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Tongan perceptions of cancer

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Abstract

Tongans in this study had a limited amount of information about cancer; however, they felt strongly that having cancer was the equivalent of death. Our findings will help in the development of culturally sensitive cancer education for the US Tongan community.

Background—There is little published information about cancer related knowledge, attitudes, and preventive behaviors of Tongans in the United States. The purpose of this study was to evaluate answers to the following questions: *What is cancer? What Causes cancer? And what can you do to prevent cancer?*

Methods—We completed face-to-face, semi-structured interviews with 48 self-reported Tongans (12 men and 36 women) over the age of 18 years, selected through non-probability purposive sampling with help from Tongan community-based organizations. The questions regarded demographic characteristics, and cancer-related knowledge, attitudes and preventive behaviors. The research settings were San Mateo, California and Salt Lake City, Utah. We analyzed the data using qualitative content analysis of individual interviews to identify themes.

Results—All but one of the 48 participants had migrated to the US from Tonga. The average income was approximately \$3,100 per month and average household size was six. Fewer than half of participants had health insurance. The theme that cancer was equivalent to death was pervasive through all the responses. Weaknesses in the body and exposure to toxins in the environment were dominant themes in the causation of cancer. Leading a healthy life and prayer were among the preventive measures cited by the respondents.

Conclusion—The association of cancer with death is a strong indication that cancer information is not reaching this community. Interventions must take this into account include Tongan cancer survivors in order to enhance the effectiveness of early screening efforts.

Keywords

Knowledge, attitudes, and behaviors; cancer prevention and control; special populations, Tongans

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INTRODUCTION

Previous efforts to understand the cancer control needs of underserved populations have often overlooked Pacific Islanders. Their needs are obscured in part because of the aggregation with Asian populations whose education levels and economic status are often higher. Recent studies have begun to document the cancer control needs of some Pacific Islanders: Native Hawaiians [1], American Samoans [2,3], and Tongans [4]. These studies suggest that cancer- screening rates are generally low and that cancer awareness is limited in these populations. However, there is still a paucity of information regarding the cancer control needs of Pacific Islanders.

Very little cancer control research has been conducted among Tongans, the fourth largest Pacific Islander group in the United States (US). The only study to evaluate use of cancer prevention services found extremely low rates of mammography screening in a convenience sample of Tongan women [4]. To improve cancer awareness and increase the use of cancer screening services, it is necessary to determine Tongans' understanding of cancer. Studies from many underserved populations have shown that interventions that incorporate cultural values and focus at an individual level are more effective in changing behavior than decontextualized medical information [1,5–7].

The investigation described herein will provide vital baseline data that will assist in a better understanding of how Tongans' knowledge about cancer may influence their use of screening services and in the creation of interventions tailored to the meet the knowledge and economic needs of this community. However, before discussing the study, it is important to provide background information about Tongans in the United States, concepts of health, use of medical services, and cancer control needs.

Tongans in the United States

The history of Tongan migration to the U.S. from the independent nation of Tonga is relatively recent. Sponsored by churches such as the Latter Day Saints, Catholic and Protestant, Tongans began to migrate in the 1950s in search of educational and economic opportunities [8]. The 1965 changes in immigration laws enabled many immigrants to assist their siblings and parents in joining them in the U.S., primarily in Hawaii, California, and Utah. Family and church obligations played a central role in the daily lives and the building of community for Tongans in these sites.

Tongans are the fourth most populous Pacific Islander group in the U.S. According to the Census, 398,835 "Native Hawaiians and other Pacific Islanders" lived in the U.S. in 2000 [30]. Of these, 27,713 are Tongan. There are approximately 12,000 Tongans in California half of whom live in Northern California (San Francisco Bay Area) and approximately 9,000 reside in Utah. Tongans are relatively young (average age 23 years) and have large families (4 persons). Approximately 23% of Tongans have incomes below the poverty level (compared with 10% nationally) with the per capita income being less than half the national average (\$6,144 for Tongans compared with the \$14,143 national average) [9].

