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Considerations of Culture and Social Class for Families Facing Cancer: The Need for a New Model for Health Promotion and Psychosocial Intervention

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Abstract

Cancer is a family experience, and family members often have as much, or more, difficulty in coping with cancer as does the person diagnosed with cancer. Using both family systems and sociocultural frameworks, we call for a new model of health promotion and psychosocial intervention that builds on the current understanding that family members, as well as the individuals diagnosed with cancer, are themselves survivors of cancer. We argue that considering *culture*, or the values, beliefs, and customs of the family, including their choice of language, is necessary to understand fully a family's response to cancer. Likewise, acknowledging *social class* is necessary to understand how access to, and understanding of, otherwise available interventions for families facing cancer can be limited. Components of the model as conceptualized are discussed and provide guidance for psychosocial cancer health disparities research and the development of family-focused, strength-based, interventions.

Keywords

low-income; cancer; family; culture; psychosocial

The challenges for families facing cancer are multiple. Family members of an individual diagnosed with cancer are so affected by the cancer experience as to be considered cancer survivors themselves (A National Action Plan, 2004; Rait & Lederberg, 1990). A family-focused approach to cancer allows for a wider view of the disease and its treatment than is typically addressed in clinical settings (Committee on Psychosocial Services, 2007). This

broader view suggests that influences such as *culture*¹ and *social class*² (Trans-HHS Cancer Health Disparities Progress Review Group, 2004) constitute an integral part of the family system and are essential constructs for investigating, understanding, and addressing the challenges and trauma that families with cancer face (Baum & Posluszny, 2001).

Here we use family systems and sociocultural frameworks to advance a model that incorporates culture and social class as they relate to *family-focused*³ intervention and research for families facing cancer. Pasick and her colleagues (Hiatt et al., 2001; Pasick et al., 2009; Pasick, Stewart, Bird, & D'Onofrio, 2001) who work with low-income and ethnically diverse populations found that existing theories and frameworks, developed with predominately affluent and white research participants were less than ideal in developing insights for interventions. Similarly, Rogoff (2003) argued that the study of human development has been based largely on research and theory coming from middle-class communities in Europe and North America, with little regard to cultural context.

The issues are complex. Cancer is not one disease, and the influences of culture and class may well intersect with cancer biology (Cancer Health Disparities, 2008). Low-income status is a significant factor in cancer (Singh, Miller, Hankey, & Edwards, 2003). Culture and social class are not to be equated with biology or race. For instance, according to the chief medical officer of the American Cancer Society:

We must not overemphasize biologic differences between the races as reasons for the disparities.... The vulnerable population is large. Of 285 million Americans, 35 million (12%) are classified as poor.... The absolute number of whites who are poor is larger than the black and Hispanic numbers combined. The same can be said for the absolute number of whites without health insurance. It might be more politically palatable and we might be able to persuade more Americans to support efforts to eliminate health disparities, if the problem is defined in *socioeconomic terms* instead of racial terms (Brawley, 2007, p. 499, emphasis added).

Because social class can limit the access to, as well as the understanding of, otherwise available interventions, consideration of social class and culture is essential in any and all aspects for understanding a family's response to cancer. Ethnographic research has revealed understandings about how cancer must be recognized as socially situated. Balshem's work (1991) in a white working-class community found individuals privileging family and local tradition over information about cancer from medical science. Members of the community highlighted their self-reliance and perceived lack of control in the face of scientific knowledge delivered by higher-status members of society.

While researchers have called for family-focused psychosocial intervention in cancer (Bowman, Rose, & Deimling, 2006; Kim, Loscalzo, Wellisch, & Spillers, 2006; Segrin, Badger, Sieger, Meek, & Lopez, 2006), issues of culture and social class have been largely ignored. Yet, a complex combination of cultural beliefs and structural factors affect access and utilization of cancer screening, treatment, and support (Chavez, McMullin, Mishra, & Hubbell, 2001). Our intention is to lay a broader foundation for family-focused work in cancer care by explicitly addressing the issues of culture and social class which inform

¹Among the definitions offered for culture, we use: "culture refers to the learned behaviors, values, norms, and symbols that are passed from generation to generation within a society" (Loveland, 1999, p. 18). We also note that language is an important aspect of culture (Medina, Marshall, & Fried, 1988). Furthermore, we acknowledge that culture changes over time, may involve multiple and overlapping frameworks, and has permeable boundaries.

