

Dimensions of Health-related Quality of Life among Women with Breast Cancer Following Mastectomy, Chemotherapy and Radiotherapy: Premises of a Comparative Study

by
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Abstract

The findings of four studies are discussed in this thesis. The first study was a meta-analysis of studies that aimed to statistically examine the predictive value of medical treatment on QoL and the moderating effect of age, education and illness phase, by ascertaining the effect sizes. Findings showed that excepting the variable of the education ('lower than bachelor'), none of the meta-analyses revealed statistically significant mean effect sizes. Breast cancer women with a lower educational level reported better QoL at follow-up.

The second study explored the differences and similarities in quality of life of 481 neoplastic and non-neoplastic women in Romania and UK. The findings revealed that breast cancer survivors in Romania and in the UK did not differ by age, marital status, education, illness stages and period since being diagnosed. Romanian breast cancer survivors reported more comorbidities compared to the UK participants. Statistical results revealed that the UK control group in rural areas benefited from better physical function, role, cognitive and emotional functioning. The UK survivors had better cognitive and social functioning. Romanian women under active treatment reported poorer physical, role and social functioning than breast cancer survivors and short-term survivors had lower scores on fatigue than patients. Romanian survivor group performed better than the control group on *fatigue*. The UK control group outperformed the survivor group on *social, cognitive* and *physical function*. No differences in means were found for breast cancer women undergoing primary treatment (up to one year) and those receiving extended medical regimens (more than one year).

In the third study, potential direct and indirect associations between health-related quality of life, age, education, marital status, location, illness phase, neuroticism, and extraversion, openness to experience, perceived support, treatment control, illness consequences, religious coping and perceived illness timeline were examined in a sample of 138 Romanian breast cancer women. A mediating model was postulated which predicted that advanced illness phase, older age and perceived acute/ chronic timeline would negatively influence global QoL; high educational level, urban area of residence, marital status and religious coping would positively influence QoL; neuroticism and extraversion would negatively associate with religious coping while openness to

experience would positively influence it; advanced illness phase and perceived illness consequences would positively predict perceived acute/ chronic timeline.

Correlational analysis indicated that age was significantly correlated to openness to experience; education was correlated to illness phase, global QoL and neuroticism; a significant relationship was found between marital status and location and treatment control and between global QoL and neuroticism, perceived illness timeline, illness consequences and treatment control. Associations between neuroticism, openness to experience, perceived support, perceived illness timeline and illness consequences were also reported. Extraversion correlated to openness to experience. Significant relationship was found between perceived support, perceived illness timeline and treatment control. Perceived illness timeline was correlated to illness consequences and illness consequences to treatment control. Additional analyses performed with Structural Equation Modeling using manifest variables statistically tested and supported a model which revealed that education negatively predicted QoL; perceived support was negatively associated with perceived illness timeline; illness perception positively associated with illness timeline and illness timeline negatively predicted global QoL. The analysis was advanced by testing a total and a partial mediation model for the relationship between illness consequences, perceived illness timeline and global QoL, where perceived illness timeline was the mediator. The chi-square difference between the two models was very small.

The fourth study was organized in three stages. The first phase aimed to give an in-depth account of experiences with cancer survivorship in 42 Romanian and 33 UK participants. The results of the interviews were analyzed qualitatively by using the method of thematic analysis. The (sub) themes that emerged showed that the majority of breast cancer women both in Romania and the UK suffered from negative physical and psychological consequences. Only for a small number of women the illness enabled the understanding and valuation of their lives. The second stage aimed at ensuring the confirmability of the previous study (the first stage) through the method of member checking and by analyzing statistically the written interviews with 18 Romanian and 16 UK participants. The findings indicated that the Romanian breast cancer women benefited from fewer appointments with the medical staff, had less opportunity to get free of charge wigs and prostheses and to follow breast reconstruction. Romanian women were reported as being less

valued by their community. The findings from this study also lend support to the suggestion that the Romanian medical staff would rate more highly the services provided for their patients compared to patients themselves. The third phase explored the trajectory through cancer survivorship through biographical data (three case studies) and revealed sensitive aspects relating to coping with the illness.