Given the recent history of Tongan migration, there is little published research regarding household composition and community in the United States. To our knowledge, Small [8] is the only researcher to examine Tongan migrants in the United States. Her research suggests that, like other Pacific Islander migrants, new arrivals typically live with a relative when they first arrive. This household assists in providing food, economic support and help finding employment. Once that migrant is financially stable, they may move out and begin a new household of their own. Often, elderly or young migrants may stay permanently in the original household. Even though someone moves out of the household they will be mutually obligated

to contribute aid and collecting contributions for family or community events. The success and well being of a family is achieved through maintaining obligations to care for each other.

While obligations to family and community in the United States are a component of daily life, Tongans must also maintain their relationships with their families in Tonga. Sending home remittances often helps in paying for the education of a niece or nephew, building a new home, or supporting a community improvement project in their home village. Remittances contribute to the prestige of the family in Tonga, maintain connections to Tonga, but more importantly show fulfillment of obligations to family, church and country.

The intimate link between migration to the United States and the church are reflected in the centrality of and obligation to religious functions. Churches play important roles in the daily life of U.S. Tongans. There are dedicated Tongan services, Tongan choirs, youth groups, women's groups and Tongan dances. The church is a center for community interaction, an opportunity to meet and socialize with Tongan migrants from other villages. Many weekends are often filled with Tongan community and church activities.

Concepts of Health

An explicit goal of cancer screening is to detect the disease before there are symptoms, while it is still treatable and before it has spread to other parts of the body. To attain this goal it is necessary for individuals to seek care when they feel healthy, that is they must seek care in order to confirm a state of health. These goals and expectations for preventive health care make sense if one believes that health is defined as the absence of disease, a belief that is pervasive in Western culture and the history of modern medicine [10–13]. However, the notion of preventive health care may not be salient for people who hold alternative concepts of health.

Tongan concepts of health are defined by a constellation of relationships maintained with both the living and deceased throughout life [14,15]. As McGrath [14] notes, “health in Tonga... includes having a good life, of being lucky or fortunate, of being satisfied that you are fulfilling duties to God, country and family. Health includes all of these feelings, and illness strikes when anyone is out of balance.” This social relational concept of health has important implications for Tongans' (and most Pacific Islanders') use of preventive care. Prevention, within this framework of health, focuses on maintaining obligations and relationships with the family, church, and the Tongan community. As a consequence, health care is often sought only when symptoms prevent an individual from fulfilling an obligation.

Use of Medical Services

Contemporary studies of medical care use in Tonga show that medical pluralism is the rule and not the exception [14–16]. While there are distinctions between categories of diseases, *mahaki faka Palangii* (European illnesses) vs. *mahaki faka Tonga* (Tongan illnesses) or *puke* (just sick), the cause of the illness is often determined by the treatment method that worked. For instance, if one went to a *toketa* (biomedical practitioner) and the treatment succeeded in alleviating or curing the illness, then the illness could be categorized as a *mahaki faka Palangi*. However, if that person was not healed, they would then seek treatment from a *faito'o* (Tongan medical practitioner). If the illness was subsequently alleviated or cured then the illness would be considered *mahaki faka Tonga* (either natural causes or caused from spirits of a departed relative). Thus the link between health and meeting family and community obligations is reinforced.

Interestingly, the medical pluralism evident in Tonga today is intimately linked to the Christian church. The purpose of Christian missionaries was to save the souls of the people. To attain their goal, they needed to bring native converts to their sermons, a task that was not easily

achieved. When the early missionaries noticed that villagers traveled great distances for medicines they added dispensaries as part of their mission [14,17]. Thus, the church could both save the spiritual soul and the physical body.

Cancer Control Needs

Until recently, Pacific Islanders received little attention from the cancer control research community. However, during the last decade, investigators have begun to conduct developmental research regarding the cancer control needs of Native Hawaiians and American Samoans. From that research, we know that Native Hawaiians have the highest incidence and mortality rates for breast cancer of any ethnic group [18]. These findings contrast markedly with previous findings that noted significantly lower rates for “Asian American/Pacific Islanders”. Research among American Samoans revealed higher site-specific incidence rates and late stage of diagnosis for certain cancers [19–21], limited knowledge about biomedical views of cancer [2], and low use of screening services in this population [21,22]. In response to these findings, culturally tailored intervention programs have begun to address the needs of Native Hawaiians [23] and American Samoans [24].

