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## The ethical implications of Managed Care: a matter of context

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### In this issue

Helen McCabe is a PhD student at Australian Catholic University. Her thesis is entitled "Managed Care in Australia": a philosophical enquiry into the ethical issues leading to a protocol for ethically-sound practice. Her article in this issue is the first of a two-part account of the ethical challenges thrown up by new systems of organizing health care. In this first part she outlines the history of the concept of managed care in the United States and explains how the concept has a different range of meanings here in Australia.

Mary Byrne then discusses some of the difficult issues associated with obtaining consent to medical treatment in older children, children who are developing the capacity to decide for themselves. She sets out the law on this issue, and then puts forward two concepts from philosophical ethics – respect for autonomy and an understanding of the innate dignity of every human being – to throw light on the responsibilities of the health care professional towards older children.

The concept of managed care, in itself, is a morally-neutral one. As a system of organising and financing health care services it becomes malleable, however, to the values and meanings of the broader societal and particular institutional contexts in which it is shaped and informed. In thinking about the ethical implications of adapting features of managed care into the Australian health care system, it becomes important to view this concept from within its past and contemporary contexts. For it is this contextual understanding of managed care which is critical in considering ethical implications, and it is from this particular understanding that I wish to conduct the first part of the discussion.

To begin, I shall trace a brief history of the development of managed care. Secondly, I will discuss what this term is presently taken to refer to in the United States. Thirdly, I will examine some features of the Australian health care system which suggest that it, too, is a form of 'managed care'. Finally, I will establish the points of ethical interest to be explored in the next issue of *Bioethics Outlook*.

### Some Preliminaries

The term 'managed care' is best understood as an organised means of providing health care services and, as such, presents itself as an alternative to the traditional fee-for-service

model. It is in this light that the ethical implications of managed care are frequently considered, a select vantage point resulting from a history of bioethical concern with the narrow locus of the doctor-patient relationship, and at the neglect of the broader health care context. Indeed, it was not until the recent effects of administrative intervention were felt more acutely within the doctor-patient relationship that bioethical attention was captured. And so, from a bioethical perspective, then, the first achievement of managed care was to draw open the blinds to reveal a far more expansive health care landscape.

Managed care's considerably earlier achievement, however, was to address the problem of financing health care. The cost for patients in receiving health care within a traditional fee-for-service model has always acted to exclude many from the benefits of that care, even in medically simpler times, a dilemma which gave rise to the conception of managed care in the United States in the early nineteenth century.

### A Brief History

The earliest expressions of managed care were born of inspiring visions, the fruits of pioneering endeavours to ensure access to health care for early migrants, poor women and children, and for the blue collar workers of the United States. In 1890, the Benedictine Sisters signed up loggers from the logging camps of Minnesota, deducting small premiums from their payrolls in order to establish a health care service for these workers and, later, for the whole region<sup>1</sup>. In

the same era, university-educated women of California, eager to address the welfare needs of those disadvantaged by the effects of entrepreneurial capitalism and industrialisation, set about introducing health care services for poor women and their children. These early feminists, armed with degrees in economics, established a prepaid, capitated<sup>2</sup> system to provide maternal and paediatric care, setting up their first clinic in a stable, their waiting room a former donkey stall<sup>3</sup>!

In 1929, Dr. Michael Shahid, a socialist medical practitioner and migrant from Lebanon, founded the first Health Maintenance Organisation (HMO), called Group Health, to serve the health needs of the largely migrant farmers of rural Oklahoma. These farmers purchased \$50 shares for the purpose of building a hospital and receiving affordable medical care<sup>4</sup>. Like many other early managed care organisations (MCOs), the establishment of Group Health was strongly resisted by the medical profession, wary of any opposition to private, fee-for-service arrangements. Nevertheless, Group Health prospered, so that by 1932, it supported 12,000 members<sup>5</sup>.

In 1937, Kaiser Permanente was founded to provide health care to workers building an aqueduct in the Californian desert as well as to workers building dams in Washington State. In 1942, Kaiser established a similar programme for shipbuilders in the San Francisco Bay area<sup>6</sup>. Notably, the early founders of this particular HMO included

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businessmen, who believed that health care services could be run as efficiently as any other 'business', as well as doctors committed to preventative health care and trade unionists concerned for the health of their members<sup>7</sup>. Today, Kaiser provides health care services in sixteen states, and by 1994, had 7.3 million members<sup>8</sup>.

