

## Empirical Articles

# Association Between Cancer Stigma, Pain and Quality of Life in Breast Cancer

Associação Entre Estigma, dor e Qualidade de Vida em Mulheres com Cancro da Mama

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## Abstract

**Aim:** We examined the association between cancer stigma and quality of life. We further explored the role of pain intensity in this association among women with breast cancer in the first months following diagnosis.

**Methods:** 105 women with breast cancer within 8 months of diagnosis completed self-report measures assessing cancer stigma, pain intensity and quality of life.

**Results:** Our findings show that stigma among breast cancer patients is associated with worse quality of life. Pain intensity partially mediated the relationship between cancer stigma and quality of life. We recruited a convenience sample of women with breast cancer, which may be subject to selection bias. The cross sectional design of the study precludes inferences regarding causality.

**Conclusions:** Health professionals should recognize and mitigate the impact of stigma as an important factor that is associated with impaired quality of life among patients with breast cancer. Continued attention should be paid to pain intensity and the complex relationship between stigma and pain in predicting quality of life.

*Keywords:* stigma, breast cancer, pain, quality of life, Israel

## Resumo

**Objetivo:** O presente estudo procurou analisar a associação entre o estigma e a qualidade de vida em pessoas com cancro. Foi ainda explorado o papel da intensidade da dor nesta associação, em mulheres com cancro de mama, nos primeiros meses após o diagnóstico.

**Método:** 105 mulheres com cancro da mama (até 8 meses após o diagnóstico) completaram medidas de autorrelato avaliando o estigma relacionado com o cancro, a intensidade da dor e a qualidade de vida.

**Resultados:** Os nossos resultados mostram que o estigma entre pacientes com cancro de mama está associado a uma pior qualidade de vida. A intensidade da dor mediou parcialmente a relação entre o estigma relativo ao cancro e a qualidade de vida. Duas limitações são o facto de a amostra de mulheres com cancro da mama ser de conveniência, podendo ter estado sujeita a algum viés de seleção, e o facto de ser um estudo correlacional, que não permite inferências sobre causalidade.

**Conclusões:** Os profissionais de saúde devem reconhecer e mitigar o impacto do estigma como um fator importante associado à diminuição da qualidade de vida de pacientes com cancro da mama. Deverá prestar-se atenção contínua à intensidade da dor e à complexa relação entre estigma e dor na previsão da qualidade de vida.

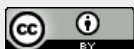
*Palavras-Chave:* estigma, cancro da mama, dor, qualidade de vida, Israel

Psychology, Community & Health, 2019, Vol. 8(1), 275–287, <https://doi.org/10.5964/pch.v8i1.310>

Received: 2018-11-19. Accepted: 2020-01-28. Published (VoR): 2020-06-05.

Handling Editor: Teresa Santos, Universidade Europeia, Lisbon, Portugal; William James Research Center-WJCR/ISPA, Instituto Universitário - Lisbon, Lisbon Portugal

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Breast cancer is the most frequently diagnosed cancer in women worldwide (Torre et al., 2015). Today early detection and treatment of breast cancer has improved and survivors now live longer (Runowicz et al., 2016). However, even after full recovery, cancer survivors continue to struggle with many difficulties that affect their quality of life. Therefore, evaluating Quality of Life (QoL) among cancer patients has been the focus of research and clinical practice in recent decades (Montazeri, 2008; Penha et al., 2016; Reich, Lesur, & Perdrizet-Chevallier, 2008), particularly as a marker for treatment outcomes (Montazeri, 2008).

Quality of Life is a broad construct pertaining to subjective well-being that incorporates different dimensions including, physical functioning, social functioning, role functioning, mental health, and general health perceptions (Montazeri, 2008). Identifying factors that may affect QoL can map directions needed for more effective treatment of cancer patients. Research that has been conducted on QoL in people with breast cancer consistently found that QoL decreased following a breast cancer diagnosis compared with pre-levels, particularly in the first year (Jones et al., 2015; Montazeri, 2008). The early months following diagnosis and initial stages of adjuvant treatment course are transition times of increased risk of developing mental health distress and decreased QoL in breast cancer patients (Hanson Frost et al., 2000).

