

Special Article

Social Isolation and its Applicability to Persons with Sarcoidosis and Alpha-1 Antitrypsin Deficiency: A Dimensional Concept Analysis

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Abstract

Background: Social isolation is a phenomenon that is a major health problem among various individuals. The chronically ill and other marginalized populations suffering from the stigma of a health condition are especially vulnerable. No studies to date have examined this meaning of this concept in rare lung diseases, including sarcoidosis or alpha-1 antitrypsin deficiency.

Aim: The aim of this paper is to gain further insight into the concept of social isolation and how it might apply to sarcoidosis and alpha-1 antitrypsin deficiency. A dimensional analysis was undertaken to examine the various uses of the concept. Dimensional analysis is a method of concept analysis that is particularly useful in exploring a concept such as social isolation that may be somewhat ambiguous.

Methodology: The analysis includes 15 papers from 15 research studies from the disciplines of nursing, social sciences, psychology, palliative care and medicine. Caron and Bowers' dimensional analysis approach informed the analysis, and coding of the perspective, context, conditions, process, and consequences of social isolation was performed.

Results: The perception of having limited or low social networks is the central organizing standpoint of individuals experiencing perceived social isolation. Social isolation often occurs in adults as the result of a chronic illness. Individuals who exist in a stigmatized environment are at risk. Individuals at risk for social isolation may benefit from such interventions as peer counseling, support groups or internet-based support. Finally, clinicians should be cognizant of the deleterious effects of social isolation, including increased morbidity and mortality.

Conclusions: Social isolation remains an ambiguous concept which has garnered considerable attention within the last decade. The type of and magnitude of social isolation can be dependent upon the context, the condition, and the tools to facilitate management of the phenomenon. Specific to rare lung diseases, further research is warranted and timely.

Key Words: social isolation, sarcoidosis, Alpha-1 antitrypsin deficiency, dimensional concept analysis

Introduction

The question of whether human beings can thrive apart from others has been pondered for centuries. John Donne (1572-1631) wrote "No man is an island...entire of itself" in his Meditation XVII (Donne, 2001). Conversely, the philosophy of existentialism suggests that human beings are essentially alone in the world (Biordi & Nicholson, 2009). According to the Oxford

English Dictionary, isolation is defined as "the action of isolating; the fact or condition of being isolated or standing alone; separation from other things or persons; solitariness" (2012). The term is further refined as "the separation of a person or thing from its normal environment or context, with for purposes of experiment and study or as a result of its being, for some reason, set apart" (OED, 2012). The term first appeared, according to the OED, in 1833, in the work *Charmed Sea*

by H. Martineau (OED, 2012). In the psychological and sociological context, the term has evolved from one of its original appearances in 1890 in the work of C.L. Morgan's *Animal and Life Intelligence*: "We may call the process by which we select a certain quality, and consider it by itself to the neglect of other qualities, *isolation*" to a more robust definition in *The Modern Dictionary of Sociology* (Theodorson & Theodorson, 1970) where the authors suggested that prolonged isolation of an individual from satisfying social involvement with others usually leads to or is a result of a mental disorder". There have been no published studies to date of the exploration of the phenomenon in sarcoidosis, alpha-1 antitrypsin deficiency or rare disease groups.

There are few, if any, colloquial uses of the term *social isolation*. In the current literature, the concept has multiple meanings. Carpenito-Moyet (2006) succinctly defined social isolation as "the state in which the individual or group expresses a need or desire for contact with others but is unable to make that contact". Others have sought to crystallize a more refined definition of social isolation. In his concept analysis of social isolation in older adults, Nicholson (2009) suggested that determinants of isolation include "number of contacts, feelings of belonging, fulfilling relationships, engagement with others, and quality of network members" (p. 1349). Killeen (1998) defines social isolation using two different perspectives: "Social isolation with choice is aloneness, while social isolation without choice is loneliness". Biordi and Nicholson (2009) state that loneliness should be considered the subjective emotional state of the individual, whereas social isolation is the objective state of deprivation of social contact and content. This is in contrast to Carpenito's belief that social isolation is more of a subjective state (Carpenito-Moyet, 2006). This overview demonstrates that the concept has not been uniformly defined and consensus agreement is elusive.

