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Social Isolation

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INTRODUCTION

Most of us actively seek human companionship or relationships. The lives of hermits or cloistered, solitary existences are extraordinary because they so vividly remind us that, usually, life is richer for the human contact we share. As valuable as life may be when we engage in a variety of relationships, time reserved for solitude is also necessary as we seek rest or contemplative opportunity in “our own space.” The weaving together of individual possibilities for social engagement or solitude develops a certain uniqueness and texture in personal and community relationships. These distinctive personal configurations of engagement and disengagement have consequences for our work and social lives. It is critical, therefore, that health-care professionals understand the value of social engagement and of solitude.

Isolation: A Working Definition

“Belonging” is a multidimensional social construct of relatedness to persons, places, or things, and is fundamental to personality and social well being (Hill, 2006). If belonging is connectedness, then social isolation is the distancing of an individual, psychologically or physically, or both, from his

or her network of desired or needed relationships with other persons. Therefore, social isolation is a loss of place within one’s group(s). The isolation may be voluntary or involuntary. In cognitively intact persons, social isolation can be identified as such by the isolate.

The literature portrays social isolation as typically accompanied by feelings related to loss or marginality. Apartness or aloneness, often described as solitude, may also be a part of the concept of social isolation, in that it is a distancing from one’s network, but this state may be accompanied by more positive feelings and is often voluntarily initiated by the isolate. Some researchers debate whether apartness should be included in, or distinguished as a separate concept from, social isolation. As seen in the literature that follows, social isolation has several definitions and distinctions, dependent upon empirical research and the stance of the observer.

When Is Isolation a Problem?

Social isolation ranges from the voluntary isolate who seeks disengagement from social intercourse for a variety of reasons, to those whose isolation is involuntary or imposed by others. Privacy or being alone, if actively chosen, has the potential

for enhancing the human psyche. On the other hand, involuntary social isolation occurs when an individual's demand for social contacts or communications exceeds the human or situational capability of others. Involuntary isolation is negatively viewed because the outcomes are the dissolution of social exchanges and the support they provide for the individual or their support system(s). Some persons, such as those with cognitive deficits, may not understand their involuntary isolation, but their parent, spouse, or significant other may indeed understand that involuntary social isolation can have a negative and profound impact on the caregiver and care recipient.

When social isolation is experienced negatively by an individual or his or her significant other, it becomes a problem that requires management. In fact, according to much of the literature, only physical functional disability ranks with social isolation in its impact on the client and the client's social support network (family, friends, fellow workers, and so forth). Therefore, social isolation is one of the two most important aspects of chronic illness to be managed in the plan of care.

Distinctions of Social Isolation

Social isolation is viewed from the perspective of the number, frequency, and quality of contacts; the longevity or durability of these contacts; and the negativism attributed to the isolation felt by the individual involved. Social isolation has been the subject of the humanities for hundreds of years. Who has not heard of John Donne's exclamation, "No man is an island," or, conversely, the philosophy of existentialism—that humans are ultimately alone? Yet the concept of social isolation has been systematically researched during only the last 50 years. Unlike some existentialists and social scientists, healthcare professionals, with their problem-oriented, clinical approach, tend to regard social isolation as negative rather than positive.

The Nature of Isolation

Isolation can occur at four layers of the social concept. The outermost social layer is community, where one feels integrated or isolated from the larger social structure. Next is the layer of organization (work, schools, churches), followed by a layer closer to the person, that is, confidantes (friends, family, significant others). Finally, the innermost layer is that of the person, who has the personality, the intellectual ability, or the senses with which to apprehend and interpret relationships (Lin, 1986).

In the healthcare literature, the primary focus is on the clinical dyad, so the examination of social isolation tends to be confined to the levels of confidante and person, and extended only to the organization and community for single clients, one at a time. For the healthcare professional, the most likely relationships are bound to expectations of individually centered reciprocity, mutuality, caring, and responsibility. On the other hand, health policy literature tends to focus on the reciprocity of community and organizations to populations of individuals, and so it deals with collective social isolation.

At the level of the clinical dyad, four patterns of social isolation or interaction have been identified; although these were originally formulated with older adults in mind, they can be analogized easily to younger persons by making them age-relative:

1. Persons who have been integrated into social groups throughout their lifetime
2. The "early isolate," who was isolated as an adult but is relatively active in old age
3. The "recent isolate," who was active in early adulthood but is not in old age
4. The "lifelong isolate," whose life is one of isolation

Feelings that Reflect Isolation

Social isolation can be characterized by feelings of boredom and marginality or exclusion (Weiss, 1973). Boredom occurs because of the lack of

validation of one's work or daily routines; therefore, these tasks become only busy work. Marginality is the sense of being excluded from desired networks or groups. Other feelings ascribed to social isolation include loneliness, anger, despair, sadness, frustration, or, in some cases, relief.

Description and Characteristics of Social Isolation

The existence of social isolation increases our awareness of the need for humans to associate with each other in an authentic intimate relationship, whether characterized by caring or some other emotion, such as anger. When we speak of social isolation, we think first of the affected person; then we almost immediately consider that individual's relationships. This chapter will demonstrate that, as a process, social isolation may be a feature in a variety of illnesses and disabilities across the life cycle.

As an ill person becomes more aware of the constricting network and declining participation, he or she may feel sadness, anger, despair, or reduced self-esteem. These emotions factor into a changed social and personal identity, but are also separate issues for the person who is chronically ill. Moreover, depending on their own emotional and physical needs, friends and acquaintances may drop out of a person's social support system until only the most loyal remain (Tilden & Weinert, 1987). Families, however, are likely to remain in the social network. As the social network reaches its limitations, it may itself become needful of interventions, such as respite care for the parents of a child who is chronically ill or support groups for the siblings of children with cancer (Heiney et al., 1990).

Social Isolation versus Similar States of Human Apartness

Social isolation has been treated as a distinct phenomenon, or it has been combined or equated with other states relating to human apartness. The literature is replete with a variety of definitions of social isolation, many of which are interrelated,

synonymous, or confused with other distinct but related phenomena.

Social Isolation and Alienation

Social isolation and alienation have been linked together or treated as synonymous in much of the healthcare literature, although these two concepts differ from one another. Alienation encompasses powerlessness, normlessness, isolation, self-estrangement, and meaninglessness (Seeman, 1959). Powerlessness refers to the belief held by an individual that one's own behaviors cannot elicit the results one desires or seeks. In normlessness, the individual has a strong belief that socially unapproved behaviors are necessary to achieve goals. Isolation means the inability to value highly held goals or beliefs that others usually value. Self-estrangement has come to mean the divorce of one's self from one's work or creative possibilities. Finally, meaninglessness is the sense that few significant predictions about the outcomes of behavior can be made. Thus, one can see that isolation is only one psychological state of alienation. However, authors frequently merge the finer points of one or more of the five dimensions of alienation and call the result isolation.

Social Isolation and Loneliness

Although social isolation is typically viewed today as a deprivation in social contacts, Peplau and Perlman (1986) suggest that it is loneliness, not social isolation, that occurs when an individual perceives her or his social relationships as not containing the desired quantity or quality of social contacts. In an even more subtle distinction, Hoefter (1987) found that simply the perception of relative social isolation was more predictive of loneliness than actual isolation. Loneliness has been referred to as an alienation of the self and is sometimes seen as global, generalized, disagreeable, uncomfortable, and more terrible than anxiety (Austin, 1989). Loneliness differs from depression in that in loneliness, one attempts to

integrate oneself into new relationships, whereas in depression, there is a surrendering of oneself to the distress (Weiss, 1973).

Nonetheless, loneliness does relate to social isolation. In fact, loneliness is the one concept most invoked when social isolation is considered (Dela Cruz, 1986; Hoeffler, 1987; Mullins & Dugan, 1990; Ryan & Patterson, 1987). However, to use social isolation and loneliness as interchangeable terms can be confusing. To maintain clarity, 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 (Bennet, 1980). Therefore, loneliness refers to the psychological state of the individual, whereas social isolation relates to the sociologic status. Although it is true that social isolation might lead to loneliness, loneliness is not, in itself, a necessary condition of social isolation. Both conditions can exist apart from each other.

Peplau and Perlman's view of loneliness is distinct from the current North American Nursing Diagnosis Association's (NANDA's) nursing diagnosis of social isolation (Carpenito-Moyet, 2006). The NANDA diagnosis extends from the person to include the possibility that a group could also experience a "need or desire for increased involvement with others but is unable to make that contact". Attached to that must be feelings of rejection or aloneness, insecurity, or lack of meaningful relationships. In the NANDA definition, the model combines psychological feelings with the sociologic state of isolation, and thus blurs the distinctions so carefully treated by others. As will be demonstrated in this chapter, social isolation becomes cause, process, or response, depending on analysis and circumstances. The complex sets of variables that figure into social isolation lend themselves to a variety of assessments, diagnoses, and interventions: Loneliness is only one aspect of social isolation.

