# Chapter 3
# Latino Cancer Survivors: The Old and the Young

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## Introduction

Latino survivors of cancer, especially the elderly and young children, have suffered from numerous barriers to treatment as a result of economic oppression, physical health, and psychological problems. This chapter explores quality of life issues among children, adolescents and older Latinos and how culturally appropriate interventions attempt to address the physical, social and psychological barriers faced by this underserved population. Long after successful treatment, survivors are often faced with the physical and mental toll of their diagnosis (Ceballos et al. 2015). For example, factors such as poverty, language barriers, lack of proper health insurance and screening for cancer create a greater risk for the advanced stages of the disease once diagnosed (Farone et al. 2008). Physical health-related symptoms of cancer affecting quality of life outcomes are pain, fatigue and physical limitations brought on by the short and long-term effects of chemotherapy, radiation and surgery (Fitzpatrick and Farone 2011). It is not surprising that the survival rate for Latinos is lower than for non-Hispanic whites as they wait longer for treatment even after diagnosis due in part to limited information and access (Wu et al. 2001). However, research has shown that targeted interventions have a beneficial effect on psychological and physical health among Latino cancer survivors (Ceballos et al. 2015).

Although some previous studies have addressed social support and physical activity interventions, they have mainly focused on Latina breast cancer survivors (Ashing-Giwa et al. 2006; Sheppard et al. 2008; Welsh et al. 2005). This chapter is unique because few studies have examined the relationship between various therapeutic interventions as they relate to the quality of life among different age

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groups of Latino cancer survivors experiencing different types of cancer (Fitzpatrick and Farone 2011). Quality of life (QOL) can be defined as the individual's subjective evaluations of physical and psychological health and also by their appraisal and satisfaction with their present level of functioning. The ultimate goal is to shed further light and understanding by exploring existing theoretical perspectives and literature describing interventions such as physical activities, leisure and household activities, church-related activities, social support groups and educational programs. The aims of the chapter will be addressed by focusing on the following:

1. Demographic information
2. Theoretical perspectives specific to Latinos with cancer
3. Review of the literature on various therapeutic interventions
4. Implications for clinical practice and future research.

## *Basic Demographic Information*

The terms "Hispanic" and "Latino/a" are used to refer to persons of Hispanic origin. Much of the research on cancer statistics has been directed towards Latinos in the U.S. and very little research has specifically focused on Latino survivors living in Canada. However, more recent investigations do include both Canada and the U.S. (Canadian Cancer Statistics Publication 2015; Singh and Miller 2004). According to the American Cancer Society (2012–2014), 50.5 million Americans (16 % of the U.S. population) are identified as Hispanics or Latino. By the year 2050, elderly Hispanics/Latinos will total 12 million, eleven times as many as in 2009 (Intercultural Cancer Council 2011; US Census Bureau 2011). As described by Wu et al. (2001), in Fitzpatrick and Farone (2011), the cancer survival rate is lower for Hispanics than for non-Hispanic whites and elderly Hispanics have less information about screening, health prevention and insurance and are diagnosed at later stages of the disease.

Many of the studies focusing on Latinos with cancer have been directed to women with breast cancer (Budhrani et al. 2014; Yanez et al. 2011; Shephard et al. 2007). Yet, older Hispanics are less likely to be screened for breast and cervical cancer than their younger counterparts. Latina women aged 50 and older have the lowest mammogram utilization rates and women 18 and older have the lowest Pap test utilization than other racial and ethnic groups (Intercultural Cancer Council 2011). In addition, elderly Hispanics have a greater number of functional disabilities than elderly non-Hispanics, especially from cancer-related outcomes. This points out the need for continuing education directed toward oncology professionals to enable them to practice more efficiently by addressing the specific challenges of this population.

## Cancer in Latino Children and Adolescence

Cancer in children is rare but in 2014, it is estimated that 15,780 have been diagnosed. Although the survival rate has increased for all types of cancer, nearly 2000 children die of cancer each year in the U.S. thus indicating the need for effective treatments to further reduce mortality (Ward et al. 2014). However, Latino and other minority groups of adolescents and young adults have not received the same survival rates as in older adults and younger children. Of the 724 AYAs studied, 36 % were Hispanics and although, being a male, increasing age, and advanced cancer were associated with elevated mortality, the survival disparity for race/ethnicity existed despite equal access to care.

