WHEN DARKNESS FALLS AT MID-DAY: YOUNG PATIENTS’ PERCEPTIONS AND MEANINGS OF CHRONIC ILLNESS AND THEIR IMPLICATIONS FOR MEDICAL CARE

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SUMMARY
Background: This study illustrates the perceptions and meanings that patients who have had the onset of certain chronic diseases at young adulthood ascribe to their condition of chronic illness. The paper further examines the implications of such perceptions and construction for medical care.

Design: Qualitative and ethnography.

Setting: Outpatient chronically ill patients were recruited from the Korle Bu Teaching Hospital, Accra Ghana. Patients were followed up and studied in-depth in their homes.

Participants: Purposive sample of 24 consenting patients diagnosed of cancer, renal disease and stroke.

Methods: Anthropological data collection techniques mainly in-depth interviews, narratives, conversation and observations were used. Issues explored included patients’ perceptions, causal explanations, meanings ascribed to diagnosis, and search for treatment and cure.

Results: Young adults had very low knowledge of chronic illnesses and did not consider themselves at risk to chronic diseases. The search for diagnosis, upon the presentation of symptoms, was long and winding. Families of young patients were more likely to make future search for “spiritual diagnoses” than elderly patients and their families. Keeping silent and maintaining secrecy about diagnosis are important ways by which young adult patients cope with their condition. Irrespective of the prognosis, young patients nurture a strong hope of cure.

Conclusion: Young adults diagnosed of certain chronic illnesses ascribe supernatural interpretations to their disease condition. These determine their attitude to their condition as well as health seeking behaviours adopted by them and their families. Responses interfered with their biomedical care and thus have implications for health promotion and healthcare planning and policy.

Keywords: young adulthood, chronic illness, causal explanation.

INTRODUCTION
There is massive evidence of an epidemiological transition and increasing incidence of chronic diseases globally, and Ghana has not been left out of this unfortunate phenomenon. In April 1996, the WHO Country Cooperation Strategy for Ghana acknowledged that non-communicable diseases are increasing with lifestyle changes in Ghana. It listed hypertension, diabetes, chronic renal diseases, cancer and mental diseases as examples of such chronic diseases. Several other studies conducted in Ghana have particularly alluded to the rising trend of chronic diseases, as well as hypertension and obesity which are major risk factors for most chronic diseases. Recently, the Ghana Health Policy acknowledged that while Ghana’s disease profile is characterized by high levels of communicable and pregnancy-related diseases, there is a rising incidence of chronic non-communicable diseases, including hypertension, cancer and diabetes.

The mean ages for the onset of certain chronic illnesses such as breast cancer, cervical and ovarian cancer, stroke and hypertension induced renal diseases have reduced worldwide. Diseases which were known to show up when one is well advanced in age are now being diagnosed at an earlier age. In Ghana, Clegg-Lamptey and Hodasi noted that breast cancer continues to affect a relatively young population. While the majority of the patients in their study were between 40 and 44 years (about 21%), those between 20 and 39 years old comprised of about 20% of the total number of patients studied. Whereas this trend could signify that people are contracting these chronic illnesses at an earlier age, the availability of improved diagnostic technology and facilities makes diagnosis quicker and more certain thereby revealing such diseases earlier. Also in view of the increased acceptance and usage of modern medicine individuals eventually report at modern health facilities with their chronic illnesses, and their data appropriately captured by the medical system. Aging is associated with frailty and the period for the onset of several chronic illnesses.
The stage of young adulthood on the other hand is conventionally the period when the individual naturally exudes physical strength and vitality. In most societies, by the time a person attains young adulthood, he is most likely to have accomplished an appreciable level of education or skill training to enable him gain some economic independence. Youthfulness signifies exuberance, vitality, strength, and productivity, and thus does not resonate with the debility, incapacitation, deformity and disability which usually characterises chronic illness. The onset of a chronic illness at this stage in one’s life is the last thing that one could expect. Most medical practitioners do not even consider young people vulnerable and susceptible to certain disease conditions.

