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Cancer Stigma and its Health Consequences

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Abstract People with cancer are stigmatized in many societies. Research investigating the causes and consequences of cancer stigma has grown rapidly; however, due to a lack of agreement among researchers as to how to conceptualize and examine cancer stigma, it is difficult to draw connections among the findings in the current cancer stigma literature. In this review, the authors developed one potential conceptual framework in an attempt to summarize/organize the existing findings. Common themes emerged at each stage of cancer stigma proposed in the framework: (1) six different dimensions of stigma that explain why patients with cancer are likely to be stigmatized, (2) negative stereotypes, prejudice toward, and discrimination against patients with cancer among the general populations, family or significant others, and health professionals, and (3) patients' poor psychological well-being and negative health-related behaviors. The utilization of the framework in the future cancer stigma intervention research is discussed.

Keywords Cancer · Stigma · Prejudice · Discrimination · Causes · Health consequences · Social image

This article is part of the Topical Collection on *Psycho-Oncology and Supportive Care*

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Introduction

Many serious diseases, including, but not limited to, leprosy, tuberculosis, HIV/AIDS, and epilepsy, are often perceived as stigmas in our society [1]. Consequences of such disease-related stigma are often serious because it not only brings distress to patients but can also lead to poor social relationships, unemployment and low income, and poor health outcomes [2••]. Cancer is one of the serious diseases that are often perceived as a stigma in many societies [3]. In fact, several studies suggest that cancer stigma is prevalent. An early study demonstrated that 52 % of people with breast cancer in the USA reported that people avoided or feared them [4]. High prevalence of cancer stigma has been further confirmed in more recent studies that have been conducted among different samples in the USA as well as across multiple countries, including, but not limited to, Japan, England, and Korea [5•, 6–8]. In recent years, there has been a rapid growth in the number of researchers who investigate the causes and consequences of cancer stigma. However, research on cancer stigma is still relatively new, and there seems to be a lack of agreement among researchers as to how to conceptualize and examine cancer stigma. Consequently, it is hard to draw clear connections between the findings from one study to those from others. This article aims to provide one potential conceptual framework of cancer stigma and summarize/organize the findings in the current literature using the framework.

A Conceptual Framework of Cancer Stigma

Figure 1 describes the conceptual framework used in this review paper. Stigma can arise from any characteristics that are perceived to be different from the norm within a given society [9]. Stigma is generally defined as “an attribute that is deeply