### Commitment to Social Justice

The early systems of managed care, it seems, were largely the creations of social reformers, propelled by a commitment to communitarian ideals of social justice: managed care was born to address the inequities in the dominant fee-for-service model of the time. That commitment responded to a variety of influences, however, including Christianity, feminism, communitarian socialism, and trade unionist philosophical loyalties<sup>9</sup>, these influences affecting, in turn, the membership of MCOs. Significantly, these early managed care entities were administered on a not-for-profit basis. They were also organised so that resources were shared, the fate of each member being tied to that of all others, including even the medical practitioners who served them. This communitarian situation was most clearly observed in the arrangements made by early Jewish migrants: while most health care was provided within Jewish homes, some migrants had arrived, bereft of family support and, therefore, vulnerable in times of illness and injury. As well, the kind of health care provided in the charity hospitals of the time frequently failed to respect the cultural norms and religious requirements of Jewish settlers. And so, Jewish communities founded a cooperative, or community-based fraternal group, *Landsmenshaften*, to arrange and finance health care for their members, employing doctors from local communities to provide culturally-sensitive medical care. In this sense, responsibility for the vulnerable members within the community was thereby assumed<sup>10</sup>.

Other non-profit expressions of managed care emerged and developed in the United States, and so by 1970 there were more than thirty such entities in operation<sup>11</sup>. The passage of the HMO Act in 1973 resulted in an acceleration of HMO development, so that

by 1995, an estimated 73% of the insured population of the United States received health care coverage through MCOs<sup>12</sup>.

For most of the twentieth century, however, the American Medical Association (AMA) has resisted the development of managed care systems, employing, in part, the ethics standards of the association's "Principles of Medical Ethics" as a basis of objection. In 1979, the Federal Trade Commission imposed a 'cease and desist order' on the antitrust use of the AMA's ethics standards, an order later upheld by a federal appeals court in 1980 and the U.S. Supreme Court in 1982. Other reactions to the managed care movement involved methods of discrediting those involved in its operations, the AMA referring to doctors employed in MCOs as communists, and second-rate practitioners<sup>13</sup>. And so, now the AMA, whose members consist of a somewhat smaller group of predominantly fee-for-service physicians, remains opposed to managed care<sup>14</sup>. Nevertheless, from its humble origins and onwards through its courageous struggle, managed care has survived to become the dominant form of health care organisation in the United States today.

In leaving this story here, it is important to remember that the early tale of managed care was centred on the need for affordable and appropriate access to health care, a need arising from the high personal costs of such care in a world of predominantly entrepreneurial medicine. And in examining managed care in the contemporary United States context, it is worth remarking that this same need, having become more urgent in light of increasingly expensive health care technology, continues to call for solutions from a somewhat more heterogenous form of managed care<sup>15</sup>.

### Health Maintenance Organization Act

The passing of the HMO Act in 1973 followed discussions between the U.S. Department of Health, Education, and Welfare and a Dr. Paul Ellwood who had been asked to devise ways of constraining the rise in the U.S. Medicare budget. (In the United States, Medicare remains a system limited to financing the health care services of the aged population.) Ellwood was eager

to foster managed care as a means of altering the incentives inherent in the fee-for-service system, incentives which acted to promote over-servicing and, consequently, high costs<sup>16</sup>. But in order to introduce managed care into the U.S. health care context, Ellwood needed to overcome two obstacles. Firstly, he needed to overcome resistance to the influence of external factors upon the autonomy of both the medical profession as well as their patients, and secondly, he had to move health care away from a traditional professional context in order to emphasise the necessary cost-containment measures. These two obstacles require some explanation.

Firstly, the provision of health care in the United States has been ordered within a culturally-dominant libertarian ethos in which individuals are morally bound by the limited requirements of a 'principle of permission' and the 'freedom to consent'<sup>17</sup>. This libertarian ideal implies a weaker conception of community, as exemplified by the strong rejection of any recognition of claims to a right to health care<sup>18</sup>. In the United States, then, health care has been largely a private matter, provided according to a patient's ability and willingness to pay, as well as to a willingness on the part of a self-regulated profession to provide. And it is this strong commitment to autonomy that Ellwood needed to consider in order to render the idea of managed care acceptable. This was only partially achieved by situating health care within the largely unregulated market of the United States, thereby avoiding the intrusion of government regulation into the private world of health care. For it has been this threat of government interference which has received the most concerted resistance in the United States where state authority has been limited by notions of the moral authority of individuals over their own choices and property<sup>19</sup>. However, in side-stepping the problem of a more powerful State, managed care has introduced alternative external influences into the professional context in the form of market forces and management policies. Consequently, the autonomy of insured patients and practitioners has been threatened by the machinations of managed care in controlling the availability of financial coverage for diagnostic and treatment procedures, as well as for hospital costs, a

factor which has met with considerable criticism ever since.