Social Isolation and Aloneness

Tightly linked with social isolation is the need for social support, which is the social context or

environment that facilitates the survival of human beings (Lin, 1986) by offering social, emotional, and material support needed and received by an individual, especially one who is chronically ill. Although social support literature has focused on the instrumental and material benefits of support, recent literature on social isolation relates isolation more to the negative feeling state of aloneness. This feeling is associated with deficits in social support networks, diminished participation in these networks or in social relationships, or feelings of rejection or withdrawal.

Social Isolation as a Nursing Diagnosis

Social isolation is defined by NANDA (Carpenito-Moyet, 2006) as a state in which a person or group experiences or perceives a need or desire for increased involvement with others but is unable to make that contact. The NANDA definition has moved beyond the person to the possibility that a group experiences social isolation. Yet, the defining characteristics are those of a *person's* subjective feelings of aloneness. In the current NANDA definition, only one of the major characteristics must be present for the diagnosis, and several minor characteristics are further described. Four major characteristics are noted: insecurity in social situations, a lack of meaningful relationships, expressed feelings of rejection, and a desire for contact with more people. Of the 12 minor characteristics, most relate to uncommunicativeness, whether in affect or decision making, or expressions of withdrawals. These are mostly personal characteristics, and although some may be generalizable to a group, it might be difficult to do so.

In the NANDA description, social isolation is a *cause* for loneliness, but it is not a response of loneliness. Related to social isolation are several other factors, for example, diseases, social situations, or secondary sequelae to social factors or environments. The current nursing diagnosis of social isolation, combining as it does both psychological and sociologic states of isolation for both persons and groups, requires systematic empirical

bases for refined distinctions of isolation. Nurses should continue to build on earlier studies (see Lien-Gieschen, 1993, for a validation study of major identifying characteristics of social isolation in the older adult) to empirically identify and distinguish the truly defining characteristics of social isolation. As it presently stands now, the nursing diagnosis of social isolation is rather holistic and resonates strongly with earlier dimensions of the concepts of alienation and loneliness. Carpenito-Moyet (2006) suggests that nurses change diagnoses from social isolation to the diagnosis of loneliness or risk for loneliness, which is conceptually a clearer approach. However, the sociologic reality of social isolation remains, and can require intervention in its own right.

PROBLEMS AND ISSUES OF SOCIAL ISOLATION

Regardless of how social isolation occurs, the result is that basic needs for authentic intimacy remain unmet. Typically this is perceived as alienating or unpleasant, and the social isolation that occurs can lead to depression, loneliness, or other social and cognitive impairments that then exacerbate the isolation.

Several predisposing reasons for social isolation have been proposed: status-altering physical disabilities or illnesses; frailties associated with advanced age or developmental delays; personality or neurologic disorders; and environmental constraints, which often refer to physical surroundings but are also interpreted by some to include diminished personal or material resources (Tilden & Weinert, 1987).

The Isolation Process

A typical course of isolation that evolves as an illness or disability becomes more apparent is the change in social network relationships. Friends or families begin to withdraw from the isolated individual or the individual from them. This process may be slow or subtle, as with individuals with

arthritis, or it may be rapid, as with the person with AIDS. Unfortunately, the process of isolation may not be based on accurate or rational information. For example, one woman with cancer reported that, at a party, she was served her drink in a plastic cup while everyone else had glasses (Spiegel, 1990).

Individuals with serious chronic illnesses come to perceive themselves as different from others and outside the mainstream of ordinary life (Williams & Bury, 1989). This perception of being different may be shared by others, who may then reject them, their disability, and their differentness. Part of this sense of being different can stem from the ongoing demands of the illness. For example, social relationships are interrupted because families and friends cannot adjust the erratic treatment to acceptable social activities. From such real events, or from social perceptions, social isolation can occur, either as a process or as an outcome.

Individuals with chronic illness often face their own mortality more explicitly than do others. For example, unmarried or younger clients with cancer express a loss of meaning in life, suggested to be due to cancer's threat to their lives as they grapple with the meaning of life; they may withdraw from their networks or the networks may withdraw from them (Noyes et al., 1990; Weisman & Worden, 1977; Woods, Haberman, & Packard, 1993).

Even if death does not frighten those with chronic illness, it frequently frightens those in their social networks, which leads to guilt, and can lead to strained silences and withdrawal. In the case of individuals with cancer (Burnley, 1992; House, Landis, & Umberson, 1988; Reynolds & Kaplan, 1990) or heart disease (Kaplan et al., 1988; Orth-Gomer, Uden, & Edwards, 1988), social support is significant to their survival. For those who lack this social support, social isolation is not merely a metaphor for death but can hasten it.

Social Isolation and Stigma

Social isolation may occur as one effect of stigma. Many persons will risk anonymity rather than expose themselves to a judgmental audience.

Because chronic illnesses can be stigmatizing, the concern about the possibility of revealing a discredited or discreditable self can slow or paralyze social interaction (see Chapter 3). In a study examining chronic sorrow in HIV-positive patients, stigma created social isolation. Women with children, particularly African American women, were more stigmatized and isolated than gay men because others perceived the women as associated with “dirty sex,” contagion, and moral threat (Lichtenstein, Laska, & Clair, 2002). Therefore, social roles and the robustness of network support affect social isolation.

The individual with chronic illness or their families grapple with how much information about the diagnosis they should share, with whom, and when (Gallo et al., 1991). If the illness is manageable or reasonably invisible, its presence may be hidden from all but a select few, often for years. Parents of children with chronic illnesses were reported to manage stressful encounters and uncertainty by disguising, withholding, or limiting information to others (Cohen, 1993), an action that may add to limiting their social network. Jessop and Stein (1985) found that invisible illnesses of chronically ill children led to greater difficulty in social interactions because of the uncertainty of ambiguity (disagreement about revealing or passing, or what courses of action to take). For example, parents of a child with cystic fibrosis may tell a teacher that the child is taking pills with meals because of a digestive disease (Cohen, 1993).

As siblings of children with cancer deal with the isolation of their brother or sister, they became vulnerable to being socially isolated themselves (Bendor, 1990). Social isolation not only burdens those with chronic illness, it also extends into family dynamics and requires the healthcare professional to consider how the family manages. Nurses must explicitly plan for the isolation in families with children who are chronically ill (Tamlyn & Arklie, 1986). Thus, with social isolation being a burden for the family, it requires the healthcare professional to consider how the family manages the illness and the isolation.

Where the stigmatized disability is quite obvious, as in the visibility of burn scars or the odor of colitis, the person who is chronically ill might venture only within small circles of understanding individuals (Gallo et al., 1991). Where employment is possible, it will often be work that does not require many social interactions, such as night work or jobs within protected environments (sheltered workshops, home offices). Regardless of what serves as reminders of the disability, the disability is incorporated into the isolate’s sense of self; that is, it becomes part of his or her social and personal identity.

Social Isolation and Social Roles

Any weakening or diminishment of relationships or social roles might produce social isolation for individuals or their significant others. Clients who lose family, friends, and associated position and power are inclined to feelings of rejection, worthlessness, and loss of self-esteem (Ravish, 1985). These feelings become magnified by the client’s culture if that culture values community (Litwin & Zoabi, 2003; Siplic & Kadis, 2002). An example of social isolation of both caregiver and care recipient occurred in a situation of a woman whose husband had Alzheimer’s disease. The couple had been confined for more than 2 years in an apartment in a large city, from which her confused husband frequently wandered. Her comment, “I’m not like a wife and not like a single person either,” reflected their dwindling social network and her loss of wifely privileges but not obligations. This ambiguity is common to many whose spouses are incapacitated. Moreover, after a spouse dies, the widow or widower often grieves as much for the loss of the role of a married person as for the loss of the spouse.

The loss of social roles can occur as a result of illness or disability, social changes throughout the life span (e.g., in school groups, with career moves, or in unaccepting communities), marital dissolution (through death or divorce), or secondary to ostracism incurred by membership in a “wrong”

group. The loss of social roles and the resultant isolation of the individual have been useful analytic devices in the examination of issues of the aged, the widowed, the physically impaired, or in psychopathology.

The Older Adult and Social Isolation

Older age, with its many losses of physical and psychological health, social roles, mobility, economic status, and physical living arrangements, can contribute to decreasing social networks and increasing isolation (Creecy, Berg, & Wright, 1985; Howat, Iredell, Grenade, Nedwetzky, & Collins, 2004; Ryan & Patterson, 1987; Trout, 1980; Victor et al., 2002). This will become even more of an issue as the number of older adults are expected to increase arithmetically and proportionately in the next two decades (Fowles & Greenberg, 2003). The prevalence of social isolation in older adults has been approximated now to be at 2–20% and even as high as 35% in assisted-living arrangements (Greaves & Farbus, 2006).

Social isolation has been linked with confusion, particularly in older adults with chronic illness. But when the socially isolated are also immobilized, the combination of isolation and immobilization can lead to greater impairments, such as perceptual and behavioral changes (e.g., confusion, noncompliance, or time distortions) (Stewart, 1986). Physical barriers (such as physical plant designs) or architectural features (such as heavy doors) also contribute to social isolation or homeboundness (DesRosier, Catanzaro, & Piller, 1992). All of these limits contribute to social isolation in ways that motivation alone cannot easily overcome.

