

Hispanic Participation in Cancer Support Groups: The Role of the Occupational and Environmental Health Nurse

by

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ABSTRACT

The occupational and environmental health nurse (OEHN) can play widely varied roles in assisting employees who have cancer. This paper explores those roles, particularly the possibilities for and barriers in referring Hispanic employees and their families to support groups or other resources. Hispanics' barriers to using support groups include the lack of Spanish-speaking groups and the fact that Hispanics often rely on familial and spiritual-care groups instead of formal support groups. When considering Internet-based support groups, further barriers arise because of Hispanics' traditionally limited access to computers and the Internet. The OEHN's other roles in assisting an employee with cancer include a clinician, a case and disease manager, an educator, a researcher, a counselor, a consultant, and a facilitator for interdisciplinary interaction among a company's human resources staff, management, legal department, and employee assistance department. Recommendations for the OEHN include the following: (a) use support groups to augment, not replace, other support mechanisms; (b) consider referral to an Internet-based support group on a case-by-case basis; (c) expect more use of face-to-face and Internet-based support groups with Hispanics as younger Hispanics, who are more familiar with computers, get older and cancer incidence rises among them.

Keywords: occupational health nursing, Hispanics, cancer support groups

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As a second-generation Hispanic reared in a socioeconomically disadvantaged family in Central Texas, I have strong personal experience with being disadvantaged in the United States, including in the health care system. My father was born and lived in Coahuila, Mexico, until he crossed the Rio Grande to start a new life. My mother was born and lived in Central Texas until 18 months of age; she then grew up in Coahuila and later moved back to the United States.

After my parents married, they worked in the United States as migrant laborers and were exposed to pesticides. Their first child was stillborn, and my father eventually died from cancer. I wondered if these events were related to their pesticide exposure. As a child, I had asthma and received some type of treatment, but no one ever asked about our housing situation or any other factors that might have contributed to my condition. In short, I relate very well to being uninsured and often not receiving basic health care, much less any in-depth preventive or diagnostic insights.

Many years later, at the University of North Carolina, I began to learn much more about underserved populations. My interest was further piqued when I discovered that many Hispanics today are still in situations like that of my childhood. My position as a health care provider and knowledge from my ongoing education give me a stronger voice than most Hispanics have. The aim of my academic pursuits, beyond broadening my capabilities as a health care provider, includes exploring my abilities to provide a voice for the disadvantaged. This paper, though only part of that journey, was important because it provided personal insight and information that should help advance health care for Hispanics.

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CHAPTER I

INTRODUCTION

The occupational and environmental health nurse (OEHN) can play varied, important roles assisting employees experiencing the cancer disease process. Research by Guevara (2009) shows that one role, that of referring an employee to a cancer support group, can be surprisingly complicated when dealing with Hispanics. There are two major barriers to Hispanics' use of support groups. The first is the lack of Spanish-speaking support groups, and the second is that Hispanics often eschew secular support groups and rely either on groups with a spiritual aspect or familial support. Internet-based support groups pose additional barriers including Hispanics' traditionally limited access to computers and the Internet. Younger Hispanics have increased access to the Internet, so they may be more receptive to Internet-based modalities as they age and disease processes begin to occur.

Many minorities, in addition to Hispanics, have historically made inadequate use of support groups. This discussion focuses on Hispanics, but the reader may see that some barriers also apply to other minorities.

The OEHN's many other roles in assisting an employee with cancer can include the following:

- A clinician who encourages the employee to use all available support systems and monitors the employee's health status and ability to perform the job;
- A case manager and disease manager who establishes a provider network and recommends a treatment plan; this entire process follows

the nursing process, which includes assessment, diagnosis, planning, implementation, and evaluation;

- An educator for the employee and health care providers; the OEHN also needs proper education in several areas;
- A researcher to expand the foundation of practice;
- A counselor who gives referrals and positive reinforcement and helps employees clarify problems and make informed decisions;
- A consultant with first-level management about the employee's case, with the community to find resources for the employee, and with the family to inform them about such resources; and
- A facilitator for interdisciplinary interaction among a company's human resources, management, legal, and employee assistance departments.

Thus, the OEHN plays a strategic role in making referrals for employees who are in need of a support group. The following chapters will provide an overview of the literature review and the role of the OEHN.

Significance of the Problem

Health Care Challenges Affecting Hispanics

Hispanics represent 13% of the total United States (US) population, or 35 million people (US Census Bureau, 2004). About 77.5% of Hispanics are of Mexican origin, followed by Puerto Rican (9.7%), Central American (5.1%), South American (4.0%), Cuban (3.5%), Dominican (2.3%), Spanish (0.3%), and other descent (US Census Bureau, 2004). This paper does not make any distinction in types of Hispanics and uses the term *Hispanics* instead of reporting on each subset of the Hispanic population.

While Hispanics represent the largest racial and ethnic minority in the US, they still face massive challenges that continue to affect their quality of life (Doty, 2003; Schur & Feldman, 2001). The most alarming area of concern is that of health (Health Coverage in Latino Communities, 2001). Hispanics are confronted with many health challenges, including the incidence of chronic and infectious diseases and limited access to health care (Doty, 2003; Schur & Feldman, 2001).

A significant need exists to learn more about Hispanics and support groups. Hispanics are a growing population with health challenges such as high cancer rates and often-limited access to health care, including social support services, which can be helpful for patients. Support groups, including Internet cancer support groups (ICSGs), can increase social support for Hispanics, just as support groups have helped other populations. Though only sparse data exist on Hispanics' use of support groups, it is safe to say that minorities have historically made inadequate use of support groups, even groups for people with cancer, which is in the category of stigmatizing diseases that often trigger patients to seek support groups.

The outcomes of this paper will help OEHNs and health care providers understand the unique possibilities of support groups for Hispanics. This knowledge should provide possible directions for future research and for the development of cancer support groups that could meet the unique cultural needs of Hispanic cancer patients.

CHAPTER II

LITERATURE REVIEW

The terminology used in this paper is defined as follows.

Definitions

Hispanic is from the Latin word for *Spain* and has a broad reference, potentially encompassing all Spanish-speaking peoples and emphasizing the common denominator of language among communities that sometimes have little else in common (Webster's Online Dictionary, n.d.). The federal government defines a Hispanic as a person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin regardless of race (US Census Bureau, 2004). For this paper, the term *Hispanic* is used for all subsets of the Hispanic population.

Social support is defined as “the exchange of resources between at least two individuals, the provider and the recipient, with the intention of improving the well-being of the recipient” (Katapodi, Facione, Miaskowski, Dodd, & Waters, 2002, p. 846).

Face-to-face support groups consist of people who have a common problem and gather regularly to share their experiences in attempts to facilitate coping. Support groups consist of “clusters of like-minded or like-afflicted individuals who share experiences and offer one another mutual support and aid” (Butler, Gertman, Oberlander, & Schindler, 1979, p. 96). The term *support group* has its origins in groups associated with clinical services (Toseland, Rossiter, Peak, & Hill, 1990) and identifies people who are directed by professionals, whereas peer support groups, self-help groups, mutual aid groups, and mutual

help groups suggest those that seem to be mostly member-directed (Ramsey, 1992).

Internet support groups consist of people who communicate about a shared problem using the Internet. Some of these groups are moderated by professionals. However, the majority of Internet support groups are led by laypeople with a personal interest in the shared problem (Im, Chee, Tsai, Lin, & Cheng, 2005).

Cancer Incidence Rates for Hispanics

Cancer is the second-leading cause of death in the US, and it accounts for 20% of deaths in Hispanics (American Cancer Society [ACS], 2009). The median age at diagnosis of cancer in Hispanics is 62 years. Overall, about 1 in 2 Hispanic men and 1 in 3 Hispanic women will be diagnosed with cancer in their lifetimes. Furthermore, Hispanics' lifetime probability of dying from cancer is 1 in 5 in men and slightly more than 1 in 6 in women (ACS, 2009). The American Cancer Society (2009) estimates that 562,340 Americans will die of cancer in 2009 alone, which is more than 1,500 people a day. In the US, cancer accounts for 1 of every 4 deaths.

