Contemporary Issues in Nigeria:

Social Scientific Perspectives

(SECOND EDITION)

Edited by:

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Chapter Five

ILLNESS INTRUSIVENESS AND QUALITY OF LIFE IN CHRONIC MEDICAL MORBIDITY

Adeniyi M. Solarin & Gboyega E. Abikoye

Abstract

Technological advances in medical practice and routine availability of clinically-effective therapies in the world today mean that most of the debilitating medical conditions, hitherto considered acute, are now chronic. Chronic diseases imply that, with care and support, sufferers are likely to live with the conditions for a relatively long period of time and must contend with a host of medical, pharmacological, psychological, physical, economic and social consequences which inevitably carry the potentials to compromise quality of life (QoL). Implicit in all these are themes of loss and deprivation as a result of inability to engage in valued activities, interests and hobbies that are attributable to an illness, its treatment and its psychosocial consequences (illness intrusiveness). This paper examined illness intrusiveness, its determinants and its mediatory role in the illness/quality of life link from both theoretical and empirical perspectives, identifying specific roles for the psychologists in reducing illness intrusiveness, and consequently enhancing quality of life of the growing ranks of chronically-ill persons.

Introduction

Technological advances in medical practice and routine availability of clinically-effective therapies in the world today mean that most of the debilitating medical conditions, hitherto considered acute, are now chronic. Chronic diseases imply that, with care and support, sufferers are likely to live with the conditions for a relatively long period of time and must contend with a host of medical, pharmacological, psychological, physical, economic and social consequences which inevitably carry the potentials to compromise quality of life (QoL). Among the factors most widely recognized as responsible for reduced QoL among chronically-ill persons are pain, disability, reduced economic power, restrictions on dietary and fluid intake, complex medical and pharmacological regimens, and a host of ensuing psychological changes (e.g., helplessness, hopelessness, and depression). Disease and disability are generally believed to compromise QoL outcomes directly. Findings have also shown that compromised QoL is more consistently due to illness-induced disruptions to lifestyles, activities, and interests (Devins, Edworthy, Guthrie & Martin, 1992; Devins, Binik, Hutchinson, Hollomby, Barre & Guttmann, 1983) rather than it is to the direct effects of functional disability or other disease and treatment variables.

Illness intrusiveness refers to lifestyle disruptions attributable to an illness and (or) its treatment that interfere with continued engagement in valued activities and interests (Devins, 1994). In many instances, chronic illnesses force people to reduce their participation in valued activities and interests such as work, leisure activities, hobbies, education, and household duties. A growing body of evidence is consistent with the view that although illness intrusiveness is a perceptual construct, this perception (not just the illness, per se) can

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Illness intrusiveness refers to lifestyle disruptions attributable to an illness and (or) its treatment that interfere with continued engagement in valued activities and interests (Devins, 1994). In many instances, chronic illnesses force people to reduce their participation in valued activities and interests such as work, leisure activities, hobbies, education, and household duties. A growing body of evidence is consistent with the view that although illness intrusiveness is a perceptual construct, this perception (not just the illness, per se) can seriously exacerbate emotional distress and reduce Qol in chronic illnesses. For instance, increasing illness intrusiveness was found to be associated with more markedly deleterious psychological outcomes (reduced psychological well-being and increased emotional distress) in multiple sclerosis (Devins, Styra, O' Connor, Gray, Seland, Klein, & Shapiro, 1996). Illness intrusiveness represents an intervening variable through which the disruptive effects of disease and treatment influence quality of life in chronic conditions. This is hypothesized to occur via two complementary pathways, both of which entail illness - and treatment-induced interference with valued activities and interests: illness intrusiveness compromises psychological well-being by reducing (a) positive consequences of participation in valued activities, and b) personal control over important outcomes (Devins, 2006).