There is widespread evidence that attitudes towards chronic illnesses, including caring for the various needs of such patients is socio-culturally determined, and based on norms, belief, and perceptions. These notions on causal explanations are built on local and traditional theories of disease causality. Such conceptions not only create excessive fear and dread which may cause family and friends to display avoidance or overprotective behaviours to the ill person, but also guide in determining behaviours and attitudes of family members towards the patient. In many societies, the attitude of patients themselves to illnesses and the extent to which they care for their sick are shaped by cultural perceptions and beliefs about the cause and treatment of diseases, and certain elements of these factors vary among ethnic groups.

**METHODOLOGY**

This paper is based on anthropological research conducted on twenty-four Ga patients diagnosed with chronic conditions within a period of ten months. The Ga are the traditional people of Ghana’s capital, Accra, the capital city of Ghana, and they speak the Ga language. Whereas trading was the dominant occupation of Ga women, the majority of Ga men were engaged in farming and fishing until the colonial administration, when a substantial number of Ga men attained some education and gained professional and clerical employment. The 2000 Population and Housing Census report that the Ga form about 3.4% of the Ghanaian population.

While the original study was conducted on patients between the ages of 25 and 60 years, this report is based on nine young adults aged 25 to 35, diagnosed of the following chronic diseases; cancer of the breast, cancer of the ovaries, cancer of the nasopharynx, cancer of the cervix, stroke and chronic renal failure. One patient had co-morbidity of cancer of the breast and ovaries. The patients were recruited from the Korle Bu Teaching Hospital in Accra, with the assistance of senior medical officers from the respective departments namely; the Center for Radiotherapy, the Department of Medicine and Therapeutics, the Diabetic Center and the Cardiothoracic Center.

The criteria for the selection of patients were spelt out to collaborating medical officers, who assisted in recruiting qualifying patients. The inclusion criteria were mainly; Ga patients within the requisite age range, with a serious and debilitating illness which is non-communicable. The Ga was the preferred ethnic group for this study in recognition of the peculiar traditional Ga beliefs on disease causation as illustrated in this paper, and the need to examine if these beliefs as still applicable. Confused patients and patients with blurred mental capacity were to be excluded from the study, and views and guidance was sought from health personnel in this regard. Patients were selected from different socio-economic backgrounds. In most cases, entry and exit interviews were conducted with key persons of the unit or facility for verification and clarity. Participating in the study was purely voluntary, and patients were guaranteed they would lose nothing if they declined to participate. Those who pledged their participation were told and often reminded that they could opt out of the study at any point in time if they felt so inclined and this would have no implications on the care they receive in the hospital.

Observing ethical guidelines was core to the success of the study, particularly in field research. Accordingly, this study was preceded by the acquisition of an ethical clearance certificate from the Institutional Review Board of the Noguchi Memorial Institute for Medical Research of the University of Ghana. Patient-centred methods of data collection were designed to ensure that the wellbeing of patients was of paramount importance in the data collection process. The needs of the study had to be balanced against and considered secondary to the needs of the patient, noting the particular sick condition of patients in order to eliminate all possible risks inherent in the process. For instance, the researcher was aware of the fact the persons under consideration were prone to fatigue, stress and discomfort and thus apart from scheduling visits on days and locations most convenient for each patient, care was also taken to ensure that the process did not pose any physical discomfort. It was important to be closely attuned to patients’ non-verbal behaviours and paralinguistic cues of physical pain and be prepared to end an interview at the first sign of fatigue or distress. During certain visits, when it was clear that the patient was in poor condition, an interview was not initiated at all. When a patient was asleep at the time of a call, the researcher left without asking for him/her to be wakened up.
Values and norms are then formulated, founded on the death, illness, old age and dis
tections to events within the family such as childbirth,
interactions, members ascribe meanings and interpret
have their culturally a
children, youth and the elderly, and these identities
ascribe identity to various categories of perso
when people interact with each other in a society, they
with medical care is from the vantage point that; first,
disease condition and how these constructions interfere
adult patient
identifying analytical themes or categories as they
drawn. Data analyses adopt the inductive process of
turns in the content of data, upon which inferences are
The Kubler-Rose (1969) stages of grieving and expe-
riencing sickness also provided a good basis for deter-
mining and understanding the outlook and posture of
the patients. Kubler-Rose describes in five discrete
states the process by which people deal with grief and
tragedy especially when diagnosed with a terminal
disease: denial, anger, bargaining, depression and ac-
ceptance.

