Ethics in Child Health

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A Practical Workbook

Edited by

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CONTENTS

INTRODUCTION

JP FLEMING, MD SHIELDS

If the term *ethics* may be defined as "the moral principles that govern a person's behaviour or the conducting of an activity[1]" then *medical ethics* may be described as the study and application of such principles, values or judgments to the practice of medicine or healthcare[2]. The modern science of Western medical ethics has drawn its form from centuries-old influences and practices (the Hippocratic Oath, early Christian, Jewish and Islamic teachings and scholarship) in addition to more recent debate with a necessary evolution resulting from rapid technological and healthcare advances. Medical ethics, while often regarded as a subject in and of itself, is foundational to all practitioners of healthcare and has been interwoven throughout the fabric of caring vocations since their beginning. More than two millennia ago Hippocrates swore to help the sick to the best of his ability and never with the intention of doing harm. Readers may be familiar with the Latin term *Primum non nocere*, ("First do no harm") as one of the underlying principles of medical care. Unfortunately, the best course of action in healthcare is not always easily defined and treatment decisions may be a fine balance between benefit and harm or a source of disagreement between patient and healthcare provider.

While the study of medical theory examines what *can* be done, medical ethics in general considers what *should* be done. Most people agree that there is a difference between right and wrong and will hold to certain moral values. These values however may differ substantially and are often derived from influences such as cultural upbringing, religious belief, previous experience, personal intuition or some other source. How these values are considered and applied comprises the subject of ethics. There are of course many areas of universal moral agreement with a declaration on bioethics and human rights produced in 2005 by the United Nations Educational, Scientific and Cultural Organization (UNESCO)[3,4].

Modern Western medical ethical approaches are generally and commonly based on a four-principle framework first proposed in the 1970s by Beauchamp and Childress in their seminal work *Principles of Biomedical Ethics* (currently in its seventh edition; 2013). The four principles are those of *autonomy, beneficence, non-maleficence* and *justice*. These will be explored in the content of this book within the context of child health. There are of course many other important ethical principles which will also be discussed, such as *integrity, honesty, motives, confidentiality, consent* and *duty*[5].

Medical ethical issues relevant to children and young people present their own specific directions and challenges. Until relatively recently, it had been long assumed that children and young people could not make decisions for themselves and therefore responsible adults (either the child's parents or their doctor) would make treatment decisions on their behalf. In general, this remains the practice for younger children who are unable to make informed decisions and they remain one of the most vulnerable group in society. However, many young people, while they cannot yet learn to drive, drink alcohol or even vote in elections, are perfectly capable of making informed decisions regarding their own treatment. It is not long since the cessation of the common, regularly accepted practice of allowing children with significant disabilities to die without proceeding to life prolonging or even life-saving medical treatment. Such became the subject of major public debate in the U.S.A. in the early 1980s with the public disclosure that routine, standard treatment was commonly advised against or withheld from infants with cognitive disabilities noted at birth. Several cases resulted in the passing of a federal law that came to be known as the Baby Doe Rules (an amendment to the Child Abuse Prevention and Treatment Act of 1974). One of the primary cases involved a child (Baby Doe) from Indiana, U.S.A. with Down syndrome (trisomy 21), who in 1982 died resulting from untreated oesophageal atresia and tracheoesophageal fistula. The parents, following advice from an obstetrician, chose for medical and surgical treatment to be withheld based on a perceived poor potential for success of surgery and the fact that the child had Down syndrome and cognitive impairment. The hospital brought the case before the courts but it was ruled that the child's parents had the right to decide on the withholding of treatment. The child died 6 days following birth of dehydration and pneumonia. Following the subsequent firestorm of public outrage and debate in the US, a campaign from the US Surgeon General and the involvement of President Ronald Regan, Baby Doe Rules were passed requiring that all infants be given medically beneficial treatment, regardless of disability, unless they are comatose, the treatment would merely prolong dying, or their death is imminent (without reference to the wishes of the child's parents)[6,7].

The Baby Doe debate shifted the emphasis of child health from "medically beneficial treatment" to "actions should be in the best interests of the child", which subsequently raised further significant questions. Firstly, "for what reasons did the parents and/or healthcare staff withhold potentially life-saving treatment to the child born with a disability?" Secondly, if the reason in denying such treatment is to prevent a life of suffering for both the child and their family then the question follows; "Who may decide the potential quality of life of another?". From these stems the broader question, "Who can or should decide or define the best interest of a child?". Considering the reasonably rigid Baby Doe Rules mentioned above, it is difficult to apply a standard of "the best interests of a child" as the rules do not consider quality of life[7,8]. Questions such as these can only be answered within the contexts and sensitivities of specific cases and cannot be answered universally.

