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## The 'Sickening' Search for Health: Ivan Illich's revised thoughts on the medicalization of life and medical iatrogenesis.

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### Abstract:

Ivan Illich's claim that the medical establishment has become a major threat to health as a result the medicalization of life and the development of medical iatrogenesis (negative medical effects on health) appears to have been accurately prophetic. Expensive, specialised, intensive, technological and professionalised care has developed to the point that the general community is now unable to understand and deal with ordinary life processes such as pain, suffering and death. Although the medical profession is closely implicated in the development of this situation, along with capitalist and financial imperatives and institutional domination, "Today's major pathogen...[is] the pursuit of the healthy body" (Illich, 1986, p. 1325).

### Introduction

Ivan Illich was among the first to question the benefits of modern medical care, pointing out that "Modern medicine is a negation of health. It isn't organized to serve human health, but only itself, as an institution. It makes more people sick than it heals." (Webster's quotations) The even more provocative assertion that 'The medical establishment has become a major threat to health' (Illich, 1975a: p. 11) has resulted in a wide variety of reactions. These range from almost complete dismissal of the claim (Navarro, 1977) and of the work in which the claim appears, to research reinforcing the empirical validation or rejection of the claim, and to philosophical investigations of its implications.

This discussion will be expanded here to include Illich's own revisions of his earlier claims. In order to achieve this, *Medical Nemesis* will be contextualised with a brief biography of Ivan Illich. The main constructs that emerge from *Medical Nemesis* will then be briefly outlined and will be followed by more contemporary revisions of those constructs. Finally, evidence and possible solutions related to these revisionary constructs, in particular Illich's claim that "Today's major pathogen is, I suspect, the pursuit of the healthy body" (1986:1325) will be examined.

## **Ivan Illich: a brief biography**

In a comprehensive account of the life and work of Ivan Illich, Smith (accessed 23.09.09) noted that Illich was born in Vienna in 1922. In 1941 he was expelled from Vienna by the occupying Nazis because his mother had Jewish ancestry. He completed his pre-university and initial undergraduate studies in the University of Florence. In order to join the priesthood, he went on to study theology and philosophy in Rome, and, later completed a PhD in the nature of historical knowledge at the University of Salzburg.

In 1951 he worked as a Catholic Priest in New York. Here he became interested in Puerto Rican culture, learned Spanish, and in 1956 became the Vice Rector at the Catholic University of Ponce in Puerto Rico. In opposition to Pope John 23's call to modernize the Roman Catholic Church, Illich formed the Centre for Intercultural Formation, later to become the Centre for Intercultural Documentation. He left the priesthood in 1969, after significant clashes with the Catholic Church.

During the 1970s, Illich published a number of books that forged his reputation as somebody who was willing to challenge institutions which have "a tendency to end up working in ways that reversed their original purpose" (Smith, accessed 25.09.09), notably *Deschooling Society* (1970) and *Medical Nemesis* (1975a). During the 1980s and 90s he held academic positions at Penn State University in the U.S. and at the University of Bremen, Germany. Throughout his life he published on a wide variety of subjects, including the Church, education and medicine (Barnet, 2003), language and literacy, industrialization, economics, technology and transportation (Illich, 1975b), gender, bioethics, and pain (Illich, 1987), and the history of the body (Illich, 1986). In the early 1990s he appeared to develop cancer, a facial tumor which was never diagnosed and for which he refused medical treatment. He died on 2<sup>nd</sup> December 2002 at the age of 80.

## **Medical Nemesis**

While *Medical Nemesis* (Illich, 1975a), is probably his most well known publication this is just one contribution from Illich's life work. It is a full frontal assault on the detrimental roles that institutions often play in society. This book proposes the "general thesis that industrialisation and bureaucracy were appropriating areas of life previously regarded as personal" (Scott-Samuel, 2003, p. 935). The opening claim in the book, that "The medical establishment has become a major threat to health" (Illich, 1975a, p. 11) is echoed by Illich repeatedly (for example, Illich, 1974) but this famous quote does not reveal the full extent of the implications of the book. In the case of medicine, as elsewhere, his main concern was not to discredit medicine *per se*, but to challenge professionalization, promote fairness (Barnet, 2003) and to confront institutional domination over ordinary life.

