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Cancer Fatalism: Attitudes Toward Screening and Care

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Fatalism and Cancer: Attitudes Toward Screening and Care

Introduction

During the last 20 years, interest in fatalism has emerged among health care researchers [1, 2]. This interest was generated by the search for efficient targets for intervention to increase healthy behaviors and screening attendance among underserved social groups [3–7]. Studies have shown that fatalistic beliefs are related to lower adherence to medical examinations and lifestyle regimens needed in the management of chronic diseases such as cardiovascular disease [8], diabetes [9], and HIV [10] and to attitudes toward health behaviors such as practicing safe sex [11, 12], smoking [13, 14], and screening for the early detection of several types of cancer [1, 3, 5–7].

Definitions of Fatalism

Although definitions vary, fatalism is usually conceptualized as a belief that events are predetermined and that human beings are unable to change their outcomes [15]. Fatalism refers to two similar but not identical beliefs: the belief

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School of Social Work, University of Haifa, Haifa, Israel e-mail: cohenm@research.Haifa.ac.il that events are beyond personal control and the belief that a person cannot change the outcome of events. Fatalism is incompatible with free will, and individuals with a strong belief in fatalism believe that very little or nothing can be done to change the course of events determined by external forces [16].

Fatalism may or may not be based on belief in God. Believers tend to accept that God has control over every detail of life, whereas nonreligious fatalism may be expressed in the belief that things happen by chance or luck [17–21]. In a modern society, which stresses free will and self-actualization, fatalism often attains a negative connotation [5] and is viewed as related to pessimism, hopelessness, and despair [3, 22].

Cancer Fatalism

Studies have defined cancer fatalism as the perception that encountering cancer is a certain death sentence and that sooner or later, the individual with cancer will die [3, 23–25]. Less attention has been given to another aspect of cancer fatalism, which is the belief that health is a matter of God's will, fate, or luck and beyond an individual's control [15, 18, 26]. It is often accompanied by an assurance that "it will not happen to me" or by the pessimistic conviction of an individual that he or she will encounter cancer sooner or later, regardless of personal actions.

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These beliefs have often been found to be related to perceptions that screening for early detection of cancer is not necessary because if the end outcome is death, it does not matter when the cancer is detected [1, 3, 7, 27-29]. These beliefs may also encourage refusal or nonadherence to cancer treatment or a healthy lifestyle due to the same reasoning—that these factors will not change one's personal fate [30-34].

Thus, cancer fatalism can act as a barrier to screening [1, 2, 18, 21, 23, 26, 28, 35–47], can be a cause for delay in seeking medical help once symptoms appear [30–33, 48, 49], or can be a cause of refusing to receive all or certain treatments for cancer [50]. However, it is important to bear in mind that similar to other health attitudes, fatalistic beliefs held by individuals vary along a continuum from extreme fatalistic beliefs to a strong belief in personal actions as determinants of one's health [17, 18, 23]. Accordingly, their effects on individuals' perceptions vary [21, 23, 35, 37, 38].

This chapter addresses empirical data on cancer fatalism—its relationship to ethnicity and socioeconomic status (SES), screening behaviors, delay in seeking help, and coping with cancer once diagnosed. Finally, based on the review of existing empirical knowledge, a multidimensional conceptualization of the concept of fatalism is suggested.

Cancer Fatalism in Diverse Population Groups

Most of the studies on cancer fatalism have been conducted in the United States, exploring the attitudes of its multicultural groups, especially Caucasians, African Americans, and Latinx or Hispanics [1, 2, 26, 28, 37–45, 47, 51–54]. Several studies have been conducted in Israel, which explored fatalistic beliefs related to cancer among Jewish and Arab interviewees [21, 25, 35–37, 55–58]. Studies assessing cancer fatalism have also been conducted in South Asian countries [59, 60] and among indigenous people in Australia, New Zealand, and Canada [61]. Despite the large advances in medical treatment

and cure rates, cancer fatalism is a widespread belief in Western countries [62]. In a study based on a random sample of 6369 Americans, 27% of the participants agreed there is "not much people can do to lower their chances of getting cancer." [34].

Several studies have been conducted by Powe and her colleagues, a central research team in this study area [1, 2, 32, 43, 49, 51, 63-65], and by other researchers [6, 24, 39, 41, 45, 47, 66] on attitudes of African Americans toward cancer. However, most of the studies assessed levels of cancer fatalism among African Americans alone, without a comparison to Caucasians or other ethnic groups [2, 32, 39, 43, 45, 63, 64, 66]. Few studies have compared fatalism among different groups [1, 6, 41, 47, 67]. In one of the first studies, 192 older persons, mostly African Americans, were asked to complete Powe's Fatalism Inventory (PFI) [1]. This inventory was developed to assess perceptions of cancer fatalism using 15 yes-or-no items that assess fear, pessimism, inevitability of death, and predetermination [1, 23]. The study found higher levels of cancer fatalism among African Americans [1]. In a study of 190 young men, significantly higher cancer fatalism was found among African Americans than Caucasians. However, the overall scores of fatalism were very low (3.0 for Caucasians and 4.5 for African Americans, on a possible scale of 0-15) [68]. In a comparison between African Americans and Hispanic men [67], moderate fatalism was reported for both groups, but it was higher for Hispanic men as compared to African Americans (6.6 and 4.8, respectively). However, the study did not control for the higher education level of the African American participants [67]. Another study reported that Latina women reported higher levels of fatalism as compared to African American women [69]. Another study found higher levels of fatalism in African Americans compared to Caucasians [46], but it did not control for the main demographic variables.