Now, having avoided the threat of, at least, state interference into health care, it was necessary to overcome the obstacle presented by the traditional professional context. That is, the medical profession had long enjoyed the privilege of self-regulation and determination<sup>20</sup>, a socially-sanctioned authority which proceeded without challenge until approximately thirty years ago when such privilege began to be viewed as a mask for what Pellegrino<sup>21</sup> has termed "selfish self-interest". Accusations of fraud and over-servicing began to emerge<sup>22</sup>, and, by training the focus of public concern on the corruptions of professional integrity, the standing of the profession was undermined to some degree. This situation not only served to challenge the powerful status of the medical profession itself, but also to undermine the integrity of a morally-significant tradition of healing entrusted to the security of the professional context. This dilemma merits a more considered understanding, and it is a task to which I will attend later. But for now, I will simply suggest that this healing tradition has been rendered vulnerable to forces from within a broader societal context, particularly market forces. Another factor has been a wider cultural change in moral perceptions concerning the way in which health care is valued, allowing for the waiving of a taboo over the use of medical knowledge. In this way, then, health care was able to be moved from the integrity of a professional context and installed into the receptive world of business and commerce: health care provision can now be viewed quite clearly from within the market metaphor. This movement confirmed both an altered perception of the value of health and its care, as well as a reinterpretation of managed care from that of a community-oriented, non-profit arrangement to a for-profit corporate entity<sup>23</sup>.

The altered arrangements for health care provision have involved a process of redefining time-honoured understandings of what it means to be in need of health care, of what is involved in responding to that need, and of what, in essence, is the very nature of health care. Within a market metaphor, that is, patients have become customers, health care professionals are called providers, and

health care emerges as a commodity<sup>24</sup>. This paradigm shift permits an array of activities formerly prohibited. Some of these are worthy and meritorious: for example, the cost considerations of health care provision may now occupy a more ubiquitous position in health care consciousness. Other mechanisms, such as the practice of putting the incomes of doctors at risk as a means of controlling clinical decision-making, are more ethically problematic. However, a brief overview of some of the features of contemporary U.S. managed care may afford some further understanding of this system.

### **Managed Care in the United States**

- Posting general practitioners (or primary physicians) as gatekeepers to the wider health care system. Prior to the introduction of managed care, patients could consult with specialist practitioners directly, without the requirement for prior referral.
- Contracting of hospitals and medical practitioners with MCOs for the purpose of providing health care to enrollees of the MCO. These contracts stipulate a range of requirements, including restrictions on services covered and limited periods of hospitalisation. Restrictions are more commonly related to procedures deemed medically unnecessary or 'experimental'. As well, doctors may be constrained in their ability fully to inform patients of treatment options.
- The promotion of evidence-based clinical guidelines in order to standardise clinical practice.
- Frequent merging of MCOs in order to maintain market power. Enrollees of MCOs are traded, along with other company stock.
- The maximisation of profit to meet the primary obligation of serving shareholders' interests.
- The introduction of financial incentives as a means of influencing clinical decision-making.
- Assessment of quality of care by means of customer satisfaction surveys (a measure normally involving perceptions of quality with regard to amenities, waiting time, and other non-medical criteria).

- The integration of professional and business concerns, whereby medical practitioners can profit directly from treatment decisions. Doctors may legally own and operate pathology and radiology services to which their patients are referred.

These mechanisms require elaboration, but for now it will suffice to acknowledge that ethical conflicts which arise from this model are related to the incorporation of market norms and strategies into the domain of health care. And for American observers, a more striking innovation of this model is the rise of administrative influence and control over what was formerly perceived of as a very private matter. This particular concern may not so easily disturb the consciences of those nations which currently sanction universal health care systems and their necessary administrative support as can be seen in the Australian system.