Although substantial research has focused on assessing QoL among women with breast cancer in general, and as a marker of treatment outcome, in particular, less attention has been paid to the factors affecting the documented decreased QoL particularly following diagnosis. Possible factors that may affect the QoL of women with breast cancer include depression and its associated symptoms such as fatigue and helplessness/hopelessness (Reich et al., 2008), anxious preoccupations (Andritsch, Dietmaier, Hofmann, Zloklikovits, & Samonigg, 2007) body image and sexuality, and other social stressors such as financial burden (Andritsch et al., 2007).

Another factor that was found to be associated with decreased QoL among women with breast cancer is pain intensity (Fenlon et al., 2013; Starkweather, Lyon, & Schubert, 2013). Experiences of pain are prevalent among cancer patients and it has been demonstrated to be clinically relevant in 10% to 50% of patients undergoing various common operations, including breast cancer surgery (Kehlet, Jensen, & Woolf, 2006) and adjuvant therapy, such as chemotherapy and radiotherapy (Jung, Herrmann, Griggs, Oaklander, & Dworkin, 2005). Pain affects QoL through its direct impact on physical comfort and mobility. Pain also affect QoL through its impact on the perception of the illness and tendency to catastrophize as well as trigger concern about mortality (Lin, Lai, & Ward, 2003; Sullivan et al., 2001). Indeed, research has documented that pain is associated with lower sense of control, affects patients' ability to perform activities, and increases fear of death (Caffo et al., 2003; Gärtner et al., 2009).

In recent years, there has been growing interest in examining how negative attitudes toward chronic illness may affect patients' QoL. Within this context, stigma (Chambers et al., 2015), which refers to severe social disapproval of properties, beliefs or behaviors that are associated with one's illness, and are perceived to be deviant from cultural norms (Goffman, 1963) has received growing attention. The World Health Organization (WHO) referred to stigma as the hidden burden of mental disorders (WHO, 2001), while the US Surgeon General documented it is an obstacle to the receipt of care (US Surgeon General, 1999). Stigma negatively impacts people's self-identity and the social responses they receive (Fife & Wright, 2000) and acts as a significant barrier to seeking mental health care (Corrigan, 2004; Nakash, Nagar, & Levav, 2015). It may delay or impede consultation or hinder the course of treatment (Corrigan, 2004). When stigma is internalized (i.e., self-stigma), the negative perceptions can lead to shame, guilt and fear of discrimination (Major & O'Brien,

2005), negatively impacting QoL (Heijnders & Van Der Meij, 2006). Indeed, studies conducted primarily with lung cancer patients have consistently documented that stigma is associated with poorer QoL (Brown Johnson, Brodsky, & Cataldo, 2014; Chambers et al., 2015; Heijnders & Van Der Meij, 2006).

Despite the extensive research documenting the impact of stigma on QoL among patients with chronic health conditions in general and lung cancer in particular, this topic has received very little attention among persons with breast cancer. In a qualitative study conducted among women with breast cancer, stigma has been cited as one of the concerns dominating the women's experience (Ashing-Giwa et al., 2004). In another study examining stigma and psychological adjustment among lung, breast and pancreatic cancer survivors (Else-Quest, LoConte, Schiller, & Hyde, 2009) no significant differences were observed between stigma and type of cancer suggesting that breast cancer stigma is an area of need for further exploration.