In *Medical Nemesis*, Illich (1975a) introduced a number of startlingly revolutionary concepts and explored their implications. First was the concept of medicalisation, which has been defined as "that process in which market forces...define what is appropriate for health care" (Barnet, 2003, p. 276). There is, as argued by Moynihan et al. (2002, p. 886), "a lot of money to be made from telling healthy people they're sick." In the development and refinement of hospitality and care, what had been the responsibility of individuals and their friends, family and the general community was redefined by, and became the responsibility of, the medical profession (Illich, 1975b). Medicine assumed responsibility for the diagnosis and treatment of disease and many aspects of the whole life process, from birth to death, including sickness, pain and death (Moynihan and Smith, 2002).

This process, according to Illich, was not developed out of an interest in promoting general or individual health, with philanthropic or humanitarian aims, but rather it was financial, where

“external forces, both market and professional have isolated activities, redefined them, taken control and profited” (Barnet, 2003, p. 277). Illich (1974) likened the plight of those who were exposed to medicalisation to that of the Greek God Nemesis, who was placed in irons and had to suffer “a vulture [that] preys at his innards, and heartlessly healing Gods [medicine] keep him alive by regrafting his liver each night” (p. 918).

Ultimately and inextricably linked to such nemesis and medicalisation is the concept that nothing more is achieved than “ailments, helplessness and injustice, [that] are now side-effects of strategies for progress” (Illich, 1974, p. 918). This was his second emergent and multi-faceted concept, which he labeled medical iatrogenesis (Illich, 1975a). These observations have been further sharpened by Barnett (2003, p. 277) as the “disorder or illness that a physician unintentionally causes...through diagnosis, manner or treatment” , or alternatively, per Illich (1995, p. 1652) as the “symptomatic side-effects suffered by individuals in their encounter with physicians, drugs, or hospitals [and]...the superstitious reshaping of society and culture through the internalization of medicine’s myths.” Iatrogenesis can either be clinical, being “injury done to patients by ineffective, toxic and unsafe treatments” (Smith, 2003, p. 928); social, the medicalisation of life; or cultural, which is “the destruction of traditional ways of dealing with and making sense of death, pain, and sickness” (Smith, 2003, p. 928).

In summary, Illich (1975a) was saying that medicine, and in particular the process of the professionalization and institutionalization of medicine, had removed the need for non-professionals to be involved in caring for those who experience ill-health, disease, pain, suffering and death, aspects of which had been defined and re-defined by the profession itself.

In addition, he maintained that the ensuing treatment and medical process can be so harmful that it caused greater harm than previously employed non-professional interventions and ways of coping. Medicine has become little more than “capital-intensive commodity production...a prolific bureaucratic programme based on a denial of each man’s need to deal with pain, sickness and death” (Illich, 1975a; cited in Bunker, 2003, p. 927).

It has been pointed out on the one side that *Medical Nemesis* has been ignored by the medical profession (Bunker, 2003, p. 927), did not provide an adequate critique of capitalism, and that it “gave insufficient credit to the achievements of medicine” (Scott-Samuel, 2003, p. 935). On the other side, this seminal work has been credited with stunning the establishment and, if nothing else, had “pried open the historically impenetrable vault of true belief that medicine is above critique” (Levin, 2003, p. 925). For example, it revealed to the editor of the British Medical Journal that what could be seen “on the wards...was more for the benefit of doctors than patients” (Smith, 2003, p. 928).

## **Contemporary evidence**

Thirty years after the publication of *Medical Nemesis*, the work would appear to have been, to a far greater extent, accurately prophetic. For instance, in a recent article Barnett states (2003, p. 276):

“...malnutrition and infectious disease, including typhoid, malaria, dysentery, cholera and now AIDS, Ebola and SARS, are more important issues. A few simple, inexpensive approaches such as immunization, simple antibiotics and intravenous fluids with the means to administer them, are often what is most appropriate. Yet only a few people worldwide have access to truly beneficial medical interventions. Unfortunately, these...are often given lower priorities than sophisticated medical technology”.

