

Essay: The experience of Health, Illness, Disease, Death & Dying

Introduction

Our experiences relating to health, illness, disease and death and dying are socially constructed based on the individual and group factors which exist in our families, cultures and political environments. The experiences and factors which relate to health have changed dramatically due to the changing patterns of disease and the multiple complexities relating to the diagnosis and cure of chronic diseases (Gilbert et al, 2002). The doctrine has changed from the diagnosis and treatment of infectious diseases to the prevention and management of chronic diseases, which has altered how healthcare professionals and patients communicate and experience health (Nettleton, 1995).

The classical bio-medical model which focuses on the biological, aetiology of a disease and its treatments has been forced to broaden its scope to include many of the elements put forth by the psycho-socio environment model of health (Gilbert et al, 2002). The psycho-socio environmental model focuses more on the social and economic conditions which impact health, with an emphasis on the promotion and maintenance of health through behavioral changes (Nettleton, 1995). Health has been defined by the World Health Organisation as a “state of complete physical, mental and social well-being and not merely the absence of sickness or infirmity (WHO 1948:1)”. Many sociologists have argued that this definition of health is too broad in scope to be effective or measurable, however it has been seen as a positive step for the basic elements are social in nature where the bio-medical model fails to account for social inequalities (Nettleton 1995; Blaxter 2004; Curtis et al 1996).

In trying to understand how people process the various sources of information made available, sociologists have tried to research how lay beliefs impact health (Aggleton, 1990). Lay beliefs can be defined as “commonsense understandings and personal experiences, imbued with professional rationalizations (Blaxter, 2004:46)”. The experience of illness and health may be studied on several analytical levels, the

individual (age, gender, health history, ethnicity), *microcultural* (interpersonal roles and interactions; household and group traditions) and *macrocultural* (economy, ecology, environment, politics, organizations) (McElroy, 2000:192)". The lay person's perceptions are based on many of these individual, micro and macrocultural factors, including societal attitudes and beliefs regarding specific symptoms and illness (Curtis *et al*, 1996:43).

Concepts of health and illness have been socially constructed and contested, which highlights the "tremendous range of professional and lay concepts, together with their dynamic and contingent nature (Curtis *et al*, 1996:43)". The two most common theories developed for presenting the lay perspective; are Health Belief Model (HBM) and Locus of Control (LC). These two theoretical approaches of health were developed based on research that focused on how to get people to adopt healthy lifestyles and practices. The LC theory is based on the concept that people believe their behaviour can influence their health (internals) or one believes they have no control and take a fatalist view (externals) (Nettleton, 1995). If the health care community understands the persons perception on life it will help to provide the proper forms of health education and practices.

The HBM theory is based on the concept of identifying those factors that influence individuals to act in a way that prevents diseases, including the use of health services (Radley, 1994:53). The HBM wants to understand a person's belief in order to understand if one is motivated to change their health behaviour (Nettleton, 1995). Recent research has shifted its focus from behavioral to social action and as such is more theoretically informed: "it recognizes that laypeople's beliefs about health, illness and disease have their own logic and validity and are worth studying in their own right (Nettleton, 1995:41)".

In many of the earlier studies of lay beliefs the research was focused on help-seeking behaviour and compliance, where recent studies have been preoccupied with health-related behaviours (Nettleton, 1995). Most significantly the shift in scope has been reflective of the assumption that disease is caused by social and behaviour factors of

an individual. The medical industry as a collective whole has encouraged patients and non-patients to participate in preventative health procedures and practices, such as screening, checkups, immunizations, healthy eating and exercising. To assist in this process of providing health information many medical and health organizations have turned to utilizing the internet as a form of distribution.

The internet has the power to provide individuals with global access to medical and health resources that previously were considered private or simply inaccessible for many. Research has shown that lay people consider “trustworthiness” and “consistent message” as critical criteria for their healthcare selections on the internet (Nettleton *et al*, 2005). The research showed that the lay people’s comfortability and familiarity with a company’s website is critical in selecting data to use in practice or in consultation with a medical doctor (Nettleton *et al*, 2005). The benefits a lay person can gain by having the ability to research and understand health issues through “reasonable” usage of the internet is one method for empowering a person in their health education and choices (Nettleton, et al, 2005).

In looking to gain a better understanding of the experiences of being unhealthy we can look to two basic concepts; the illness behaviour and the sick role. Mechanic (1995:1208) defines illness behaviour as the varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilise various sources of formal and informal care. The micro-sociological conceptualization of illness behaviour has been broadened to include “economic, cultural, psycho-social, structural demographic, geographic and organizational factors that influence the reaction of the individual to illness, both chronic and acute (Young, 2004:2)”.