²Acknowledging that the terms *social class* and *socioeconomic status* are often used interchangeably in the literature, we prefer the

Acknowledging that the terms *social class* and *socioeconomic status* are often used interchangeably in the literature, we prefer the term social class unless we are referencing work of an author who refers to socioeconomic status. As a category for analysis, *social class* arises from the construction of particular social relations that determine hierarchical relationships (Mullings & Schulz, 2006).

The literature also uses the terms *family-centered*, *family-based*, and *family-oriented*, see discussion at http://familycenteredcare.org/faq.html.

cancer health disparities (Trans-HHS Cancer Health Disparities Progress Review Group, 2004).

We argue that in intervening with families facing cancer, it is not sufficient to use existing models based on individuals and families who are predominately affluent and white, or who come only from middle-class communities in Europe and North America (Hiatt et al., 2001; Pasick et al., 2001, 2009; Rogoff, 2003). A model is needed that focuses on how both culture and social class are immediate and central to understanding how families experience cancer. The purpose of this paper is to use the frameworks of both family systems and sociocultural theory to call for a model that can be applied to health promotion and psychosocial interventions in family-focused cancer care. We begin by addressing the need for family-focused intervention, provide justification for such interventions to be based in an understanding of culture and social class, and conclude with examples of how understanding what we do not now usually consider, will help.

Understanding Families and Cancer

Families serve fundamental social roles in our society. From various theoretical lenses, families are thought to exist for the purposes of survival and attachment security (Bowlby, 1969/1982; Hrdy, 1999). Further, family members provide protection and nurturance for their young, support and care for their ill (Rait & Lederberg, 1990), and scaffold one another through generational experience for life transitions. This work of families is both bolstered and informed by culture and social class—by family values, beliefs, customs, and language. Individuals and culture mutually influence one another, a major tenet of sociocultural theory (Rogoff, 2003).

The term "family" is used broadly in the literature and may refer to a primary caregiver or support person, a close relative, or a spouse, among others. Gilgun (1992) noted that in addition to legal and biological factors which define family, persons define themselves as members of families, demonstrate commitment, and share a personal history. While much of the understanding regarding the role of the family in cancer has been based on understanding the role of the family in other chronic illnesses (Baider, Cooper, & Kaplan De-Nour, 2000; Ell & Northen, 1990; Nijboer, Triemstra, Tempelaar, Sandman, & van den Bos, 1999; Weihs, Fisher, & Baird, 2002), family support is believed to be a significant factor in coping with cancer (Guidry, Aday, Zhang, & Winn, 1997; Mokuau & Braun, 2007; Suinn & VandenBos, 1999; Woods, Lewis, & Ellison, 1989), and may affect the cancer survivor in terms of improved disease outcome (Weihs et al., 2005).

Family members serve as a resource for patients making critical decisions about treatment (Speice et al., 2000). Issues of culture, social class, and family support among medically marginalized patients have surfaced in the psychosocial oncology literature. For instance, in a study of women from four ethnic groups, family members of low-income Latinas with cervical cancer were found to provide critical social support and motivation for recovery (Ashing-Giwa et al., 2004).

It is important to understand not only the supportive and instrumental roles family members can play in cancer treatment, but also how providing support affects the quality of life of family members (Feigin, Barnetz, & Davidson-Arad, 2008). Family members can be recognized as co-survivors of cancer—among those so affected by the cancer experience as to be considered cancer survivors themselves (A National Action Plan for Cancer Survivorship, 2004). Many studies have documented that family members face significant stress themselves from a relative's diagnosis of cancer (Baider & Kaplan De-Nour, 2000; Bowman et al., 2006; Ferrell, Ervin, Smith, Marek, & Melancon, 2002; Gustavsson-Lilius, Julkunen, Keskivaara, & Hietanen, 2007; Raveis & Pretter, 2005; Sheldon, Ryser, & Krant,

1970; Weihs, & Reiss, 2000). The psychological impact of a cancer diagnosis—for instance, stress and depression—on the lives of family members is understood (Alferi, Carver, Antoni, Weiss, & Durán, 2001; Badger, Segrin, Meek, Lopez, & Bonham, 2004, 2006; Carter, 2003; Edwards & Clarke, 2004; Mokuau & Braun, 2007; Rothschild, 1992; Speice et al., 2000).

