

Health and the quality of life¹

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Thank you for the invitation to address the opening ceremony of your fourth Nursing Academic International Congress. It is a double pleasure for me. First, I welcome the opportunity to return to the academic environment and rekindle memories of the kinds of debates and discussions that ideally characterize this kind of setting. Secondly, I will always feel a debt of gratitude to the nursing profession. Not only did it provide me with a wife, but nurses throughout the years of my medical practice taught me almost as much as my more formal teachers. In addition, I recall with much pleasure receiving the Archon Award from your prestigious honor society last year. The fact that this is an academic congress has stimulated me to think more deeply about the topic that is the focus of your deliberations, and to perhaps be more philosophical than I would normally be.

I was amazed at the amount of literature that surrounds the issue of quality of life and the number of research tools and constructs that have been developed (1). There is an International Society for the Quality of Life. I was particularly struck by the fact that the various efforts to quantify or measure quality of life frequently involved some health-related attribute. In general terms, the characteristics could be roughly divided into the internal and external factors. There were many excellent descriptions of the kind of physical and social environment that I consider among the external factors that contribute to life of good quality. Conversely, there were factors that related very much to the individual's inner self. It is possible to imagine that there are some five main domains of quality of life: health and wellness, interpersonal relationships, community and home presence, personal growth and dignity, and self-esteem. The World Health Organization (WHO) defines quality of life as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. WHO has developed instruments to measure quality of life (2).

It is perhaps intuitively obvious that health and life are inseparable and, therefore, that matters of health must enter into any conceptualization of quality of life. However, the ethical and policy dimensions of the relationship between health and the quality of life are not that straightforward. I suppose in simpler times there was no question

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about this relationship. So why has there been such growing interest recently in measuring quality of life, especially the relationship with health? First, the rapid growth of technology in medicine has made it possible to do things previously unheard of. There is constant debate as to whether these miracles of modern medicine are making it possible for persons to be biologically alive and still cease to be functional in the other domains encompassed in the descriptions of quality of life. Societies are being called upon to examine whether they can afford the cost of maintaining life at any cost. Resources are limited in every society. The expenditure on prolonging life that is perhaps of dubious quality means that there are fewer resources to be spent on other things.

I must acknowledge from the beginning that I am in good company when I admit difficulty in defining with precision what constitutes the quality of life and, more precisely, the exact contribution that health makes. A friend of mine, Sir Kenneth Calman, who is now Vice Chancellor of Durham University and was formerly Chief Medical Officer of the United Kingdom, gave me a book of his entitled *Healthy Respect* (3). In it he examines the ethics of health care and the moral judgments to be made in delivering such care. He refers to the issue of health and quality of life thus:

Quality of life is an idea which is difficult to do without in health care, and yet it is a source of embarrassment because it is also difficult to make precise and quantify. It is related, on the one hand, to objective features of health and welfare—such as freedom from pain or discomfort, mobility, abilities to think, read, talk, etc.—and, on the other hand, to more subjective reactions such as the individual's tolerance of the absence of such features and his hopes of recovering them.

It is this combination of the objective and the subjective that makes the idea both hard to analyze and impossible to discard.

Philosophers over the years have debated what constitutes the good life. I am always tempted to say that a life of high quality is a good life, and to construct a continuum between the good and the bad life with some indicator or indicators of quality marking the various locations along that continuum. I am no ethicist, but I have liked the formulation by one of them, Frankena. He states very simply that the good life must have some subjective form, some content, and a discernable pattern (4). Once one uses these characteristics, it becomes very difficult to establish measurements, and, of necessity, there will be great variation in terms of reality and perceptions of reality. As one considers the no-

tion or ingredients of a good life and the use of some indicator of quality as a measure of goodness, one might reasonably propose that good in relation to life may also relate to what the life of the person means to others. And if I might find some small criticism of many of the concepts of quality of life, it is that they tend to be too inward looking. They consider the quality as seen and valued by the individual and less of what the life means to others in the society at large. If we examine the five domains to which I referred previously, at least three of them are very much related to the person's own self. Perhaps only interpersonal relationships and perhaps community and home presence could be seen as being possibly external to the person in some way. I do not wish to deprecate the personal individual perspective, but a good life or a life of quality may be one in which there is benefit to others, that is, the extent to which those touched by that life are improved in some way.

I do believe that there is a certain intrinsic equality of value in every human being, but I have to accept that there are substantial differences in all manner of capabilities of individuals. Thus, there will be tremendous variation in the perception and experience of what constitutes the good life of high quality.

