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The Impact of Cancer and Quality of Life among Long-term Survivors of Breast Cancer in Austria

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Degree to be awarded: M.P.H.

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An abstract of

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Abstract

The Impact of Cancer and Quality of Life among Long-term Survivors of Breast Cancer in Austria

Objective: This study explores the relationship between the perceived impact of cancer among long-term breast cancer survivors, key socio-demographic and clinical variables, and mental and physical health-related quality of life outcomes in Austria.

Methods: One hundred and fifty-two long-term survivors of breast cancer (on average 13 years after initial diagnosis) completed three mailed surveys including the SF-36 to determine self-reported mental and physical health functioning, the Impact of Cancer (version 2) to assess the perceived positive and negative aspects of long-term cancer survivorship, and a general questionnaire to gather socio-demographic and clinical variables of respondents. Linear regression models were constructed to determine the various effects of the perceived positive and negative impact of cancer, while controlling for additional socio-demographic and clinical variables, on mental and physical health-related quality of life.

Results: Respondents reported a physical health status that centered on population norms for Austria, but scored lower on mental health status. After controlling for age, chemotherapy, exercise, and BMI, the positive impact of cancer was associated with improved physical functioning ($p=0.0014$), and the negative impact of cancer was associated with poorer physical functioning ($p<0.0001$). After controlling for age, marital status, the belief in emotional distress as a cause of cancer, and high stress levels, the negative impact of cancer was associated with poorer mental functioning ($p<0.0001$). Higher perceived positive impact of cancer was not associated with mental functioning.

Conclusion: Long-term survivors of breast cancer in Austria perceive both positive and negative impacts of breast cancer. These perceptions, in particular the negative impact of cancer, appear to influence, or are potentially influenced by, physical and mental health-related quality of life.

The Impact of Cancer and Quality of Life among Long-term Survivors of Breast Cancer in Austria

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I. BACKGROUND

Breast cancer as an increasing global health issue: In both developed and developing countries, breast cancer is a significant and costly public health issue (1). It is the most frequently diagnosed malignancy among women, resulting in 1.7 million new cases worldwide each year (2). Globally, incidence of breast cancer has increased by 20% and mortality by 14% since 2008 (3). While half of all breast cancer cases occur in developed countries, developed countries only have 38% of the mortality burden (2). Survival statistics differ widely between more developed and less developed nations, as well as across cancer subtype and stage at diagnosis (4). Increases in breast cancer incidence are likely due to changes in reproductive behaviors (including fewer births and less frequent breastfeeding), increasing overweight and obesity, decreasing physical activity (5), and participation in mammographic screening programs (6).

In general, incidence rates for breast cancer remain high in the 27 nations comprising the European Union, including Austria (7). In Austria, breast cancer is the most frequently diagnosed cancer among women, followed by lung and colon cancer (8). The age-standardized incidence rate for breast cancer is 90.7 (per 100,000 women), which falls below the average in the European Union of 108.8 (3). Although incidence rates have increased since 1986, mortality rates have started to decline (8). The current mortality rate of 21.3 per 100,000 women is on par with the European Union average of 22.4, indicating that the incidence to mortality ratio is slightly worse than the E.U. averages (7). Nevertheless, five-year survival rates in Austria have improved steadily within the last two decades, and currently 84.7% of women diagnosed with breast cancer

will survive at least five years after their initial diagnosis (8). At present, there are approximately 64,000 women living in Austria who have been diagnosed with breast cancer (8). These statistics reflect the excellent care provided by Austria's top-tier universal healthcare system.

The growing population of breast cancer survivors: There are approximately 28 million people living with cancer worldwide (9). The burgeoning population of cancer survivors is attributable to improvements in adjuvant and neo-adjuvant therapies, the increasingly aging population, and in some cases, to the early detection of cancer (10). These improvements in breast cancer survivorship are accompanied by novel challenges in understanding the long-term effects of a cancer diagnosis on survivors' physical and mental health and wellbeing, especially at a time when healthcare systems around the world are strapped for resources (11, 12).

The term 'survivor' denotes a medical and social label for all who are living with a cancer diagnosis until death, irrespective of the cause (13). However, the many challenges presented in the various "seasons of cancer survival," including acute, extended, and permanent, have long been identified (14). Despite the increased attention and resources allocated to studies of cancer survivorship in the United States and Europe (12), there are no evidence-based and/or standardized guidelines for optimizing follow-up care for most adult cancers, including breast cancer (15).

Although there are no specific ranges to delineate newer from long-term survivorship, long-term survivorship is often operationalized as five years or more after an initial diagnosis (16). It is important to distinguish long-term from newer survivors, as it has become clear that those who live years past an initial cancer diagnosis often face

different physiological, psychological, and psychosocial than those who more recently experienced a diagnosis and/or were treated for cancer (10). Long-term cancer survivors often display high levels of functioning on generic measures of quality of life (17-19), which does not always capture the persistent issues stemming from a cancer diagnosis, such as fear of recurrence, body image concerns, or fatigue (20). For example, body image concerns may not be as salient to those still undergoing treatment for cancer, but may be of more serious concern as survivors strive to return to their former lives. In addition, an earlier comprehensive review of quality of life among a range of cancer survivors showed wide variation and limited knowledge of the long-term sequelae of cancer affecting the daily lives of those living five to ten years after their diagnosis (21). There is also evidence to demonstrate that cancer is a serious stressor in one's life (22); however, there are also data to suggest that the experience of having cancer can bring out positive changes in a survivor's life, including personal growth, a renewed sense of purpose, positive relationship changes, and overall 'benefit finding' (23, 24). The Impact of Cancer Scale, employed in the current study, was created as a means of capturing the salient themes and multidimensionality of long-term cancer survivorship (16, 20, 25).

Long-term breast cancer survivors are often faced with an array of mental and physical health issues affecting including: neuropathy, lymphedema, fatigue, pain, sexual function, depression, fear of recurrence, body image concerns (especially those related to femininity and the loss of the breasts) (26, 27). Due to the cascade of issues related to breast cancer-related survivorship, as well as the sheer number of breast cancer survivors, breast cancer survivorship studies have become a top priority (17, 26). It is critical to note that the physical and mental health outcomes of long-term breast cancer survivorship

are mediated by social support (28), ethnicity (29), living situation and partnership status (10), sexuality issues (30), socioeconomic status (31), and fatigue level (32). Thus, breast cancer survivorship is differentially experienced across sociodemographic and clinical factors.

While some work has addressed long-term issues such as infertility and neurological issues among adolescents and young adults diagnosed with cancer (33), the call has been made to more systematically address psycho-oncological concerns among long-term cancer survivors in Austria (34). The current study aims to contribute insights into the association between the perceived impact of cancer and physical and mental health-related quality of life among long-term survivors of breast cancer in Austria. Furthermore, this study can also shed light on the experience of cancer survivorship in a context where breast cancer remains to some degree a stigmatized condition (35).