In a study that focused on African Americans only, substantially higher levels of cancer fatalism were reported for the older African American women compared to younger women [63]. However, in another study of women aged 28-78, cancer fatalism scores were similar in the younger and older participants (4.4 and 5.6, respectively) [43]. These low scores are especially interesting because 361 of the women were from primary care centers in the southeastern United States. The authors noted that these centers serve an underserved population, with about 66% at or below the poverty level and 75% uninsured or on Medicaid. In a study on breast cancer knowledge and perceptions among African Americans, only 16% of 179 women agreed that a "woman's chance of surviving breast cancer is very low, even if it is found early." [64] Several other studies focused on correlates of fatalism, but did not provide details on fatalism scores [6, 19, 32, 40].

Another group of studies examined cancer fatalism in the Latinx and Hispanic population [26, 28, 42, 44, 69–74]. Several of these studies found higher levels of cancer fatalism among Latina women compared to Caucasian women [26, 69, 71–73]. A large-scale study with a random sample, although conducted in 1992, compared Latina and Caucasian women regarding various health perceptions and beliefs [72]. It found that a higher proportion of Latinas believed that having cancer is like receiving a death sentence (46% vs. 26%, respectively), that cancer is God's punishment (7% vs. 2%), that there is very little one can do to prevent contracting cancer (26% vs. 18%), and that it is uncomfortable to touch someone with cancer (13% vs. 8%).

In another study with 803 Latina women and 422 Caucasian women, the Latina women, especially those born outside the United States, expressed more fatalistic beliefs regarding cervical cancer [26]. A study among Latina women revealed moderate levels of fatalism (mean of 2.4 on a scale of 1–5), with higher scores among lessacculturated women. However, the scale was a combined fatalism and fear measure, consisting of five items, including perceived risk, fear of cancer, and lack of control over developing cancer [48]. In a qualitative study of 29 rural Latina women, many of them believed in fate or God as the cause of breast cancer; however, the report did not mention whether participants discussed beliefs regarding the possibility of a cure for cancer [70].

Several studies assessed cancer fatalism among Jewish and Arab women in Israel [35, 37, 38, 56–58]. Baron et al. [56] assessed cancer fatalism using two items representing fatalistic beliefs in external forces as a cause of cancer (God and fate) in a random sample of 1550 women recruited from one of four major health care services in Israel. The sample included four culturally distinct groups: ultra-Orthodox Jewish women, Arab women, Jewish women who were secular to moderately religious, and recent Jewish immigrants. The authors found moderate fatalistic perception in the non-ultra-Orthodox Jewish women (mean of 2.5, range 1-5) and higher fatalistic perceptions in ultra-Orthodox Jewish women (3.7) and Arab women (4.5). Differences were significant for the Arab group only compared to the other groups. Azaiza and Cohen [35] conducted a qualitative study with Arab women in Israel in which the women expressed fatalistic beliefs regarding their chances of contracting cancer; they perceived that life and death were in the hands of Allah (God). Thus, cancer might be a punishment for bad deeds, a test for believers, or a way of atonement. Interestingly, these beliefs were expressed by the participants together with notions regarding biomedical knowledge of causes of cancer such as genetic predisposition, lifestyle, or environmental causes such as radiation from electrical appliances and cellular networks. Some of the participants in the focus groups said they believed that cancer is a death sentence and that medical interventions only postpone the inevitable death. This fatalistic view was strengthened by witnessing cancer survivors from their own surroundings who had later died from cancer. It should be noted that some of the participants who expressed the belief that cancer is a test from God, although admitting their belief in an external force that causes cancer, believed that God places the outcome of the disease in individual's hands. Thus, they perceived a substantial level of control over the outcome.

In another study, a comparison was made between Palestinian women residing in Israel and the Palestinian Authority (N = 697) [37, 38]. Cancer fatalism was assessed using a two-item perceived cancer fatalism scale, which is a part of the Arab Culture-Specific Barriers scale [21]. The scale was developed based on focus groups' content analysis and further validated in a quantitative study using content, criterion, and divergent, convergent, and construct validity. The Israeli Arab women expressed lower cancer fatalism than the participants from the Palestinian Authority. The authors noted that although some of the differences may be explained by disparities in SES and sociopolitical status, the results may represent differences in location along the traditional Westernizing continuum. They also noted that although the two groups had similar cultural origins, they represented different phases of Westernization, which might have affected their perceptions of cancer [37].

The existing empirical data on fatalistic beliefs among ethnic groups should be regarded with caution. Many of these studies reported statistical differences between ethnic groups as compared to Caucasians or other mainstream groups. However, this review shows that the overall levels of fatalism, when reported, were mild to moderate in most studies. Another misconception may arise from studies reporting on correlates of fatalism in specific ethnic groups, but not reporting the actual scores obtained for fatalism. These data may lead to a simplistic conclusion that cancer fatalism is mainly a cultural characteristic [23, 29, 75].