One approach to elucidating the salient features of this multidimensional phenomenon is through concept analysis. Concept analysis presents strategies necessary to dissect key components of the phenomenon under consideration, affording a

multifaceted lens with which to view the attributes of the construct. This then begs the question of which approach to use for a given phenomenon of interest. Schatzman's method of dimensional analysis (1991) is particularly suited to exploration of social isolation. Dimensional analysis offers an approach to the understanding of social isolation through its social construction and examination of differences across perspectives and contexts (Udlis, 2011). Using the dimensional method, the purpose of this analysis is to explore the concept of social isolation within the context of the various dimensions identified through the literature. Since repeated and extensive searches of the literature revealed no publications of social isolation in the context of sarcoidosis, the identified populations were broadened to include chronic disease limited to adult populations.

Social isolation in the context of sarcoidosis and alpha-1 antitrypsin deficiency

Social isolation is gaining increased attention as an integral component of health (World Health Organization, 2002). Social isolation has been demonstrated to be directly correlated to morbidity and mortality (House, 2001; House, Landis, & Umberson, 1988; House, Umberson, & Landis, 1988; Berkman, 1995; Berkman & Syme, 1979). There is little work done within the context of rare lung diseases and no published literature identified regarding any investigation into social isolation in the context of sarcoidosis or alpha-1 antitrypsin deficiency.

Sarcoidosis is a rare granulomatous disease of unknown etiology. Many organ systems can be affected, although lung involvement is most common, occurring in greater than 75% of patients (Patterson, et al, 2012). While more than half of patients undergo remission with no significant morbidity, a subset of patients (about 30%) develops chronic disease (Patterson et al., 2012).

Because the disease is rare, there is limited public awareness or support of persons with this condition. Delays in diagnosis and/or misdiagnosis may promote distrust of health care providers and counselors. The combination of these factors can lead to perceptions of social isolation. Young and colleagues (Young, et al,

1997) reinforced the importance of social support in sarcoidosis by suggesting that it is best to refer the patient to a sarcoidosis support group for reassurance and to allay anxiety, reduce stress, and share similar experiences with others.

Ireland and Wilsher (2010) suggest that sarcoidosis patients may have significant psychological distress relating to perception of their disease and that distress is likely underestimated by their clinician. Social withdrawal has been documented as a result of the combination of the disease and the onset of stressful life events (Trombini & Trombini, 2012). The combination of these factors can lead to perceptions of social isolation.

Similarly, alpha-1 antitrypsin deficiency (AATD) is an uncommon genetic disease which that affects approximately 1 in 2,000 to 1 in 5,000 individuals and predisposes to early-onset emphysema and liver disease (Stoller and Aboussouan, 2012). Previous studies have confirmed adverse psychosocial effects related to an AATD diagnosis (Stoller, et al, 1994). Social isolation has been explored in individuals with COPD (Ellison, et al, 2012; Seamark, et al, 2004) but no published studies were identified that investigated social isolation in AATD patients specifically.

Measurement of Social Isolation

Operational definition

There have been many attempts to operationalize a definition of social isolation. Warren (1993) offered four criteria as defining characteristics of the phenomena. The first, *stigmatized environment*, implies that a person has been designated as different from others, they perceive this difference; and is hesitant, unwilling, or unsure of how to participate in interactions with others. This characteristic was also noted by Joachim and Acorn (2003) in their focus group interviews conducted with individuals suffering from scleroderma, another rare disease. The second criterion is that of *societal indifference*, where the person perceives loneliness, or a lack of enduring or meaningful relationships with others. The third criterion is *personal-societal disconnection*, where society rejects and alienates the stigmatized person by denying them access to satisfying social situations.

Last is the criterion of *personal powerlessness* where the stigmatized person believes the perception that society has rejected them; they feel as if they have no control and others possess all control.