### **Managed Care in Australia**

In Australia, as elsewhere, health care is managed. It always has been<sup>25</sup>. And many of the features inherent in Medicare look a great deal like those of managed care as it is understood in the United States. Some examples of these similarities include:

- Capped global hospital budgets which act to restrict hospitals in what services they can provide.
  - Restrictions on funding for services not considered medically necessary or socially useful, for example, cosmetic surgery and the prescription of particular medications.
  - Promoting competition within the public sector by using benchmark comparisons between services, then allocating funding according to the standards of the most efficient.
  - Defining the role of the General Practitioner in Australia as gatekeeper to the wider system of health care.
- More recently, other innovations have emerged to resemble 'U.S.-style' managed care even more closely. They include:
- Coordinated Care Trials
  - Integration of for-profit nursing home chains, and of for-profit corporations as

owners and administrators of private hospitals.

- Corporatisation of general practice arrangements as well as of pathology and other diagnostic services.

- Changes to the Trade Practices Act to include, among other considerations, prohibitions on price fixing, as well as on collective action to prevent the signing of contracts between private health funds and doctors (medical purchaser provider arrangements) and private hospitals and doctors (practitioner arrangements)<sup>26</sup>.

Other features emulating a system of managed care have been integrated into the Australian context in an effort to contain health care costs. And, as this process unfolds, it becomes apparent that the role of the health care institution holds increasing sway in determining such matters as the availability, cost and quality of health care. As well, the science of economics is increasingly employed to constrain the practice of medicine in ways unprecedented in former times. Significantly, these emerging developments remain bereft of a thoroughgoing ethical analysis, a contribution to which will be deferred to the second half of this discussion.

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16 Fox, P. in Kongsvedt, P. [ed] op. cit.

17 Englehardt, H.T. 1996 *The Foundation of Bioethics*, Oxford University Press, New York, Oxford, p 288.

18 Englehardt, H. T. op. cit. p 375

19 Englehardt, H. T. ibid.

20 See, for example, Heer, F.W. "The Place of Trust in Our Changing Surgical Environment" in *Archives of Surgery*, Vol. 132, August 1997

21 Pellegrino draws on an Aristotelian understanding of self-interest, in which there is a distinction between "good...and noble forms of self-love" and a "selfish self-interest" or "vicious sense of self-love in which self-interest is pursued "at the expense of others". See his article "Interests, Obligations and Justice: Some Notes Toward an Ethic of Managed Care" *Journal of Clinical Ethics* Winter, 1995, 6 (4), pp 312-317.

22 See for example Palmer, G & Short, S. 1990 *Health Care and Public Policy*, Macmillan Publishing Company Pty Ltd, South Melbourne, p 168.

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# Consent to the medical treatment of older children: ethical issues

Mary Byrne

## Mary's Case

Last year a fifteen year old girl, Mary,<sup>2</sup> suffered sudden severe heart failure and was given a week to live unless she received a new heart.<sup>1</sup> She had two days in which to come to terms with the possibility of a heart transplant. Mary refused the procedure, knowing that she was likely to die and despite the fact that her parents were strongly in favour of the procedure and had consented to it. The transplant team, reluctant to go against the girl's wishes despite having the consent given by the parents, went to an English High Court judge seeking guidance. Mary's reasons for refusing the transplant were that "she was 'depressed' at the prospect of taking treatment for life, and worried that she would be 'different' with someone else's heart."<sup>3</sup> It was the view of the Official Solicitor (appointed by the court to represent Mary) that she was too overwhelmed by the sudden discovery of a fatal illness to be in a position "to weigh up all the considerations and make an informed decision."<sup>4</sup> The judge accepted the recommendation that the surgeons be allowed to act according to their clinical judgement and Mary agreed to undergo the procedure.

## Steven's Case

Two years ago in Australia a fifteen year old boy, Steven, was assessed for a lung transplant. He had suffered from cystic fibrosis all his life and his health was deteriorating. He was found to be a good candidate. If Steven were to be placed on the waiting list for a lung transplant, he would require daily maintenance treatment at a much more aggressive level than he was presently receiving. Steven refused the lung transplant, reluctant to face the required aggressive treatment and uncertainty.

Nevertheless, he was convinced over a few weeks by his parents to change his mind and agreed to go on the waiting list. Steven died eighteen months later, on the waiting list, while still receiving aggressive therapy.

## Rose's Case

Several years ago a nine year old girl, Rose, was diagnosed with a stage four neuroblastoma.<sup>5</sup> Rose was treated with surgery and chemotherapy, but suffered relapses. She then received an autologous bone marrow transplant. Despite this, Rose developed metastatic disease in her bones, including the spine, requiring opioids for pain management. Rose's parents were told of an experimental chemotherapy programme. However, the doctors thought that it had a very small chance of being successful for Rose. Furthermore there was a reasonable risk that Rose could develop leg pain during the infusions. Rose's parents chose to start the chemotherapy. Near the end of the course of treatment Rose developed severe leg pain and other complications. Despite increasing doses of analgesia the pain was not controlled. The only remaining possible option for controlling the pain was to sedate Rose. While it was thought that this would control the pain, there was a risk of inducing respiratory depression and a respiratory arrest. Rose's parents were informed of this and of Rose's prognosis. They requested that Rose be resuscitated in the event of an arrest, even though they acknowledged that Rose had extensive disease and a further remission was unlikely.