The risks of cancer may differ based on a Hispanic subgroup's background, including whether they are US or foreign born and their country of origin, heritage, degree of acculturation, or socioeconomic status. The US population of Hispanics carries a cancer burden similar to that seen in the countries from which they emigrated. Compared to rates in the US, the incidence rates of breast, colon and rectum, lung, and prostate cancers are lower in Puerto Rico, Cuba, and Central and South American countries than in the US, but rates of cervical, liver, and stomach cancers are higher (ACS, 2009).

While rates of some types of cancer may be lower in Hispanics than in non-Hispanic whites, approximately 2 out of every 10 Hispanic families lived in poverty in 1990, compared with 1 out of every 10 non-Hispanic families. More Hispanic females, children, and elderly people were living in poverty than non-Hispanics, and poverty rates vary among Hispanic groups (US Census Bureau, 2004). Increased poverty levels in any group often occur concomitantly with the diagnosis of cancer and constitute a major barrier to accessing early diagnosis and ongoing treatment and support, including access to support groups through face-to-face means or via online support groups.

Lack of Cancer Support Group Participation by Hispanics

Guidry, Aday, Zhang, and Winn (1997) researched the roles of formal and informal social support networks in overcoming barriers to treatment for Caucasian, African American, and Hispanic patients with cancer. The results showed the significance of support networks in assisting the cancer patients with continuing their treatment. An important finding indicated that most health professionals did not provide information regarding support groups to the cancer patients at the time of the diagnosis. Fewer than half of the participants were asked whether they would be interested in joining a formal support group. In addition, minorities were more apt to report that the support group networks helped with continuing treatment. Furthermore, the informal support group networks, such as extended families, were seen as being more helpful for Hispanics than for whites.

A further possible explanation for a lack of support group participation by Hispanics might be related to late-stage cancer diagnosis. Roetzheim et al. (1999) discovered that Hispanic patients lacking health insurance, as well as those

ensured by Medicaid, were more likely to be diagnosed with late-stage cancer at diverse bodily sites than whites. The racial differences in the stage of diagnosis were not explained by insurance coverage or socioeconomic status. Efforts to improve access to cancer-screening services are warranted for these patients.

In addition to late diagnosis and treatment, economic barriers, such as a lack of finances and insurance coverage and challenges in communicating with the physicians, might explain why the support group resource is a lower priority for the Hispanic population. Guidry, Aday, Zhang, and Winn (1998) reported multiple economic barriers to cancer treatment, including lack of insurance coverage, cost of transportation and lodging, and cost associated with lost workdays. Additional barriers included paying for insurance premiums, medications, diagnostic testing, and hospitalizations. The Hispanic population had noticeably higher out-of-pocket expenses for cancer treatments due to inadequate insurance coverage. Moreover, Ashing-Giwa, Padilla, Tejero, and Kim (2004a) showed that Hispanics faced difficulties in accessing quality care, obtaining health insurance, and communicating with physicians due to language differences, physician time constraints, insufficient knowledge about the disease process, and a lack of control over the treatments. Thus, complementary and alternative therapies, such as dietary and herbal therapies, are used widely by patients (Alferi, Antoni, Ironson, Kilbourn, & Carver, 2001; Lee, Lin, Wrensch, Adler, & Eisenberg, 2000) as adjunct therapy to increase the potential benefit of standard cancer-related treatment. In general, Hispanic women who had higher educational levels or incomes, were younger, had private insurance, and exercised or attended support groups were more likely to use alternative therapies. Thus, the alternative and complementary modalities might have substituted for the support group structure for this population.

Juarez, Ferrell, and Borneman (1998) concluded that Hispanic culture, family beliefs, and religion contributed significantly to the management and expression of the pain associated with cancer. Patients approached pain stoically; they also demonstrated reliance on folk beliefs and non-drug interventions. It was useful to approach the patients by being nonjudgmental, sensitive, and above all, respectful of the individual. Once again, culture, family, religion, and folk beliefs probably sufficed as the support group structure needed for this group.

Support groups tend to build genuine interpersonal resources for the group members and their families (Gartner, 1982) by helping people learn from the experiences of others (Silverman, 1982). Nearly 10 million people in the US take part in self-help, mutual aid, and support groups yearly (Lieberman & Snowden, 1994). Of these groups, 33%–50% are established for those suffering from chronic ailments such as cancer, heart and lung disease, arthritis, and diabetes (Wuthnow, 1994). Statistics reported by foundations for common chronic diseases have revealed that the groups and their programs help between 20% (Powell, 1990) and 66% of newly diagnosed patients in a given year (Checkoway, Chesler, & Blum, 1990). A study on support group participation by cancer patients during the first year after diagnosis showed that a smaller figure may be more accurate because only 14.2% “received counseling or joined a support group” (Hewitt, Breen, & Devesa, 1999, p. 1482).

Davison, Pennebaker, and Dickerson (2000) evaluated patterns of patient support, both in face-to-face support groups and through the use of Internet support groups. The investigation of support-seeking behaviors indicated that people suffering from disorders that are both stigmatizing and serious (such as AIDS, alcoholism, breast cancer, or anorexia) are most likely to want help from face-to-face support groups. Further, the researchers report that, due to stigma,

people are not as likely to seek support for equally serious illnesses, such as hypertension, migraines, ulcers, and chronic pain that are less stigmatizing than the aforementioned conditions. Similar patterns emerged with the online support groups as those participants had the highest levels of support activity in areas of multiple sclerosis, chronic fatigue syndrome, breast cancer, and anorexia. The lowest activity areas were noted for participants who had chronic pain, ulcers, hypertension, and emphysema. The researchers posit that the online and face-to-face support patterns were significantly correlated, which suggests that broad tendencies to seek support vary by diagnostic category. However, as noted above, Caucasians and African Americans have been shown to benefit from support groups (Cordova et al., 2003; Coriel & Behal, 1999; Henderson & Fogel, 2003; Michalec, Van Willigen, Wilson, Schreier, & Williams, 2004), but very little is known about the Hispanic population and support groups.

Hispanics in the United States

Hispanic Population Growth

Hispanics comprise the largest minority group in the US (US Census Bureau, 2004). Because *Hispanic* is not a race, a Hispanic can descend from a variety of races, including Caucasian, African American, Asian, American Indian, or mixed [by race, African Americans make up the country's largest minority (US Census Bureau, 2004)]. During the 12 months preceding July 1, 2004, the Hispanic population grew at more than three times the rate of the total US population (US Census Bureau, 2004).

By mid 2050, the nation will have 81 million Hispanics; they will compose 24% of the nation's total population (US Census Bureau, 2004). Two of the primary factors for the rapid growth of the US Hispanic population are higher

birth rates and rapid immigration from South America, Central America, Mexico, and the Caribbean. Among US citizens and immigrants of Mexican derivation, the population doubled between 1970 and 1980 and doubled a second time by 1990. Also, the number of US citizens and immigrants of Puerto Rican and Cuban derivation increased four times more than the growth of the rest of the nation (US Census Bureau, 2004).

Legal Immigration Among Hispanics

Almost 3 million legal immigrants from all nations came to the US between 1980 and 1990. Before 1950, most immigrants came from European nations. However, between 1950 and 1990, Latin Americans took the lead, with nearly 20 million legal immigrants migrating to the US (US Census Bureau, 2004). Half of the foreign-born Hispanics in the US arrived between 1980 and 1990, usually because they wanted to be with family or were refugees of political upheaval (US Census Bureau, 2004).

Assuming that immigrants from other nations that have less per capita wealth than the US generally have less access to computers in their native countries, it will be interesting to see whether the rate of computer usage among Hispanic immigrants rises after they have been in the US for an extended period.

Locations of Hispanics Nationwide

Ten states are home to 90% of the total US Hispanic population. The US Census Bureau (2004) shows that the chief concentration of Hispanics is in the Southwestern US, mainly New Mexico, Texas, Arizona, and California. In those areas, they are mainly of Mexican derivation. Florida's Hispanics are primarily Cuban, and the Northeast has a mixture of Puerto Ricans and Dominicans. South

Americans are mostly located on the East Coast, while Central Americans tend to be found on the West Coast (US Census Bureau, 2004).