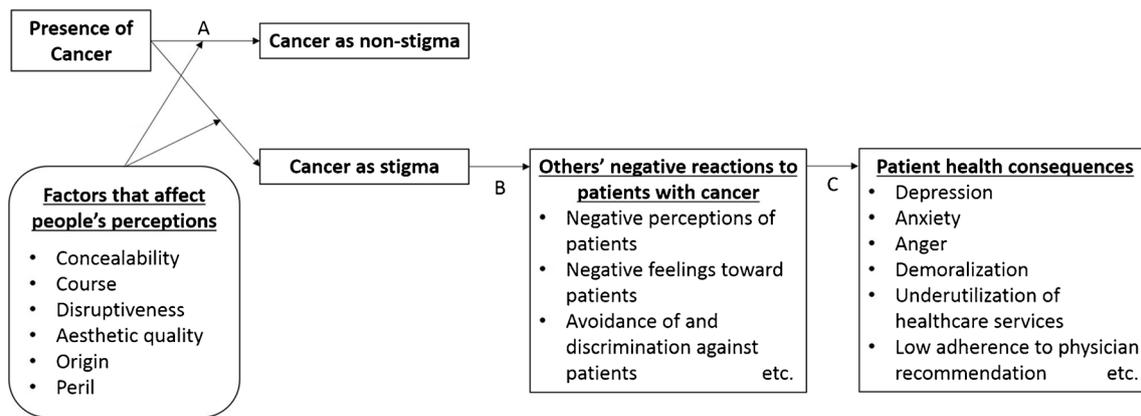


Fig. 1 A conceptual framework of cancer stigma

discrediting” or a mark that reduces the bearer “from a whole and usual person to a tainted, discounted one” [9]. According to these definitions, cancer is considered as a stigma when it signals people a potential deviation from the norm or is associated with an undesirable quality. This suggests that the presence of cancer in itself is not always considered as a stigma, particularly when it does not convey deviation from the norm and/or is not associated with undesirable quality (Path A in the model). However, once individuals are stigmatized, they are often stripped of their social status, stereotyped, discriminated, and isolated or even ostracized from the society [10]. That is when cancer, once labeled as a stigma, can induce negative reactions among the general population toward the patients (Path B). Finally, such negative reactions from others can, in turn, impact patient health status (e.g., psychological well-being, stress-related inflammatory reactions) as well as health-related behaviors (e.g., healthcare utilization, adherence) (Path C).

The current review is limited to the most recent peer-reviewed journal articles written in English that were published between 2011 and 2015. To conduct the literature search, we used PubMed Advanced Search Builder. We entered “stigma” and “cancer” into separate lines as keywords and specified that both terms have to be present in a given article, although the terms could appear in any field (e.g., title, abstract, body, references, etc.). We also placed two filters (i.e., year, language) so that articles published before 2011 and written in a language other than English were excluded from the search. This resulted in 205 potential abstracts on January 20th, 2015. The first author (DF) reviewed a title and an abstract of each of the 205 hits and determined if the paper addressed at least one path in the conceptual framework described above. For the abstracts that met the initial screening, the authors retrieved full articles and verified the fit of the paper to the current review. Finally, other relevant articles that were considered as benchmarks or seminal works but did not meet the year or language criteria were added back to the list of the relevant articles. This resulted in a total of 27 articles. In

the following sections, we review the findings from these 27 peer-reviewed journal articles by organizing them into each path presented in the conceptual framework of cancer stigma presented above.

Findings of the Recent Cancer Stigma Literature

Factors That Affect People’s Perceptions of Cancer (Path A)

According to the theory of social stigma proposed by Jones et al. [11], there are six dimensions to stigma: concealability, course, disruptiveness, aesthetic quality, origin, and peril. We propose that this theory can be applied to explain when cancer is considered as a stigma. *Concealability* concerns how easy it is for the patients to conceal cancer from others. Certain types of cancer are less concealable than others due to location of cancer (e.g., head and neck cancer vs. gastrointestinal cancer) or due to effects of treatments (e.g., alopecia caused by chemotherapy). *Course* concerns people’s beliefs about cancer prognosis and mortality. Cancer is frequently associated with death, even though the advancement in cancer treatment has enabled the majority of patients (approximately 60 %) with cancer to live long after diagnosis [12]. For diseases with poor prognosis, which often result in death, treatments are considered as futile [13••]. *Disruptiveness* concerns the degree to which cancer blocks or hampers smooth interactions and communication between patients with cancer and others. Meeting with a person with a serious illness, such as cancer, makes people feel uncomfortable, usually because they do not know what to say to them [5•, 14•]. *Aesthetic qualities* concern to what extent cancer makes the patients visually repellent, ugly, or upsetting. For example, head and neck cancer may cause remarkable disfigurement in the face of the patients, or colostomy may cause distressing odor. For another instance, chemotherapy may cause alopecia. It should be noted that aesthetic qualities are related to concealability as aesthetic

qualities become particularly important when cancer is not concealable. However, they are still separate constructs. For example, alopecia, which is not concealed by the patient, may be considered as more visually repellent among female patients than male patients. *Origin* concerns whether the patients are believed to be responsible for their cancer (e.g., smoking, poor diet) or not (e.g., heritability, environmental populations). For example, a telephone survey conducted in the USA in 2008 revealed that 59 % of the participants drawn from the general populations without a history of cancer ($n=1071$) reported that patients with lung cancer are at least partly to blame for their illness, despite 94 % of them correctly stated that people can get lung cancer even if they do not smoke [15]. Finally, *peril* concerns people's beliefs about imminence and seriousness of danger to themselves posed by cancer. Cancer is sometimes considered as a hereditary disease; therefore, having a family member with cancer makes people feel that their sense of security (e.g., "I am immune from cancer") is endangered. Furthermore, in some communities, people erroneously believe that cancer is contagious, which results in an increased sense of insecurity [16].

