UNDERSTANDING ILLNESS BEHAVIOUR, DEATH AND BEREAVEMENT IN ADULTHOOD.

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ABSTRACT

To aid our understanding of the ways various individuals perceive, evaluate, and respond to symptoms of illness, the literature on illness behaviour was reviewed. Two competing hypotheses (the linking hypotheses and the substitution hypothesis) and two theoretical paradigms (the health belief model and the behavioural model) which attempt to explain illness behaviour were presented. Kastenbaum's (1975) conceptualisation of death, kubler – Ross's (1969) five stage theory of dying and Parkes' (1972) four sequential phases of anticipatory grief were presented in the hope that they will not only illumine our understanding of the mystery of death and the rituals associated with it but also place these within a wider social milleau that surround them. Attempts were made to clarify and highlight the roles of the counsellor not only in meeting the psychological needs of the ill and dying and of the health caregivers but also mitigating the emotional responses associated with the loss of a loved one.

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INTRODUCTION

The primary purpose of this paper is to examine the patterns and theoretical models of illness behaviour, the process of dying and the social circumstances surrounding it, and the rituals and cultural practices associated with grief and bereavement. Secondarily, the paper attempts to clarify the dual roles of the counsellor in assisting the ill and dying meet their psychological needs, ideals and expectations within societal expectations of dying well as well as helping the bereaved cope with the grief associated with the loss of a loved one. The issues and processes discussed in this paper are limited to expected death and bereavement and exclude sudden and unexpected death and bereavement.

PATTERNS OF ILLNESS BEHAVIOUR

Generally defined, the study of illness behaviour is concerned with the ways symptoms may be differentially perceived, evaluated and acted or not acted upon by individuals (Mechanic, 1978). One individual experiencing symptoms of malaria, for example, may opt for medical attention in a hospital or formal health institution. Another with the same symptoms may go to a herbalist while others may prefer self care at home. The very religious individual with malaria symptoms may earnestly ask for a miracle cure. All these ways and others not mentioned here are response patterns to symptoms of illness and constitute what social scientists refer to as illness behaviour. Trends that emerge from the literature point to three major types of illness behaviour:

FORMAL SERVICE: Formal service utilisation refers to the use of formal medical care such as emergency room and outpatient services and in-patient hospitalisation. The determinants of the utilisation of formal health services include the age, type of illness, and such life circumstances as the availability or otherwise of financial resources, accessibility and knowledge of the availability of medical services. To buttress this, Verbrugge (1987) indicates that physician visits for older adults are much more likely to involve fatal chronic diseases than are physician visits by younger persons. This is also true of in-patient hospitalisations, where the main reason for hospital stays is almost entirely the result of life threatening disease. Rice and Feldman (1983) have also shown that older adults are the largest single consumers of formal health care services.

SELF CARE: Levin and Idler (1984) defined self care as the activities individuals engage in to promote their own health, prevent their own disease, limit their own illness and restore their own health. These self care activities have been categorised into two major clusters – preventive health behaviour and responses to acute illness. Preventive health behaviour includes such activities as healthful living, physical exercise, stress management exercises and healthful food culture. Self-care responses to acute illness may involve chemotherapy and herbal cure.

INFORMAL CARE: Krause (1990) defined informal care as care provided by family members and friends. This form of illness behaviour appears to be the commonest and most widely utilised in Nigeria, especially in rural areas where other forms of care are unavailable or rather inaccessible either due to ignorance, cost or entrenched cultural beliefs and practices.

A major theoretical problem that emanates from this western categorisation of illness behaviour and limits its practical usefulness in Nigeria and other traditional societies relates to some illness response patterns that either overlap or do not squarely fit into any of the three types of illness behaviour. For example, to which cluster of illness behaviour does one classify traditional medical care – self-care, informal care or formal service? Your guess is as good as mine.

A review of the literature by Krause (1990) revealed two competing hypotheses of the linkages between formal health care utilisation, self-care and informal care. Proponents of the linking hypothesis propose that informal and self-care facilitate access and entry into the formal health service system. For example, significant others such as family members and friends (informal) may foster symptom recognition (self) and facilitate access to formal health care by providing financial assistance.

The import of this hypothesis appears questionable given the Nigerian situation. For one thing, are users of self-care not more apt to avoid formal medical service and vice versa? Advocates of the substitution hypothesis predict that self care and informal care are used in place of formal medical services. This hypothesis appears move plausible and to explain illness behaviour in Nigeria as informal and self care more often than not substitute rather than compliment formal health service. Patrons and matrons of herbal medicine are likely to call at the 'Babalawo' each time they are sick than call at a hospital.

