The Gray Zones of Birth and Death

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Abstract

How can we deal with the increase in 'grey zones' that arise from our deepening scientific understanding? Science will not solve the puzzles associated with such grey zones, nor will it reduce their scope. Increased scientific research will increasingly extend the area of uncertainty associated with birth and death. As more infants survive earlier and earlier births and as more aspects of brain death are reversed, the grey zone will increase. The deeper understanding of the process of birth and death forces us to make more decisions about life and death and their relation to what it means to be human. These decisions have less to do with our scientific understanding than with what it is that we value. It is by recognizing this that we may work towards a richer understanding and acceptance of what it is to be human and to further humanize the processes of birthing and dying.

At the same time the overwhelming situation appears to be antithetical to this. These very human issues have been ignored. We are far from a fair and open social discussion of them. The vast majority of people still believe that the highly medicalized version of birth and death is most appropriate. However many options are created by our deeper understanding, we are still being born and dying in hospitals, even though all the medical evidence suggests that in most cases, there is little genuine need for this. If this survey paper has any merit it is to demonstrate that in reality science has loosened up these proprieties and freed us to explore other options as individuals and as a society.

Introduction

At a conference several years ago, a very successful physicist declared that she was giving up on particle physics because there was no longer a hope of any definitive clarity. The field would go on and on forever in a fog of uncertainty and indeterminacy. The particles would become ever more abstract; the uncertainties surrounding the theoretical frames would only increase. Solutions would become ever more temporary. One is tempted to say that there would be no end to the matter…

She decided to spend the rest of her career working on Astrophysics where she believed that there might be some answers that stuck. Space was the future: answers might come at this very macro level. At the time, I wondered why she believed that things would be different there. I thought of her when Pluto was disenfranchised and wondered what she thought about it.

The Grey Zone seems to be extending rather than diminishing in even the most "scientific" areas of research. The scientific study of birth and death is no different. In this paper, I will try to trace the growth of uncertainty about the boundaries surrounding birth and death. I will begin by sketching the place of birth and death from ancient times to today.

Birth and Death: A Short History

Before the rise of modern science and deep into recorded history, both birth and death had a special place. The events surrounding them were marked by formal ceremonies of all kinds - from religious rituals to community festivals. Both birth and death mark important life transitions, not only for the people who are born and who die, but for everyone close to them.

An extraordinary number of myths and legends highlight birth and/or death. In creation myths, the world often emerges from the womb of a goddess: it is born. Namma, the Sumerian goddess of the primeval sea, gave birth to heaven and earth and to the first gods. She represented the fresh water ocean, which the Sumerians believed lay beneath the earth, the source of life-giving water and fertility in a country with almost no rainfall. Similar stories abound, from the birth of Gaia in ancient Greece to the Earth mother Coatique in Aztec mythology, both of whom were the mothers of other gods.

Death is often marked in myths, and in particular, by the notion of death as relocation to another place. In Mongol mythology, the world has three levels: the upper is heaven where gods and goddesses live, the middle one is earth where humans live, and the lower one is where we go when we die. In some myths, the god associated with death is created soon after the world comes into being. In Navajo mythology, the god of death is as much a person as the Monsters or the Coyote.

In some myths, birth and death are linked. In ancient Egyptian Mythology, Amentet, the goddess of the dead, not only welcomed the newly dead to the ‘Land of the West,’ she

also helped with the rebirthing process as a goddess of fertility. In the bible, birth and death are linked in the Eden story. When Adam and Eve are forced to leave the garden, they become mortal – they will die. And this mortality is one in which women like Eve will begin to feel the pain of childbirth.