Barnet goes on to say that, at least in the U.S and from the time of the health reforms of the 90's, a system was created that:

“brought in the entrepreneurial forces and put greater control in self serving institutions... Since then, the driving force has been to “profit” from health care... “Managed care” has been largely motivated by the recognition of those outside medicine of the potential profit from an expanding “market”... There has been an expansion of medicine into a wide range of personal and societal spheres including not only diet, weight reduction, exercise but more recently baldness and sexual potency... Many of the conditions that are identified as illnesses are the result of modern distortions of human activity... The influence and power has shifted...to for-profit organisations” (p. 282).

Empirical evidence to support the increasing medicalisation of life and medical iatrogenesis is so extensive that it is almost overwhelming. One review of medical errors (Weingart et al., 2000) found evidence of significant risk from just about all areas of health care. In acute hospital care adverse events occurred in 3.7% of all cases and 69% of these were attributable to medical error. In intensive care units, medical practitioners made 1.7 errors per patient day. In out-patient care, 18% of patients experienced drug-related complications.

Patients are not only likely to encounter errors while they are hospitalized in intensive care units, but they are in some cases hospitalized in the first place as a result of medical error. For instance, Trunet et al. (1980) found that from a one year sample of 325 patients, 12.6% of patients had been admitted as a result of “iatrogenic *disease*” [sic, author’s own emphasis], which was life-threatening in one case in every twenty, and fatal in eight cases.

Finally, post-discharge statistics reveal the longer-term dangers of medical care. For example, it was found in a study of 400 discharged patients that 76 experienced adverse events following discharge, of which 23 were thought to be preventable, and 3% resulted in permanent disability (Forster et al., 2003).

Even the relatively modern speciality of palliative care, a subject clearly identified as problematic in *Medical Nemesis*, has not managed to adequately deal with the problems associated with the medicalisation of dying. The hospice movement, although originally charged with developing a systematic understanding of the process of dying and providing dignified care in the face of “total pain,” has been criticized for failing to maintain a balance between the emphasis on controlling “physical symptoms at the expense of psychosocial and spiritual concerns” (Clark, 2002, p. 906).

Nowadays it is quite likely that anybody admitted to a hospice for end of life care will receive good pain control management, but also unrealistic treatments such as late chemotherapy, all under the misguided guise of human-centred compassion and holistic and/or spiritual care. Clark (2002, p. 907) identifies that the current challenge facing medicine is “how to reconcile high expectation of technical expertise with calls for a humanistic and ethical orientation for which they [physicians] are unselected and only partially trained”.

The unproven benefits of mass cervical, mammary and bone-density screening programmes, unnecessary surgery, and “the current rise in antibiotic resistant micro-organisms through the over-prescription of antibiotics” (Milligan and Robinson, 2003, p. 9) are just a few examples that exist of the maladministration of treatment to the disembodied patient, one who has become more of a “residual body, then a technological construct” (Illich, 1995, p. 1652). In general, Illich wrote in *Tools for Conviviality* (1975b) that:

“Every year medical science reported a new breakthrough. Practitioners of new specialties rehabilitated some individuals suffering from rare diseases. The practice of medicine became centred on the performance of hospital-based staffs. Trust in miracle cures obliterated good sense and traditional wisdom on healing and health care. The irresponsible use of drugs spread from doctors to the general public” (p. 4).