Stigma, much like pain can affect the perception of the illness and tendency to catastrophize its outcomes (Lebel, Castonguay, Mackness, Irish, Bezjak, & Devins, 2013) suggested that the extent to which head, neck and lung cancer patients perceived the illness as disruptive to their valued activities and interests partially mediated the relationship between stigma and subjective well-being (Lebel et al., 2013). Stigma has also been linked to perceptions about treatment being futile and death inevitable among lung cancer patients. Stigma therefore may heighten patient's negative appraisals of cancer threat (Chapple, Ziebland, & McPherson, 2004), such that if a patient appraises their cancer as a challenge they can meet, they are expected to experience less emotional distress than a patient that perceives the cancer as a threat (Chambers et al., 2015). Stigma can also impact the experience and appraisal of pain. Recent research has documented that social stigma can impact empathy for pain (Decety, Echols, & Correll, 2010). Although no research to date has examined the association between stigma and pain in the context of cancer patients, it is plausible that during early stages following diagnosis, when the experience of intensive pain is often prevalent, pain may play a significant role in the association between stigma and Quality of Life (Caffo et al., 2003; De Ruddere & Craig, 2016; Gärtner et al., 2009).

In the current study we examined the association between stigma and QoL among women with breast cancer and investigated the role pain intensity may play in this association. We hypothesized that stigma will be negatively related to QoL and that pain intensity will partially mediate this association.

## Method

### Participants

The study was conducted in oncology units in three large academic health centers across Israel. All units offer oncological services under Israel's National Health Insurance Law. Healthcare providers in each unit include physicians (oncologists) and nurses as well as mental health professionals (social workers and health psychologists).

A convenience sample of 105 women with breast cancer was recruited by their treating oncologist through person-to-person solicitation upon presentation for a medical appointment. Participants ranged in age from 27 to 83 years old ( $M = 54.58$ ,  $SD = 13.04$ ). A majority of the patients were born in Israel, were Jewish, and were married or living with a partner. Approximately half of the patients were employed, and a majority had

an average and/or above average income. All participants were within 8 months of diagnosis and receiving curative oncological treatment. This specific time frame was selected based on past studies, documenting that psychiatric morbidity is highest during the first 6-12 months after diagnosis (Ahn et al., 2010). We imposed minimal exclusion criteria for patient participation (i.e., absence of metastasis) to maximize generalizability. Regarding clinical information, approximately, a third of patients received chemotherapy, 16% received radiation, 46% received both treatments and a handful received neither treatment. Approximately 9% of the sample has been diagnosed with a similar or different cancer in the past, and over 70% of the patients reported having a close relative who was also diagnosed with cancer.

## Measures

### Demographic and Clinical Information Questionnaire

A self-report questionnaire was used to collect sociodemographic and clinical information. Questions included: age, marital status, country of birth (Israel/other), ethnicity (Ashkenazi/ Mizrahi/ Arab/ mix/ other), and income (considerably below average/ slightly below average/ average/ slightly above average/ considerably above average). Clinical information included questions about active treatment (chemotherapy/radiation), information about cancer diagnosis and medical history and items asking about cancer in close relatives.

### Cancer Stigma Index

The *Cancer Stigma Index* (CSI; Edelen et al., 2014). is a 12-item self-report that assesses cancer stigma. Items are rated on a 5-point Likert-type scale (1 = *not at all* to 5 = *very much*). This measure is unidimensional scale while higher score indicates higher levels of stigma about cancer. For the current study we used a Hebrew version of this measures using back-forth translation. Internal consistency in the current study was high (Cronbach's  $\alpha = .82$ ).

### Pain Intensity

The Pain Intensity (Jensen, Turner, Romano, & Fisher, 1999). is composed by an 11-point scale anchored at 0 (no pain) and 10 (as intense as you can imagine). Participants rated their current pain and the occurrences of the average least and worst pain they felt over the preceding two weeks. The authors suggest few ways to use this tool by calculating average score of two, three or four items. In the current study we used all four items. For the current study we used a Hebrew version of this measures using back-forth translation. The measure shows good psychometric properties for assessing chronic pain (Jensen et al., 1999). Cronbach's  $\alpha$  was calculated including all four items (Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995). In the current study internal consistency of the measure was high (Cronbach's  $\alpha = .91$ ).