These cases highlight the difficult area of consent to medical treatment for older children.<sup>6</sup> In this paper I will present the basic principles arising from the legislation that

covers the provision of medical treatment for children. I shall then discuss two philosophical conceptions of consent to use as a basis for approaching such difficult cases. I will return to these cases at the end of the paper.

## Issues

There are several pertinent issues relating to the consent for medical care of children highlighted in the above cases. When a competent adult is considering the possible options for medical treatment, the decision making usually involves that adult and the relevant healthcare professional. At times the family may also contribute to the person's deliberations, but it is generally a process with two main participants. However when children are involved, there can be up to four participants in the decision making: the child, the child's parents (or relevant guardians), the healthcare professionals and, at times, the government either through the courts or through legislative requirements. This can set up quite a different dynamic from that which exists for an adult patient. While the responsibilities of the healthcare professional are to the patient, that is the child, they must seek consent from the parents. Though problems are infrequent they do occasionally arise. This can happen when there is a level of disagreement amongst all the participants in the decision making. For example:

\* A child may refuse treatment that the healthcare professionals suggest and to which the parents agree. This can range from something relatively forgoable to something potentially life-saving.

\* A child may request treatment, such as an experimental therapy, with which the parents do not agree. Alternatively a child may request medical care, such as treatment for a sexually transmitted disease, without the parents' knowledge.

\* There could be a disagreement, over (say) the level of treatment, between the healthcare professionals and the parents.

Considering the different people involved in the decision making and the ways in which problems can arise, some of the ethical issues are:

What input to the decision making should a child have? What is the relative weight of that input compared to the input of the parents and others? How important is evident reluctance on the part of a child? How much consideration should be given to the refusal or request of a child that is in conflict with parental and/or medical perspectives? Who finally decides when disagreement exists? How does the healthcare professional maintain a primary responsibility to the patient while being accountable to the parents and, at times, also to the government? There are no simple answers to these questions. However, the law provides some guidance.

## Legal principles

For all medical procedures, the right to treat a patient is based upon gaining the consent of the patient to the performing of the procedure. If a healthcare professional does not gain the consent of the patient, she or he is open to a criminal charge of assault and a civil suit of bodily trespass.<sup>7</sup> This is the basic legal position premised on a competent adult. However, some modification is required when considering children. There is no one simple statement concerning the legal position for consent to the medical treatment of children. There are, in fact, several basic principles that need to be taken into consideration. The relevant legislative acts are: the *Family Law Act 1975 (Commonwealth)*, the *Minors (Property and Contracts) Act 1970 (NSW)*, the *Children (Care and Protection) Act 1987 (NSW)* and the *Guardianship Act 1987 (NSW)*.<sup>8</sup>

Someone has to consent to the medical treatment of children. In the *Family Law Act 1975* parents are recognised as the custodians and guardians of their children. Custodianship is restricted to the right and responsibility to have and make decisions concerning daily care and control. Guardianship concerns long term rights, responsibilities and duties including medical treatment, religious upbringing, schooling and place of residence. It is as a guardian that a parent normally has the right to seek medical care for her or his child.

This right is described more specifically in the *Minors (Property and Contracts) Act 1970*. In this legislation it is stated that parents can give consent to medical and dental treatment



for children under the age of sixteen years and that the consent has the same effect in relation to a claim for assault or battery as if an adult had consented. Secondly, a child who is fourteen years or older may consent to medical or dental treatment and, again, the consent has the same effect as if an adult had consented. The *Children and Young Persons (Care and Protection) Act 1998* extends these legal rights to guardians and other people responsible for children in out-of-home and protective care. Finally the *Children (Care and Protection) Act 1987*<sup>9</sup> states that medical practitioners can provide emergency treatment without the consent of the parents or the child to save a child's life or to prevent serious damage to the child's health.