Social isolation has been shown to be a serious health risk for older adults (Findlay, 2003), with studies indicating a relationship between all-cause mortality, (Ceria et al., 2001), coronary disease (Eng, Rimm, Fitzmaurice, & Kawachi, 2002), and cognitive impairments (Barnes, Mendes de Leon, Wilson, Bienias, & Evans, 2004; Holtzman et al., 2004; Zunzunegui, Alvarado, Del Ser, & Otero,

2003). In a converse finding, older adults with extensive social networks were protected against dementia (Fratiglioni, Wang, Ericsson, Maytan, & Winblad, 2000; Fratiglioni, Paillard-Borg, & Winblad, 2004; Seidler, Bernhardt, Nienhaus, & Frolich, 2003; Wang, Karp, Winblad, & Fratiglioni, 2002). And, as described earlier, although low social engagement may not be a form of social isolation per se, it is a psychological isolator and thus a risk factor in social isolation (Howat et al., 2004). For example, depressive symptoms in older adults were shown to be decreased by social integration (Ramos & Wilmoth, 2003). Isolated older adults were shown to have increased risk for coronary heart disease (Brummett et al., 2001; Eng et al., 2002) and death related to congestive heart failure was predicted by social isolation (Murberg, 2004). Similarly, post-stroke outcomes, for example, strokes, myocardial infarction, or death, were predicted by pre-stroke isolation (Boden-Albala, Litwak, Elkind, Rundek, & Sacco, 2005). Isolated women before a diagnosis of breast cancer, when compared with socially integrated women, were found to have a 66% increase in all-cause mortality (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). Quality of life among breast cancer survivorship is impacted negatively by social isolation (Michael, Berkman, Colditz, Holmes, & Kawachi, 2002). Finally, and perhaps most relevant to health and cost outcomes, socially isolated older adults were found to be four to five times more likely to be re-hospitalized within the year (Mistry et al., 2001).

The extent and nature of a social network (Litwin, 1997; Wenger, Davies, Shahtahmasebi, & Scott, 1996) from local to community, and integrated to contained, as well as the positive or negative nature of the social relationships in the social network, impact health as well as social isolation (Seeman, 2000; Wenger, 1997). In fact, the quality of the social relationship may have more impact than the number of ties (Pinquart & Sorensen, 2001), which suggests that a few solid relationships may be more beneficial than many ties of poor quality.

CASE STUDY

Dorothy is a 77-year-old woman who is also your charming nextdoor neighbor. She has a wonderful attitude, and loves to visit to gossip about the little things. She just has a way of telling stories. Dorothy's busy social life and calendar also make her memorable. She often jokes that she is the queen of the dance at the senior center and has to beat away the gentlemen with a stick.

Dorothy is very active in the community and at the local senior center, which include volunteering for a service driving other older adults to their appointments in her late husband's car, bowling regularly, and being president of the walking club. In addition, Dorothy knits. You have lost count of the number of hand-knit sweaters she has made for you.

One day, just as you suddenly realize that you haven't seen Dorothy for quite a while, you receive a telephone call from her son saying that Dorothy had fallen down the stairs and will be in the hospital for some time with arm injuries, which will also require a move to skilled rehab for even more time. He asks if you can look in on the house from time to time: of course you agree.

When Dorothy returns home, months later, she is helped by her son and other medical personnel because she now has a walker. A week goes by and you haven't seen Dorothy, so you go over to her house to look in on her. There you find that her bed is now in the downstairs living room and that Dorothy is extremely afraid of going up the stairs because of the injury she had sustained. In more conversation with her, you discover that she quit the bowling league and resigned her position in the walking club. She assures you that she will still walk. However, she states unhappily that the doctor has taken her driver's license away and she just doesn't know what to do about all those older adults who need her services to ride to

their appointments. As she is saying this, you remember seeing her son and a tow truck at her house a few days earlier, and the tow truck took away her car.

You also notice that her calendar is completely empty except for doctor's appointments. You offer to write in her social outings because you thought that she hadn't had time to do so with all the recent commotion. But Dorothy responds that she is now a little more frail and she feels she shouldn't keep so busy. Knitting by herself is still fun, but it's becoming more and more difficult to complete the sweaters since she "has the visiting nurses coming in twice a day for wound changes, not to mention the nerve damage" that she has suffered from the fall. You jokingly parry with her about how much the gentlemen must miss her at the senior center. Dorothy replies that she doesn't seem to fit in at the senior center, since it's difficult to get there and she doesn't really know what's going on there anymore. On the way out Dorothy assures you that another sweater is right around the corner.

A few more weeks go by and one day, as you arrive home in the early afternoon, you can see Dorothy through the window, sitting in her bed. You go over to say hello, and when she answers the door you notice she is wearing nightclothes. Dorothy is also crying, saying that she is losing touch with everybody because she cannot leave her house. This is making her so sad that she now cries regularly and wonders what is the point of living.

Discussion Questions

1. How would you define Dorothy's current condition? What are some of the factors that contributed to Dorothy's current condition? If her condition worsens what is she at risk for developing?

(Continued)

CASE STUDY *(Continued)*

2. If you were Dorothy's nurse during a clinic visit, what services might you recommend for her? Who might you contact to help with Dorothy's plan of care?
3. What other information would be helpful for you to know to intervene on Dorothy's behalf? What assessments are most important to perform on Dorothy? Recommend an intervention to help with Dorothy's condition.
4. If you were going to devise a research study examining older adults who are socially isolated list the following: your study question(s), the independent variables, the dependent variables, and the proposed study design.

Although much of the current research in social isolation with older adults has used community-dwelling adults, one growing segment of study has been in settings of assisted-living arrangements, which is one of the fastest growing segments of senior housing (Hawes, Phillips, Rose, Holan, & Sherman, 2003). In assisted-living settings where there are many internal (to the setting) social networks, life satisfaction, quality of life, and perception of home were positively reported (Street, Burge, Quadagno, & Barrett, 2007). Assisted living has the potential to focus on health promotion and function maintenance, such as the identification of social isolation and appropriate interventions (Resnick, 2007).

Strictly speaking, social isolation is not confined to a place. The socially isolated are not necessarily homebound or place-bound, although that is typically the case. That being said, however, environments that are removed (such as rural locations) or those not conducive to safety (such as high-crime areas) can contribute to social isolation (Klinenberg, 2001). Social isolation as a function of location has been demonstrated, particularly for the older adult in urbanized settings, in a number of countries other than the United States (Klinenberg, 2001; Russell & Schofield, 1999). In these cases, elderly individuals cannot leave their homes because of lack of transportation or for fear of assault, so they increasingly isolate themselves from others. This situation is intensified by distrust, socioeconomic status, or locale, and it is worse if the older adult has a chronic illness compounding their constraints. Vehicular driving

cessation may be an eventual reality as one ages. Limited or no driving confines activities outside the home (Marottoli et al., 2000) and thus limits interactions with others for the older adult.

One objective of planned senior housing is to provide individuals with a ready-made social network within a community (Lawton, Kleban, & Carlson, 1973; Lawton, Greenbaum, & Liebowitz, 1980; Lawton, Moss, & Grimes, 1985), although this objective is not always met. However, the frail elderly are found to be less interactive with more mobile, healthier older adults, possibly because healthier older adults have few extra resources to expend on others who may have even fewer resources, or they may have better health and networks that are incongruent with, and less likely to cross, those of the frail elderly (Heumann, 1988).

Nursing home residents with chronic illness or sensory impairments tend to be more isolated than others. In England, for instance, those in residential care who are ill or disabled are considered socially dead, impoverished by the inactive nature of institutionalization and unable to occupy any positive, valued role in the community (Watson, 1988). Stephens and Bernstein (1984) found that older, sicker residents were more socially isolated than healthier residents. The investigators found that family and longer-standing friendships served as better buffers to social isolation than did other residents. Impressionistically, however, the number of research citations about social isolation in England and Ireland, as well as in other European countries seems to have increased from the two previous decades in contrast to the research in

social isolation in the United States. More recent social isolation research in the United States focuses on policy that seems to incorporate the socially isolated individual into more viable social networks.

Social Isolation and Culture

As globalization and sensitivity to United States multiculturalism increases, with its concurrent absorption of multiethnic, multilingual, and multi-religious individuals into yet other cultures, there is an overlap into mainstream healthcare systems. This is especially true of cultural groups that have not assimilated into the dominant culture. Language differences and traditional living arrangements may impede social adaptation. In addition, many immigrants, especially those who are chronically ill, are less able to engage in support networks, given their long working hours, low-paying jobs, lack of health insurance, and changes in family life-styles and living arrangements. Changes may occur over the second and third generations, but this is less true where the immigrants' home cultures are geographically close, such as Mexican Americans who live along the United States–Mexican border, or have reminders of traditions that are more visible (Jones, Bond, & Cason, 1998).