If one thing is certain in the field of medical ethics, the answering of one question will undoubtedly lead to more arising. There is often (usually) no black and white answer to ethical dilemmas. What may seem the best decision in one context may be most inappropriate in another. It is the purposeful and informed process of working through the grey areas of discussion to come to a decision that is both the challenge and skill of medical ethics. This book, with an emphasis on working through cases of medical ethical dilemmas in the context of child health, does not seek to give the reader the answers to ethical problems, but hopes to assist them in learning how to approach such dilemmas and to analyse the reasons for and against different or conflicting courses of action. Specifically, it aims to raise awareness of the moral aspects of child health practice; to assist the reader to identify and examine the assumptions and values underlying their own moral beliefs and those of others and to help develop skills in identifying and critically evaluating the moral considerations in difficult medical situations. It is hoped that the book may assist the reader to broaden perspectives and foster empathy and tolerance of opposing points of view.

A wide range of issues arise where either there is no clear morally right choice or there exists a high level of disagreement or uncertainty. Individuals may believe that they have the absolute right answers to moral dilemmas based on their cultural or religious beliefs and practices. It should be borne in mind that background, experience or religious belief will significantly influence an individual's view on how an ethical issue may be approached or on what action might be taken in aiming for a resolution. The reader is thus encouraged to consider each ethical dilemma from the varying points of view and beliefs of those involved as well as their own, even if they do not necessarily agree with them. Although this book will look at cultural and religious beliefs in the context of the ethical issues at hand, it will not attempt to discuss or portray objective moral truths. The reader should also note that this book outlines the approach to medical ethics largely from a "Western" point of view. Other countries and cultures may have differing approaches and principles in their ethical practice.

It is hoped that this book can serve as a basic introduction to the topic of medical ethics in general, as well as a focus on the issues related to approaching ethical problems in the setting of child health. It is not an exhaustive text nor is it definitive in its scope, but it aims to assist the reader in the recognition of ethical problems (help develop ethical sensitivity) and in the development of skills in identifying and analysing the key moral considerations within difficult child health cases. This book is thus primarily aimed at those new to the topic of ethics in child health including undergraduates, medical and nursing students and other health professionals involved in the care of children[9,10]. However, it may also provide a useful resource for more experienced healthcare professionals who want to review their knowledge and skills in the approach to ethical issues in child health or as an aide in education.

CHAPTER 1

THE NATURE OF ETHICS

LK SHIELDS, JP FLEMING, MD SHIELDS

Ethics may be defined as the science of morals or moral philosophy, which are concerned with human behaviour; especially the distinctions between good and bad or right and wrong. They provide the personal framework that dictates what is right and wrong. The science of ethics seeks to evaluate human conduct and the rules and principles that are used to control it. Ethics is concerned with conscious and purposeful behaviour and with the obligations and rules that relate to it, aiming to discover what factors make actions good or bad, right or wrong both for individuals and for social groups. It is concerned both with theory and with how the various theories can be put into practice[1-4].

Some frequent words used in the study of ethics are defined below. They might be regarded as part of an ethical vocabulary, and thus may be useful for reference when considering ethical cases throughout the course of reading or practice:

Right and Wrong: these terms assume comparison with some absolute standard of morality outside of the action being judged.

Good and Bad: to judge an action good or bad goes beyond its mere rightness or wrongness. An action can be right in the sense that it conforms to a rule but, if the motives are unworthy, it might not be regarded as a good action.

Motives: motives are the desires and the intentions that move us to action. A good motive/intention can make an action better than it otherwise would be, but it cannot turn a bad or immoral action into a good one.

Obligation/Duty: that which is due by the individual to meet some moral necessity. It could be duty in relation to a code of ethical behaviour imposed by custom or religion or in relation to the inner promptings of a person's own conscience.

Conscience: this is a faculty within us which judges our actions or our intended actions and which seeks to direct us to produce actions it judges right or good.

Moral Rights: these are the entitlements of an individual to be treated in certain ways and to have his interests considered. For example, a basic human right is the *right to life*. Such a right goes beyond the *negative* concept of**,** "a person is entitled *not* to be deliberately or in any active way killed". It has a strong *positive* aspect that places an obligation on others, including healthcare workers, to do whatever they can to help the individual to experience and enjoy his or her life to its fullest extent. It is a *right to life* and not just a *right not to be killed*. (This will be discussed further in the next chapter). A further fundamental human right is *the right to health*, meaning that to all humans some standard of health care should be provided. This also is a *positive right*. There are however several caveats to such rights. It should be impossible to regard these rights as absolute that allow no exception and that over-ride all other moral considerations. For example, such rights do not mean that physicians and healthcare workers can or should always be required to attempt to prevent someone's death in every circumstance. In some circumstances, it may be considered as morally wrong to attempt to extend life artificially by hi-tech methods as it is to allow a life to end prematurely. In addition to this, many countries do not have robust and well-funded health care systems that provide the same rights to health as exist in the United Kingdom.