Thus, although parents generally have the legal right to seek and agree to medical treatment for their children, this authority is not absolute. According to the *Family Law Act 1975* parental authority is limited to what is in "the best interests of the child". To give an example: A parent could not seek to have the healthy limb of a child amputated so that the child could work more effectively as a beggar. In New South Wales the *Guardianship Act 1987* further limits the scope of parental authority. It defines certain treatments that are designated as "special medical treatment". Such procedures may not be performed on a child unless a Supreme Court order permits it. "Special medical treatment" covers treatment that will render a child permanently infertile or is of an experimental nature such that it is not yet supported by a substantial number of medical practitioners. The principles that guide these decisions are that the treatment must be the only or most appropriate way of treating the patient and must be manifestly in the best interests of the patient.

The basic conclusions that can be drawn from this set of legislative acts are:

\* Parents have the right and authority to consent to medical treatment for their children until the age of sixteen. This arises from their duty as guardians of the child.

\* Children fourteen years and older can consent to their own treatment.

\* As guardians, parents must decide on the basis of what they think is in "the best

interests of the child".

The law is thus reasonably clear for a child up to the age of fourteen and for young people<sup>10</sup> sixteen years and older. However, it is unclear for children aged fourteen to sixteen, where there is the right both for the child to consent and for the parents to consent. While it is important to have the general legislative guidance of an appropriate age to be accepted as legal competence, there is now a growing acceptance of the differing capacities of older children and young people to understand and consider the treatment proposed for them. A new concept, the Gillick test of competency, has been used in recent years.

Mrs. Gillick challenged a directive circulated to some English medical practitioners by their local area health authority. It concerned treatment and contraceptive advice for children under sixteen years of age. She had several daughters and was concerned that they could seek and receive such advice not only without her consent but also without her knowledge. The case<sup>11</sup> eventually went to the House of Lords who found that parental authority is a diminishing authority. While the authority is almost absolute when a child is very young, it becomes more circumscribed as the child develops and matures. While parental rights do not fully disappear until a child is eighteen years of age, a child is also to be treated as a person with capacities and rights. The Gillick test of competency has been proposed from the judgement of this case. Lord Scarman, in his part of the judgement, held that a child was legally competent to consent when she or he had achieved "a sufficient understanding and intelligence to enable him or her to understand fully what is proposed"<sup>12</sup>The assessment of competency is to be undertaken by the doctor.

Gillick supports the principle that parents have the authority to consent to medical treatment for their children. However, by establishing that parental authority is not only not absolute but also diminishing to the extent that a child has the capacity to consider the options and make decisions for herself or himself, it has raised a difficult challenge for doctors who have to assess a child's capacity to consent.

### Philosophical bases for consent

In a widely used textbook<sup>13</sup> it is claimed that a fundamental principle in health care practice is to respect the patient's autonomy. Seeking a patient's informed consent generally shows this respect. A competent and informed patient has "the right to be free of unwanted medical interventions". Such a bald statement does not offer any guidance in the case of a person, such as a younger child, who is not fully autonomous.

In perhaps the best known bioethics textbook, Beauchamp and Childress<sup>14</sup> also present respect of autonomy as a fundamental principle. They focus on autonomous action, rather than the autonomous agent. The three aspects of autonomous action are: intentionality, understanding and freedom from controlling influences. Intentionality is essential to autonomous action. However, there may be degrees of understanding and freedom from controlling influences. Therefore, an autonomous action is one with substantial understanding and freedom, along with intentionality.<sup>15</sup> Such a description can allow a way of thinking about children who are maturing in their ability to understand and act free from controlling influences.

Further to this understanding of autonomy are the activities that mark respect for autonomy. Such respect requires more than simply nonintervention in the autonomous activity of other people. This respect requires a positive fostering of people's ability to act autonomously and maintain their capacity to act autonomously. While this is the fundamental principle, it has to be expressed in more specific norms to be of practical assistance. One such norm that derives from this principle is the importance of informed consent. The elements of informed consent derive from the elements of autonomous action and the obligations of respect for that autonomy. Therefore, appropriate information has to be given to the person in a setting free from coercion and in such a way that the person is able to understand the information and choices. Finally, there needs to be the opportunity for the person to make a decision and authorise the particular intervention.<sup>16</sup>

However, in considering people who are not autonomous, and never have been

autonomous, Beauchamp and Childress opt for the use of a best-interests standard in decision making by others. In suggesting this standard, they allow for the inclusion of the person's preferences and values, if they are expressed or known, when determining the best welfare of the person.<sup>17</sup> While this standard is of great benefit for guiding decision making, it does not offer guidance for considering the participation of children who are maturing in their capacity as autonomous agents but who cannot be considered substantially autonomous. There is very little indication about how to incorporate the preferences and values of the child. We need to look elsewhere for guidance in considering these children.