Austria also presents an interesting context for examining breast cancer survivorship because of the popularity of the belief that acute or chronic emotional distress can cause breast cancer (35). In an ethnographic study, newly diagnosed breast cancer survivors who believed emotional distress caused their cancer were more likely to instigate positive changes in their lives (35). The hypothesis that stressful life events, emotional distress and certain personality types are risk factors for developing breast cancer is not supported by systematic reviews (including those with data from prospective and retrospective cohort studies) (36-41). However, it still remains a meaningful explanatory mechanism for many Austrian women with breast cancer.

The current study seeks to briefly explore the complicated nature of breast cancer survivorship in Austria among long-term survivors in order to understand how women's perceptions of breast cancer come to bear on health-related quality of life.

II. METHODS

Study Population: All aspects of this study were approved by the Emory University Institutional Review Board and the Ethics Commission of the Medical University of Vienna. The study population was comprised of women diagnosed and treated for breast cancer in the Vienna General Hospital (*Allgemeines Krankenhaus der Stadt Wien*). This is a teaching hospital that houses a certified breast health clinic and services women from the city/province of Vienna as well as women from nearby suburban and rural populations.

Long-term survivors in this study are defined as women who first received surgical treatment for breast cancer between 1995-2008. All study participants were covered by the national health insurance at the time of the surgery. A study nurse with access to the hospital database randomly searched for women treated for their first breast cancer diagnosis in the clinic within the chosen time frame. In her selection, she included 100 women who participated in a 2004 study comparing post-operative satisfaction among patients and surgeons following a surgical procedure for breast cancer. In 2004, demographic data were collected and medical personnel had aimed to compare demographic variables to recurrence and mortality rates. Unfortunately, hospital databases were often unreliable in regard to recurrence and mortality, so this portion of the research could not be assessed. It remains a potential future topic of research.

In total, 230 women were recruited to join the study. Three questionnaires (described below) with a randomized study number, a letter explaining the study, and a self-addressed stamped envelope were mailed to potential study participants. Postage fees were generously donated by the Austrian chapter of Europa Donna– The Breast

Cancer Coalition. The response rate was 66% (n=152). This relatively high response rate may represent the salience of the study to long-term survivors, and/or the excellent rapport of the study nurse who assisted with recruitment. Study participants were excluded if they had a relapse or new diagnosis at the time of being surveyed, or if they had recurrence after 2010, as this did not fit the definition of long-term survivorship set for this study. On average, women were diagnosed 13 years prior to the start of this study (2001) (SD: 3.17). Additional descriptive statistics on select independent variables are found in table 1.

Scales: The first questionnaire (see appendix) gathered basic demographic (e.g. age, marital status, education), clinical (e.g. treatment received, year of diagnosis, recurrence), and behavioral health (e.g. alcohol consumption, exercise routine, attendance of a self-help group) data.

The Short-Form-36 (SF-36) scale is a widely used and standardized self-report instrument for assessing health-related quality of life (42). The SF-36 has been translated and validated in German-speaking populations (43) including Austria (44). The instrument is comprised of 36 questions in 8 different domains. These domains contribute to two meta-domains: the physical component summary (PCS) and the mental component summary (MCS). PCS contains the domains: physical functioning, pain, general health perceptions, and physical role functioning. MCS assesses vitality, emotional role functioning, social role functioning, and mental health. The scores for both PCS and MCS range from 0-100, with 100 reflecting the best possible functioning.

The Impact of Cancer Scale (see appendix) is a recently developed self-report instrument that measures how long-term survivors interpret the overall impact of having

cancer in their lives, both positively and negatively (16, 25). This advantage of this scale is that it is based on extensive qualitative research, which elicited salient themes to long-term, rather than short-term cancer survivorship in the United States. Although the scale was initially tailored to cancer survivors in the U.S., the original scale and its shortened version (Impact of Cancer version 2, IOCV2) have been used in a range of settings including Italy (45), Norway (46-48), and the Netherlands (49). The IOCV2 has also been used in cross-national studies comparing a Dutch and American sample (49). The items are asked in a five-point Likert scale format where respondents are asked to give their overall agreement from 1 (strongly disagree) to 5 (strongly agree). Mean scores are compiled for each domain and then aggregated into the two meta-domains, the “Positive Impact of Cancer” (PIC) and the “Negative Impact of Cancer” (NIC).

From the original 81-measure scale, Crespi et al. (20) performed exploratory factor analysis, cross-validation, psychometric evaluation, and analysis to determine internal validity shortened the IOCV1 to 41 measures. Only data from breast cancer survivors 5-10 years after diagnosis were used in the development of IOCV2, which would potential limit its applicability to other forms of cancer, but is useful for the current study (20). The subscales used to compile a composite score for the PIC are: Altruism and Empathy, Health Awareness, Meaning of Cancer, and Positive Self-Evaluation, which yield a mean score with a range of 1-5, with 5 meaning that the respondent found an overall positive impact of cancer. The subscales pertaining to the negative impact of cancer (NIC) were Appearance Concerns, Body Change Concerns, Life Interferences, and Worry. This also yielded a mean score from 1-5, with 5 being the most negative perceived impact of cancer.

To the best of my knowledge, the IOCV2 had not been employed in a German-speaking nation prior to the start of the study. The author translated the questionnaire into German, had it back-translated from two scholars in the field who are fluent in English and German, and pilot tested it on five people who work in cancer care and/or have had cancer.

Hypothesis: Respondents who reported an overall negative impact of cancer would also score lower on physical and mental health-related quality of life. Those who reported an overall higher score on the positive impact of cancer would also report improved measures of physical and mental-health related quality of life.

Analyses: The respondents (N=152) varied based on the following predictor variables: age (years), age at diagnosis (years), geographic setting (rural or urban), alcohol consumption (from seldom to daily), perceived stress level (low to high), use of complementary and alternative methods (yes or no), marital status (married/in a long-term partnership or single), salary (< €1,000, €1,000 < €2,000; and €2,000 <), use of chemotherapy (yes or no), BMI, exercise two or more times per week (yes or no), highest level of education attained (based on the Austrian education system), and whether or not a woman believes emotional distress could have caused her cancer (yes or no) (table 1). All observations were independent and descriptive analyses of the study variables were performed for the overall sample (table 1). After checking the dataset for implausible values and extreme outliers, normality statistics were assessed for gross violations. In some cases, predictor variables were deemed to be slightly skewed using the Kolmogorov-Smirnov or the Shapiro-Wilk tests. However, based on acceptable levels of skewness in the social sciences (50) and after reviewing residual plots, only the BMI

variable was log transformed. Key predictor variables of interest (the positive and negative impact of cancer) and key outcome variables (physical and mental health-related quality of life) across select independent variables are summarized in table 2. The multiple comparisons drawn from t-tests, ANOVA, and Pearson correlation coefficients were exploratory and initiated the selection of select predictor variables in the multivariate analyses. Bivariate analyses through simple linear regression were used to assess the relationship to the outcome variables and key study predictors (not depicted). Predictor variables such as stress and the negative impact of cancer were also examined as interaction terms, but none were applicable.