An extensive literature review on health care and its relationship with culture demonstrated two overarching issues: (1) The definitions of culture are conceptually broad and/or indistinct, and (2) mainstream health care struggles to integrate these multicultural groups with varying degrees of success. When one speaks of “culture,” many concepts are mixed, even confused (Habayeb, 1995). The dominant white society in the United States and its healthcare system is secular, individualistic, technology- and science-oriented, and tends to be male dominated (Borman & Biordi, 1992; Smith, 1996). Other European-based cultures have similar situations. Social isolation must be viewed from the client's cultural definition of the number, frequency, and quality of contacts, the longevity

or durability of these contacts, and the negativism attributed to the isolation felt by the individual involved.

Studies done during the last decade indicate how women, minority groups, the poor, and so forth, have not received the same care as the dominant male caucasian middle or upper classes (Fiscella et al., 2000). Fortunately, current cultural healthcare literature indicates a greater awareness of cultural groups and their values. One factor that may be influencing this change is that during the last two decades, other healthcare providers, including nurses, psychologists, case managers, and a variety of technical support personnel, have made significant advances in providing higher quality health care to formerly disenfranchised groups (Biordi, 2000).

Many ethnic and religious groups in the United States value community closeness, family kinship, geographic proximity, and social communication. They seek acknowledgment of their right to mainstream or alternative care (Cheng, 1997; Helton, 1995; Keller & Stevens, 1997; Kim, 1998; Kreps & Kreps, 1997). The task of attempting to deliver “tailored” culturally competent care to so many groups is overwhelming and lacks an integrating strategy that appeals across all groups. One can now find a large number of articles providing hints, tips, or insights into cultural groups targeting mainstream healthcare providers.

Social Components of Social Isolation

Mere numbers of people surrounding someone does not cure negative social isolation; an individual can be socially isolated even in a crowd if one's significant social network is lost. This situation is true for such groups as those living or working in sheltered-care workshops, residents in long-term care facilities, or people in prisons. What is critical to social isolation is that, because of situations imposed on them, individuals perceive themselves as disconnected from meaningful discourse with people important to them.

Associated with social isolation is reciprocity or mutuality, that is, the amount of give and take that can occur between isolated individuals and their social networks. Throughout the years, much evidence has accumulated to indicate that informal networks of social support offer significant emotional assistance, information, and material resources for a number of different populations. These support systems appear to foster good health, help maintain appropriate behaviors, and alleviate stress (Cobb, 1979; DiMatteo & Hays, 1981; Stephens & Bernstein, 1984).

Examining reciprocity in the relationships of social networks focuses not only on social roles and the content of the exchange, but also on the level of agreement between the isolated person and his or her “others” in the network (Goodman, 1984; Randers, Mattiasson, & Olson, 2003). The incongruence between respondents in a social network regarding their exchanges can help alert the healthcare professional to the level of emotional or material need or exhaustion that exists in either respondent. For example, the senior author observed, during a home visit by a nurse, that a homebound older woman complained that her children had done very little for her. However, it was discovered that the children visited every day, brought meals, shopped for their mother, and managed her financial affairs. In this case, the elderly mother felt isolated despite her children’s visits and assistance.

Demographics and Social Isolation

Few studies focus directly on demographic variables and social isolation; typically, this topic is embedded in other research questions across a variety of illnesses. Nevertheless, when these disparate studies are taken together, the impact of demographics on social isolation in the individual with chronic illness is evident. Issues of gender, marital status, family position and context, and socioeconomic standing (such as education or employment) have been shown to affect social isolation.

Socioeconomic Factors

Changes in socioeconomic status, such as employment status, have been correlated with social isolation. The lack of employment of both caregiver and care recipient, cited in much of the caregiver literature, can have an adverse effect. A study of caregivers of frail elderly veterans noted that these caregivers are more at risk for physical, emotional, and financial strain than are other populations, because disabled elderly veterans receive fewer long-term care services than do other elderly populations (Dorfman, Homes, & Berlin, 1996).

Unemployment of the older adult is just one component of the maturational continuum; parents worry about the potential for employment and insurance for their children who have chronic illnesses (Cohen, 1993; Wang & Barnard, 2004). Lower income status, especially when coupled with less education, negatively influences health status and is associated with both a limiting social network and greater loneliness, which, in turn, impacts health status and social isolation (Cox, Spiro, & Sullivan, 1988; Williams & Bury, 1989). For instance, almost half of the head-injured clients in one study could not work, which then affected their families’ economic status and increased their social isolation (Kinsella, Ford, & Moran, 1989).

In addition to problems of employment potential, there are economic and social concerns over the costs incurred by health care, employment discrimination, subsequent inability to secure insurance, and loss of potential friendship networks at work—all of which are factors in increasing social isolation or reducing social interactions. In fact, economics exaggerates the costs of chronic illness. People with disabilities suffer disproportionately in the labor market, which then affects their connections with family and community social networks (Christ, 1987). This is particularly evident in the examination of those with mental illness and their social isolation (Chinman, Weingarten, Stayner, & Davidson, 2001; Melle, Friis, Hauff, & Vaglum, 2000).

General Family Factors

As chronic illness persists, and given tasks must be managed, relationships are drained, leaving individuals with chronic illness at high risk for social isolation (Berkman, 1983; Tilden & Weinert, 1987). When isolation does occur, it can be a long-term reality for the individual and their family. However, if there is social support and involvement, people with chronic illnesses tend toward psychological well-being. Particularly important is the adequacy, more than the availability, of social relationships (Wright, 1995; Zimmer, 1995).

There is evidence that social isolation does not necessarily occur in every situation. In fact, the negative impact of social isolation on families with children who are chronically ill has been questioned. One study, which used a large community-based, random sample, found that families with children who are chronically ill did not experience a greater degree of social isolation than those with healthy children, nor did they function differently, except for modest increases in maternal dysfunction (Cadman et al., 1991). Cadman and his associates argue that prior studies were subject to biases because the families in those studies were in the clinic populations of the hospital or agency. By definition, such populations were receiving care for illnesses or responses to illnesses and hence were experiencing an unusual aggregate of problems, which is why they were at the clinic or hospital. Therefore, such families were not representative families of those throughout the community.

In another study, classroom teachers evaluated children with cancer or sickle cell disease with a matched sample of controls. The authors found that the children who were chronically ill were remarkably resilient in the classroom setting, although those who survived their brain tumors and could attend regular classes were perceived as more sensitive and isolated (Noll et al., 1992). On the other hand, adolescents with chronic illnesses have been marginalized, which predisposes them to feelings of isolation and low self-worth (DiNapoli & Murphy, 2002).

Similarly, some studies of older adults found that isolation did not always occur as they aged (Victor et al., 2002). Although childless older individuals tend to be more socially isolated than those with children, when adult children live nearby, older people frequently interact with at least one of them (Mullins & Dugan, 1990). Interestingly, older African American women, even if they lived alone, tended to have more visits from their children than did older African American men; the difference was not explained by needs, resources, or child/gender availability (Spitz & Miner, 1992). It is also interesting to note that older people tend to be less influenced by their children than by contacts with other relatives, friends, and associates (Berkman, 1983; Ryan & Patterson, 1987). One study found no relationship between the elders' emotional well-being and the frequency of interaction with their children (Lee & Ellithorpe, 1982).

Findings indicate that in every group from age 30 to older than 70 years of age, it was primarily those with the fewest social and community ties who were nearly three times as likely to die as those with more ties (Berkman, 1983). In other words, maintaining social contacts enhanced longevity. These individuals tended to be widowers or widows and lacked membership in formal groups (Berkman, 1983), thereby limiting their social contacts. In another study, the older adults who lived in senior housing complexes showed little difference in friendship patterns and life satisfaction (Poulin, 1984). Both of these studies found that living alone, being single, or not having family does not necessarily imply social isolation. Rather, if older people have social networks, many developed throughout a lifetime, and if these networks remain available to them, they are provided with support when needed (Berkman, 1983).

Gender and Marital Status

Typically, women have more extensive and varied social networks than do men (Antonucci, 1985). However, if one spouse is chronically ill, married couples spend more time together and less time

with networks and activities outside the home (DesRosier, Catanzaro, & Piller, 1992; Foxall, Eckberg, & Griffith, 1986; Smith, 2003). Although gender differences in caregiving occur (Miller, 1990; Tilden & Weinert, 1987), women caregivers indicate greater isolation, increased loneliness, and decreased life satisfaction than do men. Yet both genders show psychological improvement if social contacts, by telephone or in person, increase (Foxall et al., 1986).

Although women caregivers may have professional, community, and social networks to aid them in coping with their disabled spouses, over time, they reduce their links to these potential supports. Physical work, social costs and barriers, preparation time for care and outings, and other demands of caregiving become so extreme that women curtail access to and use of support networks external to home. As these caregivers narrow their use of social networks, they unwittingly isolate their chronically ill spouse as well. Although women reported needing personal or psychological time alone for relief, the subject of their isolation, the person with chronic illness, also became their greatest confidante as the pair struggles in their joint isolation (DesRosier et al., 1992).