In the second opinion in *Marion's Case* Justice Brennan<sup>18</sup> based his judgement on an understanding of the innate dignity of every person, regardless of how strong or weak and capable or incapable that person may be. While the law protects every person, the way in which that protection is provided may differ from one person to the next depending on the physical and mental needs and capacities of each person. A second way of conceiving of consent, therefore, is to base it on respect for the dignity of the person, rather than on the autonomy of the person. The following ideas expand this basis when it is recognised that the patient is the person usually best placed: (a) to mediate amongst her or his interests, (b) to integrate the medical treatment with other aspects of her or his life, (c) to limit the treatment in accordance with her or his other responsibilities, and (d) effectively to carry out her or his part in the treatment.<sup>19</sup>

This conception presents a different perspective on autonomy as it relates to consent for medical treatment. It is not opposed to the standard autonomy concept but highlights different aspects of autonomy as the basis for consent. It is possible to use this "dignity" conception to develop an understanding of how to involve children in medical decision making.

Parents are usually the people best placed to mediate amongst the interests of a child and will be aware of other responsibilities that a child may have. A child's developing capacity to consider the options and make

decisions will be matched by a developing level of other responsibilities and interests and a developing capacity to mediate amongst those responsibilities and interests. The impact of a treatment on a child is not simply the physical impact, but the impact it will have on the whole child. This includes the effect on a child's self perception if the procedure is undertaken. Every person, including every child, has to be able to integrate the treatment she or he is receiving with other aspects of her or his life (regardless of the level of self-consciousness that person may or may not have). Secondly, every child has to be able effectively to participate in the treatment. If the child does not participate appropriately, many treatments will be less effective and some, such as rehabilitation exercises for example, will not be effective at all.

The significance of these points will vary depending on the age of the child, the ability of the child to make decisions and the seriousness of the treatment being considered. However, they are important points for the parents and healthcare professionals to consider, and can be used to guide the level of involvement by the child in the decision making. This way of thinking about consent supports the changes developing in the law, marked by the increasing significance of the Gillick test of competency. Many factors will impact on a child's ability to make medical decisions, including the seriousness and length of the illness, the severity of the proposed treatment and the child's experience of other treatment. It was recognised in Gillick that a child's ability to make such decisions may vary in accordance with these factors and in the same child at different times. A child's competence, therefore, needs to be (re)assessed each time a decision has to be made.

### **Application to the Case Studies**

The cases of Mary and Steven are in many ways similar. Mary and Steven were both confronted by the possibility of an organ transplant and life time maintenance treatment. However, there is one significant difference. Mary's experience of her illness was very short compared to Steven's experience of his. While she feared the long term treatment implications, Mary had no

experience of them. Steven had a long experience of his illness and was well aware of the treatment regime that would be required for preparation for the transplant. For this reason it may have been appropriate to give greater weight to the refusal by Steven. While Steven could acknowledge that a transplant would offer a better hope of life with less illness, he may well have desired simply having less treatment for a limited time than aggressive treatment in the hope of receiving a lung transplant. This had to be taken seriously.

A further issue can be identified in Mary's case. Her second reason for refusal was a fear that she would be "different" with someone else's heart. Considering the full impact of the treatment includes thinking about how the transplant would change Mary's perception of herself. While this is not necessarily a reason for accepting Mary's refusal of the heart transplant, it needs to be addressed. Both these cases highlight the challenge of respecting a child's wishes when the child refuses potentially life sustaining treatment.

Two issues arise in the case involving Rose. The first concerns how to involve Rose in the decision making. At nine years old she would be capable of expressing an opinion but would probably not be able to comprehend the significance of the different options. She would, however, be well aware of what was happening to her and how she felt. It would be important to ensure that Rose could continue effectively to participate in her treatment. It seemed that there was not such a willingness to involve Rose in the discussions and decision making. The second issue concerns how to determine what is in the best interests of Rose and what respects her dignity as a person. Requesting full resuscitation for Rose in the hope of her being able to undergo further chemotherapy could be perceived as simply seeking to keep Rose alive at all costs rather than respecting her dignity. Again, at this point, Rose's wishes should also be sought and seriously considered along side those of her parents.

### **Conclusion**

While neither the law nor philosophical reflections issue in strict guidelines applicable

in all circumstances, some general guidance can be derived from the above discussion.