Few studies are available on statistics among young children and adolescents of Hispanic origin with cancer published in either the U.S. or Canada. However, one study that was published in São Paulo, Brazil (2010), including 10 children and 8 adolescents between the ages of 8 and 18 years, sought to understand the physical and psychological effects of chemotherapy from the perspective of children and adolescents (Chico de Cicogna et al. 2010). Results indicated that chemotherapy is the most employed treatment. The responses from the children interviewed remembered the experience as that of suffering and pain but over time as recovery and cure mainly as a result of the chemotherapy. Quality of life stands out as a priority for the families and their children who have cancer. Several major themes related to quality of life were discussed such as loneliness, isolation, loss of normal childhood, decreased employment opportunities among adolescents, physical discomfort, disability, and emotional responses (Chico de Cicogna et al. 2010).

## Theoretical Perspectives

Many of the theories on ethnic and cultural perspectives that were mentioned earlier may also apply to the elderly, young children, and adolescent Latino cancer survivors. Although, not specific to Latinos, there are several that relate to older adults from minority populations. They are presented in more detail here to further clarify and highlight the experience of cancer and quality of life among these groups. The *double jeopardy hypothesis* (Butler et al. 1991; Dowd and Bengston 1978) was developed to accommodate differences and disparities between Blacks and Whites (Butler et al. 1991), yet it is applicable to other minority groups. This hypothesis is characterized as a double burden resulting from “devaluation in status in society” (Alemán et al. 2000, p. 6). A triple jeopardy scenario can also be applied to those being elderly, being female, and being from a minority group plus having low economic status. *Modernization theory* postulates that as each ethnic society modernizes and becomes more industrialized, the less status the elders’ position in the family carries (Cowgill and Holmes 1972; Markides and Mindel 1987), This may be true in America today as Latinos are becoming a large part of society and changes in the traditional family structure are evident. For example, some elders are now being placed in long-term care facilities when younger family members feel that they can no longer take care of them at home similar to their American and Canadian counterparts. *Assimilation theory* (Markides and Mindel 1987) is also explained by Alemán et al. (2000) in that ethnic and minority status becomes temporary, as when one moves up the socioeconomic ladder towards a middle-class position, cultural distinctiveness becomes absent. This is contrary to the process of a*cculturation* and *cultural pluralism* (Healey 1996; Fitzpatrick 2000; Tran et al. 1996) as now many ethnic groups similar to the Hispanics who have been in America for generations continue to follow their traditions and customs as well as those of the mainstream. *Acculturation* is a process based on language and education (Tran et al. 1996), which for many elderly Latinos can be a major issue and barrier for seeking appropriate health screening and treatment for cancer.

Alemán (2000) in Alemán et al. (2000) explains the system of "*compadrazco*" as a trait in which Mexican American families continue to rely heavily on extended support that is intergenerational, which can include non-blood relatives. The family usually assists in the elder's health care decisions that value the group over the individual. This in most cases can be beneficial for the elder; however, service providers must understand this important family dynamic in order for assistance to be helpful for the family. "*Personalisma*" is another important trait common to most Latinos (Alemán 2000). It is customary and important for the elder to feel that the provider is a trusting person and one who is willing to share his or her person information. If this is not the case, the elder may not return for much needed assistance. For example, the elder may ask the health-care professional personal questions such as, "How old are you? Do you speak Spanish?" or "How many children do you have?" This may seem too personal for the professional but it is essential to "self-disclose" to a certain extent to foster a good working and trusting relationship between the provider and the elder client. While these perspectives are not exhaustive, they do provide further understanding as to how necessary it is for healthcare providers to assess cultural values and make appropriate interventions to older and younger Hispanics and their family members (Alemán 2000).

## *The Cancer Experience Among Latino Children and Adolescents*

Most of the literature on the experience of cancer among children and adolescents addressing conceptual perspectives is directed toward the general population (Bruce 2006; Haase 2004; Simon et al. 2003; Stuber et al. 1997). Few researchers have focused on Latino children and adolescents with the exception of a group of researchers from São Paulo, Brazil. In a study examining motherhood among Hispanic children with cancer, Moreira and Angelo (2008) introduce the perspective of *Symbolic Interactionism.* The main ideas are based on the process of interaction among individuals in which meaning is found between human beings. Therefore, the meaning of the cancer experience for mothers of children is found with interactions between the mother, the disease, the child or adolescents, and the health care team. This interaction includes *interpretation* of important life experiences, which will enable further knowledge and understanding of the reality of the situation (Moreira and Angelo 2008). This will bring a new direction to the lives of the mothers who are caring for a child with an often fatal disease. Another study by Chico de Cicogna et al. (2010) focusing on the experience of chemotherapy and quality of life found revealed several major themes such as loneliness and isolation, loss of normal childhood, decreased enjoyment of food, physical discomfort and disability and emotional responses to cancer. These themes are useful for oncology professionals to understand the experience of the disease in order to help Latino children and adolescents with cancer "to find new ways of coping and living well." (p. 2).