Ages of the Hispanic Population

The Hispanic population consists of a larger number of young adults and children but fewer elderly than the non-Hispanic population in the US (US Census Bureau, 2004). Seventy percent of Hispanics in 1990 were under age 35, in contrast with 50% of non-Hispanics. Almost 4 out of every 10 Hispanics were younger than 20 years old at that time, greater than the 28% of non-Hispanics. Only about 5% of Hispanics were 65 or older, in comparison with 13% of non-Hispanics. The report demonstrates a high birth rate among recent Hispanic immigrants (US Census Bureau, 2004).

This information may hypothetically apply to this paper or future research because overall computer usage among Hispanics, like that of many other groups in the US, may increase as young Hispanics increasingly use computers for schoolwork and other tasks. This familiarity with computers may increase computer usage later in life, which may in turn increase participation in cancer support groups. Another factor hypothetically encouraging such usage may take effect as the Hispanic population in the US ages; they likely will follow the trend common among other population groups and develop an increased incidence of cancer (ACS, 2009).

Educational Attainment for Hispanics

Hispanics have achieved limited advancements in education. In 1990, 1 in 11 Hispanics earned at least a bachelor's degree, with half of the population earning a high school diploma; 1 out of 13 graduated from college; and 4 out of 10 finished 4 years or more of high school (US Census Bureau, 2004). There are

variations in educational progress among the various Hispanic subgroups: 44% of Hispanics of Mexican derivation got a high school diploma or higher, compared to 53% of Puerto Ricans and 57% of Cubans (US Census Bureau, 2004).

Languages Spoken at Home by Hispanics

The common bond between Hispanics is the Spanish language. Fourteen percent of people in the US in 1990 spoke a non-English language at home, usually Spanish. Half of those who spoke Spanish at home reported speaking English very well. Among the Dominicans, Central Americans, and Puerto Ricans, fewer spoke English very well (US Census Bureau, 2004). As English proficiency increases among Hispanics, computer usage may also increase, especially usage of cancer support groups and other medical resources commonly provided in English.

Occupations of Hispanics and Non-Hispanics

The proportion of professional jobs and managerial positions held by Hispanics was lower than that of non-Hispanics in 1990. The category of jobs most often taken by Hispanics was technical sales and administrative support, including about 39% of Hispanic females, while non-Hispanic females took up to 45% of such jobs. Managerial positions and professional jobs were held by 12% of Hispanic males; non-Hispanics held 27% of such positions (US Census Bureau, 2004). If Hispanics held more jobs involving computer usage, their computer usage for medical and other personal needs hypothetically would increase.

Poverty Rates for Hispanics

Approximately 2 out of every 10 Hispanic families lived in poverty in 1990, compared with 1 out of every 10 non-Hispanic families. More Hispanic females, children, and elderly were living in poverty than were non-Hispanics

(US Census Bureau, 2004). Poverty rates varied among Hispanic groups (US Census Bureau, 2004). Increased poverty levels in any group often occur concomitantly with factors commonly thought to inhibit computer usage, such as lower education levels and less computer access (Fawcett & Buhle, 1995).

Hispanic Culture

The Hispanic population is a mixture of many nationalities (Marin & Marin, 1991). The term *Hispanic* generally refers to all persons from Spanish-speaking countries but does not account for specific differences in cultural beliefs, values, education, socioeconomic status, or the influence one country has on another (Campos, 2006). In addition to having an understanding of the socioeconomic characteristics of the Hispanic population, one must become acquainted with several cultural values of the Hispanic population.

Any generalization about a large population comes with a caveat: one must be careful, especially in individual interactions, not to assume that all the general characteristics of the Hispanic culture apply to everyone in all Hispanic subgroups. On a larger scale, different Hispanic subgroups can have differences as numerous as those between Hispanics and other cultures. Nevertheless, the overall Hispanic culture has some classic, signature characteristics.

Familism

The family, or familism (Marin & Marin, 1991; Moore, 1970), is important in the Hispanic community. The family nucleus typically consists of a husband, a wife, and their children (Keefe & Padilla, 1987). The crucial value of familism denotes a strong identity and attachment to the nuclear and extended families, as well as loyalty and reciprocity in helping other family members (Marin & Marin, 1991; Triandis, Marin, Betancourt, Lisansky, & Chang, 1982).

Ideally, the family unit should participate in a support group involving a patient in order to promote familism and personal-space values common among Hispanics. A possible explanation for the lack of participation by Hispanics in formal support groups might be related to this cultural value of familism (Marin & Marin, 1991). Weller, Baer, and Pachter (1999) demonstrated that family support was vital in participants' adherence to medication regimens. If family support was absent, then the patients were less likely to be motivated to continue with their proper disease management routines. In a study of quality of life conducted by Juarez et al. (1998), Hispanic cancer patients reported "having their family as most important" (p. 15) for dealing with the cancer. The term *family* referred not only to immediate and extended family but also to those chosen by the patient to be a part of his or her family. Concerning the idea of social well-being, Hispanic cancer patients indicated the high priority of family support for physical and emotional issues. In Hispanic culture, when one family member is ill, the entire family is expected to help. The patients in a study by Juarez et al. (1998) indicated that friends and family would help by bringing food and doing chores. Companionship is also an important function of the family (Juarez et al.). Furthermore, Palos (2004) reported that Hispanics tend to include the entire family in decision making. In general, Hispanic culture tends to be collectivistic. Family members consider themselves to be enmeshed with the other members of the family in a collectivistic manner (Rogers & Steinfatt, 1999; Sorrell & Smith, 1993). Due to previously mentioned factors, the family may already perform the functions that traditional support groups can provide. There is a clear need to further explore this value.

Hierarchical Power

Falicov (1982) and Portillo (1990) asserted that the Hispanic family is paternalistically and hierarchically based. A person's age and gender are important components. Men are higher in the hierarchy than women. Older men have more control over younger men and others, as well as more power in decision making. Older women are also higher up in the hierarchy than younger women, but women as a rule are lower in the hierarchy than men. Respect is interwoven in social interactions and is significantly relevant in the treatment of the Hispanic elderly population (Cox & Monk, 1993).

Fatalism

Numerous Hispanic groups have a fatalistic view of life and believe that disease processes are the results of divine intervention (Larkey, Hecht, Miller, & Alatorre, 2001). Though such beliefs might be attributed to religious, not cultural, beliefs, the ingrained influence of the Catholic Church in Hispanic culture may make the origin of such beliefs indeterminable in many cases. Religion and spiritual perspectives are very important in dealing with health issues in this population (Campos, 2006). Zaldivar and Smolowitz (1994) affirmed that the patients in their study believed that they were ill because it was God's will. Such studies help in understanding the importance of discerning the patients' spiritual perspectives (Campos, 2006).

Allocentrism

Hispanics also commonly value *allocentrism* (Marin & Marin, 1991), otherwise known as collectivism, which involves the notion of interdependence, conformity, a readiness to be influenced by others, and a willingness to sacrifice for the benefit of the group (Araan & Gallapher-Thompson, 1996; Marin &

Marin). Additionally, trust of group members and friendly interactions are very important qualities of this group (Marin & Marin). The lack of face-to-face interaction on the Internet is not conducive to *allocentrism*.

Simpatica

Another value involves *simpatica* (Marin & Marin, 1991). This cultural norm is characterized by deemphasizing negative behaviors in conflicting situations but establishing positive behaviors in agreeable situations by using smooth, pleasant social relationships in conjunction with personal dignity and respect for others (Marin & Marin; Triandis, Marin, & Betancourt, 1984). Distinctly for Hispanics, the idea of *simpatica* might involve issues of reciprocity, which may involve compensating the participants, although not monetarily. Reciprocity may be further explained by using the example of a person choosing to participate in the support group and in return expecting the group leader to assist with a problem that he or she is currently experiencing.