The findings from studies that specifically focused on causes of cancer stigma speak to the six dimensions of social stigma. For example, Marlow and Wardle [14•] have identified six distinct domains associated with cancer stigma. Of those six domains, three are relevant to the factors influencing people's perceptions of cancer, while the other three domains are relevant to people's behaviors toward patients with cancer or societal discrimination in response to cancer stigma (which will be discussed in the following section). Each of the three factors relevant to people's perceptions of cancer nicely maps with one of the factors proposed by the theory of social stigma as proposed by Jones et al. and discussed above. More specifically, the first factor concerns *severity of the illness* (e.g., "Once you've had cancer you're never 'normal' again"), which parallels with the "course" proposed by Jones et al. The second factor concerns *awkwardness* (e.g., "I would/would not feel at ease around someone with cancer"), which is consistent with "disruptiveness." Finally, the third factor concerns *personal responsibility* (e.g., "A person with cancer is liable for their condition"), which parallels with "origin."

The findings from another study assessing perceptions of and beliefs about cancer among non-cancer adult population of high-income countries were also consistent with some factors proposed by Jones et al. [17•]. This study also identified six themes relevant to cancer stigma. Of those six themes, four of them are concerned about the factors that influence people's perceptions of cancer as a stigma or non-stigma: identification, social image, causes, and interpretation of personal risk. More specifically, *identification* concerns how people understand signs and symptoms of cancer and how to detect them. People's understanding of signs and symptoms of some cancer is often vague (e.g., pancreatic cancer). In this case, people

may fail to correctly identify people with cancer, resulting in cancer as a non-stigma. In contrast, signs and symptoms of some cancer are visually clear and unambiguous (e.g., neck and head cancer). In such case, people are likely to identify the presence of cancer, resulting in cancer as a stigma. This factor is consistent with "concealability" in the theory of social stigma developed by Jones et al. *Social image* concerns people's beliefs about cancer prognosis and mortality (e.g., fear, immediate death) as well as more general impression of cancer (e.g., fear, death, and weakness), which nicely maps on to Jones et al.'s "course." *Causes* concern how people attribute cancer (e.g., hereditary, age, lifestyle such as smoking, drinking, and unhealthy diet, personality, and physical/emotional trauma), which is consistent with "origin." Finally, *interpretation* of personal risk concerns people's beliefs about how vulnerable they are to cancer. In most cases, people were optimistically biased about their risk of developing cancer, which can potentially distance themselves from cancer and cancer patients. This factor is consistent with the "peril" proposed by Jones et al.

One prominent characteristic of cancer stigma that has been repeatedly identified across multiple studies was cancer as a self-inflicted disease (e.g., caused by smoking) [18, 19]. This characteristic is consistent with the dimension of "origin" proposed by Jones et al. [11]. The belief that cancer is a self-inflicted disease was particularly prevalent among patients with lung cancer, possibly due to strong scientific evidence for the causal relationship between smoking and lung cancer. However, such belief has also been observed in other types of cancer, such as breast, cervical, colorectal, and skin cancer [20•]. Taken together, the six dimensions of social stigma proposed by Jones et al. are useful for organizing the findings from the existing studies that examined factors potentially affecting people's negative perceptions of cancer.

Others' Negative Reactions to Patients With Cancer (Path B)

Once cancer is perceived as a stigma, people are likely to react negatively toward patients with cancer. However, the exact nature of reactions is likely to be different based on the type of relationship individuals have with the patients. We identified three broad relationship types: general population (e.g. strangers, acquaintance), family and/or partners (i.e., romantic relationships), and health professionals (e.g., nurses, oncologists, primary care physicians). Below, we will review negative reactions to patients with cancer within each of the three types of relationships.

