as well as decisional needs and abilities of the child. Furthermore, it requires careful and respectful attention to the family context of the child. It recognises the fact that children are embedded in their families and the interest of the child can be seen as bound up with the interest of other family members.

This is the family-centered approach which considers the effect of a decision on all family members and their responsibilities toward one another, and the burdens and benefits of a decision for each member, while acknowledging the special vulnerability of the patient.

However, this family-centered approach presents special challenges for the healthcare team when there is a disagreement between the parents and the team with respect to what is in the child's interest. This approach does not discount the parent's concerns and authority but it does recognise the child as the particular patient to whom the healthcare team has a primary duty of care.

### Examples of Clinical Scenarios

#### (i) *Parental Reluctance to Disclose Surgical Treatment*

A child who is developing decisional maturity (e.g. 10 to 12 years old) is undergoing surgical treatment. The child should be informed and be given a chance to ask about the treatment. Assent should be obtained from the child.

#### (ii) *Non-disclosure in Adolescent Gynaecology*

- Prescription of oral contraceptives.
- Treatment of sexually transmitted disease.

The adolescent should be counselled regarding safe practices and encouraged to share information with his or her parents.

### Ethical Conflicts and Their Resolutions

In the event of a conflict in decision-making or in non-disclosure, the following means could be resorted to in resolution of ethical conflicts:

- Seeking a second medical opinion.
- Short-term counselling.
- Psychiatric consultation for patient and/or family.
- Multidisciplinary family conference.
- Ethic consultation/referral to hospital ethics committee.
- In rare cases of refractory disagreement, formal legal adjudication may be necessary.

### Conclusion

Handling non-disclosure in paediatric practice will continue to be a challenge. A broader understanding including historical and legal perspectives will assist the healthcare professional in attending to these patients. Respectful involvement of children in decision-making whilst concurrently being cognizant of the parents' rights and concerns will go a long way towards a more fruitful patient-doctor relationship and hopefully better outcomes in these challenging situations.

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