

**Ethical Issues in Practice for  
Nurses, Midwives and  
Family Medicine**

**Editor:  
M.N. Cauchi**

The Bioethics Consultative Committee  
Malta 2003

# **Ethical Issues in Practice**

**for Nurses,  
Midwives and  
Family Medicine**

**Editor: M.N. Cauchi**

**Conference Organisers:  
Dr Sandra Buttigieg  
Dr Pierre Mallia**

**The Bioethics Consultative Committee,  
Ministry of Health,  
Malta 2003**

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**Section A:  
Ethical Issues in Practice for  
Nurses and Midwives**



# Ethical Issues in Practice for Nurses and Midwives

Dr Sandra Buttigieg

Nurses are daily faced with questions of ethics. Most of these questions are minor everyday issues that individual nurses can resolve on their own. From time to time, however, issues with major implications for patient care will arise that require significant ethical decisions.

The analysis of the facets of work in the everyday practice of nurses and midwives is important to ethics because of the ethical domains of character and the way of life.

Nursing work (Liaschenko 2002) can be analysed in a number of ways: as a physical transformation, as a social transaction, as information exchange work, and as identity.

- As a *physical transformation* of material reality – such as that designed to relieve, contain, or prevent symptoms – for example, nurses involved in wound care, help to change the body from one state to another.
- As a *social transaction* – several examples come to mind

Patients are distressed by a diagnosis and anxious about coping with treatment. Patients are worried about who will care for their children or spouses. Responding to this kind of distress is extra work, requires time and is not usually listed in any form of job description. It is a social transaction, not immediately visible but which contributes immensely to the quality of health care. In the absence of this social element, healthcare is inhumane, without compassion, even brutal.

- Another form of social transaction in nursing work is the amount of *information* to be communicated between many different people



and departments – such as when transferring patients from one department to another, explaining to a physician what a patient has said about symptoms and treatment, clarifying orders, and talking with families. *In the absence of this information exchange work, healthcare becomes chaotic, dangerous even impossible.*

- As *identity* - The development of organised nursing and the promotion of nursing education to an academic platform has raised the identity of the nurse to a more interesting, fulfilling and professional one.

According to the UK Nursing and Midwifery Council's Code of Professional Conduct, published in April 2002, in caring for patients and clients, a registered nurse or midwife must:

1. Respect the patient or client as an individual,
2. Obtain consent before any treatment or care is given,
3. Protect confidential information,
4. Co-operate with others in the team,
5. Maintain professional knowledge and competence,
6. Be trustworthy, and
7. Act to identify and minimise risk to patients and clients.

No one disputes that the work of nursing is indispensable for the well-being of patients and to the day-to-day operations of health care delivery. It is precisely this indispensability that raises ethical questions. One ethical question that comes to mind is the right to strike.

Looking back at my eleven years' experience as a council member of the Medical Association of Malta, I clearly remember the ethical dilemmas about the morality of striking – such that discussions used to focus on the ethical issues related to the special duty of doctors not to abandon patients. I am sure that the same dilemmas were experienced by nurses.

Other issues that come to mind are the role of the nurse as an educator, and as a researcher. Nurse educators are responsible for teaching students to observe the Code of Ethics and Standards of Nursing Practice (Morgan 2001). By attending carefully to their own behaviour, wise nursing faculty serve as helpful role models for students. This is readily apparent in patient care settings when instructors guide students in planning patient care or assist students with technical skills.

As more nurses are indulging in a research career, maintaining ethical principles can ensure that nurses can protect patients who may be subjects of research, while retaining their dignity, respect and confidentiality.

Today's seminar deals with the major ethical issues faced by nurses and midwives in their everyday practice. I am sure that this seminar will provide the right playing field to discuss, debate, analyse and hopefully reach a consensus on how to approach these issues.

I would like to thank the Bioethics Consultative Committee and the staff at IHC for working hard in organizing this seminar. I would also like to thank you – participants for positively answering our call. It is indeed a satisfaction to experience your desire to actively participate in a seminar on ethics – which I believe should have a firm position in our daily professional lives. I wish you all a fruitful seminar.

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# **Ethical Issues In Practice For Nurses And Midwives: A Historical Perspective**

**Professor John Rizzo Naudi**

I wish to welcome you all to this Seminar on Ethical Issues in Practice for Nurses and Midwives and thank the sponsors and organisers. This is the first occasion when nurses and midwives are meeting together as a profession to discuss and address this highly important area of health care practice i.e. ethical issues. One could not even imagine that such a meeting attended by so many nurses and midwives could have happened as recently as one or two decades ago. This in a way reflects the great advances and developments that have been made in the delivery of health care world-wide, and particularly in nursing and midwifery practice in the Maltese Islands during the last few decades.

Nurses and midwives today are assuming much greater responsibilities in all spheres of health care, and a clearer image of the role of the nurse and midwife and their identity and status in the health care team has been slowly evolving during the last couple of decades. Today's nurses are much better trained and prepared to assume their role and to play their part in the team.

Recognition of the status of the nursing profession was formally acknowledged when the Reform and Reorganisation of the Department of Health was being planned ten years ago, (in which exercise, incidentally, I was involved), and a separate Directorate of Nursing at par with the other Directorates was constituted. In my opinion, one of the first tasks of this directorate will be to delineate the specific roles of the various classes of the nursing services and their ethical inter-relations within the nursing service and with other members of the health care team. The question of warrants and/or licences for nurses will need also to be tackled sooner rather than later.

When we come, however, to consider the actual and specific roles and responsibilities and the matters of warrants and licences for nurses in particular, we have to admit that there are problems. With regard to midwives these have had warrants, and their practice and responsibilities were regulated for hundreds of years, but this has not yet happened in the case of nurses whose image as a profession is still somewhat blurred and the identikit of the professional nurse is still being put in place.

Whilst some other professions allied to Medicine, such as physiotherapy and speech therapy, already have a clear image of their profession, this has not yet happened in the case of nursing.

An important reason for this discrepancy and difference in the recognition and estimation of these professions is the fact that professions such as physiotherapy and speech therapy are relatively very recent in Malta. Moreover, these professions, with an already established image, were called upon to treat a particular problem of rehabilitation or deficiency in the patient more or less independently of the medical profession. Nurses, on the other hand have always looked after patients working, in shifts, twenty four hours a day as an integral part of the medical team and in most cases dominated by the medical profession. Another reason, that has to be considered, is that the nursing profession, in addition, is still burdened with problems and images of the past which have been very difficult to shake off.

A historical perspective of nursing will help to enlighten us on the past and relatively recent difficulties and travails faced by this profession over the years. It will certainly hearten us when we look at the considerable gains achieved over the recent past, and in particular, during the last decade.

Although the art of nursing in the form of tending and caring for the sick and injured, nurturing the young and protecting the helpless is as old as history, Nursing, as a profession, is of comparatively recent origin.

The evolution of nursing in different countries has been extremely uneven. In some countries, such as the United Kingdom, the nursing profession started gaining identity, respect and status after the revolution brought about by Florence Nightingale in the middle of the nineteenth century, and was further enhanced and strengthened during the first half of the twentieth century. However, in the case of lay nurses, Malta was lagging well behind, for a number of reasons.

The widespread illiteracy that was present in Malta until well after the second world war of 1939 - 45 was a major negative influence on the quality of lay nurse recruits. For example, figures for illiteracy rates at censuses taken in 1911, 1921, 1931 and 1948 were 74%, 67%, 53% and 33% respectively. For this reason, recruits for hospital attendants in the 1930's, who later became State Enrolled Nurses in 1968 by an amendment in the Medical and Kindred Professions Act, were only required to have an ability to read Maltese or any other language.

A great pioneer in the development of the Nursing profession as we know it today was undoubtedly Professor A.V. Bernard, who had the vision and the abilities to start the modernisation of the Nursing Profession, when he first introduced the Register of Nurses in 1936. Professor Bernard was the Chief Government Medical Officer who was responsible in 1937 for the constitution of the Medical and Health Department as we knew it until very recently. He was responsible for the First School of Nurses on the Nightingale principle in 1938 (later interrupted by the 2nd World War), and for the Emergency Medical Service during the war years of 1940 - 45. He also selected Sister Aldegonda, the first Maltese Tutor and personally made arrangements for her to be admitted to the School of Nurse Tutors at Kensington College, London.

I am now going to quote one of his speeches to the Council of Government in October 1940 when he outlined his plans for the Nursing profession which gives us a good picture of the state of nursing

The nursing service in the meantime continued to function as best it could. The more or less sudden disappearance of the Sisters of Charity from the wards of the hospitals in the 1970's did not help matters. The opening of urgently needed new services such as the Coronary Care Unit, The Intensive Care Unit, the Renal Unit and others put a further strain on the service.

In 1988 we took the bold step of founding the Institute of Health Care within the University of Malta against a background of a severe shortage of nurses and rapid advances in technology and medicine.

Fortunately, after some hard work by all concerned, the image of the professional nurse has become much clearer and brighter and more appealing to the general public, resulting in ever-increasing numbers of recruits for the diploma and degree courses. Courses for the Certificate in Nursing Practice have been discontinued for the last few years, and with the advancement of the SEN to SRN Conversion courses, programmes that are being run by the Department of Health, we will have eliminated one of the confusing factors that have surrounded the image of the professional nurse. Most important, we now have a Directorate of Nursing.

A lot of work, however, still needs to be done. In a way, we are in the same position that our predecessors were in, sixty years ago, when we had to work on a new scheme for the nursing profession, define the structures of the nursing service, and provide clear roles for registered and enrolled nurses, whilst not forgetting the all important community and primary services as well as present and future manpower needs.

Hopefully, we can now look forward to a future when we can really begin to have a clear image of the professionally trained nurse who knows his or her ethical and other responsibilities towards patients and the other partners in the health team.

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# The Universality of Ethics for Health Care Professionals

Dr Ray Busuttil

On the 29<sup>th</sup> May 1997, the Nursing and Midwifery Professions had their Code of Ethics published by the Nursing and Midwifery Board. This was done in accordance with the provisions made under the Department of Health (Constitution) Ordinance (Cap. 94) which provides that: -

*“The Board will prescribe and maintain professional and ethical standards for Nurses and Midwives”.*

This publication was a much-awaited step in the right direction and was very much required for the recognition of the Nursing and Midwifery professions and for them to be able to regulate themselves. The Code itself deals with universal principles of ethical and moral behaviour. These principles cannot be perceived as being principles of law typical of the “Thou shall not” type of commandments, but as principles that transcend law itself. Ethical principles are above the law because of their universality which renders them applicable to the whole of mankind.

Ethical principles do not state or declare the obvious but only point to what should be done. This is Ethics – the science of disposition. The Greek Philosopher Aristotle adopted the Greek word–‘*Ethos*’ as the key word because it means ‘an abode’ or ‘dwelling place’ signifying the interior attitudes and the disposition of the person and the communication of those attitudes/disposition to others. This prescribed behaviour is not just an outward manifestation of human behaviour, but is more akin to a teleological type of human behaviour, i.e. from the Greek word ‘*telos*’—behaviour with an aim or purpose. Ethical conduct wholly revolves around the fundamental question of “who should I be?” Nurses and Midwives or other health care professionals should all strive to develop a “good character” – a character which is

able to exercise freedom of choice in favour of the good of the patients/clients, the profession, co-workers and society at large. A person in the capacity of a health care professional who possesses a good character, is one who acts at the right and opportune time, in the right way and according to the right reason. According to Aristotle, in order for man to achieve “eudaemonia” (happiness & self-fulfilment) he needs to have this good character or live the ‘virtuous life’. This ‘virtuous life’ is not one with religious, saintly and ascetic connotations. It is a ‘life’ based upon principles associated with the delivery of excellent care, a ‘life’ based upon a rational, scientific and balanced way of choosing, and a ‘life’ full of action driven by a vision (the good of the patient — ‘an optimal state of physical, psychological and social well-being [WHO definition of Health]).

Educating the person’s disposition towards a rational emotionality and emotional rationality develops this ‘virtuous life’. These ethical principles facilitate the free decision process undertaken by these professionals, which process is always based upon rationality. The actual execution of ethical principles in the Code of Ethics presupposes the existence of a number of good character traits that can all be developed from a blank slate (*tabula rasa*). The ability to exercise freedom of choice leads to self-determination and to behavioural consistency. All of this leads to a certain internalised strength, manifest commitment and professional reliability. Coupled with a vision, the health care practitioner shapes his character according to his/her purpose (*telos*) or vision – the good of the patient. Eventually the ‘ethical’ health care professional is to be trusted to act habitually in a good way, even if there is no one to observe and praise him and feels as if he or she is violating his/her beliefs if he or she does not act in this manner.

The cultivation of these principles is not automatic. As a basic prerequisite, cognisance of these published principles is of utmost importance. The Nursing and Midwifery Board has distributed more than 2000 copies of the Code of Ethics to Nurses and Midwives. Quite recently, since the appointment of the new Director of Nursing, this Code has found itself on the Internet (on the Directorate’s webpage or

NMB webpage) and can be downloaded as a *pdf* file for any interested party in the World. But surely this is not enough. It is of vital importance that all nurses and midwives read and practise the principles stated in the Code of Ethics. Adherence to such principles is not always easy and in the course of our practice, dilemmas often threaten the ultimate objective why such ethical principles exist after all.

The age of ethical absolutism is over and ethical relativism and utilitarianism has infiltrated the thinking of many contemporary philosophers. We are passing from the 'Ethics of Certainty' to the 'Ethics of Uncertainty'. Issues that confront health care professionals on a day-to-day basis include the prolongation of life versus escalating medical costs, high technology treatments versus rationing, life expectancy versus quality of life, fighting versus accepting death. Such bioethical issues confound the health care professionals seriously because whilst on one hand I spoke about the absolute character of the patient's/society's good, one simply cannot ignore economic issues. People at the helm of the delivery of health care have to be wise enough to be able to achieve an equitable medical rationing for the widest possible benefit of people. One issue that comes to my mind is this: is it ethical to have only small amounts of funds allocated to health promotion which benefit the population at large while at the same time having a heavy investment for the needs of people who smoked and lived an irresponsible life? I cannot offer any answers because there are no clear answers. Health care professionals, including people who manage health care systems, have to live with these dilemmas trying to achieve equitable and optimal solutions.

What lies ahead? What is the future for delivery of health care in Malta? I believe that the development of the 'virtuous life' of the health care professional is something that can be common for all health care professionals. It should be their vision towards the attainment of the optimum delivery of health care for the good of the patient/client, the welfare of society at large, the public profile of their respective profession and their colleagues. These principles are by their very

nature universal and thus applicable to all. Isn't it time for all health care professionals including doctors, nurses, midwives, pharmacists, occupational therapists, social workers, dentists etc to adopt a single code of ethics underlying these fundamental principles explained previously?

I believe that this is the way forward.

# **Ethical Issues in the Practice for Nurses and Midwives**

**Prof M.N. Cauchi**

The ethical aspects of the health professions have been important at least for the last 2000 years, but it is only in the last couple of decades that there has arisen a special stimulus for the discussion of ethical issues among us, spearheaded by such organisations as the Council of Europe, UNESCO and similar bodies who have seen fit to set up specific committees for the purpose of looking into the various aspects of ethical practice.

One reason why the need for discussion of ethical issues has become so urgent relate to the expanding spectrum of activities in medicine and related disciplines. At no time in the history of health professions has there been such a upsurge of interest in issues relating to decisions to be taken, particularly at the beginning and end of life, issues such as in vitro fertilisation, abortion, cloning, stem cell research, euthanasia, and so on. With every advance in these and related areas there arise a whole range of ethical questions which have to be answered satisfactorily.

In Malta we have been doing our bit to provide a venue for dissemination of information and encourage discussion. The Bioethics Consultative Committee was originally set up just over 10 years ago, and since then we have been trying to bring to the public, as well as more specifically to health professionals, the need to tackle ethical issues.

So what is this Bioethics Consultative Committee? It is set up by the Minister responsible for Health on year by year basis. On this Committee we find persons with relevant qualifications in medicine, nursing, law, education, as well as ethicists, who are all interested in ethical issues. We meet at regular intervals, normally on the last Tuesday

of each month, and there we discuss issues which have been brought before the Committee either by the members themselves, or by Government officials or other individuals. Some of the issues that we have been biting on recently include: the use of the morning after pill, the need for informed consent before taking samples for testing patients for hepatitis or AIDS, the ethical standing of genetic testing, and so on.

One important function of the Committee is to organise meetings such as this one. Over the past five years we have had meetings every year. The proceedings of these meetings are published and are available to interested individuals and in libraries. We believe that in this way we are producing a cumulative body of knowledge which could be, or rather should be of interest to many health professionals. The topics for these conferences over the last three years were:

- *Patients Rights, Reproductive Technology and Transplantation* (2000)
- *Inter-professional Ethics in Health Care* (2001)
- *Bioethical Issues at the Beginning and End of Life* (2002).

We also issue a Newsletter at regular interval, which can be accessed at our website on the Synapse ([www.synapse.net/bioethics](http://www.synapse.net/bioethics)).

It is also of considerable satisfaction to see the Bioethics Committee working closely with other bodies to discuss ethical issues. In this particular case the Institute of Health Care has been mostly responsible for setting up this conference. In about a week's time we are having another conference in association with the College of Family Doctors and Pharmacists to discuss issues relevant to these professions. I think this co-operation is essential, not only in providing the help necessary to the Bioethics Committee to perform its work, but particularly because it emphasises the commitment of these organisations for bioethical issues. We have to convince our colleagues, particularly those who are not here today, that these issues which are being discussed are at the very basis of our profession, that they affect everybody, and that we can ignore ethical principles in our practice only at our own risk.

I wish to thank all those who have been so active in participating and preparing for this conference, and particularly, Dr Sandra Buttigieg, Mrs Grace Jaccarini, Mr Andrew Galea, and his team, as well as Ms Salvina Bonanno and Ms Therese Bugeja, also members of the Bioethics Consultative Committee.





# ETHICAL CHALLENGES OF THE FUTURE FOR THE NURSING PROFESSION

**Rev Prof Emmanuel Agius**

After the publication of *Health for All in the 21<sup>st</sup> Century* by the World Health Organisation in 1999, many articles and books on healthcare ethics began to raise the issue about the future direction of the nursing profession. Though some authors claimed that the role of nursing and midwifery in the health care systems of the twenty-first century would definitely preserve many features of the past, others argued that today's dramatic changes and rapid developments, globalisation, technological advancement and demographic changes would create inevitably future challenges and opportunities.

During the first two years of the new millennium, literature on bioethics continued to intensify the discussion on the changing future agenda of healthcare systems. Many predict that the future will force healthcare professionals to go through regular, radical changes in their job requirements. It is claimed that healthcare professionals have to emerge from their task-oriented past and to take on work that requires them to think, judge and intervene. To stay within established paradigms is to become further enmeshed in problems of a system that is really no system at all. Instead, healthcare professionals must create their own future lest they become irrelevant in a future others have made for them.

In Malta, nursing and midwifery are now well-established healthcare professions, having a place among the respected professions, with a university-based education. Health professionals in nursing and midwifery should not only look with satisfaction at past achievements and present accomplishments, they also must courageously challenge the present system, skills, attitudes and mentalities in order to prepare

themselves more adequately for the future. They must never be afraid to raise such questions: What should be the ambitions of nursing and midwifery in the twenty-first century? Have the professional goals that nursing and midwifery been moving towards become now less appropriate? Do they need to be redefined? What changes and new skills are required in order to remain relevant for the healthcare system of tomorrow?

The phenomena of change and development call for the formulation of new policies. In the attempt to be always contemporary and relevant, to address the extraordinary challenges presented by new developments, there is the risk that one fails to address the ordinary routine and ethical problems that all nurses and midwives must face. Life is characterised by both continuity and change, and while addressing the challenges of present and future change, one must keep in mind that certain features of human life do not change. For example the processes and problems, pleasures and suffering related to birth, nutrition, adulthood, reproduction, parenting, maintenance of physical and mental health, ageing and death apply to all human beings, past, present and future.

While individuals may change, for good or ill, it is questionable whether human nature changes. In fact, the problem of making sense of living, of pain and suffering, facing death and bereavement, and the meaning of happiness will remain, whatever advances are made in medicine and human sciences. The role of nurses and midwives in providing professional care and emotional and spiritual support to people in times of personal crisis around some of the most critical 'life events' is probably something that will never change, although the resources and skills available at different times and in different places will undoubtedly change.

### **1. High-tech health care and holistic care**

Advances in biotechnology are having a spectacular impact on prevention, diagnosis and treatment of illness. Technology will continue

to increase access to information and education and to create new and expanded roles and skills for nurses and midwives.

High-tech health care does not only offer immense opportunities for both patients and healthcare providers, but also risks and challenges. In modern times, impersonal, technical developments abound, and consequently, the human dimension of medicine has come under considerable pressure. New technologies separate healthcare professionals from their patients in subtle ways.

Healthcare is a form of human encounter characterised by help. Whatever the healthcare professional does for the sick person involves, by definition, a certain closeness or relationship. High-tech medicine is threatening this encounter. Technology-minded healthcare professionals are dreaming of a medical care devoid of relationship, and based entirely upon data provided by sophisticated machines and computers. This view influences every aspect of high-tech medical care. In a technical, medical utopia, sophisticated error-free tests linked with medical computer programmes would eliminate the personal relationship between the healthcarer and patient entirely, and it is claimed, improve the delivery of health care.

High-tech healthcare should not be a substitute for the humanising touch of healthcare professionals. Nurses and midwives will require more and more skills in technology assessment and confidence to use advanced technology to enhance quality of care and information exchange. However, there will be a need to balance the high-tech with the human aspects of caring and compassion. The technological environment of our healthcare systems should never lead to the depersonalisation and dehumanisation of the patients.

The focus of healthcare professionals should remain on care rather on control and power. A shift is required from a “paradigm of control” to a “paradigm of relationship”. Nurses and midwives have to detach themselves from a “position of observation and rational explanations” to a focus on relationship. They must interact more intimately with the patient as a human being.

The view of 'medicine as technology' should never substitute the view of 'medicine as an art'. Medicine remains an 'art' when care remains at its centre. The word 'caring' is derived from the Latin term *carus* (dear), designating something that is valued or expensive because it is scarce. By derivation it came to mean loved, desired or esteemed because of the intrinsic value of the object of care. Through Christian influence, caring expresses unconditional love or selfless concern for physical, emotional and spiritual well-being. The healthcare professional should avoid succumbing to the "magic" of technology by acquiring those character traits which ensure a 'caring and healing relationship' rather than a 'technological relationship' with the patient. To care for the patient means to be compassionate, competent, conscientious, committed and confident.

## **2. Globalisation and Interdependence**

Globalisation will continue to have an impact on the economic, political and social aspects of life. The opening up of the world trade and free movement of ideas, capital and people across borders will raise challenges and opportunities for nurses. It will enhance standardisation, international credentials, easy access to information and nursing networking.

Globalisation will also raise concerns about disease transmission through trade, travel and migration, as national boundaries become obsolete and people, services and goods move freely across boundaries. At the same time globalisation will facilitate a move towards a "universal culture" and easy transfer of knowledge and skills.

The local debate on Malta's application to become a member of the European Union is to be seen from the perspective of globalisation and interdependence. It is the conviction of Malta's Government that in today's globalised and interdependent world, our country should not remain isolated and segregated from the rest of the world. Malta's

membership to the European Union will enhance its national identity and at the same time open up unique opportunities that would be missed by remaining out of the EU.

What opportunities and challenges are offered by EU membership to nurses and midwives? Many students following courses in healthcare profession are already benefiting from EU programmes in education and training in other European countries. One of the EU requirements to qualify as a nurse to work in other countries is adequate knowledge of the science on which general nursing is based and also of ethics of the profession and the general principles of health and nursing. Opportunities of education and experience of work in clinical setting in other European countries will definitely increase the standard and enhance the experience and skills of our healthcare professionals. These opportunities are an immense investment in the human resources of our healthcare system.

Nurses and midwives working in other European cultural settings will face eventually the challenge of getting involved in clinical situations that bring in conflict their own ethical values. Should a nurse or midwife participate in an abortion? Is it ethically permissible to get involved in clinical decisions that will lead to active voluntary euthanasia? Many European countries have legislation on a number of medical and biotechnological issues. Are healthcare professions morally obligated to follow these legislations? All codes of ethics for healthcare professionals endorse explicitly a clause that safeguards the healthcarer's right to conscientious objection. When nurses and midwives get involved in clinical setting in which their moral and ethical values are at stake, they have the right to refuse to participate in that medical procedure on the ground of conscientious objection. The fact that European countries have legalised abortion or voluntary euthanasia is definitely not a valid argument for our healthcare professionals to refrain from exposing themselves to other clinical settings. The challenge to uphold sound ethical values should not preclude nurses and midwives from immense future opportunities offered by membership to the EU.

### **3. Public expectations**

Though the health care profession still enjoys respect and confidence, doctors, nurses and other health care providers can no longer claim to have uncontested authority on their patients. The general public has become more critical of the behaviour of those who care for them during their stay in hospitals. Patients are becoming more demanding, expect more information, more attention to holistic care, quality of care, and active participation.

The increasing number of lawsuits against healthcare professionals in Malta indicates that the general public is becoming more and more vigilant and conscious of malpractice in healthcare. In the United States, healthcare professionals are hesitant to touch a patient because they are afraid of ending in the law courts. Such situations, which definitely increase anxiety and pressure on all healthcare professionals as well as diminish their freedom in clinical settings, present a challenge to all healthcare professionals to be more vigilant of their responsibilities and professional duties. When nurses and midwives find themselves involved in a legal litigation against colleagues, their first allegiance is to the patient rather to healthcare professional colleagues.

The nursing profession requires today more than ever before a greater level of competence in communication skills, a greater sense of honesty and responsibility. Since the public is becoming better informed and more assertive about health services, professional decisions are sometimes challenged. Patient groups are increasingly negotiating with professionals about the care they want. In the future the public will expect better and more convenient access to health care, more information and more attention to holistic care. At the same time, concerns with human rights, equity, accountability and ethical issues will come to the forefront of debate and action.

In the future, nurses and midwives will be expected to take more and more the roles of patient's facilitator, patient's advocate and whistleblower. In adopting the approach of patient's facilitator, the nurse

seeks to enhance the autonomy of the patient or client. This role lies within the client-centred and educational approaches that invite the participation of individuals. As a facilitator, the nurse should enact her/his role with warmth and empathy, building confidence, sharing skills and knowledge and encouraging the individual to enter into a relationship of trust and openness.

In the exercise of their professional accountability, nurses and midwives are expected to accept the role as an advocate on behalf of her/his patients. Advocacy is concerned with promoting and safeguarding the well-being and interests of patients and clients. Nurses deal with human rights issues daily, in all aspects of their professional life. They have an obligation to safeguard people's rights at all times and in all places. There is a need for increased vigilance and a requirement to be well informed about how new technology and experimentation can violate human rights. The application of human rights protection should emphasise vulnerable groups such as women, children, elderly, refugees and stigmatised groups. A commitment to protect human rights includes assuring that adequate care is provided within the resources available and in accordance with nursing ethics. The nurse is obliged to ensure that patients receive appropriate information prior to consenting to treatment or procedures, including participation in research.

Whistleblowers are people who draw the attention of the public to negligence, abuses or dangers, such as professional misconduct or incompetence, which exist in the organisation in which they work. The decision to blow the whistle on a colleague is never as easy one; unless there is a legal obligation to report, it should be considered a step one takes when all else has failed. In health care institutions, threats to patient safety may come from prescribed treatments, environmental hazards, staffing inadequacies, or illegal, incompetent or unethical conduct of any employee or person.

Do nurses have the right to blow the whistle? Some authors claim that in some situations there is a moral obligation to disclose harms.



#### **4. Changing demographics**

The twenty-first century has been termed the age of ageing because it witnessed a revolution in longevity. The average life expectancy has increased by 20 years since 1950 to 66 years, and is expected to increase a further 10 years by 2050. Every month, a million persons in the world turn 60 years of age. The number of persons over 60 years will increase from 600 million to almost 2,000 million by 2050. The oldest old (80 years and over) are the fastest growing segment of the population. Indeed, by 2050, for the first time in history, the number of older persons in the world will exceed the number of young. This phenomenon has already occurred in the developed world by 1992. These demographic trends which every country is undergoing, are having social, economic and political effects on society and on its institutions such as the family, social and health services.

Today, the dominant medical ideology is to provide a cure, and thereby contribute to the prolongation of life. However, given the increase in the number of elderly people beset by chronic and non-chronic illness, the objective of medicine can no longer be solely that of curing. As far as the elderly are concerned, medicine can, and should, have new aims that are not so much to do with the number of years people live but with the quality of their lives. While an increase in the elderly will challenge healthcare delivery, nursing actions in wellness clinics and homes will enhance positive health and healthy ageing so that older people will lead active and productive lives with minimum disability.

In the future, healthcare systems will invest more and more in geriatric care. More health carers will be involved with the care for the elderly. As a consequence, healthcare professionals will have to face more issues in geriatric ethics: when is it morally permissible or even mandatory to withhold or withdraw life-sustaining treatment to an elderly patient? Who should decide when the elderly is incompetent? By what criteria should decisions be taken? Is quality-of-life a valid criterion in issues of life-supporting treatment? Is old age a valid criterion in the allocation of scarce medical resources?

Healthcare professionals should never discriminate against the elderly because of old age. Ageism is wrong. The Declaration on Ethical Issues on Ageing, presented by the Government of Malta to the Second World Assembly on Ageing organised by the United Nations in Madrid, Spain, on April 2002, states explicitly that the use of language about older persons, in particular, by the young, by those professionals whose work brings them in contact with older persons, and by the media deserves serious consideration so as to ensure objectivity and respect.

## **5. Scarcity of medical resources**

Maintaining a healthcare system in the face of ageing societies, constant and usually expensive technological developments, and ever-rising public demand is proving difficult. A new model of health care is needed, what is called a ‘sustainable’ model. By that I mean a model that is affordable over the long run’ – indefinitely into the future – and that is equitably available to all. Rationing will be necessary in any and all future health care systems. No system, however efficiently managed, is likely to be able to keep up with the constant stream of new and expensive technologies, most of them offering only marginal improvements over those that have gone before. And none will be able to cope through managerial techniques with the combination of ageing societies and technological innovation.

The current model of healthcare features a commitment to constant medical progress, assuming that progress is an indispensable good. This model aims at the conquest of all diseases, one disease at a time. It seeks an indefinite increase in average life expectancy. Such a model has helped to engender a number of characteristic biases in the provision of healthcare. There is a bias towards cure rather than care, another towards length of life rather than quality of life, still another toward technological interventions rather than health promotion and disease prevention.

On the contrary, a sustainable model of healthcare would start with a more limited idea of progress, not an open-ended one. It would have

finite, achievable goals, beginning with the goal of helping people to avoid a premature death, not death itself. It would have a different set of biases. It would accept death as an inevitable part of the human condition just as it would understand that not all suffering can be eliminated. It would understand that some degree of dependency is a necessary feature of life together in community, just as it would understand the necessity of setting limits and rationing healthcare. If everyone is to have access to a decent level of care, not everyone can have access to the most optimal care.

The problem is that individualism is itself the major obstacle to an affordable, sustainable medicine. A healthcare system dominated by individualism has no good way of saying no to individual needs, however much they may hurt the common good. It takes all rationing and all limits as an offence to human dignity. Respect for the rights of the patient is based on human dignity. However, human dignity can be achieved and protected only in solidarity with others. The essence of a common-good approach to ethics is that the individual is never seen as existing separate from the community. The individual has freedoms, rights and privacy that must be respected, but he or she also has responsibilities to others.

The sick individual is not only a patient with rights but also a citizen with duties. The patient is an individual-in-community. The dominant social value of Western society focuses on the freedom and rights of the individual and gives less recognition to community obligations. Without undermining the importance of individual rights, the tradition can be modified to recognise the ethical importance of solidarity, relationships, and commitment to common goals and to meeting the needs of others.

Individualism plays too strong a role in the area of treatment decision making, frequently to the exclusion of any other consideration. An individual has a legitimate claim only to a fair share of healthcare resources, not to every treatment that might well be beneficial. There are economic and ethical limits in providing all and every possible

medical intervention. Using a common-good or community-based ethic as a framework for treatment decision making may provide appropriate balance to the emphasis on patient desires. Everyone has a legitimate claim to a basic level of healthcare. On the other hand, no one has a legitimate claim to treatment that is being withheld as part of a just rationing system. A just healthcare system is one in which individual desires for medical treatment beyond the basic level are accommodated whenever possible but not when they undermine the primary purpose of medicine to meet the basic healthcare needs of all persons.