Because illness intrusiveness limits participation in valued activities, it may in turn decrease psychosocial well-being as it lowers an individual's exposure to positively-valued interactions. Illness intrusiveness may cause further psychosocial decline by reducing an individual's personal control over both positive and negative outcomes in important situations, especially among patients with chronic conditions (Devins et al., 1993). Studies indicate varying degrees of illness intrusiveness across treatment modalities and illnesses (Devins et al., 1993). Among chronic illness populations, a number of illness-related factors contribute to the construct of illness intrusiveness, including disease factors, such as pain and disability, and treatment factors such as time required for treatment and mode of treatment (Devins, 1994). Illness intrusiveness among chronic illness populations has been shown to have a significant and unique relationship to several psychological variables, including positive and negative mood, life satisfaction, and depression, and is further influenced by psychological and social characteristics such as social support and coping resources (Binik, Devins & Orme, 1989; Devins, 1994). Devins' (1994) model hypothesizes that factors of an individual's disease and treatment psychosocially impact QoL through their relationship with illness intrusiveness. The model also accounts for direct effects of psychological and social factors on both illness intrusiveness and quality of life.

Abraý´do-Lanza and Revenson's (2006) study valuably extends earlier work documenting illness intrusiveness as a fundamental determinant of quality of life in chronic disabling conditions by examining the important refinement that the illness-induced loss of activities and interests compromises QoL to the extent that affected domains are highly valued and central to the patient's sense of self. The researchers observed that illness intrusiveness was especially deleterious in relation to QoL outcomes when it impinged on important roles, when these roles were highly valued by people with chronic conditions. Therefore, the benefits of supportive psychosocial interventions may be maximized when efforts target the patient's most highly valued life domains.

Theoretical Framework

The concept of illness intrusiveness relates to illness-induced disruptions to valued activities and interests that compromise QoL in chronic conditions, such as epilepsy, hypertension, diabetes, rheumatoid arthritis, etc. The disruptions are induced by disease and its treatment (antecedents) and compromise quality of life (consequences). Conceptualized as a facet of the chronic-disease experience that is common across conditions, illness intrusiveness is a fundamental determinant of health-related quality of life (HRQoL). The central hypothesis is that disease and treatment factors influence subjective well-being indirectly through their effects on illness intrusiveness (a mediating variable), which, in turn, directly affects well-being. Illness intrusiveness intervenes between the circumstances of disease (e.g., pain, fatigue, disability) and its treatment (e.g., complications, untoward side-effects), on the one hand, and subjective well-being (e.g., happiness and distress), on the other (Devins, 1994; Devins, Mandin et al., 1990; Devins, Edworthy, Guthrie, & Martin , 1992; Devins, Seland, & Klein, 1993; Devins & Edworthy, 2000).

The theoretical framework maintains that QoL is compromised to the extent that disease and treatment factors interfere with valued activities and interests, reducing the availability of rewarding experiences and personal control (Devins, 1994). Since illness intrusiveness derives from illness-induced interference with meaningful activities, it is construed as an illness-related stressor that threatens subjective well-being.

The Illness Intrusiveness Framework (Devins et al., 1983) provides a model for explaining how disease factors (e.g., vaso-occlusive pain episodes) might impact the patient (e.g., QoL) and their caregivers (e.g., parent adjustment). Illness intrusiveness refers to when disease-related factors (e.g., pain) interfere with valued activities and interests. This theory postulates that disease (e.g., pain) and treatment factors (e.g., disruptive treatment schedules) influence subjective well-being (e.g., quality of life and psychological distress) indirectly through their effects on illness intrusiveness (Devins, 2010). Moreover, illness intrusiveness is a cognitive appraisal mechanism, which indirectly compromises psychological adjustment through reducing both perceived control and the resulting positive outcomes associated with participation in valued activities (Devins, 1994; Devins, Seland, Klein, Edworthy, & Saary, 1993).