Variables that were significant in both bivariate analyses were considered to be potential confounders and tested in the final multiple linear regression models. Significant predictors of physical and mental health-related quality of life were also considered for the final multiple linear regression models. All-possible-regression analyses using all predictors were then constructed and evaluated based on adjusted-R², Mallows' C_(p) and MSE values. Model parsimony was also considered when evaluating all possible models. An associative manual model-building strategy was used to measure changes in the beta estimates of the predictor variables of interest, the positive impact of cancer and negative impact of cancer. Predictors that changed the direction of the beta estimates of these variables or changed the estimates by more than 10% were identified as confounders. Two models, one to assess physical health-related quality of life and one to assess mental health-related quality of life, were then created with all significant predictors and all potential confounders. Model diagnostics, including collinearity issues, were assessed on the final model by examining residual plots, partial plots of the

predictors, and the variance inflation factors (VIF). The interaction term was depicted through an interaction plot. Significance tests were performed at $\alpha=0.05$. Statistical analyses were performed with SAS 9.2 (SAS Institute, Cary, NC).

III. RESULTS

Mental health-related quality of life: The mean score for mental component summary (MCS) was 47.34 (SD: 10.40), which is slightly lower the standardized mean score of 50 for population norms on the SF-36 (51). Of the demographic and clinical variables, women with a spouse/partner, higher salary, lower stress level, and those who rejected the belief that emotional distress was associated with the onset of cancer reported better mental health-related quality of life (table 2). Bivariate analysis showed a significant correlation between the negative impact of cancer (NIC) and MCS. Current age was also retained in the model because of its correlation to both the positive and negative impact of cancer and its salience to long-term survivorship. Since the negative impact of cancer differed significantly between respondents who believed that emotional distress caused their cancer and those who did not, as well as those with higher stress loads, these factors were included in the final model (table 3). Results from the all-possible-regressions strategy showed the negative impact of cancer, high stress level, and having a spouse/partner to be significant. The positive impact of cancer however was not significant, but was retained in the model because of its centrality to the research topic. Variance inflation factors (VIFs) in the final model ranged from 1.06 to 1.40, which posed minimal collinearity issues. In the final model, a one-unit increase in the negative impact of cancer decreased the MCS by 5.75 points (SD: 1.14; $p < 0.0001$). Experiencing daily stress also lowered MCS, but having a spouse/partner was associated with increased MCS. The adjusted- R^2 for the model was 0.39 ($p < 0.0001$).

Physical health-related quality of life: The mean score of the physical component summary (PCS) (51.64, SD: 9.26) centers on the standardized mean score for population norms in Austria (51). Of the demographic and clinical variables, physical health-related quality of life was higher among women who lived in rural regions, were younger at the time of study and diagnosis, had a higher salary, did not receive chemotherapy, had a lower BMI, and exercised at least twice weekly (table 2). Having received chemotherapy and older age were correlated with the negative and positive impact of cancer, and were retained in the model to control for confounding. In the bivariate analysis, both the positive and negative impacts of cancer were significantly correlated with PCS. In the final model, a one-unit increase in the positive impact of cancer raised PCS by 2.68 points (SD: 0.82, $p=0.0014$), while a one-unit increase in the negative impact of cancer lowered PCS by 6.20 points (SD: 0.84; $p<0.0001$) (table 4). As expected, older age, higher BMI, and having received chemotherapy also lowered PCS. A regular exercise regime of two or more times per week was associated with increased PCS. VIFs in the final model ranged from 1.05-1.33, therefore posing minimal collinearity issues. The adjusted- R^2 for the model was 0.47 ($p < 0.0001$).

IV. DISCUSSION AND IMPLICATIONS FOR PUBLIC HEALTH

These exploratory analyses demonstrate a relationship between the impact of cancer and mental and physical health-related quality of life. These results suggest that the positive and negative ways in which long-term breast cancer survivors interpret the impact of cancer in their lives may affect, or be affected by, physical and mental health functioning. It is also important to take into account the potential role between having a spouse/partner and high stress levels on mental health functioning. Furthermore, an overall positive impact of cancer was not associated with improved mental health-related quality of life. This study also contrasts with other findings that a positive impact of cancer is related to mental health-related quality of life (16) and it may point to continual struggles women face to implement the positive changes they experienced shortly after diagnosis in the long term. Although the emotional distress belief was not significant in the final model of mental health functioning, those who reported it as an explanatory mechanism scored higher on *both* the positive and negative impact of cancer scales. This is potentially representative of the previous finding that this belief is associated with making positive life changes, but also the fact that some women may not be able to maintain these changes, or may be prone to experience further emotionally distressing situations. More broadly, it demonstrates that the challenges and the potential positive changes of living with cancer change over time.

It is also critical to note that having received chemotherapy treatment and having higher BMI are related to physical health-related quality of life, as these clinical variables can be addressed throughout follow-up treatment. The clear association of the positive impact of cancer to physical health-related quality of life is also telling of the potential of

a cancer diagnosis to impact the decision to engage in more health-promoting behaviors. Overall, this study points to the need to understand the factors associated with quality of life following completion of adjuvant therapy for breast cancer.

Strengths and weaknesses: This cross-sectional study only captures the impact of cancer and health-related quality of life at one time point. Hence, it is not possible to know if the perceived impact of cancer has an effect on the mental and physical health-related quality of life, or if self-reported mental and physical health-related quality of life can influence the ways that survivors reflect on their experiences with breast cancer. Thus, it may be worthwhile to perform a prospective study to understand how these perspectives change over time and how the relationship to quality of life is altered. It may also be useful to consider interventions that may be insensitive to causal direction; that is to say, the causal direction for some may be the impact of cancer on health and wellbeing, whereas for others it may be that health and wellbeing shape the perceived impact of cancer. It may also be useful to consider potential clinical interventions that take seriously the perceived impact of cancer for women with breast cancer. As noted in the literature, the IOCv2 scale may be an applicable instrument for monitoring these effects (16, 45).

This study offers some initial insights into how long-term survivors of breast cancer in a high-income, welfare state interpret the impact of breast cancer years after their initial diagnosis. It does not however include a physical and mental comorbidity index as a potential predictor variable, which likely would have had an impact on measures of health-related quality of life.

This small glimpse into the long-term impact of breast cancer is limited by a host of factors. While care for breast cancer in Austria is generally excellent, there is wide regional variation in access to this care. Also, this study did not explicitly take ethnicity or immigrant status into account. The sample size was also relatively small. Thus, the results of this study may not be generalizable to the Austrian public. The other issue is that those who survive cancer longer were often diagnosed with far less aggressive forms of breast cancer, so to speak of breast cancer survivorship is really only representative of a subgroup of those diagnosed with breast cancer. Additionally, although the response rate was high (52%), it is entirely possible that the women who did not respond were mentally or physically worse off (or better) than those who did. Unfortunately, unreliable record keeping in the hospital made it impossible to determine mortality and relapse rates since initial diagnosis. Lastly, questionnaires only offer a limited insight into a complex experience like cancer survivorship and quality of life, which itself is a psychological construct that can be critiqued for its oversimplification.

Despite these limitations, the findings described here point to the need to further understand how socioculturally mediated perceptions of cancer shape women's subjective quality of life.