The sick role characterised by Parsons (1975) is a social role, defined by the duties and obligations to the doctor-patient relationship, and it is shaped by society to which the parties belong (Young, 2004). The sick person role is defined by the following conceptual rules: “they are exempt from normal social roles during their illness, they are considered not responsible for their illness and beyond their personal control; they

have the duty to try to get well; and they must seek reliable and accurate help (Cockerham, 2000:161)". Parsons (1975) went on to criticize the sick role as being limited to acute illnesses without consideration for behavioral variations in the model (Young, 2004).

The research relating to culture and health and the impact it has on an individual's illness or sick behaviour has been broadly classified as either an individualist approach (personal characteristics) or from a collectivist approach (outcome from social forces) (Morgan *et al*, 1985:76). The collectivist approach "emphasises the differences in the values and attitudes to health among different social groups that have implications for illness behaviour as well as the particular social and situational forces which prompt or delay professional help seeking behaviour (Morgan *et al*, 1985)". Gilbert (2002:47) highlights the following key areas when looking at the values and beliefs of a community and its impact on health: "prevailing concepts about the nature and cause of health and disease; recognition of symptoms as abnormal; reaction response to symptoms; the ways and time of seeking help; and reaction to treatment.

The World Health Organization pointed out, stress (and the disease that result from it) represents an unsuccessful attempt on the part of the body to deal with adverse factors in the environment (Helman, 2001:205). The factors that influence stress are: individual's concerns; physical environment; social support available to them; economic status; and cultural background (Helman, 2001). Further more culture has the ability to protect an individual against stress through social conditioning and norms or it can increase the likelihood of stress (Helman, 2001).

In relationship to how one experiences pains Engel (2002:53) stated, pain has two components: "the original sensation and the reaction to the sensation" This reaction, whether voluntary or not, has been called pain behaviour which is seen as private pain or public pain (Helman, 2002). Research studies performed on understanding pain highlight how similar pain events can be expressed differently based on the ethnic background and culture one lives in or adapts (Helman, 2002). Further more the view

of pain being normal and abnormal plays significantly on how an individual assess their pain, if someone consistently lives with daily back pain it becomes expected and considered normal for their lives (Holman, 2002). When seeking health or evaluating ones health it has become important to understand how the patient thinks of pain, which will help to ensure the proper medical advice and attention needed (Holman, 2002).

The last area to discuss in this essay is the overview of death and dying, sociologists have used the concepts of dying trajectories to explain the dimensions and experiences of dying, which has two properties of duration and shape, the three main death trajectories are: expected quick, unexpected quick, and lingering (Glaser an Strauss, 1968). The concept of trajectories is of a sociological nature where the equivalent psychological concept is the 'stages' of dying outlined in *Death & Dying* (Kubler-Ross, 1969). It has been argued that the psychological concept has had a greater impact in the medical community perhaps due to its emphasis on the patient's problems versus evaluating the actions or motives of health care professionals (Gabe *et al*, 2001).

The 'expected quick' trajectory as named is when a patients death is expected such as in the elderly or those that have had a chronic disease however the dying process is not considered lingering (Glaser an Strauss, 1968). This trajectory is considered the most routine for the medical community based on the relatively small problems it creates for their organization (Gabe *et al*, 2001). However inherent in its definition of quick, the process of death for the patient's families and friends is not considered routine and may cause great distress. The challenging debate within this dynamic of a quick death is the potential to prolong life through euthanasia methods (Gabe *et al*, 2001). Zimmerman argued that denial plays a significant role in the stopping of futile treatments; she however pointed the finger of contention at physicians, health care providers and the overall western society in general instead of the patient or its family fear of dying (Zimmerman, 2007).

The 'unexpected quick' trajectory is considered to be the most difficult to manage for the medical community and may be the most traumatic for the patients friends and family due to its unexpected nature (Gabe *et al*, 2001). A woman giving birth, an unexpected surgical death, the unexpected heart attack, the child that dies from the flu, are all examples of an unexpected quick death (Gabe *et al*, 2001). In this trajectory all parties involved are unprepared for the death, which can create an environment for engaging in accusations, negligence and in competency claims. The impact of unexpected deaths that occur in the operating room can cause significant pressure and implications for medical staff and their organization.