Power Distance

Sometimes the fear of disagreement in the Hispanic community is linked to an authoritative person who has powerful influence (Marin & Marin, 1991). Power distance, which Marin and Marin explained, is interpersonal power or influence that exists between two individuals. Furthermore, one individual typically has more power than the other as a result of intelligence, money, or education. Thus, as a result of power distance, Hispanics promote deference and respect toward more powerful individuals. In addition, Hispanics tend to support authoritarian attitudes and fear disagreeing with those with higher power, if only because the less powerful individual can be in a vulnerable position or undefended against exploitation (Marin & Marin). Dominguez (1996) asserted

that in the Hispanic culture, individuals generally hold health care professionals in high regard and view them with honor.

Close Personal Space

Close personal space (Marin & Marin, 1991) is another important characteristic. Hispanics are known to gravitate toward a physical closeness to others and desire the one-on-one interaction that this mode of interaction provides, according to Marin and Marin. It is interesting to note how the attitudes toward ICSGs affect this type of one-on-one interaction typically associated with traditional support group or family support group structures as opposed to the Internet medium of support.

Time Orientation

Another important value is a present-oriented mode of time orientation. This mode may be explained further by characteristics such as a lack of planning for the future, being inefficient, and not being punctual (Marin & Marin, 1991). It will also be interesting to note how this value affects the attitudes of the participants toward ICSGs as the Internet offers a medium of little organization that is not as efficient in structure and has a synchronous or asynchronous type of format.

Gender Roles

Gender roles are important for the men and women of the Hispanic population (Marin & Marin, 1991). The Hispanic man is characterized by *machismo* (Marin & Marin), which includes being strong, having control, and helping to meet the needs of the family. On the other hand, women are characterized as being submissive and without power or influence (Heller, 1966). Women's place in this structure tends to result in their making sacrifices for their

families and relatives, sometimes at the expense of their own health needs (Flores & Mata, 1995). In addition, the machismo mind-set may repress open communication.

Trust and Caring

Another value very important to the Hispanic community is the need for trust, or *confianza*, and personalized caring, otherwise known as *personalismo*, during interactions (Larkey et al., 2001). A person who is ill often tries self-management of symptoms and often consults family members or friends of the family. If such advice does not work or if specialized medical intervention clearly becomes necessary, the person will seek medical attention. Specifically with *personalismo*, the individual might expect a higher degree of intimacy with the health care provider. Galanti (2003) found that as the relationship developed between the provider and the client, so did the compliance of the patient with the treatment. Since the trust and caring aspects are demonstrated in a one-on-one relationship, these characteristics certainly affect the attitudes toward ICSGs, which do not involve the personal side of trust and caring.

Types and Characteristics of Support Groups

Essential Characteristics

Gottlieb and Wachala (2007) explain that a support group should have two essential characteristics. The first characteristic is leadership by a professional leader, and the second is that the support group should be a planned activity, which involves the sharing of experiences and mutual support among the individuals in the group. In support groups, there is a common exchange of informational support, which includes facts about cancer, treatment, and resources available in the community. The support group researchers also explain that a

difference exists between official support groups and self-help mutual aid groups in that the support group structure has a professional leading the group.

Furthermore, the researchers reviewed 44 empirical studies and concluded that the participants had a common theme of characteristics: they were well-educated, white, and female, middle-class individuals who used the services of other community groups; they were likely to report problems with their medical challenges; and they had diminished mental health capabilities. Another finding was that the participants preferred physician- and nurse-led support groups. Typically, 20% of those who were invited to join the support group declined, and another 20% of those who chose to attend any group meeting often dropped out before the final session or the post-test. Other findings from the evaluation revealed that the participants in support groups felt less alone, better understood, and more hopeful after their support-group participation. In fact, many of the participants longed for the group to continue after the final session. Yet Ussher, Kirsten, Butow, and Sandoval (2006) found no differences between the professional-led and peer-led support groups. These researchers affirmed that it was not the professional background of the leader that mattered but whether the group provided a supportive environment, mutuality, and a sense of belonging and if it met the perceived needs of those who attended the group meetings.

Researchers found that if the patients received limited psychosocial interventions, they would often look for support from other sources, especially cancer support groups, in order to meet their needs (Ahlberg & Nordner, 2006; Evans, 1995). Herrera (2007) studied 8 Latina women who participated in a bilingual breast cancer support group. She discovered that the women benefited from a strong group leader and were comforted by the women who were able to speak in their native language. Taylor, Falke, Shoptaw, and Lichtman (1986)

stress that the support may come in various modes to an individual, such as from a spouse, children, other family members, friends, caretakers, community ties, or a structured support group.

Key Attributes

Katz and Bender (1976) described key attributes that are found in support groups. The groups are typically small and include face-to-face interaction. They also place importance on personal participation and voluntary attendance. The main purposes of these groups is to come together and help solve a problem or assist individuals in coping with an illness and to provide emotional support during hard times. Last, Guidry, Torrence, and Herbelin (2005) studied diverse populations and cancer survivorship. They affirm that potential barriers to minorities' participation in research and support groups include socioeconomic status and a lack of resources to take part in the cancer support groups.

The support groups may be generally divided into two main categories: those that are nondirective and professionally led (Hogan, Linden, & Najarian, 2002) and the directive group intervention type (Fawzy, Fawzy, Arndt, & Pasnau, 1995).

Nondirective and Professional

Hogan et al. (2002) reviewed studies on the nondirective and professionally led groups. These groups dealt with support interventions involving a combination of emotional support, informational support, and instrumental support. An example is a professional intervention that provided instrumental support for mentally challenged participants. Improvements in social support, family burdens, and satisfaction were noted. In addition, the participants also

reported less hospital care, greater workforce participation, fewer group and institutional housing arrangements, and more leisure activities.

Directive Group Intervention

The directive group intervention oftentimes introduces expert information, education, training, and/or therapy (Gottlieb & Wachala, 2007). Humphreys and Rappaport (1994) reviewed the literature on self-help and mutual help groups, and they affirm that the self-help groups are different from the peer and lay services offered by a professionally supervised group. Myer and Mark (1995) assert that individuals who participated in the support group structure showed improvement in quality of life, coping, and affect. Conversely, Helgeson, Cohen, Schulz, and Yasko (1999) found that not all participants benefited from the support groups.

In another study conducted by Fawzy et al. (1995), the researchers reviewed four types of interventions: education, behavioral training, individual psychotherapy, and group interventions. The findings highlighted the various options for cancer patients and the psychological and physical health benefits of the interventions.

In 1990, Fawzy et al. reviewed immune measures, particularly with regard to natural killer cells. Based on a six-month follow-up after the intervention, it was noted that the killer cells were different than at the beginning of the intervention. Indeed, there was also an increase in coping and effective status of the patients after the intervention. Thus, positive outcomes were related to the immunological response and support group participation.

In two seminal pieces of work, Spiegel and Yalom (1978) and Spiegel, Bloom, and Yalom (1981) studied the effects of weekly support group meetings, which included women with metastatic carcinoma. In the 1978 study, the

researchers dealt primarily with a group of terminally ill women with metastatic breast cancer, and they found that the group had a positive impact on the members' families. Friends and family members were encouraged by the group members to observe the group interaction and benefit from the group participation as a learning experience. Ultimately, the members were able to support one another through personal visits and socialized outside of the group therapy sessions.

In the second study by Spiegel et al. (1981), the participants were assessed in a one-year, randomized prospective outcome study. The hypothesis of the study was that the intervention would lead to improved mood, coping strategies, and self-esteem for the individuals in the treatment group. The participants in the treatment group were found to have significantly lower mood-disturbance scores on the Profile of Mood States scale, fewer maladaptive coping responses, and fewer phobias than the control group. The results of the study affirmed that support group intervention and participation for women with breast cancer had psychological benefits. At the time of the study, cancer was still a hidden and highly stigmatized disease (Gottlieb & Wachala, 2007).