In the U.S., health care has been ranked 37<sup>th</sup> in overall effectiveness by the World Health Organization (Wikipedia, Accessed 2/26/10). In another article, it was assessed 12<sup>th</sup> worst out of 13 countries on performance (Starfield, 2000), and iatrogenic damage is calculated to be the cause of at least 225,000 deaths per year. Although this may be an underestimate, it still represents “the third leading cause of death” (p. 484) after cerebrovascular accidents and cancers. At an annual cost of \$4.6 billion, this represents a “serious epidemic confronting our health care system” (Zhan and Miller, 2003, p. 1872). The reasons that Starfield gives for such poor health care systems performance are not simply “that the American public 'behaves badly' by smoking, drinking, and perpetrating violence” (p. 483), rather it is much more complex and multifactorial, and includes having a poor primary health care structure, poor access to primary and secondary health care, particularly for the 40 million people who do not have health care insurance, significant social group disparity and income inequality, and may have emerged from an overuse of high technology, particularly in diagnostics. There comes a point when increasing the amount of medical intervention becomes counterproductive (Moynihan and Smith, 2002). Starfield (2000) concludes her analysis of the situation:

“recognition of the harmful effects of health care interventions, and the likely possibility that they account for a substantial proportion of the excess deaths in the United States compared with other comparably industrialized nations, sheds new light on imperatives for research and health” (p. 485).

Kouyanou and colleagues (1997), found that there was a high prevalence of iatrogenic factors in 125 patients attending a pain clinic. Thirty-four patients (27%) were over-investigated and of the 39 patients (31%) who were referred to a psychiatrist or psychologist, 12 (31%) were inappropriately referred. Fifty-nine patients (47%) were over-treated; that is, they had “more than five different types of treatment” (Kouyanou et al., 1997, p. 600), and many received inappropriate pharmacological prescriptions or advice related to those prescriptions.

On another note, it is important to consider the impact of poor medical management on prescribing, which contributes a significant portion of the annual \$7 billion that is spent on pharmaceutical industry promotions and inducements in the US (Steinbrook, 2009). Inadequate advice, information and explanations appeared to be frequent, and 31 patients (25%) “reported that at least one doctor had directly disputed their pain” (p. 602).

A refined analysis of these results clarified more specific assessments of iatrogenesis include, for example, the work of Kouyanou, et al. (1998) who carried out a case controlled study that examined a variety of factors related to of the above 125 patients in a pain clinic. Data was collected on a wide range of issues that included “over-investigation, over-treatment, information received, satisfaction with treatment, and advice on management” (Kouyanou et al., 1998, p. 420) iatrogenic cycles that involved extensive investigative procedures were frequently identified, particularly in patients who did not have adequate medical explanations for their pain, or with those who the doctors felt did not have legitimate pain

Further support for the unfolding of Illich's observations comes from another study that clearly reinforces the current biomedical, sensation-based model of pain (Bendelow and Williams, 1995), where the authors concluded that:

“in the population of chronic pain patients studied, there was evidence of iatrogenesis. This in turn suggests that iatrogenic factors may, at least in part, contribute to the intractable nature of disability...” (p. 604).

A final example of the kind of evidence that can be found to support the concepts of medicalisation and iatrogenesis can be found in a study by Little et al. (2004) of 847 patient consultations in general practice. It was found that “a significant minority of examinations, prescriptions, and referrals, and almost half of the investigations, are only slightly needed, or not needed at all” (p. 2) but arise from the pressure placed on doctors by their culture of defensive medical practice to engage in ostensibly objective activity. In the same vein, Dans (1993) stated that:

“paying for tests is easier to justify than paying for a primary care physician's time. The x-ray and test results are tangible evidence of 'health' - never mind that the marginal information gain may be zero and that the costs may outweigh the benefits. We live in a 'just-do-it' society. Some of our activity is legitimate but much, as in the rest of our commercial society, involves meeting induced demand” (p. 228).

### **Medical nemesis: revisionary constructs**

Slightly more than ten years after the publication of *Medical Nemesis*, Illich published an article (1986) titled, "Body History" in the *Lancet*, updating the developments in his thinking about modern health care systems. As has been stated earlier, the prime concern that was expressed in *Medical Nemesis* was “that the medical establishment was the major threat to health” (Barnet, 2003, p. 282). In *Body History*, Illich went on to claim that “Today’s major pathogen is, I suspect, the pursuit of the healthy body” (p. 1325). Historically, this has emerged from the capitalist imperative and

“the emergence of the nation state. People came to constitute a resource, a 'population.' Health became a qualitative norm for armies...for workers; later for mothers...for productive workers and fertile reproducers” (p. 1325).