The 'lingering' trajectory is based on those dying from what would be considered a chronic disease such as cancer, most often care is provided from different locations such as the home, hospital, hospice, and nursing home (Glaser and Strauss, 1968). It should be noted that in the lingering stage the location for treatment will vary over time based on the diseases progression or remission (Zimmerman, 2007). The ability to prepare and plan for death either spiritually or financially is considered to be a positive experience for the patient, however as Glaser and Strauss noted if the trajectory lasts to long it may become a negative experience for the patient and medical staff (Glaser and Strauss, 1968). It was argued that patients whose dying experience continues over a prolong period could indeed die socially before the biological time based on the feeling of being abandoned by their friends, relatives and medical team who may become weary of their tasks (Gabe *et al*, 2001; Glaser and Strauss, 1968). The anxiety and demands of providing adequate and appropriate long term medical care and locating resources to provide patients with emotional support during the lingering death underscores why the hospice movement started and is considered irreplaceable for many who are dying.

In understanding death and dying Bury (1995) focused concepts on the ideal of a 'good death' which would provide the individual with a feeling of empowerment and the control to manage the process of ones dying experience. The definition of a good death allows us to understand how cultural, family, religious and personal choices can shape our dying experience. This leads me to the case study of my mother's death.

Case Study

The following case study covers the experiences that my mother and my family encountered during her chronic fight with bladder cancer and her ultimate passing. My mother passed away on January 9, 2007 almost two years to the day that she was first diagnosed with bladder cancer.

To provide a historical background, my mother was 68 years old when she died, white, middle class, mother of three girls, and wife of my father who is 68 years old. My family retired to a rural region of America seven years before her diagnosis, the region is extremely religious and predominately Southern Baptist. My mother grew up as a catholic and had the following health conditions before her cancer diagnosis; since her early 30's she had suffered from high blood pressure and took prescribed medicine; in her late 40's she became a diabetic which progressed to a stage 2 insulin level; she had always been slightly overweight, however one year before the cancer diagnosis she gained a significant amount of weight most noticeably in the stomach area. My mother was a fun, quiet, reserved woman who had worked as a book keeper most of her life, she was a mother and wife first most, that was her love. She was an active woman who loved to travel and who had historically walked a lot, her fitness was not ideal, however she and our family would consider her healthy.

In January 2005 my mother choose to seek medical advice after she had a consistent occurrence of blood in her urine, the condition had persisted over time, and from my mothers account this had taken place for over a year before her actual disease was diagnosed. Before this time she had her regular checkups for diabetics, heart and she had sought medical advice for her weight gain which appeared to be at such time a case of water retention. During this same time period my parents had gone through checkups and vaccinations for a trip to Africa, which was to take place in April 2005. At this point in time our family had been noticing considerable changes in my mother's mood and weight gain; she had become extremely irritated and appeared to be gaining a significant amount of weight.

The family was surprised with the diagnosis of bladder cancer for two reasons, the first being my mother's family had never had cancer knowingly in its history, and secondly bladder cancer was a disease most commonly related to smokers, my mother had never smoked. During the early stages of her disease the treatment was to have outpatient coating of the bladder, it was considered a successful and experimental procedure. This strategy went on for six months - she was cured, the cancer was back, she was cured, and the cancer was back. During which time my parents canceled their trip to Africa due to her treatment schedule and the doctor's advice. The family had collectively researched bladder cancer and recognized that if the disease was treated and caught early, there was a 5-10 year life expectancy or greater. Previously my uncle (father side) had colon cancer, he had been cancer free for over 10 years, thus this example emphasized that cancers could be treated if managed. My mom was nervous during this time period however the overwhelming consensus was all would be fine. She did not talk a lot about her illness, it was considered minor and treatable at this point in time

This all changed in September 2005, after nine months of treatments in the local Murray hospital which was approximately 45 miles away from their home, in a college university town of approximately 100,000 citizens, we received word. My mother's bladder cancer had never gone away and she needed immediate expert care, she had a massive tumor on the inside wall of her bladder, any further treatments were beyond the urologist skills. We needed to locate a specialist to most probably remove the bladder, the dynamics of her disease changed at this moment. Based on my sister living in St. Louis Missouri and its access to specialists, my parents choose this facility to receive treatment. The location was 5 hrs from my parent's home; however the doctor was regarded as one of the best in the world.

The specialist's expert pathologist reviewed my mother's files and reported that the bladder should have been out 9 months ago, the local hospital was too conservative in their treatments, her cancer was spreading, and immediate surgery was planned. My mother had a choice of a bag or a neo-bladder, this is where they take part of your intestines and build a new bladder, my mother refused to have a bag she wanted to

travel and a bag would be a burden. The family, friends, and church community all came together to support my mother during this dangerous surgery.