### European Organization for Research and Treatment of Cancer Quality of Life Questionnaire

The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30; Aaronson et al., 1993) is a 30-item self-report questionnaire that includes global health status (QoL scale), five functional scales (physical, role, emotional, cognitive and social), three symptoms scales (fatigue, nausea and vomiting, pain) and six single items that are also related to symptoms (dyspnea, insomnia, appetite loss, constipation, diarrhea, financial difficulties). Items are rated on a 4-point Likert-type scale (1 = *not at all* to 4 = *very much*) except for the two questions regarding to global health rating that are rated on a 7-point Likert-type scale (1 = *very poor* to 7 = *excellent*). All scales and single item measures range in score from 0 to 100, such that a high score represents a higher response level. Therefore, a high score for a functional scale

represents a high / healthy level of functioning, while a high score for a symptom scale/item represents a high level of symptomatology/problems. The measure has demonstrated acceptability to patients internationally, scale reliability, and clinical validity, including responsiveness to change. The questionnaire has been widely used in clinical trials to assess impairment in functioning among patients with chronic illness including breast cancer (Brunault et al., 2016). In the current study we used Hebrew version of the questionnaire, which was approved by the European Organization for Research and Treatment of Cancer, and was already used in previous studies (<https://www.eortc.org/>).

## Procedure

The study was approved by the Institutional Ethics Committees in all participating hospitals, and data collection was in compliance with human subject protocols at all participating clinics. After participants were recruited to the study by their treating oncologist and signed an informed consent form, the research assistants handed them a packet of self-report questionnaires in their native language (Hebrew or Arabic). Completion of questionnaires lasted approximately 20 minutes.

## Statistical Analysis

Statistical analyses were performed using SPSS version 21.0 (SPSS Inc., Chicago, IL). One sample *t* tests were performed to investigate differences between the current sample and data from the general population in all QoL dimensions. In order to examine the correlation between QoL dimensions, cancer stigma and pain intensity Pearson correlation coefficient tests were computed. We also conducted mediation analyses to examine the role of pain intensity in the association between cancer stigma and QoL general scale using PROCESS macro (Hayes, 2013).

## Results

The mean score of cancer stigma ( $M = 15.27$ ,  $SD = 5.84$ ) and pain intensity ( $M = 2.19$ ,  $SD = 2.04$ ) were in the lower range of the scales. Participants' ratings on the Quality of Life measure scales were compared to data published by the *EORTC QLQC* Group (Scott et al., 2008). The comparative data represents the general cancer population that was collected from individuals and organizations from around the world (e.g. cancer clinical trials, epidemiological studies and some large studies of the general population; Scott et al., 2008), see Table 1. Our participants' average score on the global health scale (general Quality of Life) was similar to ratings recorded by *EORTC QLQC* Group ( $M = 62.78$ ;  $SD = 24.27$ ). Participants in the current study reported higher scores on the functional scales including on role and emotional functioning and lower cognitive functioning compared to ratings from the general cancer population reported by *EORTC QLQC* Group. Additionally, regarding symptoms scales, patients in the current study reported higher levels of fatigue, insomnia, diarrhea and financial difficulties and lower levels of dyspnea compared to ratings from the general cancer population reported by *EORTC QLQC* Group.

Table 1

*M and SD of Quality of Life Questionnaire Scales for Participants in the Current Study Compared with General Sample of Cancer Patients*

