

The lonely marginalized: Psychological determinants

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The marginalized experience loneliness to a larger extent than the rest of the population. This article reviews the concept of marginalization, and the loneliness experienced by those with mental illness, the homeless, war vets, the physical disabilities and terminally ill who are dying.

Keywords: Loneliness; physical disabilities; terminally ill; marginalized; HIV

The marginalized

Several population groups are seen as marginalized, ostracized, and stigmatized. Those include the homeless, the physically disabled, psychiatric patients, Lesbian, Gay, Bisexual and Transgender (LGBTs), and those afflicted with Human immunodeficiency Virus (HIV) or with Acquired Immunodeficiency Syndrome (AIDS), to name just a few. This article will shed light on the ill, and the dying, which are two groups which are out of the main flow of life. Marginalization, by its very nature brings about a sense of disconnection, dissociation from society at large, and a sense of aloneness and loneliness. The ill and the disabled share their feelings of anxiety, and the experience of loneliness. Those tormented by psychological disturbances also experience loneliness when they struggle to contain their problem, and when they attempt to hide it from others. It is known, for instance that clinically depressed people are lonely prior to developing depression as well as after they have been suffering from it [1].

Mental illness, its severity and loneliness

Chrostek et al [2] maintained that intense loneliness may constitute an important barrier to recovery for people with mental illness, and that "among all psychiatric disabilities, schizophrenia and related psychotic disorders seem to particularly predispose a person to the experience of loneliness due to their often chronic course, the severity of their psychopathology, the extent of accompanying social deficits and the strength of the associated social stigma. On the other hand, it is also plausible to hypothesize that social isolation and loneliness may increase the probability of triggering the active phase of schizophrenia among vulnerable individuals" (p. 191).

Whatever the direction of causality, loneliness and psychosis are closely connected. Chrostek et al. [2] opined that psychiatric symptoms may disturb social relations, possibly elicit social rejection and consequently loneliness. The more severe the psychopathology, the deeper the loneliness. Patients with a longer duration of illness, frequent hospitalizations and under inpatient care would be more likely to experience difficulties in maintaining close interpersonal relationships and, hence, experience increased levels of loneliness. They added that in order to be able to appropriately respond to their patients, clinicians should be aware of, and attempt to respond to the social and psychosocial needs [2]. They found that internalized stigma of their mental illness was closely related to loneliness. There have already been revealed consistent associations of internalized mental health stigma with poor self-esteem, decreased quality of life, weakened social support/integration, and worse treatment adherence. Chrostek's study added to it the association of loneliness to the stigma felt by mental health, and psychosis prone, patients.

Physical disability

"When severe illness occurs, it seems like an unending nightmare that robs us of our resources, insults our dignity and often pushes us to the brink of desperation" (3; p. 333).

The World Health Organization (WHO) distinguishes between impairment, disability and handicap. Impairment was referred to as the loss of function of a specific body organ or system (i.e. muscular weakness). Disability is a restriction on performing normal activity (such as walking). A handicap is the result of impairment or disability, which consequently prevents the individual from fulfilling a social role, such as an inability to work. This model has been widely used as it aids in understanding and identifying the physical, psychological and social impact of a disease, injury or congenital disorder [4]. Disability applies to a multitude of medical and traumatic conditions ranging from mild to severe. It may happen suddenly (such as a spinal cord injury as a result of an accident) or occur gradually and slowly such as in multiple sclerosis [MS], or Parkinson's disease. The disabled person is disadvantaged in reaching personal and economic independence and may be unable to function autonomously in one or more areas in life, on a temporary or even permanent basis [5].

Physical disabilities may cause (depending on the organ or the bodily system which is affected) problems related to dexterity or movement, vision or hearing and consequently communicating with others. The occurrence of disability is a jolt, a psychosocial shock [6]. Some commonalities that Dell Orto [3] found amongst those with disabilities are that it brings out the best and the worst in people, it can deplete or create resources, coping with a chronic disability is an ongoing process, and what usually serves as the only source of support is one's family. He observed that life is composed of many 'mini losses' and hassels, such as a dent in a new car, forgetting the house key and not being able to enter home, or heartache caused by one's loved ones. . Such temporary losses may occur throughout our lives and inflict in their wake anxiety and unhappiness. Yet, they are reversible. Serious losses, such as physical disabilities are, undeniably, the most painful losses to bear. Such permanent losses may, according to Robinson, West and Woodworth [5] violate our identity and negatively affect our dreams and hopes. Kennedy [4] saw chronic disability as interwoven with emotional distress, turmoil, and pain. Consequently, he highlighted the emotional impact and psychological distress that the disabled experience, including feelings of powerlessness, helplessness, and social isolation. People with acquired disabilities (vs. those with congenital defects) need to cope with loss of ability, loss of body parts, loss of significant others or loss of employment. Life style disruptions, such as inability to proceed with one's plans, interruption of ongoing projects, and inability to meet daily responsibilities may all bring about sadness, anger, frustration and fear [7]. Being different, disabled, dependent on others for what the rest of us may take for granted, and basically being (usually) visibly different, results in stigmatization and marginalization. And "while the person with a disability may not feel ill or be in pain, her or his body is coded as a dysfunctional body. It culturally exists as a transgression, a body that straddles boundaries and therefore is anomalous, 'matter out of place,' and threatening to the social order" (8; p. 1852). Falvo [9] highlighted the commonality of negative emotion, experiences and reaction in those afflicted with chronic illnesses and disability. He emphasized that chronic illness can produce significant and harmful stress and causes psychological turmoil, as the ill and his/her family must cope with changes in the way they live, loss of control, pain or discomfort which some illnesses impose, and potential loss of independence. Minimization of opportunities for social contact and loneliness often follow.