\* The responsibility of the healthcare professional is primarily to the patient. The focus of the healthcare professional has to be what is in the best interests of the patient, namely the child.

\* As the people who generally know the child best and have the best interests of the child as their primary focus, the parents need to be fully engaged in the decision making process. Therefore, they must be provided with the relevant support and information to enable them to make good decisions.

\* The dignity and the rights of the child must not be violated. This requires (a) an effort to explain the procedures and medical conditions to the child at a level appropriate to that child, (b) a willingness to enable the child to respond to the proposed treatment and participate in the decision making, (c) a willingness to respect and consider the child's response, and (d) an effort to enable the child effectively to participate in the treatment.

A child's ability to participate in the decision making will be influenced by her or his understanding of what is happening, ability to consider the options and possible outcomes of the different options and ability to make decisions. It can be further influenced by what the child has already experienced and knows of the particular condition.

I do not wish to claim that any of this is easy. It is incredibly difficult to provide the best possible care for each child while also involving each child in that treatment as fully as possible. Both the law and good ethics highlight the fact that there is no simple point at which children and young people suddenly become capable of giving consent when previously they were not capable. Rather the capacity to consent needs to be assessed with respect to each child and with respect to each decision that needs to be made about her or his care. The goal is to involve the child, to acknowledge the dignity and rights of the child and to enable the appropriate participation of the child in decision making regarding medical treatment.

## References

<sup>1</sup> This article is based on a presentation entitled "Health Care for Older Children" given at the Plunkett Centre For Ethics Annual Intensive Bioethics Course at New Children's Hospital, Westmead on May 10<sup>th</sup>, 2000. I gratefully acknowledge the assistance of Dr Peter Cooper (New Children's Hospital, Westmead) in providing help with the cases.

<sup>2</sup> In the case the girl was identified as "M". I have referred to her as Mary for ease of reading.

<sup>3</sup> Dyer, C., "English teenager given heart transplant against her will", *British Medical Journal* 319 (July 24, 1999) p. 209.

<sup>4</sup> *Ibid.*

<sup>5</sup> This case is based on one presented in *Ethics Rounds*, Collins, J., "Case Presentation: Terminal Sedation in a Pediatric Patient", Vol 15 (April 1998), p. 258.

<sup>6</sup> There is no specific definition of an "older child" (in contrast to babies and young children). In this paper I will simply mean children who have the capacity, to a greater or lesser extent, to participate in a discussion, to consider what may or may not happen to them and to express a personal opinion about this.

<sup>7</sup> Tobin, T.K., "Foregoing Life-Supporting Treatment: the Civil and Criminal Law" *Bioethics Outlook* Vol 4 (June 1993) p. 5.

<sup>8</sup> As this article is based on a presentation given in Sydney, it focuses on the relevant legislation in New South Wales. Similar legislation exists in the other States of Australia.

<sup>9</sup> This legislation will be repealed when Section Three of the *Children and Young Persons (Care and Protection Act) 1998 (NSW)* is commenced. However, the same basic principles are contained in the new legislation.

<sup>10</sup> The *Children and Young Persons (Care and Protection Act) 1998 (NSW)* defines a young person as aged sixteen or seventeen years old.

<sup>11</sup> *Gillick v West Norfolk AHA* (1986) AC 112.

<sup>12</sup> *Gillick*, at 189.

<sup>13</sup> Isselbacher, K.J., Braunwald, E., Wilson, J.D., Martin, J.B., Fauci, A.S. & Kasper, D.L. (eds.) *Harrison's Principles of Internal Medicine* (13<sup>th</sup> edn.) (Vol. 1), New York: McGraw-Hill, 1994, p. 6.

<sup>14</sup> Beauchamp, T.L. & Childress, J.F. *Principles of Biomedical Ethics* (4<sup>th</sup> edn.) New York: Oxford University Press, 1994.

<sup>15</sup> *Ibid.*, p. 123.

<sup>16</sup> *Ibid.*, pp. 125 & 145-6.

<sup>17</sup> *Ibid.*, p. 179.

<sup>18</sup> *Secretary, Department of Health and Community Services v J.W.B. and S.M.B. (Marion's Case)* (1992) 175 CLR 218 Judge 2 at 7.

<sup>19</sup> These points are based on similar points presented by Germain Grisez; *The Way of the Lord Jesus: Difficult Moral Questions* (Vol. 3) Quincy, Illinois: Franciscan Press, 1997, p. 280.

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