Scale	Sample in the current study ( <i>n</i> = 105)		General cancer patients		Statistic <i>t</i> ( <i>df</i> )
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Global health status / Quality of life general scale	62.78	24.27	61.3	24.2	<i>t</i> (102) = 0.62
<b>Functional scale</b>					
Physical functioning (PF)	75.64	18.36	76.7	23.2	<i>t</i> (103) = -0.59
Role functioning (RF)	75.96	25.74	70.5	32.8	<i>t</i> (103) = 2.16*
Emotional functioning (EF)	75.40	24.06	71.4	24.2	<i>t</i> (103) = 1.70
Cognitive functioning (CF)	76.92	25.58	82.6	21.9	<i>t</i> (103) = -2.26
Social functioning (SF)	70.51	29.67	75	29.1	<i>t</i> (103) = -1.54
<b>Symptom scale / item</b>					
Fatigue (FA)	51.07	26.52	34.6	27.8	<i>t</i> (103) = 6.30***
Nausea and vomiting (NV)	11.70	20.23	9.1	19	<i>t</i> (103) = 1.31
Pain (PA)	31.89	31.08	27	29.9	<i>t</i> (103) = 1.60
Dyspnoea (DY)	11.86	24.1	21	28.4	<i>t</i> (103) = -3.87***
Insomnia (SL)	43.6	32.2	28.9	31.3	<i>t</i> (103) = 4.65***
Appetite loss (AP)	18.91	27	21.1	31.3	<i>t</i> (103) = -0.83
Constipation (CO)	18.27	28.59	17.5	28.4	<i>t</i> (103) = 0.27
Diarrhoea (DI)	14.42	25.76	9	20.3	<i>t</i> (103) = 2.15*
Financial difficulties (FI)	25	32.43	16.3	28.1	<i>t</i> (103) = 2.74**

Note. EORTC QLQ-C30 reference values obtained from Scott et al. (2008).

\**p* < .05. \*\**p* < .01. \*\*\**p* < .001.

## The Association Among Cancer Stigma, Pain Intensity and Quality of Life

Pearson correlation were used to examine associations between cancer stigma, pain intensity and QoL scales. Cancer stigma and pain intensity were negatively correlated with QoL global health status, functioning scales and role and cognitive functioning, such that higher cancer stigma or pain intensity were associated with lower QoL and emotional, social functioning, role functioning and cognitive functioning. Pain intensity was also negatively correlated with physical functioning (see Table 2). Conversely, cancer stigma and pain intensity were positively correlated with QoL nausea and vomiting, pain, diarrhea and financial difficulties scales. Accordingly, higher cancer stigma and pain intensity were associated with higher levels of these symptoms. Pain intensity was also positively correlated with fatigue, dyspnea, insomnia and appetite loss (see Table 2).

Table 2

*Correlations between Cancer Stigma, Pain Intensity and Quality of Life Scales*

Scale	Cancer stigma	Pain intensity
Global health status / QoL (QL2)	-.30*	-.53***
<b>Functional scale</b>		
Physical functioning (PF2)	-.16	-.43***
Role functioning (RF2)	-.22*	-.42***
Emotional functioning (EF)	-.30**	-.34***
Cognitive functioning (CF)	-.22*	-.31**
Social functioning (SF)	-.32**	-.55***

Scale	Cancer stigma	Pain intensity
<b>Symptom scale / item</b>		
Fatigue (FA)	.15	.57***
Nausea and vomiting (NV)	.33**	.39***
Pain (PA)	.32**	.71***
Dyspnoea (DY)	.14	.31**
Insomnia (SL)	.10	.51***
Appetite loss (AP)	.08	.26**
Constipation (CO)	.09	.16
Diarrhoea (DI)	.22*	.24*
Financial difficulties (FI)	.38**	.35***

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Cancer stigma was associated with both QoL ( $\beta = -.3, p < .01$ ) and pain intensity ( $\beta = .29, p < .01$ ), such that higher cancer stigma was associated with lower rating of QoL and higher rating of pain intensity. Additionally, beyond cancer stigma, pain intensity was negatively associated with QoL ( $\beta = -.49, p < .001$ ). The effect of cancer stigma on QoL remained significant after controlling for pain intensity ( $\beta = -.24, p < .05$ ) indicating partial mediation (see Figure 1). We used the Sobel test (Sobel, 1982) to confirm whether the indirect effect of cancer stigma on QoL through the mediation of pain intensity was significant. The Sobel statistic,  $z = 2.43, p < .05$ , indicated that pain intensity partially mediated the link between cancer stigma and QoL.