Hispanic Participation in Cancer Support Groups

Cancer Support Groups' Availability

Cancer support groups have been shown to be beneficial in helping patients with coping strategies and psychological well-being (Cella, Sarafian, Snider, Yellen, & Winicour, 1993; Coriel & Behal, 1999; Presberg & Levenson, 1993; Samarel, Fawcett, & Tulman, 1997). Numerous individuals have taken advantage of the benefits from ICSGs (Childress & Asamen, 1998; Crandall, Zitzelberger, Rosenberg, Winner, & Holaday, 2001; Curl & Robinson, 1994;

Fawcett & Buhle, 1995; Fernandez et al., 2004; Forkner-Dunn, 2003; Im & Chee, 2005). However, members of the Hispanic population seem to be lacking from participation in traditional face-to-face support groups (Guidry et al., 1997; Juarez et al., 1998; Kaskutas, Weisner, & Caetano, 1997; Lieberman & Snowden, 1994; Miano, Rojas, & Trujillo, 1996; Palos, 2004).

Hispanics' Lack of Participation

Hispanics are generally not involved in formal support groups, as are other minority groups. A possible explanation for this lack of involvement might be related to their cultural values of familism, personal space, *allocentrism* (collectivism), and *simpatica* (Marin & Marin, 1991). All these values are supported by the nuclear and extended family (Ashing-Giwa et al., 2004a; Sabogal, Marin, Otero-Sabogal, Marin, & Perez-Stable, 1987). Families fulfill a patient's needs in ways that make the family function like a formal cancer support group (Rogers & Steinfatt, 1999; Solis, 2004; Sorrell & Smith, 1993).

A very important factor is that a patient's family members might have had positive experiences in their own family support group; thus, they might directly or indirectly discourage the patient from attending a formal support group because support is already received at home. Only minimal research has been done on Hispanic cancer patients' families' feelings about participating in any kind of support group. Yet, Hispanic families might benefit from other families in support groups. Discussing caregivers' stress and the benefits of support groups, Garstka, McCallion, and Toseland (2001) stated that caregivers' stress levels are related to their evaluation of the situation, coping behaviors, and perceived social support, but involvement in support groups can help with such problems by developing social support for caregivers, offering them better coping responses, presenting

opportunities for social comparisons to individuals who may be facing greater obstacles than their own and therefore helping change caregivers' evaluation of the situation. Indeed, the support group structure may reduce stress and improve caregivers' health and well-being (Garstka et al., 2001). Almost certainly, these support groups could provide information for caregivers that could help them with coping.

Medical Providers Often Do Not Refer Hispanics

Ashing-Giwa et al. (2004b) found that there were several issues related to Hispanics' often not receiving optimal care from physicians for their cancer care treatments. Due to socioeconomic and cultural factors, Hispanics from their communities perceived that they had less control over their medical care than the mainstream society, and they were consequently less inclined to cross the line to inclusion and participation as health care consumers. Also, Hispanic women, due to their status as immigrants receiving financial assistance, believed that the health care staff did not view them as deserving of public assistance and as a result experienced delays in diagnosis or indifference to their conditions. Furthermore, these participants believed that the medical staff made assumptions based on participants' inability to speak English and their manner of dress that led to participants' receiving suboptimal care. Instead, this group noticed that the medical staff gave more information about cancer to those who were more educated. Language was also important in receiving quality care for the Hispanic women. Being able to communicate with the health care provider was essential in order to relay their concerns and to understand the physician's advice and recommendations. Last, the women conveyed some dissatisfaction with the quality of their relationships with their physicians. These women expressed

concerns about their inclusion in the treatment decision-making process and expressed a desire for greater involvement.

Support Group Studies Not Specific to Hispanics

Numerous studies show, in a variety of ways, that minorities, including Hispanics, are underrepresented in support groups, and sometimes the studies identify contextual influences on participation. Among the non-Internet support group studies not specific to Hispanics, the lack of non-whites in such groups is once again apparent. Taylor et al. (1986) reported that cancer support group attendees are more likely to be white, middle-class females; have more problems than nonattendees; and use all available kinds of social support resources more than nonattendees. However, a limitation to the study was that the sample was disproportionately female, white, and middle class to upper-middle class. Thus, the support needs of minority, working-class, and male patients were underrepresented. Taylor (2002) also affirms that the support groups may be a redundant resource and appeal to the same segment of society that traditional mental health services appeal to—specifically, middle-class women. Last, the researchers imply that a segment of the population might not have their needs met with respect to cancer and other disorders. In particular, male, low socioeconomic status, and minority individuals are underrepresented in cancer support groups and in other mental health services.

Cella and Yellen (1993), in a literature review related to cancer support groups, affirmed the need for support groups that serve a large number of people with cancer and the family members. The researchers noted an underrepresentation of people of color, men, and the poor among group participants. The researchers concluded by calling attention to the need for more

resourceful and variable outreach methods to help underserved groups (a category that includes Hispanics because most studies show that they are medically underserved and underrepresented in support groups). Coriel and Behal (1999) concurred with the need for outreach efforts to increase support group participation among underrepresented segments of at-risk populations, specifically ethnic minorities of lower socioeconomic status.

Demonstrating the potentially beneficial role of support groups, Cordova et al. (2003) studied mood disturbance in community cancer-support groups. His aim included magnifying the roles of emotional suppression and the fighting spirit. His main finding was that the expression of a negative effect and an attitude of realistic optimism may enhance the adjustment and reduce the stress for the cancer patients in support groups. Such findings are among many documented benefits of support groups. If Hispanics and other minorities can overcome contextual and other barriers to participation, they hypothetically should be able to enjoy the benefits of support groups.

Studies have shown that cancer patients view cancer support groups positively. Such studies have primarily focused on support group structures, which have traditionally been hospital based. These hospital-based groups are less accessible to the members of the Hispanic population (Camosy, 1996) because they are sometimes not referred to this valuable network system.

People of minority backgrounds say social support networks assist them with the continuation of cancer treatment (Guidry et al., 1997). Since support groups may be considered a type of social support network and the development of such a network is one of their benefits, health care professionals should be aware of the benefits of developing ways to reach out to minorities to increase their participation. In Hispanics' definition of social support networks, they

include extended family and friends (minorities use these two groups more than whites do). Minorities' receptivity to resources that fit their definition of social support networks implies potential openness to support groups such as ICSGs, or perhaps minorities would use family and friends instead of support groups.

This discussion of non-Internet support groups that were not specific to Hispanics showed that minorities' low participation in support groups and other aspects of the health care system may contribute to their heightened health problems and troubles in handling health problems. Though support groups benefit participants, several contextual factors may negatively influence minorities' participation. However, minorities say social support networks (one of the major benefits of support groups) help them. This potentially positive predisposition toward support groups (a type of social support network) may be negated by the fact that minorities use family and friends as major social support networks.

Cancer Support Group Studies Not Specific to Hispanics

As for online cancer-support groups, studies provide direct or indirect insights about Hispanics' feelings or beliefs about such groups. For instance, Klemm et al. (2003) analyzed a review of the research literature on online cancer-support groups. The researchers found that in nine of the ten published studies, online cancer-support groups were shown to help people cope more effectively with their cancer. In other findings, six of the ten studies did not include men, and six focused on Caucasian women with breast cancer. Only one of the studies (McTavish et al., 1995) had a minority population, which included eight African American women with breast cancer, who were of low socioeconomic status and educational level. Interestingly, higher depression rates and more severe social

isolation were associated with increased Internet use. The researchers affirm that the use of technology, which is necessary to access the Internet, is a comparatively new phenomenon and could possibly be a barrier to participation. Other barriers mentioned by the authors were low literacy levels and visual impairments. They further revealed that traditional face-to-face cancer support groups have underrepresentation among minority groups, men, elderly people, and people of low socioeconomic status. Participants were more likely younger and more educated, and this same disparity in membership seems to be true of online support groups as well. Thus, the research studies mainly focused on small groups of Caucasian women with breast cancer. Therefore, the results could not be generalized to a larger population of individuals with cancer. Further, most online support groups are hosted in the US, with English being the language of choice. Klemm, Hurst, Dearholt, and Trone (1999) also recommended that attention should be given to facilitating the entry of underserved groups into the ICSGs. Thus, having the Internet as a support group structure does not change the underrepresentation of minorities in the support groups.