Almost all cultures have had and continue to have life-cycle rituals associated with birth and death. Birth rituals vary enormously, from the circumcision associated with the Jewish Brith Milah to the painting of the child with the marks of a deer in the Deer-Head clan of the Omaha. The preparation of a body after death is widely associated with ritual body "cleaning" and involves a range of specific wrappings and special containers. Special physical settings are often devoted to birth and/or death, such as death lodges and birthing houses, which appear in many cultures. Similarly, natural locations, such as ones close to water or near meaningful cultural sites, were often connected to birth and death. There are many special, rather sophisticated technologies associated with birth and death. Implements for easing birth have been found in ancient sites, and the Egyptian technologies associated with mummification are still being studied because of their remarkable success in preserving the dead body.

The Scientific Revolution

Although birth and death remain central to our understanding of what it is to be human, our attitudes to these two events have changed dramatically since the advent of modern science. Very early in the scientific enterprise, such proto-scientists as Francis Bacon had

the expectation that science would begin to solve the riddles of nature. For Bacon, this would rid us of the Idols of the Tribe – when humans tend to mythologize, exaggerate and distort reality, rather than understand it scientifically. Early scientists were in opposition to the orthodoxy of Aristotelian science. In health, they had to struggle against the Galenic practice of medicine. Both were thought to be infected by the Idols of the Tribe and too distant from reality.

Descartes went even further. He believed that with proper scientific investigation there would be "clear and distinct" ideas about such things as sickness and health, and birth and death. He went so far as to say in a letter to the Marquess of Newcastle that "the preservation of health has always been the principal end of my studies" (1991: 275). He declared that he hoped to devise "a system of medicine which is founded on infallible demonstrations" (1991: 17), His goal was nothing less than a geometry of medicine, something that would bring mathematical certainty to the then current vagaries about health and illness. The nature of birth and death would be made precise and determinate. Science would bring knowledge and certainty to all of the health related areas that had so far not been properly studied.

Descartes believed that the human body was very much like a clockwork mechanism. In illness it continues to observe the mechanical laws of nature, much like a badly functioning clock still observes them. In the Sixth Meditation, for example, he says,

> And as a clock, composed of wheels and counter weights, observes not the less accurately all the laws of nature when it is ill made, and points out the hours incorrectly, than when it satisfies the desire of the maker in every respect; so likewise if the body of man be considered as a kind of machine, so made up and composed of bones, nerves, muscles, veins, blood, and skin, that although there were in it no mind, it would still exhibit the same motions which it at present manifests involuntarily, and therefore without the aid of the mind, [and simply by the dispositions of its organs] (1998: 33).

The clock metaphor was applied not only to the human body, but to the world as a whole. Debates between Leibniz and Newton about the nature of the world were whether God as the clockmaker ever had to intervene in his creation to wind and adjust his clock. The most extreme version of this mechanistic and deterministic account of the world appears in Pierre-Simon Laplace's work. He hypothesizes that,

> An intelligence which could comprehend all the forces by which nature is animated and the respective situation of the beings who comprise it – an intelligence sufficiently vast to submit these data to analysis – it would embrace in the same formula the movements of the greatest bodies of the universe and those of the lightest atom; for it, nothing would be uncertain and the future, as the past, would be present to its eyes" (1996: 4).

Robert Boyle like other early scientists takes up a mechanical metaphor for the human body. His dissection of animals replicates William Harvey's results about the (mechanical) circulation of blood. His experiments using the air pump considered not only the nature of gasses, but also how partial vacuums affected small animals. But along with the mechanical model, Boyle incorporates a chemical component. He spends as much time researching chemical (and alchemical) compounds, and in the end, can be considered one of the founders of a chemical-mechanical view of the human body.

Boyle had among his objectives the indeterminate prolongation of life and the elimination of illness and pain –including the pain of childbirth. His vision of returning to the Garden of Eden and overcoming all disease and indefinitely deferring death is a recurring one in modern science. Boyle spent a good deal of effort seeking a chemical panacea, partly because he himself was seriously debilitated by early illness. He also spent a great deal of his money buying recipes, drugs, nostrums, and media to prolong life, many of which he tested on himself.