In contrast, very little cancer control research has been conducted among the other major U.S. Pacific Islander groups, like the Tongans. In the only study to evaluate the cancer control needs of Tongans, Park Tanjasiri examined breast cancer knowledge, attitudes and screening behaviors of these Pacific Islander women in Los Angeles and Orange County, California [4]. Using convenience sampling, she found that cancer-screening rates were lower than the national average for Tongans. She also found that Tongan women faced considerably more structural barriers (income, insurance, transportation) to mammography screening (only 23% of Tongans had ever had a mammogram). Additionally, answers to questions regarding cancer KAP from National Health Interview Survey (NHIS) Cancer Control Supplement and focus groups revealed that the women were less likely to agree with biomedically defined risk factors, signs, and symptoms.

Park Tanjasiri’s study gave us a glimpse of the barriers that must be overcome to address the cancer control needs of Tongans. However, much more information about the meaning of cancer and cancer prevention services is necessary in order to develop effective culturally tailored programs to address those needs. The purpose of this study was to assess cancer-related knowledge, attitudes, and behaviors among Tongans residing in the United States. The results provide important insights into the Tongan knowledge as it pertains to cancer and may serve as a foundation for future cancer prevention programs.

MATERIALS AND METHODS

We conducted in-depth qualitative interviews to accomplish our research goals. The interviews, which were based on an ethnographic method, allowed us to elicit the cultural meanings of cancer and individual cancer narratives. Ethnography, which is a systematic description of social groups, focuses on patterns in cultural knowledge and practices, and does not assume that researchers are aware of all relevant questions and issues [25]. This approach is particularly useful for this study. The participant is permitted to tell the researchers what they know and think about cancer prevention and detection. In our previous research, we found that ethnographic methods were very effective as an initial approach to learning about cancer-related knowledge, attitudes, and behaviors (KAB) [26–30]. The research settings were San Mateo, California and Salt Lake City, Utah, cities that contain two of the largest populations of Tongans in the United States. The University of California, Irvine Human Subjects Review Committee approved the research protocol.

Research Design and Recruitment Strategy

In order to begin to understand what the US Tongan community thought about cancer and cancer prevention, the Pacific Islander Cancer Control Network Tongan community advisory boards [31] and our research group drew on the strong ties between community and church. Using a non-probability purposive sample design, community partners contacted local churches, described the parameters of the study and asked for Tongan volunteers 18 years of age or older. Once potential participants were identified, a time was scheduled for a face-to-face interview in a location where the participant would feel comfortable. A total of 57 individuals volunteered; however, only 48 of them (32 women and 16 men) completed the survey.

Survey Instrument

We developed a semi-structured survey instrument containing closed ended and open-ended questions. The questions regarded demographic characteristics, and cancer-related knowledge, attitudes and preventive behaviors. We focused specifically on three questions: What is cancer? What causes cancer? and What can you do to prevent cancer.

Data Collection

After obtaining verbal informed consent, a total of 48 interviews were conducted by trained bilingual Tongan research assistants and the lead author (JMM). The interviews lasted between one and four hours and were conducted in either Tongan or English, depending on the participants' preference. With the participant's permission, the interviews were audiotaped. Participants were given a gift of thirty dollars for their participation.

Qualitative Data Analysis

In preparation for analysis, the interviews were transcribed, and those that were conducted in Tongan were translated into English by certified translators. The transcriptions were first analyzed for recurring themes. Once key themes were identified the transcripts were reread and coded for these themes. We then coded each interview for those themes in a text analysis program (QSR N-Vivo). This iterative process allowed us to determine the frequency of the themes and recognize any patterns within the text of the interview.

RESULTS

All but one participant had migrated to the US from Tonga (Table 1). The majority had obtained most of their schooling in Tonga before migrating. The average income was approximately \$3100 per month and average household size was six. Fewer than half of participants had health insurance.