Rights arise in the context of natural, religious, national or international laws and of social and societal conventions or agreements made between fellow citizens. Often in these arrangements individuals surrender a degree of personal liberty to live in an ordered society and become entitled to certain rights in return (the principle of universality).

There are several ethical theories (perspectives) that have predominated in modern times. Each perspective advocates a different approach to addressing ethical or moral problems with the overall aim of concluding the most appropriate course of action. Ethical theories and perspectives have been debated and developed over many years, and have differed among cultures, ethnicities and societies. Important amongst the normative ethical (the study of ethical action) theories in Western philosophy are the broad groups of consequentialism, deontology and virtue ethics which will be discussed below. Other approaches include the theory of ethics of care[5] (or relational ethics, which argues that moral action arises out of interpersonal relationships and the experiences of compassion and empathy) and pragmatic ethics which acknowledges the appropriateness of each ethical theory but does not take any theory as assumed. A pragmatic ethical approach is closely linked to scientific advances and focuses on society rather than on individuals[6].

Consequentialism

Key figures: David Hume (1711-1776), Jeremy Bentham (1748-1832), John Stuart Mill (1806-1873, Peter Singer(1946-present)

The theory of consequentialism holds that an action or course of action is morally right based solely on the outcome or consequences of the action. Consequentialism could be simplified to the maxim "*the end justifies the means*". Thus, a consequentialist approach suggests that anything should be permitted if the overall outcome is more beneficial[2,7]. A modern example of consequentialism may be encountered in the controversial imprisonment and arguable torture of suspected terrorists in Guantanamo Bay. The detainees in Guantanamo have not been put on any formal trial or proven guilty of any wrong doing and have been detained against their will. A consequentialist argument would state that such action is morally justified because of the overall damage terrorism causes in the world and while keeping a few men against their will may not be good in and of itself, the benefits to society vastly outweigh the means. However, many will argue against this idea considering this to be both a major breach of human rights and morally wrong.

The most common and probably most well-known form of consequentialism is utilitarianism. Utilitarianism determines whether an action is morally right or wrong based on weighing up each potential action and assessing which will result in the most happiness for the greatest number. It may be summed up in Jeremy Bentham's (18th Century English philosopher regarded as the founder of modern utilitarianism) famous maxim that a moral action should result in "*the greatest happiness for the greatest number".* This could be regarded as a simple calculation and once it has been worked out it will lead to the moral action to take. According to Bentham's term "*hedonistic calculus*", happiness may be quantified and calculated from three standards by which happiness can be measured; intensity, duration and extent (the number of people affected)[2,8].

There are several limitations with the consequentialist approach. Firstly, it is impossible to know with absolute certainty what the outcome of any course of action will be. Consequentialists would counter this argument with the belief that we can make an educated guess of an outcome based on logic and prior knowledge of results of similar actions. Secondly, consequentialism does not take into consideration the intentions (bad or good) of the person carrying out the action. The 19th Century English utilitarian philosopher and liberalist thinker John Stuart Mill argued that committing an action with a bad consequence in the belief that the action would create more pleasure than pain means that, although the action itself was wrong, the person is not bad or immoral. Consequentialists also argue that someone who solely tries to act in a way that results in the best possible outcome has good intentions even if what they do in the end of the day produced a bad outcome.

In the context of healthcare for consequentialism to be a practical guide, *expected consequences* rather than actual consequences would have to be the basis on which decisions are made. That the end justifies the means is an unsatisfactory basis for moral decision making (See introduction). For example, if it were thought to be in the best interests of a suffering disabled newborn that he/she die, would it then be morally acceptable to actively terminate their life? Clearly the common good is a desirable outcome for society, but should it be achieved by the sacrifice of an innocent individual, i.e., by paying little regard to the individual's freedom and rights or in the case of infants and young children those of its parents?

It is difficult to define a good outcome, and this may vary with people's differing views. Who decides or can decide what comprises the maximum benefit?

Deontology

Key figures: Immanuel Kant (1724-1804),
Thomas Nagel (1937 to present)

It is easy to think of deontology as the opposite of consequentialism; deontology does not consider the outcome of an action to be the reason why an action can be deemed moral or immoral. In deontology, what makes a choice right is how it conforms to a moral norm[2,9], these norms are universal and do not change depending on the situation.

18th Century German philosopher Immanuel Kant is regarded as the definer of deontology[10]. He believed that there is only one way to work out if an action is moral and that is if someone has acted in good will. For Kant, someone acting in good will is motivated solely by doing their duty i.e. doing the right thing (whether it is deemed good or not). Kant outlines factors by which people can work out whether they have an absolute duty to perform a certain action; he called these the *categorical imperatives*. Categorical imperatives are a set of absolute duties that do not (and should not) take into account the consequences of actions.