Theoretical Framework Considerations

There is a paucity of information in the literature that speaks to conceptual models related to social isolation, rendering the concept persistently ambiguous (Nicholson, 2009). Roy's Adaptation Model can guide examination of the concept of social isolation, as it describes the nurse as facilitating an adaptive process to restore health. In the model, individuals are biopsychosocial beings required to adapt to external stimuli (Barone, Roy, & Frederickson, 2008).

Once a stimulus is received (in this case, the diagnosis), it is exhibited in four distinct adaptive models: physiological, self-concept, role function and interdependence (Nicholson, 2009). Of particular interest is the interdependence mode which encompasses the development and maintenance of satisfying relationships with significant others. These relationships are missing in those who are socially isolated.

Refined Definition of Social Isolation

Social isolation is thus defined as a state in which an individual exists, and which is not by choice. Individuals suffering from social isolation lack feelings of belonging, fulfilling relationships, engagement with others, and a lack of support persons. The individual feels stigmatized by their disease, and powerlessness to change their situation.

Dimensional Analysis

The dimensional analysis method will be used to examine the concept of social isolation. Dimensional analysis (DA) is a method focused on identifying all that is involved with a phenomenon (Hobbs, 2009). It can be particularly useful when evaluating an unclear or potentially ambiguous concept (Kools, McCarthy, Durham, & Robrecht, 1996), such as social isolation. It is also particularly useful in the case of the social isolation, where it would be useful to understand how the concept might be socially constructed, and how it may vary across

perspectives and constructs (Caron & Bowers, 2000).

This dimensional analysis will be executed using Schatzman's theory, and sorted via the concept matrix into one of the five dimensions as illustrated by Schatzman: perspective, context, condition, process and consequences (Schatzman, 1991).

Sample and Search Strategy

Whittemore and Knafl (2005) advocate a five-step process as critical for a robust integrative review of the literature. The first two will be discussed here as a segue to presentation of the concept matrix. The first step involves identification of the problem, in this case, the ambiguity of the concept of social isolation. Through previous searches and anecdotal discussions, the concept of social isolation holds different meanings depending upon the context, the population, and the disease state (if any) in which it occurs.

The second step consists of a well-defined and exhaustive search of the literature (Whittemore & Knafl, 2005). The purpose of this search was to review the literature for the purpose of locating papers and other published information (e.g. book chapters) for the most frequently used definitions of social isolation. Examination of papers that had "social isolation" in either the title or the abstract were the primary focus of the search; other papers and works that appeared in the electronic searches were also reviewed for pertinent information. Results from a previous search on methods and instrumentation were utilized as a baseline reference model from which to frame the current search, expanding on concepts and constructs, rather than methods of measurement.

Scientific databases were searched individually, and included MedLINE, CINAHL, and PsycINFO. In addition, GoogleScholar was searched for variations on and of the search terms. Keywords included "social isolation", "social support", "chronic disease", "lung disease", "pulmonary disease", "respiratory disease", "sarcoidosis" and "social support", "concept analysis", "dimensional analysis", "evolutionary analysis" and combinations of these terms. Due to the lack of information

regarding social isolation as it relates to sarcoidosis, alpha-1 or rare diseases, articles were included regardless of setting or disease state. Studies were further limited to human studies in adults (19+ years of age), written in English, and encompassed the years 1992-2014. This two decade time span was included so as to include any seminal works that may have been published.

The MedLINE database yielded an initial pool of 4791 articles, despite the filters imposed upon the search terms. This pool of publications was reviewed over the course of multiple sessions for appropriateness for inclusion.

The CINAHL database was searched using the same limitations and terms. Publications were excluded from this search if they appeared in a MedLINE search. This search yielded a total of 502 articles. PsycINFO was searched as the third database; a total of 35 articles were obtained for review. Lastly, GoogleScholar was searched for combinations of and variations on the search terms as stated above. This search yielded a total of 86,800 results, which were reviewed in a cursory manner for potential inclusion.