MODELS OF ILLNESS BEHAVIOUR

Two common theoretical models which have been considerably used to explain illness behaviour are the health belief model and the behavioural model.

THE HEALTH BELIEF MODEL: though does not refer to a single theoretical statement, posits that four beliefs must be present before the decision to seek help for medical problems is actually initiated:

i.   the belief that one is susceptible to illness
ii.   the belief that one's symptoms are sufficiently severe to warrant attention.
iii.   The belief in the efficacy of medical care
iv.   The belief that the costs or barriers encountered in pursuing treatment options are reasonable (Krause, 1990 : 230).

Apart from these beliefs, Kasl (1974) also identified the role played by social support in the help seeking process and observed that one's social network may help him or her interpret his physical symptoms in terms of severity and threat posed. The network may also suggest actions to be taken to alleviate illness symptoms and even provide assistance in implementing the health care decisions made by individuals. Kirscht (1974) has also extended the frontiers of the health belief model. He proposed that psychosocial characteristics such as age, sex, socio-economic status and psychological orientations such as alienation, fatalism and scepticism may also influence health beliefs.

THE BEHAVIOURAL MODEL: The behavioural conceptual scheme was initially developed by Andersen (1968) to investigate social structural barriers to formal health care, though in recent times, it has been extensively used to examine other forms of illness behaviour as well. According to this model, the utilisation of health care can be explained by three generic block of variables namely 1. Predisposing, 2. Enabling, and 3. Need characteristics.

Predisposing characteristics are viewed by Andersen (1968) as those factors existing prior to the onset of illness that reflect the propensity to use formal health care services. The three clusters of this category include demographic (age, sex and marital status), social structural (education, race, social class), and health beliefs (e.g. belief in the efficacy of medical care).

Enabling characteristics define the individual's ability to utilise health care services should the need arise. The two divisions of this category are family resources (e.g. income) and community resources (e.g. the cost of health care services and the ratio of doctor to population).

The individual's need characteristics are those factors that determine whether or not an individual actually uses formal health care services when appropriate predisposing and enabling characteristics are present. Perceived need is typically assessed with indicators that measure functional disability, self reported overall health status and symptoms of physical illness (Krause, 1990: 231). Owing to the conceptual and theoretical weaknesses associated with the behavioural model, efforts have been made to integrate additional constructs into the framework. Coulton and Frost (1982) attempted to introduce social support into the model and propose that social support may function as predisposing factor and influence the way symptoms of physical illness are evaluated.

Although the health belief model and the behavioural model appear to share a common nucleus of constructs including perceived illness symptoms, demographic and economic factors, belief in the efficacy of medical care and social support, Krause (1990) observed that these constructs appear to be disjointed. He therefore proposed the life stress model which is an integration of these two perspectives with assistance from the literature on stressful life events.

DEATH AND DYING

Death is a fluid concept – it assumes different meanings at different times and even at the same time to different people. Personal experience and the literature support this assertion. Perhaps, this informed Kastenbaum's (1975) conceptualisation of death in six different ways as a variable, a statistic, a state, an analogy or a mystery. In his postulation, death as a state of being may mean the end point in a biological process, as an abstract state of 'nothingness', of 'nonliving'. Death as a mysterious paradox is often the reason for living and affects our developmental course even though we experience it at the end of life. As an analogy, a person who is no longer considered important or useful or whose role or function no longer exists may feel or be considered dead by family members and associates. As a statistic, attempts are made to determine people of what sex, age and socio-economic status will die of what and when. Death may also be perceived as an event in the community or family like any other, such as birth, marriage, graduation, etc. As an event, it may be natural or not, violent or peaceful, of an important person or of a common man. As a variable, death

assumes many images which serve as death stimuli or responses. A coffin, a cemetry or corpse too often reminds one of death. Whatever meaning or perception we hold of death, it is incontestable that it marks the end of life of oneself or others on planet earth.

WHY THE CONCERN FOR DEATH

Counsellors, like other social scientists are challenged by the impact of death on the social organisation, maintenance and survival of society. The fundamental problems which death creates at the individual and societal level which necessitate the concern for it include among others:

(1)   Death threatens the capacity of a society to survive itself and disrupts community functioning.
(2)   The vacuum created by the deceased and the refilling of the social roles of the dead often pose a problem to society.
(3)   Death may threaten the legitimacy of a society's meaning system and shake its moral foundation as the search for meaning in death raises the question of meaning of life.
(4)   Practical problems to self and others left behind include problems of replacement such as relocation of social roles, inheritance arrangement, reconstitution of kinship structure and relational networks and having to do mundane work - moving, cleaning and disposal of the deceased possessions.
(5)   The cessation of relationship with others and inability to complete projects and plans also constitute a problem to the dying and those left behind.