To determine if an action is a categorical imperative (an absolute duty) you must apply the test of universality and the principle of humanity. The test of universality asks two questions. Firstly, is it possible for society to function if everybody engaged in this action (universal application)? If it cannot be universally applied, then it should never be engaged in at all. For example, if every person started lying and never telling the truth society would cease to function, people would no longer trust one another and could no longer live in communities.

Secondly, if it may be possible to universalise this action then, would it be practically inconceivable? (i.e. would it create an unbearable existence for everybody?) The principle of humanity asserts that a person acts in such a way that they always treat humanity (whether oneself or other) as the means of an action but also as an end. An example of this would be if everyone stole from each other, this would break down the ability for a human to own anything and therefore no one could steal anything anymore.

Another important aspect of deontology is the free will of the moral agents making the decisions. Kant believed we can only be held responsible for our own actions; that we cannot be held accountable for the actions of others. Thus, even if we could commit a morally wrong action that would stop another human being committing a far worse action we should not commit that action because that would be treating the other person as a creature not capable of making their own decisions.

This theory can be applied to many religious ethical frameworks. Often religions have their own set of moral laws that their followers adhere to in order to be morally righteous people. For example, the Ten Commandments in the Old Testament set out easy to follow laws that Jews and Christians can follow. The Ten Commandments tell people that certain things are prohibited in all circumstances like the examples above of stealing and lying.

One major criticism of deontology is that it is too rigid and could lead to immoral actions being taken. For example, Kant believed that we have an absolute duty to be honest at all times. As an example, this would imply that those in Nazi occupied countries during World War II who lied about the presence of Jews that they were hiding in their houses were committing immoral actions. If they had told the Nazi secret police the truth, those whom they were hiding would have been sent to concentration camps where they would have been subjected to unimaginable cruelty and probable death. Someone holding an absolute deontological stance would thus be required to tell the truth and condemn those under their care. A utilitarian would say that it would have been immoral to tell the truth in this situation as it would not have benefitted anyone and would have added to the total pain and suffering of the world.

Virtue Ethics

Key figures: Aristotle (384 BC- 322BC), St Thomas Aquinas (1225-1274), Philippa Foot (1920-2010)

While deontology is largely action based where decisions are made on the morality of an action, the virtue ethics approach suggests that morality (and thus moral decisions) are derived from a person's character or intrinsic values. The focus is thus upon *being* rather than *doing*. A right act is thus one that would be carried out by a virtuous person in the same circumstance[11,12]. It advocates the roles of alleviation of suffering and compassion. The key concepts of virtue ethics derive from Greek philosophy (particularly Aristotle). Aristotle asserted that the goal of human life is *Eudaimonia* ("well-being", "happiness" or the "good life") achieved by the regular practising of moral virtues such as truthfulness, temperance, courage etc and intellectual virtues such as intelligence and wisdom (especially in the resolution of moral dilemmas). It has the advantage of centring ethics around the person, including the whole of a person's life. In order to become virtuous, one must find a median between the extremes of excess and deficiency, for example the vices cowardice and rashness are the two extremes of courage.

One strand of virtue ethics is the modern approach termed ethics of care. Ethics of care, developed by feminist writers in the mid-20th Century, holds relationships, community and benevolence as central tenets. It is these along with strong emphasis of care towards family and those close that inform moral decision-making. Advocates of ethics of care do not believe that rules and principles can be used to ascertain the moral value of an action or an entire. Human relationships are deeply complex and have so many sides that fixed moral principles or universal rules cannot possibly lead to a moral action every time.

The idea of virtue ethics does however have its limitations. While it may provide general ideas on how to be a "good" person and how to grow as an ethical person, it does not provide clear guidance on how to approach or act upon an abstracted ethical dilemma[11,12]. Another major point of weakness is the difficulty in defining virtues and the differing of opinions of what constitutes a virtue across cultures and ethnicities. This being the case it is argued that virtues are relative, and that virtue ethics cannot be used as a universal approach. A further criticism is that it is concerned more about the individual than any actions and may be thus regarded as self-centred rather than looking outward at those of whom an ethical action may affect. Proponents however contend that a virtue by nature must be universal in nature i.e. it is regarded as such by all cultures and societies and is therefore universal and valuable.

A Hybrid Approach

All three theories discussed have both validity and appeal, but it is only those that acknowledge standards of morality (in the deontological group) that can provide universal absolutes. Is there a possible compromise between the theories?

Many people find deontology too restrictive, especially when Kant and others say “do not lie” even when there are lives at stake. Many find consequentialism too loose and dangerous when it could allow for innocent people to suffer or be tortured. Others find virtue ethics too subjective and relative. Some philosophers have attempted through various means to bridge the gaps between theories. *In practice, it is likely that most healthcare professionals base their ethical decisions on elements of each set of theories.* They take a “hybrid” or “blended” approach and balance what they deem to be right with the expected consequences of their actions.