Illich’s original thesis claimed that the medical and health care system had a tendency towards promoting negative, objectifying social, cultural and institutional effects which had led to the “iatrogenic reshaping of pain, disease, disability and dying” (p. 1325). In addition, he pointed out that medicine had “reached toward a monopoly over the social construction of bodily reality” (p. 1327). In more recent times, people have begun to reclaim and address the problems of their own bodies, creating in the individual the “current trend towards ‘body building’” and the pursuit of, and obsession with, perfect health (Illich, 1999). From the pursuit of health emerges the concept and risk of bodily iatrogenesis which demands, for example, that:

With the greater the offer of health, more and more people will argue that they have problems, needs and illnesses. Everybody will demand that the progress should put an end to physical suffering, will be able to maintain youthfulness for as long as possible and to infinitely prolong life (Translated from French, Illich, 1999, p. 28).

### **The sickening pursuit of health**

Ultimately, the pursuit of health, according to Illich (1990), is a “sickening disorder” (p. 8), that will ultimately end, upon death, in failure. There is only the “daily task of accepting the fragility and contingency of the human situation” (p. 8), “we suffer pain, we become ill, we die. But we also

hope, laugh, celebrate; we know the joy of caring for one another; often we are healed and we recover by many means. We do not have to pursue the flattening out of human experience" (p. 8). Agony should only exist and be "seen as the effort of a medical team, and death as the team's frustration by an ultimate act of consumer resistance" (Illich, 1995, p. 1653).

This point has been reinforced by Rubinow (2005), who writes that "death, from the perspective of unconditional healthcare, was construed as failure and the ultimate surrender" (p. 3). This emerges as a result of medical education failing to confront and adequately deal with the significance of death, beyond acknowledging that "it was to be resisted, avoided and postponed at all costs" (p. 3). Echoing Illich, he adds that "Affluence and the conveniences of modern living have granted us zero tolerance for suffering" (p. 4).

The pursuit of being better than well (Elliott, 2003), and the steady, insidious medicalisation of life, means that with the apparent help of medicine in the pursuit of health, bodies can now be built and re-built. "Disease mongering" (Moynihan et al., 2002) has redefined masculinity (Riska, 2000), and men can become women, and women can become men. Medications can alter behaviour. Cosmetic treatment can alter skin and hair, and baldness has been pathologised (Moynihan et al., 2002). The problems of osteoporosis, erectile dysfunction, irritable bowel syndrome and social phobia are exaggerated in order to provide a lucrative market for the pharmaceutical industry (Moynihan et al., 2002). Cosmetic surgery can alter appearance, racial characteristics can be changed or eliminated for those who wish to achieve a desired body image. According to Hamlin (2003), these enhancements may be a "means of healing and easing pain, but they may also represent a pandering to fads, or selling of a commodity" (p. 1521), and they represent a more radical side of medical interventions.

However, as it has already been seen in the research findings from Kouyanou et al. (1997), Kouyanou et al. (1998) and Little et al. (2004), medicine seems to respond to society's insistence on the pursuit of physical health, the avoidance of pain, illness and suffering and the authentic engagement with certain aspects of life's processes such as death and grieving.

Fisher and Welch (1999) examine further evidence of orthodox medicine supporting the quest and the pursuit of being better than well. In the same way that Starfield (2000) identified that advances in care technology do not lead to overall improvements in health status, Fisher and Welch clearly identified that "more medical care may at times be harmful" (p. 448). They found that it could lead to increasing assignment of pseudo-disease diagnoses for sub-clinical, asymptomatic issues that are identified in laboratory tests but that have no clear clinical significance. The pursuit of balanced cholesterol levels in the blood with various medications – with a lack of evidence in the vast majority of people that this improves health - is one of the current fads of this sort. At the same time, doctors are lowering thresholds for treatments, thereby actually generating more worry and disability, unnecessary treatment, more mistakes and more adverse events.