Across cultures, female caregivers are particularly burdened (Mittelman, 2005). For instance, female partners of those with cancer reported more anxiety and depression than male partners (Gustavsson-Lilius et al., 2007). Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008) found that during the cancer experience, women were more distressed than men regardless of whether the women were in the survivor or co-survivor role. While we can learn a great deal from interventions found to be effective that involve the spouse/partner (Shields & Roussseau, 2004), our review of the literature confirms that family members beyond the spouse/partner are affected by cancer and may benefit from intervention as well (Badger et al., 2004, 2006).

Researchers recognize that little research has been done that directly addresses the family system in cancer intervention or treatment (Carter, 2003; Isaksen, Thuen, & Hanestad, 2003; Marshall & Crane, 2005; Northouse, Kershaw, Mood, & Schafenacker, 2005). Much work remains in developing sustainable community-based and community-appropriate intervention for families affected by cancer. A recent Institute of Medicine report found that psychosocial interventions in cancer care are "the exception rather than the rule" (Committee on Psychosocial Services, 2007, p. 1).

Cancer Health Disparities: A "Complex Interplay" of Culture and Social Class

"My parents came from poor people who came from poor people who came from poor people, all the way back to the very first poor people."

Sherman Alexie, 2007

The Absolutely True Diary of a Part-time Indian

Culture shapes how individuals obtain and express their need for social support (Kim, Sherman, & Taylor, 2008). Culture, as values, beliefs, and customs, is passed on, and enacted, through family. Consideration of culture often means consideration of family (Marshall, 2006, 2008; Robertson & Flowers, 2007). One comes to the importance of working with families both from their role in the cancer-related system (Weihs & Reiss, 2000) and from a perspective of culturally-appropriate intervention (Rogoff, 2003). We must think about culture in developing and testing interventions to help families cope with cancer.

Acknowledging the work of Pope-Davis and Coleman (2001) among others, Liu et al. (2004) stated that "along with race and gender, social class is regarded as one of the three important cultural cornerstones in multicultural theory and research" (p. 3). Social class is a complex topic, and becomes more complex as it intersects, for instance, with ethnicity and race (Cohen, 2009; Cole, 2009; Reid, 1993). While social class often refers to income status, it also indexes people according to education and type of work. We argue that as social class figures largely in cancer prevention and control (American Cancer Society, 2003; Leybas-Amedia, Nuno, & Garcia, 2005; Marshall, 2008; Nijboer et al., 1999), it cannot be ignored in the science leading to or in carrying out interventions with families facing cancer (Cella, et al, 1991). The American Psychological Association provides assistance to organizations intending to provide interventions in cancer health disparities through its Socioeconomic

Status-Related Cancer Disparities Program (http://www.apa.org/pi/ses/programs/index.aspx).

We understand that "delay in diagnosis of cancer is ... found in patients of lower socioeconomic status, particularly in minority populations" (Raghavan, 2007, p. 495). Moreover, income and social class have been shown to affect the type of cancer treatment and support individuals and families seek or are offered (Eversley et al., 2005; McGinnis et al., 2000; Maly, Liu, Kwong, Thind, & Diamant, 2009). Low-income women are more likely to receive mastectomies instead of breast conserving lumpectomies (McGinnis et al., 2000) and to suffer symptoms from treatment (Eversley et al., 2005). Low-income women are also less likely than higher income women to discuss breast reconstruction with their doctors (Maly et al., 2009). Socioeconomic status (SES) has been found to account for differences in caregiver experiences (Nijboer et al., 1999).

After reviewing the available research for his work *Poverty, Culture, and Social Injustice: Determinants of Cancer Disparities*, Freeman (2004) noted that "poverty drives health disparities more than any other factor" (2004, p. 74). Among his conclusions: "Residents of poorer counties, irrespective of race, have higher death rates from cancer. Moreover, within each racial/ethnic group, viewed separately, those living in poorer counties have lower cancer survival. Disparities in cancer are caused by the complex interplay of low economic class, culture, and social injustice, with poverty playing the dominant role" (p. 76). Consider the inhabitants of Appalachia, a diverse group in terms of race, ethnicity, and culture. The region has long been of concern in regard to cancer health disparities (Kirschstein & Ruffin, 2001).