Terminal illnesses

Loneliness occupies a significant role in the life of the diseased, as has been shown with individuals living with chronic physical illness [10] and with terminal illness [11, 12]. A terminal illness is a disease that is incurable. Although a terminal illness may come in the form of a chronic condition such as Multiple Sclerosis (MS) or Cystic Fibrosis (CF) [13]; as a progressive degenerative disorder such as Amyotrophic Lateral Sclerosis (ALS) [14,15] or a life threatening illness such as cancer [16] or HIV/AIDS [17], where death at the end of the disease process is inevitable (18). Terminal illness is by definition a chronic condition. The chronicity of terminal illness carries a great amount of psychological burden that only those afflicted can understand [18].

Psychological distress, depression and suicidal ideation [19] may be experienced by those afflicted with a terminal illness. Following, is a brief review of several of these illnesses and their effects on the person.

Acquired Immune Deficiency Syndrome [AIDS]

Since its outbreak in the early 1980s, the Center for Disease Control [20] reported more than 36 million deaths worldwide associated with human immunodeficiency virus (HIV), which later develops into AIDS, with 2.3 million annually new cases in the world. Although, initially, no one was able to identify its cause or its origin, the health care authorities began to see connections and resemblances from cases of hemophiliacs, who after using contaminated blood products for transfusions contracted the same virus [21]. HIV is now seen as a communicable disease transmitted via exchange of body fluids. The HIV virus significantly hampers the immune system of the person who contracted it, and that puts them at high risk of opportunistic diseases, such as cancer, bacterial and viral infections, as well as neurological diseases [22]. Treatment, however, increases life expectancy, and HIV is now considered an eventually terminal but chronic disease [23]. As a result, and based on the belief that HIV may be contracted simply via human interaction, People Living With HIV (PLWH) face such social consequences as ostracism and isolation [24], in addition to rejection from their social networks, workplace, schools, housing, and even members of the healthcare system [17]. Those who contracted HIV are highly stigmatized and this stigma produces increased anxiety and depression [25] and decreased self-esteem, and intentional self-isolation in order to avoid disclosure of one's HIV status [26]. The virus produces extreme weight loss, emaciation, and lipodystrophy syndrome which are impossible to hide, adding to the social isolation of the sick person [27]. The reality is that HIV is most prevalent among populations that are already stigmatized because of either gender inequalities (women); racism (minorities such as Black people); sexual orientation (homosexuals and bisexuals); or antisocial behaviour such as IV drug users [28]. Rokach and Sha'ked [29] stated that "the interpersonal isolation dimension of loneliness addresses the feelings of alienation, abandonment, and rejection that are commonly related to a general lack of close relationships" (p. 61). And indeed, internalizing the stigma, "meaning that the stigmatized person now endorses the negative beliefs" (22; p. 25) is linked to a variety of psychosocial factors in those afflicted with HIV, including increased psychological distress; suicide attempts; increased feelings of shame [30]; increased incidence of depression [23]; lower self-esteem; poorer physical health (30); and poor social integration that results in diminishing social support [31]. Preoccupation was observed on the part of the ill that their entourage may leave them, deny them, disgrace them, and even feel disdain toward them. There is a vicious cycle wherein the stigma of an individual's illness will decrease their perceived social support which may eventually lead to a reduction of the person's actual social support, by means of avoidance and social reclusion [32]. This "self-imposed social isolation" (24; p. 402). The relationship between social support and loneliness in HIV also has been demonstrated to play an important role in the progression of the disease. On one side, studies in psychoneuroimmunology have shown that increased loneliness due to a lack of social connections reduces the efficacy of a person's immune system [33] who, therefore, cannot fight the virus as effectively.

Loneliness of the dying and of the terminally ill

It has been established that the end-of-life experience encompasses feelings of hopelessness, death anxiety, fear, guilt, doubt, and loneliness [34]. The dying person, often, awaits a “death sentence”, feelings that are reinforced by one’s poor prognosis [35]. Patients who were aware of their terminal diagnosis and understood the implications of such prognosis rated the quality of their life as lower and showed a significant increase of emotional distress and anxiety. Feelings of emotional isolation and loneliness set in, and one starts to feel a loss of contact with the world, especially when one is institutionalized [36]. First, the dying person feels that no one can truly understand the situation, and no one can imagine what it is to die. This internalized conviction is characterized by a feeling of aloneness and loneliness in the face of death. Second, as one becomes terminally ill, one begins to lose their identity and sense of self. Everything that made them unique begins to fade and, as a result, the dying person may feel a lack of relatedness with the world. Third, this overwhelming loneliness also is fueled by the growing awareness that, as one becomes disconnected from one’s social world and others who may feel shut out of their life, one is left to die alone [35]. The physical limitations imposed by the illness and its treatment, and the emotional distress that those terminally ill patients struggle with [36] contribute to the progressive isolation from others and eventually to the loss of social interactions, which leads to profound feelings of loneliness. Sadly, while the majority of ill people wish that they would die at home, surrounded by family and loved ones – which would appease their loneliness – the truth is that most people die alone, in hospital beds [37]. That way of dying ushers in loneliness, isolation, and a feeling that no one can truly understand them [38].

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