General Population

Marlow and Wardle [14•] assessed people's attitudes toward patients with cancer among the general population in the UK through a Web-based self-administered questionnaire. They then categorized people's negative reactions toward patients with cancer in three broad categories: avoidance (e.g., "*If a colleague had cancer I would try to avoid them.*"), policy opposition (e.g., "*More government funding should/should not be spent on the care and treatment of those with cancer.*"), and financial discrimination (e.g., "*It is acceptable for banks to refuse to make loans to people with cancer.*"). Likewise, Balmer et al. [17•] systematically reviewed how non-cancer adult population of high-income countries react to cancer and found that people often actively avoid talking about or acknowledging cancer. Cancer is rarely addressed in day-to-day life by healthy, unaffected people because it is uncomfortable and anxiety-provoking for many people to even think about cancer [3]. For many people, cancer is something that they discuss only "when it becomes personal" [16]. Finally, Cho et al. [7] conducted a survey using a self-administered questionnaire in a sample of 1011 men and women in Korea with no history of cancer and found that 42.6 % of participants believed that people with cancer would not be socially active after the diagnosis and 71.8 % believed that cancer patients would not be able to make contributions to society. Furthermore, 42.3 % of participants reported that they felt uncomfortable being with cancer patients and that 27.6 % of participants avoided interacting with neighbors who had cancer. These findings demonstrate that negative reactions among individuals with no history of cancer to individuals with cancer are prevalent across countries.

Family and Partners

Cancer stigma not only influences strangers'/acquaintances' reactions but also family members'/spouses' reactions toward the patients with cancer. For example, Dirkse has shown that greater self-reported shame among patients with cancer was associated with decreased amount of time spent to talk about their relationship with the family/spouse and lower marital satisfaction [21]. Lobchuk et al. have also shown that caregivers' judgments on patients' responsibility for controlling lung cancer is associated with dysfunctional helping behavior [22].

Health Professionals

Two studies examined health professionals' attitudes toward patients with cancer. In one study, oncology social workers reported that some cancer patients, especially, but not limited

to, smokers, expressed concerns that their physicians may not treat them fairly because of their history of smoking or because of poor prognosis [23]. Unfortunately, there is evidence that such concerns expressed by patients with cancer may be legitimate. For example, Marteau et al. studied nurses' and physicians' attitudes toward patients with cancer [24] and found that both nurses and physicians rated patients with lung cancer who were smokers, on average, as less concerned with their condition, less knowledgeable about cancer, less likely to adhere to treatment regimens, and less pleasant to interact with as compared to patients with lung cancer who were non-smokers.

Patient Health Consequences of Cancer Stigma (Path C)

The final path in our conceptual framework of cancer stigma addresses negative impacts cancer stigma could have on patient health. Health consequences of cancer stigma can be either direct (poor psychological well-being due to experience of prejudice and discrimination) or indirect (poor health-related behaviors due to fear of prejudice and discrimination). Below, we address both the direct and indirect health consequences of cancer stigma.

Poor Psychological Well-being

Cancer stigma has been found to be strongly and consistently associated with negative psychological state, including depression [5•, 7, 25•, 26], anxiety [25•], anger [27, 28], low self-esteem [29], and demoralization [30]. Some of these relationships were mediated by patients' coping (e.g., self-blame [28] or self-disclosure of illness [31]) and social support [25•]. For example, patients who blame themselves for their cancer experience have worse psychological outcomes as compared to patients who do not experience self-blame [28].

Although evidence supporting the link between cancer stigma and poor psychological well-being is strong, there is still limited research investigating mechanisms underlying the link. This question can be partly informed by the findings from the health disparities. There is abundant evidence that experience of discrimination is a source of chronic psychosocial stress and results in poor mental health. Such association has been found in many social groups that are often marginalized in many societies, including, but not limited to, racial [32, 33] and sexual minorities [34, 35]. It is likely that discrimination that patients with cancer often experience [7, 14•, 16, 17•] can also be a source of psychosocial stress, which, in turn, leads to poorer psychological well-being. However, more empirical studies that directly

examine causal relations between cancer stigma and patients' psychological well-being are strongly encouraged.

