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Consent & refusal: selective respect for a young person's autonomy

Jackie Vasey discusses the ethical and legal dilemmas facing health professionals who work with children and young adults

Key words:

Consent & refusal to treatment
Moral principles
Paternalism

Nurses regularly face ethical and legal dilemmas when caring for young people (Griswold & Griswold, 2000). A potential area of concern for nurses can be in supporting young people in decisions regarding consent to and refusal of treatment. In order to guide nurses and other health care practitioners in decision making, Beauchamp and Childress (2001) have developed a set of principles that attempt to provide an analytical framework representing the general values underlying rules in the common morality. Beauchamp & Childress (2001) proceed to describe these as clusters of moral principles or four *prima facie* moral obligations or commitments, which are; respect for autonomy, justice, beneficence and non-maleficence. Gillon (1986) proposes that the four *prima facie* moral principles help bring order and understanding to our medico - moral judgments in modern day healthcare. The *prima facie* obligation of respect for the principle of autonomy will form the framework for this discussion, as this would appear to be the most relevant *prima facie* principle, of those described by Beauchamp and Childress (2001).

Crittenden (1990) and Collins *et al.* (1997) define autonomy as being the need to express ones authentic self, taking responsibility for ones own behaviour, relinquishing dependence on parents and making decisions regarding ones own life. Whilst Glasper & Richardson (2006) define autonomy as "*self-determination*", it is the determination of the point at which a young person relinquishes dependence on their parents and demonstrates self determination that creates the dilemma.

Recent changes to legislation (Children Act, 1989; United Nations, 1989) have resulted in the rights of children and young people being recognised and protected to ensure that their views are taken into consideration. According to Casey (2007), in principle, there is no longer a question of whether a child has the right to participate in decisions

concerning what happens to them. However, Casey (2007) goes on to question whether those decisions are respected in practice and maintains that managing a competent child's refusal remains a grey area.

The British Medical Association (2001) suggest that there is a growing awareness of the ability of children to make decisions providing they have been given age - appropriate information. According to Gillon (1986) doing things to someone without their consent constitutes overriding their autonomy. It would seem that treating a young person who has refused that treatment, goes one step further than this, as not only has treatment been provided without their consent, but also against their expressed wishes. According to Harris (1985) and Miller (2003) this is a clear example of paternalism. For nurses, enforcing treatment in young people who have refused that treatment is clearly in conflict with the principles of the nurse's role in acting as an advocate for the young person (Glasper & Richardson, 2006) and is ethically and legally questionable. Applying physical force in enforcing treatment may be legally tested by human rights legislation in the future, according to Didcock (2006), who goes on to propose that all people have the fundamental right to decide what happens to their own bodies.

The age at which young people become autonomous appears to be governed by the law. According to the Department of Health (DH, 2001) the law states that young people under 16 years cannot provide valid consent, unless they have been assessed as "Gillick" competent or competent according to Frazer guidelines. The terms "Gillick" competence and competent according to "Frazer" guidelines are used interchangeably (Wheeler, 2006). The case law relates to a case involving Mrs Gillick (Gillick v West Norfolk and Wisbech AHA, 1986, cited by Parekh, 2007), who challenged her local health authority's decision to allow young people under 16

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years to be prescribed contraception without parental consent or knowledge, hence the expression "Gillick" competence. Lord Fraser was the judge involved in the case, who chaired the working party that produced guidelines for respecting the confidentiality of young people in relation to sexual health, hence "Fraser" guidelines. For the purpose of this paper, "Gillick" competence will be used, although, this does not indicate that this is the preferred term. In the eyes of the law, young people deemed "Gillick" competent are able to make informed choices, such as consenting to surgery (Wheeler, 2006; Glasper & Richardson, 2006). Therefore, it would seem reasonable to assume that this should also apply to refusal of treatment. However, there appears to be conflict with regards to a young person's ability to consent to treatment, depending on whether the young person is deemed "Gillick" competent and their ability to refuse treatment. Whilst a person under 16 years old, if deemed "Gillick" competent, can provide consent independently, the person with parental responsibility can provide consent for treatment, when that young person refuses, thus superseding their autonomy.

Although not included in this discussion, the issues clearly relate to young people aged 16 and 17 years old warranting clarity on how this age group are affected. In the 16-17 year old group, this becomes even more contentious, as this age group can legally consent to treatment without having to demonstrate "Gillick" competence, but can have their refusal overridden by the person with parental responsibility, as only one person is required to provide consent. The *Mental Health Act* (DH, 2007) has begun to address this issue for young people with mental health disorders. Since 1st January 2008 the act has sanctioned that young people aged 16 and 17 years old cannot be admitted for treatment without their consent, even if the person with parental responsibility consents to this.