One contentious issue which highlights the difficulties of taking a singular approach to an ethical dilemma is whether there is a difference in the actions of allowing a patient to die and in the active killing of a patient. There is a clear distinction between the two in British medical law; you cannot actively take measures that are primarily intended to take the life of a patient. However, you may withdraw care and allow a patient to die naturally. What are the real differences between these two courses of action, if there are any? American moral philosopher Judith Jarvis Thompson argues that the difference is not that clear. She uses the example of a man who hates his wife giving two scenarios. In one scenario, the man actively kills his wife by putting cleaning fluid into her coffee. In the second scenario, she puts the cleaning fluid into her own coffee by accident and the man, even though he possesses an antidote, lets her die[13]. From a legal standpoint one of these scenarios is criminal and the other not (bear in mind this is not universal, in countries such as Australia you are held legally responsible if you let someone die when it is in your power to save them and saving them is not detrimental to your life.) From a moral or ethical standpoint is there a clear difference?

A classic illustration of the problem of two opposing ethical theories, deontology and utilitarianism when it comes to actions and omissions is the Trolley Problem. The trolley problem was posed by Oxford philosopher Philippa Foot (1967)[14]. Foot asks that we put ourselves in the position of a bystander who sees a runaway tram trolley hurtling down the line with no driver and with no signs of stopping. The trolley is going to hit a group of five workmen working on the tracks with heavy machinery, they cannot hear the trolley due to the noise they are making, and they are too far away for you to warn them of the impending disaster. However, beside you is a lever that switches the track so the trolley will go down a different track not hitting the five workmen but killing a single workman who is working on the other track. By doing nothing in the scenario you will let the five men die. Surely this is immoral, you should do whatever is possible to save these men? However, if you switch the track, then you are actively killing one man who would not be in any danger if it were not for you switching the tracks. Doing nothing results in five deaths by omission, whereas pulling the lever saves five men but actively kills an innocent man. For a utilitarian (consequentialist) the answer would be simple, you switch the track. The outcome of five people dying will surely be worse for the world's benefit than one person dying. A deontologist would argue however that the trolley speeding in that direction was caused by someone else, who could have foreseen the damage that it would have caused, and you have nothing to do with their action. By pulling the lever you yourself are actively getting involved and killing an innocent human being who would have survived if you hadn't been there. Someone with a virtue ethics approach would ask, "What would a virtuous person do?"

As with these general ethical problems, ethical decisions encountered in healthcare may be equally as challenging. The most prudent course of action is not easily attained.

CHAPTER 2

MEDICAL ETHICS AND CHILDREN

MD SHIELDS, JP FLEMING

Medical Ethics may be defined as the analytic activity in which the concepts, assumptions, beliefs, attitudes, emotions, reasons and arguments underlying medico-moral decision making are examined critically and applied in governing the practice of medicine[1,2]. Up until relatively recently, Western healthcare was delivered with a paternalistic nature. In other words, decisions relating to medical treatment were usually made unilaterally by the medical doctor with responsibility for a patient's care. It was generally assumed that the doctor (and on occasions family members) had the absolute knowledge of the best course of actions to take for their patients (and these were always assumed to be correct no matter the consequences!). Treatment decisions did not necessarily consider the wishes of the patient and were rarely discussed or questioned. The same was generally true when ethical issues arose. It was often the medical doctor who decided what was in the best interest for their patient.

Modern Western medical ethical analysis and practice has evolved significantly and now differs considerably in its approach. Ethical problems are commonly framed around the four-principle approach postulated by Tom Beauchamp and James Childress in their 1970's seminal work entitled *Principles of Biomedical Ethics* (now in its seventh edition)[3]. The approach is not a rigid process or detailed method to give definitive answers but proposes four important principles each of which should be considered and measured against one another in any given problem to aid the ethical decision-making process. The four-principle approach is not without its weaknesses[4] and other approaches to ethical problems have been put forward. However, it remains the most widely recognised and used approach across the sphere of bioethics. The four principles are autonomy, beneficence, non-maleficence, and justice[5].

Autonomy

"A thinking intelligent being that has reason and reflection
and can consider itself as itself, the same thinking thing,
in different times and places"
—John Locke

Translated from ancient Greek, autonomy means self-governing or law. Autonomy is concerned with whether a person can make decisions regarding their own life. The quote above from the seventeenth-century British philosopher, John Locke, attempts to describe the nature of an autonomous being. Autonomy is a very important principle in both modern healthcare and medical ethics. In modern healthcare, autonomy has gained a particularly strong emphasis and the individual's right to choose their preference in any decision pertaining to their own life or body can often override other ethical principles. To discuss the right or wrong (or good or bad) of this is a philosophical argument in and of itself and is beyond the scope of this book[6].

Autonomy is a very important and serious issue in the area of ethics in child health. It poses the question, "How might it be decided if a child is capable of making a personal and fully informed decision about their own medical care free from coercion?" It also asks, "Should there be an absolute age at which a child becomes fully autonomous and thus is able to make their own decisions?"