At this time the family was greatly concerned, living wills and plans for death were discussed due to the complexity of her surgery and her existing conditions of diabetes and high blood pressure. The surgery took over ten hours and the entire family was present, including members of my parent's church who drove the 5 hours for the surgery. My mother told us before surgery how and where she wanted to be buried, it was a difficult and stressful time. The period after the surgery was extremely difficult she had to be reemitted numerous times do to her failing kidneys and anemic condition. During this time my parents stayed at my sisters for almost two months before returning home, this was highly stressful for both my parents not to the fault of my sister, however due to the feeling of lack of power, discomfort and control one loses when not in their own home environment.

Before returning to their home in November 2005 the results of my mothers biopsies that had been taken during her bladder replacement surgery came back, her cancer had spread outside the bladder. However due the many complications my mother had since post surgery the doctors recommended that my parents return home in hopes the familiar surroundings would help my mother's recovery. At this time she was too weak to have chemotherapy, the treatment would have to wait till the 2006 New Year. My parents returned home and I returned back to America to help my mother with Thanksgiving and Christmas, at this time in my mother's illness the family felt this would be her last Christmas. We decided to buy presents, however we did discuss the rising medical bills and the cost of her medications, insurance only covered a certain portion of their expenses. My mother took efforts to alleviate the fear and we all celebrated Christmas as a family.

At the start of the 2006 New Year, my parents started the weekly drive (5 hrs) to St. Louis for Chemo treatments. After one round of chemo, my mother was told she had to receive another, my mother had the worst form of bladder cancer it was the most aggressive strain possible and she was at stage four. During the second round of

Chemo my mother took a turn for the worse, while at home she became severely ill and had to be airlifted from the local hospital back to St. Louis, her condition was too severe for the local hospital to manage. After spending three weeks in the hospital in St. Louis, my mother returned home, at which time she took another turn for the worse and was placed back into the local hospital three days after leaving the specialist center. There would be no more chemo treatments; her body could not handle the medicine.

In March of 2006 the family gathered at my parents home, the doctors were anticipating my mother's death. During this time my family had accepted that my mother would die, the statistics were grave, she had stage four cancer and was getting sicker each day. The community where my family lived was wonderful they brought meals to us everyday and many visited my mom at the hospital. My mother still was hopeful during all of this, she was tired of being sick and stated over and over if she had known this she would have never done the treatments. The amount of cards, gifts, and support my mother received was amazing.

My mother got better after losing 50lbs of water in two weeks, upon returning home I stayed with her from April 2006 till September 2006. My father needed someone to help him and my mother needed support. During this time few people came to visit, many felt that because I was home it was best to let the family be alone. In time my mother got better, she went on five trips to see places she always wanted to see, and she went back to her home town to visit friends, life went on. Life was back to normal; however my mother still lived with severe back pain and personal embarrassments of her bladder and her chronic diarrhea. The discomfort of her personal hygiene limited who and what she did, if my Dad or I was with her she felt fine however, she was always worried she would mess someone's car, I felt so bad for her. My mother did not stop life she went on, which is what she wanted her girls to do, she hated that we had all sacrificed our lives for her, she felt guilty that I stayed with her instead of going on with my life.

During this time my mother received homecare visit and made regular visits to the local doctor. After her last hospital stay in the St. Louis hospital she and my dad decided it was best to stay with the local doctor and hospital that brought her back to life. My mother had anger towards the major medical center in St. Louis, she felt they did not care about her like the local hospital; she was just one of many dying cancer patients at the specialist hospital where at the local hospital she felt special. Thus at this stage of her disease, she moved to local treatments and care.

During April to December 2006, my mother would have spot urine checkups and minor x-ray scans however no extensive cancer screens were performed do to her limited kidney functions. During this time my mother would tell me she had back pain and was tired, however she knew my dad wanted her up and moving so she would sleep when he was not around and getup when he came home. My mother went 6 months cancer free, two days before Christmas 2006, my parents informed me that my mother's cancer was back and it appeared to be in the bones, she had been in the hospital for four days however, my mother told my father not to tell me for fear I would return home and not get my study permit in South Africa. My mother felt positive, she stated no need to come home, she was going to start Chemo next week. I was shocked she was going to do Chemo again after all she had been through, however she had lived life and saw hope so she decided it was worth the discomfort.