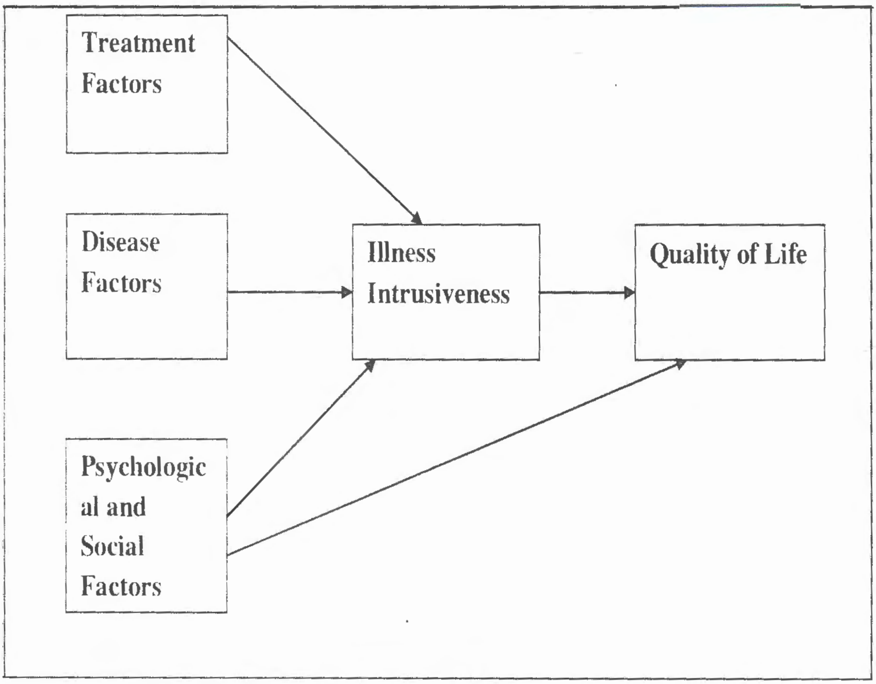

Figure 1: Hypothesized Relations among Illness Intrusiveness, its Determinants and Quality of Life (Devins, 1994).

The illness intrusiveness framework also takes into account psychological, social, and contextual factors. These factors are hypothesized to contribute directly and indirectly to subjective well-being. Specifically, stable factors such as gender and cultural heritage are thought to moderate the relation between disease/treatment factors on illness intrusiveness and state-specific factors such as developmental stage and stigma are thought to moderate the relation between illness intrusiveness and psychological adjustment (Devins, 2010).

Illness-related disruptions to ongoing interests and activities may occur in many chronic physical illnesses and psychological disturbances through the physiological effects of chronic conditions (such as reduced physical strength and stamina, drowsiness, nausea, concentration difficulties), indirect effects bordering on perceptions of the chronically-ill person held by family, friends, colleagues and significant others which may significantly alter family roles and substantially erode the person's autonomy and independence. Secondary consequences of decreased involvement in valued activities may introduce additional disruptions or losses. Increased feelings of helplessness and depression among patients, for instance, may lead to even further withdrawal from daily patterns of involvement. Chronic conditions that induce sexual dysfunctions may introduce significant challenges to marital adjustment or may simply exacerbate pre-existing difficulties.

There is an extensive body of literature supporting the illness intrusiveness theoretical framework in over 36 chronic disease populations including cancer, heart disease, HIV, end-stage renal disease (ESRD), multiple sclerosis, non-insulin dependent diabetes mellitus, lupus, and transplant (Devins, 2010). Originally, Devins et al. (1983) developed the Illness Intrusiveness Rating Scale (IIRS) to assess this construct in ESRD patients. However, it has been successfully adapted for its use with pediatric patients (Wagner et al., 2003) and their parents (Andrew et al., 2009). The IIRS assesses the following three life domains: Relationships and Personal Development (e.g., family/ social relations, self expression and improvement, religious expression, community and civic involvement, passive recreation), Intimacy (e.g., relationship with partner, sex life), and Instrumental Life (e.g., health, work, financial situation, active recreation; Devins et al., 2001). To date, the illness intrusiveness theoretical framework has not been examined in pediatric SCD.