RESULTS
The Effects of Patient’s Age on Attitude towards Ill
Health
Age was a significant criterion in the selection of pa-
tients for the study, and there were significant findings
with respect to patients’ age. Basically, patients were
categorized into two main age groups; those who were
thirty-nine years and below, hereby referred to as young patients, and those above forty years being the older patients. It became evident from this particular
study that it is much more difficult for young patients
and their families to cope with their condition of being
chronically ill and issues that emerged with respect to
this category of patients (9 out of 24) are illustrated
below.

The long and winding search for diagnosis
The event of discovering one’s disease condition is a
decisive and phenomenal event in the life of the pa-
tient, and highly significant to the whole journey of
coping with and battling chronic illness. Whereas a
condition such as stroke is more obvious and easy to
diagnose, the road to discovering most of the disease
conditions under investigation was long and rough. The
accurate diagnosis of one’s illness is extremely im-
portant, in view of the fact that it is a key factor in effi-
cient disease treatment and the wellbeing of the patient.
Narratives by patients on how they dis-
covered their diagnoses always came spontaneously and eloquently
at our first meeting without any such request. To them,
the event of disease discovery and disclosure was the
turning point in their lives, aspirations, activities and
priorities. Many patients keep recounting this phenom-
enon at different times in the course of our interactions,
and a high level of consistency was noted in their nar-
rations.
All patients first presented their initial signs and symptoms to a modern health facility, that is, a clinic or a hospital. It was evident that until the onset of a serious illness, none of the young adult patients studied ever undertook a routine medical check-up to determine hidden health problems, when they had not seen signs and symptoms because they probably considered themselves young and fit. Generally, it took most patients long periods if ill-health, pain and obvious pathophysiological changes, accompanied by a series of medical investigations before their diagnoses were made. A few patients only had mild symptoms prior to diagnosis, and the stroke patients had sudden onset of fatal condition characterized by physical impairment. Three out of nine patients unfortunately were wrongly diagnosed initially and received the wrong treatments respectively, for periods ranging between four months and a little above a year.

About seven years ago, Tettey started experiencing severe headache. He took several brands of analgesics but he did not find relief. Then suddenly he noticed a boil-like swelling under the right side of his jaw. People said it was tsina asane so he should neither touch it nor send it to the clinic. [Tsina asane, literally translated as “cow boil” is a kind of boil known by local people to be very deadly especially when pierced with a sharp instrument. People who suffer from tsina asane are discouraged from seeking hospital treatment because it is believed that the patient will die if he is given injection.] People gave him all kinds of local medicines to smear on it but the swelling still remained. A private clinic diagnosed him with tuberculosis and for close to one year, Tettey was on tuberculosis treatment yet his situation worsened. Then someone advised him to take a referral note from his doctor to the Ear and Throat Clinic at the KBTH. He had to undertake a series of test from which it was detected that the tumour-like swelling under his chin was cancerous. Tettey said he was greatly amazed at the diagnosis because he was young, in his late twenties, and considered himself very healthy. Although the discovery of diagnosis was unpleasant and unexpected, he was however relieved that his long journey of searching for diagnosis was over and he could now concentrate on treatment.

Usually when the young patient reports signs and symptom of illness, they expect that the diagnosis will reveal a mild malady, especially if the symptoms are not severe in nature. In the course of time, their symptoms worsened yet most of the patients indicated that they did not live in great fear, tension and uncertainty as they waited for the results of their needle aspiration, histology, x-ray, hemanalysis, Pap smear, renal clearance tests and other medical investigations.

Kailey, 29, noticed a bloody discharge from her nipple one morning, while a University student and aged 24. Although she knew that bloody discharge was one of the signs of breast cancer, she least suspected it for herself because she did not know women as young as her could have cancer, and thus did not worry much while she went through the series of medical investigations.

The feelings of the patient at this time largely depend on the extent of his knowledge on the symptoms and medical investigations being conducted, and what they could possibly point to. This was so because patients considered themselves too young to contract any chronic disease. It became clear that it was more unbearable for patients with intimate knowledge of their condition to cope with the period of waiting for the results and its interpretation, than those with little knowledge.