This initial search strategy yielded a total of 92,139 results. Further critical review resulted in a total of 15 articles and one book chapter (which was requested and obtained). The vast majority of these were excluded due to the interchangeable use of the term "loneliness" with "social isolation". Duplicates were excluded, as well as dissertations and theses. In addition, the search term of "social isolation" resulted in topics related to the biologic sciences (isolation of viruses, bacteria) which were excluded. Following this electronic search for articles, a hand-search of the references of the selected articles was conducted. This search yielded a total of 2 articles, one being a seminal work on mortality as an outcome of isolation, and was included in the review (Berkman & Syme, 1979).

In consideration of information that might be present in the public domain, or in potentially obscure databases or databases not chosen by the author, the search term combinations of "social isolation AND chronic illness" and "social isolation AND chronic disease" were searched using the Google search engine via the Internet.

The combination of “social isolation and chronic illness” yielded 2,240,000 results while the combination of “social isolation and chronic disease” yielded 3,350,000 results. Although the search was limited to the first twenty pages of these resources, none of the results reviewed yielded additional information or articles included in the review.

A diagram of the search strategy, excluding the basic Google search is presented in Figure 1, Literature Search Strategy. The concept matrix of the published literature is presented in Table 1.

Results

Common themes and dimensions were sorted according to Schatzman’s methodology. The dimensions of perspective, context, condition, process and consequences as they relate to social isolation were examined and categorized according to best fit, since some of the findings from the literature overlapped in terms of applying to multiple dimensions.

Perspective is presented first since it frames and organizes the remaining dimensions of the concept (Hobbs, 2009).

Perspective

The perception of having *limited or low social networks* as well as the *lack of personal relationships* is the central organizing standpoint of individuals experiencing perceived social isolation. This was evident in the majority of the papers reviewed. Hawthorne (2006) found that personal relationships were the key correlate of social isolation in his research. Biordi and Nicholson (2009) suggest that when we think of social isolation, we “think first of the affected person, then we immediately consider that individual’s relationships” (p. 87), and that the key correlate of social isolation is often viewed as a deprivation in social contacts. Nicholson (2009) defined social isolation as “a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and they are deficient in fulfilling and quality relationships” (p. 1346). He later found that individuals who have a minimal number of social contexts were at risk for social isolation (Nicholson, 2012). Pedersen, Andersen and Curtis (2012) found that

individuals who perceived isolation also reported low levels of social support. Jonsdottir (1998) observed that the inability to reach out and make connections with other people, resulting in isolation, was a prevalent theme in individuals with chronic obstructive pulmonary disease (COPD), another chronic lung disease often stigmatized due to its association with smoking.

Context

A number of the dimensions reviewed in the literature were categorized as contextual, reflective of the environment or setting where the phenomenon occurs and unfolds (Crighton, 2004). Social isolation often occurred in older adults, and as the result of a chronic illness or disability (Biordi & Nicholson, 2009; Cacioppo & Hawkley, 2009; Cornwell & Waite, 2009; Hawthorne, 2006, 2008). None of the literature reviewed addressed social isolation as occurring in an inpatient setting; the phenomenon was addressed in populations of community-dwelling adults (Biordi & Nicholson, 2009; Cacioppo & Hawkley, 2009; Cacioppo, Norris, Decety, Monteleone, & Nusbaum, 2009). The majority of sarcoidosis and alpha-1 patients are treated on an outpatient basis with the exception of exacerbations of the disease, and for those for whom the disease becomes chronic, they are left to grapple with the issues within their community of residence (Baughman et al., 2001)

Condition

Conditions are elements that facilitate, block or shape actions, interactions and consequences within the phenomenon. The specific issues related to the limited or low social networks or the lack of social support are the conditions necessary for social isolation to become a real challenge to the patient. For example, the disease condition (chronic illness) may dictate the ability of the individual to reach out for help when needed. Younger individuals with chronic illnesses such as fibromyalgia were also found to report social isolation, since the individuals were reluctant to reach out for help for fear of being ostracized (Cudney, et al, 2002). Individuals who existed in a stigmatized environment were also found to suffer from social isolation. These stigmatized populations can range from those suffering from addictions, chronic disease,