STAGES OF DYING: Kubler-Ross (1969) based on clinical interviews with the terminally ill developed a five stage theory of dying anchored on the concept of hope. These five sequential stages which are briefly reviewed here include 1. Denial, 2. Anger, 3. Bargaining, 4. Depression, and 5. Acceptance.

During the first stage, the individual resists the reality of the impending death. Such denial may be manifested in the individual seeking other professional opinion, religious assurance or miracle cure. The seeming failure of these other activities sets in the second stage -- anger -- which is often displayed in hostility, resentment and envy directed at one or more family members, friends and associates, the medical personnel, the environment or even God. Because the question -- why me? Cannot be satisfactorily answered at this stage, the individual enters the third stage - bargaining,

that is, making deals with fate, seeking favours that will postpone death. These could he conducted covertly or overtly in interactions with God and others. Because these deals are never honoured, depression sets in at the fourth stage. At the fourth stage the imminence of death can no longer be denied and the individual experiences a deep sense of great loss of family members, friends, of body, self control and identity. The final stage is acceptance – the pain is as if gone, the struggle is over and the time comes for the final rest. The individual, though not happy is resolute about death. However, Kubler – Ross (1974) has cautioned that these stages are not invariant and universal and not all people go through this stage sequence.

A major contentious issue concerning dying is the context for dying. Answers do not come easy to such questions as – where do most people want to die? Where do family members prefer their member to die – at home or in the hospital? Where an individual dies has serious implications for the role of medical personnel, family members and care givers and for the needs of the dying. For example, dying in a hospital often presents problems to the medical team. As Hultsch and Deutsch (1981) observed, for physicians and health care-givers, death often presents failure and defeat and the majority of physicians avoid patients once they begin to die. This avoidance is associated with the personality structure of physicians, which is often reinforced by training. When physicians come face to face with the dying, they become aware of the temporal limits on their own lives. To shield themselves from the trauma of personally experiencing death with the dying, the physician – patient relationship is usually one of detached concern. Another major problem which dying in a hospital poses to the medical personnel is whether or not to inform the patient and his or her family members about his or her condition. While some practitioners suggest that the patient should take the initiative in requesting information which should be given honestly and completely with the patient controlling the quantity and quality of information flow, others add that such information be provided within the framework of sensitivity.

Meeting the needs of the patient also poses another problem. Such needs usually include the need to maintain feelings of self worth, control pain and receive love and affection (Hultsch and Deutsch, 1981). Participation in decision making concerning treatment engenders patients' feelings of dignity and control over their destinies. Physical closeness achieved by touching and holding, empathic understanding and genuine concern for the patient often reassures him or her that he or she is loved and will not be abandoned.

GRIEF AND BEREAVEMENT

Fulton (1970) identified depression, heightened concern for the ill person, rehearsals of the death and an attempt to adjust to the consequences of death as the four stages family members experience in the process of anticipating grief. Other researchers (e.g. Parkes, 1972) conceptualised grief into four sequential phases namely: 1. Initial response, 2. Coping with anxiety and fear, 3. Intermediate phase – obsessional review, and 4. Recovery.

The first phase of the normal process of grief – initial response to bereavement, is characterised by feelings of shock and disbelief, numbness, emptiness and confusion and an all embracing sorrow. It's duration is short and often ends a few days, or weeks after the funeral. The second phase is marked by concern about coping with anxiety and fear of breaking down physically and emotionally. During this stage which may last for a month or two after bereavement, the individual experiences psychosomatic symptoms, eating and sleep disorders and may therefore turn to alcohol, sleeping pills and tranquillisers. During the intermediate phase the bereaved individual engages in obsessional review, searching for an understanding of death and searching for the presence of the deceased (Hultsch and Deutsch, 1981). This phase may last till the end of the first anniversary of the deceased . The fourth and final phase is recovery which is marked by a positive attitude to life once again by the bereaved and usually occurs during the second year of bereavement. The gravity and duration of each of these phases is usually a function of the amount of support received and the specific mourning rituals and funeral rites associated with death. While funeral rituals may provide a social vehicle for managing grief, building new social relationships, controlling the disruptiveness of death, providing social, emotional and financial support for the bereaved family, elaborate and extensive rituals are self serving and may aggravate the burden of the bereaved.

COUNSELLOR ROLES

Four major issues emanate from the above discussion and call for therapeutic intervention:
(1)   The perception, evaluation and response patterns of individuals to symptoms of illness.
(2)   The needs of the dying
(3)   The needs of the medical team, family members, associates and other significant others in the life of the dying.
(4)   The grief of bereavement.