Illness Factors and Social Isolation

Chronic illness is multidimensional, and persons who are chronically ill or their networks must assume a variety of tasks: managing treatment regimens, controlling symptoms, preventing and managing crises, reordering time, managing the illness trajectory, dealing with healthcare professionals, normalizing life, preserving a reasonable self-image, keeping emotional balance, managing social isolation, funding the costs of health care, and preparing for an uncertain future (Strauss et al., 1984) (see Chapter 2). As people with chronic illnesses struggle to understand their body failure and maintain personal and social identities, they may become fatigued, sicker, or lose hope more readily. Should this happen, they may more easily withdraw from their social networks.

It has been suggested that isolation not only influences the individual's social network (Newman et al., 1989), but also can lead to depression and even suicide (Lyons, 1982; Trout, 1980), particularly in the elderly (Frierson, 1991). Women whose illnesses required more physical demands on themselves and greater symptom management reported greater depression but no effect on their relationship with their partner. Women who had concerns about the meaning of their illness reported greater marital distress and lower satisfaction with their family network (Woods, Haberman, & Packard, 1993).

Persons with the HIV or AIDS had psychological effects that depended not only on the diagnosis, but also on the age of the person. Older individuals showed significant differences in a number of variables, including social isolation (Catalan, 1998). In addition, HIV-negative men who cared for their partners or friends often lived in social isolation with their care recipients (Mallinson, 1999).

In the case of individuals with severe head injuries, it was not the chronic physical disability that disrupted family cohesion as much as the resulting social impairment (Kinsella et al., 1989). The greatest burden identified was social isolation brought on by the impaired self-control of the head-injured person and their inability to learn from social experience. However, the social isolation was particularly burdensome for the families, because the head injury reduced the client's capacity for recognition of and reflection on the deficiencies in social relationships and precluded formation of new close relationships. Consequently, although friendships and employment possibilities were reduced for the client, the real impact was felt by the constrained family (Kinsella et al., 1989).

Healthcare Perspectives

People with chronic illnesses struggle to understand their body failure and its effect on their activities and lives (Corbin & Strauss, 1987). In doing so, they also struggle to maintain their

sense of personal and social identity, often in the face of altered self-image and enormous financial, psychological, and social obstacles. If individuals with chronic illness lose hope or become otherwise incapacitated, they may withdraw from their social networks, isolating themselves and others important to them.

Frequently, the daily management of illness means working with healthcare professionals who often do not recognize the inconspicuous but daily struggles of the person's realities of a "new" body, the issues of care, and the development of a new self-identity (Corbin & Strauss, 1987; Dropkin, 1989; Hopper, 1981).

With the advent of high technology, the aging of the population, and changes in economics, chronic illness has begun to assume major proportions in the United States. Concomitantly, the literature contains more articles describing various chronic illnesses, the strategies used to manage them, and issues of social and psychological well-being, including social isolation. More recently, the literature has been extended to consider how chronic illnesses and related technologies are impacted by cultural variety.

The impact of prevailing paradigms of care interventions held by various constituencies is evident. For example, most healthcare professionals still see clients only episodically, using the medical model of "cure" and within the model of the dominant healthcare system. But, in the case of children with cancer, the child focuses on the meaning of his or her impairment (which varies by age); the parents focus first on the immediate concern with their child's longevity and cure and later on the impairment and long-term effects; the healthcare professional focuses on client survival; the mental health professional focuses on identifying and minimizing impact, impairments, and social barriers; and the public (third-party payers, employers, schoolmates, partners) focuses on contributions and cost. All of these views center on the interaction and exchange, as well as the specific responsibilities and obligations, incurred by the various networks that

touch them. Interactions are intensified by the potential withdrawal of any party from the network (Christ, 1987).

Given the variety of care-versus-cure paradigms, the real, daily micro-impositions of chronic illness on social identity and social networks are often lost. The compassion felt by many healthcare professionals is evident in the increasing number of articles available and the attempts to present evidence of the isolation felt by clients and their networks. Nevertheless, these articles may not be explicit; therefore, the proposed interventions for the isolate are unclear, irrelevant, or even discouraging. For example, when discussing facial disfigurement, one article noted that the healthcare professional expected evidence of the client's image integration as early as 1 week postsurgery (Dropkin, 1989). That same article suggested and reiterated that, although the surgery was necessary for removal of the cancer, the resulting defect was confined to a relatively small aspect of the anatomy and that the alteration in appearance or function did not change the person (Dropkin, 1989). Both points of emphasis are added. The terminology and the interventions in this article focused on the acute postoperative period and did not take into account what disfigured clients were likely to feel later than 1 week post-surgery or that the word defect gives a strong clue to the understanding that the disfiguring surgery is obvious and emotionally charged toward the negative.

For a clearer view of the impact of such surgery as seen by the client, Gamba and colleagues (1992) asked postsurgical patients, grouped by the extent of their facial disfigurement, questions about their self-image, relationship with their partner and social network, and overall impact of the therapy. Those with extensive disfigurement reported that it was "like putting up with something undesirable" (p. 221), and many patients were unable to touch or look at themselves. Those with extensive disfigurement also reported more social isolation, poor self-image, and/or a worsened sexual relationship with their partner, even

though they maintained satisfactory relationships with their children. In another study, reported in the Gamba article, half of the individuals who underwent hemi-mandibulectomy for head and neck cancers became social recluses, compared with 11% of patients who had laryngectomies. As can be seen, in more than one study, respondents attached a negative meaning to their disfiguring surgery and its results.

Such findings take into account the client's personal meaning of illness and treatment and their effects on social isolation, demonstrating that the isolating treatment or illness (e.g., disfigurement) often is not associated with objective disability. In fact, others have found that the degree of isolation is not directly proportional to the extent of disability (Creed, 1990; Maddox, 1985; Newman et al., 1989). It is important that healthcare professionals not ignore or discount the meaning of illness to the client, regardless of any professional opinion about objective disability or the desirability of treatment.

INTERVENTIONS: COUNTERACTING SOCIAL ISOLATION

In social isolation, the interventions of choice need to remain at the discretion of the client or caregiver. As can be seen from this chapter, writers focus largely on definitions and correlates of social isolation and relatively less on interventions. When interventions are reported, they often relate to the aggregate, such as the policy-related interventions of community housing. The results of many of these larger-scale interventions have been noted in this chapter. Other interventions are mentioned herein, although the list is not all-inclusive.

Because the situation of each person with chronic illness is unique, interventions can be expected to vary (see Holley 2007, for examples). Nonetheless, certain useful techniques and strategies can be generalized (Dela Cruz, 1986). Basically, these strategies require that a balance of responsibilities be developed between the

healthcare professional and the client, with the following aims:

1. Increasing the moral autonomy or freedom of choice of the isolate
2. Increasing social interaction at a level acceptable to the client
3. Using repetitive and recognizable strategies that are validated with the client, which correlate to reducing particular isolating behaviors

The approach to interventions can also be matched, layer by layer, to the social layering model presented earlier in this chapter, that is, from community, to organization, to network, to person. Therefore, interventions might be cast as ranging from community-based empowerment (transportation-system improvements, for example), work-related enhancements (computer telecare), network and family support group enhancements (nursing), case management, neighborhood watches, or client-professional clinical treatments or care. Examples of these are discussed in this chapter.

Another point to remember is that evaluation is a key principle in any problem-solving system, such as the evaluation found in the nursing process. Throughout the assessment and intervention phases, the healthcare professional should explicitly consider how effective the intervention is or was. The effect of cultural and social differences should be taken into account. The willingness and flexibility to change an ineffective strategy is the mark of the competent professional.

Assessment of Social Isolation

When social isolation occurs, a systematic assessment can help determine proposed interventions, which the professional must validate with the client before taking action. Guiding people, rather than forcing them to go along with interventions, requires the healthcare professional to offer a rationale for the proposed interventions. One must ask if one is giving reasonable rationales, assurances, or support. At the same time, the professional should

remember that some cultures value the authority and the expertise of other family members over that of the individual. Consequently, the healthcare professional may have to provide a rationale for suggested interventions to the ranking authority within the support group. Frequently, this is a male figure, often older, who is considered most deserving of any explanation. Other cultures may be matriarchal, so it would be a woman who is the ranking authority.

The key to assessing social isolation is to observe for three distinct features: (1) negativity, (2) involuntary, other-imposed solitude, and (3) declining quality and numbers within the isolate's social networks. Social isolation must be distinguished from other conditions such as loneliness or depression, both often accompanied by anxiety, desperation, self-pity, boredom, and signs of attempts to fill a void, such as overeating, substance abuse, excessive shopping, or kleptomania. In addition, loneliness is often associated with losses, whereas depression is frequently regarded as anger turned inward. Because social isolation, loneliness, and depression can all be destructive, the healthcare professional must be resourceful in assessing which issue predominates at any particular point in time.