Moreover, several scholars argued that higher cancer fatalism in ethnic groups should be analyzed in relation to social and structural factors that characterize many individuals who belong to ethnic groups [23, 29, 75]. For example, lower SES and lower education were found to be consistently related to higher cancer fatalism [18, 34, 47, 69, 74]. In addition, lesser knowledge about cancer causes and cancer treatments, lower acculturation, and language barriers [29, 44, 72] were also found related to higher fatalistic perceptions of cancer. Relevant to this discussion, Pasick [76] argued that caution is needed regarding an overgeneralized view of fatalism as a cultural component and attested that fatalism should be understood in its socioeconomic context. Poverty,

racism, discrimination, and inadequate access to health care services may be mistakenly interpreted as fatalism [29, 74, 77]. Moreover, ethnic groups living in Western countries or even those residing in their original countries are going through modernization processes that affect their knowledge, perceptions, beliefs about diseases and medical treatments, and health behaviors [35, 78–81]. Thus, conclusions from studies regarding health perceptions or beliefs should be reached with a deep understanding of the dynamic and changing nature of health perceptions and the complexity of research.

Cancer Fatalism and Screening for Early Detection of Cancer

Cancer fatalism has often been reported to be related to lower performance of various health behaviors [15, 34, 59, 62, 82]. Analysis of data from 6369 respondents revealed that individuals with high fatalistic beliefs led less healthy lifestyles: they performed less regular exercise, were less likely to eat fruits and vegetables, and smoked more [34]. Other studies reported that higher fatalistic perceptions of cancer were related to a lower rate of attending screenings for breast cancer [39–41, 53, 58], colorectal cancer [2, 26, 51, 52, 54], and cervical cancer [26, 44, 60].

Mixed results on the associations between fatalism and screenings were obtained in studies that controlled for possibly confounding or intervening variables in their data analysis [18, 26, 28, 37, 38, 41, 44, 46, 47, 74]. When adjusted for demographic variables, some of the studies demonstrated significant links between fatalism and screening attendance. For example, in a study with Chinese, Malay, and Indian women, adherence to mammography, clinical breast examination, breast self-examination, and Pap smears was predicted by fatalism (measured by the FATE [18], a seven-item scale consisting of fatalistic attitudes toward health in general, medical screen testing, and individual responsibility for wellbeing). However, the authors did not describe the demographic variables for which the regression

model was adjusted [18]. In a study of more than 1200 Latina and Caucasian participants, adjusting for confounding variables, fatalistic beliefs predicted attendance of cervical cancer screening [26]. Similar results were obtained by Harmon et al. [44] in a study of 566 Latina women and in other studies [28, 41]. Several studies reported that higher education and higher cancer knowledge were related to lower cancer fatalism [66, 73, 83, 84]. However, education served as a moderator between online information seeking and fatalism, such that for less-educated participants, more exposure to information about cancer via medical and health websites led to an increased level of cancer fatalism, whereas among moreeducated participants, greater exposure lowered cancer fatalism [85].

In contrast, several studies found no or marginal associations between fatalism and screening attendance after adjusting for demographic variables [46, 47, 85–87]. For example, Russel et al. [46] reported that in a multivariate logistic regression, fatalism did not predict mammography attendance in a sample of 175 African American and Caucasian women. In Mayo et al.'s [47] study of 135 African American women aged 70 or older, the association between fatalism and mammography attendance stopped being significant in a multivariate regression analysis when adjusted for age, education, and doctors' recommendation. Also, in a study using a stratified cluster sampling to recruit 1364 women aged 50-70 years from six ethnic groups, fatalism did not predict mammography screening in a logistic regression model [6].

Higher cancer fatalism (measured by two items assessing belief in cancer as a fatal disease) in Palestinian women residing in the Palestinian Authority was also found to be associated with lower attendance of mammography. This association remained significant after adjusting for demographic characteristics, health beliefs, and situational barriers [37]. In addition, situational barriers related to the sociopolitical situation were correlated with attendance of mammography and clinical breast examinations, but did not predict their attendance in a multivariate logistic regression, whereas cancer fatalism remained a significant predictor [38]. Baron et al. [56] assessed the effect of fatalistic perceptions (using two items from the PFI [1]) on mammography attendance among 1500 women in Israel. Similarly, adjusting for possible demographic confounders, they found a significant association between fatalistic beliefs in external forces as a cause of cancer and attendance of mammography as reported by claims records among Arab women and ultra-Orthodox Jewish women, but not among Jewish veterans or new immigrants [56]. In addition, a recent study found that among Muslim women and ultra-Orthodox Jewish women, cancer fatalism was a significant predictor of undergoing mammography, after controlling for background variables [58].

However, comparison between results of the studies reviewed is difficult due to principal variability in definitions and measurement tools of fatalism, size and type of samples, age ranges, and methodology used. Of special concern is the divergence in defining adherence to screenings. Most of the studies relied on self-reporting [42] or face-to-face interviews [18, 37, 38, 47, 63], and only a few used claims records to assess adherence to screening [56]. Most studies defined adherence to mammography, clinical breast examinations [18, 36, 37, 47, 56], or Pap smear tests [44] as ever attended or never attended, whereas others assessed frequency [41], being on time with screenings [88] or frequency of more than four mammograms per 10 years [6], at least one mammography in the last 5 years [45] or compliance with overall screening guidelines [40]. Flynn [19] calculated clinical breast examination adherence as the total number of clinical breast exam tests reported divided by the maximum number that a woman of her age should have if she complied with screening guidelines. This wide diversity is probably responsible to some extent for the mixed results and difficulty in coming to conclusions regarding the relationships between cancer fatalism and adherence. Also, many questions should still be investigated, such as whether the nature and direction of these relationships differ for different screening methods, different types of cancers, or among different ethnic groups and what factors moderate or mediate the associations between cancer fatalism and screening behaviors.