Patients’ apprehension becomes heighted when, in spite of felt physiological symptoms and signs, a series of medical investigations have not been able to discover the cause of their symptoms and diagnosis. Besides breast cancer, which is more apparent in manifestation, patients suffering from the other cancers studied, such as cervical and nasopharynx could hardly suspect any such diagnosis at the time of going through the series of medical investigations because they had absolutely no prior knowledge of the conditions they were diagnosed as having and how they manifest.

When Odarley, 35, was having smelly discharge from her vagina, she thought it was candidiasis and got drugs from a chemical shop to treat it. She was still discharging and this time it was bloody. Her friend told her is could be due to the family planning device she was using. It was when the discharge became unbearable that she visited the clinic and was referred to the Korle Bu Teaching Hospital (KBTH). She was diagnosed of cervical cancer.

It was apparent that during the period of searching for disease diagnoses, patients in this study were not anxious about their various pathophysiological changes and their possible outcome. A patient for instance who presents with extremely high blood pressure, coupled with acute stomach pains, swollen face and legs, and other symptoms, who is asked to do a renal clearance test would least suspect that the results of the test could possibly lead to the diagnosis of renal failure- which is a fatal condition, and expensive to manage in Ghana. A patient who presents gangrene in the toe or one who is requested to do a mammogram and needle aspiration would hardly know that they could be having diabetes and breast cancer respectively.
Their lack of prior knowledge of their disease conditions kept them at rest while they waited for the results of their medical investigations.

In contradiction to Kubler-Ross’s stages of grieving, which asserts that the individuals’ initial reaction to the news of a tragedy particularly ill health is shock, disbelief and denial, narratives by patients specify that they readily accepted medical reports and diagnosis as theirs and did not entertain any feelings of denial in the first instance. This is mainly because many patients reported to the hospitals late, and by when their signs and symptoms were acute and very likely pointing to a fatal illness, associated with pain and wilting. At this point, patients were rather relieved of the winding search for diagnosis and hope to concentrate on treatment and possible cure. Again, patients held medical practitioners in high repute and trusted them implicitly with diagnosing correctly, which caused them to believe that health practitioners almost do not make mistakes. This however did not lead to a state of utmost shock, disappointments and devastation when patients are told the results of their investigations and the severity of their condition. By this time patients might have suffered enough symptoms which coupled with the relatively longer search for diagnosis to suspect that they may be suffering from a fatal condition.

Causal Explanation of Young Patients

Young patients and their family members in the study were more likely to attribute the cause of their condition to supernatural causes. There was a strong belief among this category that their condition had no physiological or natural causality. Many of the participants could not grapple with the fact that it was natural for a twenty-nine year old to have breast cancer or cancer of the brain. Such notions greatly influenced their attitude to the disease, and places where they seek treatment and their care. High educational status of patient and high knowledge of disease condition were not noted to significantly affect beliefs on disease causality.

When a young person has been chronically ill extensively, one of the important ways relatives exhibit care is to consult a traditional priest, shrine, clergy, malam (Islamic spiritual healer) or prophet, depending on their religious orientation, to establish the cause of the disease. This is sometimes done without the knowledge of the patient. Seven out of the total of nine patients under consideration had ever visited a prayer camp, herbalist or spiritual healer, because they deemed it unnatural to be affected by such serious diseases as renal failure, cancer and the like. Generally, people’s reaction to young people acquiring these conditions is that, ene dsee efolo, esani atao mlii “This is not a mere disease, it must be looked into (spiritually)”. Two male patients within this category who had been actively involved in sporting activities had more reasons to believe that their condition was not natural, because they had considered themselves fit, sporty and healthy from years of training and physical engagements in sports.

When Nii Odartey, at age 31, got terribly sick, had swollen legs and stomach, with acute wilting and atrophy, his mother and sisters became very worried and consulted a traditional priest to enquire the cause of their son and brother’s illness. This was when they were told that a man he was litigating over land with, had cursed him, hence the sickness. Although he indicates that he would not have gone to do such an investigation, he saw the initiative of his mother and sister as normal and appropriate. He was later diagnosed with acute renal failure at the Korle Bu Teaching Hospital.