Future Directions: The health psychology literature has made the call to prioritize interventions that promote cognitive reframing for long-term breast cancer survivors (52, 53). This would open up space for helping survivors throughout the transition to long-term survivorship and to address issues such as fear of recurrence or body image concerns. Attention to the cultural aspects of breast cancer survivorship could also help tailor population-based awareness campaigns in order to increase the

public visibility of survivors and their particular needs. Previous ethnographic research among breast cancer survivors in the United States demonstrated how cultural constructions of cancer mediate women's coping mechanisms for breast cancer (54). In addition, ethnographic research among breast cancer survivors in Austria showed how the sociocultural stigmatization of breast cancer, as well as culturally specific beliefs such as the emotional distress explanatory mechanism for breast cancer, impacted the illness experience of breast cancer (35). Future directions in understanding the experience of long-term breast cancer survivorship should more systematically include data on socio-cultural constructions of cancer.

As stated, studies of cancer survivorship would be strengthened by a prospective study design, in which the psychosocial and physical vicissitudes of cancer survivorship can be more adequately addressed. Cancer survivorship is recognized as an important aspect of the cancer control spectrum in the United States. Whereas countries like Austria provide far more equitable access to healthcare than the United States, systematic studies and treatment throughout cancer survivorship has not readily been taken up. Future interventions could also examine the impact of visiting a state-sponsored *Kur*, or health spa trip, or oncological rehabilitation center (both of which are provided by state health insurance in Austria, but are not always optimally utilized) on the impact of cancer and quality of life. In addition, future studies could also focus on specific side effects of breast cancer treatment, including breast removal/reconstruction, shoulder and arm pain, and lymphedema as they pertain to the impact of cancer and quality of life.

More attention to the long-term impact of breast cancer may be beneficial to the burgeoning population of breast cancer survivors. This study demonstrates the utility of

the Impact of Cancer Scale in attending to issues pertinent to long-term breast cancer survivors.

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VI. TABLES

Table 1. Demographic, Clinical, and Behavioral Characteristics of the Study Sample

| Demographic, Clinical, and Behavioral Characteristics of the Study Sample | | | |
|---|-----------------|--|------------------|
| Geographic location | | Year of diagnosis | 2001 (SD: 3.17) |
| Rural | 55 (37%) | Emotional distress belief | |
| Urban | 94 (63%) | no | 55 (37%) |
| Occupational status | | yes | 94 (63%) |
| Full-time | 32 (22%) | Exercise 2+ per week | |
| Part-time | 22 (15%) | no | 50 (34%) |
| Unemployed | 4 (3%) | yes | 99 (66%) |
| Retired | 88 (60%) | Used complementary/alternative medicine | |
| Education | | no | 94 (65%) |
| No advanced high school degree | 19 (13%) | yes | 51 (35%) |
| Advanced high school degree | 14 (9%) | Perceived stress level | |
| Secondary school degree | 56 (38%) | seldom | 63 (47%) |
| Professional school | 42 (28%) | often | 57 (43%) |
| University degree | 18 (12%) | daily | 13 (10%) |
| Salary (total household) | | Breast cancer recurrence | |
| < €1.000 | 14 (10%) | no | 118 (84%) |
| €1.001 ≤ €2.000 | 48 (36%) | yes | 22 (16%) |
| >€2.000 | 73 (54%) | Had chemotherapy | |
| Marital status | | no | 87 (60%) |
| single | 49 (32%) | yes | 57 (40%) |
| Married/long-term partner | 102 (68%) | Age (Mean) | |
| BMI (Mean) | 26.84 (SD:6.10) | Age at Diagnosis (Mean) | 48.78 (SD: 8.79) |

Table 2. Comparing Physical and Mental health-related Quality of Life and Key Predictor Variables, the Positive and Negative Impact of Cancer, across select independent variables

| Comparing Physical and Mental health-related Quality of Life and Key Predictor Variables, the Positive and Negative Impact of Cancer, across select independent variables | | | | |
|---|----------------------------------|--------------------------------|---------------------------|---------------------------|
| | Physical component summary (PCS) | Mental component summary (MCS) | Positive impact of cancer | Negative impact of cancer |
| Geographic location | | | | |
| Rural | 54.09 (6.81) | 47.80 (10.96) | 3.49 (0.81) | 2.32 (0.78) |
| Urban | 49.98 (10.27) | 47.31 (10.16) | 3.53 (0.82) | 2.49 (0.83) |
| p-value | 0.0048 | NS | NS | NS |
| Marital status | | | | |
| single | 50.45 (9.48) | 43.78 (11.23) | 3.53 (0.87) | 2.45 (0.83) |
| Married/long-term partner | 52.02 (9.20) | 49.17 (9.62) | 3.51 (0.80) | 2.41 (0.81) |
| p-value | NS | 0.0087 | NS | NS |
| Chemotherapy | | | | |
| no | 53.32 (7.80) | 48.47 (9.35) | 3.50 (0.85) | 2.24 (0.75) |
| yes | 49.12 (10.36) | 46.35 (11.56) | 3.53 (0.79) | 2.71 (0.85) |
| p-value | 0.0125 | NS | NS | 0.0007 |
| Breast cancer recurrence | | | | |
| no | 51.94 (9.19) | 47.60 (10.52) | 3.54 (0.80) | 2.41(0.79) |
| yes | 51.22 (9.58) | 48.25 (8.85) | 3.32 (0.96) | 2.46 (0.85) |
| p-value | NS | NS | NS | NS |
| Salary (total household) | | | | |
| < €1.000 | 48.09 (9.35) | 44.77 (10.32) | 3.56 (1.25) | 2.56 (0.88) |
| €1.001 ≤ €2.000 | 49.78 (9.55) | 43.31 (11.97) | 3.54 (0.66) | 2.50 (0.79) |
| >€2.000 | 54.08 (8.44) | 50.58 (7.92) | 3.49 (0.82) | 2.35 (0.81) |
| p-value | 0.0119 | 0.0004 | NS | NS |
| Perceived stress level | | | | |
| seldom | 50.92 (9.23) | 49.79 (9.16) | 3.47 (0.94) | 2.28 (0.71) |
| often | 52.89 (8.86) | 47.02(9.54) | 3.60 (0.67) | 2.48 (0.81) |
| daily | 53.26 (7.37) | 38.82 (14.34) | 3.79 (0.54) | 3.02 (0.74) |
| p-value | NS | 0.0028 | NS | 0.0079 |
| BMI | | | | |
| | -0.36 | -0.0002 | -0.16 | -0.09 |
| p-value | <0.0001 | NS | NS | NS |
| Used complementary/alternative medicine | | | | |
| no | 52.00 (8.72) | 48.94 (9.36) | 3.43 (0.89) | 2.29 (0.81) |
| yes | 51.40 (9.91) | 45.88 (11.24) | 3.64 (0.63) | 2.67(0.79) |
| p-value | NS | NS | NS | 0.0080 |