As physicians are required to take on more and more technology, particularly in the use of computerized recording of consultations, quality time with patients is reduced. For instance, on the UK the average allowance of time for a consultant with a family physician (GP) is around 7 minutes. This reduces the nature of the consultation to mere fact finding and problem solving, and less and less to do with the central issues identified by Illich, the pain, suffering and death that still remains unavoidable irrespective of the degree of technological sophistication that has been achieved by modern medicine. Citing numerous examples, Fisher and Welch (1999) identify that, in the pursuit of health, increased monitoring of "women at risk of pre-term labour had no effect on the primary outcomes...but did lead to significantly more unscheduled visits and a greater use of prophylactic tocolytic (labor suppressant) drugs (p. 447). In addition, those provided with free care

received more care than those who paid for part of their care, but the latter experienced more pain and worry and no improvement in function (p. 477).

## **Suggested solutions**

There is clear evidence of a need for all to “shift their gaze, their thoughts, from worrying about health care to cultivating the art of living. And, today, with equal importance, to become aware of the art of suffering, the art of dying” (Illich, 1990, p. 8). Illich suggests that medicalisation and medical iatrogenesis could be countered by improvements in sanitation, inoculation, better health education, safety at work, equal access to primary health, including dental care, and a “culture that fostered self-care and autonomy.” Medicine, rather than expanding, needs to reconsider its concerns, begin to consider systems-based research, and re-define diseases according to the true state of nature (Fisher and Welch, 1999) and also needs to be cognisant of the possible benefits of considering cultural, rather than purely medical, discourses in relation to pain and suffering (Bendelow and Williams, 1995).

Our society would do well to consider a patient-led humanizing agenda (Todres, Galvin and Dahlberg, 2007). It also needs to consider its boundaries of responsibilities between people addressing their own healthcare needs and where medical interventions have their best and most appropriate place. Currently, medicine has been given the task of dealing with “The bad things in life: old age, death, pain, and handicap [which] are thrust on doctors to keep families and society from facing them” (Leibovici and Lièvre, 2002, p. 866). These authors graphically illuminate the invidious dangers in blurring these boundaries with a number of narratives, including the following:

“A 92 year old woman is admitted to a department of medicine because she refuses to eat and drink. She speaks little and peeps between the folds of the blanket. Her sons talk in terms of depression, brain tumour, rare diseases; her physician talks in terms of old age, her home, her own room. Day by day the sons are more abusive. The physician gives in and does a series of tests. The physician is frustrated and angry: she does nothing good to the patient, but some harm” (p. 866).

It is not at all uncommon to see relatives, who are struggling with anticipatory grief, asking or insisting that physicians do everything to prolong life – in reality, just staving off the pain at losing someone dear to them. The person who is ill has already made their peace with dying already and would actually rather be left alone, to pass on without medical interventions that are more intrusive, uncomfortable, distressing or painful than they are helpful to a dying person. If they do manage to prolong life, these interventions most often increase rather than decrease suffering.

Until such situations and solutions are seriously considered by medicine and society, the claims made by Illich that “The medical establishment has become a major threat to health” (Illich, 1975a) and that “Today’s major pathogen is, I suspect, the pursuit of the healthy body” (illich, 1986) will continue to suggest more than a modicum of truth. Furthermore,

“The consequences of this continuing modernist deconstruction of mortality have brought us to the current postmodern impasse in which dying patients are trapped between two evils: a runaway medical technology of ventilators, surgeries, and organ transplants that can keep bodies alive indefinitely and – as if this prospect were not frightening enough – an understandable but reckless public clamour for physician-assisted suicide as the only alternative to such ignominious physician-assisted suffering” (Morris, 1998; as cited by Heath, 2002, p. 907).



## **In Summary:**

Illich's observations and predictions from thirty-five years ago have been borne out in the increasing depersonalization of modern medical care. The public, buying into the manipulations of modern medicine and the pharmaceutical industry, has been disempowered and has come to accept the diagnoses and interventions of medical professionals, often to their own detriment.

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