imprisoned individuals, to those who perceive alienation because of their race or gender (Warren, 1993). Jonsdottir (1998) found this to be the case in COPD patients, where the individuals repeatedly expressed a wish to have others understand their disease. Biordi and Nicholson also echoed a similar sentiment of disenfranchisement when they suggested that one component of social isolation was the loss of place within one's group, or the weakening or diminishing of one's social role. Holley (2007) also found that social isolation can be more pronounced in individuals who have experienced loss of income due to their disease, and pointed out that such loss of income can also have a negative impact on social activities, which become luxuries for those with scarce financial resources, thus magnifying the issue of isolation. For example, in sarcoidosis (or alpha-1), where the affected individual may have been the primary wage earner in the family, this role may be diminished due to the inability to work secondary to the dyspnea that accompanies the illness. (Baughman et al., 2001; Yeager et al., 2005)

Processes

Conditions such as the type of illness influence processes that evolve within the phenomenon of social isolation. These processes are defined as the actions or interactions that occur within the phenomenon (Schatzman, 1991). Individuals experiencing or at risk for social isolation may benefit from such interventions as peer counseling, support groups, enhancement of family networks, or internet-based support (Biordi & Nicholson, 2009; Cudney et al., 2002; Holley, 2007). (Weinert, Cudney, & Hill, 2008). Aladesanmi (2004) suggests that for the primary care clinician, the role of online discussion groups as a source of patient advice is gaining value, and that many patients with chronic medical conditions (including sarcoidosis and alpha-1) participate in these groups.

Consequences

A number of consequences and processes are also consequences of social isolation. One of the most compelling to date is the Alameda study by Berkman and Syme, conducted over 30 years ago. In that study of over 6000 residents, the

researchers found that individuals who lacked social and community ties or social networks were more likely to die in the follow-up period than those with more extensive contacts (Berkman & Syme, 1979). In terms of mortality, age-adjusted relative risks for those most isolated when compared to those with the most social contacts were 2.3 for men and 2.8 for women (Berkman & Syme, 1979).

Cacioppo & Hawkey (2003) found that even in young adults, the presence of perceived social isolation had a profound impact on health-related outcomes. In young adults, stress and repair and maintenance were directly correlated to an individual's perceived state of social isolation. The researchers found that perceived social isolation may weaken anabolic processes that serve to repair and maintain physiological functioning and foster recovery from stress (Cacioppo & Hawkey, 2003). In a disease such as sarcoidosis, where auto-immunity is thought to play a role (Planck, Katchar, Eklund, Gripenback, & Grunewald, 2003), the potential impact of management of such isolation cannot go unrecognized.

Limitations

The most obvious limitation was the paucity of literature speaking to the concept of social isolation in chronic lung disease. According to Caron and Bowers (2000), one "critical consideration is that the selection of sources of text should not be determined by the researcher's assumptions" (p. 300), but one cannot completely eliminate bias. Another limitation was the fact that since the concept remains so poorly defined, the interchangeable use of the term 'loneliness' with "social isolation" persisted, and resulted in a search that proved challenging for both reference librarian and author.

Discussion

The results of this analysis reflect varying uses of the concept of social isolation. This may be dependent upon the population that it is used to describe. However, one predominant theme in the literature was that of limited or low social networks, characterized by lack of personal relationships. In addition, the condition was found often in individuals with chronic illness in

a community setting. These individuals were often in a stigmatized environment, and may be a group that benefits from peer support or peer intervention. This preliminary analysis provides evidence for the need for further characterization of the phenomenon from a disease-specific perspective, as well as perhaps as contextual perspective.

Conclusions

Social isolation remains an ambiguous concept which has garnered considerable attention within the last decade. The aim of this analysis was to examine the concept of social isolation through the lens of dimensional analysis. This approach provided for a more precise dissection of dimensions by the examination of various components of the phenomenon across multiple scenarios and perspectives.

Further research examining the concept in the context of rare lung diseases and/or rare diseases is warranted and timely. Based upon the findings of such investigations, pilot projects could be designed that examine best practices for managing the phenomenon.

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