Under-utilization of Healthcare Services

Cancer stigma not only affects individuals' well-being but also their health-related behaviors. Because stigmatized individuals often experience discrimination and/or social isolation, as mentioned earlier, it is not surprising that fear of cancer stigma often discourages individuals from seeking medical help [30, 36–38]. For example, research has shown that individuals with lung cancer tend to expect to be stigmatized as a smoker and blamed for their illness even if they were non- or ex-smokers [38]. This fear of stigma and blame has been found to be associated with delay in reporting symptoms of lung cancer [27]. Another study has shown that feelings of shame and embarrassment of having cancer discourage individuals from seeking medical information, treatment, or emotional support [36, 39].

Low Adherence to Physician Recommendations

Even if healthcare providers were able to encourage individuals who expect to experience discrimination due to cancer and/or other forms of stigma to utilize healthcare services initially, there is another hurdle—these individuals are less likely to adhere to physician recommendations than other individuals. For instance, Black/African Americans with higher, as opposed to lower, levels of perceived discrimination were less likely to adhere to primary care physicians' recommendations 16 weeks after the medical visits, and this relation was partially mediated by less trust in a physician [40]. The association between perceived discrimination and low adherence is not unique to primary care patients and has been found among patients with specific diseases, such as hypertension [41], strokes and transient ischemic attacks [42], and HIV/AIDS [43].

Research that specifically focuses on perceived discrimination and adherence among patients with cancer is very limited at this point. However, one study provides initial evidence supporting that perceived discrimination may play a role in predicting adherence to physician recommendations among patients with cancer. More specifically, Pérez-Stable et al. have shown that women who reported higher levels of perceived discrimination were less likely to complete follow-up evaluations within the recommended 60 days after receiving abnormal mammography results as compared to women who reported lower levels of perceived discrimination. This, in turn, resulted in a delay in the diagnosis of breast cancer, which clearly has serious implications for patient survival [44].

Clinical Implications

The framework proposed in this review paper can also inform future intervention research. Specifically, effective interventions would differ depending on which path in the model researchers/clinicians are trying to address. For example, in order to discourage people to see cancer as a deviation or unwanted quality (i.e., interventions addressing Path A), public education on cancer may be required. The aim of cancer education is to promote people's accurate knowledge about the causes and prognosis of cancer with an ultimate goal to address course, origin, disruptiveness, and peril. Additionally, the development of techniques/tools to better manage physical deformities due to cancer or cancer treatment may be beneficial to directly address concealability and aesthetic qualities.

The nature of interventions to reduce people's negative reactions to patients with cancer (i.e., interventions addressing Path B) would be different from the ones proposed above for addressing Path A. We posit that effective interventions addressing Path B can be developed by drawing on social psychology research on stereotyping, prejudice, and discrimination. For instance, contact hypothesis has shown that repeated interactions, particularly positive and constructive ones, can increase positive feelings and perceptions between individuals with and without stigma [45, 46]. One potential intervention drawing on this theory is to increase opportunities for the general population to interact with patients with cancer by organizing social events for them to mingle. In fact, in the racial health disparities research, several researchers have already started to attempt to develop an intervention to reduce non-Black physicians' negative reactions to Black patients by drawing on social psychology research [47, 48].

Finally, interventions addressing Path C should focus on helping people with cancer to better cope with stigma. To do so, researchers should uncover protective factors that make some people with cancer more resilient to negative health consequences of stigma than others. For instance, people with cancer should be encouraged not to attribute their cancer to themselves, that cancer would not deprive them of their identity, and that they can combat potential social disadvantages that they may encounter by seeking proper social support. For example, Chambers et al. conducted a pilot study of a 6-week acceptance-focused cognitive behavioral intervention targeting stigma in lung cancer patients, which resulted in moderate to large improvements in psychological and cancer-specific distress [49].