Cancer Fatalism and Delay in Diagnosis

Delay in seeking medical care when or after symptoms are identified often leads to a later stage at diagnosis and lower survival rates [89]. Studies reported that delay in seeking help is not a rare situation. The estimated rate of delay ranges in different studies from 16% to 30% [90]. Norsaadah et al. [91] reported a 2-month delay of 72% and a 6-month delay of 45% among Malay women. Higher rates of delay were related to lower income [90, 92], lower education [32, 49, 90, 92], lack of a regular health provider or health insurance [90, 92], and belonging to ethnic groups [90, 93-95]. Also, delay in seeking help was found to be associated with less knowledge about cancer and greater misconceptions of symptoms [90].

Only a few studies assessed delay in diagnosis in relation to cancer fatalism. Gullatte et al. [30, 49] studied 129 African American women aged 30 to 84 years who were diagnosed with breast cancer after self-detecting a symptom. Time elapsed from the onset of symptoms to seeking medical care was 5.5 months on average. Religiosity, spirituality, and fatalism did not predict length in delay or stage at diagnosis, whereas lower education and being unmarried were significant predictors of delay. In addition, women who talked about their breast symptoms only to God were more likely to delay seeking medical care. In contrast, women who told a person about their breast symptoms were more likely to seek medical care sooner [30, 49].

Using medical records, Weinman et al. [33] reported that of 2694 cancer patients with advanced and early-stage breast cancer, 7% (195 women) refused provider advice to further examine symptoms or abnormal results. These women tended to be at a more advanced stage of breast cancer at diagnosis, were older, and had high parity. The most frequent reasons the women gave (as documented in the medical records) for their

initial refusal were related to fatalism, avoidance or denial, fear of mammography pain or discomfort, and fear of surgery.

In a very small-scale study that assessed 11 women with locally advanced breast cancer and 11 women with early-stage cancer, semistructured interviews identified that late diagnosis was associated with not being aware of screening guidelines, denial, fatalism, and reliance on alternative therapies. Also, the spouses of the women in the late diagnosis group tended to be more passive about their wives' medical care and also expressed fatalistic thinking and denial [48].

Burgess and colleagues [31] conducted interviews with 46 women newly diagnosed with breast cancer. Of them, 31 had waited 12 weeks or more between noticing symptoms and approaching their physicians. Women who delayed seeking medical care differed from nondelayers in their fatalistic beliefs about the consequences of cancer treatment and perceptions of other priorities taking precedence over personal health. In a qualitative review of 32 papers, Smith et al. [30] found that fear, of either embarrassment or pain, suffering, or death from cancer, was among the main reasons for the delay, in addition to not recognizing or misconceiving the symptoms.

The few studies that focused on the role of fatalism in delay in seeking help are not sufficient to draw conclusions. Gaining more knowledge on the nature of this relationship is necessary for planning future interventions among women at risk of delay in seeking medical care.

Cancer Fatalism and Cancer Survivors

Although numerous studies were conducted to assess cognitive, emotional, and behavioral aspects of coping with and adjustment among cancer survivors, relatively few studies focused on fatalistic beliefs of cancer survivors and the impact of the beliefs on the process of adjustment [96–100]. Therefore, very little is known about perceptions of fatalism among cancer survivors and their effects on psychological reactions, adherence to treatment, and other relevant issues.

One of the very few studies on fatalism among cancer survivors was conducted by Sheppard et al. [96] This study involved a small sample of 26 African American breast cancer survivors aged 42 to 73 years and at different stages of breast cancer. Cancer fatalism was assessed using the PFI [1]. The authors reported that 80% of the sample had at least one type of fatalistic belief, but the overall score of fatalism was low. Interestingly, many of the women said they believed that contracting cancer was a matter of fate, but a low rate of positive answers was given to items that referred to cancer as causing an inevitable or imminent death. For example, none of them said they believed that "if someone gets breast cancer, their time to die is soon" or "if someone has breast cancer, it is already too late to get treated for it."

An intriguing but unanswered question in this regard is whether fatalistic perceptions change in individuals once they are diagnosed with cancer [97, 98]. An indirect insight into the process of change may be gained from the contrast that exists regarding fatalistic beliefs of healthy women and those of cancer survivors, as depicted in qualitative studies. For example, as previously reported, healthy Arab participants in focus groups reported many fatalistic beliefs regarding the causes and the fatal outcome of breast cancer [35]. In contrast, in a qualitative study using indepth interviews with 40 Arab breast cancer survivors who were about a year post-treatment and without evident signs of disease, all the women were optimistic about the outcome of their disease and confident that they would defeat it, with God's help [99].

Another qualitative study with 16 Chinese individuals with colorectal cancer revealed that most participants perceived their cancer as a predetermined destiny. This belief was followed by passive acceptance alternating with a focus on positive aspects. However, the authors identified a flow in fatalistic beliefs that was strongest at early diagnosis and lowered as treatment progressed. Upon treatment completion, fatalism reemerged regarding disease recurrence [100].