Keywords: health-related quality of life, participatory research approach, breast cancer survivorship, biographical data, research ethics

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1. Breast Cancer and Health Care in Romania and the UK

DiSipio and colleagues (2010) estimated that breast cancer was a considerable public health concern in Europe, ‘with one in eight women developing the disease before the age of eighty five years in developed countries of the world’. Accordingly, 425 000 new cases of breast cancer are diagnosed each year in Europe (IARC, 2011). In Romania, in 2010, the rate of breast cancer mortality accounted for 22.6 %, while for the UK the percentage was 24.5%. The breast cancer incidence rate was lower in Romania in 2008 compared to the UK (OECD, 2012).

Overall, death rates from all forms of cancer have decreased in most European countries since 1995, but central European countries, among which Romania, were an exception to this declining pattern. More specifically, cancer mortality remained static or increased; although the incidence was lower (OECD, 2012). Between 1990 and 2000, breast cancer mortality in Romania increased by 7%.

Although in most European countries, treatment for cancer is free of charge (Rowland et al., 2013), the accessibility of new medicines and technologic improvements might differ. The differences in terms of participation in screening programmes for women aged 50-69 between Romania (8%) and the UK (73%) in 2010 were conspicuous. Other studies, like the National Oncology Surgical Society Survey, cited by the United Nations System in Romania (2003) suggested that the real figure may be closer to 90%, particularly among women of low socioeconomic status and in rural areas where women are much less likely to be tested.

The differences in health status and access to medical services apply to different areas of Romania and not only to the comparison with other countries (often used as the only argument in national analysis) (Valceanu et al., 2012). As a consequence of OUG 48/2010 legislation, the number of medical personnel, beds and services in Romanian public hospitals was reduced and medical institutions became dependent on local budgets. This resulted in great discrepancy between rural and urban areas, as public hospitals became dramatically insufficient in Romania

and almost inexistent in villages. As a main consequence, people with low income from rural areas have been facing great difficulties in accessing public health services, as transport costs are not covered.

By contrast, the Board of Science of the British Medical Association (2005) recognized rurality as an issue worth having its own health policies. Another report, *Keeping the NHS local – A New Direction of Travel* (Rygh et al., 2007), described modernization strategies, among the inclusion of extended roles for medical staff and networking between hospitals to answer the needs of populations in rural areas. Additionally, financial assistance for transportation to and from provider sites for people with low income and the use of telemedicine facilitate the access to medical care regardless of time and place. Nevertheless, the evidence about health status of urban and rural women needs more support in international literature.

2. Breast Cancer Survivorship

2.1. The concept of breast cancer survivorship

The term *survivor* entered the talks on cancer in 1985, when Dr. Fitzhugh Mullan described his experience with cancer in a New England Journal of Medicine article, ‘Seasons of Survival’ (Kaiser, 2008). A couple of years later, survivorship was defined as the journey from the time of diagnosis to the moment of a stable life. This definition was criticized for its ubiquity and ambiguity, as it overlooked the interplay between person and environment characteristics.

In the booklet published by Macmillan Cancer Support in the UK (2012), survivor was defined as ‘anyone who is living with or after cancer’. Therefore, this broad definition allows those undergoing treatment or who experience diverse side-effects to be considered survivors. Other definitions suggest that survivorship is the absence of any signs or symptoms of recurrence, or analyze the concept in terms of surviving an acute or severe illness (Smith 1979; Peck, 2008).

More recently, survivorship was defined as the recovery from a life-threatening experience. These alternative definitions created space for many people to adopt the title of survivor.

According to different scholars, *acute* survivorship is defined as the period of active treatment. *Extended* survivorship is represented by the post-treatment remission period, and potentially occasional treatment. Finally, *permanent* survival does not result at a single moment, but progresses from an extensive period of free-survival.

2.2. Theoretical models of breast cancer survivorship

Two models of breast cancer survivorship have been identified to give an account of how women frame their disease. The first approach, proposed by Swidler (2001) suggests that survivorship is a *tool* that shapes women's understanding of their illness. The experience with cancer affects the entire human being; physical scars, vulnerability and disruptions associated with cancer make survivorship a tool to re-organize the self and daily routine. As Kaiser (2008) stated, the breast cancer culture 'left many women searching for representations which acknowledge their fears and the continued presence of cancer in their lives'. Consequently, discourses on breast cancer survivorship did not create space for a manifold of positive substitutes. Therefore, as Schover (2004) claimed, 'it is unclear what alternative meanings they embrace, given that other images of breast cancer are largely negative or less available'.