Table 2 summarizes the themes that emerged in the qualitative interviews. Review of the transcripts revealed that participants were deeply concerned that the incidence of cancer was increasing within the community. This concern was magnified by numerous reports of loved ones who had been diagnosed with cancer and did not survive the treatment. Indeed, there was a striking amount of fear and dread about the disease. While some respondents focused on cancer as a disease of the white man, these comments were mentioned among only a few of the participants. Interestingly, the disease was individualized, focusing on individual practices, "weaknesses" in the body, and how those weaknesses were exacerbated by exposure to toxins in the environment and food. As a result, issues of prevention focused on individual practices, but were also infused with the view that little is known about the disease and thus, there is no way to survive a cancer diagnosis. Consequently there is a sense that if cancer is equivalent with death then there is certain amount of futility in attempting to prevent something that is as

inevitable as death. What follows is a presentation of some of the voices of our participants and their thoughts on what cancer is, how it is caused and how one might prevent the disease.

What is cancer?

Our conversations highlighted the scarcity of cancer information on biomedical advances in detection or treatment available to the Tongan communities. While the majority of participants said that they had very little knowledge of what cancer is exactly, they knew that this disease was linked to death. Some of the participants noted that it is a disease where germs, viruses, and cells grow out of control. Likewise, they compared cancer to HIV/AIDS, it is a disease for which there is no cure. That there is no cure for cancer was a perception held by 35 of the 48 participants. Cancer was very much viewed as a death sentence.

“What I have heard is that cancer is a disease that wipes out humanity.”

“I believe that cancer is an internal disease. There is a germ that causes the cells to multiply nonstop in one of your organs or a part of your body. This causes malfunction in that organ.”

“Yeah, it’s a nasty disease that eats your body up, it’s almost like AIDS.”

“I think cancer is a kind of a tumor or something, it started in your body and whenever in your body it started it started spreading and is so harmful.”

“Something that is not curable. It’s like your passage to the graveyard.”

“Cancer is a very strong word because there is really no cure for it yet... To me it’s kinda like AIDS. They’re still playing round with things that they think will cure it.”

The understanding of cancer as a death sentence was often informed by the cancer experiences of family and friends. Among our 48 participants 43 mentioned knowing someone who had been diagnosed with cancer. Of those 43 individuals, only two mentioned knowing someone who had not succumbed to this disease.

“Yes, my cousin, [had] leukemia, it is now 18 years. His mother has cancer also but she’s alright. ~Interviewer - *What kind of cancer?*~ Cancer of her kidneys, but she underwent chemo and she’s now in remission. Many people die from cancer because of their fear. They are diagnosed with cancer and they are scared.”

“My mother died of cancer last November. It was in her kidneys. They didn’t find out until let’s say 3 weeks before she died. ~Interviewer - *Did they say what caused the cancer?* ~ No, I didn’t find out, but also my aunts who lived in Tonga and who raised me died also [of cancer]. She smoked like a chimney. [My mother] refused to be treated. She was 74yrs old. She was in so much pain. But she was alert right until the time she died. ~Interviewer - *Why did she refuse treatment?*~ She just thought that it was just too much for her to bear. She was given morphine and pain killers.

What causes cancer?

While a few of the participants said that they did not know what caused cancer (n = 10), heredity (n = 18), weaknesses in the body (n = 15), smoking (n = 15) were among the causes most frequently mentioned (some respondents mentioned more than one cause). The emphasis on these three causes are similar in that they focus on the individual, however there is clearly a difference in the amount of control that one has over their exposure to these causes. Heredity and weaknesses in the body are out of the control of the individual and can be linked back to the idea of health as “being lucky or fortunate.” In contrast, smoking as an individual lifestyle

practice is under the control of the individual, to a certain extent she/he decides whether or not to engage in the practice. Exposure to pollutants in the environment (n = 12), which included chemicals in processed foods, was another commonly mentioned cause. What was notable about the interviews and their discussion regarding causes of cancer, was that while participants would simply list other causes; smoking, being overweight (n=2), alcohol use (n = 5), when they spoke about toxins in the environment it was a cause that elicited more detailed narratives. Toxins in the environment, and their relationship to food, was a cancer cause that was woven in with ideas about weaknesses in the body, and individual control over exposure.