Devins, Bezjak, Mah, Loblaw, and Gotowiec (2006) evaluated the moderating effects of contextual factors (e.g., age, education, income, stressful life events) on the experience of illness intrusiveness in an adult cancer population. Results indicated that younger, lower income, and patients experiencing at least one or more stressful life events reported higher illness intrusiveness scores. Moreover, results revealed significant 2-way interactions among the Instrumental Life factor and each of the hypothesized contextual moderator variables such that younger, more highly educated, higher income, and patients who experienced at least one stressful life event differentially reported significantly higher illness intrusiveness ratings in the Instrumental Life domain as opposed to the Relationships and Personal Development and Intimacy domains. These results suggest that lifestyle disruptions across domains vary as a function of the context in which the illness is experienced.

The Illness Intrusiveness/Quality of Life Link

With the effective control of most infectious diseases in the past half-century, chronic illnesses have become a major health concern in most parts of the world (Fayer & Bottomley, 2002; Reiber, 2009; Thacker, 2006). With the advent of modern diagnostic and treatment technology, chronically-ill persons may continue to live for significant periods of time with these conditions, rather than die or recover from them. Hence, as a conventional population health indicator, "mortality" no longer adequately measures the overall impact of diseases. To address the limitations associated with the measure of mortality, the concept of health-related quality of life (HRQoL), which measures how well people live despite their disease, has emerged. HRQoL, a multidimensional and subjective concept, has historically proven difficult to define (Fayer & Bottomley, 2002). Quality of life is based on how patients feel about themselves and their state of health, which would include coping with the symptoms of their disease and the side effects of treatment. HRQoL has developed into one of the most important tools available to evaluate the well-being of patients.

Active participation in valued activities is an important aspect of quality of life (McDowell, 2006) and chronic diseases and the associated treatments interfere with these activities. A method of measuring these interferences is to examine illness intrusiveness, the extent to which an illness and/or its treatment interferes with engagement in important life activities (Devins et al., 1983). The Devins (1994) model stems from research involving the role of illness intrusiveness in quality of life among End-Stage Renal Disease patients, and has indicated that perceived illness intrusiveness was significantly correlated with three quality of life measures including satisfaction/happiness, pessimism/illness-related concerns, and depression/distress (Devins, Mandin, Hons et al., 1990). Specifically, higher levels of perceived illness intrusiveness were significantly correlated with decreased life satisfaction and happiness, increased pessimism and illness-related concerns, and increased depression and distress. These results remained stable over time, even after controlling for response style and background variables (Devins et al., 1990).

Similarly, an additional study with rheumatoid arthritis patients revealed a statistically significant relationship between illness intrusiveness and physical disability, such that after controlling for physical disability, illness intrusiveness maintained a unique, significant relationship with depression (Devins, Edworthy, Guthrie et al., 1992). These data illustrate the role of illness intrusiveness as a mediator of the psychosocial impact of chronic illness.

Illness Intrusiveness and Quality of Life in Selected Chronic Conditions: Empirical Evidence

Epilepsy

Epilepsy is a chronic disorder, characterized by unpredictable, uncontrolled seizures and physiological changes that interfere with lifestyles, activities, and interests. The condition introduces a number of psychosocial challenges and adaptive demands, threatening quality of life (QOL). Unpredictable seizures introduce uncertainty, inconvenience, embarrassment, frustration, anxiety, or depression for affected individuals. The bizarre nature of some seizures (e.g., loss of awareness of surroundings, hyper-salivation, wandering or convulsions) can lead to social consequences, such as stigma or difficulty in finding a job (Faircloth, 1998; Snyder, 1986). Collectively, these stressors disrupt daily activities, interfere with lifestyles and interests, and generally compromise QOL (Jacoby, 1992), although the extent of such effects varies widely among individuals.

The majority of people with epilepsy achieve seizure control with the use of antiepileptic drugs (AEDs). The success rate for AEDs is approximately 60 – 70% (Kwan & Brodie, 2000). Thus, even in the United States, Canada and other industrialized countries where many AEDs are readily available, 30 – 40% of patients continue to experience seizures that are not adequately controlled (Kwan & Brodie, 2000) or develop severe side-effects [e.g., fatigue, drowsiness, dizziness (ataxia), nausea and vomiting, rash, gum overgrowth, weight gain (or loss), aplastic anemia and liver toxicity] (Brodie, 2003). These people are often admitted to an Epilepsy Monitoring Unit (EMU) to investigate their eligibility for surgical intervention.