Finally, the development of interdisciplinary healthcare to Latino children and adolescents with cancer in pain situations is examined from the perspective of the *Complexity Paradigm.* This paradigm attempts to address the multidimensional characteristics and the complexity of the reality of the experience without isolating the biological, psychological and social dimensions (Menossi et al. 2008). For example, the pain associated with cancer is seen as a complex phenomenon for healthcare professionals who are attempting to understand the work involved in the process of providing healthcare, and to transform the knowledge into collective actions for children and their families of Hispanic origin.

## Age and Culturally Appropriate Interventions

Interventions designed to improve health and quality of life for vulnerable populations of Latino cancer survivors will be explored along with implications for appropriate clinical practice and future research.

*Physical Activities*: Regular physical activity is said to enhance health and physical functioning in older populations (Satariano et al. 2002). Specific to cancer survivors, different types of sports and physical activities were related to activity levels before and after a diagnosis of breast cancer. For example, decreased activity levels were associated with poorer quality of life after the diagnosis. The need to increase physical activity may provide physical benefits to women with a higher perceived risk of breast cancer (Audrain et al. 2001). A recent study by Fitzpatrick and Farone (2011) indicated that leisure activity participation and especially, household activities were significantly related to self-reported health, cutting down on activities, and depressive symptoms among older Mexican Americans with cancer living in the southwest USA. Household activities such as cleaning the house, preparing meals (light household activities), carrying water and wood, repairs, caring for others, and gardening (heavy household activities), were valued as important activities among Mexican elders.

Although not focusing on Latino elderly, Fitzpatrick et al. (2012) found that physical fitness activities such as any body movement produced by skeletal muscles that results in energy expenditure on a daily basis, is said to help reduce the cognitive effects of chemotherapy among older cancer survivors over the short and long term. Another study promoting the beneficial affects of physical activities by Leimanis and Fitzpatrick (2014) revealed that physical activities preformed at a cancer support center and others preformed at home had a significant effect on distress, in that distress was reduced among the group of cancer survivors.

## *Support Groups*

The *family systems and sociocultural framework* that integrates culture and social class relates to family-focused interventions for families facing cancer (Marshall et al. 2011). Family-focused interventions emphasizing social class (SES), especially among low income families, are necessary for health care professionals to understand in order to provide guidance to cancer survivors and their families. For example, intervention approaches would include the following suggestions; (1) *Flexibility* is needed when working with culturally diverse and low income populations in regards to scheduling of interventions such as health appointments, school, work, and other family responsibilities, (2) Interventions should consider *language* differences and the need to provide bilingual interpreters and providers, (3) *Travel and transportation* may be costly for low income and immigrant families, therefore bringing information into schools and community health centers may be more convenient and assessable, (4) As *financial concerns* may be present, information regarding financial resources should be made available as part of a cancer education program, (5) To create a *child and family-friendly environment*, allowing time for eating and food preparation should be included in the overall program interventions, and finally, (6) *Follow-up and referrals* to community agencies is needed. “Perhaps scheduling a Saturday morning using in-home cancer education programs may result in a referral to a family support groups or even a hospice program for example” (Marshall et al. 2011, p. 91).

In line with the recommendations presented from Marshall et al. (2011), Munet-Vilaró (2004) discusses the delivery of culturally competent interventions for Latino children with cancer and their families. There is a scarcity of research that investigates the factors that can influence the responses to cancer. It is suggested that in order to practice culturally competent care, clinicians (eg., nurses, social workers, oncologists) collaboration between multidisciplinary teams should provide increased awareness and knowledge to help serve the needs of this population. Besides language and information dissemination, clinicians should acquaint themselves with a comprehensive understanding of issues of childhood cancer such as the etiology of specific types of cancer, different treatments, and community resources, and how this knowledge may reflect differences in cultural values and outcomes among Latino children and their families. For example, understanding cultural values such as fatalism, death and dying, suffering, along with differences in coping strategies, can lead to culturally competent interventions that address more adequately the needs of this underserved population (Munet-Vilaró 2004).