A recent significant public example concerning the issue of childhood autonomy was the case of Hannah Jones[7]. Hannah Jones was a thirteen-year-old girl who had required hospital care intermittently since she was four years old for leukaemia. She required a heart transplant in order to survive; however, she did not wish to proceed with the transplant as she did not believe the process was worth it. Having spent much of her childhood in hospital, her desire was to die with dignity and suffer no longer. Although Hannah was only thirteen years old, the court ruled that she was perfectly capable of making her own decisions; in other words, Hannah was deemed fully autonomous. The healthcare trust under whom she was being treated had applied for a court order to force the transplant. Currently, in the UK a child is only automatically deemed autonomous if sixteen years of age or older. However, as the above example illustrated, many children who are younger than sixteen years old may be regarded as fully autonomous (see next chapter for more detailed explanation). How then may a child under the age of sixteen be deemed autonomous?

No legal case in the UK has brought the issue of autonomy in children under sixteen years to prominence more than that of *Mrs. Victoria Gillick* *vs West Norfolk and Wisbech Area Health Authority* in 1984. So much so that the term *Gillick competence* is often used in defining whether a child under the age of sixteen years should be regarded as autonomous and has the ability to make his or her own decisions with regard to their medical treatment. The case concerned a mother (Mrs. Victoria Gillick) who brought her local healthcare trust to court because she believed that doctors by giving under sixteen-year-olds contraception (without the knowledge of their parents) were encouraging sexual activity amongst minors[8]. However, the courts ruled that doctors could prescribe contraception to anyone under sixteen years of age at their own discretion without having to tell the family of the child (see below for the case "Consent and Confidentiality" and the specific guidelines by Lord Fraser on when a health professional may give contraception to a person under the age of sixteen years). Consent to the child's own medical treatment without parental permission or knowledge could only be given if the child was deemed able to meet three criteria. Firstly, the child needed to demonstrate the ability to understand the future implications of their actions on themselves and those around them. Secondly, they were required to have the ability to make informed decisions based on reason and rationality. And thirdly, that they had freedom from coercion when making decisions (which is often extremely difficult to determine).

Beneficence and Non-maleficence

The principles of beneficence and non-maleficence in medical ethics are primarily concerned with when it is right or wrong to continue treatment. Often decision making in this area involves a healthy balance of these two principles. While similar, the terms are not exactly the same.

Beneficence is the idea that one should act always towards the benefit of others and is a central tenet of medical ethics. Doctors practicing beneficence would appreciate that when treating patients there is always the risk of doing some form of harm (medication side-effects for example) and thus benefits must be weighed against the risks of the treatment. Similarities can be drawn between beneficence and the theory of utilitarianism - both are concerned primarily with benefitting others.

The term *non-maleficence* is derived from the Latin phrase *'primum non nocere'* meaning 'first, do no harm'. In the world of medical ethics this means that a medical professional should avoid doing anything that could potentially be harmful to a patient.

Beneficence and non-maleficence are usually considered together as at their core they are inextricably linked. There are however differences when considered in reality and these may emerge in their application to practice in the medical world. For example, the absolute avoidance of harm to the health of a patient (non-maleficence) would mean that many treatments could never be considered due to their side effects. In attempting to avoid harm at all costs many patients would die due to lack of medical intervention. In most cases however, the benefits (beneficence) of treatment outweigh the side effects and in treating patients the aim therefore is to provide a net benefit. The duty of non-maleficence thus requires that the potential good is not outweighed by the potential harm. It does not only apply to treatment. For example, it may not be acceptable to subject a child to a potentially harmful and painful investigation, if the resulting diagnosis will not result in any useful benefit. In contrast, always focusing on the potential benefit (beneficence) of a treatment or investigation without regard to unacceptable or potentially dangerous side effects could be regarded as equally detrimental to a patient’s wellbeing.

Justice

Justice is mainly concerned with the distribution of resources (material or otherwise) that are considered valuable or necessary for people in a society. For any society to function well and fairly, there must be a high level of importance placed on justice and the fair treatment of all citizens. The stability of political systems in modern times often reflect the extent of how just the systems are perceived to be by the subjects who are governed by them. For example, in countries where there is perceived low levels of justice there are more likely to be protests, riots and strikes. The image of justice pertained to by courts of law is a woman with scales in one hand representing fairness and a consideration of all sides, and in the other hand a sword representing the punishment for acting unjustly. She is blindfolded, meaning justice has no prejudice against any human based on their colour, creed, nationality or ability.

Justice is also a key concept in medical ethics as it asks questions such as, “Should the state pay for medical treatment?” or “Who should be treated first?” Many believe that medical treatment is a basic human right and that a country should make health care completely free while others believe that it is a business like any other and the state should not be responsible for a citizen’s medical treatment. This is all underpinned within the broader question “What does the state owe us?”