Fatalism in cancer survivors was also studied from a different perspective, as a coping style [101, 102]. Although scholars in the area of coping usually differentiate between cognitive perceptions (e.g., optimism or fatalism) and coping strategies [103], Greer and colleagues [101, 102, 104] combined cognitive perceptions and coping responses into a single construct termed coping styles (also referred to as adjustment styles) [102]. They constructed a profile of five coping responses: fighting spirit, hopelessness and helplessness, anxious preoccupation, fatalism, and avoidance [101, 102, 104]. Fatalism was described as "a perception that no control can be exerted over the situation and the consequences of lack of control can and should be accepted with equanimity." [101, p.13] As a result, the attitude of women with a fatalistic coping style toward cancer is one of passive acceptance [101]. Studies using this typology of coping styles reported that higher use of fatalism was associated with lower adjustment and higher emotional distress. The same was found for cancer survivors using coping styles of hopelessness or helplessness and anxious preoccupation in contrast to the use of fighting spirit [13, 105, 106]. Also, an intervention study using cognitive behavior therapy showed a significant decrease in anxiety and depression concomitant with an increase in fighting spirit and a decrease in the less adaptive coping strategies [104]. However, in a sample that included 101 women with advanced breast cancer, no association was found between emotional distress and using fatalism as a coping style [107]. One study assessed 353 women treated for primary breast cancer within 1 year of diagnosis for emotional distress, anxiety and depression, adjustment, and coping style [108]. The authors combined fighting spirit with fatalism to create a coping style termed "positive reappraisal." The multivariate analysis conducted suggested an association between this combined coping style and lower fatigue.

Greer and his group [101, 102, 104] conducted longitudinal studies in which cancer survivors were followed for long periods to assess the role of coping styles in survival. They reported that survivors who responded with fighting spirit or denial were significantly more likely to be alive and free of recurrence 5, 10, and 15 years after diagnosis than survivors with fatalistic or helpless responses [102, 109]. These results were obtained after controlling for demographic and disease-related variables. When the prognostic factors were examined individually, psychological response was the most significant factor in predicting death from any cause, death from cancer, and first recurrence.

A similar view of fatalism as a means of coping was suggested by Sharf et al. [50] The authors proposed that fatalism may be used by cancer survivors as a mode of coping with the uncertainty imposed by cancer diagnosis. Similarly, other researchers referred to fatalism as a means of coping with self-blame [110].

The extent and nature of fatalistic views in cancer survivors and their effect on psychological and physical health are still mostly unknown and understudied. The distinct ways of conceptualization of fatalism in cancer survivors in the few existing studies hinder reaching conclusions and point to the necessity of expanding the research in this area.

Understanding Cancer Fatalism as a Multidimensional Construct

The mixed results on cancer fatalism and its consequences [1, 2, 39, 40, 44, 47, 52, 53, 111] described in this chapter point to the complexity of the structure of fatalism and emphasize the need to consider interrelations among cultural, structural, and individual factors.

I propose a multidimensional conceptualization of cancer fatalism derived from our preliminary research [112]. The construct comprises four dimensions: fatalistic beliefs and their extent, fatalistic causal attributions of cancer, antecedents of fatalistic beliefs, and outcomes of fatalistic beliefs (Fig. 18.1). For these purposes, fatalistic beliefs consist of the extent to which individuals believe that cancer occurrence is out of their control and that death is inevitable, casual attributions are the perceptions of causality underlying the fatalistic beliefs, antecedents are the socioeconomic and environmental factors that may affect fatalistic beliefs, and the outcomes are the health behaviors of individuals.

Extent of Cancer Fatalism

This dimension refers to the extent to which individuals believe that the occurrence or outcome of cancer is predetermined and beyond personal control or behavior and that a cancer diagnosis is the equivalent of a death sentence. These two aspects of the cancer fatalistic beliefs accord with previous definitions of cancer fatalism [18, 26, 32, 33, 55, 113]. However, these two fatalistic beliefs are often interchangeably addressed in the literature as cancer fatalism [34]. Yet some evidence points to the different nature of these constructs. For example, several qualitative studies showed that although participants believed they had no control over developing cancer (occurrence fatalism), most did not express fatalistic attitudes concerning their chances of surviving cancer (outcome fatalism) [114]. Therefore, individuals may believe that contracting cancer is not in their personal control but may also believe that treatment can be effective. Also, when fatalism was studied in relation to culture or ethnicity, often no distinctions between the dimensions were made [29]. However, some evidence exists as to the different nature of the constructs. For example, in a study of Latina women, 54% believed they had no control over developing cancer, yet most did not express fatalistic attitudes concerning the chances of surviving breast, uterine, or cervical cancer [71]. Note that attributions of causality and cancer fatalism intensity may be related to background factors, such as education, economic status, health literacy, and access to health services [34, 41, 44].

Fatalistic Causal Attributions of Cancer

Based on prior conceptualizations [18, 34] and preliminary findings [112], I define four types of fatalistic causal attributions of cancer, each

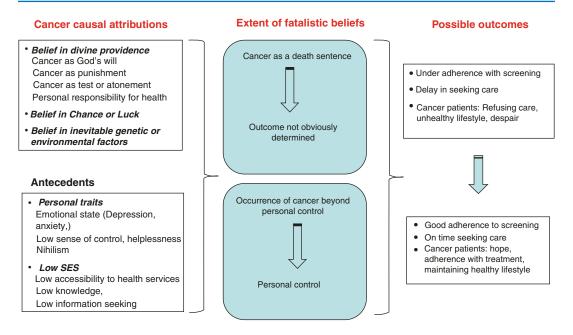


Fig. 18.1 A multi-dimensional model of fatalism

of which leads to perceptions of cancer or its outcomes as predetermined: belief in divine providence, belief in chance or luck, and belief in the inevitability of environmental or genetic factors.