## *Senior Centers*

Although not directly related to younger age groups with cancer, participation in senior centers has been shown to moderate stress-related distress among Latino elders (Farone et al. 2005). The results of these studies revealed that for those Latinos who were experiencing stressful life situations, participation in senior center activities lowered their psychological distress. Community Senior Centers provide an array of social supports for older adults and have been "conceptualized as a resource that provides a variety of services, including health, social, nutrition and meal plans, education, and recreational activities, which provide ample opportunities for social interaction" (Farone et al. 2005, p. 66). These centers also serve immigrant populations with cancer. Senior Centers can be seen as an intervention strategy to moderate the harmful impact of stressful life situations (Fitzpatrick et al. 2005a, b). Therefore, the promotion of Senior Centers by professionals can serve as a useful community support for Latino elders with cancer and their families (Farone et al. 2005). Regardless, linguistic and cultural barriers make the use and access to community supports such as senior centers a greater challenge for Latino cancer survivors.

## *Focus Groups*

Ceballos et al. (2015) conducted bilingual and bicultural focus groups by "*promotores*" and face-to-face interviews to address a wide range of burdens that Mexican American cancer survivors and their families experience such as depression, isolation, fear of recurrence, stress and changes in body image. This intervention strategy proved to be beneficial to the cancer survivors who participated. The support groups provided an opportunity for healing and the ability to better understand and cope with their disease on a daily basis. A key role in the successful intervention was played by the promotores, which should be taken into account by oncology professionals when providing future supportive interventions for this group of cancer survivors (Ceballos et al. 2015).

### *Educational and Church-Based Interventions*

Between 1998 and 2001, two church-based interventions aimed at reducing the cancer screening rates were introduced to Latinas with breast cancer living in Colorado, U.S. The objectives of The Tepeyac Project attempted to compare two Tepeyac interventions on the mammogram rates of Latinas and non-Latina whites in the Medicaid fee-for-service program (Welsh et al. 2005). There were 209 churches included in the study that provided educational printed material in Spanish and English. The second intervention involved peer counselors (*The Promotora Intervention*) in which the subjects received personalized education. The effects of the interventions on the rates of mammogram use were assessed between the two groups aged 50–64 years already enrolled in the Medicaid program. The results revealed that the personalized community-based education (*Promotora Intervention*) was effective but only modestly for increasing breast cancer screening rates among the two Latina groups. The authors point out that other services and supports along with church-based education may be necessary (Welsh et al. 2005).

The *Nueva Luz* is an educational intervention developed to address quality of life among Latina breast cancer survivors in the City of Hope, Duarte, CA. The main goal of the program was to provide strategies to assist in the transition to survivorship (Jaurez et al. 2014). The English and Spanish educational intervention was used to access psychosocial issues, which utilized a purposive sample of eight Latina breast cancer survivors. The results indicate that the one-on-one approach, which provides bilingual printed information plus verbal instruction from a bilingual and culturally competent professional, can serve as an effective resource in helping Latina women with breast cancer transition into survivorship and improve quality of life.

Finally, using art therapy as a psychosocial intervention, six young women with a recent diagnosis of breast cancer explored the multi-faceted artist's fold book in an art therapy group at a community cancer support center in Montreal (Laux 2015). The results revealed that young women with breast cancer benefited from participation in weekly art groups allowing themselves to reveal their feelings and concerns in a safe and supportive environment thus helping to improve their quality of life. This would suggest that an innovative intervention such as art therapy would also serve as an effective means for self-awareness among young children and adolescent cancer survivors.

## Summary and Discussion

This chapter has highlighted some of the important survivorship issues, which present considerable challenges for Latinos with cancer, especially among the young and older age groups. Demographic information, theoretical perspectives, and innovative therapeutic interventions have been presented in an attempt to shed light on the cultural context in the delivery of appropriate educational programs and services. Despite improvements in survival rates and more advanced treatments, the cancer survival rate remains lower for Hispanics than for non-Hispanic whites. Elderly Hispanics have less information about screening, health prevention and insurance and are diagnosed at later stages of the disease (Fitzpatrick and Farone 2011; Wu et al. 2001). As described earlier in the chapter, many of the studies focusing on Latinos with cancer have been directed to the delivery of psychosocial services and programs for women with breast cancer (Budhrani et al. 2014; Yanez et al. 2011; Shephard et al. 2007). Yet these educational and supportive interventions are just as relevant for all ages of Latinos despite the fact the older Hispanics as a group experience greater challenges and have less access to education, health and screening services and face limitations due to language barriers and functional disabilities. Young children and adolescents from Latino backgrounds are just as likely as their older counterparts to experience the same barriers and difficulties during survivorship. Furthermore, adolescents and young adults from all racial and ethnic backgrounds (AYAs) continue to experience inferior survival rates compared to older adults and younger children.