| | PCS | MCS | Positive impact of cancer | Negative impact of cancer |
|----------------------------------|---------------|---------------|----------------------------------|----------------------------------|
| Emotional distress belief | | | | |
| no | 50.35 (9.08) | 50.28 (9.78) | 3.31 (0.77) | 2.12 (0.72) |
| yes | 52.07 (9.43) | 46.10 (10.43) | 3.65 (0.78) | 2.60 (0.83) |
| p-value | NS | 0.0205 | 0.0097 | 0.0004 |
| Exercise 2+ per week | | | | |
| no | 47.30 (10.55) | 45.10 (11.84) | 3.42 (0.83) | 2.48 (0.82) |
| yes | 53.37 (8.03) | 48.76 (9.44) | 3.58 (0.77) | 2.39 (0.80) |
| p-value | 0.0010 | NS | NS | NS |
| Education | | | | |
| No advanced high school degree | 50.49 (8.59) | 47.35 (11.06) | 3.63 (0.84) | 2.58 (0.78) |
| Advanced high school degree | 56.01 (6.02) | 48.37 (7.50) | 3.63 (1.13) | 2.29 (0.82) |
| Secondary school degree | 49.37(10.56) | 46.33 (11.33) | 3.50 (0.80) | 2.35 (0.74) |
| Professional school | 51.57(8.46) | 49.90 (10.56) | 3.49 (0.81) | 2.40 (0.99) |
| University degree | 55.28 (8.42) | 45.99 (9.06) | 3.70 (0.57) | 2.68 (0.65) |
| p-value | NS | NS | NS | NS |
| Age | -0.31 | 0.014 | -0.20 | -0.18 |
| p-value | 0.0002 | NS | 0.016 | 0.026 |
| Age (Diagnosis) | -0.29 | -0.0035 | -0.16 | -0.10 |
| p-value | 0.0008 | NS | NS | NS |

Table 3. Regression model examining the Impact of Cancer and select independent variables on Mental Health Functioning (SF-36, Mental Component Summary)

| Regression model examining the Impact of Cancer and select independent variables on Mental Health Functioning (SF-36, MCS) | | | |
|---|--------------------|-----------------------|----------------|
| Covariate | Coefficient | Standard Error | p-value |
| Intercept | 68.31 | 7.67 | <.0001 |
| Positive impact of cancer | -0.38 | 1.07 | NS |
| Negative impact of cancer | -5.75 | 1.14 | <.0001 |
| Age (10-year intervals) | -1.15 | 0.92 | NS |
| Having a spouse/partner | 6.91 | 1.68 | <.0001 |
| Emotional distress | -2.33 | 1.72 | NS |
| Stress (frequent) | -2.21 | 1.73 | NS |
| Stress (daily) | -7.73 | 2.86 | 0.007 |
| Model F Statistic | 11.83 | | |
| Adjusted-R ² | 0.39 | | |
| Model Significance | <.0001 | | |

Table 4. Regression model examining the Impact of Cancer and select independent variables on Physical Health Functioning (SF-36, Physical Component Summary)

| Regression model examining the Impact of Cancer and select independent variables on Physical Health Functioning (SF-36, PCS) | | | |
|---|--------------------|-----------------------|----------------|
| Covariate | Coefficient | Standard Error | p-value |
| Intercept | 68.31 | 7.67 | <.0001 |
| Positive impact of cancer | 2.68 | 0.82 | 0.0014 |
| Negative impact of cancer | -6.20 | 0.84 | <.0001 |
| Age (10-year intervals) | -2.59 | 0.66 | 0.0001 |
| Received chemotherapy | -2.50 | 1.28 | 0.05 |
| Regular exercise | 3.18 | 1.72 | 0.0174 |
| BMI (log transformed) | -21.84 | 6.82 | 0.0017 |
| Model F Statistic | 19.27 | | |
| Adjusted-R ² | 0.47 | | |
| Model Significance | <.0001 | | |

VII. APPENDIX

A. Impact of Cancer version 2 Scale (English Version)

This tool is provided courtesy of Brad Zebrack, PhD, University of Southern California School of Social Work.

Impact of Cancer Scale Tool



EMPLOYMENT

1. Are you fully retired from paid employment?

_____ 1 Yes ***go to NEXT PAGE***

_____ 2 No

2. Were you employed and earning income at some time during the last 12 months?

_____ 1 Yes _____ 2 No ***go to NEXT PAGE***

Please circle the number for each statement below that best describes how much you agree or disagree with the statement.

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|------------------------------|-----------------|----------------|--------------|---------------------------|
| 3. I am concerned about not being able to work if I were to become ill again..... | 1 | 2 | 3 | 4 | 5 |
| 4. Concerns about losing health insurance keep me in the job I have now..... | 1 | 2 | 3 | 4 | 5 |
| 5. I worry about being forced to retire or quit work before I am ready..... | 1 | 2 | 3 | 4 | 5 |

LIFE OUTLOOK

We are interested in knowing about your personal views or perspectives on life. Given your life **as it is now**, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

| | Strongly | Disagree | Neutral | Agree | Strongly |
|--|-----------------|-----------------|----------------|--------------|-----------------|
|--|-----------------|-----------------|----------------|--------------|-----------------|

| | Disagree | | | Agree | |
|--|----------|---|---|-------|---|
| 5. Having had cancer makes me feel unsure about my future..... | 1 | 2 | 3 | 4 | 5 |
| 6. I worry about my future..... | 1 | 2 | 3 | 4 | 5 |
| 9. I feel like time in my life is running out..... | 1 | 2 | 3 | 4 | 5 |

YOUR BODY AND YOUR HEALTH

We are interested to know how having had cancer **NOW** affects your body and your health, if at all.

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|
| 1. I do not take my body for granted since the cancer..... | 1 | 2 | 3 | 4 | 5 |
| 2. Having had cancer has made me more concerned about my health..... | 1 | 2 | 3 | 4 | 5 |
| 3. I am more aware of physical problems or | 1 | 2 | 3 | 4 | 5 |

changes in my body since having had cancer..

| | | | | | |
|---------------------------------|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
| 5. I worry about my health..... | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
| 8. New symptoms (aches, pains, getting sick or the flu) make me worry about the cancer coming back..... | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
| 10. I am concerned that my energy has not returned to what it was before I had cancer.... | | | | | |

| | | | | | |
|--|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
| 11. I am bothered that my body cannot do what it could before having had cancer..... | | | | | |

| | | | | | |
|--|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
| 12. I worry about how my body looks..... | | | | | |

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|----------------------------|--------------------------|-----------------|----------------|--------------|-----------------------|
| | 1 | 2 | 3 | 4 | 5 |
| 13. I feel disfigured..... | | | | | |

| | | | | | |
|--|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
| 14. I sometimes wear clothing to cover up parts of my body I don't want others to see..... | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 15. Having had cancer has made me take better care of myself (my health)..... | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|

FEELINGS ABOUT CANCER

Given your life as it is **NOW**, how do you feel about having had cancer?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|--------------------------|-----------------|----------------|--------------|-----------------------|
| 1. I consider myself to be a cancer survivor..... | 1 | 2 | 3 | 4 | 5 |
| 2. I feel a sense of pride or accomplishment from surviving cancer..... | 1 | 2 | 3 | 4 | 5 |
| 3. I learned something about myself because of having had cancer..... | 1 | 2 | 3 | 4 | 5 |
| 6. I feel that I am a role model to other people with cancer..... | 1 | 2 | 3 | 4 | 5 |
| 8. Having had cancer has made me feel old..... | 1 | 2 | 3 | 4 | 5 |

9. I feel guilty today for not having been available to my family when I had cancer.....

1 2 3 4 5

MEANING OF CANCER

Given your life as it is now, how much do you agree or disagree with each of these statements about cancer?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|------------------------------|-----------------|----------------|--------------|---------------------------|
| 3. Having had cancer turned into a reason to make changes in my life..... | 1 | 2 | 3 | 4 | 5 |
| 4. Because of cancer I have become better about expressing what I want..... | 1 | 2 | 3 | 4 | 5 |
| 5. Because of cancer I have more confidence in myself..... | 1 | 2 | 3 | 4 | 5 |
| 6. Having had cancer has given me direction in life..... | 1 | 2 | 3 | 4 | 5 |
| 7. I feel like cancer runs my life..... | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 8. I view having had cancer as a private experience..... | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| 9. I am constantly reminded that I had cancer.... | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|

ACTIVITIES AND RELATIONSHIPS

This section includes questions about your social activities and about important relationships in your life.