In the future, governments will continue to search for cost-effective ways to increase access to health care, and the trend is towards shorter hospital stays, reduced staff and early discharge of patients. In this environment, nursing's potential and competencies in areas such as home- and community-based care, team leadership, budgeting, supervision, negotiations and entrepreneurship would flourish. Increasing professional autonomy and the expanded nursing role in which nurses function in areas previously performed by physicians will be a dominant trend in the future, according to the 1998 Royal College of Nursing.

Future healthcare reforms will continue to provide nurses with new career prospects in preventive, promotive, curative and rehabilitative services and opens up avenues for nurse-led practices in such areas as specialised clinics, cancer care, etc. Nurses involved in health promotion will have to present a clear message to the general public: take care of yourself and do not count on medicine to save you from yourself.

## **6. Partners of care-planning process**

The emergence of quality improvement movements in healthcare has resulted in two major changes in patient care. It has broken down barriers between hospital departments and reshaped systems for patient's benefit. Traditionally, nurses have been co-ordinators of care.

In a case management model, nurses become true collaborators in the patients' care process. They no longer simply take orders, but actively participate in designing a plan of care.

Collaborative case management is a multidisciplinary approach to patient care. It involves the development of "clinical pathways", plans of care for a single diagnosis as directed by a specific physician or group of physicians. From a certain pathway, an organised care "map" (multidisciplinary action plan) is developed and individualised to meet the needs of each patient. In developing these plans, the nurse works directly with the physician and personnel from all other hospital departments involved in patient care, such as radiology, laboratory, pharmacy, quality management, food and nutrition, home care and pastoral care. As relationships mature, everyone involved begins to speak the same language and to learn more about the role various disciplines play in patient care. In this process, what was once a "nursing care plan" now becomes a "patient care plan".

In addition to breaking down departmental barriers, collaborative case management also removes barriers between physicians and nurses. While nurses have always co-ordinated the care for the patient, they now become partners in initiating the care and setting goals for the patient. One key to this partnership is that everyone has access to all the information relevant to the patient care process. Good communication is critical to effectively implement this system.

Collaborative case management has many advantages, including maximised quality, improved efficiency, increased patient satisfaction and enhanced collaborative team practice. But the major advantage of the process is that it puts the patient at the centre of health activity. By gathering and co-ordinating input from all personnel involved in patient care, the procedures are attuned to the clients' genuine needs. By making the patients more aware of their treatment plan, they become true collaborators in the care process.

## 7. Enhancing ‘teamwork’ spirit in health care

Few people, with the exception of a small number of self-employed practitioners, work on their own. Most people in their working lives are employed in institutions of some kind and have to learn to work together, and make decisions together, with other people in teams. These teams would, almost by necessity, comprise people with a variety of professional background and expertise. This diversity, like that of a football, is not only the basis of the strength of the team, but also a potential source of weakness. Our power is enhanced by participation in teams; we can do more together by co-operation, pooling our resources and a sensible division of labour.

However, lack of trust, non-co-operation, confusion of roles, and inability to share power effectively can be a disaster. For a smooth and efficient functioning of a hospital, nursing, paramedical and administrative, technical and service staff, there has to be some clear division of labour, with a clearly understood hierarchy of power and authority, roles and responsibilities.

Research in teamwork in health care settings suggests that doctors, nurses, paramedics and administrative staff are generally ill-prepared to work in teams with other professionals – segregated as they are from one another in basic training. Put another way, many professionals are trained as ‘soloists’ rather than as players in a symphony orchestra, and are ill-equipped or inexperienced in sharing power and responsibility.

All medical practitioners have one primary goal, namely to ensure measurable and positive outcomes of their medical treatment. With this commonality in mind, it is crucial that an interdisciplinary teamwork should be aimed at in order to provide optimal care for the patient.

Studies show that the quality of healthcare professionals’ relationship affects the outcomes of care. Quality of care and teamwork are

inseparable. Good teamwork aims to produce a better outcome for patients and to make each team member feel valued and fulfilled. Effective interdisciplinary teams can enhance the efforts of quality improvement. Unfortunately, when teamwork is not functioning optimally, patient may have a less satisfying experience, leaving them with little confidence in the process. Without a team approach and good communication throughout, a favourable patient outcome is jeopardised. Harmful health care often happens as a result of no communication or a breakdown in communication between several providers who may or may not be from different disciplines or between providers and patients.

All health professionals have the same overriding goal, namely the restoration and/or maintenance of their patients' health. This calls for a co-ordinated effort from all of them. The input of team members can influence the treatment plan. There are two characteristics which the members of health-care teams should consistently display: first, solidarity with and mutual respect for one another, and secondly, a willingness to co-operate with one another for the good of patients. Where these characteristics are absent, the well-being of patients may be put at risk.

Membership of a well functioning team – one with clear team and individual goals, that meets together regularly, and that values the diverse skills of its members – reduces stress levels and increases performance. Thus coherent teamwork is crucial for the delivery of good quality patient care both directly in terms of efficient and effective services, and indirectly via its effects on reducing stress. Teams need to be aware of all the responsibilities of a unit, with knowledge of each other's work, developed ways of working together and supporting each other.

### **Concluding remarks**

Nursing is at present at a crossroad in its development. It is a relatively young, fast-growing academic discipline and comprises an occupational

group numerically larger than any other in health care. It has a legacy of being in a subordinate relationship to a dominant medical profession. However, nurses are developing a sense of identity and confidence of their own. This is based not only on 150 years or more of accumulated experience of nursing, but also on more secure knowledge arising from the application of the methods of the behaviour and social sciences to nursing research. All this adds further impetus to the desire of nurses to articulate the unique insights they can bring to health care, and to develop a body of knowledge and area of practice for nursing which they can claim as their own.

Nurses and their associations must show vision, strength and strategy if they are to pass on a strong, socially relevant, vocationally satisfying profession to the future generations of nurses and citizens. Now is the time to reflect on accomplishments, learn from failures and decide what direction to take in the next millennium to further advance nursing, nurses and health.

We must support the dynamic evolution of nursing practice in facing today's changes and challenges and to ensure quality health services. Nurses must respond creatively to present challenges in shaping a vital future. They need to re-educate and redefine themselves professionally. They need to prepare themselves for vital roles in outpatient care, home healthcare, and community-care. Nurses' need for a more varied and complete education will pose a challenge to academic institutions. Our Health Care Institute will have to respond quickly to new demands by creating a curriculum that prepares students for more challenging clinical and managerial responsibilities. The education system also will have to develop courses that enhance nurses' flexibility, improve their decision-making skills, and familiarise them with the profession's basic values.

In the twenty-first century, nurses will have to tap what, historically, has been one of their greatest strengths – their adaptability. They will have to stretch everything – their power, their knowledge, their influence – to remain relevant to the healthcare system of tomorrow. This is a challenge not to be missed!





# **Ethical issues in nursing and midwifery from a local perspective**

**Antoinette Attard**

Ethics is concerned with what is right or wrong, good or bad. This may appear to be misleadingly simple. Trying to determine what is good or bad in different situations, for different people, different cultures and different moral values can be confounding, especially as each of us brings something of their own history, experience, beliefs and values to any given situation (McHaffie 1995). This is why although there is such a vast amount of literature on health care ethics, it is sometimes impossible to find a clear cut solution to the different practical problems that one encounters in the clinical area.

I would like to explore how some local factors such as the size of our country, our culture and religion can have a bearing on the common ethical issues encountered in the clinical area.

## **Size**

Malta's size as well as the fact that there is only one public general hospital, has implications for maintaining patients' right to choose, privacy and confidentiality.

## **Life style**

The family in Malta is still very close knit. Although it is becoming increasingly difficult to physically look after elderly parents, with more married women now working, families are still very involved with each others' welfare.

## **Religion**

The majority of Maltese are brought up in the Roman Catholic religion. So, whether still practising or lapsed, they have an awareness of the

implications of being Roman Catholic. But is there such an emphasis on the implications of other religions on the needs of patients? The Roman Catholic religion also influences our laws, such as in matters of divorce, abortion and euthanasia.

Having given this brief overview of local factors I will now explore how these can affect ethical issues locally. In order to determine the most common issues, I decided to prepare a questionnaire which I analysed following the introduction of the first Ethical and Legal Issues Course offered by the post registration section within the Institute of Health Care. I would like to stress that though this was not a scientific study but an analysis of answers given by the 33 managers, nursing officers and deputy nursing officers who attended for the first lecture, it does throw light on some of the pressing issues of nursing and midwifery ethics locally.

### **Common ethical concerns**

One of the questions asked was:

*‘Which are the common ethical concerns you encounter in your clinical area?’*

The answers were analysed and grouped into four themes (Table 1). As can be seen from the table the most common theme mentioned was that of information giving, and this incorporated truth telling to patients who are diagnosed with a terminal illness or a chronic condition, gaining patients’ consent and questions relating to who would give consent when children have parents who were separated.

This was followed by issues of confidentiality especially when nurses come from the same locality as the patient, those who are HIV positive and are reluctant to reveal their diagnosis to their partners, and the involvement of relatives in confidentiality issues.

The problem of when to let patients die with dignity, or whether to continue with treatment even when patient's condition is very poor was another issue of concern.

These were followed by issues of ward management such as lack of resources or prioritisation and the issue of reporting colleagues who are not up to standard.

**Table 1: Common Ethical concerns encountered in clinical area**

Theme	Frequency
Information giving Truth telling Chronic conditions Separated parents	16
Confidentiality Same locality HIV Relatives	9
Letting die	6
Accountability Reporting Ward management issues Resources Priorities	5
Miscellaneous Attitudes Labelling Rights Social cases Others	11
No Comment	3

The three most common issues mentioned were information giving, confidentiality, and issues relating to letting a patient die. Despite the changes in health care and the increasing impact of technology, clinicians are still faced with these fundamental ethical problems. Therefore, I will be focusing on these aspects for this presentation and I will start by outlining the issues related to informed consent.

## **Information Giving and Informed Consent**

Ethically, it is our collective responsibility as health carers to ensure that competent patients are given information that they can understand and which will help them make a decision. This information must be in a language that they can understand, without the use of jargon or complicated language. It is also important to give them enough time to ask questions and clarify points. The importance of this concept is acknowledged in the Patient Charter (Hospital Management Committee 2001) which dedicates a whole section to Informed Consent, and in the Maltese Code of Ethics which states that:

“nurses and midwives should: within their sphere of responsibilities, ensure that patients / clients are given adequate and correct information enabling them to make a free informed choice as to the provision of their own care” (Nursing & Midwifery Board 1997).

The development of the Maltese Code of Ethics was a milestone in the development of nursing and midwifery ethics, as it provides local guidelines to practitioners to carry out responsibilities consistent with ethical obligations of the profession and with high quality care.

However, this statement poses a problem for practising nurses. This statement specifies that nurses and midwives are bound to give information ‘within their sphere of responsibilities’, but what exactly are the boundaries of one’s responsibilities? Legally, I am sure Dr Gafa, the next speaker, will explain that it is the doctor who is responsible to give information about diagnoses. Nurses are bound to give information

about nursing care, but nurses and doctors do not work in isolation. If patients are really going to be informed about any procedure, investigation or treatment, then nurses, midwives, doctors, physiotherapist, radiographers and all the health care team have to work together.

This is particularly important in view of the fact that it is common for patients to accept whatever the doctor tells them, irrespective of whether they had fully understood the implications of the information given to them, and then ask other health carers about care, diagnosis and treatment. In such a situation, are nurses and midwives to give or re-enforce information, wait and ask the doctor to explain again if the patient had not understood the information given, or, refer the patient back to the doctor, knowing that the patient will most probably spend the rest of the time worrying about the problem, and having difficulty asking the 'busy doctor'?

Patients tend to shop around for information and may not ask the doctor, and may instead ask the junior nurse who in their eyes may seem to have more time than the doctor or senior nurses. It is therefore, imperative that the team members caring for a patient are aware of what the patient knows or does not know. Withholding information from patients for whatever reason can have far reaching consequences (Vetch 1981) as patients will never be sure whether they are being told all the truth. This can have negative effects even on patients who have minor disorders, who, on experiencing anything they had not anticipated, would assume the worse, however unfounded their fears might be.

Informed consent does not only refer to giving the patient his/her diagnosis. Patients should also be aware of the implications of this information on their lifestyles even if it merely refers to taking a diuretic and not being able to go out to places that do not have access to toilet facilities. Likewise the implications of submitting to investigations and knowing the results, whether this is checking a blood glucose level, a blood pressure, a HIT test, a removal of a lump, or an HIV test.

The advent of HIV and its implications brought into focus the issue of whether patients are aware of what investigations are being carried out, and made us think about preparing patients for a negative result. But do we ever stop to think how devastating it is for a person to be told that s/he is a diabetic and has now to change his/her life style, and take treatment for the rest of his/her life? Can we ever really prepare anyone for a free informed choice when it is so difficult to really appreciate what a person is going to feel, and how that person is going to react to changes in life? Whilst it is easy to explain to a patient that following this or that procedure they would need to rest for a period of time, or adopt a different diet, have we ever stopped to think what it means to a person to become a patient – to become dependent on outside forces? Perhaps the majority of you have not experienced the transformation from a ‘person’ to a ‘patient’ but this change is like a leap into the dark unknown. And it is a leap which we tend to take for granted.

To have to depend on others for the most basic needs for a limited period of time is difficult to describe; to prepare people to change their life style for the rest of their life is a mammoth task, especially as people react to changes in such different ways. Therefore, preparing patients for a totally free and informed choice is not easy to achieve.

The principle of autonomous decision-making is relative, and is not an absolute principle (Beauchamp & Childress 1989). Moreover, whilst we believe that patients are autonomous, health carers also have a duty to be beneficent and promote patient welfare, and prevent harm. But does this mean that we can be paternalistic and take decisions on behalf of patients? Beauchamp & Childress (1989) argue that paternalistic interventions are seldom justified, as patients’ right to act autonomously almost always outweigh health carers obligations of beneficence. But there is always a grey area, such as when patients want to know the truth, but their relatives indicate that the patients will not cope with bad news, or that they may commit suicide if they know the truth.

When promoting autonomous decision making, one is always aware of the importance of assessing the patient’s ability to understand and cope with the level and type of information being given. But assessing

this ability requires time and expertise. It requires the ability to be objective, as well as assessing and communication skills. However, would this assessment really be so objective, given that health carers are also influenced by their beliefs and culture? A health carer who believes that the principle of beneficence, that is the duty to protect and not harm patients, overrides the principle of autonomy, may find it difficult to give bad news to a patient for fear that the patient may not be able to cope with the information.

In the questionnaire I mentioned earlier, candidates were asked whether ‘Relatives have a right to request to withhold information from patients?’. The answers were interesting (Table 2). Seventeen participants (53%) stated that **patients** and not their relatives have the right to information and to make decisions about their care, making comments such as “patients have a right to all care”, and ‘I would want to know’. On the other hand 12 participants (38%) felt that relatives have the right to make such a request, with three not being sure. These participants felt that relatives know the patient and how information would affect him/her. Relatives can prepare the patient in the first instance, and then the patient would be given information. However, some stated that they feel that relatives know the patient best, and they would not be ready to lie to patients.

***Table 2 – Do relatives have a right to request to withhold information from patients?***

Response	Frequency	Comments
No	17	Patients have a right to information Patients have a right to ‘all care’ I would want to know’
Yes	12	Relatives know the patient best Relatives can prepare the patient first Relatives can support patient Patient may commit suicide
Unsure	3	Depending on the patient I would not be ready to lie to patient



Relatives know the patient better than health carers, and may be in a better position to determine whether a patient is capable of accepting a negative diagnosis. On the other hand, keeping in mind the family structure in Malta, is an unwillingness to disclose information always an objective assessment of patients' ability to cope with information or could it sometimes be the result of the paternalistic attitude arising from the characteristic dependency and protectiveness of Maltese families?

However, until an objective assessment has been carried out, one has to determine whether to rely on the relatives' plea to withhold information and risk upsetting the patient; or go against relatives wishes, disclose information and risk causing a set-back in the patient's condition. This dilemma is a common problem that most health carers face. In most countries, it is assumed that the patient should be the first to get information, however, in Malta, where families are so involved, and where young and old are still so protected, it seems that this dilemma is intensified. This is obvious from the fact that the Patient Charter (HMC 2001) even states that 'Patients have the right .....for their condition not to be divulged to next of kin, if patients so request in writing.'

The fact that patients need to express their wish to withhold information from relatives in writing seems to go against the common interpretation of confidentiality where the patient expects the health carer to refrain from sharing personal information obtained in the course of their work (Rumbold 1993). I will now discuss this notion of confidentiality in more detail.

## **Confidentiality**

The importance of maintaining confidentiality has been widely discussed in health care ethics since the Hippocratic Oath (Beauchamp & Childress 1989). Patient care is built on trust. Patients have to entrust health carers with intimate information, to allow them to arrive at an accurate diagnosis. Health carers have to trust patients to give them all

relevant details to ensure that they can carry out their duties. Therefore, patients have a right to have personal information kept private and a responsibility to give health carers all the information necessary irrespective of how intimate and embarrassing this information may be. This dual right and responsibility is acknowledged locally by both the Patient Charter and the Maltese Code of Ethics for nurses and midwives.

But is confidentiality a reality or a myth? Patients' cases are discussed between practitioners, students, in academic journals, and sometimes even in social occasions when professionals meet socially and discuss cases forgetting that partners not involved in care may be present. Moreover, storage of files can lead to breaches of confidentiality, especially with the modern trend to store information electronically, and the ease with which hackers seem to be able to breach even the most secure national systems.

Confidentiality is also a problem in research or in education. It is common for students to discuss interesting case studies they have encountered, and due to the size of the island, identify patients even though they do not mention patients' names. The same situation can arise in research studies. If I carry out a study on nurses and midwives in, say, the special care baby unit, I have already identified the exact location. When describing the respondents – age groups, sex, and years of experience, I run the risk of identifying people. Therefore, sometimes one has to avoid giving certain data to protect respondents' confidentiality.

Another problem is that it is hardly possible to go to hospital whether for an outpatient appointment or as an in-patient and not meet people one knows. Whilst most times this is a bonus – as when one knows a member of staff and so can avoid waiting for a long period of time, it can be a problem if one wants to keep the visit a secret. Whilst health carers are bound by professional secrecy as stated in the code of ethics, other patients and visitors are not, and therefore, it is more difficult to

have a secret hospital appointment than a secret affair in Malta. However, a bigger problem for most patients will be maintaining their privacy when using hospital facilities. We repeatedly hear of how embarrassed patients feel when having to undergo intimate examinations by a doctor. How much more embarrassing is it to have the doctor interrupted by a nurse, a nursing aide, or sometimes even by security guards or porters coming in to talk to the doctor or get something from the cubicle?

In-patients have to talk to their doctors, nurses or midwives and discuss intimate details about problems relating to digestion, excretion, sexuality etc. in front of other doctors or students they might not have met before. They are usually separated from other patients by means of inadequate curtains which are ineffective in maintaining not only auditory privacy but even visual privacy, as attested by the common sight of nurses carrying pegs around with them to clip curtains to maintain privacy. Can we begin to imagine how horrendous it would be to be the patient nursed in the middle of a corridor? This problem is compounded by the fact that like most Mediterranean people we tend to have loud voices.

How would we like to come up here on the podium and discuss whether we have opened our bowels this morning, whether we have seen any discharge, experienced pain on sexual intercourse, or whether we have had unprotected sex and are afraid of having contacted a sexually transmitted disease? But these and sometimes even more personal questions are being asked everyday in our wards and we expect patients to answer truthfully, and moreover, to ask questions themselves if they had not been given the required information.

### **Boundaries to confidentiality**

As we have discussed, confidentiality is essential to protect patients. However, there are exceptions to this rule, such as when information is required by law, or when information is necessary to safeguard the

well being of society. It is an undisputed fact that health carers have to report criminal offences such as a suspected attempted murder or a case of child abuse. Problems also occur in situations such as patients who find out that they are HIV positive and do not want to inform their partners. The infectious nature of this condition coupled with the life-threatening factor, has led to ethical debates about confidentiality.

In health care it is accepted that confidentiality should not be broken unless it is in the interest of society. The arguments put forward are that whilst the patients or clients have a right to confidentiality, their partners should be told about the risks involved. Perhaps this issue is particularly relevant when the client has a long-standing partner, as it is assumed that in casual relationships it is the responsibility of whoever participates in high-risk activities to ensure that protective measures are taken. However, in long-standing relationships, refusing to tell the partner violates the trust upon which the relationship should be built. Health-carers also feel that they have a duty to protect people from harm.

Should health-carers share this information with partners for their safety, or withhold that information to maintain patients' trust and thus be in a better position to try to persuade the patient to reveal information him/herself, as well as encourage other patients to come forward when they suspect that they have problems? Ethicists are divided on this problem. One school of thought is that a strict rule of confidentiality is essential, as absence of strict confidentiality will prevent certain patients from seeking and making use of health care, thus creating even more problems to society. On the other hand, what about the problems to those harmed by maintaining confidentiality? Health-carers are also obliged to protect society from harm, as well as offering care in a family-centred care approach, which implies that care should be directed at the whole family and not just the person who has an illness. This dilemma poses a fundamental question relating to which rule of confidentiality would save most lives in the long run.

## **Letting die**

The debate about 'sanctity of life' and 'quality of life' incorporates a number of ethical concerns in health care such as abortion, euthanasia, and prolonging life. Although abortion and euthanasia are illegal in Malta, local nurses may still come across situations where patients ask to be helped to die. This situation can cause conflict for those who, although aware of the legal position, may believe that these procedures are acceptable in certain situations. However, there is not enough time to discuss this complex issue today.

The issue that was commonly raised in the questionnaires, and in discussions during sessions, was whether nurses are expected to initiate resuscitation measures to patients who do not have a 'do not resuscitate' note documented in their files, even though they are terminally ill.

Nurses have traditionally left decisions related to prolonging life and assisting death to medical doctors. Ideally it should be patients who decide whether to continue receiving treatment or not (Bandman & Bandman 1990), however, as discussed previously, patients are not always aware of the implications of their condition. Even when patients have been given all the information, it is not always easy to assess what they want.

When patients refuse to continue receiving treatment, health-carers are also faced with the conflict of whether to accept the patients' request not to continue treatment, or abide by their responsibility of saving lives. This was another question that was explored in the questionnaire.

Candidates were asked whether patients have a right to refuse life-saving treatment (Table 3). Twenty-four respondents (73%) stated that competent patients have a right to make such a decision as it is their responsibility. They also stated that it is the quality of life which is important, and if this was to relieve suffering and the patient had a terminal condition then they had a right to refuse treatment. However,

6 candidates (18%) did not agree, as they felt that it is our responsibility to save life and moreover, patients may change their ideas later, and they can be irrational during a time of crisis. Two candidates were unsure, stating that they felt that it is a very difficult decision to make.

**Table 3: Do you think that a patient has the right to refuse life saving treatment?**

Answer	Frequency	Comment
Yes	24	Patients have the right / responsibility to make decisions Relieve suffering Quality of life
No	6	Patients may change their minds Irrational at time of stress Sustain life
Unsure	3	Difficult to decide

These decisions are difficult when there is time to discuss the situation with patients, but the difficulty is greater when patients are admitted in an emergency. When faced with a patient who has collapsed, health carers would do their utmost to prevent the patient from dying. But it is essential that we avoid subjecting elderly or terminally ill patients to the undignified rigours of enthusiastic but futile resuscitation measures. (McHaffie 1995).

The problems arise because it is difficult to have clear guidelines of when to resuscitate or not for all possible occurring situations. It is therefore, essential that when elective decisions about whether to resuscitate have taken place, these should be clearly documented in patients' files to avoid any confusion (Aarons and Beeching 1991). It is also essential that more multidisciplinary discussions about patients' suitability for resuscitation take place.

## Conclusion

From this brief exposition it is clear that health care ethics is a very complex subject. I have attempted to look at the most common problems that are encountered in local practice, and looked at some specific factors which make our problems unique. I am aware that I have raised more questions than given solutions, but I hope that these questions will provoke more discussion during the workshops this afternoon, which I have no doubt will be very stimulating. Ethical issues are by their very nature complex, and when associated with health-care they become even more complicated because health carers deal with different people who have only one thing in common, that is their vulnerability. Nurses and midwives do not work in isolation but as part of a multidisciplinary team which incorporates patients, relatives, society and all professionals making up the health care team. The only way that some of the issues effecting the provision of high quality care to patients can be tackled is by multidisciplinary discussion and co-operation. I am sure that we need more common fora where we can get together to discuss these issues.

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# **NURSING AND MIDWIFERY – A LEGAL PERSPECTIVE**

**Dr Bridget Gafà**

Personally, I believe that nursing is an art and a science, and its focus is on health. The essence of nursing lies in the unique interplay of intuition, logical thought, knowledge and compassion for others. Nowadays nurses are required to be competent in a variety of areas ranging from patient physical care to organisation, planning and interpersonal relations. Nurses now have to adapt quickly to changing circumstances for the benefit of the patient and for the benefit of the profession itself. Failing to adapt not only exposes the patient to unnecessary risks but also stultifies professional development. The role of nurses has expanded over the last two decades and is undergoing continuous development in order for it to meet the ever-demanding increasing demands of society. Though a very demanding profession, nursing provides an excellent opportunity for continual professional development or a career path in a wide-ranging variety of areas.

Yet due to this diversity and continuous change and evolution in knowledge and development, it is inevitable that legal provisions reflecting these rapid changes are absent. Logically, the most common query is about the nurses' and midwives' position at law. During my talk I shall be tackling this legal perspective from two angles namely: those provisions which provide for the regulation of the profession in so far as qualifications are concerned and secondly other more general provisions which deal with the regulation of the professional's actions.

Under Maltese Law, precisely under the Medical and Kindred Professions Ordinance one comes across Part VII, Sections 72 to 80. These sections set up the Nursing and Midwifery Board and regulate the registration of nurses. Section 78 makes it an offence for a person to practice the profession of nurse for the sick or to take or use the name or title of registered nurse or of enrolled nurse unless he is so



registered. Hence registration is a *sine qua non* for the practice of the profession. It is worthwhile noting that although here the legislator has attempted a definition of nurse —“nurse of the sick” – this is very vague and does not provide clearly the parameters of the nurse’s role.

Midwives are also catered for under the Medical and Kindred Professions Ordinance, precisely Part V. The Midwife still has to be registered to practice as such. In her case however the legislator was more specific in that the provisions of the law provide specifically for certain circumstances that might arise during labour and lay down what should be done by the midwife under those circumstances. Whereas, as far as the midwife is concerned, the law provides for the regulation of the role as well as the profession, in the case of nurses the law regulates the profession rather than the role. It is important to note that the profession has evolved, and these provisions do not reflect the progress made.

The second tier of regulation affects the nurse or midwife in her day to day chores. Here I am referring to the provisions of the law under the Civil Code and the Criminal Code. Under these two one will not come across a definition of the nurses’ role. The law in these two codes simply refers to actions which give rise to damage. These codes do not single out the profession. On the other hand they are applicable to every person carrying out a task, irrespective of what this might be. The obvious question then is, where can one find a definition, if the law does not provide one? My answer to this is that I prefer the law as it is. Definitions are by their very nature restrictive, and in the sphere of nursing and midwifery it is not practical and workable to have a defined written-down role. Personally, I opt for the definition given by the profession itself. In other words, I believe that it is the profession which should determine the role of its members. How this is done is very simple. A procedure followed by the profession becomes standard by use across time. It then acquires the force of law without there being the need to write down that procedure in some legal instrument.

Even courts of law have followed this position. For example in *Hunter v Hanley (1955 SC 200)* Lord Clyde held that to establish whether

there are grounds for damages due to breach of normal practice the following test has to be carried out:

- a) There is a usual and normal practice
- b) The nurse has not followed that practice
- c) The action taken by the nurse is one that no other nurse would have taken if she had been acting with ordinary care.

The problem in these cases is very often one of actual proof. What is usual and normal practice? Protocols and guidelines play an important role in this sphere of material proof. Though these are not prescribed by law, yet they acquire the force of law once followed by that particular profession. It is important therefore not to depart from a particular standard set by the profession unless sure of the outcome. This is not to mean that if healthcare professional deviates from the norm of one or more accepted modes of practice he runs the risk of being found guilty of negligence. In fact ***Lord Diplock in Sidaway v Bethlem Royal Hospital Governors [1985]*** held that:

*“ Those members of the public who seek medical or surgical aid would be badly served by the adoption of any legal principle that will confine the doctor to some long established, well tried method of treatment only, although its past record of success might be small, if he wanted to be confident that he would not run the risk of being held liable in negligence simply because he tried some modern treatment, and by some unavoidable mis-chance it failed to heal but did some harm to the patient. This would encourage “defensive medicine” with a vengeance.”*

It must be remembered that first and foremost the patient should not be exposed to unnecessary risks and that, secondly, nothing should be undertaken which goes beyond one's capacity. In the absence of guidelines and protocols we would have to rely quite heavily on the evidence of other professionals working in the same field. The problem with this is that not every one would be ready to take the witness stand,

not everyone can express himself clearly, very often evidence is required after a considerable number of years have elapsed and so memory sometimes fails us as well. This makes our position quite crumbly and definitely not satisfactory. Apart from their use as evidence, guidelines provide a more stable work environment as they can easily be accessed. But in my opinion their unsurpassable importance stems from the fact that they can easily be changed as the profession evolves without any need to undergo cumbersome parliamentary procedures.

One of the recurrent questions posed by healthcare professionals is whether or not they are competent in carrying out a particular task. Competence is a quality which courts look into. Registration with the Nursing and Midwifery Board, or a degree obtained from recognised institutions do not *per se* prove competence. They are pointers, but the onus rests heavily on the nurse or midwife to prove that he/she could carry out a particular task. It is his/her duty to keep up to date with all the developments. Refusing to carry out a particular task claiming incompetence smacks of gross negligence unless that nurse takes the initiative to update his/her knowledge. It is imperative to keep in mind that patients and relatives sue both when they feel aggrieved by a commission as well as by an omission. In other words, if a nurse fails in her duty of care through an omission she can still be found guilty of negligence. On the other hand if a nurse or midwife is aware that she cannot for example give a particular treatment regime she should refrain from giving it. Obeying higher orders is not an excuse. Patients should not be exposed to unnecessary risks.

Another problem I personally encounter when defending a healthcare professional in a court of law is one regarding the medical records and their upkeep. Medical records are the only document, which ideally gives a clear picture of an individual state of health. Hence any information in that file should be accurate. Very often minute details are left out, as they are deemed unimportant. This unfortunately is a far cry from the truth. In court, every detail counts, and minute details may turn out to be very strategic pointers in the future. Nothing should be taken for granted.

Another important aspect of the medical records is that these records pertain to the institution as well as to the patient – not his relatives. These records are official documents and should not leave the ward or hospital unless with the proper authorisation of whoever is in charge. Furthermore they should be sent back and forth in sealed bags. This would narrow down the possibility of having third parties researching the contents. It is becoming quite common to have patients claiming breach of their right to privacy because someone used their medical history outside a hospital setting without their consent. Healthcare professionals may only use information about a patient within a hospital setting, and in the interest of that patient, unless of course there is a court order ordering the release of the records. It may not be used for research purposes without the express consent of the patient. Furthermore, the relatives and spouse of the patient do not have an automatic right to any information regarding the patient unless that patient consents to it. It is important to register that consent in writing in the medical history of the patient.

On this issue of consent I feel I should take this opportunity to once again stress the fact that the ability to consent to treatment or care is not directly linked with age. If a patient is 16 years old and capable of understanding the nature of the treatment or care to be given to him, then he should not be turned out or asked to wait till his parents come along. It is also legitimate for him to ask for confidentiality to be respected. The nurse or midwife should not, if precluded by the patient, divulge any information to third parties even if the patient is under the 18-year threshold they commonly apply to date. One can have a patient who though under 18 is still mature enough to understand the information given to him. It is wrong to apply the 18-year-old threshold in the medico-legal sphere. What happens if the patient is unconscious? Do relatives have a say? The answer is no. If the patient cannot give his consent then it is the doctor's duty to act in the best interest of that patient. The only relatives who can consent instead of the patient are the parents in the case where the patient is a minor who cannot give valid consent due to immaturity. However, this is not to say that the

relatives should be pushed aside and disregarded. It is good practice to consult relatives about what to do. Their comments have no legal effect except insofar as they may evidence the attitude that the patient would have had towards the giving of consent for the relative treatment. Yet the final decision rests with the healthcare professional.