One common cultural trait is shared by northern and southern mountain people: poverty. Overall, the people of Appalachia are unemployed more often than people in the rest of the United States, have a lower median family income, and have lower educational levels. They also have higher levels of health-risk behaviors ... [i.e.,] high levels of smoking and physical inactivity and low rates of mammography and colon cancer screening. Where there is poverty, there are high rates of disease. Compared with the U.S. population as a whole, residents of Appalachia have higher death rates from heart disease, cancer, cerebrovascular disease, obstructive pulmonary disease, diabetes, and infant mortality.... (Wilcox, 2006)

As a second example, consider the specific needs of low-income Hispanic families facing cancer. Hispanics, also referred to as Latinos, and also a diverse group (Flores, Aguado Loi, San Miguel, & Martinez Tyson, 2010), "are now the largest race/ethnic minority group in the United States" and "by any measure of social class, Latinos are concentrated in the lower segments of the national socioeconomic distribution ... [with] Latinos of Mexican origin ... [having] less than a high school education" (Zsembik, 2005, pp. 40–41). Similar to the "complex interplay" observation by Freeman (2004), Angel and Angel (2005) referred to the "complex interactions among factors associated with poverty, such as race and Hispanic ethnicity" (p. 157) as having a major influence on family health and access to health services.

While it is understood that low-income status puts one at risk for cancer, it is also possible that cancer puts one at risk for low-income status. From a social class perspective, "one-third of cancer patient families, especially those who are younger and have lower income, face a substantial threat to their financial security from cancer in the USA" (Weihs & Reiss, 2000, p. 26). The full direct and indirect economic effects of cancer on families may be substantial but they are also unknown. Studies have described the economic consequences for the individual cancer survivor, but the impact on the family can be only inferred. For instance, researchers have found that in addition to individual earnings, total household

earnings fell for cancer survivors, suggesting that the productivity and/or economic status of the family was affected (Chirikos, Russell-Jacobs, & Cantor, 2002).

A Model that Considers Culture and Social Class

"All patients with cancer *and their families* should expect and receive cancer care that ensures the provision of appropriate psychosocial health services....It is not possible to deliver good-quality cancer care without addressing ... psychosocial health needs" (emphasis added).

Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs, 2007

Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting Institute of Medicine of The National Academies

The connection between social class, cancer, and cancer health disparities is established. It is therefore surprising that social class is not systematically acknowledged as a relevant factor in psychosocial oncology—in particular, in research providing evidence for family-focused intervention. It would appear that a new model is needed—given the likely impact of class and culture on family dynamics and cancer care access —a model that makes explicit the possible influence of both factors. As a suggested starting point, we conceptualize a model (see Figure 1) allowing for multiple intersections of culture and social class to serve as a guide for the development and testing of new psychosocial interventions for families facing cancer.

To develop our model, we drew on family systems (Kantor & Lehr, 1975) and sociocultural theory (Rogoff, 2003). From a family systems perspective, families are considered to be mutually dependent or interconnected. The family system must be considered in its entirety and viewed as a whole, rather than understood simply from the combined characteristics of each individual family member (Kantor & Lehr, 1975). Family exists and is maintained through its interconnectedness with all family members. The cancer experience is understood then to involve the family rather than being understood via focus on only one individual (e.g., the person with cancer).

The use of sociocultural theory provides the understanding that culture is *not* a separate, individualized entity that influences individuals, and families indirectly (Rogoff, 2003), but instead argues that people contribute to the creation of culture and culture contributes to the creation of people. In contrast to theories that place culture as more distal influences on individuals and family (e.g., Bronfrenbrenner, 1979), sociocultural theory argues for the proximal influence of culture on individuals and family.

There does not appear to be a similarly relevant "socioeconomic theory," yet a family systems framework based in clinical application provides specific direction for working with low-income families (Minuchin et al., 2007). In sum, and from both family systems and sociocultural theory, the idea is that in order to understand how individuals and families seek and use cancer-related services, emphasis needs to be given to how family members are interconnected and mutually influence once another, as well as how culture is essential and proximal in the lives of individuals and families. We argue that social class stands with culture in regard to providing essential context for understanding families and agree that "socioeconomic factors and social class are fundamental determinants of human functioning across the life span, including development, well-being, and physical and mental health" (American Psychological Association, 2007, p. 1).

Finally, researchers have found that Mexican-American and Appalachian families, for instance, reach first to resources that are known and comfortable when learning about cancer

—the wisdom to be gained from the stories of relatives and friends—before seeking information from the unknown and the unfamiliar (Behringer & Friedell, 2006; Wells, Cagle, Bradley, & Barnes, 2008). Because families, operating within the context of their culture (Rogoff, 2003), both inform and support the treatment of their ill family member, interventionists need to identify and work with this family-based effort to achieve optimal results in their health promotion, preventive intervention, or treatment.