Im et al. (2005) noted that in doing Internet cancer research among ICSGs, minority patients definitely had limited access, with only a small number of ICSGs for any minority group. The researchers' final conclusion was that there are many problems involved in getting an adequate representation of all groups, verifying participants for inclusion, and addressing ethical and privacy concerns. Potential problems for the ICSG members included a lack of face-to-face contact, having to deal with the negative emotions expressed by others, and problems in assessing and verifying the posted information.

Nolan et al. (2006) described spiritual issues addressed by users of a pancreatic cancer informational website. Six hundred postings on the site were

evaluated, and the themes discovered were spiritual convergence, reframing suffering, hope, and acceptance of the power of God and eternal life. Importantly, 6% of the postings were made by family members who were reporting the death of the loved one. This finding suggested that the website also served as a bereavement function for the family members. An outcome from the study was that a separate chat room for bereavement was established.

Owen, Yarbrough, Vaga, and Tucker (2003) examined communications among 167 people, both male and female, participating in ICSGs. The aim of the study was to examine emotional disclosure and cognitive processing in online support groups by using a controlled, experimental design. It was hypothesized that females would demonstrate more emotional disclosure than males and that preparation directed toward increasing emotional disclosure would affect the communication of both males and females. Those eligible for the study included students who had access to the Internet and had a close friend or family member who had been diagnosed with cancer. A portion of the sample, 16.9%, was self-identified as being Hispanic, Asian, Native American, or Arab. The sample was 28.4% male and 71.6% female. Surprisingly, gender differences in the content of the communication were not observed, and preparation for participation in the online group was not associated with greater emotional disclosure or cognitive processing in the expected directions.

Klemm et al. (1999) evaluated gender differences in ICSGs. The aim of the study was to determine if categories of responses in ICSGs differed when the majority of the participants were of a single gender. A second aim of the study was to determine if the response categories observed in gender-specific support groups were different from those used equally by men and women. Data were evaluated from prostate, breast, and mixed ICSGs. The themes that emerged were

information seeking and giving, encouragement and support, personal opinion, and personal experience. For the prostate, male gender-specific group, information seeking was rated as the first priority. Conversely, for the female breast cancer gender-specific group, personal experience was at the top of this list. Interestingly, men were more than twice as likely to give information, while women were twice as likely to give encouragement and support.

Klemm et al. (1999) also stressed that the availability of Internet access has greatly increased and that very soon universal access to the Internet might be a reality due the advent of Web television. Another observation by the research team was the lack of participation from underserved populations, which also exists in traditional face-to-face support groups. An implication of this study is for nurses to support underserved populations in gaining access to information on the Internet. Finally, the Internet support groups might provide a creative medium for persons with rare cancers to seek information and support.

Klemm and Hardie (2002) examined depression in members of ICSGs as compared to those of face-to-face cancer support groups. An exploration into Internet use and levels of depression was conducted using an exploratory descriptive design. A convenience method of recruitment was used to garner the 14 participants of the traditional face-to-face group and 26 from the ICSG were evaluated. All of the 14 participants in the face-to-face group were males. In the Internet group, 56% were male and 44% were female. There was no mention of ethnicity for either group. According to the researchers, the data suggested that the more depressed patients with cancer became, the more they used the Internet support groups instead of the face-to-face groups. An implication from this study was that the efficacy of the ICSGs in providing psychoeducation and psychotherapeutic intervention needs to be further studied.

Klemm, Reppert, and Visich (1998) refer to the ICSGs as nontraditional support groups. The researchers assert that the Internet support groups are a means of recommending support to cancer patients, the families, and the caretakers in a very nontraditional arrangement. The important advantages of using the Internet support groups include 24-hour availability, accessibility for the homebound, a representation of diverse geographic locations, anonymity being stressed, and a potential for having more males to participate in the support group function. The disadvantages of the Internet support groups were the lack of Internet access, lack of a professional facilitator for the group, potential unreliability of information posted, potential for individuals with low literacy levels to be excluded from participation, and visually impaired individuals might not be able to participate.

The preceding studies showed that minorities could benefit from support groups, but few participate. Having support groups on the Internet did not change this pattern, partially because few minority-specific Internet groups exist and because whites use the Internet in general more than Hispanics do, so whites are more likely to access Internet support groups.

Hispanic-Specific Studies of Cancer Experience and Support Groups

There are Hispanic-specific data about some aspects of cancer and support groups. Researchers found that ethnic disparities exist for Hispanics and other minorities concerning cancer stage, diagnosis, and survival (Ashing-Giwa et al., 2004b; Haynes & Smedley, 1999; Miller, Wilder, Stillman, & Becker, 1997; Ries et al., 1994; Shinagawa, 2000). For instance, Ashing-Giwa et al. (2004b) found that, because the diagnosis of cancer for Hispanics is often made when the disease is at an advanced stage, this group has greater severity for morbidity and

mortality. Also, when a late diagnosis is given, the person often does not have enough time left to become involved in either formal face-to-face or Internet support group structures.

In their multiethnic study, Ashing-Giwa et al. (2004b) found that Hispanic women had less knowledge about their bodies and lacked awareness about the benefits of breast-cancer screening and early detection. Hispanic women operated under cultural taboos about touching their bodies, which often resulted in avoidance of self-exams and screenings. In addition, after some participants had mastectomies, their husbands abandoned them. It was also noted that the women relied more on alternative medicine rather than on Western medicine for treatment and looked to the family as a primary source of support and recovery. The socioeconomic barriers included a lack of insurance, a lack of transportation, and financial concerns. Immigrants with significant financial constraints were concerned that their monetary status caused health care providers at county hospitals to give them inferior treatment.

Harmon, Castro, and Coe (1996) asked a community-based sample of Hispanic women about their knowledge, beliefs, and behaviors regarding cervical cancer, and found that the women held attitudes of fear and fatalism about cancer. Huerta and Macario (1999) and Solis (2004) also found that Hispanic women had fear of and fatalistic attitudes toward cancer. Such results have implications for educational and support programs for health care professionals who serve this population.

The preceding studies showed that numerous factors can impede good cancer care, including support groups, for Hispanics. Carpinello (1995) focused on the advantages of having a Hispanic self-help group. Initially, the group members did not know how to communicate in English, yet a part of the group's

goal was for the participants to learn the English language and be able to participate in the self-help group. One outcome of the group was that the members were able to have relationships with other people through intercultural exchanges.

Another exception to the general underrepresentation of minorities in support groups is the Brown, Garcia, Kouzekanani, and Hanis (2002) study showing that socioeconomically disadvantaged Mexican Americans had the highest attendance rate at diabetes support groups. The researchers suggested that attendance was good because the groups served a social function for individuals who did not have many other social outlets.

Ashing-Giwa et al. (2004b) studied the breast cancer experience of women and reported on multiethnic cultural issues that included language barriers and the fact that minority women did not seek a second opinion or question the advice of the physician. This is due to the cultural value of respect for physicians as authority figures. The participants in the study said the health care system contributed to treatment delays, which subsequently caused participants to be unfamiliar with and distrustful of the system as a whole. The participants also noted that they had less control over their medical care and were less inclined to participate as health care consumers. Essentially, the participants stressed a need for more affordable and accessible health care. They felt that it was the responsibility of the health care system to become more culturally responsive to minorities by increasing staff diversity and being more knowledgeable about community resources and psychosocial service partnerships or programs. It is likely that many of these attitudes contributed to the facts that minority women were diagnosed with more advanced disease and experienced greater morbidity and mortality. Finally, the women believed that cancer was caused partially by a stressful life and was controlled by having a positive attitude, which they believed

was critical to overcoming the cancer and had numerous cultural manifestations. The participants discussed attitudes of gratitude and faithfulness in overcoming the disease. The researchers posited that minorities' challenges to treatment included language barriers, cultural factors related to beliefs about the illness, gender roles, and family obligations, for example, self-sacrifice. These women expressed that a background in spiritual beliefs was central to their way of coping. In addition, the women had fatalistic attitudes toward cancer in general and viewed cancer as a death sentence. They believed their cancer diagnoses were willed by God, a punishment from God, or their fate, including a belief that the outcome of the illness was in God's control. Many had a strong belief in the power of prayer and thought their spiritual beliefs were more important than help from their health care providers. These factors need to be evaluated in order to understand why some Hispanic women choose to not participate in ICSGs.