“I think it has to do with how immune they are to terrible things or whatever. Whatever cancer is or bacteria that causes cancer, some people can’t fight that and others can. ~Interviewer - *When you say immune..* ~ I mean being able to stand up to that. Some people are healthy and have been brought up fit. I can see that in a plant. If you put that seed in good soil and you fertilize it there is a tendency for it not to be overcome with disease. That’s how I see a healthy body should be... Yeah, it has to be a pretty forceful thing to happen to a person’s body. Some people complain of parts of their body wearing out. If it’s a healthy part, it is highly unlikely that some kinds of diseases would like... I’ve seen trees being treated badly and the trees growing back. So you think if the body is so healthy even cancer can be fought off. I think there is a good chance. If you bring up a baby healthy and they maintain their good health in their lifetime there is a chance... ~Interviewer - *But in general you think cancer is by chance and is not caused by anything?* ~ I think it is caused by something but it’s a matter of fighting it. I think that’s our problem. The word cancer means to me you will die.

“[Cancer is] generally caused by untreated diseases. I know smoking causes cancer too... It is a part of the body that is dead due to death of cells. ~Interviewer - *and what kills off those cells?* ~ Poisoning by the food you eat such as food with lots of chemicals. Some fruits have had chemicals fed to them and is not cleaned properly or meat that is not fresh or meat from an animal that was not healthy, nicotine from tobacco.”

“I think it is the way you take care of health when you grow up. For example if you were well taken care of as a child, ate the right foods, keep warm and clean. ~Interviewer - *What is the right food?* ~ Eat very little red meat, eat plenty of fish, etc. In those days in Tonga, you cooked a pot full of taros, cassava, yams, etc. in coconut milk and that was your meal. Now there are so many different kinds of food and of course so many different kinds of diseases.”

“I think it depends on their... I think physically some people, when they get cancer get cured. They go and get treatment and get healed or they have more days to live and some are just cut short... I think it depends on your physical well being... I think it has to do with your individual self.”

What can you do to prevent cancer?

Given the perception of cancer as a death sentence, combined with the sense that inherited or developed weaknesses in the body can cause cancer, there were relatively few suggestions for the prevention of cancer. Some participants mentioned changes in lifestyle; eating healthier foods, getting exercise. Others mentioned prayer and accepting death as part of life. More often than not, obtaining regular check-ups was accurately viewed as a practice necessary not only for preventing cancer, but as a means for prolonging life.

“I think if I go always to have my regular checkups by my doctor, it will help me to know what I need to do to avoid me and my family from getting cancer.”

“It’s a horrible word. It is strange but for all these people who have died of cancer or who have cancer, it still comes as a shock, because we don’t really know what all the cause of cancer

are. We've heard all the Tongan... "because of eating too much this, and too much of that" but it is because we don't check up. We don't go for check ups so if detected early, it helps a lot."

"You can get to the stage where one gets emaciated and one looks like nothing but bones and that is when there is so much cancer in the body. ~Interviewer - *What can one do to lessen fear?* I can only think of going to the doctor. He can screen you early enough so that cancer can be caught early enough. That way he can do something about the cancer. Even have surgery to remove the cancer while it is still early and one has a chance of recovery."

"I have no fear at all against cancer. ~Interviewer - *Why do you say that?* ~ Because, the reason why, because if I die of cancer I know that's how God wants me to die. ~Interviewer - *Accept it?* ~ Yes. If you try to cure and nothing happens hey that's life."

"When I hear of cancer I think of death... I hear of the cancer treatment, chemo, radiation etc... some live and some don't. That is why it's important for us to go for screening because if cancer is caught early it can be treated. I have heard of people dying because cancer is caught later, there is nothing that could be done."

DISCUSSION

Tongans in this study had a limited amount of information about cancer or its causes but believed strongly that having cancer was equivalent to a death sentence. They also told us that they had little information about cancer prevention services. Since the best methods of cancer control are prevention and early detection, this finding is particularly troublesome. Moreover, the belief that there is little one can do to prevent cancer, that there is no cure for cancer, and that cancer leads to an early death, make it clear that much more cancer information should be disseminated to Tongan communities.

Given the emphasis of cancer causing death and linking of cancer to weakness in the body, one might be tempted to say that Tongans have fatalistic views regarding cancer. However, to do so would overlook the ways in which weaknesses in the body was linked to environmental pollutants and chemicals in food. Fatalism is a general outlook on life founded on the belief that life events are inevitable and that one's destiny is not in one's own hands [32]. While individuals understood that they did not have complete control over pollutants in their lives, they knew that they could take steps to mediate exposure to them. In addition, many participants emphasized that leading a healthy life improved their ability to withstand exposure to toxins that cause cancer. Thus, the locus of control was within the individuals rather than outside their control, as one would expect with fatalist beliefs [32].