The Mortality Shift and the Rise of Modern Medicine

Despite the rise of more modern scientific theories, the mainstream practice of medicine remained tied to Galen until well into the nineteenth century. Population mortality fluctuated according to plagues, earthquakes, floods and droughts, but did not change substantially as a result of medical advances. A dramatic shift in these numbers only occurred from the middle of the nineteenth century in the more developed countries.

From 1850 to the year 2000, the average life expectancy at birth increased from a little less than 50 to almost 80 years (Riley) Although this dramatic increase in longevity has not been completely explained, many of the factors include increasing general prosperity, accompanied by improved housing, cleaner air and water, better food distribution, as well as a more effective response to many communicable diseases.

In the middle of the mortality shift, the work of Koch and Pasteur advanced germ theory and provided a more mature understanding of the nature of communicable diseases. Some would argue that their work marked the beginning of modern medicine. In any event, it is generally agreed that soon after this modern scientific professionalized medicine took hold.

Dramatic changes in maternal and infant mortality from the mid-nineteenth century to the mid-twentieth century were a substantial contributor to the mortality shift. Child mortality was reduced from over 200 deaths per thousand to less than 10 in most developed countries. Maternal mortality was similarly lowered from almost 500 deaths per hundred thousand to fewer than 20. (Sources to be found) Although the extent to which modern medicine contributed to these changes remains controversial, and despite the fact that it is now generally agreed that medicine alone was not responsible for them, it was widely felt that twentieth century medicine was the basis for improvements in the health of the population.

There was philosophical and general scientific reinforcement for this view. The early Wittgenstein and the Vienna Circle declared that scientific evidence was the only valid basis for knowledge. Everything else was "metaphysics." And metaphysics was outside the debate. Rigid scientific criteria would lead to dramatic increases in all knowledge, including medical knowledge. Scientific realism, which asserted that modern science was the final arbiter of descriptions of the world, was widely accepted. Scientific truth, in other words, was the only truth.

In the early twentieth century, the great success begun by Pasteur and Koch in dealing with communicable diseases like tuberculosis, small pox, and typhus; the dramatic reductions in maternal and infant mortality; and the general increase in longevity were all largely attributed to the increasingly scientific nature of modern medicine. Medicine made every effort to transform itself from practical art to evidence based science. Medical education in turn gradually moved from clinical apprenticeship to theoretically grounded scientific training. Diagnostic procedures became more and more instrumental and began to include multiple laboratory tests and X-Rays. Drugs became far more effective and widely used. Surgery became possible for many previously debilitating conditions. Soon after the middle of the twentieth century the transformation was complete.

More resources were being devoted to health care, and funding for scientific medical research was dramatically increased. It was widely believed that medical science was about to fulfill the promise that Descartes had made in the seventeenth century. In the

1970's Richard Nixon in the United States launched the War on Cancer. This was his response to Kennedy's Space Race to the moon. Nixon believed that with enough funding, American modern medical science would soon find a cure for cancer just as American know-how had reached the moon several years before. So far, more than $30 Billion has been spent on this war.

Specialization became the order of the day as medical disciplines took shape throughout the twentieth century. Physician scientists devoted themselves to the study and treatment of individual organs and even to parts of organs. They also became specialists in particular conditions and ones that were ever more recondite. Endocrinologists became diabetologists; ophthalmologists became retinologists. This also occurred in the areas of birth and death: at the beginning of life, obstetricians became neonatologists who could save immature babies. At the end of life, anesthetists became intensivists who could extend the lives of evermore moribund patients.

At the same time as medicine was becoming more specialized and scientific, there were movements afoot that began to rethink the mechanistic-deterministic model of the world. Modern physics became significantly less mechanistic and has even begun to reconsider the deterministic nature of the world. Philosophers like the later Wittgenstein, Hans Georg Gadamer, and Richard Rorty worried that rigid positivistic philosophies provided an inadequate account of human aspects of the world such as language and human knowledge. These worries paralleled a growing concern about the increasing instrumentalism, greater degree of specialization, and even the general scientization of medicine.