Belief in Divine Providence The three main monotheistic religions-Christianity, Judaism, and Islam-share the belief that major life occurrences are in God's hands and beyond our personal control [15, 35, 57, 115]. Nevertheless, contracting cancer and other diseases is believed not to be arbitrary but rather God's response to an individual's deeds or behaviors. A cancer diagnosis may be punishment for unfaithful or unacceptable behaviors, or it may be a test of an individual's faith in God [35], similar to Job's story. A young Arab woman said in a focus group: "God tests our patience, the same as what happened to Job. God tried him with all kinds of diseases and disasters to test how strong his belief was. God strikes those He loves, as He wishes to test them." [35, p. 37] Women in the focus groups also raised the idea that cancer may be God's act

to stimulate atonement or change in a person's attitudes and way of life [35].

Although the main religions convey the belief that everything is in God's hands, they also state that a person's body is a gift given to the individual to take care of until the time comes to give it back; thus, the individual has a personal responsibility to preserve their health [35, 116]. In contrast to passive acceptance and neglect of personal health often reported to be related to fatalism [1], these religious perceptions of fatalism encourage the individuals to actively act to preserve or promote their health [39, 115]. Of course, it cannot be ruled out that religious beliefs may be used as an excuse for a passive attitude toward health [15].

A distinction should be made between attributing to God a diagnosis of cancer or the view that death is inevitable. In a study described earlier in the chapter, breast cancer survivors who participated in in-depth individual interviews [99] expressed a strong belief in self-responsibility stemming from their wish to overcome the disease for their own sake and for their families, but it was also rooted in religious writings and their belief that it was God's will. Also, healthy participants in focus groups expressed strong beliefs that cancer is an incurable fatal disease [35, 55]. However, in another study, these beliefs were countered by more optimistic voices [78]. Also, in focus groups with Hispanic participants, most participants reported that their religious beliefs encouraged them to use health services, including cancer screening tests [117–119].

This view of religious-related fatalism can provide an explanation for the unanswered paradox regarding the relationships between fatalism, religion, and health: on one hand, fatalism was reported to be more prevalent among ethnic minorities, who are often considered to be more religious [15, 117], whereas on the other hand, religiousness was reported to be related to a healthier lifestyle and better health indexes [118, 120, 121]. In addition, several studies revealed that different perceptions may coexist in specific population groups [15]. For example, in focus groups and qualitative studies with religious Arab women [35, 56] and ultra-Orthodox Jewish women [57], women differed in the degree of their perceptions of health as a completely uncontrolled fate or a factor within their responsibility, although governed by God.

Belief in Chance or Luck The belief that cancer is a matter of chance or mere luck, and not guided by higher forces or controllable by an individual's behavior, is also widespread [18, 34]. Powe and Johnson [3] connected it to a sense of nihilism common in modern Western society. Several scholars have suggested that the attribution of cancer to luck or chance is in part due to the nature of cancer research, which is difficult to communicate to the lay public [34, 113]. A mass of findings regarding the causes of cancer is frequently communicated to the public by the media [114]. These findings are often conflicting and cause confusion and mistrust [113]. An example is the previously strongly disseminated knowledge that high-fiber diets have cancer-preventing properties, which scientists concede is now unclear based on newer results of studies [62]. A

national survey found that 47% of the American public believed that "it seems like almost everything causes cancer" and 71% agreed that "there are so many recommendations about preventing cancer, it's hard to know which ones to follow." [34] Therefore, they react with fatalistic beliefs in the lack of control over cancer occurrence.

Belief in Inevitable Genetic or Environmental Factors A comparatively new aspect of fatalism—genetic fatalism—was recently presented [110]. Research in this area appeared following the identification of familial risk of specific types of cancer such as breast, ovarian, or colorectal cancer. About 27 years ago, breast cancer mutations in the BRACA1 and BRACA 2 genes were identified as increasing susceptibility to breast and ovarian cancer [122]. The identification of these specific mutations has increased the sense of genetic fatalism in first-degree relatives of people with breast or ovarian cancer [110, 123].

Previous studies concluded that people often respond in fatalistic ways when they hear about genetic causes of disease [124]. This reaction has been explained by misconceptions people often have regarding the role of genes in disease susceptibility. Walter et al. [124] argued that once a disease is perceived to be caused solely by genes, the individuals' reaction may be one of lack of control and fatalism. One of the few similar studies involved parents of neonates who had received a positive screening test result informing them that their child was at risk of hypercholesterolemia, an inherited predisposition to heart disease [116]. Parents who regarded this condition as a genetic problem perceived the situation as uncontrollable and, hence, more threatening.

Very few studies assessed fatalistic perceptions in persons with familial history of cancer or diagnosed as carriers of identified mutations of susceptibility [44, 125–127]. The existing studies were mainly conducted with women who had first-degree relatives with breast cancer, and in almost all of these studies, fatalism was measured indirectly or was not the primary focus of the study. For example, it was reported that women at high risk often overestimate their lifetime risk of developing breast cancer [128, 129] and experience higher levels of anxiety and depression than matched controls [125, 130– 133], although several studies did not find higher distress among high-risk individuals [134–136].