I would like to take this opportunity to end my talk with the following observation: Whilst it is true to say that nursing provides an excellent opportunity for continual professional development or a career path in a wide-ranging variety of areas, it is also true that the role of nurses has expanded over the last two decades and is undergoing continuous development in order for it to meet the needs of a demanding and complex society. It is the responsibility of each individual therefore to ensure that the environment (in its widest meaning), he/she is working in is conducive towards the best patient care available. Team work, effective handing over, proper communication, record keeping, complaint tackling from the very start, are all factors which provide the safety net for the professional when faced with formal demands for damages. We should not be afraid of these demands. We are equipped to tackle them. The Department stands behind its employees and you should definitely not feel alone, as long as you obviously follow the rules and principles enunciated by the Department.

# **Patients' perceptions of information-giving during hospitalisation.**

**Dr. Donia Baldacchino**

## **ABSTRACT**

This cross-sectional research study is part of a longitudinal study which was conducted in the main general teaching hospital in Malta. The aim of this study was to explore patients' anxiety during the recovery period and their perceptions of information-giving during hospitalization. A systematic sample of 70 patients were recruited in the Coronary Care Unit (CCU). Both quantitative and qualitative data were collected on patients' transfer to the medical ward from CCU, between July 2000 and March 2001.

Anxiety and depression was measured by the Hospital Anxiety and Depression scale (Zigmond and Snaith 1983). Patients' perceptions of information-giving by the nurses and multidisciplinary team (MDT) were explored by face to face interview during the first 48 hours of their transfer to the medical ward.

Findings revealed that patients rated themselves within the normal (0-7) and mild (8-10) range of anxiety. This may be due to the threatening experience of myocardial infarction (MI), related to the uncertainty in life. However, anxiety may be considered as an effort to adjust to their new life style. The interviews revealed lack of information from the MDT, including the nurses. Searching information about the severity and progress of their illness was perceived as a means of coping and adaptation to their new lifestyle following MI.

This paper recommends further research in order to increase awareness of the nurses and MDT so as to bridge the gaps in the current practice identified by patients.

## **Introduction**

My clinical experience as a staff nurse and the two research studies on patients' participation in care conducted in Malta (Baldacchino 1992) and the United Kingdom (Baldacchino 1993), triggered me to explore the factors, such as information giving on rehabilitation, which may contribute to stress and coping with illness. Research demonstrates that the MDT, including the nurses and midwives, tend to neglect the informational needs of patients (Thompson 1989, Havik and Maeland 1990)

According to Maltese code of ethics (1996),

*Nurses and midwives should, within their sphere of responsibility, give adequate information to the client in relation to his/her condition and to treatment options, in terms which he/she can understand..... The extent of information has to be adapted according to how much the individual patient wishes to know. ( No. 1.5. : 8)*

The concept of giving tailored and sufficient information is in accordance with Florence Nightingale's recommendation stating, that the environment should do no harm to patients.

Consequently, Henderson (1969) proposes the unique function of the nurse, that is, to assist the individual to perform those activities, contributing to health or its recovery that he would have performed unaided if the patient had the necessary strength, will or knowledge.

The aim of this paper is to present the perceptions of a sample of 70 Maltese patients regarding information-giving in hospital, on their illness and rehabilitation, following their first acute myocardial infarction (MI).

## THEORETICAL BACKGROUND

### 1. **Orem's Theory of Care (1985): The educative-supportive mode of care.**

Orem identifies several factors which may influence self-care such as, motivation, knowledge, skills, confidence and limited range of behaviour. The educative mode of care identifies the nurse as being the main resource of information to enable the patient to participate in his or her own care. The nurse helps the individual by developing appropriate learning environment to enable the individual to learn new skills. In doing this, the nurse guides, directs, instructs and supervises the individual to achieve self-care. Eventually, this support will assist the individual to achieve independence.

### 2. **The Cognitive Stress-coping Theory (Lazarus and Folkman 1984): Interpretative mode of coping.**

During a crisis situation or illness, the individual identifies whether the crisis is threatening or challenging (*primary appraisal*). Also, the person determines whether the available resources are sufficient to cope with the situation (*secondary appraisal*). Consequently, the individual may seek information in an attempt to adapt to the new life-style (*secondary appraisal*).

## Literature Review

Research suggests that anxiety tends to be common in patients with illness, such as myocardial infarction (Roebuck *et al.* 2001, Thompson *et al.* 1995). This is because patients with MI face both an acute life-threatening illness and the potential for living with a major illness (Thornton 2001, Kim *et al.* 2000). Additionally, the patients' whole sense of meaning and purpose in life is at stake (Walton 1999, Burnard 1988). Illness may make the person undertake life review (Baldacchino 2002, Walton 2002, Simsen 1985) which may lead to a change of lifestyle. However, it is argued that adaptation to a new lifestyle may



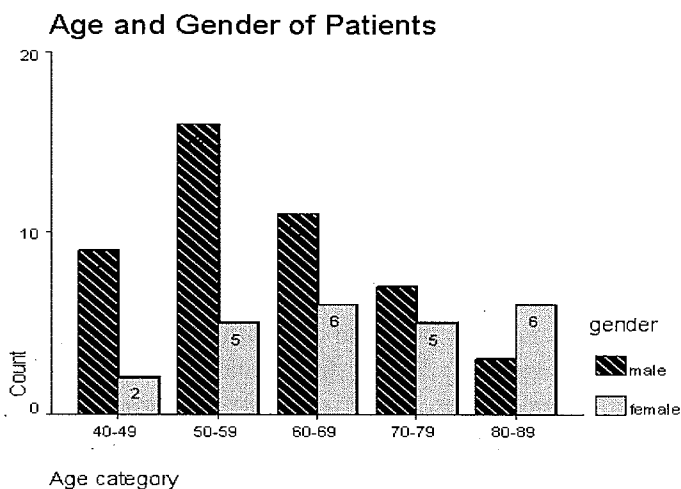
occur only if the person is surrounded by an educative and supportive environment (Roy 1986).

Consequently, since nurses are present day and night with patients, they are in a position to be the main resource of information during hospitalisation. Additionally, the nurse can liaise with other members of the MDT, such as the medical doctors, dieticians, and others to help them adapt to the new life style following illness (Stewart et al. 2000, Havik and Maeland 1990, Thompson 1989).

### Research Design And Methodology

This descriptive research is part of a longitudinal study conducted in the main local general hospital. A systematic sample of 70 patients was recruited on alternate basis, aged 40 years and over, capable of participating in interviews and self-administered questionnaires in Maltese.

**Figure 1: Systematic random sample of patients with first acute MI**



It is noted that the majority of patients (66%) were males (n=46 males, 24 females) and most of them were middle aged between 50-59 years (n=21) (Figure 1).

The two instruments used to assess anxiety and patients' perceptions of information-giving were:

- a) **The Hospital Anxiety and Depression (HAD) Scale**, an established tool developed by (Zigmond and Snaith 1983) with a history of survival of translations into several languages, such as Arabic.

Due to the problem of illiteracy in the Maltese population, the Hospital Anxiety and Depression scale was translated into Maltese for improved comprehension. According to the Malta Central Office of Statistics (1999), only 16.4% of the Maltese population were reported able to read basic English, whilst 46.7% were able to read Maltese. Reliability test-retest statistical analysis revealed satisfactory value of Cronbach's alpha of 0.73 for the Maltese version.

- b) **A semi-structured interview schedule** was devised for this study to elicit patients' experience in hospital during the recovery stage of their heart attack. The interview was conducted by me on patients' transfer from CCU to a medical ward. Two of the questions were oriented towards the information they received as part of their rehabilitation. Another question addressed the role of the nurse in information giving while in hospital.

- Kif qed jiehdu hsiebek in-nurses f'din is-sala tal-medicina?  
*In what ways are the nurses taking care of you on the medical ward?*
- X'informazzjoni tawq fuq kif ghandek taddatta lilek innifsek biex tirpilja minn dan l-attakk tal-qalb?  
*What information were you given on how to adapt yourself following your heart attack?*

- Kif tahseb li n-nurses jistghu jghinuk l-aktar biex ittejjeb il-qaghda tieghek?  
*How do you think the nurses can help you best to improve your condition?*

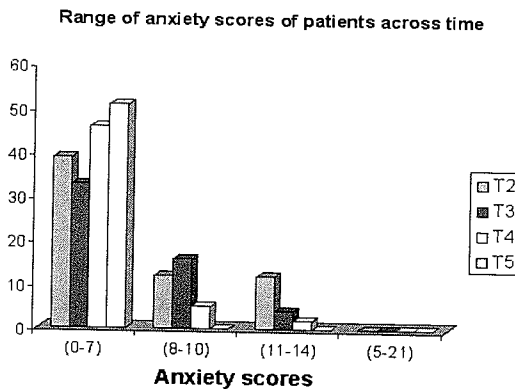
This data was collected on patients' transfer to the medical ward, between July 2000 and March 2001. Each interview was audio-tape recorded and transcribed for better interpretation of data.

### Ethical Considerations

Permission to conduct this research was granted by the Chairperson of the Medical Services and Director of nursing services. A written informed consent was obtained from the sample of patients. Since this study is part of a longitudinal study, confidentiality was ensured in the use of coding system to inhibit identification of patients. Finally, precautions were taken to maintain participants' privacy and to protect them from any harm or discomfort.

### Findings And Discussion

Figure 2 shows that on transfer to the medical ward (T2), 61.8% of patients (n=39) were found within the normal range of anxiety level



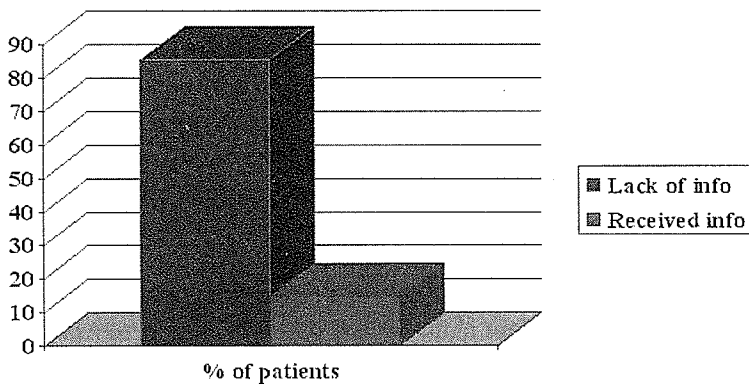
**Figure 2. Range of anxiety scores of patients across time.**

(0-7). This was further sustained by 62.3% of patients (n=33) on discharge home (T3) and 86.8% (n=46) at 6 weeks after discharge (T4). Three months after discharge all patients were within the normal range, (T5).

These findings are congruent with results of research where patients rated themselves within the normal (0-7) and mild (8-10) range of anxiety during their recovery period (Terry 1992, Chiou *et al* 1997). This is possibly because anxiety may be associated with threat, such as uncertainty about the cardiac health status and feelings of vulnerability (Havik and Maeland 1990, Stewart *et al.* 2000). However, according to Bowman (2001), anxiety may be considered as an effort to adjust to the situation. One of the strategies sought by patients was searching for information about the severity and progress of their illness and ways of adapting themselves to a new lifestyle.

### Figure 3. Information-giving to patients as perceived by patients

Unfortunately, findings revealed that the majority of patients (n=60, 85.3%), perceived lack of information-giving from the MDT, including the nurses. One is to note that during this data collection, an occupational therapist, working on a part-time basis, took the initiative to visit patients with MI individually while on CCU. A list of *do's and*



*don'ts on rehabilitation* were explained to them individually. However, these patients felt the need to have these explanations in the presence of their spouse for better comprehension. Moreover, they expected further information-giving from the nurses and MDT on the medical ward, on their way to discharge. Thus, the need of family participation in the rehabilitation process is consistent with the literature highlighting its successful impact in the recovery period. (Thompson 1989).

For clarity purposes, patients' quotes are presented in Maltese, as Maltese language can be highly explicit about the role of the nurse and MDT as information givers, as stated by this female patient,

*'In-nurses m'ghandhomx cans wisq biex joqogħdu  
jitekllmu naqra miegħek u jfehmun xi jkun qed jiġri minnek.  
Ara bil-lejl iva, jekk jarawk imqajjma, jiġu u jaraw kif  
jistgħu jgħinuk u ġieli qagħdu jitekllmu naqra miegħi.  
Kienu jissollevawni ħafna meta kienu jiġu hdejjja.....  
Jiena għadni żgħira u barra l-attakk tal-qalb, messitni  
wkoll id-Dijabete. Qas naf fejn se nagħti rasi!  
(crying). ..... S'issa qed inhalli f'idejhom, imma nispera  
li xi nurse jew tabib ifehmuni sewwa x'għandi nagħmel  
għal meta nsib ruħi waħdi d-dar..... X'waħda din hajti  
mbiddlet mill-lejl għan-nhar! (crying)' (F1, 51 yrs).*

This patient had a hectic life before the onset of this illness which threatened her life and interrupted her independence. This interview was carried out 48 hours after her transfer to the medical ward from CCU where she had stayed for five days. According to the literature, education of patient should start from day one of hospitalisation. It is well known, that rehabilitation of this middle-aged patient entails the contribution from various members of the MDT. Therefore, one would wonder why this patient, had not received any formal information by the seventh day of her admission, in preparation for her discharge. This may be because there is no *formal rehabilitation programmes* in hospital for patients with MI or Diabetes.

Furthermore, the nurses and MDT may take things for granted as expressed by this male patient:

*'Ma nistax ingerger minn nurses. Kienu jiġu jqassmu l-pilloli u anke jittestjawli d-demm għaz-zokkor. Għalkemm qaluli li kelli attakk tal-qalb, imma x'wa'da din, tibqa b'xiber imnie'er għal xi informazzjoni li jistgħu jagħtuk. .... Ma jgħidulek proprju xejn, donnhom jistennew li aħna nafu kollox. Kif ngħidlek jien, iħalluk lampa stampa! (M04, 59yrs)*

Additionally, the paternal role of the medical team may hinder patients' participation in decision making about their own care as illustrated by this male patient prior to discharge,

*'Deherli li kont smajt il-professur li wara jumejn li ġejt f'din is-sala, kellu jibgħatni d-dar. Imma tqarraqt għax dewwimni ġimgħa hemm. .... Baqgħu sejr in-bl-investigazzjonijiet. Għall-ewwel jiena ħsibt li hemm xi ħaga ħażina. Santa Marija, lanqas jgħidulek xejn, iħalluk fil-għama. .... Jaħasra n-nurse ma kienx mal-Professur meta ġie jarani, għax kieku ma kontx niddejjaq nistaqsih kif u x'fatta meta narah wara. Madankollu, il-'head nurse' ġieli ġie jtkellem miegħi, imma aktar tkellimna fuq in-Naxxar [fictitious] fejn noqgħodu, milli fuq dak li xtaqt inkun naf għalija personali'. (M02, 68yrs)*

This patient was expecting the nurse's assistance during the ward round. This denotes that the nurse is still considered by patients as their advocate in order to clarify misunderstandings during communication between the patient and medical team. Thus one would ask:

- Why is it that the nurse's presence is not available to patients during these visits?
- Is it simply because the wards are overloaded by patients? Or

- Perhaps because there are too many medical firms on the ward, with too many doctors attending patients at one time? Or
- Is it because the nurse has resigned from her advocacy role in the care of patients? Or
- Is it because the nurses are taking for granted the following Maltese code of ethics statement,

*'Patients who wish not to be told certain things, and who prefer to leave everything in the hands of their carers, whom they trust to do the best for them, should have their wishes respected'.*  
(No 1.5., 8)

On reflection, one can say, that whenever we, as nurses, have a close relative in hospital, our preference would be to be present during the ward round. This is to ensure that we won't miss any useful information, for the benefit of our beloved relative. Therefore, why don't we try to assist patients as if they are one of our closest relatives?

Moreover, the findings revealed that patients received information about their progress *only* when they or a member of their family, took the initiative themselves to ask specifically for the information from nurses or MDT, as expressed by this male patient,

*'Sew tas-sala fejn kont u sew t'hawn, mhux għax jagħtuk xi nformazzjoni ta' l-għageb....Anzi mill-inqas!...Jekk ma tistaqsihomx int, m'hemmx ans li tiegħu xi informazzjoni fuqek innifsek minn għandhom'.*  
(M10, 51yrs).

This was echoed by another male patient with a higher level of education stating,

*Sinċerament ma tantx nara differenza wisq bejn is-sala li kont fiha u s-sala tal-medicina. F'waħda għandek nurses b'moħħ*

*tekniku għall-aħħar u fis-sala tal-medicina jidhru li ma jistgħux ilaħħqu max-xogħol kbir li għandhom minhabba li hemm numru kbir ta' anzjani. Il-problema fit-tnejn qegħda, li jekk ma tistaqsix inti, lanqas biss jindenjaw ruħhom li jgħidulek x'riżultati ġew, wara li jkunu ħadulek id-demm jew xi jfissru xi investigazzjonijiet li jkunu saru fuqek. Huwa l-pazjent għandu bżonn isaqsi, ngħid jiena???. Mind you, jiena saqsejthom ta, bla waqfien, għax jien, irrid inkun naf-fejn jien'*  
(M22, 58 yrs).

This patient appeared to be assertive enough to seek information himself on his own initiative. However, literature asserts that the nurse's role is to assist patients, to obtain the necessary information, according to the policy of the hospital, to enable adaptation to the new life situation.

Unfortunately, one is to note that the nurses might not be considering themselves as a resource of information which may help in relieving anxiety. This was expressed by several patients stating,

*'Hawn, fis-sala tal-medicina, hawn bruda tremenda, orrur! Kemm jagħtuk the 'bear minimum'. Fis-sala l-oħra n-nurses kienu jaqđuna b'interest kbir, imma hawn, għax jarawk forsi fuq saqajk, jaħsbu li inti 'self-sufficient'. Imma, Alla jaf minn x'hiex tkun għaddej. Għalhekk jeħtieġ li n-nurses ma jqisux bħala xogħol dak ix-xogħol ta' l-idejn biss, bħal pereżempju, jqassmu l-pilloli. .... Imma tajjeb li jiddedikaw xi hin biex jitekllmu mal-pazjenti. Jiena taf x'qed ninnota li l-ftit hin li jkollhom free n-nurses jingabru hdejn id-desk, jew jaqraw il-gazzetta jew ipaċpċu bejniethom. .... Eh jaħasra, kemm jistgħu jgħinuh pazjent, kieku kellhom isibu naqra hin biex joqgħodu jitekllmu miegħu halli jgħinuh jiċċara xi diffikultajiet qabel ma johrog mill-isptar'.*  
(M10, 51 yrs)

Thus, nurse-patient communication appears to be considered by patients as a means of support to cope with their illness, and a stepping stone to ask the necessary information, as exhibited by this female patient,



*'Forsi qed nistenna hafna minnhom! Għax kieku x' se jtilfu kieku jiġu naqra hdejna u joffrulna tbissima? Tbissima tan-nurses qisha fjamma tixgħel! Kieku forsi, naslu ngħidulhom x' inhu jinkwetana u nistaqsuhom x' għandna bżonn nagħmlu biex ma jergax jaqbadna dak l-uġiegh. Anke kieku kellha tiġi hdejek, taqbadlek naqra jdejku u tghidlek bongu, kif inti? Ukoll tagħmillek kuraġġ u s-salib tħossu eħfef. Unfortunately, minn dan, ftit li xejn isir... Imnalla nitkellmu bejnietna l-morda, għax hekk ngħinu lil xulxin mill-esperjenzi tagħna, sirna qisna familja f' qasir żmien. Barra minn hekk, imnalla li t-fal marru jkellmu l-professur privat, għax hekk naf fejn jien f'saħħti'.*

*(F45, 82 yrs).*

This statement exhibits the Maltese culture whereby patients and their family may use various ways and means to obtain the necessary information about the patients' health and rehabilitation at all costs. Through experience from this study, I could realise how much patients appreciated the fact that at the end of my visit for data collection, I allowed some time for their queries and also referred them to the respective consultations, such as dieticians, physicians and radiographers.

Finally, the factors pointed out by patients, such as reluctance of MDT to give information to patients, work overload and time constraints, may inhibit the process of information-giving in hospital. However, it could be argued that several other factors may still be concealed, such as hospital policy and reluctance or unwillingness of MDT to give information. Thus, to overcome this weakness, it is suggested that nurses and MDT 'get into the patient's skin' (Henderson 1969) so as to empathise with patients' needs and problems.

## **Recommendations**

Current assessment of patients by the MDT may recognise a fraction of their informational needs, just the tip of an iceberg. Hence, formal rehabilitation programmes are recommended to equip patients with the necessary information to enable them to adapt to their situation.

Moreover, further research is suggested to increase awareness of the MDT on the importance of information-giving to patients by:

1. replication of this study on patients with other diseases.
2. conducting a comparative study, whereby the informational needs expressed by patients, are compared to those, as perceived by nurses and MDT.

Finally, understanding by the nurses and MDT of the importance of information-giving to patients will pave the way towards change of attitude. This will enable patients to rehabilitate themselves to the new lifestyle with relief of anxiety. It is well known that the construction of the new hospital, *Mater Dei*, is at an advanced stage. However, I hope that reconstruction of nurses' attitudes be promoted by further education in order to bridge the gaps identified by patients and to actualise information-giving in care, which is ultimately the right of the patient.

### **Aknowledgements**

I would like to acknowledge the contribution of the University of Malta for funding this research project, and the 70 patients who participated in this study. Their experience of a life threatening illness may increase our understanding of the informational needs of the Maltese patients in order to help them cope with their illness.

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# Workshops Reports

## Report of Workshop A: Information giving

**Rapporteurs: Cecilia Xuereb & Ray Grixti**

- The participants at the workshop were presented with five questions relating to patients' right to information. The group divided into five subgroups and each one discussed a different aspect of the issue. There was, however, quite a bit of overlapping in the discussions. This was to be expected since the questions were interrelated.
- All the groups mentioned that there is a lack of inter-disciplinary communication. Information-giving is doctor-centred, and nurses feel that they are considered inferior. As members of the team they are different players on the same playing field. Very often they find themselves pressed by patients who ask for information, which they would like to, but cannot divulge since this has not yet been given to them or to the patients by the doctor or the consultant. While diagnosis and prognosis should be strictly the field of the doctor/consultant, sometimes they feel that they are in a better position to communicate other information since patients feel that they have built a relationship with them and feel more at ease with them than with the doctor. Passing of information among members of the team is not breaking confidentiality provided this is used in the care of the patient.
- Nurses do not know where they stand: they feel that they are voiceless since there is no provision for any set-up similar to the customer service which is available for patients.
- The need for on-going professional training was also stressed by most groups. Training in social and psychological skills,

the presence of psychology nurses, counsellors, social workers in hospital and specialist nurses at health centres was stressed.

***Q.1 Why do you think there's so much lack of information giving?***

- The main reason was that the consultant/doctor withheld the information from the nurses and from the patients in the first place. Thus nurses felt they could not divulge this information even when the answers to patients' questions were obvious to them.
- There was a lack of financial and human resources.
- Pressure of time (foreign professionals seemed for some reason to find more time for the patients).
- The level of education of patients, the language as well as their religion also led to militate against information giving.

***Q.2 What ethical issues guide information giving?***

- The group felt that this question should have read as "what ethical issues hinder information giving", since they found more elements that hinder than any that guide.
- In paediatrics and midwifery it is often difficult to find out who the legal guardians are in the case of separated parents and minors.
- The members of the team are not treated equally.
- The preparedness and capacity of patients to understand and cope with the information.
- The right of close members of the family to such information, especially when the patient is unable to receive such information. Care must, however, be taken in the case of relatives who ask that the patient should not be informed of his/her condition, since this is often due to selfish reasons, since they would not be able to face the patient who knows about his/her condition.

***Q.3 What is the hospital policy in giving information to patients?***

- As far as persons present know, no such policy exists, and information giving to patients is at the discretion of the consultant.
- There should be a policy and this should be clearly stated in writing.
- Information should include post-hospitalisation care and treatment, which should be given in writing to the patient when s/he is discharged from hospital. Specialist nurses should be present in health centres where patient gets such post-hospital care.

***Q.4 How does our culture influence information giving?***

- Malta being a small island in which the extended family is closely-knit culturally, differences do not present a big problem. However, it is important to keep in mind that each patient is unique, and there can never exist a single blueprint for the nurse/patient relationship.

***Q.5 Recommendations to be taken to increase awareness and action in giving information.***

- On the whole the profession is very much aware of the need and the right of the patient to be given information.
- Preparation for information-giving should form part of the nurse's continuing education. The patient too should be prepared to receive such information which is to be given in simple words free of medical jargon.
- The patient should have access to documents, charts and reports, which might need to be interpreted by the nurse.
- The patient should be encouraged to ask questions, since often s/he is too inhibited to do so.
- Better patient allocation and a different roster for nurses would foster information-giving. The present roster system interferes with continued care of patients.



- There should be special places where the information is given to patients/relatives by the consultant. The nurse should be present during these sessions.
- In case of information which is traumatic, there should be a place for cooling down and counsellors should be available.
- It was even suggested that information packs be made available to patients both when they are admitted to hospital as well as when they are discharged.
- Finally the group noted a big paradox: patients have a right to access the file containing his/her medical history while on the file there is written “Confidential: not to be handled by patients”.

## Workshop B: Confidentiality

**Rapporteurs: Claire Farrugia & Jesmond Sharples**

***1. Is it really possible to maintain confidentiality with so many people involved in providing health care?***

Confidentiality should always be maintained, even though many people are involved. Unfortunately, however, this is not the case. Many health care workers are not aware of how sensitive and personal the information disclosed to them is.

***2. Should relatives have a right to know especially in a situation where one's partner is infected with HIV?***

This question raised several difficulties. If one is involved in a long-term relationship, one is offered counseling to help him/her reach the decision to let the partner know. The nurses working in this area said that many eventually decide to do so themselves. If the person does not make up his mind, then a target date is given and after that the consultant may inform the patient that he will let his partner know himself. Public good would override individual good. On the other hand, this may pose a problem since confidentiality is the crucial point behind HIV testing promotions. If confidentiality cannot be guaranteed, people might not come up for testing later on.

In short - term relationships, one may not inform the partner because both involved were aware of the risks encountered in this one night stand. It was said that in other countries, when this happens, the HIV positive person is asked to recall all the persons with whom he/she had a casual sexual relationship. These are then informed by post to go for HIV testing, because one of the persons they went with became HIV positive. If they do not turn up, health workers from the unit call personally at their home.

## **REPORT ON WORKSHOP C: ACCOUNTABILITY**

**Rapporteurs: Maria Abela & Winifred Buhagiar**

The following were the issues discussed in this workshop, and points raised during discussions.

### ***1. What are the ethical and legal implications of accountability in clinical practice?***

- Everyone is responsible for his/her action.
- There should be standardisation of procedures to be carried out identically in the same in the same hospital.
- There should be good documentation, i.e. it should be clear and well defined.
- That all treatment is to be prescribed beforehand and not given over the phone. Consensus was reached that it is illegal to administer non-prescribed treatment but it is very daring to challenge doctors.
- That there should be double checking before giving drugs.
- That junior staff/newly qualified staff should be given adequate training

### ***2. Who is really responsible for the patient?***

- All members of the multidisciplinary team are responsible, including the clerk and the maid.
- In a ward setting the nurse is responsible for every decision taken regarding the patient including the prescription of drugs.
- The training of newly qualified staff has also been emphasised.

### *3. How can accountability be encouraged in clinical practice?*

- It was agreed that education is very important for being accountable, i.e. every member of the team should be knowledgeable, and that on-going educational programmes/ in service training should be compulsory.
- Standardisation of procedures and the setting of guidelines and policies are very much needed.
- The importance of the Patient's Charter was also discussed.
- Communication systems should be enhanced, e.g. the setting up of regular meetings amongst all members involved.

## **Report on Workshop D: Significance of code of ethics and the patient charter**

**Rapporteurs: Sarah Saliba & Michael Bezzina**

### ***1. What is the relevance of the code of ethics in clinical practice?***

Codes of ethics in clinical practice serve as guidelines for the healthcare professional that include the rights, responsibilities and limits within the profession. They also guard both the healthcare professionals and the patients against abuse.

### ***2. To what extent are health carers aware of this Code of Ethics?***

Most of the nurses felt that although they are aware of the Code's existence and have been given the booklet, some are still not aware of its contents. It was argued that there could have been better "launching" of the Code. Suggestions were put forward regarding periodic awareness sessions of the Code. This may be done through seminars at the workplace. The nurses felt that the Code could be better understood if discussed with examples by case studies.

### ***3. What are the characteristics of the health care professional according to the Malta Code of Ethics?***

The characteristics of health care professionals should encompass the qualities of maintaining confidentiality and patient empowerment. The importance of projecting a professional image was highlighted. This can be achieved by keeping up-to-date with current issues and practice development.

### ***4. Are patients aware of their rights and responsibilities? How do they become aware of them?***

Patients may not always be aware of their rights and responsibilities. There are several ways of how one can promote awareness of the patient

charter. For evaluation purposes, some suggestions included giving relevant booklets on admission and self-administered questionnaires upon discharge. These serve as an audit to assess patient satisfaction.

One also needs to invest in more education of staff to reduce the paternalistic attitude that obstructs patients' rights. Since some patients who take on the sick role tend to have a submissive attitude, it is even more important to empower them with information. Media may also be utilized to promote patients' rights and responsibilities.

**5. *Should the nurse act as a patient's advocate when the patient's rights are violated?***

Yes. However one needs to assess the situation and go through the appropriate people.

**6. *When something goes wrong in the clinical situation, should the health carer act as a whistle-blower?***

Yes. However one needs to use tact, knowledge, good communication skills, and be assertive. Prior to whistle-blowing on malpractice, one needs to know and have evidence based knowledge on practice.

# **Ethical Issues for Nurses and Midwives: Conclusion**

**Grace A. Jaccarini**

This morning we had Dr Sandra Buttigieg, Prof J Rizzo Naudi, Prof Maurice Cauchi and Dr Ray Busuttill, the Director General Health address this large gathering of nurses and midwives!

They all noticed your keen interest to be here on a rainy Saturday in November to learn more about ethical and legal issues in health care.

This seminar provided a much-needed opportunity for reflection and dialogue about ethical dilemmas which you face in your daily practice. We also listened to some excellent presentations about a Maltese perspective, a legal perspective, the patient's perspective and about the challenges for the future. We participated in the workshops. But now you may ask, what next? We will have achieved the first step if we go away from here feeling that we need to do something to improve our practice in this regard. We will change things if we want to change things. As Donia Baldachinno mentioned, "we must bridge the identified gaps".

Maybe a formal committee as an offshoot of the Bioethics Committee should be set up to develop guidelines on mechanisms to help nurses and midwives to review their rights and responsibilities in their practice. Although the study of ethics is an integral component of the nursing curriculum on our courses at IHC, what about continuing education in the workplace? As Dr Busuttill said "the cultivation of these principles is not automatic and not always easy." The code of ethics may state that nurses are responsible for furthering their education and development, but what about the need for an institutional culture with supportive conditions, where nurse leaders together with other health caring professionals, (it is important to have interdisciplinary working)

could engage in regular meetings to discuss case studies to further knowledge and confidence in this area?

The busy work schedules must not be used as an excuse to put off doing something concrete. But if we really want to do something about it, then we will need to talk more, to lobby, to assess, to plan, implement and evaluate matters in our immediate field of work.

We must carry out research, set up networking and encourage discussion in order to be able to move forward. If we can build up an enabling practice environment, then we will be able to create the opportunities, the confidence, the authority and the accountability to identify and to try to solve these practice-related problems.



**Section B:**  
**Ethical Issues in Family Practice**

# Ethical Issues in Family Practice: Future Perspectives

**Professor M.N.Cauchi, Chairman Bioethics Consultative Committee**

We live in an age where ethical issues are becoming ever more significant. This has been the result of recent advances in medical research in many areas of medicine particularly those that relate to early human development, including stem cell research, which is currently ushering a revolution in our thinking about therapeutic modalities. Likewise, genetic research and pharmacogenetics in particular promise to revolutionise our practice in relation to use of medical products. Not least, we see a fundamental change in the expectations of our patients who now demand to be treated as equals by their treating doctors, and not as passive receptors of medical largesse.