Tettey was diagnosed with cancer of the nasopharynx in his late twenties. In spite of having had surgery and treatment in Malaysia and South Africa, he still consulted a Malam because he was convinced his condition had a spiritual cause.

Although Kailey, diagnosed with breast cancer at age 28, and ovarian cancer at age 31, would not seek the views of a spiritualist on her disease causality, she speaks convincingly and philosophical of her belief that whatever happens in the physical is a correspondence of what happens in the spiritual, thus her ailment is a manifestation of something that happened in the spirit.

Relatives of young patients believed that if they were able to eliminate the spiritual cause of the disease the patient will be cured. They thus invested a lot of time and resources into spiritual and traditional modes of disease treatment.

Odartey has so far spent a cumulative time of nine months living in the prayer camp. This excludes his travels to Nigeria for prayers from a pastor.

Young chronically ill patients also adhered to the instructions of spiritualist than those of medical practitioners since they saw the former as key in their care and cure. They gave premium to supernatural activities towards their cure.

The renal failure patient (Odartey) once announced to me that he wanted to travel to Nigeria the following week for prayers from a renowned “man of God”, as he puts it. As at this time, the patient had reduced his weekly dialysis treatment from three to one due to financial constrains.
At the time of travelling to Nigeria, he had just enough money for either his treatment for that particular week or his travel expenses to Nigeria. In view of the fact that he considered the prayers by the pastor as more potent than orthodox treatment, he decided to dodge dialysis and travel to Nigeria, knowing the danger involved in neglecting dialysis for more than a few days for an end stage renal failure like his.

Tettey was once suspended by his employers because he initially refused to undertake surgery in Malaysia, which was to be sponsored by the organization he works for. His reason for refusing surgery was that his condition is spiritually instigated and the surgery was unnecessary.

Suspicion was high among this category of patients and their family members. In many cases, neighbours, relatives, and friends were suspected of having a hand in the illness. The most suspected were those who had sour relations with the patient or their parents prior to their predicament. Such suspicions were based on beliefs in witchcraft causations of illness, as Field observed among the Gas in the 1950s.

Further Search for Spiritual Diagnosis
In seven of the young adult cases studied, there was a further search from “spiritual” sources after hospital diagnoses to seek confirmation of what has been declared by biomedical practitioners; to find out if there was a human element in disease causality, to know the prospects of treatment and recovery, and to search for a cure. People would often use expressions such as; ayaa tao mli- “to find what is in it”, or ayaa bi mli – “to ask what is in it” in reference to such searches. Such practice is based on the belief that catastrophic events do not occur at random, but are caused by a person or a metaphysical being for diverse reasons.

When Odarthey was diagnosed with end-stage renal failure, and his gloomy prospects of recovery and treatment, his mother thought she needed to find out what was really happening to her son. She thus consulted a traditional priest in her community who indicated to her that her son had been cursed by a man known to them all, who was litigating with them (Odarthey and his family) over land.

Adu, 34, was hypertensive, asthmatic and suffered a stroke. His wife and his sister thought it was not normal for someone of his age to suffer such malady. They consulted a traditional priest who revealed that he was encountering ill health because he had refused to perform twin rites for his twin children.

Tettey was urged by his friend to see a “malam” (Islamic spiritual healer) for diagnosis and treatment of the boil-like swelling under his jaw, which had been diagnosed as a fall-out of cancer of the nasopharynx. He was told by the “malam” that his work colleague had inflicted a curse on him because he was jealous of Tettey’s promotion.

These affirm the fact that illness beliefs affect attitude and health seeking behavior of patients. These are also in line with the fact that care behaviors are greatly influenced by the processes of reflection and subjective construction of meaning to the illness phenomenon, which informs the formation of values and beliefs, as projected by the theory of symbolic interactionism.