Fatalistic beliefs were examined by Ryan et al. [126] using focus groups with 29 first-degree relatives of cancer survivors. The authors noted that some of the women reported fatalistic beliefs regarding their risk of contracting breast cancer. Harmon [44] reported that individuals who reported a family history of cancer were more likely to endorse fatalistic beliefs. Cohen et al. [125] assessed cognitive perceptions, coping strategies, and emotional distress in 80 adult daughters of breast cancer survivors as predictors of levels of stress hormones and immune cytotoxic functions. To examine cognitive perceptions, the participants were asked to grade their sense of control over contracting breast cancer. They expressed a lower sense of control over contracting breast cancer than the participants in the control group. In addition, lower levels of perceived control were associated with higher psychological distress, higher levels of stress hormones, lower natural killer activity, and lower secretion of cytotoxic cytokines (interleukin [IL]-2, IL-12, interferon gamma). These immune functions take part in immune defense against viruses, infections, and cancerous cells. Of special interest was the relationship between lower sense of control and lower IL-2-induced natural killer activity against breast cancer target cells [125]. Higher perceived control over contracting breast cancer predicted higher adherence to screenings for early detection of breast cancer [125].

Another study used focus groups with firstdegree relatives of ovarian cancer survivors. The participants in this study expressed an increased sense of vulnerability. They perceived that vulnerability to cancer was much higher than for other diseases in their family such as heart disease or other cancers. They felt fatalistic and helpless about ovarian cancer because they believed there were no lifestyle risk factors that they could control by living a healthy lifestyle [127].

A view of high susceptibility and a sense of inevitability about contracting cancer among individuals at high risk of breast cancer may affect health behaviors in two directions. It may reinforce a sense of lack of power to affect the inevitable fate; thus, health behaviors or screenings may be perceived as not needed and thus avoided. In contrast, the sense of vulnerability may encourage them to engage more in health behaviors, screening, or even prophylactic action. Informing individuals at high risk about the meaning of genetic predisposition and that cancer cannot be caused solely by genetics may reduce their sense of fatalism [124] and encourage active involvement in prevention or early detection efforts, thus increasing chances for survival.

Causal attributions of cancer to environmental factors is represented by the notion that in the modern age, individuals tend to consider themselves surrounded by environmental risk factors for cancer [35]. Individuals believe they cannot influence or change the environment, nor can they protect themselves from factors that can cause cancer occurrence or affect its outcome [18, 34, 35]. This concept is based on widely disseminated scientific information stating that exposure to a wide variety of factors, such as radiation, natural and artificial substances in the environment or food, certain drugs, hormones, bacteria, and more, is responsible for at least two-thirds of cancer incidence [18, 21, 34, 35].

Antecedents of Cancer Fatalism

Cancer fatalism may develop as a result of socioeconomic conditions and education or other environmental factors. According to the studies that found associations between cancer fatalism and level of knowledge or education [34], the lack of knowledge of options of treatment and cure or of the impact of early detection on survival may indeed foster fatalism [27, 44, 72]. Peek et al. [39] cited one woman as saying, "I didn't know that it was a possibility to live after you had breast cancer or had been found having breast cancer. Everybody I know who had breast cancer [has] died. I [wasn't aware] of anything different." (p. 1851)

Higher fatalism was often found among individuals from ethnic minority groups in Western countries or ethnic groups in their original countries [1, 2, 38, 49, 51, 63, 67, 72]. Thus, fatalism was often referred to as a cultural belief. However, it may also emerge from social structures that are characteristic of disadvantaged groups [23, 29, 75, 76]. Low socioeconomic circumstances may reinforce beliefs that death is inevitable when facing cancer independent of culture. Poor people have lower access to health services, they may not have health insurance or regular health providers [29], and even if they have health insurance, they often cannot provide themselves with the cure opportunities that people with higher incomes have. Also, studies have reported that physicians impart less information and recommend less screening and checkups for individuals from minority groups or disadvantaged individuals [80, 137]. As a result, individuals witness around them more cases of cancer that were not cured, and this may reinforce the fatalistic belief that death is an inevitable outcome of cancer [35, 62].

Another issue that needs consideration relates to the complex relationships between different psychological factors (e.g., self-efficacy, helplessness, hopelessness, sense of control, fear, anxiety, depression) and fatalism. Very little empirical knowledge exists regarding the nature of these relationships and whether these factors act as antecedents to fatalism or outcomes of fatalism or are perhaps coincidently related. Considerably little attention has been given in fatalism research to the role of personal traits or psychological characteristics of individuals in the development of fatalism. Although most studies stress the cultural and ethnic connection of fatalism, it may develop due to personal characteristics at least partially independently from the cultural perspective. Several studies found high fatalism to be related to low self-efficacy [46, 138, 139], with the underlying notion that when an individual perceive themselves as ineffective, they will believe that events in life are out of their control [45, 46, 138]. Also, external health locus of control was mentioned to be related to higher fatalism [140] and lower performance of good

health behaviors [78, 81]. However, external locus of control may also imply higher adherence to physicians' recommendations [140] or higher belief in God, which might be related to healthier lifestyle and performance of health behaviors [121].

Several other personal traits may be related but not studied yet in relation to fatalism. For example, helplessness is a personal trait that develops following early and later life experiences. It provides the person with a sense of lack of resources and power to affect life circumstances, including health. Helplessness was often found to be related to lower utilization of health behaviors and worse health outcomes [141]. This personal attitude may, as a result, reinforce a fatalistic view that life happens to the individual without an option of exerting personal control over it. However, the nature of the relationships between perceived helplessness and fatalism is yet to be explored.