Maturity

It is remarkable that a young person under the age of 16 who is deemed Gillick competent can have their consent to treatment accepted, but up to 18 years can have their refusal overruled by the person with parental responsibility or the courts (DH, 2001). As Stokes & Drake-Lee (1998) suggest, in practice it appears that a young person must demonstrate a greater maturity and understanding to

refuse treatment, than to agree to it.

The age at which a person becomes an autonomous being, able to make rational decisions is difficult to assess. Wheeler (2006) suggests that whilst the ability to provide independent consent is proportionate to a child's competence, age alone is not a reliable indicator of competence, a view supported by Didcock (2006). It is hardly surprising that health care professionals struggle with respecting the young person's autonomy, as it would require them to make an accurate and defensible judgment of the young person's understanding and perhaps comply with the young person's wishes, which may be in direct conflict with their own beliefs. According to Lowden (2002) nurses often have to weigh up whether to respect a young person's wishes or risk breaking the law. It is evident that more clarity is required in order to ensure that the decisions made, are in the best interests of the child. This also raises the question of whether a young person's autonomy is actually respected when assessing their mental capacity to consent. In theory, the health care professional makes that decision and could be influenced by whether the young person truly demonstrates mental capacity, or just happens to agree with the practitioners wishes to proceed with treatment.

The reasons why young people refuse treatment may be valid and fully informed or due to a lack of understanding. It would seem reasonable to ensure that the young person has all the required information, provided in a way that they can understand. It is usually the responsibility of the medical staff to provide this information, however, nurses who usually have the most contact with the young person and their family should act as an advocate for the young person and the family (Glasper & Richardson, 2006). This process can place the nurse in a difficult position if the wishes of the young person are in conflict with that of the family, the medical staff or their own views, therefore, it is important for nurses to recognise whose rights they are protecting. It is acknowledged that nurses caring for children view the family as an integral part of the child's life (Callery, 2004; Department of Health, 2004; Coleman *et al.*, 2007) and actively promote the principles of family centred care. However, whilst parents may have valid reasons for insisting that their child has treatment against their wishes, the nurse has a duty to advocate on behalf of the young person (Nursing & Midwifery Council, 2004; DH, 2004).

Supporting young people

It is clear that the literature and to some degree the law supports young people's involvement in decision making to a point. However, it is clear that it does not appear to support young people who disagree with those decisions. It is a legal requirement that health care professionals gain consent prior to commencing any interventions (DH, 2001) and when young people's decisions conveniently match those of the parent/carer or practitioner, then this is honoured and regarded as good practice, according to Glasper & Richardson (2006) and Parekh (2007). However, when it does not, then the wishes of the young person are weakened, on the basis that the adult knows best (Glasper & Richardson, 2006; Parekh, 2007). As a result of this, it is difficult for the nurse, whose role it is to promote the rights of the young person (DH, 2003), to then justify to that young person that they can provide consent, if they demonstrate understanding, but cannot refuse treatment.

According to the Department of Health (2001), despite the law supporting young people in consent, but not in refusal of treatment, this rarely results in legal proceedings and is usually resolved at local level (Stokes & Drake-Lee, 1998). On the rare occasions when it is not, health care professionals have appealed to the courts to make the young person a ward of the court, so that refusal can be overruled. In the majority of cases it could be assumed that either the young person's wishes are respected or the young person is persuaded or coerced into complying with the practitioners and parent/carers wishes. The former option may indicate a need for change in the rules of "Gillick" competence in order to support young people in the refusal of treatment and may be necessary in order to clarify the situation for nurses and other health care practitioners.

Whereas, the latter option may indicate that health care professionals do not always view young people as autonomous beings. If this is the case and no justifiable argument can be provided for respecting the principle of autonomy in young people who refuse treatment, then this raises the question of whether they should be deemed autonomous beings in relation to consent as well.

One possible, and perhaps obvious suggestion would be to apply the principles of Gillick competency to the refusal of treatment as well as consent. Whilst

Crosbie (2007) claims, there has been a shift towards respecting the autonomy of children (DH 2004), this does not appear to have translated into practice with regards to refusal of treatment.

In conclusion, it has become apparent that within health care there is selective respect for the principle of autonomy in young people (Stokes & Drake-Lee, 1998; Parekh, 2007) with regards to consent and refusal of treatment. This can result in difficulties for the nurse who is attempting to maintain the principles of family centred care and at the same time acting as advocate for that young person, in situations where there is disagreement between health care professional, those with parental responsibility and the young person (DH, 2003). In addition to this, the nurse can be placed in a predicament where, on one hand the nurse is striving to promote the rights of the young person and on the other, is trying to justify to a young person that, whilst that young person can consent to treatment, if they are assessed as being "Gillick" competent (Wheeler, 2006) they are not afforded the same respect in relation to refusal of treatment. Some possible explanations for this anomaly have been proposed. However, it is clear that this does not constitute a rational explanation for the paternalistic approach of healthcare professionals who may impose their views when it suits them (Miller, 2003).

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