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But as I indicated above, health and wellness figure prominently in all considerations of quality of life. Having said that, I must also admit that there is a zeal of health professionals in general to adopt such a wide interpretation of health that it almost equates the healthy state with maximal happiness. Sometimes we forget that health is only one aspect of life and that enjoyment of a life of quality is not absolutely or exclusively dependent on good health in the sense of bodily integrity. We all have met individuals who amaze us with their serenity, their stream of consciousness, and their sense of self-fulfillment, and who are certainly not whole in terms of their bodies. But I would still wish to insist

that in spite of these experiences, bodily integrity—and I use body to include the physical and mental parts—is a very, very important ingredient in the life of good quality. I would go further and claim that bodily integrity is instrumental in securing and maintaining such a life.

Kenneth Calman and most of the health experts whom I have consulted deal predominantly with the quality of life of the individual, and they naturally focus deliberately on health care in relation to that quality. This is the aspect that is most likely to be of interest to your Congress, as I suspect that the majority of your participants are involved in clinical care. Later, however, I will have to go beyond the individual and examine the quality of life of groups or populations. While the ethical and policy considerations may be different, they are not any easier to comprehend or to accommodate in terms of definitive action.

The ethical debates about quality of life have also been driven by the changes in health patterns that accompany the demographic transition that is now a feature of all societies. In the Region of the Americas, the population of older adults is increasing in all countries. In Uruguay, for example, the percentage of adults over the age of 60 years is higher than in North America (5). Medical care that once was synonymous with extending life and decreasing mortality can no longer continue to claim the exclusivity that it did for extending that life. Much of the extension of life that we see in modern times is due to improvement in the environment, improved nutrition, and to the application of new technologies through health services. Technology keeps improving, but if we accept that there is some more or less finite life-span, then towards the end of that span technology is not as effective as it was in terms of extending life as when the life expectancy was less. But I do not wish to give the impression that I am a technology Luddite and do not welcome new technological advances in health. I do look forward to the development of new vaccines, for example, to treat many of the health problems we now face, and the discovery of new pharmaceutical products. The point I wish to make is that in those societies in which life expectancy is high, or better in those persons who have come to what may be regarded as their final days, the application of sophisticated life-maintaining technology sometimes threatens the maintenance of life of quality. The technological imperative to do everything possible, as well as the fear that many caregivers have of being deemed culpable, lead to many of the excesses of which we are all aware. These excesses sometimes take away the personal autonomy that should allow the individual to participate in the basic decisions about the kind of life he or she wishes.

Much of the debate about treatment at the extreme of life has ingredients of concern for both the quality of life and the cost of extending that life. I am fond of referring to Daniel Callahan, who presents this dilemma in his book entitled *What Kind of Life?* (6). As he examines the spiraling costs of health care in the United States of America, he agonizes that no amount of tinkering with managerial approaches will be appropriate as long as “choice is king.” He writes:

Nothing is more potent in driving up costs than the quest for unlimited improvements in quality combined with the unlimited desire to maximize choice. In the case of the health care system this has meant an exultation of the freedom of providers to provide quality care as they define such care, and for consumers to seek the best possible care, and where and how they choose to define it as well.

I place emphasis on the aspect of the providers providing such care as they define to be good, which in many cases is not really equivalent to ensuring life of quality. But I am sure you are aware, probably better than I am, of the strong trend towards permitting more personal autonomy, and the growth of the hospice movement. That movement seeks, among other things, to lend dignity to the final years, without many of the technological interventions that do no more than demonstrate that man is acquiring the capacity to bend nature to his will.

I was impressed with a series of articles that appeared recently in *Time* magazine on the “American way of death,” which painted a gray picture of the final moments of life of most people in the United States. Those persons wish to die at home with dignity, but three-fourths of them die in institutions surrounded by strangers. I felt that the articles portrayed the ultimate in the removal of the autonomy that must characterize the life of quality at the end. As a physician, I was particularly taken by one piece that was entitled “A Physician’s Lament” (7). Physicians, it said, are “biomedical gladiators, and their arena is the hospital. Unlike the gladiators of ancient Rome, they always win. Well, almost always—and only for a while.”

The article went on to describe the attitude toward a dying patient:

But what if no victory is possible? At first, the defeated physician withdraws psychologically, then physically. He rationalizes that consolation is best left to clergy and family. Truth be told, it is difficult to face the evidence of failure, and difficult to face one’s own fears of death and impotence, which psychologists tell us are often a major motivation in choosing a medical career.

As I have said before, it is these kinds of approaches to the patients at the end of life that have led to the growth of the hospice movement, with the kind of care that allows patients to die with dignity and free of pain. I understand that nurses are playing an increasingly important role in hospice care.