Properly conducted, an assessment yields its own suggestions for responsive intervention. For instance, the assessment may indicate that the client is a lifelong isolate and that future isolation is a desired and comfortable life style. In this case, the professional's best intervention is to remain available and observant but noninterfering.

If, on the other hand, the client has become isolated and wants or needs relief, then the intervention should be constructed along lines consistent with his or her current needs and history. In a study designed to be culturally sensitive, Norbeck and associates (1996) applied a standardized intervention using designated individuals for person-to-person and telephone contacts for pregnant African American women who lacked social support networks. Their study showed significantly reduced low-birth-weight infants.

In another example, if the healthcare professional discovers that a support network is lax in calling or contacting a client, the provider can help the client and support network rebuild bridges to each other. Keep in mind that there are usually support groups to which those in a social network can be referred for aid. As an illustration, if the network is overwhelmed, information can be provided about respite programs. Interventions such as these will help members of the social network maintain energy levels necessary to help their chronically ill relative or friend.

Assessment typically involves the clinical dyad of caregiver and client. It is at this level that assessment is critical to the development of appropriate and effective interventions. Without an adequate and sensitive assessment, interventions are likely to be ineffective or incomplete.

Measurement of Social Isolation

The major issue in measuring social isolation in instrumentation is that the instrumentation does not fully capture the conceptual definition of social isolation. For example, social isolation, as described in this chapter, has no specific instrument of measurement. Some researchers have used instruments that define social isolation as an extreme lack of social networks or support, whereas others use a group of questions that purport to measure social isolation.

A review of the literature found that the two most commonly used and reported research measures were the Lubben Social Network Scale (LSNS) (Lubben, 1988) and the Berkman-Syme Social Network Index (SNI) (Berkman & Syme, 1979). Both of these tools measure, essentially, the amount of contact one has with others.

The SNI was cited in 209 articles and the LSNS was cited in 38 articles found in MEDLINE, CINAHL, EMBase, and PSYCinfo. The SNI is a nontheoretical summed aggregation of several items that examined a range of social ties and networks and how they directly affected people. Both the importance and the number of social contacts

are aggregated into four weighted sources. The weighting is cumbersome and potentially error prone, therefore, making it less appealing to researchers and clinicians. Nevertheless, it is useful for secondary data analysis and remains a popular choice.

The Lubben Social Network Scale was developed to measure social networks among older adults (Lubben, 1988) and is somewhat based on the SNI and its original questionnaire. The LSNS has 10 equally weighted items, which place individuals into four quartiles with a cut-off score for social isolation. Reliability and validity have been examined (Lubben, 1988; Lubben & Gironde, 1996; Rubenstein, Josephson, & Robbins, 1994). The LSNS is typically administered prospectively during data collection, and is difficult to use in secondary data analysis, although this has been attempted (Lubben, Weiler, & Chi, 1989). Lubben has developed several other scales, most of which are still undergoing psychometric testing.

Given the state of the science, it is suggested that when measuring social isolation, the researcher choose from the SNI or LSNS dependent upon one's research purpose and question, and also use semi-structured interviews or questionnaires to confirm a diagnosis of social isolation. Once social isolation is identified in an older adult, it is important to use evidence-based recommendations as interventions to decrease negative health-related consequences.

Management of Self: Identity Development

The need for an ongoing identity leads an individual to seek a level where he or she can overcome, avoid, or internalize stigma and, concomitantly, manage resulting social isolation. Social networks can be affected by stigma. Managing various concerns requires people who are chronically ill to develop a new sense of self consistent with their disabilities. This "new" life is intertwined with the lives of members of their social networks, which may now include both healthcare professionals and other persons with chronic illnesses. Lessons

must be learned to deal with new body demands and associated behaviors. Consequently, the individual with chronic illness must redevelop an identity with norms different from previous ones.

The willingness to change to different and unknown norms is just a first step, one that often takes great courage and time. For instance, one study indicated that clients with pronounced physical, financial, and medical care problems following head and neck surgery exhibited prolonged social isolation 1 year post-surgery (Krouse, Krouse, & Fabian, 1989). Although no single study has indicated the time necessary for such identity transformations, anecdotal information suggests that it can last several years, and indeed, for some, it is a lifelong experience.

Identity Transformation

Clarifying how networks form and function is a significant contribution to the management of the struggles of the client who is chronically ill and isolated. The perceptive healthcare worker should know that much of the management done by the chronically ill and their networks is not seen or well-understood by healthcare professionals today (Corbin & Strauss, 1987). However, we can use Charmaz's findings as guides for assessing the likely identity level of the individual as we try to understand potential withdrawal or actual isolation.

Charmaz (1987), using mostly middle-aged women, developed a framework of hierarchical identity transformations that is useful in diagnosing a chronically ill individual's proclivity to social networking and in discovering which social network might be most appropriate. This hierarchy of identity takes into account a reconstruction toward a desired future self, based on past and present selves, and reflects the individual's relative difficulty in achieving specific aspirations. Charmaz's analysis progresses toward a "salvaged self" that retains a past identity based on important values or attributes while still acknowledging dependency.

Initially, the individual takes on a supernormal identity, which assumes an ability to retain all previous success values, social acclamation, struggles, and competition. At this identity level, the individual who is chronically ill attempts to participate more intensely than those in a non-impaired world despite the limitations of illness. The next identity level that the person moves to is the restored self, with the expectation of eventually returning to the previous self, despite the chronic illness or its severity. Healthcare workers might identify this self with the psychological state of denial, but in terms of identity, the individual has simply assumed that there is no discontinuation with a former self. At the third level, the contingent personal identity, one defines oneself in terms of potential risk and failure, indicating the individual still has not come to terms with a future self but has begun to realize that the supernormal identity will no longer be viable. Finally, the level of the salvaged self is reached, whereby the individual attempts to define the self as worthwhile, despite recognizing that present circumstances invalidate any previous identity (Charmaz, 1987).

Not only does social isolation relate to stigma; it can develop as an individual loses hope of sustaining aspirations for a normal or supernormal self, which are now unrealistic. As persons who are chronically ill act out regret, disappointment, and anger, their significant others and healthcare professionals may react in kind, perpetuating a downward spiral of loss, anger, and subsequent greater social isolation. The idea of identity hierarchies thus alerts the caregiver to a process in which shifts in identity are expected.

The reactions, health advice, and the experiences of the individuals with chronic illness must be taken into account in managing that particular identity, and also the various factors that help shape it. Both the social network and adapted norms now available play a role at each stage in identity transformation. At the supernormal identity level, individuals who are chronically ill were in only limited contact with healthcare professionals but presumably in greater contact with

healthier individuals who acted as their referents; at the level of the salvaged self, a home health agency typically was used (Charmaz, 1987).

Integrating Culture into Health Care

Isolation, by its very definition, must include a cultural screening through which desired social contacts are defined. When one speaks of social isolation among unique ethnic groups, the number, type, and quality of contact must be sifted through a particularistic screen of that person's culture. Not only the clients, but also the provider's communication patterns, roles, relationships, and traditions are important elements to consider for both assessment and intervention (Barker, 1994; Cheng, 1997; Groce & Zola, 1993; Kim, 1998; Hill, 2006; Margolin, 2006; Treolar, 1999; Welch, 1998).

Some feel that matching culturally similar providers to clients would be a way to meet needs with effective interventions (Welch, 1998). However, healthcare educators and service providers recognize the issues of a smaller supply of providers and the greater numbers of clients in a struggling dominant healthcare system coping with multiculturalism. To meet supply and demand issues, as well as cultural needs, the idea of cultural competence is being promoted. Education about cultures is being advanced as the key to effective interventions that intersect the values of two disparate groups of individuals (Davidhizar, Bechtel, & Giger, 1998; Jones, Bond, & Cason, 1998; McNamara et al., 1997; Smith, 1996). Cultural education not only results in outcomes of culturally relevant compliance (Davidhizar et al., 1998) but also helps alleviate the isolation of individuals with chronic illness (Barker, 1994; Hildebrandt, 1997; Treolar, 1999).

For those who find that such culturally based education is unavailable, and assuming there are more groups and more traditions than can possibly be understood by a single healthcare provider, a fail-safe strategy remains. This approach requires the provider to approach each person, regardless of their cultural milieu, with respect and dignity,

in an explicit good-faith effort to inquire, understand, and be responsive to the client's culture, needs, and person. The provider must set aside prejudices and stereotypes and instead use an authentic sensitive inquiry into the client's beliefs and well-being (Browne, 1997; Treolar, 1999).

By seeking to understand differences, one can find pleasure in the differences and move beyond them to enjoy the similarities of us all. This approach is undergirded by a culture of "caring," and moves toward a model of actively participating groups exchanging concerns of identity, egalitarianism, and needed care (Browne, 1997; Catlin, 1998; Keller & Stevens, 1997; Treolar, 1999). In so doing, social isolation can be managed within the context most comfortable to the client, who is the *raison d'être* of the healthcare professional.