For this and many other reasons, ethics has become an urgent imperative that needs to be tackled by all health professionals. We cannot any longer ignore the need to familiarise ourselves with the issues raised and discussed in current ethical literature. We have to be familiar with the problems, and devise mechanisms of solving them.

It is for this reason that the British Medical Association has recently published a Handbook on *The Medical Profession and Human Rights* (2001), which encapsulates issues relating to human abuses worldwide. It makes a very strong plea for ensuring that medical ethics is taught in medical schools as a compulsory subject, because, as it well says, "Doctors need to have skills in moral reasoning to reach a justifiable balance between conflicting moral imperatives and the duties owed to both individual patients and society at large. It requires objectivity and access to sources of sound ethical advice" (p 8). A more detailed resume relating to this topic was published in the Bioethics Newsletter last October. This is also one reason why it is so

disturbing that our University Medical School still finds it unnecessary to have formal ethics teaching to medical students, a topic which has found its way as a compulsory subject in most of the medical schools in Europe.

The Bioethics Consultative Committee endeavours to ensure that the topics of bioethics is kept at the forefront. Organisation of conferences of this kind, in collaboration with bodies such as, in this case, the College of Family Doctors, and the Malta Chamber of Pharmacists, enable us to share our ideas with practitioners in the field, a process which hopefully will be found beneficial to all those who participate. We have been publishing these proceedings regularly for the last five years, and we hope that we shall continue along these lines in the future. As I am sure you are aware, we also publish the Newsletter which I mentioned earlier, and which is distributed to all family doctors and now also pharmacists and other health professionals. I would like at this point to make a plea to you to participate also in this exercise, by sending your comments and points of view. Finally, we try to reach the general public through participation in radio programmes, such as the one currently organised by Dr Pierre Mallia and Dr Janet Mifsud on University Radio, as well as by writing articles of relevance to the daily papers.

I believe that the issues to be tackled in this conference are of considerable interest and importance. They cover a broad range of topics dealing with the family doctor and pharmacist within our changing society, emphasising the role of the individual practitioner, the speciality, as well as aspects of research and collaboration in tertiary care.

# The Ethics of Family Medicine: A Dutch Perspective

G.K.Kimsma, MD, MPh

## 1. Family Medicine

In my contribution I shall approach my subject both philosophically and medically. I shall orient myself to the problematic nature of family medicine more than ethics.

The term *ethics of family medicine* suggests the existence of a specific field, called family medicine, and the presence of a set of values, norms, rules and guidelines, that in their totality are the 'ethics' of that specific entity called family medicine. Family medicine as a form of medicine, usually practised near where potential patients live in their natural habitat, that is distinguished from other types of medicine, such as specialist medicine, as practised in institutions such as hospitals. Sociologically there are major differences between the structure and function of family medicine and medicine practised in institutions.

A description of the ethical aspects of family medicine must be preceded by understanding what family medicine is, at least how one presently describes it. In this description both the ideology, the aspirations and self understanding and self perception of that field become clear.<sup>1</sup>

In the second place, ethics in medicine is not a clear, fixed given either, nor is the field rich in literature. The book by Christie and Hoffmaster, *Ethical Issues in Family Medicine* (1985) has no comparable successor, even though there are extremely interesting parts in Dowrick's and Frith's *General Practice and Ethics* from 1999.<sup>2, 3</sup> Also in the

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<sup>1</sup> Kimsma GK. Huisartsgeneeskunde. (Family Medicine) In: H ten Have, D Engberts. GK Kimsma et al.(eds) *Ethiek en Recht in de Gezondheidszorg (Ethics and Law in Health Care)*, Houten, Bohn Stafleu Van Loghem, 1992; XII: 1-23.

<sup>2</sup> Christie RJ. CB Hoffmaster. *Ethical Issues in Family Medicine*, New York/Oxford, Oxford University Press, 1986.

<sup>3</sup> Dowrick C. L Frith. *General Practice and Ethics*, London/New York, Routledge, 1999.

Netherlands there are few publications, considering the fact that more than half of the daily medical activities in this country are within the confinements of primary care.<sup>4,5,6</sup>

The conception of ethics in medicine in itself has gone through several changes and needs further analysis. These changes can be summed up as:

- a) medical ethics as ethics and etiquette of the profession,
- b) medical ethics as a branch of general ethics within a specific field of application namely, medical practice.<sup>7</sup>
- c) Medical ethics as the application of ethics to medicine, such as an engineer applies general rules to particular problems.

Ethics in that conception has a universally valid set of basic statements or principles. It is an interesting issue whether family medicine has an internal morality, reflecting it's specificity. I shall not go into detail with respect to this question, with the exception of 'psycho-social' complaints. Mainly I shall be descriptive of what the issues in some of the particular areas of family medicine are, such as the beginning an end of life.

## 2. Epistemological processes in health

First of all, I shall concentrate on the epistemological processes in health care in general and then describe Dutch primary care in its self understanding.

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<sup>4</sup> Dillmann R. E van Leeuwen. GK Kimsma (eds) *Ethiek in de medische praktijk*.(Ethics in medical practice) Utrecht, Bunge, 1993.

<sup>5</sup> Heijerman E. H ten Wolde. *Practische Wijsheid. Morele vragen in de huisartsenpraktijk* (*Practical Wisdom. Moral issues in family medicine*),Utrecht, De Tijdstroom/Stichting O&O, 1994.

<sup>6</sup> Willems D. M Hilhorst.*Ethische Problemen in de Huisartsenpraktijk* (*Ethical Problems in Family Medicine*), Maarsen, Elsevier/Bunge, 1999.

<sup>7</sup> Ten Have HAMJ. GK Kimsma. *Ethiek in de gezondheidszorg* (Ethics in health care). In: H tenHave, D Engberts GK Kimsma et al (eds) *Ethiek en Recht in de Gezondheidszorg*. Houten, Bohn Stafleu van Loghem ,1992; I: 1-52

In its most general form one can assess medicine as an institution that shapes the destiny of individuals and of societies in ways that explicitly are agreed upon, but also through implicit social contracts. Medicine is one of the basic social institutions, in each society. Medicine, law and religion all relate to man as a finite being, capable of good but also evil. Each discipline shapes human destiny by exercising certain approaches involving *human behaviour as deviant behaviour*.<sup>8</sup> And each discipline exercises a certain form of control to realise its ends. Medicine's goal and deepest orientation is *on health and disease*, the law's area of interest is *crime and punishment*, and religion concentrates upon man as a sinner and behaviour to please the gods or the acquire *an afterlife* after earthly life.

It is important to look at the interactions between these various professions in order to see the ideologies. I have always been struck by the observation that in the Middle Ages the doctor was allowed at a deathbed only after the priest had provided the sacraments. Nowadays it is the physician who dominates the final phase of life. In the sixties sociologists like Rieff<sup>9</sup> and Zola observed the replacement of hospitals as opposed to churches and parliament as the archetypical institution of Western culture. This replacement started with the Enlightenment ideal of control through rational interventions during the French Revolution. Foucault has pointed out the replacement of the priesthood by physicians and the adoption of medicine as the institution that could provide life without the evils of disease. Medicine besides democracy was viewed as an instrument to further the ideals of a revolution.

In a certain way this applies also to modern medicine. Family medicine can be called the most sensitive institution to changes in societal culture and norms. In a certain way, without going into detail, family medicine can be seen as the amalgam of currents that are known as the post-modern phase of our culture, reflecting the influx of the individual and the loss of absolute criteria and fixed points.<sup>10</sup>

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<sup>8</sup> Scheff T. *Being Mentally, Ill*, Chicago, Aldine, 1966.

<sup>9</sup> Rieff Ph. *Freud and the Mind of the Moralists*. New York, Viking Press, 1959.

<sup>10</sup> Smith S. Ethics and postmodernity, in: Dowrick C and Frith L. (eds) *General Practice and Ethics*, London & New York, Routledge, 1999: 91-107.

Medicine's area is behaviour that is deviant from the health norm, as in sickness. The Law realises the norm of justice and religion's function is the realisation of a good moral life to procure eternity or to prevent evil through the anger of the gods. Each social discipline has a specific set of language games that is called a 'discourse', more or less a unity of thinking, of speech and of action. Each discipline organises itself around a particular subject. In *medicine* we speak of the deviant as a *patient*, in *law* we speak of the *criminal or the accused* and in *religion* we speak of the *sinner*.

This abstract angle is necessary in order to show the shifts in mobility of the various domains and the shifts in interactions, where certain forms of deviant behaviour come to fall within the domain of another discipline. Examples of social behaviour that have shifted discipline of control are, for example, sexuality, sexually transmitted diseases, abortion, alcoholism, emotional problems, suicide and drug abuse, just to mention a few.<sup>11</sup> Even the meaning of poverty has shifted: now it is accidental, formerly it used to be a crime, and in even earlier times it was an expression of the wrath of the gods. This shift to define social ills as medical problems without treatment of the context has come to be known as the 'medicalisation' of life.

The medicalisation of life, hardly a theoretical problem in the present reflections, can be seen as the medical expression of the domination of technology and the rational state of mind, the project of the Enlightenment. At least two names were indirectly related to this awareness, even though it was not customary to refer to them: Herbert Marcuse<sup>12</sup> and Ivan Illich.<sup>13</sup>

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<sup>11</sup> Zola IK. *De Medische Macht. De Invloed van gezondheidszorg op de maatschappij.* (Medical Power. The Influence of Health Care on Society), Boom, Meppel, 1973.

<sup>12</sup> Marcuse H, *One Dimensional Man. The Ideology of Industrial Society.* London, outledge and Kegan Paul, 1964.

<sup>13</sup> Illich.I. *Limits to Medicine. Medical Nemesis. The Expropriation of Health.* London, Marion Boyars, 1976.

### 3. Dutch Primary Care

What is family medicine in the Netherlands? 'First line medicine, gate keeper and bookkeeper'.

Family medicine in the Netherlands, but not only there, is not a static field or practice. Consequently, its description and self perception reflect changes in goals and aspirations. To make matters more complex: family medicine as a specific field is part of the medical enterprise and this larger enterprise certainly not static, but in constant flux and changes under pressure from other areas of social life and other professions dealing with deviant behaviour. Consequently, the goals are not limited to cure, care and prevention, but are also directed at transforming bodies, individuals and even life styles, sometimes without adequate reflection, simply following the developments of science.

Dutch primary care is practised by family physicians most of whom (60%) are still in a home-based practice, working alone with an administrative/medical assistant, even though, more and more, they tend to practice as group practices and share facilities in formalised co-operation with other professions, such as physical therapists, nursing staff and social workers. A normal practice has about 2350 patients. Patients 'belong' to one practice and families usually have one and the same physician, sometimes for generations. Each patient 'has' his own physician and often there are long term relationships between doctors and patients, depending on how stationary a population is. The number of 2350 is the norm on which calculations of the income of physicians are made. Physicians are reimbursed for providing interventions 'in natura' as they are called: prescriptions, surgery, advice and guidance.

There is no free medical care, as in Malta. Patients carry insurance: about 70% have mandatory insurance as part of their employment, and insurance premiums are paid by both employer, the largest share, and employee, a token fee. The physician is reimbursed by the insurer through a lump sum, irrespective of how many times a patient sees his physician. Part of this is paid every month. For the other 30% of the



patients there is the option, taken by almost every one, of a voluntary insurance. These patients pay their physicians on a fee for service basis, and receive bills at the end of each month, they pay and are reimbursed by their insurance companies.

Family physicians have a formal obligation to assist their patients 24 hours a day, but can share this task and divide the duty among each other for evening, nights and weekend duties. It now has become customary to form large groups that function in one location for this duty and have one or two physicians, with a support staff, covering the acute care for about 100,000 people.

#### **4. Fundamental Aspects of Dutch Primary Care**

Fundamental for Dutch primary care is a contractual doctor-patient relationship. Four factors or currents are observable in the development of Dutch primary care: anti-one sided technological approaches, emancipatory, legal and economical, as in dealing with limited resources.

##### **4.1. Introduction**

Dutch family medicine is the result of social and societal changes. In the present phase, it is the result of resistance to a dominant technology, based on a pathologico-anatomical conception of disease. On the one hand, the idea was to correct the elimination of social causes of illness and disease. In this respect one can observe a *critical anti-establishment approach*. Dutch primary care was forced to re-evaluate its mission in the fifties, when technological medicine became the dominant force to address health care problems. This domination of technology and technological answers to health care problems resulted in a loss of professional self esteem and a fear that primary care might disappear altogether, because family physicians lost the ability to help patients because of their inability to use technological instruments, to which they had no access. In this period, medical students almost automatically choose to become specialists, and a minority choosing to become GP's

were more or less pitied and placed lower within the professional 'pecking order'.

The resistance to this social current led to a revival of the field.<sup>14</sup> A new society was founded, *het Nederlands Huisartsen Genootschap (NHG) (The Dutch Society of Family Physicians)*, a new definition was agreed upon, describing family medicine as 'continuous, personal and integral care for the health of the entrusted individuals and families'. Research facilities were made available and Chairs of family medicine were established at all universities, some were occupied by well known physicians without a PhD. This emancipation led to a new awareness and reflection on the specific type of health problems family physicians encountered beyond the clinical diagnoses, and beyond organic and psychiatric pathology.

This emancipation and recognition resulted in developing mandatory post-graduate programs in order to be licensed as a family physician and to be able to 'settle oneself' and open shop.

There was a debate on the 'paradigm' of family medicine. Its major value was the realisation that the paradigm was a more complex issue than the desires of its practitioners for recognition were capable of realising. More important, to advance quality in family medicine, the NHG started an ongoing project to define and describe 'standards of medical care' for 'first line pathology' as professional guides for 'good medicine', integrating new developments in a process of continuous review of these standards.

#### ***4.2 The definition and the role of gate keeper***

The definition of family medicine as '*continuous, personal and integral care for individuals and families*' however gave impetus to deeper reflections on the differences between family medicine and hospital medicine. Family physicians considered their position as located

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<sup>14</sup> *Hoe helpt de dokter? (How does the doctor help?)* NHG Report, 1975.

between the 'lay system' and 'the medical system' and developed a view of their locus as 'gate keepers' to the medical system, based on the conviction that many persons with health related complaints do not necessarily profit from receiving an interpretation and a 'label' as a disease.

The difference between 'illness' and 'disease' became the corner stone of the 'project family medicine'. This new awareness translated itself in the critical realisation that many health problems could not, but also, should not be defined within the nomenclature of the systems of clinical nosology. The problems that were meant were described *as psycho-social*, and the main task of the family physician was to relate the problems to the context of their origin. And it became a fundamental conviction that doctors not only do not always cure, but can be dangerous in labelling illness as a disease and change the self-perception of persons into the role of patients. Terms as proto-professionalisation became en vogue to express the medicalised self-perception of feelings of discomfort and illness by patients, who in effect qualified for normal societal duties, such as paid labour.<sup>15</sup>

### **4.3. Paternalism**

A second current was the integration of the emancipatory movement of the sixties and the development of centres where primary care physicians worked together with social workers, physical therapists and social nurses, doing home care. The emancipatory movement of the seventies wanted to eliminate all forms of unnecessary paternalism in society: at work, in the schools and universities, and in institutions such as health care. Paternalism became the dirty word and medical paternalism needed to be replaced by a liberated definition between doctor and patient as in a co-operative relationship, such as the equality model (Veatch), the contract model, or the transparency model (Brody). The position of patients was viewed as too dependent, the relationship

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<sup>15</sup> Kunneman HP. De Huisarts als Normative Professional. (The Family Physician as a Normative Professional). In: Bakker R. et al.(eds) *De Huisarts in 2010. (The Family Physician in 2010)*, Utrecht, De Tijdstroom, 1995: 147-163.

too asymmetrical in the division of power, and the patient too vulnerable because of these inequalities. Society viewed medicine as a backyard of paternalism and especially primary care integrated this awareness in trying to rid itself of unwanted limitation of responsibilities of patients. Hospital care, specialist medicine, with its technological orientation and its rigid hierarchical structures, were less sensitive to social desires and less capable of change.

#### ***4.4. Health Law***

The wave of emancipation was supported by health law, a profession and discipline that did not exist in the Netherlands before the sixties. Health law established itself as the advocate of patients' rights and succeeded in developing law that has become the cornerstone for medical practice. In 1995 the *Wet Geneeskundige Behandelingsovereenkomst (Law on the Medical Treatment Contract)* became effective, stipulating the rights of patients and the duties of physicians. The rights of patients are:

1. to be informed before consent, but also the right to refuse being informed.
2. the condition of consent
3. the duty to produce medical records,
4. the right to delete information from the records
5. the right of confidentiality, and information for third parties only after written consent
6. the physician cannot end a treatment relation except for important reasons
7. no medical research with bodily material without the patient's consent
8. medical records must be destroyed after a period of ten years.

There is much irritation about this legal tendency, because its fundamental preconception is an opposition between the interests of physicians and the interests of patients, as law is founded on the premise of opposite interests. This legal philosophy is not shared by doctors

and patients alike, and the law main frame is patients' rights as opposed to 'patients' duties, as many family physicians would have liked it to be also.

## **5. Ethical issue in primary care.**

One can locate the primary principles of medicine in primary care with different issues and at different moments in the course of treatment.

*Beneficence* for example can be expressed in the notion of due care, making options acceptable to a patient, effecting compliance, discussing quality of life issues, and realising confidentiality within the relationship.

*Non-Maleficence* can be observed in the areas of presumed consent, intending no harm by providing adequate information on the hardships patients have to endure in the course of medical investigations, explaining acceptable risks, and finally, at the end of life, in the area of treatment of serious symptoms that may cause inevitable death.

*Respect for autonomy* can be observed in the process of informing a patient, to get consent before interventions, showing the options of treatment refusal, and finally, at the end of life, having patients choose a death with dignity when medical options to cure fade, and comforting is only a partial possibility.

*Justice* in primary care is present in effecting equality in treatment options, in helping patients receive equal access to interventions and measures, in helping to divide scarcity and in the end, effecting 'fitting care' to the individual patient based on personal and individual needs.

Ethical issues in primary care are in many respects similar to the issues in clinical medicine, but there is a major difference, based on the location of family medicine between the medical and lay system. This difference concerns the specificity of family medicine: it is an expression of the internal structure of primary care as opposed to the concept of external morality.

*Central and opposed to clinical medicine is the notion of gate keeper ethics: necessary, fitting and just care, without unnecessary, redundant interventions.*

The limiting morality of that notion is, as an anti-medicalisation norm, as opposed to the clinical norm. The clinical norm reads that it is less offensive or more appropriate to presuppose the presence of a disease than its absence. The aim is to exclude the possibility of the presence of a disease rather than its opposite. The translation of this founding norm is the step by step approach in using medical technology to exclude the presence of a nosological entity, with a pathological term. In primary care it is as important to exclude the presence of a disease as to prevent the fixation in the mind of a patient that a disease is the cause of feelings of illness. In primary care there is an awareness that medical diagnostic interventions themselves carry a certain psychological meaning for patients and have effects for feelings of illness or wellness. This is what could be called an expression of the 'internal morality of family medicine'.

### ***5.1 The definition***

The morality of family medicine is also reflected in its definition: it is a *moral* definition. Family medicine's mission statement relates to a *continuous, personal and integral care of individuals and families and other forms of social cohabitation*. These terms are intentional ethical terms, stating goals to be attained and reflect visions of good care.

*Continuous* means developing a continuous relationship between doctor and patient, a relationship with a long time-span, that allows physicians and patients a functional relationship over time, with the hope that continuity will provide a better basis for fitting care, based on the presumption that previous episodes of illness are significant for interpreting and understanding illness behaviour. Continuity is a basis for familiarity, one that does not breed contempt but, on the contrary, trust and a better framework for good medical practice.

The term *personal* is like a double-edged instrument. On the one hand, 'personal' is used in opposition to 'functional', in the meaning of distant, or too objective. On the other hand, 'personal' expresses also the idea that having a personal relationship between doctor and patient is a paramount condition for better care. Knowing the patient as a person translates itself in a better understanding of why this person comes to see a physician with this particular complaint at this particular moment. For the physician, the term 'personal' means, that the doctor uses his personality as an instrument to promote the quality of care that is provided, with a knowledge of 'blind spots' and inhibitory tendencies in the relationships with particular patients, especially those with psycho-social complaints. The influence of Balint has been large in the Netherlands, and even today there is something of a revival of his ideas in groups that practice 'intervision', to discuss 'difficult issues' and 'difficult patients' and the reason for that experience in the physician's personality.

The term *integral* denotes the intention to place the patients' complaints, after analysis, back within the totality of a patient's life, viewing a patient as a totality, and not as a separate physical, psychical and social being. Integral in effect has also come to mean that any reason for encounter as the patient sees fit, must be taken seriously and scrutinised as to its meaning for the medical condition of a patient. That in effect means a vision on the medical domain that is quite totalitarian and exhaustive. The background idea is that any sign, any feeling of illness may be significant for further research, but after scrutiny may lead to a conclusion of 'innocence', and returned to the patient's life-world. The aim is to prevent what has been called by different terms, 'somatic fixation', the notion that an experience of discomfort may indicate a serious disease. Family medicine as an enterprise is keenly aware of the potential harmful effect of this change in meaning. And physicians in these phases can be the reason for additional harm.

### ***5.2. The beginning of life***

Family medicine, except in some rural areas without adequate structures of midwifery, has moved out of the function of delivering new born

babies. The medicalisation of normal pregnancies has become mediated with the integration of home deliveries and 24 hours hospital deliveries by midwives, with the option of medical interventions in case of endangered birth. Family medicine has become the area of prevention of pregnancies, through active oral contraception, where about 50% of the women in potentially child bearing age use oral contraceptives, with a slow lowering of that percentage due to risks of the so called third generation hormonal contraceptives. Family physicians routinely place IUD's. What is important to note, on moral grounds, is that this prescription policy also applies to young unmarried women, reflecting liberated views on sexuality before marriage as an adaptation to social changes of the sixties and pragmatic views on the additional harm of pregnancies as compared to the risks of hormonal contraception.

Since abortion has become a legal possibility by law, the personal views of physicians on the admissibility of artificial abortion have become irrelevant, because the law allows abortion up to 16 weeks gestation on specific indications. Yet in practice, any woman wanting an abortion can have one, since special clinics, related to hospitals for emergency events, admit women even without a referral of their family physician. The protection of life has shifted to the protection of the right of being free to choose to carry out a pregnancy, or to prevent, or to end it.

This shift especially has become visible in the area of genetic screening for Down syndrome or other genetic malformations in pregnant women over 36 years of age. This option, not a duty, usually leads to an abortion if and when the diagnosis confirms the presence of a deformity.

### ***5.3. Confidentiality and professional secrecy***

In this area, changes in societal pressures and extra-medical social developments are prominent. The static conception of confidentiality was based on an absolute secret of all information about a patient, with the exceptions of a physician's duty to report a serious infectious disease to the authorities. This absolute position has been mitigated and become more subtle over the last years, especially in conflict with



legal ideas about providing information. One can distinguish between *unsolicited information* and *requested information*.

*Requested information:*

With respect to this subject, the structure of arguments seems simple, but has complications. In general, no information may be shared, with third parties, not even authorities, without written consent of patients. That statement obtains also where it concerns the knowledge of criminal actions, such as wounds sustained during burglaries or in fights. Even with the police, the doctor must be silent, based on the conviction that no person should be restrained from seeking medical care. The value of a right to care and the protection of life overrides the value of bringing a person to justice. There are some possible exceptions to this problem: when a physician receives knowledge of a potential crime with threats to others, a decision can be made to tell the police when, on balance, the higher value of protection of life is chosen. But in a possible re-evaluation the physician must prove that there were no other options, and every alley has been tried, such as trying to convince the patient not to commit the crime.

Especially in modern society, with interactions between medical care, insurance companies and the right to financial compensation in sickness and disabilities, much information is requested especially from family physicians who have a 'complete' view of the medical history over a long time.

What complicates the issue is the fact that sometimes the information may be detrimental to the patient without clear realisation by the patient. Especially past diseases may have an impact on, for example, the cost of health care or disability insurance policies, that the patient is not aware of. Inadequate preliminary discussions are sometimes a cause of bitter disputes.

*Unsolicited information* can itself be divided into information relevant for a patient or for a third party, who may or not be a patient in the practice.

Especially where it concerns sexually transmitted diseases, the issue of confidentiality creates dilemmas that are difficult to deal with. How about talking to the wife of a man with chlamydia, or vice versa? The subject of positive HIV tests in particular has created a new domain of legally-inspired prohibitions based on the recognition of a right to refuse knowing about a disease, because there is no cure available and the disease which ultimately leads to a certain death. Even though the treatment options of HIV and AIDS have increased remarkably over the last years, there has been no waving of this right to refuse to have the status on infection become more open, in the interest of other parties, including medical staff. Outside of family medicine there is presently a movement to force accused criminals to submit to a test, in view of the risks to caretakers, guards and police officers. This has not yet become law.

A final development has taken place in the area of confidentiality relating to conflicts between medicine and 'the law' in general, the police and public prosecution. In the past it was accepted almost universally that wounded suspected criminals were 'safe' from being reported to the police, in order to agree with the higher order value that no person in need of care would not seek it for fear of being reported. A few years ago in one case the police and the prosecution have forced an academic clinic to hand over records of a patient who might have been implicated in poisoning his wife. So, a shift has taken place: a more general interest, rather than the interest of one person, could be a reason to breach the confidentiality rule.

#### *5.4. Preventive Medicine*

Family medicine has shown ambivalence towards a program of preventive medicine, especially where it concerns primary prevention: preventing diseases from happening earlier in life or at all. As a positive sign of prevention, family physicians have deemed it their business to help people through periods of crises in their lives, irrespective of their origin. Visiting patients and families at home after major disasters and helping them to cope has been a long-held goal of normal practice. In

the past less affinity has been shown towards participating in, and maintaining programs of prevention in the area of cardiovascular diseases or chronic pulmonary diseases.

For some decades the view has been that preventive medicine could, more or less, be seen as a further step in the medicalisation of life and creating dependence on the 'the medical system', where independence was the more important social norm of autonomous and self-conscious citizens. Moreover, preventive interventions, information and medication, were not part of the system of reimbursement. Family physicians have had to change their attitude from 'reacting' to requests and diseases to a pro-active approach, with the aim to prevent diseases from developing or having these develop later in life. From a system of reacting to 'beeping' family medicine has become more of a 'management' of disease. This concerns for example 'secondary prevention', such with the late onset vascular and organic symptoms of late-onset diabetes mellitus. One next step in this line of 'defence' has been the introduction of 'nurse practitioners' in many group practices, with the aim to increase the effectiveness of treatments with better patient compliance through regular checks and more information.

The critical underpinning of preventive medicine, namely that many people with a potential disease must take medication in order for a few to be free from this development or even have it later, nowadays is rarely heard.

### *5.5. Life-style medicine*

Even though family medicine plays an important role in this area, the approach to different life style issues is not consistent.

There is an overlap between preventive medicine and life style medicine. Preventive medicine deals with the assessment of health risks, and health risks invariably concern basic behaviour that may be deleterious to persons' present, but especially future health. The medical subjects are: obesity, smoking, intake of fatty food, lack of exercise,

alcohol or other substance abuse, and last but not least: depression and sexuality. What is philosophically at stake is the issue of what is called a disease or potentially risky behaviour. What is medically interesting is the fact that disease prevention calls for treatments of ‘invisible’ diseases, that are preconceived on the basis of statistics, such as the prognostic meaning of protein loss in the urine of a diabetic patient, or the need to lower the blood pressure of diabetic patients below the internationally accepted standards of non-diabetics, based again on statistics. Thus in the area of prevention it has become customary to prescribe ace-inhibitors when there are signs of vascular damage in the kidneys even though the blood pressure is normal.

The significant relationship between the level of cholesterol and vascular (especially heart) damage, has become a cornerstone for life style interventions. Often, after an initial attempt at maintaining a low cholesterol diet, one is tempted to continuing with bad food habits, relying on medication to take care of the eventual bad effects. Thus the attempts at self denial are changed into a dependence on medication and continuance of poor food habits.

The second area where life style medication has changed family medicine is the area of *obesity*. The development of medicines to prevent fat from being absorbed into the digestive system has been received with some reservation, since in this area the moral conviction that physicians maintain is that patients should strive to loose weight through dieting rather than pharmaceuticals. So, even though obesity is a high risk factor, the medical indication for treatment is weakened by the moral conviction that eating too much and the wrong food is behaviour that individuals choose for themselves and thus carry a responsibility for. Calling it a disease is an ambivalent notion in family medicine.

A third area is the application of the *modern anti-depressants, especially the SSRI* pharmaceuticals. In this area, success seems to be self defeating. Where the older statistics always pointed to ‘under diagnosis’ of depressions in the general population, the so called ‘iceberg phenomenon’, and family medicine being negligent in this respect,

the success of this family of medicines now leads to a claim of 'over treatment', because of the magnitude of prescriptions. What has become fuzzy is the clear demarcation between depression and normal reactions of grief and sorrow, reflecting negative life events, that may lead to growth in personality and character. The notion of disease, even through semi-objective tests as the Zunge scale of the Minnesota Mental Scale, has become so widely applied that there is a major cost overrun in this area, and criticism often is founded on economic arguments instead of medical ones.

The last example of life-style medicine that I will discuss in this contribution concerns the notion of having a right to an approved and effective medication in the area of *male sexuality*. The development of erection stimuli, such as sildenafil, has confronted the medical system with the conflict between what is technically possible and the desirability of using it, and making it accessible through the system of insurance. Since impotence has always been considered a medical diagnosis of a physical ailment, it would follow that these medicines should be allowed to be prescribed at the proper indication.

Here the philosophical issue has become the question of normalcy of sexual functioning at a later age, with an expected decline in activities, and at what stage does this symptom become a disease. A moral point of view has been taken by the insurance companies, based on economic motives, not to include these pharmaceuticals in its prescription package but to have people pay for it themselves, even though a physician's signature is necessary to have access to them. That is quite a new scene: available, for a medical disease, but not reimbursed through insurance, because sexuality is different from depression and different from obesity. What is a disease and what is a normal change in functioning due to age or life events? Family medicine reflects the ambivalent morality in dealing with these issues, without adequate philosophical reflection.

Where this development will lead in the developed societies is not entirely clear, but one can safely assume that life style medicine will

be a major area where philosophical, medical and economic issues and options will collide and lead to limiting 'packages' of prescription medicine and a reformulation of what is a disease and what is to be accepted as degenerations of 'normal life'.

### ***5.6. End of Life care: 5 ways to die in a medical context in the Netherlands***

Since it would be naïve to discuss ethical issues within the Dutch context without mentioning the one development in the Netherlands that commands international attention, I shall describe the particular policies on helping patients die, being well aware of the Maltese tradition and culture in this respect. There is a basic justification for this subject in this contribution, because euthanasia and physician-assisted suicide especially take place within the context of family medicine. Up to 80% or the reported cases of these interventions are carried out by family physicians, because terminal, including palliative, care has shifted from the clinic to the home, to the 'first line'.

Compared to the international vocabulary relating to euthanasia, namely, passive or active, direct or indirect, voluntary or involuntary, the Dutch have opted for a different line of reasoning and definition. In the Netherlands one distinguishes *5 ways to die within the context of medicine*, thus after a medical decision:

1. through non-treatment decisions, mainly the area of clinical care,
2. in the course of treatment of suffering, mainly in the clinic but also in primary care,
3. through ending life of a patient without a request, because communication is no longer possible, mainly in the context of clinical care,
4. through euthanasia, meaning ending some one's life after a request, with no other option, mainly in the area of family medicine but also in the clinic, and

5. through helping someone die after a request, again mainly the area of family medicine and sometimes in the clinic.

Over the last thirty years euthanasia has become an accepted practice under certain conditions. The final version of these conditions has been spelled out in the recently effected Euthanasia Law (April 1, 2002). These are:

- 1) the presence of a request that is voluntary and well considered, of a competent patient,
- 2) the presence of suffering that is unbearable to the patient, without options for improvement,
- 3) the patient must be fully informed on the situation,
- 4) there should not be acceptable alternative treatments for the patient,
- 5) there must be an inter-collegial consultation to establish the presence of the conditions of the request and suffering,
- 6) the ending of life must be according to professional standards,
- 7) the act must be reported to the local coroner with detailed information on the case.