Silence and Secrecy on Illness by Young Patients
Another remarkable observation with respect to age of patient was that younger patients talked very little about their condition. Even when they were in severe pain, they would prefer to say very little about their experiences and condition, and rather prefer to discuss other matters that are not relevant to their condition of ill health. Going by Kubler-Ross’ grieving process, it seemed young patients went through a longer period of denial of their disease condition than older people. They never wanted to be identified with the group of people suffering from their condition or a chronic illness. An older patient on the other hand could find lots of comfort from peers and cohorts with similar diagnosis. This could also be one of the reasons why young patients are fond of seeking health care from places other than the hospital, probably so they are not identified with labels such as “diabetics”, or “cancer” patients.

Adoley, 31, typically goes to the Radiotherapy Department at KBTH for her routine check-ups and treatment very late so that she is not seen by any familiar persons, and identified as a cancer patient. She usually uses the back door instead of the main entrance.

It was also noted that the immediate family members collaborated with young patients to keep their condition secret and confidential. This was more common with young patients than it was with elderly patients. Cases of prolonged illness had been kept so confidential that household members had no idea of what transpired. When symptoms and signs become visible or a patient was hospitalized, or deteriorating, neighbours and household members were given misrepresented versions of the condition. In line with this, finding creative ways of keeping the condition confidential was one of the core care activities of the few close family members who know about the disease.
Such actions, as illustrated above, being important attitudes and behaviours towards the onset of chronic illness at young adulthood conform with the theory of symbolic interactionism in the sense that the incidence of chronic illness in young people (as categorized in this study) is an unexpected phenomenon which presents a stimulus. Reaction to this stimulus is not perfunctory but interpretations are given, subjectively, mainly based on the fact that the patient is considered “too young” to be afflicted by such serious illness. The illness is considered to be of supernatural cause and requires supernatural intervention. This belief informs and influences the line of action to be resorted to, thereby family members show care by seeking the “suitable treatment”, and through appropriate behaviours including the keeping of patient’s condition confidential and resorting to spiritual sources for treatment.

The Strong Hope of Cure by Young Patients
Another feature of young patients is that they nurtured a stronger hope of getting cured than older patients. Qualitative studies conducted among HIV/AIDS and cancer patients in Accra and among old persons in Kwahu Tafo in Eastern Ghana reveal the resilience of older person towards chronic illness and mortality. Alternatively, young patients and their families maintained a very strong belief that they will be cured soon, irrespective of the diagnosis and their knowledge of fatality of the disease condition. They guarded this virtue very well, and in many ways, as one patient said;

“I have stopped attending “Reach for Recovery” [Reach for Recovery is an organization of breast cancer survivors affiliated with the Korle Bu Teaching Hospital/ meetings because when you go and you ask of this person or that person, you are told she is in a bad state or she is dead. I don’t like hearing such things, I like to hear good things.”

Another indicated that;

“I don’t like reading stuff on my condition because it puts fear in me. I want to live and I know none of the things they have written will ever apply to me.”

Such strong belief of receiving a cure and survival made them very determined and persevere in their efforts towards their cure. They cultivated plans for their personal advancement, such as business plans, building plans, career and family pursuits.

CONCLUSION
Most studies on chronic illness in Ghana have usually focused on children and the elderly, and the stage of young adulthood has not gained much attention in this regard. Evidently young adults diagnosed of certain chronic illnesses ascribe supernatural interpretations to their disease condition. These determine their attitude to their condition with respect to the health seeking behaviours of their family and them. Such attitudes were noted to interfere with their biomedical care and thus have implications for health promotion and healthcare planning and policy.

The increasing incidence of chronic illness among young people makes it imperative to target and capture this category of persons as well as elderly persons in health promotion programmes on chronic diseases. Young people should be made aware of the fact that they are also at risk of contracting chronic diseases so they employ preventive lifestyle and also facilitate their diagnosis and disease management. It is obvious that young patients undergo immense internalised psychological and emotional conflicts because they are diagnosed of a condition which they do not consider themselves at risk to. Health workers and social workers thus need to pay ample attention to their peculiar counselling needs particularly with respect to their health seeking behaviours.

Cultural beliefs and perceptions on the causes of chronic diseases among the Ga are still quite influential. Beliefs in supernatural causation of chronic illness were very prominent among young patients and family caregivers, although there are variations in their constructions. Beliefs in supernatural causation were noted to influence patients’ course of treatment, causing them to combine orthodox medicine with other forms of therapy, including spiritual healing and herbal medicine.

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