ACORN AUSTRALIAN COLLEGE OF PERIOPERATIVE NURSES | JOURNAL OF PERIOPERATIVE NURSING

Volume 30 | Issue 2 Article 1

6-1-2017

'When no means no' – adolescent right to refuse an elective surgical procedure: A case study

Peer-reviewed article

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Abstract

At law, adults are presumed to have legal competency to provide consent for or refusal to consent to health care treatments unless they have cognitive impairment. But what of the adolescent who is, at law, a child but who refuses to undergo elective surgical treatment? This paper discusses the issues surrounding the case of Keith, a 14-year-old boy with ulcerative colitis, who refuses consent to undergo an elective ileostomy.

Introduction

There are five elements within the doctrine of informed consent.

1. Competence: does the patient have legal capacity to understand the information presented to them by the medical officer and to be able to make a decision regarding treatment?
2. Disclosure: has the medical officer discussed and disclosed all relevant risks and benefits of the proposed procedure to the patient in terms which are easily understood?
3. Understanding: does the patient understand what the proposed procedure entails?
4. Voluntariness: does the patient agree to the proposed procedure voluntarily and without duress from health care staff or family members?
5. Consent: has the patient consented to undergo the proposed procedure after considering all information provided to them?

Except for emergency situations, health care treatment cannot be provided for an adult individual unless they or a decision-maker provide informed consent[1]. The issue of obtaining informed consent or the ability of an adolescent to refuse consent for a surgical procedure is not so well delineated. A parent is considered at law to have absolute power to make health care decisions for their child, with this power diminishing as the child matures until they are deemed at law to have reached the age of majority and are legally able to make their own health care decisions. In Australia, the age of majority is 18 years of age except for New South Wales and South Australia where statute allows children aged 14 and 16 years, respectively, to consent to their own treatment if they are deemed competent[2,3].

The leading case in assessment of assessing competency in underage individuals is Gillick[4]. Previous to this case, the common law prevailed with the view that all underage individuals lacked legal capacity to make their own decisions. This case dealt with a British health department decision that doctors could prescribe contraception, at their discretion, to underage children without parental consent. Mrs Gillick, a mother of five teenage daughters, campaigned against the decision, stating it was illegal to provide treatment without consent as consent could only be given by the parent. The House of Lords found that in certain circumstances, a minor could consent to treatment, which the parent had no power to veto. This

decision had far-reaching effects for decision-making by minors and allowed for the reduction in reliance in parental decision-making as the child reached maturity.

In Australia, minors who demonstrate a comprehensive knowledge and understanding of the procedure and or treatment may be assessed by medical staff to be 'Gillick competent' and thus be entitled to give or withhold consent for certain medical procedures, but this is not a guaranteed legal right. It should be noted that in the Gillick case, the issue was the provision of consent by a child for a procedure, not the refusal of consent to undergo an elective surgical procedure.

The rights of children have been recognised under the United Nations Convention on the Rights of the Child[5], ratified by Australia in 1990. The major principle regarding medical procedures for children considers that all actions must be in the child's best interests and the child's views (if capable of forming them), are to be considered. Unfortunately, although the Convention has been ratified by Australia, it does not form part of Australian legislation regarding informed consent for children and so is not binding on decision-makers.

Exemplar case study

In this article, we examine a case study involving Keith, a 14-year-old boy with ulcerative colitis, who refuses to consent to an elective ileostomy. His parents have provided both written and verbal consent for the procedure but Keith refuses to undergo the procedure.

Keith lives with his parents, Wendy and Gavan and his 5-year-old sister, Bethany. Keith was diagnosed with ulcerative colitis five years ago and has undergone multiple surgical procedures including two diagnostic laparoscopies and an exploratory laparotomy. Keith had continued to experience severe abdominal pain, diarrhea and bloating despite medical therapy, and also experienced growth retardation and delayed sexual maturation as a result of his prescribed medications. The colorectal surgeon treating Keith decided that appropriate treatment included a complete proctocolectomy with permanent ileostomy due to its efficacy, and low morbidity and mortality rates. Keith's parents provided both written and verbal consent for this procedure.

Keith is articulate, intelligent and informed regarding his disease process and progression and was involved in the discussions with both his parents and his surgeon. Keith had undertaken extensive online research into ulcerative colitis and treatment options following his diagnosis, and regularly posted on Facebook and his personal blog about his experiences as an adolescent living with ulcerative colitis. Following the discussions relating to undergoing an elective ileostomy, Keith went online, requesting comments from other adolescents living with ulcerative colitis that had undergone or refused to consent to an ileostomy. He received multiple comments from other adolescents aged from 12 to 17 years who discussed their experiences regarding living with an ileostomy and the lifestyle challenges they continued to face.