One week later the day she was to start Chemo she entered the hospital in the middle of the night for back pain, I had already planned a trip home and she sounded in high spirits even though she was in pain. The pain had become uncontrollable they had to give her experimental pain killers. The hospital as in all previous situations asked for my mothers living will and do not resuscitate orders, these were her wishes and they had to be legally followed. My dad spoke to me on January 8, 2007 saying my mom still had a month to live at least, based on the doctor's opinions, they had started to talk about putting her into a nursing home due to the severity of her pain, and hospice was not a choice. Three hours later I got on a plane and headed home, I planned to stay with my mother till she died. Upon landing in Amsterdam I had a voice mail, my mother had died, the shock was overwhelming, the flight attendants escorted me to

my very long flight back to America. My mother died on my way home which was unbelievable, my father had consulted with my mothers doctors who advised my father that he needed to tell me before I arrived home. The pain and anger that I experienced was awful, she died by herself, I wanted to see her one last time, however in true Mom fashion she waited till my dad left the room and died alone, she didn't want to be a burden to anyone.

The funeral home held my mothers body without embalming until I arrived, my mother wanted to be cremated with no public viewing except family. We all viewed the body except for my older sister, she choose not to base on how she wanted to remember my mother. For the rest of us it was special, we were glad that we got to see her, she looked beautiful and at peace, no more pain or fights for life, she was in a better place.

We held a service at their local church and took my mother back to her hometown to bury her a week later. I must comment that my mother on Mothers Day 2006 was baptized in my dad's church; she had always remained a Catholic, however in the end she felt the community of the Baptist Church had done so much for her and her family she wanted to be baptized before her death.

We received hundreds of cards and donations on behalf of my mother's memory, the church and community brought endless amounts of food and supported my dad throughout the process. The church gave us a dinner after my Mothers funeral which was greatly appreciated. Her friends in Ohio hosted a dinner for her when we brought her to be buried which was also very kind and generous. My dad works and volunteers at a National Park, thus government officials sent us special State certificate honoring my mother's volunteer work in the community and her life. The Park was also rebuilding the Exploratorium and left a chair in my mother's memory.

In the end my mother died quickly it surprised many do to her travels and attitude, it even took me by surprise, you think today modern medicine can tell you when someone is going to die, however doctors were unable to help with that diagnosis. My

father is still living in their house and will do nothing for a year, my mother left a note book with items for each of us girls, and we will not pass out the items for awhile. There is so much more however at this time I think this is a good overview of the experiences that my family went through during my mother's disease.

Side note: I did ask my family about the internet and was taken back at the response; they used it to find out the death statistics for my mother's type of cancer. I used the internet to understand the type of cancer she had, the possible types of treatments, who were the doctors and lastly as everyone did the probably life expectancy. She made the two years.

Analysis and Discussion

In relating the case study back to approaches presented we can see the sociological influences of family, community, culture and economics.

The original diagnosis of my mother's illness was influenced by gender issues within healthcare, it is not as common for women to have bladder cancer and I feel in many ways this limited her initial diagnosis and treatment. When looking at the limiting resources and skills that existed in my family's local community, we can see how social capital and geography contribute greatly to the types of services made available. My mother's initial treatments were limited by the expertise available in a rural area. In addition to the areas medical limitation, my mothers own personality influenced her trust and acceptance of the local medical staff.

The case study highly reflects the influence of culture and access to American Medical Systems. The amount of procedures and ongoing treatments my mother went through was based on an American model of illness which relies heavily on medical procedures and experimental treatments. In addition to the types of treatments the emphasis placed on medication can also be seen as cultural in nature.

During my mothers final stages of death she was in extensive pain; however, based on her stoic nature she hid her pain, which in turn hindered the doctor's ability to understand and treat the severity of her disease. The lack of understanding of her pain resulted in delaying the proper pain management controls and compromised the doctor's ability to further diagnose the disease progression. My mother died a painful death; I can only reflect that without any scientific means for measuring pain we are left to looking at a better social understanding of how people express or choose not to express their pain.

My mother's illness behaviour and sick role was textual in nature, she was allowed and expected to be sick and in many ways her retired status greatly influenced how she was received by the community. My mother was in many ways respected based on her desire to get healthy and not stay in the sick role. The ability to control her death and influence those around her allowed my mother to have a good death, she used her power to articulate her wishes and died knowing her affairs were in order.

Lastly, I feel Bury (1995) account of how chronic illness is no longer a linear path to death is highly relevant to understanding my mother's illness; it was an ongoing cycle of hope and defeat, hospital and home, surgery and recovery, and pain and happiness. However I would argue that the sociologists emphasis on death and denial needs to be further studied, my mothers decision to go back to having chemotherapy after all she had been through demonstrates a lay persons desire to live not die.

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