Given your life as it is now, how much do you agree or disagree with each of the following statements? *(Circle the number for each statement that best describes how much you agree or disagree with the statement.)*

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|------------------------------|-----------------|----------------|--------------|---------------------------|
| 2. I feel a special bond with people with cancer.. | 1 | 2 | 3 | 4 | 5 |
| 3. Because I had cancer I am more understanding of what other people may feel when they are seriously ill..... | 1 | 2 | 3 | 4 | 5 |
| 4. Having had cancer has made me more willing to help others..... | 1 | 2 | 3 | 4 | 5 |

| | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| 7. Having had cancer has made me feel alone... | | | | | |
| 8. Having had cancer has made me feel like some people (friends, family, co-workers) do not understand me..... | | | | | |
| 10. Uncertainty about my future affects my decisions to make plans (examples: work, recreation/travel, get married, get involved in relationships, have a family, go to school)..... | | | | | |
| 11. Having had cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family)..... | | | | | |
| 13. On-going cancer-related or treatment-related symptoms (for example bladder or bowel control, lymphedema, hair loss, scars, infertility, premature menopause, lack of energy, impotence/sexual problems, aches, pain or physical discomfort) interfere with my life..... | | | | | |

Circle the number for each statement that best describes how much you agree or disagree with the statement.

14. Are you currently married, living together as married, or in a significant relationship?

_____ 1 Yes

go to ***QUESTION 19 on NEXT PAGE***

_____ 2 No

Given your life as it is now, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|------------------------------|-----------------|----------------|--------------|---------------------------|
| 15. Uncertainties about my health or my future have made me delay getting married or getting involved in a serious relationship..... | 1 | 2 | 3 | 4 | 5 |
| 16. I wonder how to tell a potential spouse, partner, boyfriend, or girlfriend that I have had cancer..... | 1 | 2 | 3 | 4 | 5 |
| 17. I am concerned about how to tell a spouse, partner, boyfriend, or girlfriend that I may not be able to have children..... | 1 | 2 | 3 | 4 | 5 |
| 18. I worry about not having a spouse, partner, boyfriend, or girlfriend..... | 1 | 2 | 3 | 4 | 5 |

STOP HERE

Please answer the following questions ONLY if you are currently married, living together as married, or in a significant relationship. Otherwise, please stop.

Given your life as it is now, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|------------------------------|-----------------|----------------|--------------|---------------------------|
| 19. I am open and willing to discuss my cancer with my spouse/partner..... | 1 | 2 | 3 | 4 | 5 |
| 20. My spouse/partner is open and willing to discuss my cancer with me..... | 1 | 2 | 3 | 4 | 5 |
| 21. Uncertainty about my health has created problems in my relationship with my spouse/partner..... | 1 | 2 | 3 | 4 | 5 |
| 22. I worry about my spouse/partner leaving me if I were to become ill again..... | 1 | 2 | 3 | 4 | 5 |

B. Impact of Cancer version 2 Scale (German Version)

This tool is provided courtesy of Brad Zebrack, PhD, University of Southern California School of Social Work. This tool was translated and pilot tested by Kathryn Bouskill.

Ihr Leben nach einer Krebserkrankung



BESCHÄFTIGUNG

3. Sind Sie bereits in Pension?

_____ 1 Ja **gehen Sie zur FRAGE 6**

_____ 2 Nein

4. Waren Sie in den letzten 12 Monaten angestellt bzw. haben Sie ein Gehalt bekommen?

_____ 1 Ja

_____ 2 Nein **gehen Sie zur FRAGE 6**

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

| | trifft nicht zu | trifft eher nicht zu | weder- noch | trifft eher zu | trifft zu |
|---|--------------------|-------------------------|----------------|-------------------|-----------|
| 3. Ich bin besorgt, nicht weiter arbeiten zu können, falls ich wieder krank werden sollte..... | 1 | 2 | 3 | 4 | 5 |
| 4. Ich bin immer noch berufstätig, weil ich besorgt bin, ansonsten finanzielle Einbußen hinnehmen zu müssen | 1 | 2 | 3 | 4 | 5 |
| 5. Ich mache mir Sorgen, in Frühpension gehen zu müssen | 1 | 2 | 3 | 4 | 5 |

LEBENSAUFFASSUNG

Wir sind an Ihren persönlichen Ansichten bzw. Ihren Lebensperspektiven interessiert. Wie weit sind Sie mit den folgenden Aussagen einverstanden?

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

| | trifft nicht zu | trifft eher nicht zu | weder- noch | trifft eher zu | trifft zu |
|---|--------------------|-------------------------|----------------|-------------------|-----------|
| 6. Meine Krebserkrankung hat bewirkt, dass ich die Zukunft als ungewiss empfinde..... | 1 | 2 | 3 | 4 | 5 |
| 7. Ich mache mir Sorgen um die Zukunft..... | 1 | 2 | 3 | 4 | 5 |
| 8. Ich habe das Gefühl, dass die Zeit davonläuft..... | 1 | 2 | 3 | 4 | 5 |

KÖRPER UND GESUNDHEIT

Wir möchten wissen, ob und in welchem Maß Ihre Krebserkrankung Ihren Körper und Ihre Gesundheit beeinflusst.