Despite these growing fears, birth and death were now the province of medicine. The doctor had become a medical scientist and the hospital was the locus of birth and death. Midwifery and home nursing for the dying were considerably reduced in most developed countries. Fewer and fewer people gave birth at home or died at home. To give some sense of this, in 1915, 40% of births in the United States were performed with the aid of midwives at home. By 1935, that had been reduced to 10% and these were predominantly for poor people and in particular African Americans. By 2006, that number was 5%. [[Again, I can't find the exact source of this information, other than its inclusion, without reference, in the Enkin lecture. Same goes for the institutional death statistics below]]. In Canada, the practice of midwifery was not granted professional status and more or less disappeared. Recent data about death and dying has more than ¾ of deaths to occur in institutional settings rather than at home. (53% in hospital and 24% in nursing homes.) (Wass and Neimeyer)

Determining the moment of viable birth and irreversible death are good examples of how the search for certainty in medicine has come undone. For a time, it was widely believed that these questions would soon be settled by medical research. A commission founded in the 1960's was expected to provide a definitive scientific account of the end of life. It was finally disbanded in the 1990's without definitive results. The following sections describe how and why these efforts have failed.

The Emergence of the Grey Zones of Birth

In the case of birth the vast majority of premature babies (under 37 weeks) now survive unharmed. Many infants that would have died or been severely disabled even fifty years ago, now develop normally. There remain questions about the "limit of viability" of premature infants. Although there is no overall agreement about the detailed meaning of this term, it describes the point in gestation when an infant can survive outside its mother's womb. Two recent definitions are "the gestational age before which 50% of infants or more die within 28 days of life," and, "the gestational age at which infants can survive without a serious risk of disability." The limit of viability has been slowly reduced on both of these definitions. Some now have it as low as 20 weeks and others as high as 23 weeks. The result is a kind of grey zone within which premature infants may survive using the special measures that can be taken in the modern neonatal intensive care unit. A significant number of these premature infants require full time nursing care for their entire lives or suffer from a variety of disabilities. Many others become normal adults.

For policy purposes, the limit of viability is important not only to determine how much support is given to neonatal care, but also to help us set out limits for abortions. We would in general not want to abort those infants who could survive outside the mother's womb. "Late-term abortion" is an ambiguous expression in much the same way as "limit of viability." It can refer to abortions any time after the 20th week of pregnancy or to abortions after week 27 in the third trimester of pregnancy. According to yet others, it refers to abortions that occur after fetal viability. Policies about abortion on demand vary

from country to country, but the limit is extended until as late as the 24th week of pregnancy in Canada and even beyond this in countries like Spain. The result is a second grey zone for the performance of abortions in countries where infanticide is prohibited. In Canada, this grey zone is between weeks 20 and 24. In other countries, it may be between weeks 20 and 27 of pregnancy. As neonatology advances, this grey zone is bound to increase rather than diminish. There is no longer the expectation that a definitive answer will emerge.

Grey Zones of Death and Dying

In ancient times someone was considered to be dead when breathing stopped. “Breath” or “Psyche” meant “life” in ancient Greece. If the mirror was not fogged by someone’s breath or the feather did not flutter, they were declared to be dead. Once the importance of blood circulation was recognized, the stopped heart became an additional condition of death. Now if the feather did not move and there was no pulse or heart beat, death could be declared. This form of death is now called “clinical death.” Clinical death is reversible: some people who for some reason stop breathing and whose hearts stop (people who, in a word, suffer sudden clinical death) can be resuscitated and may fully recover. In addition, patients whose hearts and lungs are defective and would otherwise stop can be kept alive indefinitely using artificial life support systems that provide them with the needs for the continuance of life.