With a cancer diagnosis, "serious deflection of the family's life course is likely to include distress and dysfunction for family members, and perhaps compromised medical outcome for the patient" (Weihs & Reiss, 2000, p. 26). Teschendorf et al. (2007), for instance, found that conflicts among family members were related to different opinions about how best to assist their loved one and recommended that those intervening needed accurate understandings of both challenges faced by the family and help desired. Experts in family and chronic disease have called for practitioners to "de-emphasize a one-size-fits-all intervention philosophy" and to "tailor application of the intervention so that it ... fits the family's lifestyle, culture, and level of need for intervention" (Weihs et al. 2002, p. 26). Thus the proposed model could provide guidance for testing and understanding which psychosocial interventions in oncology work best for which families in a given cultural and social class context.

For instance, a family-focused approach has been called for in working with Hispanic families facing cancer (Flores et al., 2010). Our proposed model makes explicit the cultural context and subsequently, the imperative to allow for more than one family member at a time to accompany a person during chemotherapy. An illustrative example: a Mexican-American, 51-year old women receiving chemotherapy at a comprehensive cancer center reported, "They won't let more than one person stay with you. My first day of treatment, my mother and my son were with me—my son was so upset. They made my mother and son take turns who was going to sit with me—one had to go outside to that waiting area while one was sitting with me. Then they would switch off" (personal communication, December 4, 2007).

Culture needs to be explicitly considered in terms of health promotion and psychosocial interventions for families facing cancer, as demonstrated by the family with depressed parents intervention as recently adapted for use in low-income Hispanic families (D'Angelo et al., 2009). Further, as we have argued throughout this paper, social class, while not generally considered by practitioners in developing interventions, indeed has a role, along with culture, in tailoring interventions appropriately as in understanding and documenting cancer health disparities.

Since social class stands along with culture in our proposed model, its influence can not be ignored when the model is used as a framework for either research, health promotion, or psychosocial intervention. Researchers have recommended that SES be acknowledged in research design, to understand any confounding influences (Aranda & Knight, 1997; Connell & Gibson, 1997). Cella and colleagues concluded in their seminal work regarding SES and cancer that "because SES is related to survival independent of all known prognostic variables, it should be included in the data bases of clinical trial groups to provide a more accurate test of the effectiveness of new therapies" (Cella, et al.,1991, p. 1500). Such inclusion has not occurred over the past 20 years (Education Network to Advance Cancer Clinical Trials, 2008).

Suggested Approaches in Constructing Cancer Education Programs and Research

It is our hope that a better understanding of how culture and social class contribute to cancer-related health disparities may enable practitioners to eliminate undesired disparities

using appropriately tailored interventions and research. Having established the disproportionate cancer burden affecting low-income populations, we take direction for our suggested approaches from the position that "SES factors are mutable with appropriate effort and program planning that has a national scope but a local emphasis" (Cella, et al., 1991, p. 1507). Here we intend that our suggested approaches, focused on cancer education and awareness of treatment options, demonstrate how components of the model as conceptualized can inform others both in constructing programs and in designing research that can provide evidence for program effectiveness.

A focus on culture and social class, particularly as the latter relates to low-income families, can bring into focus pejorative perspectives of the populations served—certainly this has been the case historically. As a counter to this concern, it is recommended that the model be used with a strength-based orientation. A strength-based perspective (Beardslee, & Knitzer, 2004; Beardslee & MacMillan, 1993) has been promoted by practitioners and researchers working in wide range of human interventions and problem-solving. Such a perspective constitutes an important step in working with low-income and ethnically-diverse families (Bell-Tolliver, Burgess, & Brock, 2009; D'Angelo et al., 2009) and has been used in interventions with families facing cancer (Bugge, Helseth, & Darbyshire, 2009; Nieto & Day, 2009; Niemelä, Väisänen, Marshall, Hakko, & Räsänen, in press)

While disparities due to lack of knowledge about signs, symptoms, screening/early detection programs, and availability of treatment have long been documented in regard to low-income families (Cella, et al.,1991), barriers to accessing available psychoeducational cancer information related to low literacy and comprehension continue (Messner, 2005). Cancer education should be appropriate for a given local culture; processes employed in delivering the education should consider accommodating social class as well. Below, we give specific examples of processes and content from our local experience in working with low-income and ethnically-diverse populations. Our examples are not unknown and are substantiated in the work of others (Cowan, Cowan, Kline Pruett, & Pruett, 2007; D'Angelo et al., 2009; Messner, 2005).