After acts of euthanasia and physician-assisted suicide, the forms are sent to a regional Euthanasia Evaluation Committee, consisting of a lawyer, a physician and an ethicist, who check *a posteriori* the presence of the conditions and decide on the 'carefulness' of the act or, in case of absence of certain conditions or irregularities, to relay the case to the legal authorities. These committees have been established by the State and have been in existence since 1998, about the same time when the government decided to support the development of a national network of independent medical consultants for the so-called 'second opinion', the Support Consultation Euthanasia Netherlands, the SCEN.

This network has been built up in four years to cover the whole country, with now more than 500 qualified consultants, who can be called upon from 8 in the morning till 10 at night, seven days a week, for information and consultation.

In roughly 40% of all deaths in the last years, a medical decision is involved. Figures of national research in both 1990 and 1995 have provided a detailed insight into the extent of each category. In 1995 for example of the 135,000 people that died, euthanasia and physician-assisted suicide was involved in 2.7% (in absolute numbers: 3,600), after alleviation of pain and suffering 19.1% (22,750), after a non-treatment decision 20.2% (22,270), and after a life ending without explicit request 0.7% (900). This last group concerned patients in poor condition without the possibility to communicate, that in other countries would die through terminal sedation. The Achilles heel of the Dutch procedure is the low level of reporting: in 1995 only 42% of the cases were reported. Since the number of cases that have been reported to the Regional Euthanasia Evaluation Committees, established in 1998, has been more or less constant, the impression is that an increase in reporting, one of the reasons for the Committees' existence, has not been realised.

Since the Royal Dutch Medical Society adopted the option of euthanasia and physician-assisted suicide in 1984, there has been a growing support among Dutch physicians, now standing at about 90%. This compares to the support in the Dutch population, also around 90%. Physicians on the average receive a request to assist in dying about once a year, and end a life on the average every two or three years. The number of requests is about four times higher than the number of cases where life is actually ended. One of the main reasons for this difference is the fact that there are still palliative options that the patients are not aware of, or have not been informed of. As stated, more than 80% of the cases concern patients with a malignant disease, in a terminal situation, without hope for improvement. That is the category of patients who spent their last days confined to their own home, being supported and comforted by their next of kin with professional support of home-care



nurses, who can stay around the clock if need be, for a period of up to six weeks, paid for by the national government.

When a request has been put forward, a special process starts as part of, or within the in general complex process of care at the end of life. When and if there are no more acceptable medical and palliative options to the patient, and the physician is convinced of the presence of the conditions, a legally required consultation takes place to check before the deed if that really is the case. The consultant is also required to assess the competence of the patient, and to exclude the presence of compromising mental states, such as depression or delirium. If in doubt about this state, the advice is to ask for a second consultation from a psychiatrist.

In principle, the manner of dying is the patient's choice, being either through injections (euthanasia), or by drinking a potion of barbiturates. Even though officially there is no waiting period, it is advised to have a go-slow motion and not to be seduced into a 'rush action'. After a date and a time has been agreed upon, it is the physician who collects the pharmaceuticals personally at the pharmacy and takes it along to the patient's home. After farewells have been said the physician injects the barbiturate, followed by a curare-derivative, or the patient drinks the potion. With the injection the patient usually dies within a short time, sometimes within seconds or minutes. With the potion, the patient falls into a deep coma and dies within minutes to hours. At all times the physician is expected to stay with the patient and the family until the patient dies. When the patient has died, the physician calls the coroner, who visits the home and receives the forms for further delivery to the Regional Euthanasia Evaluation Committee. For the physician the phase of helping families come to term with the demise of one of their members then starts: there is a high level of care for family members in the Netherlands.

This procedure is the result of a long co-operation between 'the law' and the medical profession. From an ethical point of view, it can be seen as a recognition of respect for autonomy, not only during life but

also including its end, and of a wish for a death with dignity. Dutch physicians, as all physicians elsewhere, consider it their responsibility to prevent unbearable suffering and unnecessary suffering, a goal that together with the recognition of respect for autonomy, leads to ending lives at the time of choice of their patients, saying their goodbyes while they are still capable to do so, in good mental standing. They see this procedure as one way not to abandon their patients at the end of life. And most fundamentally, ending a life is only possible within a meaningful medical relationship between physician and patient.

The possibility of euthanasia and physician-assisted suicide have also created 'new' ethical quandaries in family medicine, as expressions of the integration of these procedures within society. I mention some of these issues and questions, without extensive discussion. Sometimes patients want their lives ended even when not all palliative options have been exhausted, because they are convinced of the utter hopelessness of their situation. There may be differences in the assessment of the unbearable nature of the patients' symptoms between the patient and the physician, or between the family and the physician. Within society several pressure groups advocate the option of helping people die when 'life has nothing to offer any more', and old people are suffering from degeneration of functions and increasing invalidity of loss of capacities. At present a case is under jurisdiction of the Dutch Supreme Court that concerns this question: is suffering of old age and all its foibles adequate justification to help a patient die? The answer to that question has just arrived (in December 2002): the Supreme Court's decision is that 'being tired of life and living' in the absence of a disease that leads to a certain death within a given time, does not fall within the framework of legally acceptable conditions to end the life of a patient.

This overview is far from complete in detail, but hopefully informative enough as to stimulate discussion on local family medicine issues. Central to the paper is the idea that family medicine is not a static enterprise, but by its very nature it is dynamic, sometimes defensive. Developments force this societal medical institution also to continuous

reflection on medicine's goals and the position of primary care. Even though there has been a period of self-confidence in the Netherlands, at the start of the present millennium family medicine in the Netherlands finds itself in need of reformulation of its goals and self image. That is a challenging task and not new to the profession.

# Ethical issues in Maltese General Practice – a look to the near future

**Dr. Pierre Mallia**

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On the eve of Family Practice becoming a speciality, it is only appropriate to discuss the ethical implications and also the problems still seemingly unresolved in this area. I shall divide my short time between a reflection on family medicine as a speciality as expressed in the thought of Dr. Edmund Pellegrino, himself a specialist in internal medicine but who believed and advocated family medicine as a speciality before it became such in the United States, and the current state of affairs in Malta. Edmund Pellegrino was founder of the Kennedy Institute of Ethics in Georgetown University, Washington, D.C. Whilst the latter has become somewhat of a Mecca for bioethicists, Pellegrino himself is the guru, if not the father, of modern bioethics. A proponent of virtue-based ethics, he is a staunch believer in the tradition of medicine as based in the doctor-patient relationship. It is in this phenomenon that we should look for resolution of ethical dilemmas and not merely in the algorithmic invocation of principles and rules.

‘By tracing a series of papers between 1965 and 1988, one may appreciate the evolution of Pellegrino’s philosophy of family practice’<sup>16</sup>. Howard Brody<sup>1</sup> notes that Pellegrino began to address, in print, the ‘academic base for family practice’ four years before the new Board was established and the first family practice residency programs were begun. Here he stated clearly the theme to which he would frequently return, the need for the generalist physician:

Human diseases do not come in neatly labelled categories nor are humans so tractable as to develop disorders in only one

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<sup>1</sup> Brody, H., “Edmund D. Pellegrino’s Philosophy of Family Practice”, in *The Influence of Edmund D. Pellegrino’s Philosophy of Medicine*, ed. David C. Thomasma, Kluwer Academic Press, 1997: 7-20, p. 9

organ system at a time. The very development of specialization, while essential, only accentuates the need for a corresponding development of the integrative functions of the generalist.<sup>2</sup>

The sphere of activity for this generalist physician is that of first contact care for family members of all ages, with special attention to prevention and health maintenance. This activity, Pellegrino argued, was intellectually different but equally demanding as training in a more limited medical specialty. Here and elsewhere Pellegrino anticipates definition of 'primary care' offered by later experts – for example that, "Primary Care includes not only those services that are provided at first contact between the patient and the health professional but also responsibility for promotion and maintenance of health and for complete and continuous care of the individual including referral when required".<sup>3</sup>

Although there was a point in time where, after the establishment of the new specialty, he warned against having too much concern for research and academia, fearing a loss of reality from the community, he later made clear that there is no real dichotomy between the academic vs. the community 'base' for family practice. He also believed strongly that the name 'family practitioner' was no mere cosmetic re-naming of 'general practitioner', but that the designation 'family' is to be taken seriously in defining the content of this specialty. Adequate research and training on family dynamics was then lacking from most academic departments (in the seventies and eighties) of family practice. This is much the situation we are facing in our own department which is still in its infancy.

Pellegrino also addressed the unavoidable political questions of how family practice should relate to other medical and allied health specialties, urging family physicians to gain strength by increasing the

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<sup>2</sup> Pellegrino, E.D., "An academic base for family practice", in *Ohio Gen Practitioner*, 1965 (May): 8 (quoted in above)

<sup>3</sup> See for example, *Ontario Ministry of Health: Report of the Health planning task force*, Toronto, 1974, p. 27.

quality and sophistication of their work and not by fighting turf battles with other primary care providers, specialists or otherwise.

It is clear that Malta lags behind somewhat in the development of family medicine as a specialty. Many still laugh at the idea of GPs calling ourselves specialists. This fear is also a result of an inferiority complex within many family doctors – witness the unwillingness to hand out a membership of the college in the past few years, even after satisfaction of certain criteria, so as not to turn other specialists against us or at best to be made the laughing stock or standing joke of our MRCP-cultured colleagues.

Clearly this attitude has to stop. Only we, as family doctors, can and should establish criteria of what it takes to be a family doctor. We should not stand to be ridiculed or told what to do by others who, with all due respect, have never practised in the community full-time, or spent years seeing children grow and in turn get married themselves. Family medicine is a specialty in most of the developed world and if we are to offer the best primary care to our patients, then we must follow suit.

Hence outcries against Family Practice becoming a specialty is uncalled for and unfounded. Even where we do not enter the European Union, where GPs or family doctors are considered and paid as specialists, respect must start with self-respect. Family practitioners are more aware than ever before of their need for further professional development – witness the participants in courses and diplomas the Malta College of Family Doctors offers in collaboration with other European colleges.

There are problems to be ironed out and surely changes must occur in the logistics and infrastructure of the bodies which represent family doctors. Until there is general agreement with other specialists about our own status and respect as specialists, we need to be our own union and cannot allow bodies with other interests to take over talks at high level. Government and other specialists must understand that only we can and should define, according to international criteria, what a family

practitioner should be. Thus while it is understandable that a gastroenterologist, say, may also want to register as a physician in internal medicine, this request for double specialisation should not translate into an ability for someone caught in a registrar or senior registrar post in secondary or tertiary care to register as a family doctor as well without fulfilling the criteria of the specialty. Having an MRCP does not automatically grant you the status of a Family Doctor. We must move away from the idea that an MD alone is a sort of 'O' level which grants GP status and the MRCP or FRCS takes someone to 'A' level status allowing him to pursue his 'O' level interests. Conversely we should consider academics, such as epidemiologists and public health doctors, into the specialty because traditionally many come from the field of family medicine as well and can contribute considerably to its advancement.

Whilst there must definitely be a grandfather clause, as has occurred in Great Britain and other countries for long established family doctors, it would make the proposed Vocation Training futile if someone with a different specialist qualification be exempt from this training. For this reason Vocation Training must steer away from merely a rotation among specialties and focus directly on Family Medicine and Practice. The move by the government to sponsor GP-trainers and to put VT in the hands of the Malta College is thus a move in the right direction.

It is understandable that many specialists will feel the need to protect their ground, but just as some specialties do their own share of primary care, so should it be accepted that GPs, as abroad, be able to train in tools and services which render primary care more amenable and effective. Many GPs in the UK perform endoscopy lists. Ultrasound has been shown to be an effective tool in the primary care physical examination, detecting pathology before any signs and symptoms. Thus it should enhance the quality of care we provide to our population. Government should thus make radiology and endoscopy departments as training centres where family doctors may also participate as GPs are not exempt from providing the same standard of due care and quality of results as specialist counterparts. Many private Family Doctors, who

are the only source of family medicine, can dedicate such time to their practice once government takes considerable load of patient attendance.

This brings me to Health Centres. Only the private family doctor provides a true family practice in Malta. Primary care centres are walk-in clinics in which one does not choose a doctor, nor is one able to continue seeing the same doctor over a long period of time. If we are to hold on to these centres there must definitely be more co-operation between the two. I have spoken at length in the past on this issue and find no need to elaborate here but I wish to re-iterate an experience which happened to me a few weeks ago which speaks for itself. A patient of mine turned up at a health centre one evening. She suffers from a migraine-like headache which recurs every two or three months. No medication works on her and we had tried everything. The only thing which works wonders is an intra-muscular injection of Aspegic or a NSAID – a recognised remedy in this situation. The health centre doctor refused to give her this treatment. No one can blame him, as it was his first contact with this patient. Moreover, the aggressive personality of this woman did not help at all so that when she contacted me on my mobile from the police station I immediately realised the problem. I was too far away to go and tend to her myself so she begged me to call the health centre to ask them to give her the injection. We both thought that an explanation from her doctor would solve the issue. The health centre doctor did not accept my explanation. Still recovering from the verbal abuse he had suffered, he disagreed with my treatment and said that he would not give her the injection anyway because of the way she had treated him. Understanding his position I asked him if there was another doctor who may give her the injection and he passed me a to a colleague who after listening to my explanation said she agreed with her other colleague. Now why on earth she came to the phone therefore is beyond me. But to cut a long story short, the chief then came who made me state that I was taking full responsibility and acceded to giving the blessed intra-muscular.

Yet health centre doctors persist in telling people to ‘call their family doctor’ in cases of death certification and refuse to prescribe certain



drugs unless a green card is filled by the family doctor who should take the responsibility of any drug prescribed. Yet they too have complaints against some private GPs. We should be able to resolve these issues if the two systems are to persist in parallel to provide a service in primary care. Otherwise, such a dichotomy can hinder the progress of Family Practice to the level of a specialty.

There is great scope for family practice in the near future. With the advent of the new hospital it is hoped that the role of the family doctor will increase in the continuation of treatment and in communication during in-stay of patients. Family Doctors can and should be patient advocates. We still have to introduce the idea of an Advance Directive which allows the patient to participate in future treatment when he or she is unable to act autonomously. With the advent of genetic screening, it has been suggested that the family doctor is the most strategically placed individual to provide counselling on tests such as for breast cancer. Not only are specialist genetic counsellors not enough to cope with the envisaged increase in demand, but they should remain the professionals to continue seeing to the cases needing specialist counselling.

I augur that this and similar conferences will speed the recovery of family medicine in Malta and elevate it to the status it deserves. With Pellegrino I pray that rather than fighting turf battles with specialists or between private GPs and health centre doctors, we dialogue together to know where we are and where we want to go. We need to choose carefully those among us who are willing to go the extra mile and disinterestedly fight on our behalf to introduce the change that is much needed. We have been drinking out of the stagnant water of a status quo and many of us have come to believe it is wine, thinking that the Maltese patient has a good deal. They do not see that since the introduction of polyclinics general practice has changed very little in Malta and has definitely not kept up to date with the status that family practitioners share abroad.

Surveys show that there is a strong correlation between what family physicians do and what patients want. Moreover, if you have a serious

problem then internal medicine might be better for you, but if you have a lot of serious problems together, then the family physician is by far your best bet<sup>4</sup>. Family physicians may be better at pulling up aggregate data for Hb A1c, blood pressure and lipid level for the diabetic population of a practice telling them if they are really making a difference in their community<sup>5</sup>. The AAFP has made it its goal to assess the future of Family Medicine in a project; goals that we would do well to take up. Stoever says these can be boiled down to three questions: What is the role of the family doctor today? What can we do different in the future to meet the needs of people and society? And how do we grow as a discipline? Moreover, he says, ‘we want to make it a joy again to practice family medicine’.

Some of our older colleagues refer nostalgically to the era when they delivered babies and had extremely busy practices – sometimes taking patients to hospital themselves. It should be the aim of the new department and college to restore pride in family medicine – a pride based on interaction with patients, reliability of care and economic and financial viability for both physician and patient. At a recent award giving ceremony, a family physician who made it his goal to train and to provide training in critical care for patients, after having practised for twenty years, said: “Because I’ve been in the same place forever, these patients are friends. They’re people who I go to church with. They’re people I see on the street. It’s really rewarding to be able to treat people through some of their life crises. Family physicians, in general, have that luxury that many other physicians do not. People grow to depend on you for all kinds of help and all kinds of guidance. That is a very rewarding life”<sup>6</sup>.

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<sup>4</sup> Stoever, J., “Town hall meeting explores specialty’s future”, in *FP Report*, November, 2002, pp. 1-14.

<sup>5</sup> *Ibid.*, p. 14.

<sup>6</sup> Young, D., “Critical care training crucial for rural professionals, says FP of the Year”, in *FP Report*, November, 2002, p. 11.



# Patient Empowerment in Pharmacy Practice

Mary Anne Ciappara

A practice does not have a fixed goal for all times but this goal is developed by the history of that practice. In pharmacy this goal has been partly determined by pharmacists' different roles in relation to medicines and professional services according to patients' needs.

Pharmacy practice had developed to support and complement the medical care delivered. It is now evolving into the provision of pharmaceutical care, whereby pharmacists will be exercising their specific and crucial role in the health care system as members of a team involved in the provision of health care. Pharmaceutical care was developed as a concept in response to the extent of drug-related morbidity and mortality in the healthcare system (Manasse, 1989).

The pharmaceutical care concept forms the basis of two important international guidelines for Good Pharmacy Practice, by the International Pharmaceutical Federation (1993) and the Pharmaceutical Group of the European Union (1993). These guidelines define the mission of pharmacy as "the provision of medications and other health care products and services and to help people and society to make the best use of them", that is, enabling patients and societies to secure good health and to make the best use of their treatment through the provision of adequate care.

Pharmaceutical care is a significant transition in the profession of pharmacy where the primary focus is the patient, rather than distribution of medicines and dissemination of information about medicines. It is a "Philosophy of practice in which the patient and society are beneficiaries of the pharmacists' action" (WHO, 1994). Central to the provision of pharmaceutical care are the relationships between the pharmacist and the patient and other health care professionals;

responsibility to the patient for the quality of care provided; and the cultivation of appropriate attitudes and character traits.

This evolving process calls for a refocusing on the ethical dimension of the relationship of the pharmacist with the patient, which is the fundamental feature of pharmacy. The good of the patient can no longer be defined by the pharmacist, what the pharmacist, using his knowledge and experience, thinks is best for the patient, but must be established in mutuality with the patient, taking into consideration the values, wishes and feelings of the patient. The emerging relationship between the pharmacist and the patient is one based on partnership whereby the patient is an active participant in his care.

### **Patients' expectations of their pharmacist: a study analysis**

Findings of a study (Ciappara, 1999) analysing and investigating the character traits and attitudes guiding pharmacists in their relationship with patients revealed that the majority of patients interviewed (92%, n=80) had a positive view of pharmacists as health care professionals, and this was found to influence their perception of their relationship with the pharmacist. The characteristics of a good pharmacist identified by patients can be summarised under three headings: interpersonal qualities, a professional approach to services rendered, and knowledge. Patients attached great importance to interpersonal qualities. The interpersonal qualities considered most important for patients, were: promoting the good of the patient (49%), communication (38%) and a friendly approach (30%). It established that pharmacists have the interests of their patients at heart and want to help them. When a pharmacist takes an active interest and communicates well with patients he or she starts to build a relationship with them. Patients gave importance to a friendly approach. A friendly approach makes people feel at ease and enable them to confide their problems and their queries; and to discuss such issues as medications and lifestyle. The quality of this relationship in turn influenced their perception of the importance of such a relationship to be based on trust. Over 96% (n=80) of the patients interviewed stated that they trusted the pharmacist. The trust that patients had in their pharmacist demonstrated their judgement on

whether the pharmacist met their expectations. The attitudinal and environmental factors influenced the relationship of patients with their pharmacist. Patients' expectations of being given more information about medicines (39%) and to actively participate in decisions about their health (15%) which pharmacists were not fulfilling, negatively influenced their relationship with their pharmacist. Conversely, patients' desire for more privacy (68.8%) did not influence the quality of this relationship.

The findings also revealed that patients recognised pharmacists' efficacy in giving information about medicines (61%). Conversely, patients did not recognise to such an extent pharmacists' responsibilities for the medicines they dispense (26%). Patients gave importance to co-operation between pharmacists and doctors (74%) and to care and concern about patients needs (61%). An evaluation of patients' expectations is important as this enables the profession to meet today's challenges, set practice standards and develop the services pharmacists' render to meet patients needs.

### **Patients' right to information and to make informed decisions**

Patients are becoming more knowledgeable and informed about health and medicines, and are becoming more inquisitive, wanting to take a more active role in their treatment. *"The involvement of individuals, families and whole communities in improving and maintaining their health"* has been described by the retired Director General of the World Health Organisation, Dr. Halfdan Mahler, *"as one of the main pillars of primary healthcare"* (D'Arcy, 1989), and forms part of the Ljubljana Charter on Reforming Health Care (World Health Organisation, 1996). This need and interest for information about health and medicines is reflected in the number of printed articles, broadcasts and information on the Internet.

At the same time more attention is being given to patients' rights and responsibilities to strengthen the patients' position and safeguard them. Patients' organisations are lobbying for recognition of patients' rights. The Charter of patients' rights and responsibilities published by the

Hospital Management Committee, St Luke Hospital (2001) is a step in this direction. The recognition of patients' rights to be involved in decisions about their treatment, and about their right to information about their treatment forms part of a Declaration on the Promotion of Patients' Rights in Europe of the World Health Organisation (1994). Treating patients with honesty and openness by giving them information about their treatment or the different treatment options, including their benefits and risks, is a basic right. Patients also have a right to refuse information. Patients' rights always entail the imposition of duties on health care professionals, duties that are established in practice standards. However, the relationship between a patient and a professional should not be reduced to communication of information.

While, today the emphasis is on patients' rights, and on considering the complexity of the relationship between the patient and the healthcare professional, it is the character of health care professionals, their dispositions and attitudes which will ultimately promote the well being of patients and society. Personal values and attitudes govern the character and the quality of the clinical interaction on the personal level (Mrtek and Mrtek, 1991) Every clinical decision, and not just the ethically obvious, is guided by a unique highly complex set of personal values (Veatch, 1991). Moreover, there is a complex relationship between professional values to practice (MacIntyre, 1981). Baldwin and Alberts (1991) suggest that honesty, dedication, carefulness and dependability, apart from the traditional qualities of compassion, faithfulness and fairness are the character traits internal to pharmacy that define the relationship with patients and society.

### **Patient empowerment**

Patients should be key partners in their own care. They need and desire to be empowered to be able to be proactive. Empowerment is seen as the capacity and the freedom to make informed choices based on information and knowledge about their care and in self-care. Illness is an assault on the whole person. The patient is frightened, anxious and perhaps distressed because of uncertainties of what is going to happen, and because of lack of knowledge and skills. Through empowerment

the patient will be able to manage his or her condition both at the physiological level and at the psychological level (Anderson *et al.*, 1995). This will help the patient to become more knowledgeable about his condition, and comprehend the complexity of his treatment and understand its effects. Thus the patient will be able to take on responsibilities to pursue healthy lifestyles and to co-operate on mutually accepted courses of action.

### **Pharmacists' role in patient empowerment**

How can pharmacists help patients acquire as much understanding of, and control over their bodies as possible?

Medicines do not only produce therapeutic effects but there is the risk that they may induce adverse drug reactions. By providing patients with information and helping them assess the benefits and risks of their medication, pharmacists utilise their knowledge and expertise to enable patients to comprehend their treatment and understand its effects. Pharmacists are in a position, and are competent to enable healthy people to remain healthy and prevent disease. Moreover, in the case of patients suffering from chronic conditions, pharmacists educate and counsel them about their condition and enable them to acquire the skills to cope with the psychological challenges and with the techniques and knowledge to self-manage their condition. This education empowers them to make daily decisions essential for beneficial outcomes of their treatment and improve their quality of life.

Patient empowerment is a value-laden concept. Inherent to patient empowerment is beneficence, dialogue, respect for the patient's autonomy, mutual trust, honesty, care, truth telling, justice and solidarity.

Beneficence entails that professionals act to advance the interest of the patients (Pellegrino and Thomasma, 1993). It seeks to promote the good of patients by helping them in their individual needs. Through giving them information and advice, pharmacists promote the good of



the patient. This promotion of patient well-being is, however, defined in part by the values, beliefs, feelings and preferences of the patient and his or her attitude towards the illness and risks of medicines. Each person views treatment and illness in a different way. These beliefs/views are an integral part of the personal, familial, and cultural experience of each individual patient.

Through dialogue with the patient, pharmacists will be able to understand them in terms of needs, concerns, their attitudes and feelings towards risks of the medicines. It involves listening to and understanding what patients have to say, exploring in depth their concerns, guiding their medicine-taking behaviour (Dolinsky, 1993), and when necessary guiding them to modify their lifestyle. Dialogue with patients also involves talking in a simple and clear language that they can easily understand, being honest and enabling them to believe in that information. This is important when conveying information about their treatment. Dialogue between patients and pharmacists has as its core, mutual trust and care (Zaner, 1990).

In seeking information, patients desire to know the truth from a person whom they can trust to have this knowledge. Being truthful by disclosing pertinent information will engender trust and indicates respect for the autonomy of the patient. Treating individuals so as to allow or enable them to act autonomously is a sign of respect for the person (Beuachamp and Childress (1989). The International Pharmaceutical Federation in its code of ethics for pharmacists states that pharmacists should “respect the individual’s right to freedom of choice” and to “strive to treat and inform each individual according to personal circumstances.”

Justice demands that all patients be treated equally, independent of whether they are regular patients, their level of education, or the service or extent of services they might require. Pharmacists need to show the same dedication, and give the same care and attention, to all patients depending on their needs. This encapsulates the need for pharmacists to render patients their due as persons who are worthy of respect and

dignity (Pellegrino and Thomasma, 1993). The virtue of justice has its roots in compassion and care. Justice is also expressed in the care and concern that pharmacists must show to those who are vulnerable and those who have specific needs. Pellegrino and Thomasma (1993) explain that justice transformed by concern is expressed in actions towards the good of specific patients.

Illness creates vulnerability, and effects the person physically, psychologically and emotionally. The nature of illness, how it is going to effect patients' future, anxiety and fear are forms of disintegration of the person because they threaten the person's well-being (Pellegrino and Thomasma, 1993). Patients need to feel cared for, supported and to share their feelings and experiences. It is about solidarity. Solidarity necessitates that pharmacists comprehend and understand the meaning of illness and suffering and to gain an insight into the patients' experience. Through solidarity and encouragement pharmacists create expectations and inspire hope and can positively influence patients' health by restoring the person's well being.

In a reciprocal relationship based on truthfulness and trust patients will be able to understand and reason through options and make an informed decision. They will be able to see the situation in the right perspective unhindered by fear and misconceptions and other limitations, which make patients vulnerable.

### **Ethical issues**

The increasingly patient-centred roles and the more knowledgeable and demanding patients have increased the ethical issues facing pharmacists. I have selected some cases from my own pharmacy practice to illustrate some of the dilemmas encountered by community pharmacists.

#### ***Scenario No. 1. Benefiting the patient***

Consider the scenario in which a female patient tells the pharmacist that she has just seen her gynaecologist who told her that her pregnancy was progressing normally and prescribed "vitamin" tablets. She

presents a prescription for dydrogesterone, a preparation that is indicated in habitual abortion. The pharmacist knows that this patient had a miscarriage about six months earlier.

The pharmacist explains to her how to take the tablets but faces a dilemma. He wants to respect the doctor's decision and let her think that she is taking "vitamins". On the other hand not realising the importance of taking the "vitamins" as directed she might fail to take them on a regular basis or stop taking them because she perceives that she did not need them any more, thus the desired therapeutic outcome is not achieved. The patient has a right to know the indication of her treatment. Should the pharmacist tactfully tell her that these tablets are to enable her to have a normal pregnancy, whilst taking care not to jeopardise the patient-doctor relationship?

Patients often approach pharmacists with medicines they obtain through the Government's Dispensaries under the Social Security Act, or else they may come with a prescription, and ask the pharmacist what the medicines are for. This at times puts pharmacists in a difficult position considering they only have limited or no knowledge at all about the patients' condition, and considering that the medicine might have a number of indications. Telling them that they are used for a number of disorders and referring them back to their doctor is a passive response whereby the pharmacists are not meeting the needs of these patients. Lack of information on the doctor's therapeutic objectives can contribute to non-adherence to treatment. Conversely, in the limited time available the pharmacist can, by asking simple questions, learn more about the patients, their problems and understand their individual needs and thus may be in a position to be able to help them.

Pharmacists are not at present in a position to know whether patients are adhering to the treatment prescribed since they do not always go to the same pharmacist and thus it is difficult to monitor them. Moreover, the majority of patients suffering from chronic conditions obtain their medicines from the Government's Dispensaries under the Social Security Act where at times there is no contact with a pharmacist. Access

to patient profiles is indispensable for pharmacists to be able to give an optimal service. Such a system enhances communication between health care professionals and can be one of the ways and means to develop seamless care between secondary and primary health care and a means to monitor patients. The keeping of patient profiles is an issue that needs to be discussed at length among health care professionals and patients' organisations.

### ***Scenario No. 2 Risks of treatment***

A woman in her fifties presents a prescription for a statin. She confides that her cholesterol has remained high and admits that although she tries, she finds it hard to follow a low fat diet. Since she is taking this medication for the first time she asks about the side effects she might experience. When asked whether she discussed this with her doctor, she answers in the affirmative and that he told her that she needs not worry. Her preoccupation is that she had read an article in a glossy magazine, which attributed a number of side effects to these medications, and wondered whether she should take some lecithin tablets instead.

The dilemma presented in this scenario is whether to reassure the patient and tell her to follow the doctor's prescription; or else to respond to her request and give the information about the benefits and side effects and other advice on the treatment prescribed.

Some have argued that giving information about the side effects of medicines is not beneficial to patients, as such information may induce fear and patients might not take them, or lead them to complain (Thompsons, 1995). Health care professionals underestimate the amount of information and extent of discussion that patients need (Strull *et al*, 1984; Williamson *et al*,1992). Research findings and personal experience, however, indicate that patients are interested to know, and do ask questions about the side effects, interactions with other medicines they are taking, and about the contraindications. Such information will have positive effects, as it will enhance their ability to anticipate and cope with the side-effects of medication, and gives

them information about what to do in case they occur, thus protecting them from harm. Conversely, failure of patients to know what to expect from their treatment, and associating the side effects of medicines to deterioration or to complication of their condition or to another illness, have led to deterioration of their quality of life, to fear or to resorting to over-the-counter medication to cure that symptom. Additionally, it is recognised that failure of patients to understand and fully appreciate the importance of their treatment has led to inappropriate actions that have led to complications of illness. These include suspension of treatment by the patients on their own initiative because of side effects.

Pharmacists have an ethical obligation to warn patients of risks inherent in their treatment. Furthermore, patients may feel comfortable discussing these concerns with their pharmacist with whom they have established a good professional relationship based on trust. The Joint Statement by the International Pharmaceutical Federation and World Medical Association: *Working relationship between physicians and pharmacists in medicinal therapy* (2000) specifies that when requested by patients, pharmacists have a responsibility to discuss “medicine-related problems or concerns with regard to the prescribed medicines.” Does the patient have the right to choose not to take the treatment prescribed based on her personal attitudes towards the risks? One might argue that a patient’s decision need not be viewed as correct from the objective view of the pharmacists and doctors but rather as appropriate from the patient’s subjective view. Should health care professionals continue to support a patient in a decision with which they do not agree? Another problem is to what extent should a pharmacist influence and modify this patient’s lifestyle? How forceful should a pharmacist be?

### ***Scenario No. 3 Access to medicines***

Consider the scenario whereby a man presents a prescription for an anti-depressant, an SSRI. After explaining how he should take the tablets, and warning him of potential side effects the pharmacist concludes by mentioning the price. The man, whom the pharmacist knows to have limited means, asks for the prescription back, as he

cannot afford it. A generic brand of the SSRI prescribed which the pharmacist knows to be therapeutically equivalent and lower in price is available. The dilemma that this pharmacist is facing is as follows: how can he help this man, knowing the difficulties that he is facing, to have access to the treatment that he needs. By not intervening, the patient will be abandoned, and his condition might deteriorate. Does the patient have a right to know that a generic is available which is cheaper in price? Should the pharmacist seek his consent to the substitution, and contact the doctor? How can the doctor and the pharmacist co-operate and collaborate together to benefit this patient so that he can have access to a treatment which fits his needs and thereby attain the therapeutic objective? How can the pharmacist's role in supporting physicians to evaluate the best medications to use in particular situations be further developed?