Though a Hispanic self-help group can have benefits, these Hispanic-specific studies also showed that numerous factors can interfere with Hispanics' using a support group. A study on Hispanics' attitudes toward ICSGs is needed to determine whether these and/or other factors influence support group participation in the online milieu.

Understand and Encourage Hispanics' Use of All Support Systems

Hispanics look more favorably on support groups that are conducted in Spanish. Even then, a formal support group is not the answer for everyone. Many Hispanics prefer other support mechanisms.

Spanish-Speaking Support Groups/Interpreters

Guevara (2009) discovered that the participants in the research study affirmed their culture's credibility by seeking the use of Spanish, which is the

primary expression of their culture, in important settings such as health education materials and support groups. Perhaps more important, participants were better able to check the credibility of oral and written communications done in Spanish. For example, some study participants wanted more usage of the Spanish language in face-to-face support groups, along with information about cancer. Participants said that the use of their primary language could help them better understand information, establish trust, find acceptance, and be able to be believed. Among the participants in Guevara's study, 66% read and spoke Spanish better than English. Also, 50% had a language-based Deyo acculturation scale score of 1.0, which suggested the persistence of Spanish language use among these participants (Deyo, Diehl, Hazuda, & Stern, 1985). They further expressed that using Spanish would make them more confident about dealing with their illnesses and more willing to trust others with their feelings about their disease. In addition, they believed that their Spanish-speaking support network was one of the reasons they had survived and that the support structure was crucial to recovery because of the different levels of moral, psychological, and spiritual support. Also, they felt that they could persevere and find more acceptance, as they knew that they would receive some help through the support group.

Family Involvement

Guevara (2009) also revealed in his study that some participants clearly valued an effective social network but had no interest in support groups because they could rely on their families and friends (their traditional social supporters) to serve as an informal support group structure. These participants expressed strong identities and attachments with their nuclear and extended families and had feelings of loyalty and reciprocity in being helped by their family members. The

family members who provided the support included spouses, children, grandchildren, and siblings. Because their families were present, the participants said they were motivated to continue with their proper disease management routines and would usually complete their prescribed cancer treatments. Often, the family members would be included in making decisions about the cancer patient's care.

Participants usually held the family unit in high esteem, and for many, this cultural characteristic was an integral part of their support system. Many participants were attached to their nuclear and extended families and were very loyal to their family members, even those who were not part of the their support systems.

Spiritual Support

Spiritual support might replace or decrease the need for any type of secular support group for some participants. For one participant, a secular support group provided spiritual support (Guevara, 2009). Spiritual support came from formally organized churches, more informal spiritual groups, individual relationships with God, and combinations of those categories. Prayer was often identified as a type of support in all categories. Wherever and however participants found a supportive social network with a spiritual aspect, their comments showed that they valued such networking.

The church and other spiritual sources provided the strong support of a social network for some participants. Among these participants, wide variances occurred in their sources of spiritual support, their preferences and aversions to face-to-face and Internet support groups, and their need for a secular support group.

CHAPTER III

ROLE OF THE OCCUPATIONAL AND ENVIRONMENTAL HEALTH NURSE

Occupational and environmental health nurses (OEHNs) play a strategic role in providing information to employees on key needs such as health promotion, disease and injury prevention, health education and counseling, safety, and case management (Randolph, 2003). Importantly, OEHNs also play a key role in recommending cancer support groups to Hispanics who are enduring the cancer process.

Clinician

Randolph (2003) posits that the essential role of the clinician includes the application of the nursing process to direct care for occupational and nonoccupational health injuries and illnesses. An example of a nonoccupational illness includes the diagnosis of cancer in an employee or family member. The registered nurse who is trained in occupational health can serve as the key clinician.

Monitor Employees' Health Status

When an employee is diagnosed with a cancer disease state, many facets need to be included in the effort to provide the employee with optimal care. The oncologist will make the diagnosis and provide medical documentation to the OEHN on the ability of the employee to return to work at full duty or modified duty, as appropriate. An employee with cancer at an advanced stage may not be able to return to work or may need to take time off from work duties in order to receive the appropriate treatment, which might include chemotherapy, radiation

therapy, or surgery. During treatment, the OEHN can provide the necessary monitoring of the employee's health status and consult with the treating physician about the worker's ability to perform the job.

Referrals to Support Groups

The OEHN is in a key position to refer the employee to a support group. Oftentimes the employee is not aware of support groups that might be available. Also, a recently diagnosed employee often faces an overwhelming sense of being out of control and needing direction. One recommendation at this early point might be the support group structure.

Cancer support groups have been shown to be beneficial in helping patients with coping strategies and psychological well-being (Cella et al., 1993; Coriel & Behal, 1999; Presberg & Levenson, 1993; Samarel et al., 1997). Thus, researchers have also reported that there are benefits to early referrals to support groups (Coriel & Behal, 1999; Presberg & Levenson, 1993; Samarel et al., 1997). Thus, an important task for the OEHN is to become familiar with support group participation by minorities.

Families also benefit from support groups. Gartner (1982) discovered that support groups tended to build genuine interpersonal resources for the group members and their families by helping people learn from the experiences of others (Silverman, 1982).

Case Management and Disease Management

Randolph (2003) provides a good definition of a case manager in an occupational health role. The role of the case manager is to establish a provider network and recommend treatment plans that ensure quality and efficacy while controlling costs, monitoring outcomes, and maintaining communication among

all involved. This is important for the Hispanic population in that this promotes *simpatica* and close personal space, both important characteristics for Hispanics. An employee's experience with cancer would improve if the OEHN would coordinate the care, provide follow-up care, and work closely with the treating physician. Knowledge of the cancer disease process is necessary in order to understand the process and recommendations provided by the treating physician. This entire process follows the nursing process, which includes assessment, diagnosis, planning, implementation, and evaluation.

Assessment

Salazar (2006) provides key components of the assessment phase of case management, which is the phase that includes the process used to gather vital health and safety information. Other components of the assessment phase include identifying areas of need for the person who has been diagnosed with cancer. It is also important to take note of the patient's health insurance coverage. Typically, regular full-time employees are eligible to buy insurance coverage from their places of employment, but temporary or contingent workers sometimes do not have medical coverage from an insurance plan. This is important information to have when securing resources for the individual. Starting the rehabilitation work of employees who go through cancer treatment is also important during this phase.

Rogers (2003) summarizes the assessment phase as including initial contact with the employee, defining the areas for data gathering, collecting data, recognizing needs and motives, establishing a relationship, defining roles and expectations, defining the employee's relationship to the problem, and building support.

Planning

Salazar (2006) also provides guidance on the program-planning phase, during which an analysis of the assessment data is reviewed in order to highlight and prioritize the areas where case management services will be needed. Goals and objectives for the case are typically developed during this phase and outlined in a program plan. Importantly, the goals should be presented in broad, general terms that state the expected results of implementing the case management program. This is important for Hispanics in the cultural context, in that it promotes time orientation for those who are dealing with support groups. And, it also involves the worker and the family.

Randolph (2003) provides a summary of this phase. It includes determining timing and readiness, identifying resources, identifying power and legitimacy, determining priorities and goals, determining the appropriate type of intervention, identifying consequences of the interventions, and understanding and being able to proceed to the implementation phase.

Implementation

Salazar (2006) provides information on the implementation phase. It is during this phase that the transition from planning to execution of the plan becomes viable. The schedule for the employee's time away from work or limited duty should be evaluated during this phase, and constant communication with the health care provider and management team is in order. This is important for the OEHN to remember when working with the Hispanic population, particularly with time orientation and implementation of the support group process.

Evaluation

Salazar (2006) also points out that the evaluation phase is used to identify and improve services provided by the OEHN. Other areas to evaluate include management support and physician communication. Areas of improvement should be noted and changed as needed in order to generate better outcomes for the employee. Work accommodations might be evaluated during this phase as well. Also, this could involve active participation in a support group by the employee.