Respite

The need for respite has been cited as one of the greatest necessities for isolated ill older adults and their caregivers, many of whom are themselves elderly (Miller, 1990; Subcommittee on Human Services, 1987). Its purpose is to relieve caregivers for a period of time so that they may engage in activities that help sustain them or their loved ones, the care recipients. Respite involves four elements: (1) purpose, (2) time, (3) activities, and (4) place. The time may be in short blocks or for a longer (but still relatively short-term) period, both of which temporarily relieve the caregiver of responsibility. Activities may be practical, such as grocery shopping; psychological, such as providing time for self-replenishment or recreation; or physical, such as providing time for rest or medical/nursing attention.

Respite may occur in the home or elsewhere, such as senior centers, day care centers, or long-term care facilities. Senior centers usually accommodate persons who are more independent and flexible, often offering social gathering places and events, meals, and health assessment/exercise/maintenance activities. Day care centers typically host individuals with more diminished

functioning. Other places, such as long-term care facilities, manage clients with an even greater inability to function.

Finally, respite may be delivered by paid or unpaid persons who may be friends, professionals, family, employees, or neighbors. Although many care recipients welcome relief for their caregiver, some may fear abandonment. The family caregiver and professional must work together to assure the care recipient that he or she will not be abandoned (Biordi, 1993). Therefore, the professional has a great deal of latitude in using the four elements to devise interventions tailored to the flexible needs of an isolated caregiver and care recipient.

Support Groups and Other Mutual Aid

Support groups, or even peer counselors (Holley, 2007), have been identified for a wide variety of chronic illnesses and conditions, such as breast cancer (Reach to Recovery), bereavement (Widow to Widow), and alcoholism (Alcoholics Anonymous), or for other conditions such as multiple sclerosis (MS) or blindness. These groups or individuals assist those with chronic illness or disabilities to cope with their illness and the associated changes in identities and social roles of their chronic illness or disability. Such counseling can help enhance one's self-esteem, provide alternative meanings of the illness, suggest ways to cope, assist in specific interventions that have helped others, or offer services or care for either the isolate or caregiver (Holley, 2007). Almost every large city or county has lists of resources that can be accessed: health departments, social work centers, schools, and libraries. Even the telephone book's yellow pages can assist in finding support groups or other resources. The Internet, or World Wide Web, is also a source of information about support groups and resource listings. Some resources list group entry requirements or qualifications. Because of their variety and number, support groups are not always available in every community, so health-care professionals may find themselves in the position of developing a group. Therefore, as part of

a community assessment, the healthcare professional should not only note the groups currently available, but also identify someone who might be willing to develop a needed group. The healthcare professional also may have to help find a meeting place, refer clients to the group, assist clients in discussing barriers to their care, and, if necessary, develop structured activities (such as exercise regimens for arthritic individuals). In addition, the use of motivational devices, such as pictures, videos, audio recordings, reminiscence, or games, may be helpful in developing discussion. Demonstrations of specific illness-related regimens, such as exercises, clothing aids, or body mechanics, are also useful to support groups.

Professionals should be alert to problems the isolate may have in integrating into groups, such as resistance to meeting new people, low self-esteem, apprehension over participation in new activities, or the problems of transportation, building access, and inconvenient meeting times (Matteson, McConnell, & Linton, 1997).

Social activity groups are one way of integrating isolated institutionalized individuals or of reversing hospital-induced confusion; such groups could be recreational therapy groups or those developed particularly to address a special interest (e.g., parents facing the imminent death of a child). Given the limited financial resources typical of most persons who are chronically ill, support groups that are not costly to the chronically ill or their families are more likely to be welcomed.

Spiritual Well-Being

For many, religious or spiritual beliefs offer an important social connection and give great meaning to life. Spiritual well-being typically affirms the unity of the person with his or her environment, often expressed in oneness with his or her god(s) (Matteson et al., 1997). Consequently, assuring isolates some means of connection to their religious support may help them find newer meaning in life or illness and provide them with other people with

whom to share that meaning. The healthcare professional should assess the meaning of spirituality or religion to the individual, the kind of spiritual meeting place he or she finds most comforting, and the types of religious support available in the community. Religious groups range from formal gatherings to religiously aided social groups.

Frequently, the official gathering places of religious or spiritual groups, for example, churches, temples, or mosques, have outreach or social groups that will make visits, arrange for social outings, or develop pen pals or other means of human connectedness. The nurse or other healthcare professional may have to initiate contact with these groups to assist in developing the necessary outreach between them and the isolate.

Rebuilding Family Networks

Keeping, or rebuilding, family networks has much to offer. However, families that have disintegrated may have a history of fragile relationships. The healthcare professional must assess these networks carefully to develop truly effective interventions.

The professional must also take into account the client's type of isolation (lifelong vs recent) and the wishes of the isolate: With whom (if anyone) in the family does the isolate wish contact? How often? What members of the family exist or care about the isolate? What is their relationship to the isolate—parent, sibling, child, friend-as-family, other relative? The professional can then make contact with the individuals indicated to be most accommodating to the isolate, explain the situation, make future plans to bring them and the isolate together, and afterward assess the outcome. However, it may not be possible to bring uninterested family members back into the isolate's social network.

For family members who are interested and willing, rebuilding networks means the professional must take into account the location or proximity of family members to the isolate. If

they live near each other, and because a “space of one’s own” is a critical human need, a balance of territorial and personal needs must be managed if the isolate is to be reintegrated. Should the isolate and family agree to live together, the family’s physical environment will require assessment for safety, access, and territorial space. Not only are factors such as sleeping space and heat and ventilation important, but personal space and having one’s own possessions are as important to the family members as they are to the ill person. Teaching the family and isolate how to respect each other’s privacy (such as by getting permission to enter a room or look through personal belongings, speaking directly to one another, and so forth) is a way to help them bridge their differences.

Understanding Family Relationships

The nature of the relationship between family and isolate must be understood. The family’s meanings and actions attached to love, power, and conflict, and observations of the frequency of controlling strategies by various individuals will inform the professional of potential interventions. For example, some clients who live alone were found to be more likely to be satisfied with support when they were feeling depressed, whereas clients living with others were more satisfied with supporters who cared about them (Foxall et al., 1994). Recalling the earlier example, the elderly woman’s use of guilt with an otherwise accommodating family informed the nurse about interventions most likely to succeed.

In some families, love is thought to indicate close togetherness, whereas, in other families, love is thought to provide members with independence. Love and power can be developed and thought of either as a pyramidal (top-down) set of relationships or as an egalitarian circle. Conflict may be a means of connection or of distancing and can be expressed by shouting and insults or by quiet assertion.

Community Resources to Keep Families Together

Using community resources, such as support groups, is a way to help keep a family together. Families draw on each other’s experiences as models for coping. For example, families in which there is a child with cancer find ways to help their child cope with the isolation induced by chemotherapy. When necessary, the healthcare professional may wish to refer the isolate and family to psychiatric or specialty nurses, counselors, psychiatrists, or social workers to help them overcome their disintegration. Successful implementation of the wide range of family-related interventions requires sensitive perceptions of the needs not only of the isolate, but also of the various family members with whom that individual must interact. (See the intervention research noted in the boxed evidence-based practice section of this chapter.)

Two interesting community resources that could help alert families to potential problem situations for isolates are the post office and newspaper delivery services. If these delivery persons observe a build-up of uncollected mail or newspapers, they can call or check the house to see if there is an older adult isolate in distress. Families who are concerned about their isolated family member can provide their post office, regular mail carrier, or news delivery service with information about the isolate that can be used in the event of a problem. Nurses and social workers can also contact mail and news services or help families make these contacts. This intervention can be expanded to include any regular visitor, such as a rental manager, janitor, or neighbor, who might be willing to check on the welfare of the isolate.

In some communities, employees at banks and stores also react to older individuals who may be isolated. Should there be unusual financial activities or changes in shopping patterns, the individual can be contacted to make sure that everything is satisfactory. Although, in some communities, mail and newspaper services and banks and stores are not involved with people in their areas, these

resources are valuable and should be expanded throughout the country.

Communication Technologies

Telephone

The telephone is a method used to counteract the effects of place-boundedness. However, findings are equivocal (Kivett, 1979; Praderas & MacDonald, 1986). Still, the telephone is considered almost a necessity in reducing the isolation of a place-bound individual. In literature other than that of the socially isolated, nurses using telephone contact reduced health problems and costs of readmission for patients (Norbeck, 1996).

Computers

For many persons, including homebound older adults or people with disabilities, computers have helped offset social isolation and loneliness through features such as access to the Internet, which allows the person to reach family and friends or to find new friends, activities, and other common interests. Computers can also be used to provide fun activities, such as computerized games. In the United States, computers are more widely available than elsewhere, and more so among those with higher socioeconomic status and the more highly educated. Increasingly, on-line groups offer support, such as that described for breast cancer patients (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005).