Epilepsy surgery is the main treatment for pharmacologically refractory epilepsy. It is considered the only treatment that offers hope for a cure by removing the anatomical site of seizure origin in the brain. Before surgery can be performed to treat epilepsy, the location of the seizure focus in the brain must be identified accurately. This is accomplished through continuous video and electroencephalogram (EEG) monitoring of seizures to correlate the first clinical changes of a seizure with the onset of EEG changes in the brain. These steps are accomplished during hospitalization in the EMU. Twenty-four-hour video/EEG recording is performed by applying electrodes to the patient's head and continuously recording brainwaves until a sufficient number of seizures have been recorded (seizures must originate from the same brain region with a specific seizure focus) to indicate that the individual is a suitable surgical candidate.

When tests indicate that all seizures arise from a single dentifiable location, surgery is indicated to remove the site. High-resolution magnetic resonance imaging (MRI) is essential o determine whether a structural lesion (such as a scar or vascular malformation) is present. Neuropsychological testing may reveal lateralized or focal deficits in verbal and nonverbal learning and memory, that provide additional clues to focal brain function. Approximately half of the people who undergo investigations in the EMU become candidates for surgical treatment (McNaughton & Rasmussen, 1975; Wada, 1980).

Despite pharmacological or surgical treatments, people with epilepsy frequently experience numerous stressors. They often continue to experience unpredictable and uncontrolled seizures (with or without loss of awareness), medication side-effects, cognitive changes, reduced physical strength and memory, vocational problems, economic strains, inability to drive, dependency on medications or caregivers, and/or complications of treatment, that are generally believed to introduce significant lifestyle disruptions or limitations (Aziz, Ali, Frances, Khan, & Hasan, 1994; Engel, 2000). Understandably, such disruptions often compromise QOL and their effects extend far beyond the medical situation (Dodrill, Batzel, & Queisser, 1980; Jacoby, Baker, Steen, Potts, & Chadwick, 1996). Given both the chronic nature of epilepsy and its common psychosocial consequences, the goal of clinical intervention with pharmacological or surgical treatment has increasingly been extended beyond the control of seizures to improve QOL as much as possible (Jacoby, 1992).

Poochikian-Sarkissian, Sidani, Wennberg & Devins (2008) explored the psychosocial impacts of illness intrusiveness in epilepsy, with their results replicating earlier findings that illness intrusiveness is associated with increased depressive symptoms and decreased QOL in a number of chronic diseases. Seizure frequency was found to be positively associated with illness intrusiveness. Although illness intrusiveness differed significantly between epilepsy patients treated pharmacologically and those treated surgically, however, after controlling for seizure frequency, the groups showed no significant difference in illness intrusiveness. This implies that the difference is attributable to differences in the overall effectiveness of surgery versus pharmacological agents in achieving seizure control. Their results also suggest that surgical treatment for epilepsy, which frequently results in a seizure-free outcome, has a more positive impact than pharmacological treatment on illness intrusiveness and, thereby, the psychosocial well-being of individuals with epilepsy.

Chronic Fatigue Syndrome and Myalgic Encephalomyelitis

Chronic fatigue syndrome (CFS) is one condition characterized by severe debilitation. The first study to investigate the level of illness intrusiveness in CFS found high scores for all activities which require a certain amount of energy, such as work, sports and social engagements (Dancey & Friend, 2008). The disabling nature of CFS has also been documented by Komaroff et al. (1996) who reported that patients with CFS have lower mean scores on the 36-item Medical Outcomes Study-Short Form (MOS-SF) than groups with congestive heart failure, multiple sclerosis, depression and diabetes. Similarly, the results of Núñez et al. (2007) revealed that patients with CFS had lower scores on all the MOS-SF subscales compared to people with rheumatoid arthritis, and that co-morbid disorders had a negative influence on physical function.