Healthcare professionals also often face limited resources in addition to issues of distributive justice, i.e. to whom should these scarce resources be allocated? For example, if there is one bed left in an intensive care unit and two children are in desperate need of a bed should the approach be simply a first come first served policy? Imagine if one of these children suffered from severe underlying medical problems and learning difficulties. Should this influence the decision made by the staff when allocating the bed space or should justice stay completely blind? Another example might be whether the state should approve a very expensive novel medical treatment for a small number of individuals or use the same amount of money or resource on giving benefit to a large number of children who require a minor inexpensive treatment[9] (see cases 14 and 15 later in the book for further exploration of this).

The Four Principles of Bioethics

Autonomy
The right and ability to govern oneself and make decisions independently and free from coercion

Beneficence
The act of doing good

Non-maleficence
An obligation not to inflict harm intentionally

Justice
The fair distribution of resource, risk, cost and to act fairly and evenly

Box 1: Adapted from Beauchamp and Childress 1978

Other Moral Considerations

The four principles discussed above provide the main framework of approach to ethical issues in healthcare. In any given ethical dilemma, it is likely that one or more of the four principles will have an impact on another. As patients are rightly granted more autonomy over the decisions of their own healthcare, such autonomy may influence the degree to which beneficence and non-maleficence is perceived by the patient. Furthermore, beneficence and non-maleficence when applied to a particular treatment can only be considered if that treatment is available and deemed to be fair (justice).

There are of course other moral considerations that affect and influence ethical decision making in healthcare. While these may not necessarily be considered in detail within each ethical case, they are fundamental to the understanding and wider discussion of ethics in healthcare. Let's consider these in turn.

Sanctity and the Preservation of Life

This principle enshrines the right not to be killed and implies that there is a duty to respect and conserve life. It requires that every individual is valued for his or her own sake. It could further be construed as implying a duty to provide the means and to foster the circumstances in which life is respected and conserved. Ethical dilemmas may arise that pitch this sanctity against all four of the medical ethical principles when dealing with end of life care. In other words, should the aim of healthcare be that life is preserved at all costs?

Quality of Life

Recently medical interventions have been increasingly evaluated by how they affect a patient's quality of life. For example, if an antihypertensive drug worked to lower the blood pressure, then should it be used regularly even if it made the patient feel depressed (see above beneficence and non-maleficence)? One important way of examining the "what's it worth?" question for a given health state (such as having poorly controlled diabetes or asthma) is to ask patients in that state (with that disease) how they feel both with and without the treatment. Recently there has been an increase in the published research of patient-specific measures of quality of life to allow individual patients to place different values on particular aspects of health and wellbeing. However, it is very difficult to obtain such information on young children as we must rely mostly on parental reports which introduces a degree of subjectivity. This subsequently poses the question, "can someone accurately determine the quality of life of another?" Most often the "what's it worth?" question is answered by healthy people who are deciding treatment options for their sick relatives, and their decisions are often based on the changes in health they would least like to happen to themselves.

Best Interests of the Child

The best interest standard is a fundamental principle in the making of decisions on behalf of those who lack capacity (surrogate decision making). The best interest of the child principle is based on Article 3 of the UN Convention on the Rights of the Child[10] which requires member states to observe the best interests of the child as a primary consideration in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies. It is thus the direction of focus for all decisions made by others on behalf of a child. In the case of a medical intervention or decision, the aim is to maximise benefits and minimize the risk of harm or detriment to the child. It is however a principle without a rigid definition, and as an overarching focus is not without its critics[11,12]. Arguments against the principle include that it is subjective (the values of individuals differ), ideas of best interest are often vague and indeterminate, and may lead to behaviour that is inflexible. When many are involved in the decision-making process, the question remains, "Who should decide the best interests of the child?" (see following chapter).

A child's best interests include both the duration and quality of life (see above). The duration is a matter of time and can sometimes, though not always, be estimated with some degree of accuracy. The quality of life following treatment can be more difficult to estimate or measure. The concept of "the best interests of the child" suggests that children deserve respect as individuals separate from their parents, with their own interests and rights. A related discussion concerns whether this right extends to the unborn foetus[13] (see case 5).

The Preference of the Child

As children grow and develop, they acquire the capacity to make informed decisions and when this happens their choices need to be acknowledged, respected, and kept to the forefront of all decisions. Although a child's objections are not necessarily decisive (e.g. a young child who objects to receiving injections should still receive immunizations), the child's lack of assent should take on more weight as the child becomes more capable of making informed decisions.

The Interests of Parents and Family Members

The time and expense of caring for a sick child may compromise the rearing of other children, disrupt a parent’s career prospects or jeopardize the family home or business. Should parents be expected to devote their entire lives to a sick child? Some parents may insist on an intervention that healthcare professionals regard as futile either because it is without likely benefit or because it carries significant risk for little benefit. There is no obligation on healthcare professionals to provide such care. On the other hand, unilateral decisions taken by such professionals to withhold interventions without regard to parents’ treatment goals could be arbitrary and inconsistent.