### **Challenges to be addressed**

These scenarios identify divergences in the attitudes towards patient care among doctors and pharmacists. Some pharmacists may be taking professional decisions which take into consideration the needs of the patients, whilst other may be adopting a paternalistic attitude which is reflective of the traditional model of pharmacy practice. There is also the problem of pharmacists and doctors practising in isolation, and insensitivity to the patient's needs. Furthermore, some patients may be perceived to be passive while others want to be empowered to take a more proactive role in their care.

### **Patient-centred practice**

The practice of both pharmacists and doctors should be centred on people; the patients, their individual needs and expectations. In pursuit of a patient-centred practice, pharmacists and doctors need to develop an understanding of the meaning of illness and suffering, and to gain an insight into the patients' experience. Toombs (1992) gives a number of reasons why professionals need to acquire an appreciation of patients' level of experience. She states that this experience of illness enables professionals "*to acknowledge the patient as a person and to treat the patient as a person*" and to ensure the most effective therapeutic

interventions. Additionally, the act of healing requires that both the practitioner and the patient share a common understanding of the patient's illness. This approach of including the patients' perspective and their experience needs to be given more importance in the continuing professional development programmes of pharmacists and should be included at undergraduate level.

### **Patient-practitioner relationship**

Central to the provision of patient care is the interaction between the patient and the provider of the care. The pharmaceutical and medical professions and the university need to address ways and means on how to promote an active patient-practitioner relationship based on trust and dialogue. Through such a relationship, doctors and pharmacists will be able to meet the needs of the patients, and empower them to be key partners in their care. This attitude is different from the traditional attitude of enhancing compliance with what the practitioner has recommended, which assumed that the medical and pharmaceutical values are better for the patients than their own values, and that they are considered non-compliant if they do not accept the treatment based on the values of the practitioner (Veatch, 1991).

### **A team approach to patient care**

When patients are treated with prescribed medicines, the prospect of empowering patients is enhanced when both doctors and pharmacists together with the patient address the patient's needs. Mutual respect, mutual trust, effective communication and collaboration are vital to achieve this goal. A collective approach involves a network of interactive and intertwined models of communication-in-trust and collaboration-in-trust (Sass, 1996). It is a commitment to solidarity, which signifies that each member of the team contributes in accordance with his or her competence, skills and responsibilities and respecting the functions of others. To cultivate co-operation and collaboration pharmacists and doctors need to better know, understand and accept each other's evolving roles and responsibilities to the patient. (Carruthers, 1997). They also need to recognise the overlapping responsibilities that they have in relation to the use of prescribed

medicines. Inter-professional sessions, as part of the continuing professional development programmes, and also at undergraduate level, joint workshops and seminars and the participation in joint projects would promote better understanding between the two professions. The holding of this seminar by the Bioethics Consultative Committee is significant in that it brought together doctors and pharmacists to discuss the ethical issues they encounter in their daily practice. It is a step forward.

### **Education and training**

Pharmacists have an ethical obligation to maintain competence. They have to be motivated to acquire knowledge and to do their best to update their knowledge by using the right sources, by processing information given in journals and in scientific papers and on the internet, by being receptive to new ideas and concepts, and by being careful in evaluating evidence in a scientific and professional manner. Acquiring knowledge is also linked to having responsibility for that knowledge. Acquiring knowledge will enable pharmacists to use it to promote the well-being of their patients. Additionally, pharmacists should be in a position to guide patients to find reliable information on the Internet.

### **Public education**

The public needs to be educated about medicines, on how to attain the best results from their medicines and encouraged to take a more active role in managing this process and other aspects of their health care. They should also be made aware of sources of friendly and accessible expertise on medicines. The objective is to achieve a behavioural change in medicine-taking and enable patients to take a more active role when interacting with their doctor and pharmacist. Campaigns such as the EuroPharm Forum Project: “Questions about Medicines” (European Forum of Pharmaceutical Associations and the World Health Organisation Regional Office for Europe, 1992-9), or the “Ask about medicines” week being organised in the UK in October 2003 will enable the health care professionals to reach this aim. The involvement of patient organisations is imperative to reach this objective. Such campaigns should also educate the public about the pharmacists’ role



and responsibilities so as to enable them to make better use of their professional services. Additionally such campaigns should educate and encourage them to try to always frequent the pharmacist of their choice as this will enable continuity of care and the establishment of a good relationship. A good relationship promotes dialogue, which is the basis of patient empowerment.

## Conclusion

Patient empowerment is a challenge. It is a challenge for the public, patient associations, patient support groups, the pharmaceutical industry and health care professionals. Patient empowerment can only be attained through the collaboration of everyone concerned. This seminar can act, as a catalyst to forge closer and stronger links between the two professions of medicine and pharmacy so that together they can endeavour and take the lead to ensure that patient empowerment will become a reality. Pharmacists and doctors are bound together by a common goal: to promote the good of patients and society. This goal can only truly be attained if patients are empowered to be active partners in their care. This is the challenge for pharmacists and doctors today.

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# **Ethics and Solidarity in Malta's Health Care**

**Mary Ann Sant Fournier**

## **Introduction**

Leonardo Da Vinci in one of his famous (and might I add, ubiquitous) drawings, may be said to have placed Man at the centre of the Universe. The Creator Himself placed Adam (and Eve) above all other creations. One might also be tempted to add, therefore, that Health Care should be patient-centred and that this should be a moot point. These are some of the reflections that came to my mind in preparation for the discussion of the theme, "Equity and Solidarity in Malta's Health Care".

The perceived application of the principles of Equity and Solidarity has been amply debated over the years, nationally and internationally, particularly in the context of allocation of resources. It is a consideration of grave concern to various stakeholders. It is of course, significant, that at this moment in time, a time of challenges and changes, nationally and globally, it is addressed from a bioethical dimension. The variation on the theme here is that, given the fact that I am a Pharmacist by vocation, I shall address the bioethical consideration of "Equity and Solidarity in Malta's Health Care" with a pharmaceutical perspective and a patient - centred focus.

## **MALTA'S HEALTH CARE**

It can be stated that Malta's health care is delivered by two completely separate systems, public and private. The public or national health system is traditionally based on a paternalistic welfare state model, based on the principles of Equity, Justice. Solidarity. The terms "free medicines", "free medical treatment" and "free health care" are an integral part of our vernacular! But, over the last years, there has developed an intensifying debate at various levels, locally and globally, on:

- the sustainability of such a model,
- the extent of solidarity that is manifest,
- the equity of access to care,
- the equity in accessed care.

In this ambit, one cannot overlook the importance of the ethical consideration of the allocation of resources in healthcare at various levels.

To begin with, let me define below, the limited glossary that I shall be resorting to:

**EQUITY**, may be defined as - “fairness, justice, and fairness in the adjustment of conflicting interests; and **SOLIDARITY** as, “unity of fellowship arising from common responsibilities and interests”; and characterised by, or involving community of responsibilities and interests”.

In the bioethical domain, management of resources must be based on equity. The entire population should have access to the necessary health services with particular regard being given to those who have specific needs - the disabled, the elderly, indeed, all the weaker members of the community. Health Professionals themselves have a(n) (bio)ethical obligation to exercise the principle of Human Solidarity in extending their help to the weaker members of society.

Solidarity in the bioethical domain can be understood as responding by contributing to the needs of the people, standing together as a multidisciplinary healthcare team to deal with “life’s misfortunes”. It involves a network of interactions, and intertwines models of communication in *trust*, and *co-operation* in trust, whereby each member of the team contributes in accordance to his competence and skills whilst being mindful and respectful of the functions of others (WHO, 1988). Moreover, solidarity necessitates that members of a community, i.e., the health care team, understand the meaning of illness and suffering, and gain an insight into the patients’ experience. Such

understanding would ensure the most effective therapeutic interventions, but, and perhaps even more significantly, they would ensure that the patient is treated *as a person*.

Indeed, contributing to the needs of people should not be provider-centred but should, in turn, be based on the Principle of Subsidiarity, whereby decisions are taken as close to patients as possible, so that with suitable support, taking into consideration their values, conscience and beliefs, they can make decisions about their health, in a spirit of friendly fellowship with their health care provider.

The challenges brought about by new knowledge - the explosion of information following the decoding of the human genome is a case in point - innovative expensive medicines and interventions, new technologies, an ageing population (demographic changes), emerging unhealthy lifestyles (e.g., explosion of teenage female smokers) environmental factors, increasing patient awareness, and patient expectations call for developments in the healthcare sector. These necessitate the adaptation of new strategies so that society will have access to health services that are comprehensive, efficient, effective and affordable. Inherent to the provision of quality health care that is sustainable, are the principles of equity and justice and *partnerships with all stakeholders*.

The World Medical Association (WMA, 1996) had issued a statement on allocation of health care resources and one of its working groups issued a guidance paper for the National Medical Associations. This paper addresses the diversity of views regarding the ethics of allocation of health care resources which, “can be due to the diverse national health systems or understanding of the key terms”. In this regard, the term ‘**ALLOCATION**’ was defined as “*an act of distribution of resources, tasks, etc., which does not necessarily imply any shortage among things to be distributed*”; whilst ‘**PRIORITIZATION**’ as “*the establishment of a rank order among things (values, tasks, outcomes etc.) usually when not all goods can be attained at once.*”

I share the hesitation expressed by the WMA Working Group to include the term '**RATIONING**' to which the paper attributes the following two distinct meanings:

- (1) distribution of limited resources according to specific criteria where needs of recipients are fairly uniform and predictable e.g. foodstuffs; it implies a just and equitable distribution apart from the ability to pay and
- (2) deliberately restricting access to needed and potentially beneficial resources on the grounds of cost alone. This is considered to be bad especially if health professionals are involved.

Thus this term was considered ambiguous and omitted.

The dimension of the issue includes:

1. **the macro-level** decisions taken by governments, insurance companies and other major healthcare funding bodies. In Malta, the bulk falls on Government, together with the private sector, which is separate and distinct, but which may be considered to be complementary to the public system, with hospitals and doctors' clinics, and a network of 204 pharmacies, many of which are pharmacy-clinics providing to a certain extent still untapped synergies in the interest of patient-centred clinical pharmaceutical services.

2. **the meso-level** allocations of categories of patients to treat, which medicines, equipment, etc. to procure and allocate. The principal decision makers are physicians, administrators, members of elected or appointed boards. Pharmacists play an important role at this level through their practice in the areas of drug selection, procurement, the spearheading, establishment and implementation of national drug policies, *the setting up of protocols and formularies*, their proactive participation in pharmacy and therapeutics committees and other decision-taking fora.

3. **the micro level** - individually, where, more often than not the decisions are taken between physician (e.g. which therapeutic intervention to use, for how long, etc.), and patient, depending on the authority and culture. In Malta, the pharmacist plays an important role as the *patient's advocate* insofar as he consolidates the physician's prescription and instructions; and in recommending non-prescription medicinal products (pharmacist-recommended medicines) and care. These services depend directly on the professional knowledge, expertise and responsibility of pharmacists. These may take the form of direct advice on medicines, disease and/or attaining and maintaining a healthy lifestyle; screening of the prescribed medication regimen for accuracy of dosage within safety limits, drug interactions, etc. Moreover, the pharmacist guides the patient to choose suitable medicines, when necessary for the treatment of minor ailments, through the dispensing of pharmacist-recommended medication; and refers the patient to the doctor when this is deemed necessary, often without dispensing any medicines.

### **Malta's Health Care And Resources**

It would be in context to ask here, is it immoral to discuss the cost of health care?

In Malta, the Government plays a decisive role in the allocation of health care funds. The current model of Malta's public health care system approaches closely that of the National Health Service (NHS) of the United Kingdom post World War 2 experience, which is based on fixed funding from the general taxation. Its founding principle is that of providing access to care to all on the basis of need, not the ability to pay (HMSO, 2000). The latter model has been significantly below OECD norms and lacks flexibility, having failed to fully satisfy patient expectations as measured against countries in continental Europe. Moreover, the central control system is no longer satisfactory and there is reluctance to embrace the "free for all" of the completely market-led American model, considered by all Europeans to lack the essential solidarity and equity values. (Bannister and Jonsson, 2000). In July 2000, the UK Secretary of State presented to Parliament "The NHS Plan - a plan for investment, a plan for reform" making a



commitment to increase funding for the NHS over four years; the challenge being to use the resources available to achieve maximum benefit for the patient and ensure that the NHS is modernised to meet public expectations. (HMSO, 2000).

In Malta, the sustainability of the present system, together with the need to integrate the delivery of health care by the private sector was intensively discussed locally at the consensus conference entitled *A National Agenda For Sustainable Healthcare*, organised by the Foundation for Medical Services (FMS) and the Forum of the Health Care Professions (FHCP) (February 2000)

### **The Health Care Professions' Forum**

The Forum consisting of the national medical, nursing and pharmaceutical associations, was established in 1999, to address the urgent exigencies felt by the health care professions, *independently*, with regard to the status of Health Care in Malta, the need to establish a *forum* creating an environment that promotes inter-professional communication, co-operation and collaboration; the individual professional issues to be addressed; and the matters on health of national interest, so that we could have one voice for the good of the patient, the service provision, the professions and the nation, where health is concerned. A *forum* where “we could understand each other better, understand our expertise which is different but complementary; and our concerns, and existent barriers in our health system, all of which, in most instances, are common factors to all”. (FHCP, 1999) The Forum of the Health Care Professions had also brought together the expertise of different health care professionals with their international affiliations, who have common goals and objectives (FMS- FHCP, 2000).

### **Consensus Conference: Aim and Objectives**

The aim of holding the conference was to achieve consensus on the way forward in healthcare to attain a sustainable healthcare system based on:

- solidarity in the care of medically and financially weaker members of society,
- autonomy and patient empowerment,
- flexibility,
- to present a document outlining a strategy;

Important topics were discussed. These included: The New Hospital And Associated Changes, Health Care In The Community, Financing And Quality Of Health Care, Improving Performance And Outcomes, Tomorrow's Healthcare Providers, And The Elderly - In Sickness And In Health. Significantly, there was also extensive discussion on Equity And Empowerment In Health Care, and intensive discussion between pharmacists, doctors, representatives of the pharmaceutical industry, policy makers, and patients and ethicists on Quality, Equity And Financing Of Medicines.

In the light of all the above considerations, not least those of equity and solidarity, the outcome of discussions centred amongst other on:

- finding an equitable and sustainable way of funding the health care needs of all Maltese citizens
- motivation of all health care professionals;
- the need for a reform of primary health care and the entire community health system with fruitful co-operation between the public and private systems, promoting seamless care.

In particular the working group on *Quality, Equity And Financing of Medicines* recommended that there should be “stringent criteria for entitlement and co-payment”.

In general, the conference found it necessary to consider other alternatives in addressing the problems faced with the sustainability of the present system, whilst re-evaluating such ingrained concepts as: should everything be completely free of charge? In such a scenario, the patient has no degree of responsibility and is not reminded that nothing is truly free; “waste today”, translates into having less

availability or higher payment rates later; and, should costs be moved in a controlled manner from the State towards the individual and companies who have the interest to have healthy employees? (Bannister and Jonsson: 2000).

Overall, the most significant recommendation was that of the establishment of a Health Authority with representation of all stakeholders not least of patients and professional associations and non-governmental organisations to spearhead the much needed reforms (Bannister and Jonsson, 2001).

### **Equity And Solidarity In Primary Health Care - A Patient-Centred Pharmaceutical Model**

Pharmacists' private practice in the community has always focused on the establishment of good patient-pharmacist relationship, which is fundamental to the provision of patient focused pharmaceutical services. However, those patients who receive their pharmaceutical services through the public health system are being deprived of such a service because the public system is a barrier to the development of personalised services in an area where direct pharmacist-patient contact is essential. *This is ethically and morally wrong, since it is tantamount to inequity in access to services, which are necessary to attain positive outcomes of medicines usage and a better quality of life.*

Thus people should have the equitable right of access to the services of a pharmacist, based on the principle of social justice.

Indeed, this is the main objective of the Malta Chamber of Pharmacists in insisting with successive Administrations to implement a "Pharmacist of Your Choice Scheme" by decentralising the distribution of national health service medicines to the pharmacy/pharmacist of the patients' choice so that *patients choose their private community pharmacy and pharmacist, not only on the basis of convenience in the location but significantly on the basis of the nature and quality of professional services that are delivered by the pharmacist.*

This premise is based on the principle that “Freedom is essential to make choices” which can be considered to be derived from Kant’s introduction of the concept of personal autonomy: that people, being free human beings are free to think, and free to act (in matters of morality) (Dessing, 2000). Moreover, an individual’s autonomy is a value that can be considered as basic - an individual’s right to freedom to exist, to act, to think and to communicate (Universal Declaration of Human Rights, 1948).

Our Society is organised as a state, and democracy can be organised as a system of parliamentary democracy. Thus, through the common interests of all individuals, democracy will result in a form of solidarity. Values that are considered as “essential” in today’s western society are the individual’s autonomy, democracy and solidarity, and justice. Indeed, health care as a common good is strongly connected to democracy. On the other hand, disease is one of the conditions that threatens autonomy. Thus, a compromise between autonomy and general interest is a reasonable objective to avoid a climate of anarchy. An interesting premise is that of Rorty (1989), who explained that a certain level of solidarity guaranteed a society that is stable enough to secure individual safety and prosperity. In fact, the public agreement about this is translated in a democratic political system, which forces by a majority vote every citizen to comply with this system. The result is a constant and dynamic tension between what Rorty calls the private and public domain.

In this bioethical scenario, the Pharmaceutical Profession has proposed the establishment of a public-private partnership between private community pharmacists and Government, whereby the distribution of National Health Service medicines (under the Social Security Act) from the government *bereg* (local health clinic) and the health centre pharmacies is decentralised to be dispensed from the network of private community pharmacies of the patient’s choice. This should entail the phasing out of the *bereg* system where patient and carers are deprived of any contact with their pharmacist.

It is also an excellent opportunity for the optimal use of health care resources through better involvement of private community pharmacists, whose expertise and services are at present under-utilised. Thus, the implementation of such a system would “free” such highly trained human resources in the public health sector to use in the development of clinical pharmacy services in the hospital setting, thus improving patient care and outcomes. Moreover, the scheme is envisaged to require the re-evaluation of the entitlement criteria, with the exclusion of certain items under the “pink card”, in favour of a better service in other areas, such as extension to cover other chronic diseases under the Schedule V criteria.

One must distinguish between ‘patients’ wishes’ and ‘patients’ needs’. Árnason (2002) addressed the Rawlsian/Daniels arguments on justice in health care. With regard to the “principle of individual responsibility”, it was argued that it is not a social obligation to provide health services which arise out of individual preferences and are not necessary to restore a person’s functioning; while, in the context of the present paper, it would be more relevant to support the “principle of medical need”, whereby, the Rawlsian/Daniels arguments revolve around the premise that it is more important to prevent, cure, or compensate for those disease conditions which involve curtailment of an individual’s share of the normal opportunity range than to treat those conditions that affect it less.

Indeed, the present system does not satisfy patients’ needs and requires revisiting insofar as it limits access to innovative, expensive medicines, in line with international trends for the treatment of diseases and conditions, based on proven efficacy (evidence-based), safety, cost effectiveness, and improvement of the quality of life. More consideration should be made to the prevalence of disease and conditions in Malta, and the consequences of non-treatment. In this regard, the support that government gives to those with ill-health should not be “rationed” to control expenditure on:

- innovative, expensive medicines for the treatment of those few patients with terminal or debilitating disease; and,

- treatments which can prevent serious health repercussions that can translate into expensive, invasive hospital-based treatments later on in life and a negative impact on patients' quality of life.

Rather, government should express a firmer commitment to solidarity and enable patients in their state of vulnerability to have access to medicines that not only add months or years to their life but also improve their well being (Malta Chamber of Pharmacists, 2002).

In this context, one cannot but re-emphasise the important and decisive roles that are played by continuously updated formularies, both national and local, and prescribing protocols. These are important tools to secure 'quality of outcome' intended as an optimised predictable, and uniform outcome of a specified intervention. In pharmaco-therapy, it implies that a specific disease indication or problem is treated according to principles of 'evidence-based medicine'. (Dessing, 2000). Pharmacists and Doctors as health care professionals co-operate to compile, and update regularly, protocols, and groups of protocols to set-up formularies. These contribute to the practice of rational drug use, which must not be allowed to become restrictive but educational, being continuously monitored and evaluated with attention not only to e.g., consumption and expenditure, but also to factors like efficacy and safety (Shaw et al, 1998). Indeed, they should respect patients as individuals. The protocols should be communicated to the professional domain in a clear and unambiguous way and to society, where the decision takers have the responsibility to oversee the total field of request for public interference into the individual's life and to communicate their view to the people. The individual must recognise his ambiguous role in society, his different qualities and responsibilities, as this is fundamental to the acceptance of the daily consequences of any decisions concerning health care at the personal level. (Dessing, 2000).

One such forum could be a national drugs and therapeutics committee which should include representatives of stakeholders, including, patients and professional associations, at the decision-taking level, introducing incentives for rational prescribing and dispensing and

accountability; and to be able to evaluate requests for the introduction of new medicines and inclusion of new indications taking into consideration scientific evidence obtained from the maximum possible sources and not to restrict oneself to one sole institution (Malta Chamber of Pharmacists, 2002).

### **The Pharmacist of Your Choice Scheme: Objectives**

The primary objective for the implementation of a system whereby the 'national health service' medicines are dispensed together with associated care services by the pharmacist of the patients' choice may thus be summarised as follows:

- to ensure equitable access by the public to the expertise of pharmacists in medicines management and care services;
- to promote concordance to patients' treatment ensuring, not only compliance to medication but also empowering patients' responsibility of their own health (Noyce, 2000) and the rational use of medicines and other health resources;
- to contribute to the improvement of medicines management and to discourage the indiscriminate use of medicines, decreasing misadventures due to abuse;
- to eventually decrease hospitalisation of patients as a result of drug misadventure and inadequate control of their condition;
- develop the professional service of pharmacists in the community, upgrading the professional standards in the service of society;
- to develop seamless and continuous care between primary and secondary health care structures at the interface between public and private pharmaceutical care services; (Ministry of Health, *et al* 1999).

Studies have consistently shown that there is strong support by the public for the decentralisation of these services to the private community pharmacies in the towns and villages in Malta. Significantly, a body of knowledge is also building up, nationally (Cordina *et al*, 2001) and internationally whereby research revealed evidence that pharmaceutical

services in community settings make a positive impact on patient outcomes (e.g., clinical, humanistic, economic) (Singhal et al, 1999).

### **Patients, Pharmacists and Society: Partners in Health Care**

Patients are key partners in health care. Their needs are the leading principle in care-ethics (Tronto, 1993). Community pharmacists can empower them to take a more active role in their own health care, to take on responsibilities to pursue healthy lifestyles, become more knowledgeable about their condition and their treatment. And to participate in decisions, and co-operate in accepted therapeutic regimes which should have the objective of restoring the maximum achievable autonomy.

The proposed “Pharmacist of Your Choice” model is a public-private partnership initiative between the community pharmacists and ‘society’ intended as people, i.e., patients and other health care professionals, and government. It would consolidate the role of the pharmacist as the gatekeeper to avoid negative outcomes of pharmaco-therapy and the promotion of health. In the present circumstances, this is expected to receive an increasing public endorsement. Such a focus on patients together with the social imperative to provide medicines and care are deeply held convictions of our society, which are, in turn, ingrained in the principles of solidarity and equity in healthcare.

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# **The elderly and collaboration between Primary and Tertiary care**

**Dr. Anthony Fiorini,**

## ***Introduction***

Politeness dictates that I thank the organisers for kindly inviting me to present a paper at this symposium. However, if you want me to be completely honest, I am far from thankful! I remain uncomfortable when asked to discuss ethical issues, even when the elderly are concerned. I still expect ethicists to present ethical issues and I still equate ethicists with religious people, preachers, Moses and the Ten Commandments, and judges. I certainly do not fit in this circle! Imagine a judge with his wig of wisdom and compare his crown to mine! People who know me will note that there are obvious differences!

However, I have accepted the invitation to present this talk, so here goes.

## ***What is preached***

I would like to first inform you about what is preached, because even in collaboration between primary and tertiary care, there are 'commandments' or 'codes of practice' that touch on the obligations, rights and dignity of both clients and health care professionals. In the end they all strive to lead to a better quality of care that can be given to our clients.

I will then go on to give examples to try and illustrate whether these guidelines or codes are actually adhered to in Malta. Just like the Ten Commandments I suppose. We all know them by heart, but do we break them, and if yes, how often?

## ***Definitions***

Before proceeding further, I have to take a moment to define what I will be talking about.

The elderly are those aged 70 years and over, with problems of health and frailty.

Primary care is health care provided in the community by family doctors (with apologies to other members of the primary health care team).

Tertiary care is health care provided in a specialised hospital for the elderly by a consultant geriatrician (again with apologies to other members of the hospital health care team).

Collaboration is to work together. I feel I have to remind the audience what this word still means since, in everyday practice, it is often ignored!

### ***The Commandments***

So what are the commandments or codes of practice that guide primary and tertiary care collaboration as regards the elderly? A lot of material can actually be found in policy statements issued by esteemed authorities such as the Royal College of Physicians and the British Geriatrics Society. So I have extracted some of them, threw in a few of mine and grouped them into three with the following headings:

- (1) What elderly patients want.
- (2) What family doctors want.
- (3) What consultant geriatricians want.

I would like to emphasise that these ‘wants’ are as seen through the eyes of a consultant geriatrician.

#### ***What elderly patients want***

- To be referred by their family doctor to the hospital department best able to meet their needs.

- To be assessed and admitted quickly and efficiently.
- To remain an in-patient as long as their clinical condition requires.
- To have a planned discharge with all the necessary instructions and community support.
- To be assessed in their own homes by a consultant if the situation requires it.

### ***What family doctors want***

- To decide which hospital department to refer their patient to.
- To have a clear system of referral.
- To have access to a hospital consultant when required to discuss a particular case.
- To be involved, when necessary, in the management/decision making of an inpatient (for example advance directives).
- To be informed about a planned discharge of their patient (especially if the case is complicated and in need of support).
- To have a discharge letter sent with the patient on discharge.

### ***What consultant geriatricians want***

- That their specialist expertise is recognised and requested by family doctors.
- That the admission policies of their units include direct admissions from the community.
- That they have the necessary resources to respond to cries for help from family doctors, at the time of need.
- That all the relevant information on individual patients is provided by the family doctor.
- The clinical freedom to decide a patient's admission/discharge.

### ***Levels of collaboration***

Based on these wants, collaboration between family doctors and consultants at the community/hospital interface can, therefore, be grouped at three levels:

- The *time of admission*, which is initiated by the family doctor and to which the consultant responds.
- The *inpatient period* which is conducted by the consultant and to which the family doctor can contribute, for example in making certain decisions.
- The *time of discharge* which is initiated by the consultant, with all the necessary information given to the family doctor.

All three levels have guidelines that ensure continuity and quality of care through collaboration between primary and tertiary based professionals. This collaboration requires communication. It has been stated by the British Geriatrics Society that shortfalls in communication at the hospital/community interface are the most frequent causes of complaints by patients, carers and doctors. Although this statement was aimed at services in the United Kingdom, it certainly holds water also for Malta. And when one considers how fascinated we all are with the means of communication that exist today, it is even more surprising how easily we seem to forget to contact one another!

### *So, do we practice what is preached?*

I thought I would give some examples which illustrate everyday practice and for which we can all reach our individual conclusions. I thought I should call these experiences:

*'One week in the (working) life of Dr. F, a consultant geriatrician'.*

#### *Example 1.*

Ms. A - an 82 year old woman, an inpatient at Zammit Clapp Hospital (ZCH).

Her main problems are: pressure ulcers, dementia, with nasogastric tube feeding, very dependent, bed-bound.

Her sister (aged 80 years also) wants her home at all costs: 'a strong believer that God will look after them'.

Detailed discharge planning with required community services is carried out with the family doctor contacted and involved.

Patient was discharged.

2 weeks later 'medical problem' – no place at ZCH – ended up as an inpatient at St. Luke's Hospital.

*Comments:* Good discharge planning; limited resources to respond promptly to a cry for help from a family doctor; collaboration in continuity of care interrupted.

### ***Example 2***

Mr B – 75 years old.

Family doctor phones and mentions several medical and functional problems.

Obviously a case for admission to Zammit Clapp Hospital.

But no empty bed available – 100% occupancy.

Situation cannot wait – patient admitted to St. Luke's Hospital.

*Comments:*

Again inadequate resources leading to an inappropriate admission to a general medical ward where 'their presence can be resented, their needs inadequately met'.

### ***Example 3***

Ms C, a 71 year old woman, an inpatient in a general hospital.

Main problems: brain tumour just diagnosed, refuses palliative operation.

Remains with balance problems and weakness in one upper limb.

Discharged home, nobody at home. Family doctor not informed, no support services organised.

*Comment:* Poor discharge planning.

### ***Example 4***

Mr D, an 80 year old man, an inpatient at ZCH for 2 weeks.

Diagnosis: post fracture neck of femur operation and rehabilitation.

Now walking safely with frame and is independent in activities of daily living.

Home visit carried out by therapists and social worker: will be safe at home.

Discharge date given – no further inpatient management required.

Family doctor phones, VIP phones, ‘please postpone discharge for two weeks as carer not ready’.

*Comment:* inpatient management complete; inpatient facilities will not be made available for next patient on waiting list; consultant obligations – request for further inpatient stay not possible.

### *Example 5*

Authorities change Zammit Clapp Hospital admission policy: ‘No direct admissions from the community’.

*Comment:* an impingement on the rights of patients, general practitioners, consultant geriatricians; collaboration between primary and tertiary care interrupted.

### *Example 6*

#### *The Home Consultation visit*

This is a visit to a patient’s home by a consultant, at the request of the family doctor and normally in his company, to obtain advise on the diagnosis and treatment of a patient who is unable to attend hospital because of his/her medical or functional condition. The visit is accepted practice, both abroad and locally, with known advantages. Such a visit may avoid an admission into hospital but may also lead to an admission to hospital. However, it is carried out outside the normal working hour duties of the consultant and therefore a fee is involved. Dr. F carries out such visits at the request of the family doctor.

Imagine Dr. F’s amazement and distress to wake up one Sunday morning and find this heading ‘Preferences for those who pay for private treatment’ in a local nameless, newspaper with his name splattered all

over the front page. The article basically stated that to get admitted into Zammit Clapp Hospital, a certain Dr F had to pay you a visit at home and get paid. And to add insult to injury the article also quoted our Archbishop who had recently stated that 'the sick patient should not be used as an object of business and profit'. All Dr. F. was doing was carrying out home consultation visits at the request of family doctors, getting paid for it (as he should), and admitting some of the seen patients to the geriatrics unit if required.

*Comments:* problem of overlap between private and state-run medical services;

### ***Private and State-run medicine***

So even when consultants and general practitioners are actually collaborating together, intentions can get misinterpreted. However this situation also highlights the dilemmas that can be encountered when there is an overlap between state-run and private medicine. In certain situations they are kept completely apart. However, in other cases there is an overlap, as can happen with home consultation visits. The ethical issues involved, when health professionals work in both state-run and private-run systems, can open a whole can of worms and could possibly be discussed at a future symposium organised by the Bioethics Consultation Committee.

### ***In conclusion***

It can be stated that we work in a daily minefield of ethical issues. I often feel as if I'm being made to walk a tightrope and it can prove difficult to keep one's balance, trying to juggle with all the requests and situations that arise during a normal working day. However, if existing codes of practice and obligations are adhered to, then quality care is guaranteed, and the rights and dignity of patients, family doctors and consultants will be safeguarded. We talk a lot about the rights of patients. But it is important to remember that doctors and consultants also have rights, as I have mentioned.



Finally, I would like to emphasise that it is essential for all doctors to keep collaborating, which means communicating. I would also like to ask the authorities to increase the resources to be able to provide more specialised hospital care for the elderly. We reached saturation point a while ago and cannot cope with the demand.