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

| | trifft nicht zu | trifft eher nicht zu | weder- noch | trifft eher zu | trifft zu |
|--|--------------------|----------------------------|----------------|----------------------|-----------|
| 9. Seitdem ich mit meiner Krebsdiagnose konfrontiert wurde, halte ich meinen Körper so wie er ist nicht mehr für selbstverständlich..... | 1 | 2 | 3 | 4 | 5 |
| 10. Die Erfahrung meiner Krebserkrankung hat dazu geführt, dass ich sensibler mit meiner Gesundheit umgehe..... | 1 | 2 | 3 | 4 | 5 |
| 11. Ich gehe bewusster mit körperlichen Problemen und physischen Veränderungen um..... | 1 | 2 | 3 | 4 | 5 |
| 12. Ich mache mir Sorgen um meine Gesundheit | 1 | 2 | 3 | 4 | 5 |
| 13. Ich mache mir Sorgen, dass der Krebs wieder kommen könnte..... | 1 | 2 | 3 | 4 | 5 |
| 14. Wenn etwas mit meinem Körper nicht stimmt, bin ich besorgt, dass es wieder Krebs sein könnte | 1 | 2 | 3 | 4 | 5 |
| 15. Meine Krebserkrankung bewirkt, dass ich mich in Bezug auf meine Gesundheit unsicher fühle..... | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 16. Ich bin beunruhigt, weil ich nicht die selbe Energie wie vor meiner Krebsdiagnose habe..... | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|

| | | | | | |
|--|---|---|---|---|---|
| 17. Es stört mich, dass mein Körper nicht die selbe Leistungsfähigkeit wie früher hat..... | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| 18. Mein körperliches Erscheinungsbild beunruhigt mich..... | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|

| | | | | | |
|-----------------------------------|---|---|---|---|---|
| 19. Ich fühle mich entstellt..... | 1 | 2 | 3 | 4 | 5 |
|-----------------------------------|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| 20. Ich wähle Kleidung manchmal so, dass Teile meines Körpers von Anderen nicht wahrgenommen werden können..... | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| 21. Meine Krebserkrankung hat dazu geführt, dass ich mehr auf mich und meine Gesundheit schaue..... | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|

KREBSWAHRNEHMUNGEN

Was empfinden Sie heute bezüglich Ihrer Krebserkrankung?

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

| | trifft nicht zu | trifft eher nicht zu | weder- noch | trifft eher zu | trifft zu |
|--|-----------------|----------------------|-------------|----------------|-----------|
| 22. Ich betrachte mich selbst als Krebsüberlebende... | 1 | 2 | 3 | 4 | 5 |
| 23. Ich bin stolz auf mich bzw. ich habe ein Gefühl der Erfüllung, weil ich Krebs überlebt habe..... | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|--|---|---|---|---|---|
| 24. Meine Krebserkrankung hat dazu geführt, dass ich mehr über mich selbst gelernt habe..... | 1 | 2 | 3 | 4 | 5 |
| 25. Ich sehe mich als Vorbild für andere an Krebs erkrankten Menschen..... | 1 | 2 | 3 | 4 | 5 |
| 26. Ich fühle mich wegen meiner Krebserkrankung alt Aufgrund meiner Krebserkrankung gealtert..... | 1 | 2 | 3 | 4 | 5 |
| 27. Ich habe heute ein schlechtes Gewissen, dass ich während meiner Behandlung nicht immer für meine Familie da war..... | 1 | 2 | 3 | 4 | 5 |
| 28. Ich sehe meine Krebsdiagnose als Privatsache an..... | 1 | 2 | 3 | 4 | 5 |
| 29. Ich werde ständig daran erinnert, dass ich eine Krebserkrankung hatte..... | 1 | 2 | 3 | 4 | 5 |

BEDEUTUNG VON KREBS

Wie weit sind Sie mit den folgenden Aussagen zu Krebs einverstanden?

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

| | trifft nicht zu | trifft eher nicht zu | weder- noch | trifft eher zu | trifft zu |
|---|-----------------|----------------------|-------------|----------------|-----------|
| 30. Meine Krebserkrankung hat dazu geführt, dass ich mein Leben verändert habe..... | 1 | 2 | 3 | 4 | 5 |
| 31. Meine Krebserkrankung hat dazu geführt, dass ich jetzt meine Wünsche bzw. Bedürfnisse besser ausdrücken kann..... | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 32. Meine Krebserkrankung hat mir geholfen, mehr Selbstbewusstsein zu entwickeln..... | 1 | 2 | 3 | 4 | 5 |
| 33. Seit meiner Diagnose habe ich eine Neuorientierung im Leben erfahren..... | 1 | 2 | 3 | 4 | 5 |
| 34. Meine Krebserkrankung kontrolliert mein Leben. | 1 | 2 | 3 | 4 | 5 |
| 35. Ich habe das Gefühl, dass ich auf Grund mehr Kontrolle über mein Leben habe..... | 1 | 2 | 3 | 4 | 5 |

AKTIVITÄTEN und BEZIEHUNGEN

Dieser Teil des Fragebogens besteht aus Fragen über Ihre sozialen Aktivitäten und wichtige Beziehungen in Ihrem Leben. Wie weit sind Sie mit den folgenden Aussagen über Krebs einverstanden?

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

| | trifft nicht zu | trifft eher nicht zu | weder- noch | trifft eher zu | trifft zu |
|---|-----------------|----------------------|-------------|----------------|-----------|
| 36. Ich empfinde eine besondere Verbundenheit mit anderen an Krebs erkrankten Menschen..... | 1 | 2 | 3 | 4 | 5 |
| 37. Auf Grund meiner Krebserkrankung habe ich mehr Mitgefühl mit schwer erkrankten Menschen entwickelt..... | 1 | 2 | 3 | 4 | 5 |
| 38. Die Krebserkrankung hat meine Bereitschaft, anderen zu helfen, erhöht..... | 1 | 2 | 3 | 4 | 5 |
| 39. Ich habe mich auf Grund meiner Krebserkrankung allein gelassen gefühlt..... | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 40. Auf Grund meiner Krebserkrankung fühle ich mich von manchen Menschen (Freunde/innen, Familie, Kollegen/innen) nicht immer verstanden..... | 1 | 2 | 3 | 4 | 5 |
| 41. Permanente Nebenwirkungen verursacht durch meine Behandlung (wie z.B. Narben, Unfruchtbarkeit, Energieverlust, Lymphödem, Sexualprobleme, Schmerzen) beeinflussen mein Leben..... | 1 | 2 | 3 | 4 | 5 |
| 42. Meine Unsicherheit über die Zukunft beeinflusst meine Entscheidungen und Pläne (wie z.B. Karriere, reisen, heiraten, Beziehungen, Familie, studieren)..... | 1 | 2 | 3 | 4 | 5 |
| 43. Meine Krebserkrankung hat mich in meinen Aktivitäten gebremst (wie z.B.: reisen, Hobbys, Zeit mit Freunde/innen, Zeit mit der Familie)..... | 1 | 2 | 3 | 4 | 5 |

44. Sind Sie verheiratet oder in einer langfristigen Beziehung?

- _____ 1 Ja *gehen Sie zur FRAGE 48 auf der nächsten Seite*
- _____ 2 Nein

| | trifft nicht zu | trifft eher nicht zu | weder- noch | trifft eher zu | trifft zu |
|--|-----------------|----------------------|-------------|----------------|-----------|
| 45. Meine Unsicherheit über meine Gesundheit bzw. Zukunft hat meine Entscheidung zu heiraten bzw. eine Beziehung einzugehen verzögert..... | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|--|---|---|---|---|---|
| 46. Ich überlege mir, wie ich einem/einer potenziellen Partner/in erzählen kann, dass ich Krebs hatte..... | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| 47. Ich bin besorgt, dass ich keinen/keine Partner/in finden werde..... | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|

ENDE. VIELEN DANK!