Following these online discussions, Keith expressed to his parents his concern regarding the repercussions of having an ileostomy at such a young age including having to use an ileostomy appliance for the remainder of his lifetime, the embarrassment he would likely experience during physical and social activities due to the presence of a stoma and the associated decreased quality of life he would likely experience. His parents were sympathetic and understanding of Keith's views, and discussed treatment options again with Keith's surgeon. Following this consultation, they were convinced that an ileostomy would greatly improve Keith's quality of life and would benefit his physical, emotional and social growth and development, so reconfirmed their consent for the procedure.

Keith became very agitated and upset, refusing to attend preadmission clinic appointments and to present at the hospital for the procedure. Keith's surgeon met with Keith to determine if he had sufficient capacity and maturity to fully appreciate all aspects of the matter and to be able to assess objectively the various options available to him. Following a lengthy consultation about all aspects of the surgery, alterations to lifestyle and likely prognosis if the surgery was cancelled, Keith's surgeon considered that Keith had sufficient insight and maturity to decide whether he would have the procedure or not and in the face of Keith's continued vehement refusal the procedure was cancelled.

In this situation, Keith appears to understand the risks and benefits of the proposed procedure and as he is the only person permanently affected by this decision, he could argue that he is the only person who can accurately understand the advantages and disadvantages of proceeding with the procedure. Keith's parents have a legal right to provide consent for the procedure but this right does not extend to their insisting on a procedure which will forever alter Keith's life. As there is no imminent urgency to undertake the procedure, it would be prudent to cancel this procedure

until legal clarification is obtained or by waiting until Keith reaches the age of majority and so is legally able to make this decision himself.

Discussion

It is evident from the discussion within this case study that, although parents generally make health care decisions based in the best interests of their child, their authority to consent to treatment is not absolute. The proposed ileostomy will likely provide benefits in the future but there is no urgency to proceed at this time. Keith's parents have a legal right to consent to the procedure but Keith arguably has a common law right to refuse it. The legal status of his refusal is open to debate, as he is owed a duty of beneficence by his parents and surgeon, but ethically his refusal to undergo the procedure is persuasive and his view must be taken into consideration. Beneficence is given significant weight regarding children because of their mental immaturity and emerging autonomy. The identified benefits of proceeding with the procedure against Keith's will must be considered against the potential psychological and physical effect that could result from forcibly operating on him[6].

An adult has the ethical and legal right to either give or withhold consent to undergo a procedure, unless they have cognitive impairment. The issue of whether a child has the same right to provide or withhold consent for an elective operative procedure is subject to debate and surrounded by a distinct lack of clarity at law. When parents are asked by medical practitioners to provide consent for a procedure for their child, they are required to be provided with sufficient information to make an informed decision about whether to agree to the treatment or not. This information includes the child's current condition, prognosis, treatment options and their advantages or disadvantages, details of the proposed procedure and the attendant risks involved with the procedure[7]. Children in contemporary society mature faster and, largely due to increased financial independence and the everyday use of technology, are accustomed to making decisions regarding their own welfare and health care at an earlier age than ever before. In some circumstances, children aged 16 years or younger have been able to provide legal consent for procedures if they are deemed to be sufficiently mature, but few legal cases discuss the rights of a child to refuse consent for an elective surgical procedure. Each case must be assessed individually, with consideration given to the child's mental and psychological development and health, their knowledge about the issue and their ability to logically explain and discuss their point of view.

In contrast to *Gillick*[4], courts are likely to take a rigorous view when assessing competence of a minor who refuses recommended surgical treatment, confirming the right of parents to provide consent for the procedure. In *Re E*[8], a judge ordered that a 15-year-old receive a blood transfusion, despite both his and his parent's refusal to treatment and the child having sufficient intelligence to make a decision regarding his welfare, because he lacked the maturity required to understand the ramifications of the decision. It is by no means a certainty that Australian courts will consistently apply the general principle, identified in *Gillick*, that a mature child who understands the proposed treatment is legally entitled to consent to that treatment. It would appear to be self-evident that a child who is deemed to be sufficiently competent and mature to consent to health care treatment should also be mature enough to refuse the treatment (as an adult could do), even if the result were to be adverse outcomes or death[9].

Conclusions

Statutory law, professional guidelines, codes of ethics and the common law all apply to the issue of obtaining an informed consent for health care treatment from an adult. The principles of informed consent

are based in common law and the acceptance that every adult with legal capacity has a right to decide what shall be done with their own body. In obtaining an informed consent from a patient, the medical officer must disclose details of the proposed treatment, any alternative treatment available, the risks and benefits of all treatment options, thus allowing the patient to consider all the information given and make an informed decision[7].

As identified in this article, the ethical and legal considerations surrounding this issue remain nebulous, leaving individuals including parents and health care workers, divided in their views[10].

Regardless of the legal status of a child's decision to refuse or consent to treatment, they have a legal and ethical right to have their views considered and included in conversations regarding proposed care[11]. A child may be deemed to be 'Gillick competent' to provide a valid consent; however, current Australian legislation does not support their indisputable right to refuse treatment. In non-urgent situations such as this, sufficient time should be provided for discussion and consultation with the child and parents to ensure the most appropriate outcome is arrived at given that the law remains conservative when protecting the interests of a child.

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