The developments of organ transplantation surgery and especially the availability of drugs that prevented rejection of transplanted organs by the recipient's body made the concept of “brain death” attractive in the 1960’s. Because the brain requires much more energy than other organs, if, under ordinary circumstances, its circulatory needs are not met for more than three or four minutes, its electrical function will be affected and it will suffer irreversible damage. Without external support, other organs will fail soon after because of their reliance on brain function, and the person will become clinically dead. In the interim, there is a dead brain in a dying body. The organs of people in this condition could save other lives, and after a short debate, the scientific community largely accepted the proposition that such organs could be transplanted to others. This acceptance enabled the harvest of more usable organs from people who were brain dead but could be kept clinically alive using artificial life support.

Brain death is not a single event. Different parts of the brain can become impaired and lose function. For example, if frontal lobes of the brain are badly damaged while the brain stem and other parts of the brain remain intact, cognitive function can be lost while the heart and lungs continue to operate without artificial support. In such cases, there has been some controversy about whether or not to withdraw other life support or harvest organs. Similarly, as technology advances, it becomes more possible to reverse some previously irreversible changes. We now accept that the heart and lungs can stop and be restarted. It will not be long before researchers try to restart parts of the brain that have somehow stopped working.

We can no longer speak of the "moment of death." Death is not a single event; it is increasingly seen to be a process that has multiple components, some of which are increasingly reversible while others are not so easy to determine. There is therefore a growing grey zone in the process of dying during which it is not clear that irreversible death will or has occurred.

Some Varieties of Birth and Death

Many commissions formed to identify the moment when fetuses become viable or the moment of death have failed. This is not due to a failure of the scientific enterprise but of the notion that such questions are not appropriate to the way the world is. Similarly, there can and should be no single protocol for how birth or death should occur. In fact, the more we know about these two processes, the more variety seems legitimate. A deeper scientific understanding of the processes and technologies associated with birthing results in a greater number of ways to have a baby safely (rather than one scientifically preferable way). A deeper understanding of the processes of dying has similarly expanded the ways of death rather than identified a single or even small number of scientifically appropriate ways of dying. The capacity of mature societies to recognize and embrace these types of uncertainty can result in a wide range of acceptable responses to birth and death.

I will end this paper by cataloguing some of the new ways of being born and dying that emerge technologically and also some that, although not themselves technological, are

nevertheless the result of possibilities offered by new technologies. These possibilities that surround birth and death force us to expand the social and ethical grey zone surrounding birth and death.

A Small Sample of Technological births that enlarge various grey zones

Caesarian Section: This process allows a woman to evade the biblical declared pain of childbirth. Now there is a small number of women who think themselves "too posh to push" and have Caesarian section by appointment.

Surrogate Mothers. Now it is possible for the fertilized egg of a married couple who do not want to interrupt their lives with a pregnancy to implant the embryo they create in a surrogate who will bear the couple's child. "Too posh to push" is here coupled with "Too busy to bear." The child's "genetic mother" and "gestational mother" are two different people.

Multiple births. The use of fertility drugs can produce multiple births. In England there was a storm of protest when Jean Gibbons, a single woman, was given free fertility drugs and gave birth to sextuplets.

A Small Sample of Non-Technological Births that enlarge various grey zones

Unassisted Home Birth: It is the couple's responsibility to birth the child together, without outside interference or assistance unless absolutely necessary. The joy of doing this is extolled in dedicated web sites. (A book of poetry by a new mother is entitled, "Why is Joy so Exhausting?")

Home Birth as A Family Experience: Bringing other children and relatives like grandparents into the birthing event makes it even more communal. There is no experience like that of watching your new sibling enter the world.

Home Birth as a Sexual Experience. It is argued that fellatio during the birthing increases the speed of delivery by orally delivering Relaxin a hormone found in the seminal fluid of mammals. "Why use pig relaxin, when you can get the real thing?"