Emotions studied in relation to fatalism were mostly specific cancer-related or screeningrelated emotions, such as fear, anxiety, and embarrassment [19, 41], often referring to negative emotions as an outcome of fatalism [23, 142]. No attention has been paid to emotional states such as anxiety or depression. Examining these emotional states may provide an additional way to study fatalism from an individualized perspective. Depression is defined by categories of symptoms: emotional, cognitive, and behavioral symptoms (DSM-5) [143]. Cognitive symptoms of depression consist of lack of motivation for action, perceptions of hopelessness, and lack of sense of meaning. These cognitions may be translated into fatalism when a depressed individual is asked about his or her beliefs. Moreover, depressed individuals engage much less in good health behaviors and screening, due to difficulty in making decisions, planning, and acting.

Based on clinical interviews [144], about 18–30% of the adult population in the United States is reported to be distressed, and 12-month and life-time prevalence of major depressive disorder is 5.3% and 13.2%, respectively. Rates of depression are even higher among older adults and individuals with low income and low-level education

[145]. Thus, it may be that in studies examining fatalism among these groups, the results are confined to depression. Also, higher trait anxiety or higher cancer-specific anxiety may result in higher scores of fatalism.

Outcomes of Cancer Fatalism

In accordance with the review earlier in this chapter, cancer fatalism may cause unwillingness or refusal to attend screenings [23]. It is believed that if the end outcome is already known, early detection will not change the inevitable course of the disease. Thus, individuals may logically decide that it is more worthwhile to avoid screenings [18] and thus avoid negative emotions of fear and anxiety that arise when focusing on cancer or taking steps toward screening. In addition, as reviewed above, high cancer fatalism, especially the outcome of delay or refusal of treatment, may cause feelings of hopelessness and despair and may discourage people from maintaining the healthy lifestyle that is essential for quality of life and to reduce risk of recurrence. On the other hand, it is possible that the perception that death is inevitable may be the only significant cause of adverse health behaviors, whereas the perception that getting cancer is uncontrollable can encourage early detection adherence. So, as described earlier, the perception of divine providence as a major factor can prevent healthy behaviors, but the specific perception that the individual can affect the results of cancer is also part of religious beliefs. To the same extent, the perception of cancer as an event of chance or fate or caused by genes or environment can also be associated, but not necessarily, with negative health behaviors.

The lack of clear distinctions between different aspects of fatalism and the lack of conceptualization of the causal attributions of cancer have so far not allowed a thorough understanding of the links between fatalism and health behaviors. These gaps may also explain some of the limitations of the measurement tools, which may also be responsible for the mixed and contradictory findings in fatalism literature [7]. Gaining greater understanding of the distinct dimensions of fatalism will allow the building of a multidimensional construct of fatalism. This construct may be further used to understand the fine differences among its dimensions, their specific antecedents, and their unique effects on preventive behaviors, screening adherence, and the adjustment of cancer survivors to their illness. It will also provide tools for studying specific populations, such as individuals at high risk or individuals who delay seeking medical treatment.

A more finely tuned knowledge of different dimensions of fatalism is also essential for tailoring interventions to overcome barriers of fatalism. Because delivering preventive health care information may not be enough to increase adherence to screening, a few studies measured the effect of interventions tailored to target specific fatalistic beliefs on change in health behaviors [4, 36, 54]. For example, Azaiza and Cohen [36] used a tailored intervention with Arab women to lower specific barriers to attending mammography and clinical breast examinations. Using scripts, the interviewers reframed notions of cancer as an inevitable fate and that the notion of personal ability to control the outcomes once cancer is detected early was in their control, stressing that this notion coincides with the scripture writings of Islam and Christianity. For example, the belief that cancer is a punishment from God was reframed as a motivating notion that cancer may be a test from God. The results showed that almost 48% of the intervention group and 12.5% of the control group scheduled or attended a clinical examination and 38.5% of women in the intervention group and 21.4% of the control group attended or scheduled a mammography postintervention. In another study with African American women, biblical passages about the importance of staying healthy were provided and discussed in an intervention aimed at increasing attendance at colorectal cancer screenings [52]. The selected biblical passages were used to empower participants to take control of their health [52]. In this study, 539 African American men and women 50 years of age or older participated. The intervention group had a significantly greater proportion of those receiving a colonoscopy within 3 months after the educational session than the control group.

Further controlled studies are needed to assess the effect of challenging the different types of fatalism among healthy participants to increase screening and good health behaviors and among cancer survivors to promote adaptive coping and well-being.

Discussion and Conclusions

This chapter provides a review of various aspects of cancer fatalism, including its prevalence in different population groups and correlates of fatalism with sociodemographic variables. An effort has been made to critically review the role of fatalism in screening behaviors and delay in seeking help. The effect of cancer fatalism on cancer survivors' adjustment and well-being was also addressed. In addition, the relatively new concept of genetic fatalism and the few studies related to the concept were reviewed. Finally, a conceptualization of fatalism as a multidimensional construct has been suggested.

This chapter demonstrates the complexity of the concept of fatalism, consisting of different dimensions that each may have a unique effect on health behaviors. Also, its various correlates and confounders call for caution in drawing conclusions from cross-sectional and correlative studies.

Most studies that assessed fatalism in ethnic groups have not addressed the dynamic nature of culture. Traditional societies are steadily going through a process of Westernization, incorporating cultural beliefs regarding health and illness with modern biomedical knowledge [79]. Thus, fatalism should be studied in this context of change.

It is suggested that further studies examine multidimensional aspects of fatalism based on new or refined tools. In addition, attention should be given to psychological confounders of fatalism, such as depression and trait anxiety, and their interaction with coping styles such as emotional control or use of denial or avoidance. Special caution should be paid to pitfalls of overgeneralization and simplistic linking of fatalism to specific ethnic groups.

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