Leukemia is the most common cancer in all children. Hispanic children have the highest rate of leukemia of any ethnic group, even higher than African American children (American Cancer Society 2012–2014). The survival rate has improved among Hispanic children, however, it remains lower compared to non-Hispanic children for all types of leukemia. It is suggested that access to treatment may account for some of the differences, yet these differences are also apparent in clinical trials with those who have equal treatment. The disparity may also be “due to high-risk leukemia types among Hispanic children” (American Cancer Society 2012–2014, p. 13). Symptoms affecting quality of life among all cancer survivors and especially in Latino adolescents and children include post traumatic stress syndrome (PSTD) (Bruce 2006; Stuber et al. 1997), pain, dyspnea, nose bleeds, seizures and fatigue (Van Cleve et al. 2012; Menossi et al. 2008), fear, anxiety and depression (Stuber et al. 1997).

The cancer screening rates for all Americans are relatively low; however, people from racial and ethnic minorities have the lowest rates together with those with low income, the elderly and the medically underserved (Centers for Disease Control and Prevention 2001). Many older adults with cancer tend to be underserved and the majority are women from different ethnic groups. Appropriate palliation is less frequent and they receive less aggressive therapy. Current methods of care are often based on assumptions and stereotypical thinking (Surbone et al. 2007).

## *Implications for Clinical Practice and Future Research*

The development of culturally competent care for Latino children with cancer and their families should be first and foremost in importance for oncology and health care providers (Munet-Vilaró 2004). It is important for clinicians to respond appropriately to the specific needs and behaviors that are unique to their cultural norms. For many Latino families facing a life-threatening disease, *Fatalismo* is a way of coping, which many Latinos experience as a deep acceptance of the disease and is therefore beyond their control (Farone et al. 2008). It is suggested that clinicians communicate to family members with translators when necessary, and that despite their resignation and beliefs, it is expected that the best oncology care from professionals will be provided to their child. Many child and family visits take place in the home following lengthy hospital stays, yet it can be threatening when health care providers, seen as strangers, enter the home. Parents of children and their elderly family members may not speak English, however if a translator is available it can eliminate fears of mistrust (Alemán 2000). Alemán states that the concept of trust and mutual respect between the healthcare provider and the family is of utmost importance, especially when working with children, adolescents, and elderly family members with cancer, however, this may take considerable patience and time from the healthcare provider. All members of the family need to be involved, and in most cases they insist, however, they remain in need of on-going communication, education and understanding during the survivorship experience. Although Latino adolescents have been learning English in schools and have become acculturated sooner than their elder family members, they still require information regarding their disease and an opportunity to express their concerns and fears and to also have the opportunity to be involved in decisions regarding their treatment plan.

The need to remain in control and assist in making decisions about treatment is therefore an important aspect when working with adolescents. The Adolescent Resilience Model (Haase 2004) is an example of interventions that address positive health strategies such as hope and coping together with positive support from family, friends and the healthcare team. Considering the challenges in understanding the complexity of working with Latino children, adolescents, the elderly and family members, especially when fate, suffering, resignation and differences in coping styles exist is essential for providers (Munet-Vilaró 2004). Establishing effective interdisciplinary communication is necessary to address the multiple dimensions that compose the healthcare for underserved groups of Latinos during the entire survivorship process.

Future research and policy interventions should focus on enhancing community supports by attempting to include bilingual and bicultural staff and clinicians and targeting appropriate health services, social supports and acculturation needs. Young children and adolescents should be directed toward peer support activities and services that address academic and job-related issues, along with health and disease education for their families. Future research should continue to address issues of isolation, loneliness, and other psychological needs of elderly Latinos with cancer including education and language acquisition plus ways to facilitate the survivorship needs. This will contribute to a more optimistic sense of well-being and quality of life thus reflecting on the individuals ability to remain independent and continue to live in the community for as long as possible (Fitzpatrick 2000). Additionally, and of equal importance, future investigations are needed to evaluate the education and training of oncology and healthcare professionals focusing not only on the disease and medical treatment but on the psychosocial needs. This will provide more culturally competent care for Latino cancer survivors. Oncology practitioners and healthcare workers should remain open to new knowledge, differing beliefs and innovative ways to face the numerous challenges that cancer survivors endure, which will do well to ensure the health and well-being of those we serve (Damskey 2000).

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