# Outcomes of First Meeting on Ethics in Family Medicine

**Pierre Mallia**

This meeting has produced papers by both members of the medical profession and pharmacists which have left us reflecting on the need to communicate at all levels. In the first instance at least three further meetings have been reflected upon and should finances and support from the relevant bodies continue, I personally would see that they take place during this workshop of ethics in family practice<sup>1</sup>. They can be summarised as follows:

1. A meeting between pharmacists and family doctors to iron out issues of patient sharing and obligations of each profession towards patient empowerment. In particular questions relating to where the work of one profession interfere and/or enhance that of the other need to be discussed.
2. A meeting between primary health care doctors working in the government system and those in private family practice. This follows from my first talk on the first day of this meeting and the comments I received in the ensuing days. Definitely relating an experience can translate into it being communicated as though one were speaking against one group. This is definitely not the case and many of my best colleagues and friends work in the government health centres. What is evident though is that we have never got together as two groups to see how we can co-operate effectively.
3. Following Dr. Anthony Fiorini's talk, one can see also a need to see how family doctors and government services

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<sup>1</sup>This workshop started this year and is an initiative I took on behalf of the Bioethics Consultative Committee on Ethical issues in family medicine. The workshop will last three years.

can work more closely together. If one can extrapolate from his talk on Geriatric medicine to the general government system, we must also be looking at what is the role of the family doctor in hospitals in general.

4. It pays to have our health care system based on primary care. Unfortunately, as Dr. Philip Sciortino's talk revealed, studies in this and other related areas are lacking in Malta. Although no workshop can solve this issue, it is hoped research in the future would focus in these areas.

On the third day there were three interesting talks on various aspects of family medicine as a speciality. Of course all these talks were personal and not necessarily reflective of what the word 'specialty' should mean. However, they were followed by a short discussion at the end which raised some interesting points.

Research in primary care has its advantages, as was pointed out by Dr. Jean Karl Soler, who, after giving a review of ethics in research, presented three interesting ongoing international studies in primary care in which Malta is participating. At least one, is in fact, being co-ordinated from Malta. Research is definitely a hallmark of a speciality, but it is not exclusive. There are many other things which define a speciality. One relates to its autonomy in deciding who we are and what we do as a speciality. Another is the provision of optimal standards of care in keeping with developments in other countries. My talk for instance described some special interests which family doctors may have, which although not obligatory, should indeed be encouraged by our associations and/or colleges as functions which do indeed lie within the aegis of family medicine as well. My intention was to drive in the idea that nobody can tell us that endoscopy, ultrasound, minor surgery etc, cannot or should not be done by family doctors. They indeed can be based on two reasons. The first is that only we as a speciality can and should decide if they can be practised by family doctors (of course in keeping with proper standards of care and training). Secondly, they are already trends which many family doctors are taking abroad, and which research has shown (in keeping with the first issue discussed)

that they enhance standards of care and are economically viable even to patients. As regards whether local departments should provide training, this should not be reflected upon as whether it will effect vested interest but whether it is economically viable for our health care system and whether it enhances the care we provide to patients – which would then translate into a patient rights issue. One can understand that the department of radiology, for example, has a high workload, as pointed out by Dr. Denis Soler, and thus has no obligation to train doctors with an interest, especially when it itself sends trainee radiologists abroad. But training a radiologist and training a doctor to do *primary care* ultrasound are two different things. One is a specialised instance, the other is training GPs to do basic screening. This in turn should even decrease the load on the department. In the UK many GPs go to community hospitals to help the specialists out on long lists. They provide the same quality of service.

One has to look at this also from an economic and practical point of view. It has been shown that an ultrasound done as part of a general physical examination will indeed detect pathology before any signs and symptoms have yet occurred. Thus one can detect renal or bladder tumours, or abdominal aneurysms. Therefore if someone goes to his or her GP and asks for a physical, the GP is obliged to examine the patient and also offer some tests. Of course one can offer a CT Scan, but this may expose the patient to radiation which has not been shown to balance the benefit of a yearly physical. Ultrasound however is simple, non-invasive and cost effective, even on a yearly basis. Yet there is no way, using the health care system, whereby a GP can offer an ultrasound as part of a physical examination (or check-up) to a patient. The only way would be to refer this patient to hospital out-patient, taxing on a secondary care system, which was not intended for primary care. The patient will then expend the time of a doctor who has to see him or her at out-patients, decide whether he wants to accede to the test. If so he will then probably order other basic blood tests and use up an hour of time to take a history and put it on a file, then refer the patient to the radiology department. This will in turn use up time of a department which is dedicated to secondary care. The patient would

then have to be seen again at out-patients for the result, again taxing on hospital time. All this for a basic simple ultrasound screen. This is not to mention that the whole process can take months for the patient and long waiting-room hours. Training doctors to do this simple ultrasound in the health centre setting, possibly co-operating with private family doctors, make sense when looked at from this point of view. Unfortunately, as Dr. Sciortino's paper has shown, we lack studies in Malta to show cost-effectiveness of our systems and many other things.

Now ultrasound does not make us a specialty, as has been pointed out. Neither does research, and neither does anything else. So what makes us a specialty? The answer seems to have been 'Vocational Training'. However many at the meeting were left with open questions which the forum was supposed to answer. Indeed the government, as pointed out by Dr. Denis Soler, has put the College on the Speciality Accreditation Committee (SAC) to decide what and who can be classified as a family doctor. Dr. Soler insisted that anyone with an MD has a constitutional right to practice as a GP. This leaves two cold questions: what is the difference between a GP and a Family doctor in practice? We all know they practice the same thing in the same field. They are performing, in other words, the same ball game. Secondly what significance does it have to be able to put on your card 'Specialist in Family Medicine' if at the end of the day anyone can practice family medicine? In other words what does the so-called 'specialist' do more than the non specialist? The answer is simply that they do *the same thing*. So why all the trouble of putting some doctors through Vocational Training when others still can do the same job legally without going through vocational training? If we had a shortage of GPs this would be feasible. But does a constitutional right make it moral? Even herbalists, chiropractors, osteopaths and Chinese Medicine, have a constitutional right in Malta to perform as they are not regulated as in any other country. I can open shop tomorrow and call myself a nutritionist because I obtained a three-week correspondence certificate which has no type of assessment and nobody can stop me. We all know that what is moral is not necessarily legal and what is legal is not necessarily moral.

It is here where I feel the Malta College should work hard . And may I take the opportunity to heed a word of warning which hopefully would not fall on deaf ears. This was also Dr. Fiorini’s message (which was used in a different context but which applies here):

*Communicate, Communicate, Communicate,  
Communicate, Communicate, Communicate,  
Communicate, Communicate, Communicate,*

Omit this to the Colleges’ peril. We have to decentralise decision-making. When the government empowers a body to decide who is to be considered a specialist, that is a very good thing, but also a very vulnerable position. If decisions are taken by a group of twelve people or even less, then other members and non-members may feel threatened. Creating a dichotomy now would be perilous to family practice in Malta.

I think the person who drove a strong message during these three days was Dr. Jean Karl Soler. Research indeed tells us a lot and contributes to our becoming a specialty. But we now need research which would benefit us all as a country. Research should be directed to doctor’s feelings about the College, about the dichotomy in family medicine between State and private practices, about what defines us as a specialty, about whether it is cost effective to run health care from primary care in order to produce evidence to our politicians. In other words we need what we have come to call, *Patient-Oriented Evidence that Matters (POEMs)* – and I emphasise ‘that matters’. Someone needs to coordinate studies which would make a difference to our future. I augur that the presidency of the Malta College of Family Doctors be more open to suggestion. We are not any more those few people who once met in a kitchen. We are now a body given government power. Power can empower some but may make others feel threatened. We need to embrace all in one big family of family doctors.

Finally the question relating to *who should practice family medicine* was raised. Of course, as pointed out by the President of the College,

anyone who has an MD has a constitutional right to practice medicine in Malta. But then again, in Malta, anyone who has even a correspondence diploma obtained in six weeks can practice anything. This abuse is more than evident in alternative medicine. The word 'quack' is simply not on our vocabulary. People go to so called 'nutritionists' even in Pharmacies. Moreover there is no council to regulate people practising legitimate alternative practices such as Osteopathy, Chiropractic, and Acupuncture. We even have so-called 'Chinese Medicine' doctors. Now what is Chinese Medicine? It is not listed on Woodham and Peters' *Encyclopaedia of Complementary Medicine*. Yet we allow people to operate with no control at all. I have seen patients going to 'nutritionists' who gave them advise to stop steroid treatment. Beauticians advice patients constantly to stop medical treatment for Acne. Why cannot these 'professions' be held liable?

But the point we are trying to reach here is whether only *specialists* in family medicine are to be allowed to do General Practice, or whether anyone can do so. What would be the point of being able to call yourself a specialist in family medicine, having been obliged to go through three years of vocational training, when then someone who opted not to do this would be able to do the same work in the same pool of patients that you work in?

There is a lot of work ahead. It is hoped that those who take on the responsibility will not shy away from change. Sometimes you have to step on people's toes; especially if they go against principles which you strive to implement. As yet having an NHS based on a sound primary care is only a dream. It is not even on the horizon. We have a dichotomy which our politicians have shied away miserably from changing. We still send people to hospital out-patients if they cannot afford a full check-up privately – something which the health centres are not equipped to give. To do a routine ultrasound or endoscopy people have to take up the time of at least two consultants on three occasions. This costs money. On a recent interview with the hospital's chief administration officer and superintendent, it was estimated that of the new cases which are referred to hospital every year, between

twenty to thirty percent of people could have been dealt with at primary care level. If one were to calculate how much these patients cost and how much can be saved from health centres, one would find that it pays financially to base one's health care on a primary level. This is where we have to focus our forces. It is good to have research, but this research must be effective and has to have something worth saying. Whilst it is interesting to have studies which participate internationally, it is hoped that these studies would have served as an exercise to focus our energies on convincing politicians and public alike on where we want to go. Otherwise we would fall into a category of people the Bakutu tribe, which lives in the Congo region of Central Africa, call *lolema djola feke*, "the bat that flies intensely but knows not where to go". This is how they have always seen the white man's logic.



**Section C:  
Papers Presented at the European Society of  
Philosophy & Medical History (ESPMH)**

# Phenomenological approaches to the doctor-patient relationship

**Dr Pierre Mallia**

Scholars largely agree that there is a need today for a comprehensive philosophy of medicine (Pellegrino, 2001; Wildes 2001). It is with such a foundation that we analyze moral dilemmas generated by medical technology, such as genetic technologies and the uses (and misuses) of genetic testing and screening. In this respect however there is profound disagreement on what a philosophy of medicine should look like. The socially constructed philosophy as proposed by various authors including Kevin Wildes and Robert Veatch contrasts with the teleological approaches as proposed by Edmund Pellegrino. I shall briefly look at both here, bowing admittedly in favour of a teleological approach, using the basis of genetic testing as a reason to why an ontology of the doctor-patient relationship is, in my opinion, the best approach for a comprehensive philosophy of medicine, even in the post-modern world we live in.

## *Post-modernism and medicine*

Michael Bury (1998) distinguished between postmodernism and postmodernity. 'Postmodernism' as a term points to the way events and products interact with each other in the cultural sphere where they can hardly be separated. We watch the 'news' of what is happening in Afghanistan whilst we wait to see if our lottery ticket has come up - technologies of news and lottery-play hitting our minds with equal force. 'Postmodernity', on the other hand, is the foundation of this postmodernism. It is the social and technological processes that underlie and interact with postmodern cultures. Globalization, the endless expansion of modern capitalist economic forms, seems unstoppable with European countries debating whether they should form a union or not to survive. Commodities strive to find themselves in every part of the globe, and it is this infrastructure which forms the basis for genetic technologies.

Direct-to-consumer advertising of genetic testing in fact is a profound result of a post-modernist culture, whose aims are monetary rather than teleological of a medical community striving to seek a cure the ill or prevent illness. (Chandros) Hull and Prasad (2001) object to the use of advertising to promote a genetic test for a breast cancer gene (BRCA). They encounter the advert whilst leaving a performance of a play which involves a tale of an oncology ward. The play is an adjunct, a warmer, towards an advertisement which, they say, misguides women by suggesting they contact the company directly about its BRCA1/2 genetic test rather than talk to their health care providers about genetic testing, their personal risk of breast cancer, and the potential usefulness of the test.

We are entering an era in which ever more genetic tests will be integrated into clinical practice and a direct-to-consumer increase in advertising is expected. Adverts misguide and give broad truths – ‘whiter than ever before’. Whilst it is a small cohort of women who should be interested in doing the BRCA1/2 genetic tests, the adverts Hull and Prasad refer to are broad and directed to *all* women. It reads: “If you could discover your risk for a second breast cancer or for ovarian cancer, would you? Chances are, you would. Such is the promise of (this test). It reads your genetic code to determine whether you possess the altered genes that dramatically increase your risk of breast and ovarian cancer. Knowing your family history is neither enough, nor is it always accurate” (Ibid., p.34). Whilst uncertainties surround this genetic test, the advertisement claims to ‘dispel fears’. Conversely the test can hardly ‘provide hope’ when in fact the follow-up for a positive result is really uncertain, other than having a radical mastectomy (Idem). One needs to question therefore whether socially constructed theories, that is, those theories which allow the goal of medicine to be defined only by forces within the public sphere, are justified. It is undisputed that large corporations can have a big say in policy and they may influence the philosophy and ethics of advertising to ascertain the telos of medicine to fit into their own economic telos. One need therefore consider these socially constructed theories.

### *Socially constructed theories*

Social construct theories, as put forward by Wildes (2001) propound a philosophy of medicine whose ontology is constructed by social phenomena rather than by what is solely deemed as the traditional teleology based on fundamental ontology of medical practice. It may be disconcerting, however, to evaluate what socially constructed theories really imply. Tristram Engelhardt for example is a proponent for a principle of 'permission'. In a world where we cannot find a secular moral foundation, he argues that disagreeing moral agents may come together and agree upon a course of action which is acceptable to both (Engelhardt, 1994). Yet who are the moral agents involved when it comes to offering genetic testing to the public or when decisions on population genetic screening with directive counselling is advocated as has been the case for Cyprus (Hoedemakers and ten Have, 1998)? Is it perhaps the industry reaching a moral consensus with the medical profession? And at what stage does the consumer, in this case the patient, come in? Since advertising is directed towards the potential patient, it would seem that the only motivational effort to involve the consumer in this moral debate is by 'educating' him through the means of adverts, which may be as misleading as they are intent on promoting profits. In this case, who is the voice for the consumer? One may also ask, whose side does the medical profession take when coming into symbiotic relationships with market forces? For in order to serve its goals, medicine has had a long standing relationship with industry.

Yet the very viability of genetic tests requires a great number to be done in order for their production to be economically viable to a company. The medical profession is called upon to 'test' greater numbers of people, the motive becoming profit margins rather than offering hope. Subtle coercion, as the above-mentioned advert telling consumers to go directly to the company instead of the health care professional to get proper advice, acting on induced fears, will draw larger numbers to do the test than is actually necessary. A test for this could be to ask how many people do such companies in fact advise that the test is not for them? Yet such numbers may be needed to make the test viable.

Wildes, arguing against Pellegrino's and Thomasma's (1993) teleological approach, calls for a socially constructed approach to bioethical issues (Wildes, 2001). He says that Pellegrino's basis of the philosophy of medicine on the doctor-patient relationship is too narrow in addressing the crises of contemporary medicine to have to do with these fundamental questions on the nature of medicine and its goals (Ibid., p. 74). He accuses Pellegrino of assuming what he wants to prove – that there is a nature of medicine and from this to construct a philosophy of medicine. But perhaps Wildes confuses the 'nature of medicine' with the 'philosophy of medicine'. Nevertheless he argues that medicine is practiced in a social context and that the 'art' of medicine is to capture this social context as a social philosophy and social science.

Wildes' however fails to show why the social construct theory is better than a teleological approach in the formulation of a philosophy of medicine. Perhaps Pellegrino's rebuttal of Wildes argumentation is in showing how social construction allows for no permanent theory of medicine and therefore no stable ethics of the profession. Pellegrino argues that, "these (professional ethics) can become victim of a socially aberrant society as was the case under German national Socialism, Maoist China, Stalinist Russia or Imperial Japan. In each case, medicine was redefined as an instrument of social and political purpose, and the physician was made a social functionary. Medical ethics itself became the ethic of social purpose" (Pellegrino, 2001: 177). It is very difficult to play down such a strong statement, by its very factual and historical nature an unconcealed truth. Whilst Wildes thinks that the moral boundaries beyond medicine would act as deterrents to these kinds of situations from happening again, he does not realize, as Pellegrino indeed points out that these same moral boundaries would be socially constructed and thus subject to the same pathologies that distorted medicine and its ethics in the first place and therefore can provide no guarantee. What if, as pointed out above, medical ethics comes to be directed more by economic canons than by the needs of the patient? If policy relieve doctors of their primacy towards the sick person in favour

of a higher 'social goal', then a social constructed philosophy of medicine would be entirely "extrinsic to the ends of medicine" (Pellegrino, 2001, p. 178).

Robert Veatch by contrast has pioneered an approach which undresses the doctor of any say in the mission of medicine. In one of his latest contributions (2000) he persists in attacking the Hippocratic oath and the American Medical Association's (1903) position that a physician should be mindful of his or her mission and of the responsibilities they must incur in the discharge of their duties, especially where it comes to social pressures. Veatch argues that physicians cannot know what the patient's best interests are and cannot be expected to know what is medically beneficial. The participation of the patient means that the patient knows better and that the physician is in no position to be mindful of requests (Ibid., pp. 705-707). Whilst Veatch's upholding of patient rights is to be commendable, he unfortunately persists in equating these rights against what the physician considers patient benefit. But with this reasoning, a physician will not have the possibility to refuse, or at least persuade against, a genetic test to a patient who is impressed by advertising thinking she actually needs the test. Not all women need to do the BRCA1/2 test, yet advertising induces them to believe so. Is it not the onus of the physician to explain this to the patient? In situations where physicians are gatekeepers of funds, or even in situations where they act solely on principle, has not a physician a right not to participate in this patient's faulty perception of things, especially if the latter, out of fear or ignorance, persists stubbornly in requesting such a test?

The answer to these quagmires may indeed be found in the phenomenology of the doctor patient relationship. Heidegger, in his existential philosophy (Heidegger. trans 1962), never intended to discuss ethics, let alone the goals of medicine. Yet as applied philosophy, his basic notions can be applied to everyday relationships, as it is a discursive ontology of man's existence. That existence is found in every encounter with other beings, one of which is indeed the encounter

between a patient and a doctor, each having an ontology in their own right. There are ample sources today which attest to an inherent ethics in Heidegger's philosophy. Frederick Olafson (1998) notes that although Heidegger never dealt with questions of normative ethics, there was, in *Being and Time*, a very harsh critique of the whole question of 'values' as objective criteria for the guidance of our lives. These were declared to belong to an anonymous public mode of selfhood, what Heidegger referred to as 'Das Man' (Olafson, 1998, p.3). Joanna Hodge (1995) for example confesses to read Heidegger as revealing the process of the questions of metaphysics and ethics in their simultaneous search of 'what it is to be human'. Heidegger, she says, works in the restricted conception of ethics as concerned only with the relationship of human being to being human. He reveals the universalization of ethics in the globalization of technology but does not endeavor to move from the question of 'what it is to be human' to negotiating what it means for humans to be together (Hodge, 1995, p. 27). Hodge argues there is an urgent need for a retrieval of the notion of ethics from a metaphysical fixity, and that the elements of this are to be found in Heidegger's work but if we stop solely at the question of 'what it is to be human', we risk limiting ourselves in these metaphysical 'fixities' and, in the name of ethical differences, "people are massacred, distinct groups subjected to genocide. Ethics ceases to be a set of questions about what it takes for human beings to flourish. Ethics becomes a set of issues for which there is offered a global, indeed a final, solution in all its horror" as was the case for the death camps. Moreover, "the actualizing of metaphysics in technology reduces the question of ethics to a question about the nature of human beings in terms of usefulness and productiveness" (Ibid., p. 27).

If we cannot hope for a comprehensive ethics of humans from Heidegger's work however, we can hope for a better understanding of authentic description of the ontology of the doctor-patient relationship. Through this ontological foundation we can find a means of preventing medical technology, and genetic technology specifically, from overwhelming human nature and finding usefulness in the nature of medicine, rather than in post-modern drives and economic canons.

*The ontology of the patient, the doctor and the relationship*

Heidegger spoke of the coming together of beings, of authentic relationships and modes of being-with and of leveling down of relationships. Of course he spoke of these in a general and *primordial* sense, but nevertheless in such a manner as to allow one to extrapolate and take these into particular relationships. We are thrown into a world in which illness forms an important part and hence also some form of resultant relationship between one being and another because of this illness. Societies have different characters to represent their healers – from witch doctors to present-day doctors. But the common character of these encounters remains that of one seeking help, attention or counseling, and that of the other seeking to provide what is asked for. A doctor finds his identity in the relationship, just as much as the patient finds help and possibly a cure. A person *becomes* a doctor not simply by acquiring, therefore, a degree in medicine, but within the clinical encounter; in being-in-the-world (of the doctor and patient).

Yet just as Heidegger questions the authenticity of relationships and the leveling down which occurs in encounters, we can see a parallel leveling down of relationships in the clinical context. He explains how in reality this possibility of empathy, of fullness of relationship fails to hold. In coming towards patients as ‘entities with a disease’ or ‘entities with symptoms’ to be interpreted there has been or may be a doing-away with the necessity of true empathy with the sufferer or troubled patient. Even if used, it is seen as superfluous (Beauchamp and Childress, 1994, p. 375) and the total possibility of the relationship does not occur in most everyday relationships. In the medical environment which handles many patients every day this leveling down is seen in the uniformity of medical management; in the conformity of medical education, in hospital administration and construction etc. “Distantiality, averageness, and levelling down, as ways of Being for the ‘they’ constitute what we know as ‘publicness’. And we can safely say that Medicine has indeed become a form of ‘publicness’.

‘They’ in the sense of the present argument can be taken as the medical community. In its becoming uniform and in its averageness, ‘they’ (the



doctors) do this and this in such and such a situation. This is the existential state of doctors, of the medical community, today. Each doctor may take on a ‘they’-self instead of the potential *authentic self*. This dispersal is the ‘subject’ of that kind of Being (doctor’s-Being) which we know as concerned. This ‘they’ describes (or dictates) the way in which doctors should interpret the world.

Now far from it to suggest that medicine today is in a crisis with respect to the treatment it provides. It is indeed an advantage that things are levelled down to protocols on treatment because experience gained through studies does not go in vain. In seeking to provide our patients with the best solutions and possibilities we rely on controlled trials and standard procedures. This however has left the unfortunate side effect of mechanizing to an extent the clinical encounter. What is important is to arrive at the correct diagnosis. The cost has been a loss in the art of medicine as a humanities profession besides a scientific one (Lown, 1996).

### *Truth concealed*

One can argue therefore that technologically advanced societies, protocols and post-modern ideas of libertarian attitudes may have concealed the true nature of the doctor-patient relationship. All of these concealing factors are not wrong in themselves. Indeed they have given power to the patient, reduced paternalistic attitudes, which in themselves were a concealment of a hidden agenda for the clinical encounter, and allow us to treat the masses in approximately the same optimal manner – at least to our knowledge.

Open to beings and to our own being possible, we nonetheless relinquish this openness in exchange for the security of whatever ‘they’ say is true.

Presupposed in such truths of faith or science or even the universality of life, however, is a kind of opening or openness by virtue of which something can and does show itself and let itself be seen. To *let*

unconcealment *show itself*: this is perhaps the most succinct formulation of the task of Heidegger's thinking, at the heart of which stands his formulation of Freedom. Untruth is errancy. Man's own freedom allows him to sway into errancy; and conversely it is this same freedom which allows him to un-conceal truth.

Thus looking at the post-modern consumerist society, ever ready to sell products to those who would have them, we can begin to realise the danger of the symbiotic relationship between industry, an evil necessity, so to speak, and medicine. To speak of industry as 'evil' is indeed unfair, because it is biting the hand that feeds you. After all medicines come through industry, but it is an undisputed fact that production of drugs depends also on market forces and therefore on the numbers the drug sells.

Yet this has resulted in a relieving of the responsibilities of the doctor-patient encounter on when a test is to be done. We now view diseases in numbers. For a company to find it viable to produce a genetic test, it also must see the incentive of making as much profit as possible. Tests are thus marketed to the public; people told to get advice not through their physicians but directly from companies. In this context it is more than obvious that the prime, if not the sole, aim of the company is financial. Will companies market also that test for which there are no numbers in terms of patients or will it market tests similar to BRCA1/2 for which they can raise awareness amongst the general public? Wise investment does not necessarily coincide with disease incidence and distribution.

On the other hand to ask companies to look at the phenomenology of the doctor-patient relationship calls for a laugh in the face to say the least. But if we persist in trying to ground the philosophy of medicine in a socially constructed context, then it will be more difficult to argue in favour of the benefits of allowing choices to occur within the doctor-patient relationship. What results is a market force, albeit based on a consumer right to know, in which people are induced out of fear into carrying out a specific test, and not because they really need that test.

This has nothing to do with disease or with the philosophy of medicine; it is only allowing one to take advantage of innate fears which everyone can have of being ill or becoming ill, bypassing in the process any form of clinical encounter. What is needed therefore is a thorough understanding of a philosophy of medicine in the nature of the doctor-patient relationship.

The balance of the argument is whether we would have our health care providers tell us that we are at risk and therefore merit doing some genetic tests, or whether we should allow the media and industry to instill in us a fear, always based on lack of complete knowledge, to induce us solely into falling into a trap to do the test.

### *Conclusion*

At the end of the day medicine is based on the clinical encounter. If there is to be a philosophy of medicine it has been suggested that it should start at this level. There are nevertheless incentives to make profit from medicine; a factor which become of increasing importance in genetic testing. These 'goods external' are tolerated because they allow the advancements of 'goods internal' to medicine – the hope of providing a cure and promoting public health. Any advance in genetic testing therefore must answer to this basic question: Is this test a contribution to the goods internal to medicine; or is it primarily seeking the goods external using the goods internal as an excuse to marketing the test. The best place to answer this question is within clinical encounters. It may take nerve to tell the large corporations what to do and how to market their products, but not doing so is allowing ourselves to be led evermore by market forces outside the clinical encounter. It is for this reason I conclude that it is difficult to perceive of a socially constructed theory and that the answers to who should do genetic testing are best sought within the ontology of the doctor-patient relationship.

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# In Search of a European Approach to Bioethics: The Emergence of a Common Euro-Mediterranean Bioethical Culture

Rev Prof Emmanuel Agius

In his recent study on the birth of bioethics, Albert Jonsen claims that bioethics is an American phenomenon.<sup>1</sup> The fact that bioethics began as a movement and had its first development in the United States, led Jonsen as well as other authors to think that bioethics is a typical and specific product of the American culture. Some even reached the conclusion that, outside of the United States, this phenomenon can be spread out, applied, and particularized, but not enriched in its essence. This was the general belief expressed in the papers read by a number of American participants in the conference about *The Birth of Bioethics*, organised by Jonsen in the University of Washington, in Seattle, in 1992.<sup>2</sup>

Jonsen believes that American bioethics differs from all other bioethics because of the “American ethos”. He describes the “American ethos” as, firstly, a destiny to make life better than it is and a conviction that it is possible to do so; secondly, a faith in the values of individuals and their capacity to reach consensual agreement; and, thirdly, a vague but genuine commitment to a conventional morality.<sup>3</sup> This contention is criticised by Diego Gracia who maintains that an accurate analysis of the history of bioethics leads us to conclude that Jonsen’s interpretations are extremely parochial and ethnocentric. He disagrees with Jonsen’s conclusion that bioethics is an American product, which other countries and cultures can import and assimilate, without the possibility of adding fundamental novelties.<sup>4</sup> In Charles Taylor’s terminology, Jonsen’s ‘politics of nonrecognition or misrecognition’ of the valid contribution

<sup>1</sup> Jonsen, A, *The birth of bioethics*, Oxford University Press, New York/Oxford, 1998, p. viii and xv.

<sup>2</sup> Gracia, D., “History of Medical Ethics”, in *Bioethics in a European Perspective* (H. ten Have and B. Gordijn, eds), Kluwer, Dordrecht, 2001, p.44.

<sup>3</sup> Jonsen, A., *op.cit.*, p 395

<sup>4</sup> Gracia, H., *op.cit.*, p. 45

of other cultures to bioethics is a source of damage, distortion and oppression of the cultural identity of other regions or continents.<sup>5</sup>

Gracia defends the hypothesis that the success of bioethics is not directly related to the peculiarities of the American ethos, but to two general characteristics, namely, the secularization of Western culture and the emancipation of the decision-making process in the questions related to life and death issues.<sup>6</sup> This change in the socio-cultural context of medical practice diminished the influence of religious values in the resolution of moral problems in medicine, whereas a non-religiously, secularly grounded normative view of human life has become more influential. This view emphasizes personal autonomy and each patient's right to make his or her own health care decisions.

According to Gracia, the application of normative ethics in the field of moral problems related to life and death issues was traditionally entrusted to 'moralists', who were in general clerics of different religions. 'Ethicists' were only concerned with formal and abstract problems, like metaphysics and the nature of moral discourse. Until recently, 'ethics' was conceived of as the philosophical background to morality, and 'morals' as the discipline concerned with human behaviour. Ethics, which was conceived of as rational ethics, had no normative role. Only during the sixties has this word enriched its content by encompassing also the field of normative ethics. Whereas the word 'moralist' referred traditionally to someone engaged only in formative questions, the new word 'ethicist' began to denote a lay or secular person working in the field of moral norms and applied ethics. In this context, one can easily understand the reason why the word 'bioethicist' began to refer to someone who is engaged in normative questions and applied issues related to healthcare.

The handing over of normative ethics from the hands of 'moralists' to the hands of 'ethicists' between the sixties and seventies, which was

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<sup>5</sup>Taylor, Ch, *Philosophical Arguments*, Harvard University Press, Cambridge, Mass., 1997, pp 225-256.

<sup>6</sup>Gracia, D., *op.cit.*, pp.45-46.

described by Stephen Toulmin as the shift of philosophical ethics from meta-ethical questions to normative problems, was crucial in the establishment of bioethics as a movement. This revolution, which took place not only in America but also in Europe, led to the process of secularization of Western culture.

Gracia concludes that bioethics cropped up and developed as the natural consequence of this process of human emancipation from a certain kind of tutelage or paternalism that was traditional in Western culture. This explains the reason why bioethics stresses so strongly the principle of autonomy and the respect of the different value systems proper to each and every culture. This general phenomenon has manifested itself all through Western culture, and not only in North America. Bioethics was born in the U.S. not due to some particularities of the American ethos, but because it showed the first manifestations of this general phenomenon, namely the Civil Rights movement after the Second World War, and the development of biotechnology and medicine.

### **1. Attempts to identify a European Cultural Perspective**

Though bioethics developed as a general phenomenon, it would be a mistake not to recognise the particular cultural articulation of bioethics. Bioethics is not the product of reason alone, independent of culture.<sup>7</sup> The fundamental ethos of applied ethics, its methodology and language, its concerns and emphases, and its very institutionalization have been shaped by beliefs, values, and modes of thinking grounded in specific social and cultural traditions. Moreover, bioethics literature reflects and articulates the socio-cultural value system within and through which it operates. It is, therefore, false to assume that bioethical theories and moral views are transcultural.<sup>2</sup>

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<sup>7</sup> Gbadegesin, S., "Bioethics and Cultural Diversity", in *A Companion to Bioethics* (Kuhse H & Singer P eds), Oxford, Blackwell, 2001, p. 24.

<sup>8</sup> Ten Have, H., "Principlism: A Western European Appraisal", in (E.R. DuBose, R. Hamel, L.J. O'Connell, eds), *A Matter of Principles. Ferment in U.S. Bioethics*, Trinity Press International, Pennsylvania, 1994, pp.106-7.