A Small Sample of Technological Deaths that enlarge various grey zones

Reversible Clinical Death During Surgery: Reduced body temperature or therapeutic hypothermia during clinical death slows the rate of injury accumulation and extends the survival range. Humans can sometimes survive periods of clinical death exceeding one hour at temperatures below +20°C. The prognosis is improved if clinical death is caused by hypothermia rather than occurring prior to it.

Brain Dead Pregnant women kept alive: There are several cases of pregnant women who were pronounced to be brain dead but were kept alive using a variety of life support mechanisms to allow their babies to develop to term.

Patient kept alive despite determination of brain death: Family members of Jesse Koochin go to court to disallow pronouncement of legal death and force the hospital to continue life support on brain dead relative.

Patient kept alive despite persistent vegetative state: Ariel Sharon is lying comatose in hospital since suffering a stroke in January 4 2006. According to some, he is a victim of Divine punishment because of his policy of disengagement from the Gaza Strip. He has shown little change while in the intensive care ward.

Wife unhooked from life support: The brain dead Terry Schiavo was unhooked from life support by her husband on March 18, 2005. She was pronounced legally dead on March 31 of that year.

A small sample of Non-Technological Deaths that enlarge various grey zones..

The demand for physician assisted death: Sue Rodriguez was diagnosed with amyotrophic lateral sclerosis (ALS) in 1991 and was prepared to die with the help of a physician. She lost her Supreme Court of Canada case in 1993 but nonetheless found an anonymous physician to help her die in 1994. No charges were laid.

Several possible cases of assisted death:

On Monday May 15, 1994, Jacqueline Kennedy Onassis entered the New York Hospital-Cornell Medical Center for the last time. She returned to her Fifth Avenue apartment on Wednesday, May 17 after her doctors said there was no more they could do. She went for her last walk in her beloved Central Park on Thursday, May 18 and died in her sleep at 10:15 PM on Friday May 19, 1994.

Linda McCartney, the wife of the former Beatle Paul McCartney, died on Friday April 17, 1998 in Santa Barbara, California, with her husband at her bedside. A statement from Paul McCartney's office said the cancer had spread to her liver since she had been receiving treatment. A family spokesman quoted in the April 20, 1998 issue of the London Guardian said, "The blessing was that the end came quickly and she didn't suffer." Two days before her death, she and Paul had been enjoying one of their main passions, horse-riding

Suicide is publicly accepted as a way to die; In the February 6, 2002 edition of the New York Times, Christopher Lehmann Haupt wrote the obituary of Annalee Whitmore Fadiman. She was a screenwriter and World War II correspondent who died at 85 after being diagnosed with incipient dementia. In the obituary, Haupt writes, “her daughter says that Fadiman, who as member of Hemlock Society supported right to suicide, took her own life.”

In the Guardian of July 14, 2009, an article entitled “Devoted couple end their lives together at Swiss clinic” described the assisted suicide of well known conductor Robert Downes and his wife, Joan. “In a statement, their son and daughter, Caractacus and Boudicca, said: "It is with great sadness that we announce the death of our parents, Edward and Joan Downes, on Friday 10 July. After 54 happy years together, they decided to end their own lives rather than continue to struggle with serious health problems.**”**

We seem at first to be faced with a problem: how can we deal with the increase in “grey zones” that arise from our deepening scientific understanding. Science will not solve the puzzles associated with such grey zones, nor will it reduce their scope. In fact, if anything, increased scientific research will extend the area of uncertainty associated with birth and death. As more infants survive earlier and earlier births and as more aspects of brain death are reversed, the grey zone will increase.

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them. The vast majority of people still believe that the highly medicalized version of birth and death is most appropriate. However many options are created by our deeper understanding, we are still being born and dying in hospitals, even though all the medical evidence suggests that in most cases, there is little genuine need for this. If this survey paper has any merit it is to demonstrate that in reality science has loosened up these proprieties and freed us to explore other options as individuals and as a society.

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