EVIDENCE-BASED PRACTICE BOX

Methodologically rigorous, evidence-based practice research about social isolation is difficult to find. One such study, however, is that reported by Fyrand and colleagues. This study examines the effect of a social network intervention on 264 women participants with rheumatoid arthritis (RA). Participants were randomized into three groups, that is, one intervention and two control groups. These were labeled as the Intervention Group, the Attention Control Group, and the No-Treatment Control Group.

The *research questions* guiding this study were: “To what extent, if any, will network intervention influence (1) the total size of the patients’ social network, (2) the amount of the patients’ daily emotional support, and (3) the patients’ social functioning . . .” (Fyrand, 2003, p. 72). The *intervention* in this study consisted of two separate, but related sessions, (1) a Preparatory Assessment session and (2) the Network Meeting. If the participants were randomized into the attention control group, they were given the opportunity to attend a single 2-hour meeting in which they were presented information about RA from a panel of experts who also responded to their questions about RA. The third control group had no intervention or meeting.

Three *findings* indicated that (1) the intervention group experienced a statistically significant increase in their social network size, (2) at Time 2 in the study, emotional social support was higher for the intervention group, and (3) less social dysfunction occurred in the intervention group.

The *intervention* basically assessed a patient participant’s social network and then helped the patient and the social network to assist the patient in socially functional problem solving about the illness. Through the meeting process in the intervention group, a change in attitude was observed when the patient developed an increased awareness of the need for social network members. In addition, the network members often would share problems about their own

(Continued)

EVIDENCE-BASED PRACTICE BOX *(Continued)*

lives, which normalized any feelings of stigma experienced by the patient. The authors call this a “response shift,” where both parties change their self-evaluation and make a concerted effort to support each other (p. 83).

During the preparatory assessment session, three important areas were covered: (1) information about the research project, (2) the relationship between health and social networks, and (3) how the patient experienced chronic illness. During this 2-hour preparatory assessment, the researchers mapped the participant’s present social network. The social network map helped the participants to obtain a deeper analysis of the makeup of their social networks, and allowed the researcher and participant to make decisions about which member of the network should be invited to the network meeting (the second element of this intervention). In this initial preparatory session, participant patients also discussed, in depth, how their chronic disease (RA) impacted their life. As feelings were explored, researchers took great care to ensure that the participants had adequate time and attention regarding these important topics.

The network meeting consisted of network members, typically the friends and family who were listed in the preparatory assessment, getting together to problem solve. An average of seven network members, in addition to a network research therapist, attended for an average of 2 hours. The research network therapist acted as a leader and catalyst of the group, mobilizing the participant and the group of network members to dialogue about the participant patient’s problem-solving process. The group leader opened the meeting with the expectations of the meeting and a presentation of the topics that were deemed important, as derived from the preparatory meeting. The general goal for the group was to share how they viewed the participant’s life with RA and to describe their hopes and expectations of the meetings. The goal for the participant was to elicit free discussion of those topics that were of highest importance . A consensus was formed within the group about how to best solve the problems raised, with the further intention to develop trust and involvement between members of the network. In addition to the participant learning how to best present problems to social network members, the aim of the network meeting was to help the participant and members change dysfunctional network behaviors. The researchers suggested that, by clustering the network members and the participant together in a single room, the network and participant would better sense their collective power and the participant could re-bond with any hitherto damaged social network relationships.

This article lays out a sensible intervention that targets social network members. Through a pair of relatively short meetings, the researchers created an exportable, effective intervention that reduced social isolation and rehabilitated, to some extent, dysfunctional social networks. Furthermore, not only is this intervention brief, but it also does not require technology that requires extra training. It does require that the network therapist should be a professional, such as a nurse, social worker, or psychologist, who is skilled in group therapy and mapping social networks. Therefore, this cost-effective intervention can be easily conducted in a variety of settings with a variety of patients who have social networks willing to meet together for a minimum of only 4 hours.

Source: Fyrand, L. (2003). The effect of social network intervention for women with rheumatoid arthritis. *Family Process, 42*(1), p. 71.

Advances in computer technology have created special attachments, such as cameras, breath tubes, or special keyboards and font sizes, which customize computers to the needs of the isolated or disabled, including those with visual impairment (Imel, 1999; Salem, 1998). In parts of the United States, outreach efforts are increasing, as projects aim to reduce the social isolation of the homebound by providing computers and Internet access to caregivers and care receivers. The use of information and other communication technologies has been helpful in alleviating barriers to the return to work for those with spinal cord injuries and the resulting disabilities (Bricout, 2004). Telework permitting home based work is a technology with proven effects for those with mobility or transportation limitations, or those whose illnesses or disabilities necessitate rest periods incompatible with typical work environments. Computers have also been used to relieve isolation or loneliness, and assist in the management of chronic illness and support groups located in rural environments (Clark, 2002; Hill & Weinert, 2004; Johnson & Ashton, 2003; Weinert, Cudney, & Winters, 2005).

Whether connecting with the Internet, using word processing, corresponding via e-mail, taking classes, and so on, computers also allow isolates to actively fill many hours of otherwise empty time, bringing a measure of relief to tedium while expanding their intellectual and social lives. The caveat, of course, is that the use of the computer, and especially the Internet, could itself be an isolating factor for many individuals. This creates a danger of virtual reality overrunning actual reality, in which case, isolates compound their isolation. That having been said, however, the computer offers many more advantages than disadvantages in the possibilities for overcoming some elements of isolation.

Touch

In cultures where touch is important, families and professionals must learn the use and comfort of touch. American studies indicate that the elderly are the least likely group to be touched, and yet

they find touch very comforting. Pets may be useful alternatives to human touch and human interaction; pet therapy is increasingly used as an intervention in families, communities, and in group settings such as nursing homes (Banks, 1998; Collins, Fitzgerald, Sachs-Ericsson, Scherer, Cooper, & Boninger, 2006). Feeling loved and having it demonstrated through touch can do much to reduce isolation and its often concomitant lowered self-esteem. Because some individuals find touch uncomfortable, professionals must assess (by simply asking or observing flinching, grimacing, or resignation) the family's or isolate's responsiveness to touch.

Behavior Modification

Behavior modification is a technique that is best used by skilled professionals. It involves the systematic analysis of responses and their antecedent cues and consequences; the use of cognitive therapy to change awareness, perceptions, and behaviors; and the specification of realistic, measurable goals or actual behaviors. In addition, reward structures and understanding support persons are necessary in the definition of the problem and its solution. Consistency is needed to develop stable patterns of responses. The time frame of such modification can vary with the problem.

Behavior modification is particularly useful for addressing specific problems, for example, the isolate who is fearful of going outside the house. It is also an important intervention when the environment can be held stable, such as in an institutional setting. Matteson and colleagues (1997) note that where groups are small or the motivation intense, successful behavioral interventions have been instituted for the socially isolated in institutions as well as in the home.

OUTCOMES

Ideally, the reduction of social isolation and the maintenance of the integrity of the person who is chronically ill and his or her caregiver(s) are preferred outcomes of interventions. However, so

many factors can affect social isolation, its assessment, and intervention, that it is difficult to draw simple linear relationships between structure, process, and outcomes. As shown throughout this chapter, a professional must be sensitive to, and prioritize, interventions within the cultural milieu in which the client and support network reside.

Handling the emotionally charged issues surrounding every social isolate requires that professionals recognize in their clients, as well as in themselves, those values that most drive their relationships, and build solutions that best deliver culturally and personally competent care toward a better life for their clients.

STUDY QUESTIONS

1. Is loneliness the same thing as social isolation? Why or why not?
2. How might the distance that a manually powered or an electrically powered wheelchair can go relate to social isolation?
3. List six characteristics that might incline a client to social isolation. What criteria did you use to develop these characteristics?
4. Suppose another healthcare professional said about a very new client, “Oh, we must make certain that Mrs. Jones has company. She’s a widow, you know.” With regard to social isolation, what arguments could you make, pro or con, about this statement?
5. Develop at least five questions you could adapt to assess and validate social isolation in a client. Consider how you might approach identity levels, actual isolation, network assessment, and feelings of the isolate. Add other priorities as you wish, but offer rationales for each of them.
6. Name three community resources you could use to reduce the social isolation of clients.
7. What two principles should guide a healthcare professional when developing any intervention with an isolated client? Why are these important?
8. Suppose a client said to you, “I have had arthritis in my fingers and hands for a long time now. I simply can’t do what I used to do. I now have new handles for my kitchen cabinets because the knobs hurt my hands, and new clothes especially made for people like me who can’t work buttons. My daughter was shopping and she saw them and told me about them. Now I feel better when I get together with them to see my grandchildren.” At what stage of identity might you expect this client to be? Why? Is this person an isolate? Explain your answer.
9. A gay teenager is your client. He has recently “come out” and is now depressed because his schoolmates shun him, his parents are going through a grief reaction to his announcement, and he has few other friends who share his interests or sexual orientation. Is he at risk for social isolation? Loneliness? How would you assess his social network? What interventions, if any, would you recommend? Explain your answers.

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