The link between cancer and death must also be contextualized within the economy of health care for Tongans. The lack of medical insurance and low-income status of most of our participants also may have influenced their cancer experiences. Previous research has shown that economic barriers play an important role in limiting access to cancer care [33–35]. Since Tongans in our study may have limited access to medical care and know of relatively few people who survive cancer, it is not surprising that death would be the primary focus of their conversations about cancer.

Our findings are similar in many ways to results regarding beliefs about cancer among American Samoans [2,3]. American Samoans also had limited knowledge about cancer and prevention of cancer. However, they were more likely than Tongans to stress that cancer was a *palagi* (white man) disease and to emphasize that a return to *fa'aSamoa* (the Samoan way of life) was the best way to prevent cancer. Likewise, the belief that cancer is a death sentence has been found in other populations including Latinos [36], Asian Americans [37], and low-income whites [38].

Our results suggest that more cancer education should be provided to the Tongan population. The educational efforts should be conducted with respect to the knowledge and practices of Tongans for them to be effective. In another Pacific Islander population, Banner et al. [1] found that Native Hawaiians were often offended and resisted participating in research because of the primacy given to scientific medical knowledge as opposed to lay knowledge and cultural protocols. Furthermore, Balslem's [38] work among low-income whites revealed that the cancer was viewed as an uncontrollable disease with many causes and that this viewpoint contributed to resistance to cancer control messages. The resistance was due, in part, to the way in which the cancer control messages denigrated the lay populations' experiences of cancer. This denigration took the form of classifying lay knowledge of risk factors as "myths" and "misconceptions," even when the community's own experiences of living in a cancer "hot spot" suggested that other causes of cancer, such as pollutants expelled from the surrounding factories, were just as plausible. Taken together, these studies suggest that cancer control researchers cannot afford to take for granted that the populations will agree with the biomedical model of cancer and that they should learn about the cultural meaning of cancer in the populations.

Some efforts are underway by the Tongan community partners in the Pacific Islander Cancer Control Network to provide culturally tailored cancer education [31]. These efforts have included cancer messages on Tongan radio programs and reminders for women to obtain annual mammograms that use obligations to God, family, and community as motivators for taking care of her body. The partners have also developed cancer education brochures in the Tongan language that use pictures of Tongan women and men as illustrations. The data presented here suggests that programs such as the WITNESS program [39,40], wherein survivors give their cancer testimonies at organized church events may also be effective. Stories of symptoms, diagnosis, treatment and survival embedded in their relationships with God, family and community may go a long way in severing the link between death and cancer.

The study had important limitations. First of all, it was a small qualitative study using a non-probability purposive sample design. As such the results may not be generalizable to the larger Tongan population. However, obtaining the kind of information that we desired is difficult using more quantitative approaches. Thus, the methodology was appropriate for this exploratory study. Second, reliability and validity are not concepts that can be directly taken from quantitative research and applied to qualitative research. Qualitative investigators often address these concepts through the "trustworthiness" of the results. We addressed trustworthiness by providing the results to members of the Tongan community and asking them to comment on them.

In summary, this study provided insight into knowledge about cancer in the Tongan community. The results have pointed out fertile areas for cancer prevention education and for future research. They have also provided important information that could be used in cancer control programs among Tongans.

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Table 1

Demographic Characteristics (n=48)

Characteristic	n
Sex	
Women	32
Men	16
Age (years)	
29–40	12
41–60	25
61–80	11
Monthly Income	
\$ 0 – 1500	9
1600 – 2900	8
3000 – 5000	10
< 5000	6
Refused	24
Health insurance status	
Insurance	8
No Insurance	29
No response	11
Marital Status	
Married	38
Single	5
Divorced/Separated	3
Widowed	2
Country of Origin	
Tonga	47
US	1

Table 2

Themes

What is cancer?
Know little about cancer
Cancer is like HIV/AIDS
Cancer equals death
Cancer is a virus or cells that grow out of control and spread through the body
What causes cancer?
Heredity
Weakness in the body
Smoking
Environmental pollutants
What can you do to prevent cancer?
Lead a healthy life
Prayer
Prepare for death if diagnosed with cancer