Bitte beantworten Sie diese Fragen NUR wenn Sie verheiratet sind, oder in einer langfristigen Beziehung leben. Wenn nicht, haben Sie schon den Fragebogen komplett ausgefüllt. Vielen Dank für Ihre Hilfe!

| | trifft nicht zu | trifft eher nicht zu | weder- noch | trifft eher zu | trifft zu |
|---|-----------------|----------------------|-------------|----------------|-----------|
| 48. Ich spreche offen und frei mit meinem/meiner Partner/in über meine Krebserkrankung..... | 1 | 2 | 3 | 4 | 5 |
| 49. Mein/meine Partner/in ist bereit, mit mir über meine Krebserkrankung zu sprechen..... | 1 | 2 | 3 | 4 | 5 |
| 50. Meine Unsicherheit bezüglich meiner Gesundheit war bereits ein Problem in meiner Beziehung..... | 1 | 2 | 3 | 4 | 5 |
| 51. Ich bin besorgt, dass mein Partner/meine Partnerin mich verlassen würde, wenn ich wieder mit einer Krebsdiagnose konfrontiert wäre..... | 1 | 2 | 3 | 4 | 5 |

ENDE. VIELEN DANK!

C. Demographic and Clinical Questionnaire (English version)

1. When were you born? (Month/Year **only**): _____
2. What is the highest level of education you have attained?: _____
 - a. No high school diploma
 - b. High school diploma
 - c. Secondary modern school qualification
 - d. Professional degree
 - e. University/college degree
3. What is your zip code? _____
4. Do you have a spouse or a longtime companion? (Yes/No) _____
5. Do you have children? (Yes/No) _____

If yes, how many?

Daughter(s) _____

Son(s) _____
6. If you have children, are your children of adult age? (Yes/No) _____
7. What is your height and weight? Height _____ Weight _____
8. Employment status: _____
 - a. Full-time employment
 - b. Part-time employment
 - c. Unemployed
 - d. Retired
9. Is your current employment status your **desired** employment status? (For example, If you work part time, would you rather work full time?) (Yes/No) _____
10. Which best describes your level of stress?
 - a. I am stressed out every day
 - b. I am stressed out often, but not every day
 - c. I am rarely stressed out
 - d. I am never stressed out
11. Which best describes your alcohol consumption
 - a. I do not drink alcohol
 - b. I only drink sporadically
 - c. 1 drink per day
 - d. 2+ drinks per day
12. Who do you live with? _____

- a. I live alone
 - b. with an adult/with adults
 - c. with a child/children
 - d. with a child/children and an adult/adults
13. What is your monthly salary (for you alone, not you and your spouse)? _____
- a. Less than €1000/Month
 - b. Between €1001 and €2000/Month
 - c. Over €2001/Month
14. If you have a spouse, what is your combined monthly salary? _____
- a. Less than €1000/Month
 - b. Between €1001 and €2000/Month
 - c. Over €2001/Month
15. When were you diagnosed with breast cancer (year)? _____
16. Which forms of therapy for breast cancer did you receive?
- a. Chemotherapy (Yes/No) _____ (If yes, how long?) _____
 - b. Radiation (Yes/No) _____ (If yes, how long?) _____
 - c. Anti-hormonal therapy (Yes/No) _____ (If yes, how long?) _____
17. Do you attend therapy or psychotherapy? (Yes/No) _____
18. Do you attend a self-help group? (Yes/No) _____
19. Do you use any complementary or alternative medical therapies? (Yes/No)
If so, list them here (Examples include taking mistletoe extract, traditional Chinese medicine, tai chi, chi gong, meditation) _____

D. Demographic and Clinical Questionnaire (German version)

1. Ihr Geburtsdatum (**nur** Monat/Jahr):___/ ___

2. Ihr Bildungsgrad: _____
 - a. keine Matura
 - b. Matura
 - c. Hauptschulabschluss
 - d. Höhere Berufsbildende-Schule
 - e. Studium

3. Was ist Ihre Postleitzahl? _____

4. Haben Sie einen Ehegatten bzw. einen Lebensgefährten/in? (Ja/Nein) _____

5. Haben Sie ein Kind bzw. Kinder? (Ja/Nein) _____

Wenn ja, wie viele?

Tochter/Töchter _____

Sohn/Söhne _____

Wenn Sie Kinder haben, sind alle Ihre Kinder
schon älter als 18? (Ja/Nein) _____

6. Ihre Größe und Gewicht: Größe (cm) _____ Gewicht (kg) _____

7. Ihre Berufstätigkeit: _____
 - a. Vollzeit
 - b. Teilzeit
 - c. Arbeitslos
 - d. in Pension

8. Wenn Sie berufstätig sind, ist Ihr derzeitiges Beschäftigungsausmaß von Ihnen gewünscht? (zum Beispiel: Beantworten Sie bitte mit „nein“ wenn Sie Teilzeit arbeiten, aber lieber Vollzeit arbeiten möchten, oder andersrum) (Ja/Nein) _____

9. Ihr Wohnsituation: _____
- Ich wohne alleine
 - mit einem/r Erwachsener/e bzw. mit Erwachsenen
 - mit Kind/ern
 - mit Kind/ern und einem/r Erwachsener/e bzw. mit Erwachsenen
10. Ihr Nettoeinkommen (Nur Sie): _____
- Unter €1000/Monat
 - Zwischen €1001 und €2000/Monat
 - Über €2001/Monat
11. Ihr gesamtes Familiennettoeinkommen: _____
- Unter €1000/Monat
 - Zwischen €1001 und €2000/Monat
 - Über €2001/Monat
12. Ihr Alkoholkonsum: _____
- nie
 - sporadisch
 - regelmäßig (1-2 pro Woche)
 - jeden Tag
13. Ihr subjektiver Stressfaktor: _____
- täglich Stress
 - öfter Stress
 - selten Stress
 - nie Stress
14. In welchem/n Jahr/en haben Sie Diagnose Brustkrebs bekommen? _____
15. Welche Behandlung haben Sie bekommen? (Ja/Nein)
- Chemotherapie _____ (wenn ja, wie lange?) _____
 - Strahlentherapie _____ (wenn ja, wie lange?) _____
 - Antihormontherapie _____ (wenn ja, wie lange?) _____
 - Andere Behandlungen (z.B.: Antikörper, Kinase-Hemmer, usw.) _____ (wenn ja, wie lange?) _____

16. Nehmen Sie etwas aus den zusätzlichen medizinnahen Bereichen in Anspruch? (wie z.B. Chi Gong, Tai Chi, Traditionelle Chinesische Medizin, Meditation, Misteltherapie, Yoga, Nahrungsergänzungsmittel, autogenes Training, usw.)

(Ja/Nein)_____

Wenn Ja, welche?

17. Gehen Sie zu einer Selbsthilfegruppe? (Ja/Nein)_____

18. Gehen Sie zu Psychotherapie? (Ja/Nein)_____

19. Sind Sie der Meinung, dass Stress bzw. eine schwierige emotionelle Phase einen Faktor der Auslösung Ihres Brustkrebses war? (Ja/Nein)_____

20. Machen Sie regelmäßig (mindestens 2 mal pro Woche) Sport bzw. körperliche Bewegung? (Ja/nein)_____

VIELEN DANK FÜR IHRE TEILNAHME!