The dominant concepts of bioethics developed within particular cultural contexts. These concepts are not abstract but are always linked to the particularities of the practical setting. The idea that knowledge of normative theories and principles can be applied to medical practice simply ignores the fact that moral concerns tend to emerge from experience in medical settings themselves. Only recently we became aware of the importance of examining critically the socio-cultural context in order to understand better the strengths and weaknesses of dominant concepts of medical ethics. Charles Taylor raises a similar issue in his *Sources of the Self*, in which morality and identity are considered two sides of the same coin. To know who we are is to know to which moral sources we belong. The community, the particular group to which we belong, is usually at the center of our moral experience. Even the use of ethical language depends on a shared form of life. Wittgenstein's notion that our understanding of language is a matter of picking up practices and being inducted into a particular form of life is relevant here.<sup>9</sup>

Bioethics, as Daniel Callahan maintains, is always communitarian or cultural because particular decisions reflect not only individual responsibility but also the social dimension of moral life. Culture shapes individual choices by creating the context and limits of those choices.<sup>10</sup> The communitarian approach to bioethics pays more attention to the experiences of practitioners and to the particular context in which they operate. This particular perspective emphasizes the fact that the cultural context and the community are constitutive of the values and goals of individuals. The physician-patient relationship is neither a-historical and a-cultural, nor an abstract rational notion; persons are always persons-in-relation, are always members of communities, are immersed in a tradition, and participants in a particular culture. Morality is something we all participate in, and bioethics in particular is not the result of esoteric knowledge. Anyone involved in the medical setting

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<sup>9</sup> Ten Have, H., & Gordijn B., eds, *op.cit.* p. 59.

<sup>10</sup> Callahan, D., "Bioethics: Private Choice and Common Good", in *Hastings Centre Report*, (May-June) 1994, pp 28-31. Cf. Privitera, S. (ed), *Bioetica mediterranea e nordeuropea*, Istituto Siciliano di Bioetica, Armando, 1996.

is *ipso facto* a moral participant and “expert” at least with regard to moral experience and intuitive knowledge. It follows that all moral experiences inherent in health care practice must be taken into account.

Since it makes sense to reflect on the specific cultural dimension of bioethics, it is therefore worthwhile to examine the following questions: What is typically European about bioethics? Is it possible to identify typically European approaches in the area of bioethics? Is it possible to identify a common set of values that characterize the Euro-Mediterranean culture? It is important to raise these questions in order to determine what the European culture can contribute to the bioethical movement.

Before attempting to answer these questions, it is important to raise the issue whether there is a European culture. The concept of Europe refers to an area with a relative unity because of similar ways of life and thinking. Europe is not merely a distinct geographical entity, but rather a political and cultural concept. Although in Europe there are a number of traditions, together they constitute a coherent culture, a specific sphere. ‘Europe’ is manifested outwardly as a relative unity. It partly legitimizes itself by pointing to certain economic and political choices and achievements that are said to imply moral choices as well. More importantly, it tries to defend certain values, the results of a rich cultural tradition.<sup>11</sup>

This cultural sphere has been strongly influenced by the development of Christianity, and now by the presence of other religions, particularly Islam and Judaism. It was shaped by political changes, such as the French Revolution and the First and Second World Wars, by philosophical ideas about humanism and Enlightenment, by scientific and technological progress. Various catalogues of ‘European’ values have been proposed: freedom, tolerance, equal opportunity, social justice, human dignity, and solidarity.

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<sup>11</sup> Rietbergen, P., *Europe. A cultural history*, Routledge, London and New York, 1998 p. 461

Indeed, there seems to be a consensus in Europe that looks at man in society under a threefold aspect: each man is unique, each person has to make his own choices for good and evil but, first and foremost, being human means taking responsibility for others, that means, protection of others to preserve the quality of society at large.<sup>12</sup>

When did this search for a specifically European perspective in bioethics begin? Jos. V.M Weile and Henk ten Have claim that this search started not long ago.<sup>13</sup> A series of developments have motivated the attempt to articulate these perspectives. Political and economic issues led to the need to articulate the specific European identity vis-a-vis North America, Russia and Asian countries. This need intensified after 1989 when the political changes in Central and Eastern Europe started a period of transition and transformation all over the continent.

As a result of the collapse of ideological barriers, the map of Europe has changed with the emergence of new nations. The Council of Europe has almost doubled in size. Though nationalism became widespread, there were many efforts in Europe to reassert the common cultural values and to stress human rights and fundamental freedoms. Since 1989, the European Union started an intensified cooperation programme with other countries in Europe, not only to support transition in economic and scientific terms, but also to support the protection of human rights and democracy, as well as to endorse particular values.

## **2. European Approaches to Medical Ethics**

What are the specific characteristics of a European approach to moral problems in health care? Is it possible to identify a European approach in the area of bioethics?

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<sup>12</sup> Ibid., p. 465

<sup>13</sup> Weile, Jos V.M. & Ten Have H., "Bioethics in a Supranational European Context: 1989-1991" in (Lusting, A. et al. eds.) *Bioethics Yearbook*, Dordrecht, Kluwer Academic Publishers, 1992.

Henk ten Have claims that it is problematic to identify typically European perspectives. He believes that continental philosophy is typified by an amazing variety of philosophical theories and methods without any major and dominating school. The same is true for bioethics. Many schools and approaches flourish in practice and literature: applied ethics, phenomenology, hermeneutic ethics, casuistry, post-modernism, clinical ethics, and narrative ethics. These different approaches play an important role in enriching the analysis of concrete facts. But this situation seems not too different from North America. There also a variety of approaches exist. He maintains that, although there are many similarities, there is, nonetheless, truth in the proposition that American bioethics has predominately been developed around a common methodological structure and a particular set of ethical principles.

Moreover, ten Have claims that in Europe the philosophical perspectives in medical ethics seem broader than in the United States. In Europe, the bioethical debate is enriched by a number of philosophical approaches which all contribute valid insights. He disagrees with those who believe that the Anglo-American philosophy is generally classified as empiricist, while European philosophy is more influenced by rationalism. On the contrary, he contends that Anglo-American ethics is generally more teleological and consequentialist, while European ethics more deontological.<sup>14</sup>

Furthermore, ten Have explains that, on the one hand, in many European countries, ethics is very much under the influence of philosophical and theological traditions, and multifaceted in philosophical substance – not dominated by analytic philosophy. In Central and Eastern European countries, bioethics emerged only recently from the former departments of marxist-leninist philosophy or social sciences. On the other hand, only in a very few countries, such as the United Kingdom, the Netherlands and the Nordic countries, medical ethics in particular is the specialized enterprise of a new profession. Most often it is the

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<sup>14</sup> Idem.

recognised business of medical practitioners or lawyers, who therefore dominate public debate. This is presumably also one of the reasons why the term 'bioethics' is not as frequently used as 'medical ethics' or 'health care ethics'.<sup>15</sup>

During the late seventies, Dietrich von Engelhart and Sando Spinsanti have already defended ten Have's position. They claimed that, though bioethics flourished in most European countries during the late-twentieth century, however, as a field of ethical reflection and an instrument of public policy, bioethics is hardly uniform across the continent. Medical science and technology, as in many countries throughout the world, stimulated an interest in medical ethics in many European countries. Yet they maintained that the way various countries have experienced that development differ, as has their ethical response. Although influenced by social and political events, and by philosophical, literary, religious, and cultural ideas common to the European milieu, various countries and cultures have contributed in unique ways to the formulation of bioethical ideas.<sup>16</sup>

Diego Gracia's views on the identity of European bioethics are analogous to Henk ten Have's perspective. He claims that the Western world harbors three different ethical traditions, each with its own characteristics: the Anglo-Saxon, the Central European and the Mediterranean. Because modern bioethics is a product of the Anglo-American culture, Mediterranean countries have not attempted simply to import or "translate" bioethics but rather, to 're-create' or "re-make" the discipline to their own cultural and ethical traditions.<sup>17</sup>

Diego Gracia focuses on the particular characteristics of bioethics in the Mediterranean region. All European countries surrounding the Mediterranean basin, in addition to geographical and climatological

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<sup>15</sup> Ten Have H. & Gordijn B., eds. *European Perspectives in Bioethics*, p.63.

<sup>16</sup> von Engelhart D., & Spinsanti S., "History of Medical Ethics in Europe: the Contemporary Period", in *Encyclopaedia of Bioethics*, vol. iii, p. 1554-6.

<sup>17</sup> Gracia, D. & Gracia Th., "History of Medical Ethics in Europe: Southern European", in *Encyclopaedia of Bioethics*, vol. iii, p. 1557

affinities, have for many centuries shared a common history centered on the Mediterranean Sea. Although they maintain local peculiarities and differences, the nations of southern Europe can be said to have a common identity. He claims that this common identity is particularly evident in ethical issues. Western ethics had its origin in the Mediterranean Greco-Latin culture, and since the days of the Greek philosophers, this ethics has centered on the concepts of virtue and vice. Only with the Enlightenment did a new ethical tradition, with right and duty as its main concepts, begin to take shape in central Europe. Since then, the two approaches have widely been considered opposite, although they are in fact complementary. The ethics of virtue has persisted in those countries in which the Enlightenment had less influence, such as the Catholic and Orthodox southern European countries, while the ethics of duty has prevailed in the Protestant central European and Anglo-Saxon countries.<sup>18</sup>

Salvino Leone, following Elio Sgreccia, contributes also to the idea of a Mediterranean approach to bioethics. He claims that Southern European countries elaborated a “Latin” model of bioethics.<sup>19</sup> While the Anglo-American model is structured around the four classical principles of autonomy, nonmaleficence, beneficence and justice, he bases the so-called Latin model on the four foundational values of life; liberty and responsibility; totality (or therapeutic wholeness); and social subsidiarity (the idea that smaller units are always preferred to larger ones when it comes to addressing social problems).

According to Diego Gracia, Mediterranean countries have created a “realistic” and “personalist” model of biomedical ethics, based on the classical Aristotelian-Scholastic philosophy and complemented with more modern European philosophical traditions such as phenomenology, axiology and hermeneutics.<sup>20</sup> In this perspective, the

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<sup>18</sup> McIntyre A., *After Virtue*, 1984, pp.

<sup>19</sup> Lenoe S., “Il problema del ‘valori comuni’ nelle deliberazioni dei comitati”, in *I comitati di bioetica: Storia, analisi, proposte*, , Rome, Edizioni Orizzonte Medico, 1990, pp.143-158.

<sup>20</sup> Gracia, D. & Gracia Th., “History of Medial Ethics in Europe: Southern European”, in *Encyclopaedia of Bioethics*, vol. iii, p. 1558.

idea of virtue acquired much more significance than any other Western tradition, a fact that has important consequences in the medical field. For example, trustworthiness is considered more crucial than the right to information. Patients in southern European countries are generally less concerned with receiving detailed information or having their autonomy respected than with finding a doctor in whom they can place their full confidence. One virtue is particularly important in establishing a satisfactory doctor-patient relationship, namely friendship.

Another distinctive characteristic of Mediterranean bioethics is its overwhelming concern with health-care justice. In southern European countries, the State takes the responsibility for what in other countries is considered the realm of private enterprise. In fact, the health systems of these countries are mainly state-run. While autonomy plays an important role in North-American bioethics, justice plays a decisive role in European biomedical ethics. In fact, France, Italy, Greece, Portugal, Spain and Malta have similar national health insurance systems.

The way patients' rights were established marks another distinctive feature of the Mediterranean countries. In the United States these rights, particularly the right to informed consent, took shape in the field of common law, while in Mediterranean countries their entry was directly through statutory laws and codes. In these countries, protecting patients' rights is a duty of the State more than the duty of individuals. For instance, in Spain, patients' rights were first established legally and then socially.

### **3. Towards European Harmonisation**

In several fields, the European Union is developing binding policies for its Member States. This is particularly true in economic matters, such as trade and antitrust rules, and in agriculture. In contrast, matters of morals or ethics are areas of "national competence" – each Member State establishes its own policy. General principles such as civil liberties, political freedom, legal equality, and social justice are

endorsed as the basis of European democracy. However, on specific issues, including abortion, embryo research, protection of animals, environmental protection, patenting of living organisms, or surrogate motherhood, national differences are still appalling.

As a result of these divergences in bioethical policies at the European level, the issue of harmonisation has emerged as an urgent matter. As former EU-Commissioner, Karl Heinz Narjes put it, "We cannot have a situation in which the same research might lead to a Nobel Prize in some Member States of the EEC and to prison in others". Consequently, an important question is raised: should ethical matters be left to individual member states, or should they be dealt with at a supranational European level?

As a reaction to the differences in public policies in health care issues, many ethical bodies have come into existence at a supranational level to find a consensus and to achieve harmonisation. A significant development has been the gradual expansion of the European Union that is now promoting co-operation in health protection. In fact, during the last few decades, initiatives in bioethics emanated from several EU institutions.<sup>21</sup> In 1991, the Commission of the European Union set up a Group of Advisers on the Ethical Implications of Biotechnology (GAEIB). The EU has had a number of meetings and conferences on bioethical problems and established a number of directives on biomedical problems.<sup>22</sup>

Moreover, bioethics has become a focus of the Council of Europe that has taken upon itself the responsibility of harmonising European rules and regulations in healthcare issues.<sup>23</sup> It is logical for the Council of

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<sup>21</sup> Elizalde, J., "Bioethics as a New Human Rights Emphasis in European Research Policy", in *Kennedy Institute of Ethics Journal*, vol 2, no 2, (1992) 159-170. See also Weile, Jos V.M. & Ten Have H., "Bioethics in a Supranational European Context: 1989-1991" in (Lusting, A. et al. eds.) *Bioethics Yearbook*, Dordrecht, Kluwer Academic Publishers, 1992, pp. 97-126, and Riis, P., "Medical Ethics in the European Community" in *Journal of Medical Ethics*, 19 (1993) 7-12.

<sup>22</sup> "The basic Ethical Principles in the EU and the Council of Europe", in *Basic Ethical Principles in European Bioethics and Biolaw*, Vol i., pp 281-287.

<sup>23</sup> Quintana, O., "International bioethics? The Role of the Council of Europe", in *Journal of Medical Ethics*, 19 (1993) p.5



Europe, which has blazed a trail in the protection of individuals and human rights since 1949, also to commit itself to guaranteeing harmonious progress for the benefit of the individual and society, while reiterating the primacy of the human being in relation to science and denouncing any subordination of the former to the latter. In 1985, the Committee of Ministers of the Council of Europe decided that bioethical issues should be dealt with by a single specialised committee. This committee obtained a permanent status in 1992 as the Steering Committee on Bioethics.

A landmark in this process of harmonisation and in articulating a European perspective in bioethics is the *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*, developed by the Council of Europe and signed in 1997 by 21 members in Oviedo, Spain. The objective of the Convention is to set future ethical standards for all European nations by establishing a number of general principles that will protect human rights in the changing context of medical practice.<sup>24</sup> The Convention identifies basic ethical principles necessary for the application of medicine and life sciences in all European countries. As a general framework of reference for public policy and international cooperation, the Convention is a milestone in the harmonisation of health care ethics and law.

The European Convention on Human Rights and Biomedicine is a well-intended and a carefully prepared document that may stand as a landmark in the evolution of bioethics in Europe. It builds on the earlier foundations of the Universal Declaration of Human Rights as well as on the European Treaty for the Protection of Human Rights and Fundamental Freedoms. The Bioethics Convention can be considered as the result of a number of important previous resolutions and recommendations by the Council of Europe on medical experiments with human beings, reproductive technologies, genetic manipulations, prenatal diagnosis and genetic testing, experiments and trade with

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<sup>24</sup> Rogers A. & Durand de Bousingen D., *Bioethics in Europe*, Council of Europe Press, 1995, pp13-4.

embryos, organ transplantation, and euthanasia and life prolonging treatment (including protection of terminally ill patients).<sup>25</sup>

Although the Convention provides a common framework of minimum norms there is still a lot to be done to harmonise national and international regulations. A number of problems of the Convention, concerning the protection of incapable people, the protection of the human body, the status of the embryo, etc, need to be continuously evaluated in order to reach a consensus.

#### **4. Emerging Common Bioethical Values in Europe**

Diego Gracia claims that, because of the plurality of traditions that make up contemporary European bioethics, it is not possible to isolate a single path of development.<sup>26</sup> An emerging core of bioethical values common to all European countries proves this statement wrong. Current efforts in Europe do not only aim to forge an economic and political identity, but also a common cultural identity. Nowadays, Europe is characterised by a widespread sensibility and effort to build common values that will enhance the European identity. In fact, European institutions are striving to establish above all a community of values. The aim of the European unification is to realise, test, develop and safeguard these values.

European identity is rooted in national identity, and emerges at the point where countries realise that they share a common future. Fundamental rights and parliamentary democracy are unquestionably the basis of this identity today. But they, though indispensable, are not enough to make every individual feel fully as part of a country and of Europe too. European identity will achieve its full potential through a freely accepted “community of values”. Moreover, the need of a common European ethical approach can also partly be explained by the fact that many citizens in Europe feel that they have a common

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<sup>25</sup> Ibid., pp. 287-308.

<sup>26</sup> Gracia, D. & Gracia Th., “History of Medical Ethics in Europe: Southern European”, in *Encyclopaedia of Bioethics*, vol. iii, p. 1555.

history and a common destiny. Indeed, the Treaty of Maastricht in 1992 (Article 17) introduced for the first time the notion of a citizenship of the Union that compliments national citizenship.

The promotion of a Europe characterised by common values was reflected back in 1992 in the establishment of the first European Union bioethics committee, an independent, multidisciplinary, advisory body, set up to examine comprehensively applications of biotechnology in research, medicine, and agriculture. The work of the European Group on Ethics in Science and New Technologies, combined with the growing influence of public opinion, has done much to ensure the prominence of ethical principles in the European biotechnology debate. These principles, such as the respect for human dignity, the right to confidentiality of medical data, the principle of non-discrimination and the right to safety and transparency have all been enshrined in European law. The upshot of these concerns is that they are helping to clarify what a common European political identity really means. More precisely, bioethical principles developing out of such concerns are increasingly coming to represent the building of a Europe which is no longer just a single market, but also a family of nations based on common values, which includes freedom, as well as human dignity and safety.

The report on the BIO-MED II-project, *Basic Principles in Bioethics and Biolaw*, which was written on the basis of collaboration between 22 partners, presents an analysis of the ethical principles prevalent in Europe. The idea of this analysis of European bioethics is to show the limitations of an approach to bioethics that is built solely on the concept of autonomy, a concept that has been widely influential in American inspired bioethics.<sup>27</sup> Among the four principles, it is autonomy that has been the most widely mentioned in the international debate on bioethics. It is a standard reference point in the Anglo-American bioethical debate, where the philosophies of Tom Beauchamp and James Childress in

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<sup>27</sup> Cf. Wulff, H., "Against the Four Principles: a Nordic View", in *Principles of Health Care Ethics*, (Gillon, R., ed), John Wiley & Sons, Chichester, 1994, pp. 277-286.

their influential book *Principles of Biomedical Ethics* (1979) have become the foundation of much research. This book refers to the principles of autonomy, non-maleficence, beneficence and justice. Respect for patient autonomy has largely been accepted in American, and to some extent, in European countries. But this acceptance is marked by a tendency to consider autonomy as the only guiding principle concerning the protection of the human person. Consequently, it ignores other dimensions of the protection of human beings.

Consequently, the researchers in this project claim that other supplementary principles must be taken into account when dealing with personal autonomy and the protection of human beings in bioethics.<sup>28</sup> In contrast to the scheme elaborated by Beauchamp and Childress, the new European bioethics takes dignity, integrity, and vulnerability to be the guiding values. By showing the limitations of autonomy and viewing this concept in relation to the principles of dignity, integrity and vulnerability, the BIO-MED II-project aimed to provide a more secure foundation for the protection of the human person in bioethics. In this light, the project integrated the principles in the framework of solidarity, responsibility and justice.

In contrast with the basic ethical principles proposed by the researchers of the BIO-MED II-project, the following paragraphs elaborate an analogous common set of values that are emerging in supranational institutions as general guidelines for the future direction of European bioethics and biolaw. They may be interpreted as providing a normative framework for the protection of the human person in biomedical development. Moreover, they indicate the political morality that will shape the medical and legal system of the European Union in the decades to come.

### **a) Human Dignity and Fundamental Rights**

The foundation of the culture of human rights that was to develop throughout the second half of the twentieth century was laid by the

<sup>28</sup> *Basic Ethics Principles in European Bioethics and Biolaw* vol 1. Pp. 18-19.

post-Second World War international instruments. The concept of human dignity is a seminal idea that acts as the background for the recognition of human rights and as the source of the fundamental freedoms to which all humans (*qua* human) are entitled. The idea of human dignity has its roots in the three monotheistic traditions, namely Christianity, Judaism and Islam, which all profess that every human being is created in God's image. Philosophers then radicalized it in the Renaissance and the Enlightenment, particularly Kant who maintained that every rational moral being has intrinsic value.<sup>29</sup> Dignity is the property by virtue of which human beings possess moral status.

What exactly does the concept of human dignity mean? There are two interpretations of human dignity: a) on the one hand, 'human dignity as empowerment' treats human rights as founded on the intrinsic dignity of humans; b) on the other hand, 'human dignity as constraint' on free choice is more concerned with human duties than with human rights.<sup>30</sup> This distinction correlates broadly with the contrast between the background role typically assigned to human dignity in the founding international instruments of human rights as against the foreground role assigned to it in the recent instruments that set the framework for modern bioscience. Where human dignity plays a background role, the governing conception is human dignity as empowerment; where it plays a foreground role, the distinctive conception is human dignity as constraint.

According to the BIOMED research project, dignity cannot be reduced to autonomy. Rather, dignity is defined both as an intrinsic value and as a matter for constructive morality in human relationships. It expresses the outstanding position of human beings in the universe. It refers to the inviolability of individual human life. It further expresses the moral responsibility of the human person. On this basis, human dignity can be interpreted to include the following meanings as an intersubjective

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<sup>29</sup> "Human Dignity, Human Rights, and the Human Genome", in *Basic Ethical Principles in European Bioethics and Biolaw* (Rendtorff J.D., & Kemp P., eds), vol. II, pp. 15-44.

<sup>30</sup> Beylveled. D., & Brownsword. R., *Human Dignity in Bioethics and Biolaw*, Oxford University Press, 2001, p. 1.

concept: 1) It expresses the intrinsic value of the human being in a community or society. 2) It includes respect for the moral agency of the human subject. 3) It means that every human being must be considered as being without price and unable to be commercialised. 4) This includes that human dignity refers to the indeterminant position of human beings in the universe – as they are able to create their own future. 5) Self-esteem, to be proud, shame, feeling of inferiority and degradation are essential matters of human dignity expressed in the intersubjective relations between individuals. 6) Dignity can establish restrictions on interventions in human beings in taboo-situations, because of the necessity of human civilised behaviour. 7) Finally, dignity relates to metaphysical experiences of human beings in existential limit by degrading treatment. But the relation between rights and dignity is also essential. In that context, human dignity expresses the intrinsic worth and fundamental equality of all human beings.<sup>31</sup>

The discourse on human rights and human dignity in bioscience is being interpreted as a new horizon of human rights in Europe. The ‘first generation’ of human rights – political freedom and civil liberties – are reaching the whole of the European people for the first time in history. ‘Second generation’ rights – the social charter – are still awaiting general recognition. The ‘third generation’ or ‘solidarity rights’ are accepted in principle by all European countries. But now, the institutions of the EU and the Council of Europe are rightly leading the way toward the ‘fourth generation of human rights’ or ‘bio-rights’ that imply a universal protection of the human person with intrinsic value as an end-in-itself. This ‘new generation of human rights’ is accepted internationally as an adequate development that is urgently needed to guide today’s accelerated progress in life sciences.

Thus, it is now widely accepted that scientific and medical progress must be compatible with due regard for human dignity and human rights. Such a view represents the wisdom of the Bioethics Convention.

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<sup>31</sup> Rendtorff, J. “Basic ethical principles in European bioethics and biolaw: Autonomy, dignity, integrity and vulnerability – Towards a foundation of bioethics and biolaw”, in *Medicine, Health Care and Philosophy. A European Journal*, vol. 5, no 2 (2002) 237.

The concept of human dignity is central to the Bioethics Convention. In fact, the main objective of the Convention is to protect human dignity for present and future generations. The Preamble to the Council of Europe's Convention on Human Rights and Biomedicine recites that the signatories resolve "to take such measures as are necessary to safeguard human dignity and the fundamental rights and freedoms of the individual with regard to the application of biology and medicine." And in Article 1, it is provided that the purpose of the Convention is to "protect the dignity and identity of all human beings and guarantees everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine".

Similarly, the Preamble to UNESCO's *Universal Declaration on the Human Genome and Human Rights*, whilst recognising "that research on the human genome and the resulting application open up vast prospects for progress", emphasises "that such research should fully respect human dignity and individual rights"; and Article 5 underlines the legitimate limits of such research by providing that "No research application should be allowed to prevail over the respect for human dignity and human rights, in particular in the fields of biology and genetics". Even in the Directive on the Legal Protection of Biotechnological Inventions, the need for patent law to respect dignity is emphasised. Recital 16, for example, proclaims that "patent law must be applied so as to respect the fundamental principles safeguarding the dignity and integrity of the person". Furthermore, the Preamble to the Protocol to the Convention dealing with the cloning of human beings states that the Protocol is guided by the consideration that "the instrumentalisation of human beings through the deliberate creation of genetically identical human beings is contrary to human dignity and thus constitutes a misuse of biology and medicine."

The proclamation of the Charter of Fundamental Rights of the European Union in December 2000 is a remarkable achievement. The Charter starts from the concept of human dignity and places the human person at the centre of the Union's action. Human dignity is a value that gives

a community its particular identity. Seen from a communitarian perspective, human dignity speaks less to what is special about human beings *qua* human beings and more to what is special about a particular community's idea of civilized life and the concomitant commitments of its members. The new bioethics aspires to represent Europe as a community that stands for a certain vision of human dignity; and, what is more, it is this particular vision of human dignity that identifies Europe as the particular community that it is. In principle, a particular community might conceive of human dignity in terms that give priority to the exercise of free choice, such that individual autonomy is seen as the highest expression of human dignity. However, the European project takes a different turn by conceiving of human dignity as setting limits to individual autonomy.<sup>32</sup>

## **b) Justice, Solidarity and the Common Good**

The medical sociologist R. Fox has shown how the political norms of liberalism and individualism are very much characteristics of North American bioethics. By stressing autonomy and rights of individuals, other significant considerations (e.g., community and the common good, duties and shared responsibilities) have been neglected, such as critical philosophical questions concerning the value of medical progress and personal and public health in communal life.<sup>33</sup> Although interest in the philosophy of medicine in Europe in general seems to emphasize the social aspects of medicine and the common good, rather than individual autonomy, the dominating conception of medical ethics in some countries seems in many respects not significantly different from that in the US, where liberalism and personal autonomy are stressed.<sup>34</sup>

Daniel Callahan also shares the view that North-American bioethics lacks a communitarian dimension. He maintains that bioethics

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<sup>32</sup> *Human Dignity in Biethics and Biolaw*, p. 65.

<sup>33</sup> Meulen ter R, *et al*, (eds), *Solidarity in Health and Social Care in Europe*, Kluwer Academic Publishers, Dordrecht, 2001, pp. 1-39.

<sup>34</sup> Ten Have H. & Gordijn B., eds, *European perspectives in bioethics*, pp 58.



gravitated almost from the start towards an ethics of autonomy.<sup>35</sup> The field of bioethics was from the first pushed towards an assertion of individual rights. Moreover, Diego Gracia believes that autonomy plays in European bioethics a less prominent role than in America, maybe due to the Latin sense of community, virtue and shared values.<sup>36</sup> The North-American one-sided emphasis on individual autonomy implies an underdevelopment of beneficence and justice that are concepts more characteristic of the European approach.<sup>37</sup> European authors criticise the individualistic focus of dominant bioethical discourse and the relative negligence of community values, interpersonal relationships and solidarity. Individual ethics in their view should be complimented with social ethics.

Henk ten Have claims that bioethics must develop between freedom and solidarity. To sacrifice one of these to the other is to contradict the meaning of human dignity. The challenge to find a balance is accentuated by the developments of biomedical technology which have brought into conflict the individualistic one-to-one doctor-patient relationship and the social aspects of health care decision-making, based on the physician's obligations to a group of patients or even to a broader community. The discrepancy between individualistic and social aspects of health care decision-making is not an easy one to solve. There is in Europe a widespread endeavour to find the right mixture of these two values.<sup>38</sup> In fact, the prevalent health policy in Western as well as Central and Eastern European countries has been based on the principle of solidarity and the right to equal access to health care in the sense that everybody is entitled to every health care intervention available for other.

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<sup>35</sup> Callahan, D., "Bioethics: Private Choice and Common Good", in *Hastings Center Report*, (May-June 1994) 28-9.

<sup>36</sup> Gracia, D. "History of Medical Ethics", in *Bioethics in a European perspective*, p. 47.

<sup>37</sup> Holm, S., "Socialized Medicine, Resource Allocation and two-tier health care – The Danish Experience", in *The Journal of Medicine and Philosophy*, 20: 631-637.

<sup>38</sup> Ten Have, H., eds., *Bioethics in a European Perspective*, p 200.

The application of social justice in a health care system and the just distribution of health care resources are two fundamental issues in bioethics. The model of the health care system, which a particular country aims to establish, depends on its perception of social justice. By and large, one can conclude that in Europe there is a solid basis for the common denominator in debates on social justice. Despite their cultural and socio-economic differences most European countries still base their health care policies on the principle of equality and solidarity. In many European countries, the health care resource allocation debate is characterised by a social context in which two values are generally accepted as fundamental, i.e. solidarity and equity. The guiding principles of most post-war governments, conservative and progressive, have been those of equality of access to health care and solidarity in sharing the financial burden proportionate to income. These two principles are reflected in the health care system of many European countries. Moreover, the Bioethics Convention explicitly refers to “equitable access to health care”. The explanatory report to the Convention states, however, that “equitable means first and foremost the absence of unjustified discrimination” and is “not synonymous with absolute equality” but “implies effectively obtaining a satisfactory degree of care”.

On the issue of the just allocation of health care resources, the waiting list as a rationing instrument is morally problematic, although it is organised on the basis of ethical selective principles. Henk ten Have claims that a different approach to the allocation problem is needed. This approach should take seriously the social dimension of human beings. As long as the focus is on individual needs and wants, it will be impossible to adequately resolve the issue of fair allocation of resources. The focus should shift towards the following question: What from the perspective of the community of individuals is it necessary to provide?

Ten Have proposes a communitarian approach in order to safeguard the basic notions of equal accessibility and solidarity in health care. A priority setting process focused on patient categories and community

needs rather than individual patients and individual needs is necessary to determine what are essential services that must be provided without restrictions to all citizens.<sup>39</sup> According to this community-oriented approach, health is regarded as the ability of every member of the society to participate in social life. Health care is necessary when it enables an individual to share, maintain and if possible, to improve his/her life together with other members of the community. However, it is the community to specify what is necessary care.<sup>40</sup>

### c) Subsidiarity and Participation

One objective of the EU policy is the creation of a health system in Europe that ensures the best health care possible for all citizens and to shift responsibility as close as possible to the individual citizen, based on the principle of subsidiarity.

It is neither the role nor the intention of the Council of Europe and other European institutions to impose a standardisation of “ethical thought” on its member states. On the one hand, the emerging bioethical standards have great importance as general guidelines for a harmonisation of European policy in bioethics and biolaw. On the other hand, these standards do not abolish cultural variations in Europe, but demand subsidiarity, i.e. that each European society applies these standards according to the particularity of their specific convictions. European institutions believe in the philosophy of persuasion rather than that of coercion.

In fact, the EU does not enforce any policy in bioethics in member states or candidate countries. On a national level each country must establish a balance between harmonisation on a European level and subsidiarity on a national level. Although an increasing number of EC activities give impulses for national health-promoting schemes, they do not solve the problems on implementation on a national level.

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<sup>39</sup> Ten Have, H., “Choices in Health Care”, in *Bioethics in a European Perspective*, p 233-237

<sup>40</sup> Ten Have, H., eds., *Bioethics in a European Perspective*, p 196-7..

Though there are attempts to harmonisation, in most countries these matters are regarded as domestic matters. No country, up to now, has accepted supranational interference in the way its national health care system is organised.

As a conclusion, one may remark that the emerging ethical principles discussed in the final section offer a conceptual framework within which European countries are in fact debating issues of bioethics and biolaw. It should not be thought, however, that a common language implies an easy resolution of the matters to be discussed. Facilitating debate is one thing, resolving value differences is another matter altogether. Each of the regulative values should be regarded as a guiding idea for debate and decision-making. However, these values are open to competing interpretations.

The more these basic ethical principles are realised in future European domestic policies on biomedicine in order to protect all citizens confronted with biomedical technology, the more a new generation of human rights would be developed in European bioethics and biolaw. This would be a great achievement for the benefit of both present and future generations!



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