It is common knowledge that the ill may be ignorant of their ailment, its etiology, where to obtain treatment and availability of institutional and community resources for material and social support. The role of the counsellor in this respect therefore is to assist the ill clarify their perception of illness symptoms, refer them to appropriate community agencies and resources for treatment and also liaise with the relevant social service organisations that provide financial assistance for the treatment of the particular ailment. Linkage to the relevant social service cohorts with similar ailments (e.g., the spinal cord injuries association of Nigeria) not only provides emotional and social support to the ill but may enable them see their condition within a wider social context.

As earlier pointed out, the needs of the dying centre around love and affection, control of pain and the maintenance of a feeling of self worth and dignity. Counsellors who work with the ill particularly those in health care settings must therefore communicate and assist the medical team and other significant others to communicate empathic understanding and genuine concern for the patient. Physical closeness and reassurance may assuage the fear of abandonment and bouts of depression often experienced by the ill. Encouraging the ill to take part in decisions concerning their treatment may also provide them with a sense of some control over their destinies and hence enhance their self dignity.

The needs of the medical personnel and significant others in the life of the ill and dying often concern interpersonal communication and increased health care requirements of the dying. Answers to such issues as informing the ill and dying of their condition and helping them to put their lives in order do not come easy. The role of the counsellor in this respect is to serve as a facilitator of effective communication among the ill, the medical team, family members and significants others. Breakdown of communication in such illness situations usually lead to social tension and disordered relationships. Therefore, depending on the mental and physical state of the ill and dying, the counsellor must assist them understand and accept their condition within the framework of sensitivity.

Managing grief associated with bereavement also poses a major challenge to counsellors. Bereavement, like all life – stress events produces a variety of emotional responses ranging from feelings of hopelessness, anger, sorrow and depression to psychosomatic complaints. Arranging for funeral rites and mourning rituals may also be very traumatic and stressful to the bereaved. Appropriate therapeutic interventions particularly social support and stress inoculation must be planned and provided the bereaved to enable them cope with their emotional responses to loss.

CONCLUSION

To understand the ways individuals perceive, evaluate and respond to symptoms of illness, we have reviewed the literature on illness behaviour. Theories that explain illness behaviour, the stages and phases of death and the grief of bereavement were also presented in the hope that they will not only illumine our understanding of the mystery of death and the rituals associated with it but also place these within a wider social context. Attempts were made to clarify the roles of counsellors. However, specific intervention programmes, such as social support and stress inoculation are reserved for another paper.

REFERENCES

Andersen, R. (1968). *A behavioural model of families use of health services.* Chicago: Centre for Health Administration Studies, University of Chicago.

Coulton, C. & Frost, A. (1982). Use of social and health services by the elderly. *Journal of Health and Social Behaviour, 23,* 330 – 339. .

Fulton, R. (1970). Death, grief and social recuperation. *Omega: Journal of Death and Dying, 1,* 23 - 28.

Hultsch, D.F & Deutsch, (1981). *Adult development and aging; A life span perspective.* New York: McGraw Hill Book Company.

Kasl, S. (1974). The health belief model and behaviour related to chronic illness. In M. Becker (Ed.), *The health belief model and personal health behaviour.* Thorofare, NJ: Slack Press.

Kastenbaum, r. (1975). Is death a life crisis? On the confrontation with death in theory and practice. In N. Datan & L.H. Ginsberg (Eds.), *Life – Span developmental Psychology: Normative life crisis.* New York: Academic Press.

Kirsch, J. (1974). The health belief model and illness behaviour. In M. Becker (Ed.), *The health belief model and personal health behaviour* Thorofare, NJ: slack press.

Krause, N. (1990). Illness behaviour in later life. In R.H. Binstock & L.K. George. (Eds.), *Handbook of Aging and the Social Sciences* California: Academic Press

Kubler - Ross, E. (1969). *On death and dying.* New York: Macmillan.

Levin, L. & Idler, E. (1983). Self-care in health. *Annual Review of Public Health,* 4., 181 - 201.

Mechanic, D. (1978). *Medical sociology.* New York: Free press.

Parkes, C. M. (1972). *Bereavement: Studies of grief in adult life.* New York: International Universities Press.

Rice, D. & Feldman, J. (1983). Living Longer in the United States: Demographic changes and health needs of the elderly. *Milbank Memorial fund quarterly/Health and society, 61,* 363 – 396.

Verbrugge, L. (1987). From sneezer to adieux: stages of health for American men and women. In R. Ward & S. Tobin (Eds). *Health and aging: Sociological issues and policy directions* New York: Springer.