Flexibility—D'Angelo and colleagues (2009) noted that "flexibility and appropriately adapted to meet the cultural complexities of a diverse society" (p. 272) are key when working with low-income populations, even for manualized intervention programs. Flexibility in regard to temporal requirements has also been found to be important, as has the scheduling of interventions due to work schedules and requirements of various family members.

Language—Following a model of a family intervention that includes acknowledging culture may involve conducting the intervention in languages other than English and using bilingual and bicultural providers.

Travel—Because low-income families may be lacking transportation or have problems with travel logistics, we suggest bringing evidence-based cancer information into their homes or natural gathering places such as schools or local health clinics.

Financial concerns—Because lack of access to care can be tied to financial concerns (Ell, et al., 2008), cancer education with low-income populations needs to include information regarding financial resources. Financial concerns can be exacerbated by immigration concerns so that financial resources available without regard to immigration status may also need to be a part of a cancer education program (Wells, Cagle, Bradley, & Barnes, 2008).

Child- and-family friendly environments—Child care or tolerance for children in groups should be expected. Food, often recommended for groups given various ethnically-diverse populations, might be appreciated by low-income families who may not have time to prepare or eat meals prior to a cancer education class. Even if outside organizers do not provide the food, community partners might and so time for eating the food should be calculated into the overall program time needs.

Follow-up and referrals to community agencies—Cancer education for low-income and ethnically-diverse families may not stop with the end of a given class period or program. Facilitators may find that follow-up to other community agencies is needed. In our experience, a Saturday morning, in-home cancer education program resulted in a referral to hospice.

Conclusion

In conceptualizing an initial model that considers both culture and social class for thinking about and intervening with families facing cancer, our hope is that the model will not only stimulate thinking about the issues involved, but also promote specific attention to program components and/or adaptations needed when working with low-income and ethnicallydiverse families. The model presented here draws on existing family systems framework and sociocultural theory. Given the cancer experience, the model locates cancer survivors within a family. Family members, as well as the individuals diagnosed with cancer, are understood to be co-survivors of cancer. The model provides an overall framework depicting the reality of both culture and social class as essential context within which the family and its needs can be addressed. For instance, what we know about the role of culture and social class in cancer-related health concerns such as smoking and obesity (McCarthy & Visvanathan, 2010; Nagaiah, Hazard, & Abraham, 2010; Yang, Lynch, Schulenberg, Diez Roux, & Raghunathan, 2008) may inform our understanding of culture and social class in terms of cancer care. Evidence supporting the need for family-focused interventions is poised to affect the training of health care professionals and health care policy (Aranda & Knight, 1997; Gonzalez, Steinglass, & Reiss, 1989; Marshall & Crane, 2005; Segrin et al., 2006; Wells, Cagle, Bradley, & Barnes, 2008). Using a model that considers culture and social class with families facing cancer serves to remind us in both research and practice that culture and social class are factors known to impact the cancer experience. Placing these factors in the foreground provides needed guidance for cancer-related health disparities research; for the development and testing of tailored family-focused, strength-based, psychosocial interventions; for training, and for health care policy.

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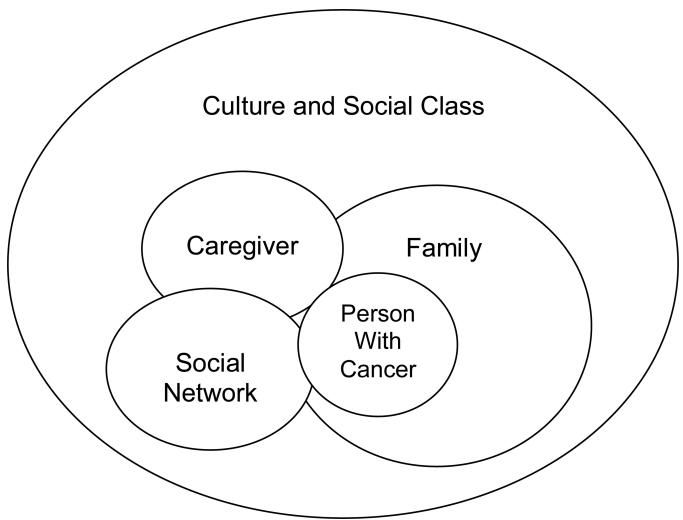


Figure 1.Conceptualizing an initial model considering culture and social class with families facing cancer