Interests to Society in Relation to Public Health

Society has, and surely must have, an interest in maintaining public health. Should it then, for example, insist through legislation that all children be vaccinated against communicable diseases?[14,15] This is the case in much of the U.S.A. and France where children are required to produce certification of immunisation before being permitted to commence state school (see case 8).

Omission and Commission

There is a difference between stopping suffering by actively ending the life of a patient and withholding a treatment to allow the patient to die naturally.

Duty

In the field of healthcare duties may be positive or negative. Negative duties are regarded as universally binding (i.e., we should never tell a lie to a patient), but the positive duty to tell the truth is not so strong, since we have the option of remaining silent. However, while the positive duty to provide the best possible care is absolute, its outworking may be limited by the lack of the necessary resources.

Integrity, Honesty and Truth-telling

Healthcare staff have a moral duty to never give misleading or false information to patients under their care. Trust from patients relies on honesty and integrity on the part of the treating healthcare professional. While it is generally accepted across cultures that a patient should not be told a lie, there has been long debate on whether information that may cause distress should be withheld from patients. For example, it is not long ago that it was common practice for doctors not to tell their patients of a diagnosis of cancer. While this has changed significantly in the past thirty years in Western countries, in many countries it remains common practice to withhold diagnoses from patients. A recent case study[16] highlights the significant differences regarding disclosure of information across various cultures. In the UK the GMC[17] recommends that non-disclosure of information to a patient should only occur when there is reason to believe that the information could result in serious harm. Serious harm, in this case, means more than becoming upset or the fact that the patient may decide to refuse treatment.

CHAPTER 3

WHO SHOULD MAKE DECISIONS FOR CHILDREN?

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As discussed in the introduction of this book paternalism was the modus operandi of the healthcare profession until relatively recently. Paternalism is defined as interfering with the liberty of another person for one's own benefit. This is usually considered a parental duty for young children. Child health doctors have historically believed that they have the right and duty to be paternalistic – usually based on the claim that they must promote the child's health and not his/her autonomy. There is a general acceptance of the correctness of paternalism in situations when there is a high probability of serious harm, when interference with the patient's liberty is likely to prevent the harm, and when there is a reasonable likelihood that the patient when in a more mature state would want to be treated in this manner or come to appreciate it later. An example of this would be completing surgery for acute appendicitis over a young child's objections. If a child objects when prevention of harm is uncertain or minimal and the proposed action to be taken is of uncertain effectiveness, the situation is less clear.

In the UK some guidance on determining the bests interests of a child or young person are given through the large body of legislation for children and young people including the Children Act 2004, The Children and Young People (Scotland) Act 2014, and The Children Order 1995 (Northern Ireland). In many situations, the course of action that is in the best interest of a young child is obvious. However, in more complex situations the course of action may not be as clear. As a result it may also be less clear who should make the decision on behalf of the child.

For children and young people who are deemed competent the situation becomes more complicated. In the UK young people aged 16 or 17 years old while not yet regarded as adults are able to consent to their own treatment independently. Unless there is sufficient evidence to suggest otherwise, young people aged 16 or 17 years of age are presumed to have the capacity to make decisions regarding their own treatment. The term capacity means the ability to remember, use and understand information in order to make an informed decision and be able to communicate that decision[1]. Capacity is regarded as a functional term and is often used interchangeably with the similar more definite term competence. For the sake of clarity, the term competence will be used for the remainder of this text.

For children and young people under the age of 16 years they are only permitted to make decisions on their own treatment if they are deemed to be Gillick competent.

Gillick Competence

As children mature, they develop the capacity to make informed decisions about their health care. In the UK doctors must assess whether a young person (usually an adolescent under 16 years of age) is competent to give informed consent by asking about their understanding of the proposed intervention, the alternatives, the risks/benefits of each and the likely consequences (see previous chapter Medical Ethics for some more detail on Gillick Competence). The young person must be deemed capable of remembering the information given, be capable of using it to make a measured decision and communicate this decision free from coercion[2]. If the young person is deemed Gillick competent then they are permitted to *consent* of treatment without the knowledge of their parents. However, a young person who has Gillick competence does not automatically have the right to *refuse* treatment in all cases. If there is an informed refusal of treatment by a competent young person that involves a potentially life-saving treatment or prevention of a permanent injury, then legal advice is usually sought by the healthcare team. The court may overrule the young person's refusal if it is considered to be in his or her best interests.

For children and young people who are not deemed Gillick competent, decisions on treatment must be taken by others with parental responsibility over them. Those who may be regarded to have parental responsibility include a child's mother or father (in the UK only if the father is married to the child's mother or listed on the child's birth certificate), a legally appointed guardian or designated local authority or individual. A mother usually acquires automatic parental responsibility for her child from birth[3].