Limitations and Future Research Directions

The present review revealed several limitations in the current literature of cancer stigma despite the fact that more

researchers than ever are investigating the causes and consequences of cancer stigma. Regarding the factors that affect people's perceptions of cancer (Path A in our conceptual framework), it appears that focus has been heavily biased on "origin" of cancer, particularly smoking for lung cancer, as a major source of cancer stigma. Although there are a few studies that investigated other factors that may contribute to cancer stigma (e.g., course, concealability, peril), more studies are required to examine all six factors proposed by Jones et al. in the context of cancer stigma. In such studies, researchers should assess all six factors simultaneously and investigate relative weights of each factor in determining cancer stigma that patients experience.

Regarding people's negative reactions to patients with cancer (Path B in the current proposed framework), the majority of the existing studies primarily focused on how people in general react to patients with cancer. Interactions that patients have with strangers and/or acquaintances are important for predicting subsequent health consequences; however, we posit that interactions that patients have with their family and loved ones as well as with their healthcare providers may play even more important roles in determining their health consequences. For instance, let us imagine two different patients with neck and head cancer who experience the same amount of discrimination by strangers or acquaintances due to their disfigurement. One patient has family and healthcare providers who listen to the patient's hardship and provide constant psychological support and assurance, whereas the other patient has family and healthcare providers who are not willing to provide support to the patients. With the first patient, the negative health consequences of discrimination by strangers/acquaintances may be mitigated by love and support provided by their family and a healthcare professional team. In contrast, the latter patient may be particularly vulnerable to the negative health consequences of discrimination by strangers/acquaintances. This example demonstrates the need for better understandings of the nature and consequences of negative reactions toward patients with cancer across different types of relationships. We also suggest that future cancer stigma research that aims to investigate people's reactions to patients with cancer should draw upon the social psychology literature of bias. According to this literature, people's reactions can be assessed at three different levels: cognitive (i.e., stereotyping), affective (i.e., prejudice), and behavioral (i.e., discrimination) levels. Although thoughts, feelings, and behaviors are closely interrelated to one another, they still involve different psychological processes [50]. Better understandings of the levels of reactions are important for the future intervention research as each psychological process (i.e., stereotyping, prejudice, and discrimination) requires different types of strategies to reduce bias.

Finally, regarding patient health consequences of cancer stigma (Path C in the conceptual framework), the review revealed that the existing studies mostly focus on prevention, access/barrier to medical care, and experience during treatment, and very few studies have evaluated the consequences of cancer stigma during the survivorship phase. As we have witnessed a rapid advancement in the field of medicine in the past few decades, more and more patients with cancer have become survivors. In order to fully understand what patients go through from the diagnosis of cancer to survivorship, more research that systematically investigates the long-term health consequences of cancer stigma is required. Additionally, many studies in the current literature of cancer stigma are cross-sectional, and thus, mechanisms that underlie cancer stigma and negative health consequences are still unclear. In order to establish a causal relationship between cancer stigma and health consequences, experimental studies as well as longitudinal studies must be conducted.

Conclusion

Patients with cancer are frequently stigmatized in many countries. Stigma is associated with a variety of clinical outcomes as well as social consequences. Although the findings in the current cancer stigma literature seem all over at first glance, we were able to see some common themes across studies by using a framework proposed in this review. It is clear that an overwhelming number of patients with cancer are subjected to others' negative reactions toward them, which, in turn, are likely to result in poorer health outcomes. Clinicians should be sensitive to cancer stigma that underlies patients' emotional and behavioral outlook and consider potential implications on the quality of life of the patients. We encourage future studies to utilize the current framework for developing interventions that are appropriately designed to address different stages of cancer stigma in order to ultimately improve health of all patients with cancer.

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Compliance with Ethics Guidelines

Conflict of Interest Daisuke Fujisawa and Nao Hagiwara declare they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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