Randolph (2003) provides a summary of the final phase of evaluation. This phase involves using the employee's criteria for success, evaluating the outcome, completing the contract, determining whether follow-up is needed, and finally, writing a report and summary.

Educator

Nurses

Randolph (2003) provides guidance on the role of the educator, saying that the educator's knowledge on issues affecting both nursing practice in general and occupational and environmental health nursing practice should be current. It is also beneficial for the nurse to have adult education and adult learning expertise so that he or she can help teach the employee about the cancer process as the employee receives treatment or progresses past the treatment phase. Much free information is available from the American Cancer Society and the National Cancer Institute. Another valuable component is understanding the culture of the Hispanic population.

Employees

The OEHN is in a strategic role well suited to helping educate the employee on general cancer disease processes. Oftentimes employees do not know who to speak to about treatment modalities or side effects of medications. The nurse is well positioned to serve as a resource for the employee in establishing the contact and making appropriate referrals to other professionals.

Health Care Providers

Due to the rapid pace at medical clinics, medical providers sometimes do not make information about support groups for Hispanics available (Ashing-Giwa et al., 2004b). The American Cancer Society provides copious amounts of information for the providers, patients, and their support systems (ACS, 2009). Such tools are important for the employee who is going through cancer to utilize.

An effort should be made to better educate primary care providers (physicians, nurse practitioners, and physician assistants) on referring Hispanics diagnosed with cancer to a cancer support group at a much earlier time in their diagnoses. Early referral might help to spur the curiosity of the Hispanic population about face-to-face support groups and might eventually lead to their participation in ICSGs.

Researcher

Randolph (2003) affirms that the role of the OEHN is rapidly growing to include research. Occupational health research is necessary to support and expand the knowledge base that provides the foundation of practice. Thus, the role of the OEHN is necessary in helping employees who are faced with the challenge of cancer.

Consultant

Randolph (2003) explains that the role of the consultant is to serve as a resource person to management and to other members of the occupational health team. The consultant assists in evaluating and developing occupational health services by recommending specific actions and alternatives. This is important for the OEHN in making appropriate referrals to cancer support groups for Hispanics who are dealing with cancer.

Line Management

The nurse plays a strategic role in helping line management by providing facts to the managers about the employee's case. An example would be workplace restrictions or accommodations. Of course, confidentiality must always be protected to ensure that any type of medical information is not communicated to the manager unnecessarily. Oftentimes, the nurse is well suited to consult with the manager about key topics related to an employee's accommodation plans.

Community

The nurse is in a key position to consult with members of the community in order to locate various types of support groups for the employee. An example would be contacting the American Cancer Society for names of support groups in the employee's vicinity. Additional information about ICSGs is available through the American Cancer Society and through the National Cancer Institute.

Family

Sometimes the nurse gets phone calls from an employee's family member asking about recommendations for support groups in the community. The nurse can help by providing resources to the family members about various types of support groups in the community. This is important because it provides a

collaboration with the family and addresses the cultural aspect of hierarchical power in attempting to partner with the family for successful outcomes.

Interdisciplinary Involvement

Rogers (2003) supports the interdisciplinary approach in helping to solve some of the challenges that employees encounter while going through the cancer disease process. This team approach involves workers from other areas, including human resources, management support, legal professionals, and employee assistance professionals.

Human Resources

The human resource (HR) professional is often involved in helping define essential job functions of an employee's job and also with assessing the reasonable accommodations process. Rogers (2003) notes that the reasonable accommodation process is a key nondiscrimination requirement of the Americans with Disabilities Act. HR might also help with insurance reimbursement and questions.

Management

The manager is a key decision maker in determining whether the employee can continue to work with restrictions and in providing approval for the employee to be accommodated at a designated work area. This person is in an essential role to provide direction for the employee seeking to be allowed to return to work while ill with cancer and in need of a flexible work schedule.

Legal

In conjunction with the human resource professional, the legal advisor is oftentimes involved in the decision to allow the employee to return to work in a modified duty role or to disallow the employee's return. The collaborative team

effort between the nurse, manager, human resource professional, and legal advisor serves to make recommendations about the employee's return to work and to make appropriate accommodations for the employee.

Employee Assistance Counselors

In some situations, the employee might benefit from counseling due to changes in his or her personal life, work life, or a combination of the two. Sometimes the medical problems, such as those related to cancer treatment, affect the employee's ability to perform the job. The employee assistance team may help employees with such problems. This helps to promote the cultural characteristic of *alloccentrism* by allowing the counselor to serve as an advocate and allow the employee to be influenced by the professional.

Randolph (2003) reports that counseling is designed to give positive reinforcement and to help employees clarify problems and make informed decisions and choices. The OEHN is in a very good position to provide valuable resources, such as referrals to face-to-face support groups, and to counsel the employee who is dealing with a cancer diagnosis.

Challenges

As Carpinello (1995) shared on the advantages of having a Hispanic self-help group in which the members did not know how to communicate in English, a part of the group's goal was for the participants to learn the English language and become able to participate in self-help groups and have intercultural exchanges. Similarly, Hispanics whose English-language skills are limited could learn the language better in an effort to communicate with all non-Spanish speakers. As English proficiency increases among Hispanics, computer usage may also increase, especially usage of cancer support groups and other medical resources

commonly available only in English. Yet another strategy, as revealed by Ashing-Giwa (2004a), is to use bilingual support group leaders in order to help alleviate the language problem. Ideally, the OEHN should be well versed in the Spanish language or have an interpreter available.

CHAPTER IV

CONCLUSIONS AND RECOMMENDATIONS

The Future of Support Groups for Hispanics

The information in this paper may help provide some insights for OEHNs interested in starting a Hispanic support group. Some influences on Hispanic support group participation usage may not change, such as the widespread, strong preferences for social support from families and people in spiritual settings. However, one goal of a support group could be to augment instead of replace preferred support. For example, a support group could have a spiritual basis, or there might be several support groups, one each for patients, families, and supporters such as friends from church. ICSGs could also target people who do not have these supports. The OEHN would also be able to apply these methods in practice and research. The ultimate goal would be to make public policy changes in promoting support groups for the Hispanic population.

The Future for Internet Cancer Support Groups

For existing fans of the Internet, such as an otherwise lonely or isolated person dealing with cancer, an ICSG could improve the online experience by giving participants a well-moderated forum containing good information. Having an ICSG in Spanish would be a major enhancement. Importantly, there is an indication that individuals should be assessed and that general assumptions should not be made regarding Hispanics' inclinations regarding support groups.

As stated earlier, ICSGs have been shown to be beneficial in helping patients with coping strategies and psychological well-being (Cella et al., 1993).

Future studies should help to identify other factors in Hispanics' preferences for face-to-face support groups and reasons they might start to accept ICSGs. Many Hispanic children and other family members are currently using computer technologies. Wuest (1993) also suggests that the research findings should be communicated with the participants and that the discussion should include growth and directions for change in the political or social order. The OEHN is in a vital position to also promote the use of computer technologies among clients and to encourage the use of technologies at home with the remainder of the family.

Research About Hispanics' Use of Support Groups

Because there has been oppression of Hispanics and this group often feels powerless in terms of financial and social status, Hispanics' lives might be enhanced by an OEHN who treats the participants with respect and places value and significance on the exchanged communication (Fawcett & Buhle, 1995). Thus, future researchers should incorporate more research studies for the Hispanic population and allow for more studies dealing with Hispanics, cancer, and the role of support groups.

While some Hispanic parents are not familiar with the computer or ways to access Internet cancer support groups, their children often have that familiarity, at least to some degree, in school. This knowledge about computers may in turn increase computer usage later in life, for example, in cancer support groups. In addition, demand for ICSGs may increase because, as Hispanics in the US age, they will likely follow the trend common to other population groups and develop an increased incidence of cancer (ACS, 2009). The OEHN would be able to promote and encourage the use of computer technology at home.

The OEHN is in an influential role in attempting to assist the employee who is being faced with the challenge of a cancer diagnosis and making appropriate referrals to the cancer support groups. This crucial role provides much direction for the employee in need and allowing a relationship to build for future interactions or further concerns posed by the employee.

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