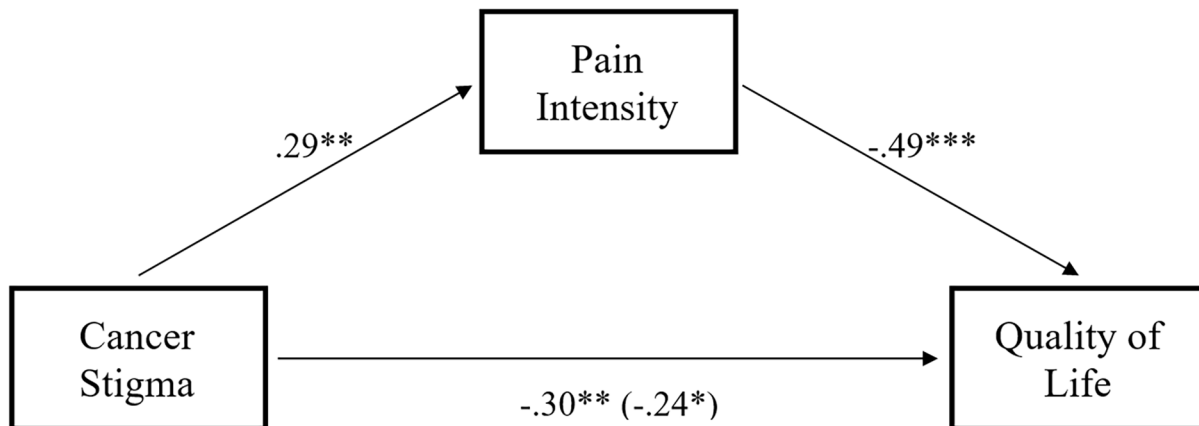


Figure 1. Path diagram showing pain intensity as mediator in the association between cancer stigma and quality of life.

Note. The value in the parentheses represents the effect of cancer stigma on quality of life after controlling for the mediating effect of pain intensity.

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

## Discussion

In the current study, we examined the association between stigma and QoL among women with breast cancer in the first months following diagnosis. In addition, we examined the mediating role of pain intensity in this association. Our findings show that stigma is prevalent among breast cancer patients and that it has significant association with lower QoL of female breast cancer patients in the first months following diagnosis.

Stigma refers to a socially constructed phenomenon where individuals with diseases or disabilities that differ from the majority of individuals are undesirable or socially unacceptable (Goffman, 1963). Social stigma (Link & Phelan, 2001) is the most common form of experienced and researched stigma, and it exists when the larger society expresses a sense of “otherness” toward individuals due to specific characteristics (e.g., physical deformity and disability). Stigma has the potential for internalization of the degraded status by those who are stigmatized—i.e., self-stigma (Wood, Barden, Terk, & Cesaretti, 2017).

Our findings fit well with recent literature conducted primarily among lung cancer patients (Brown Johnson et al., 2014; Chambers et al., 2015; Heijnders & Van Der Meij, 2006), that documented that cancer is a stigmatizing disease and that experiences of social and self-stigma are associated with emotional distress and low QoL (Wood et al., 2017). In the growing area of cancer stigma research, lung cancer has been most investigated cancer site (Chambers et al., 2012). Our study adds to this extensive body of literature and shows that also among breast cancer patients, stigma plays an important role in determining quality of life. Stigma can have severe consequences as it can affect the willingness and timing of seeking medical help (Carter-Harris, Hermann, Schreiber, Weaver, & Rawl, 2014) and can affect treatment adherence and outcomes (Hanson Frost et al., 2000). Knowledge and experiences with breast cancer and treatment effects can lead to fear and shame surrounding the disease resulting in discreditable stigma. Language used to describe breast cancer and the effect of treatments on sexual dysfunction and femininity (Fobair et al., 2006) can influence how cancer stigma is constructed.