Apart from death and dying, there are other aspects of health that figure in any consideration of the relationship of health to quality of life. The healthy person is indeed whole, and one must separate health from illness or disease. Health as a state of perceived wholeness enables the individual to enjoy the other options that life has to offer, and much of the modern therapeutic armamentarium is directed to having the person who is not indeed whole have the ability to achieve and maintain a life of quality.

These kinds of reflections bring me inevitably to consider the broad goals of medicine and the role of the various categories of health workers, of whom nurses form the largest number. Again, I am indebted to Callahan and the work of his Hastings Center in trying to tease out what should be the goals of medicine in our modern society. In one of their books (8), Callahan and his colleagues point out that the goals of medicine should be four:

- the prevention of disease and injury and promotion and maintenance of health
- the relief of pain and suffering caused by maladies
- the care and cure of those with a malady, and the care of those who cannot be cured
- the avoidance of premature death and the pursuit of a peaceful death

I could propose that all of these, perhaps with the exception of the last one, relate to preserving or enhancing the quality of life, or at least that aspect of it that relates to health. Callahan and his colleagues use language that really ennobles the practice of medicine when they write:

The greatest open and utopian frontier for medicine is that of human enhancement, using medicine not simply to overcome biological pathologies to bring about a state of normalcy but to actually improve human capacities—to optimize as well as to normalize.

Of course, the achievement of these lofty goals requires the skill of nurses as well, and I am not limiting their role only to the caring function, although it may be the most traditional. The role of medicine in enhancing health and the quality of life is being challenged both by technology and the ex-

tent to which it is shaped or responds solely to societal pressures. Callahan and his colleagues write with some feeling: “Medicine needs to have its own internal compass and abiding values, which will be stronger if resting upon its traditional and largely universal goals.”

There are, of course, other reasons besides those related to ethics that have motivated interest in health-related quality of life (9). There is the need to have some objective measure of the efficiency of health programs besides counting the output of the services in terms of such things as patients seen or length of hospital stay. If it is possible to have objective evaluations of patient satisfaction as manifested through perceived quality of life, then it may be possible to use such measures to allocate resources. The patient’s appreciation of the quality of life may be a proxy for the measurement of health status.

Quality of life measures have also been used to evaluate the clinical outcomes of one or another therapy, and it may very well be that such measures are generic enough to quantify response across various illnesses (10). The quality of life may in fact be unrelated to specific diseases. Because the measures are in general based on the psychological appreciation of well-being, they can be used across a wide range of disease conditions (11). One of the difficulties that I have always encountered in consideration of the individual’s perception of quality of life in terms of health relates to the frame of comparison. The perception will not be related to a general standard, but more to the previous state of the individual and the level of satisfaction with that state.

I have dealt until now with quality of life as it relates to individuals. However, as Director of the Pan American Health Organization, I am by necessity constrained to consider the quality of health of groups or populations, and my frame of reference is naturally the Americas (12). There is no doubt that the health of the people of the Region has improved and continues to improve. There is impressive evidence of increases in life expectancy in all the countries. Over the last 15 years life expectancy at birth has improved by 3.2 years, and it now stands at 72.4 years. Infant mortality has fallen and continues to fall. In the beginning of the 1980s, the figure for the Americas as a whole was 36.9 per 100 000 live births, and it is now 24.8.

This does not mean that there are no problems. As it moves through the demographic transition, the Region has to cope with the growing epidemic of noncommunicable diseases, including diabetes, cancer, and such cardiovascular diseases as hypertension, heart disease, and stroke. We still have to contend with many of the old communicable diseases. About 80 million persons still live in areas with a

moderate to high risk of transmission of malaria, and there are about one million new cases every year. There are about a quarter of a million new cases of tuberculosis every year. In spite of great advances in treatment, too many children still die of acute respiratory infections and diarrhea. The modern-day plague of AIDS has not spared the Americas, where an estimated 2.6 million persons are living with the infection. The Caribbean has the second highest rate of HIV infection in the world, second only to sub-Saharan Africa. Epidemics of dengue still occur in the Americas, and the morbidity from the disease is compounded by the mortality from the lethal hemorrhagic complication. There are still large numbers of our populations without access to the kinds of services that will ensure the provision of the essential care and the capacity to resolve the most basic of their health problems. Women still die in childbirth, and maternal mortality as a whole is unacceptably high in several countries.

We are greatly concerned with the essential characteristic of this pattern: the disparities that occur between countries and within countries. Even in the richest countries there are groups of persons who have deplorable health status. This differential may occur because of geography, gender, ethnic origin, or other characteristics. The health status of indigenous people is poor in all the countries of the Americas. We refer to these differences that we deem to be socially unjust as inequities, and much of our work is devoted to identifying the disparities and helping countries to reduce them. But there can be no doubt that much of the ill health that is seen here is due to poverty. It is estimated that about 40% of the inhabitants of Latin America and the Caribbean have to manage on two dollars per day or less. It is no satisfaction that the percentage of the poor is not increasing, because the absolute numbers are rising due to population increases.