In a study by Goudsmit, Stouten and Howes (2009) aimed at assessing the impact of myalgic encephalomyelitis (ME) on illness intrusiveness. Results showed that subjects had high IIRS scores (for the groups both with and without co-morbid disorders) which exceeded those documented for individuals with various forms of cancer (Devins et al., 2006), rheumatoid arthritis (Devins et al., 1993b), multiple sclerosis (Devins, Seland, Klein, Edworthy, & Saary, 1993), and psychiatric conditions such as obsessive-compulsive disorders (Antony et al., 1998) and bipolar disorder (Robb et al., 1997). Only people with anorexia nervosa have recorded higher scores on IIRS (Carter, Bewell, & Devins, 2008). The presence of co-morbid disorders increased perceived intrusiveness, as has also been reported in relation to other conditions (Devins et al., 1993a; Masellis et al., 2003; Mucsi et al., 2004). The mean IIRS scores for the patients with ME were similar to those recorded by people with CFS (Dancey & Friend, 2008).

Thus while there may be clinically significant differences between the two conditions, there is no evidence that one is more disabling than the other. As expected, the greatest impact of the illness was on the more physical activities. For example, 83 per cent had changed or lost their job because of their illness. One reason is likely to be the main symptoms of ME, that is, muscle weakness and post-exertional fatigue (Ramsay, 1988). The lack of muscle strength and the failure to recover during the 24 hours after exertion ends have been documented using objective measures in people with ME but have not yet been reported in patients with CFS (Paul, Wood, Behan, & Maclaren, 1999).

Other Findings

Devins, Beanlands, Mandin, and Paul (1997) also found that illness intrusiveness exerted a powerful impact on quality of life in end-stage renal disease. Similarly, Devins, Edworthy, Guthrie and Martin (1992) reported a significant impact of illness intrusiveness on quality of life among persons with rheumatoid arthritis. Abikoye, Osinowo & Solarin (in press) investigated the extent to which illness intrusiveness would influence emotional distress in two chronic conditions (hypertension and diabetis mellitus) among attendees of secondary health centers in Ibadan, Nigeria. The study found that high illness intrusiveness individuals (in both illness conditions) were worse in emotional distress than those with low intrusiveness. Illness intrusiveness was also found to negatively impact on quality of life in multiple sclerosis (Devins, 1994; Devins, Edworthy, & Seland, 1993), rheumatoid arthritis (Devins et al., 1992), breast cancer (Bloom, Stewart, Johnston, & Banks, 1998), psychiatric conditions (Antony, Roth, Swinson, Huta, & Devins, 1998; Robb, Cooke, Devins, Young, & Joffe, 1997), sleep disorders (Devins et al., 1995), and solid organ transplant recipients (Binik & Devins, 1986; Littlefield et al., 1996).

Conclusion And Recommendation

Illness-related disruptions to ongoing interests and activities may occur in many chronic physical illnesses and psychological disturbances through the physiological effect of chronic conditions (such as reduced physical strength and stamina, drowsiness, nausea, concentration difficulties), indirect effects bordering on perceptions of the chronically-ill person held by family, friends, colleagues and significant others which may significantly alter family roles and substantially erode the person's autonomy and independence. Secondary consequences of decreased involvement in valued activities may introduce additional disruptions or losses. Increased feelings of helplessness and depression among patients, for instance, may lead to even further withdrawal from daily patterns of involvement. Chronic conditions that induce sexual dysfunctions may introduce significant challenges to marital adjustment or may simply exacerbate pre-existing difficulties.

Given that illness intrusiveness has been theoretically and empirically demonstrated to significantly mediate the relationship between illness and quality of life in diverse chronic conditions, it should be possible to enhance quality of life of chronically-ill persons by reducing illness intrusiveness. In other words, if illness intrusiveness among chronically-ill persons could be reduced, such persons should be able to live a more meaningful life and experience an enhanced quality of life, notwithstanding their conditions.

The following approaches have been suggested in reducing illness intrusiveness: psychotherapy (Abikoye, 2002; Edworthy et al., 2003), social support (Devins, 1994; Neri et al., 2011), self-concept restructuring (Shacvitz, 2010), illness education (Abikoye, 2002), and increased participation in activities (Devins, 1994).

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