Like in other studies, our findings show that pain is prevalent among breast cancer patients and that it affects their well-being (Kehlet et al., 2006). Much like stigma, pain occurs in a social context, with interpersonal features being extremely important to experience (Vaugh, Byrne, & Nicholas, 2014). It is thus not surprising that our findings further show that pain intensity partially mediated the relationship between cancer stigma and quality of life. Past research on pain in the context of other chronic illnesses provides some insight to understand these findings. The experience of pain may heighten the patient's negative appraisals of cancer threat (Chapple et al., 2004) and possibly the perceptions about treatment being futile and fear of death inevitable. This heighten negative appraisals of cancer as a result of the experienced pain threat may thus intensify the effect of stigma on QoL (Chapple et al., 2004). Alternatively, internalized stigma can shape cognitive representations of pain by impacting the tendency to catastrophize about pain and change the perceptions regarding personal control (Vaugh et al., 2014), ultimately resulting in reduced quality of life.

Importantly, recent research has documented that stigma may reduce the empathy and tolerance of pain (Decety et al., 2010). Although the experience of pain is ubiquitous across individuals and cultures and is a characteristic of many chronic illnesses, the perception and meaning we attribute to the experience of pain can vary depending on our emotional, cognitive, interpersonal and cultural experiences and values (Decety et al., 2010; De Ruddere & Craig, 2016). As such, stigma, by virtue of its role as a social sensor can have interpersonal and intrapersonal consequence, and shape the experience and intensity of pain, and this in turn can affect the quality of life of those struggling with stigmatized illnesses. Future studies should expand this line of research and examine the possible mechanisms that might explain our findings.

The study has several limitations. First, we recruited a convenience sample of women with breast cancer, which may be subject to selection bias. Second, our study is cross-sectional, and thus, causality cannot be inferred. Future research should continue examining the influence of breast cancer stigma on QoL as well as



other potential mediators, such as hope (Snyder et al., 1991), coping mechanisms and social isolation (Chapple et al., 2004), in the association between these variables. Third, since there were no Hebrew versions for the commonly used measures to assess pain intensity and cancer stigma index we used a rigorous back - forth translation method to translate the items to Hebrew. Future research should further examine the validity of these versions to Israeli patients.

## Implication for Psychosocial Oncology

Stigma contributes to the burden of illness for both patients and their families through delayed presentation to care, premature termination of treatment, and intensification of the psychological and social morbidities (Weiss, Ramakrishna, & Somma, 2006). As our findings show, pain partially mediated the association between stigma and quality of life among breast cancer patients. Since pain and stigma are prevalent among cancer patients, more research is needed to understand the association between these variables. It is possible that stigma affects the intensity and experience of pain by altering the perception and empathy to pain experienced in the context of stigmatized chronic illness. Health professionals could recognize and mitigate the impact of stigma as it is associated with impaired QoL for breast cancer patients.

Developing evidence based clinical interventions to reduce stigma are paramount. Such interventions may focus on controlling or treating target health problems with informed health and social policies, countering the disposition of perpetrators to stigmatize, and supporting those who are stigmatized to limit their vulnerability and strengthen their resilience (Heijnders & Van Der Meij, 2006; Weiss et al., 2006). Continued attention should also be paid to treating the persistent pain that many patients experience. This will not only have a direct impact on the quality of life, but also reduce the indirect negative effect that stigma has on the well-being of these patients.

## Funding

This study was supported by the Israeli National Institute for Health Policy and Health Services Research (2014/20 to Nakash and Granek).

## Competing Interests

The authors have declared that no competing interests exist.

## Acknowledgments

The authors gratefully acknowledge Prof. Itzhak Levav, Dr. Nihaya Daoud, Prof. Michael Silbermann, Prof. Gil Bar-Sela, and Prof. David B. Geffen, for their contribution to the design of the study and data collection.

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