In the same way that we accept that health forms one of the important domains of any construct on quality of life, then similarly it must be clear that poverty relates very directly to the ability to achieve and maintain any life of quality. Thus we see poverty reduction as important in establishing quality of life of both individuals and populations.

Therefore, it is not inappropriate to examine how health and poverty are joined and interrelated. Poverty leads to reduction of self-esteem. As Adam Smith pointed out (13), every citizen needs the "basic necessities":

By necessities I understand not only the commodities which are indispensably necessary for the support of life, but whatever the customs of the country renders it indecent for creditable people, even the lowest order, to be without.

Although he referred basically to material needs, there are obviously other attributes that would allow a person to appear decently in public and maintain his or her self-esteem.

Health and poverty are linked. Ill health is a result of poverty, and attention to health can reduce the level of poverty in a society. Poverty is not only a lack of economic resources. As espoused by Amartya Sen (14), it is becoming very clear that poverty is to be seen as a loss of basic capabilities. The World Bank's most recent World Development Report is entitled *Attacking Poverty* (15). Its very first paragraph paints the picture I wish you to appreciate:

Poor people live without the fundamental freedoms of action and choice that the better-off take for granted. They often lack adequate food and shelter, education and health, deprivations that keep them from leading the kind of life that everyone values. They also face extreme vulnerability to ill health, economic dislocation, and natural disasters. And they are often exposed to ill treatment by institutions of the State and society and are powerless to influence key decisions affecting their lives. These are all dimensions of poverty.

This kind of life cannot be one of quality by any measure!

If we look specifically at the relationship between health and the availability of economic resources, we find more and more evidence of causality, of health leading to enhanced economic growth. The mechanisms that underlie this causality are not completely elucidated, but there are some that are clear. Health—and in this I include nutrition—obviously increases the capacity of the individual to produce. Health of populations also represents a resource for the countries themselves. This is very clear in the case of those countries that depend on tourism.

Health is instrumental in ensuring that those external and internal factors that are within the domain of quality of life can be optimally satisfied. Therefore, the link between health and quality of life must be seen not only in terms of the personal perception of the individual, that is, how his or her health contributes to well-being. It must be seen in the context of all factors that affect well-being and the role of health in enhancing these factors.

What is the relevance of these issues to your Congress? I would propose that your interest might be directed in three possible directions. First, there is the obvious concern that the profession, which is numerically the largest group of health workers, must have for the well-being of persons who are ill. Care and cure have always gone together. Even though we have long passed the day when all we

had to offer was care, we must never leave out that aspect of our professional responsibilities. Perhaps in this modern world it is even more important.

Second, as responsible members of your communities you must be conscious of the need to promote health as an instrument for enhancing other areas that contribute to quality of life. You cannot afford to be so inward looking that you forget the power of your collective voices in ensuring that health is appreciated not only because of its intrinsic merit, but because it is instrumental for ensuring progress in other areas that touch human well-being. This means being advocates for ensuring the kind of political action that ensures appropriate allocations for health. But you must avoid doing this only in the context of preservation of what the profession considers its rights, especially its rights to some share of the resources applied to health. Every profession must have a social role that goes beyond what might have been proper for a traditional guild. This social role does not mean only being engaged in good works at the individual level, but rather also entering into the discussion about what is in the best interest of society as a whole.

Finally, your profession and this International Congress have an academic face, and that means being involved in research. Many of you will be in ideal positions to carry out studies on the quality of

life and determine the extent to which your activities as health professionals contribute to such quality. The establishment of any valid and reliable psychometric indicator is difficult in itself, the literature shows. However, you have to be engaged both in contributing to the design of such studies and also in determining how the results can affect your own practice.

Finally, let me speak briefly about the role of my own organization in this area. We are essentially a public health organization. We have embarked on an ambitious effort to examine the extent to which the essential public health functions are being discharged in the Americas. The fundamental aspect of this exercise is to examine how the State assures the provision of health services that are needed by our populations. The basic responsibilities of these services must be to promote health, prevent and cure diseases, and rehabilitate those who have suffered illnesses. One of the tenets of our practice is to mobilize resources for health. We direct our attention not only to financial resources, but also to human resources and the resources intrinsic to networks of organizations. I hope we will be able to count on the support of the various organizations represented here.

Let me wish you luck and hope that your Congress will be an outstanding success.

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