If the paradigm of survivorship promoted by the dominant culture is incommensurate, women may build their own meanings; in other words 'they enact survivorship as a *<craftwork>*' (Kaiser, 2008). This is the second approach of survivorship and it conceives that it provides women with an active role through which they assemble their lives after cancer and the meanings of the illness (Frank, 1995). This approach to survivorship stresses on skills and self-determination to redefine and re-organize one's life. In response to medical models, where women can be socially defined by their diagnosis and its idiosyncrasy, this model suggests that individuals represent more than a diagnosis and they can work to change this public traditional perception.

2.3. The relationship between survivorship and health-related quality of life

According to the National Cancer Institute of the United States, breast cancer survivorship encompasses a series of physical, psychological and economic issues, from the moment of diagnosis until the end of life. Not only aspects related to diagnosis, treatment and late and long-term effects are included, but also health-related quality of life. Therefore, beside overall survival, health-related quality of life is the most important goal in the treatment of patients with cancer (Andritsch, 2007).

As studies show, health-related quality of life is a predictor of cancer mortality and survival and in some cases it is an indicator of the effectiveness of the treatment and care. It enables clinicians to better ascertain patients at high risk of recurrence and mortality. As suggested by several theorists (Gotay et al., 2008; Montazeri, 2009), there are a couple of explanations for the association between health-related quality of life data and survival duration in cancer outcome studies. Four possible explanations are summarized herein:

- (a) Health-related quality of life assessments include different items and thus provide more reliable and sensitive information about survival than traditional evaluations and toxicity measures.
- (b) Health-related quality of life data especially that collected at baseline before disease progression could gather relevant information previous to established clinical prognosis.
- (c) Health-related quality of life data are indicators of patients' prospective behavior because they relate to diagnosis, treatment and subsequent outcomes of the disease.
- (d) Health-related quality of life data rely on individual characteristics such as personality traits and adapting coping strategies, which affect the disease process and outcomes in cancer patients.

3. Health-related Quality of Life of Women Diagnosed with Breast Cancer: Recent Directions in Scientific Research

3.1. Evidence in the literature: Romanian studies

Although a significant amount of international literature asserts the relationship among predictors of HrQoL and their mediating role in various cancer patients, research examining the association among such factors has so far been nonexistent in Romania until recently. An examination of the published literature in Romania led to the identification of three relevant pieces of work.

A longitudinal study (Volovat, 2011) on 441 breast cancer women treated with adjuvant hormonal treatment (tamoxifen vs. aromatase inhibitors) examined the potential fluctuations in QoL scores at one month and then two years following the treatment. The results showed no difference in QoL between the two treatment groups.

Another recent study on 100 metastatic breast cancer patients during chemotherapy (Dragomir et al., 2013) concluded that major depressive symptoms were a negative predictor of HrQoL.

Yet another study using structural equation modeling (Csaba, 2011) attempted to explain the interrelation between diverse medical variables (illness phase, health status, physical activity, vital exhaustion, illness severity), social (lack of family support), coping (self-efficacy and problem-focused coping), emotional functioning (happiness, anxiety and coherence feeling) and quality of life. The path analysis revealed that health status, lack of family support, anxiety, vital exhaustion, illness phase and severity were negative predictors of quality of life; self-efficacy and problem focused coping were indirect positive predictors of QoL through happiness state.

Despite the valuable effort behind these studies, a couple of limitations in the understanding of the concept of QoL were noticed. The first study aimed at comparing two research groups in terms of their QoL (tamoxifen versus aromatase inhibitors), ignoring relevant variables such as

demographics and illness-related factors, which would explain the pattern of change in QoL or would act as confounders at a period of two years after diagnosis. The small sample size and the single site of data collection in the second study made the conclusions difficult to generalize to a Romanian population of breast cancer women. Moreover, a non-metastatic breast cancer sample would have elucidated whether the same pattern of psychological functioning applies to both metastatic and non-metastatic women. Although the number of participants was impressive (N= 420) in the last study, the heterogeneous sample in terms of cancer types and illness phases could not provide the scene for clear gender and cancer type-related discussions. Participants were both males and females, with diverse cancers, among which the highest percentages were represented by breast cancer (19.5%), ovarian cancer (11.9%), lung cancer (11.2%) and colon cancer (10.5%).

3.2. International studies: traditional and integrative models of health-related quality of life

3.2.1. Traditional models of QoL

(1) The biobehavioral model of quality of life of patients diagnosed with cancer (Al-Majid et.al, 2009) postulates that treatment and cancer related modifications associated with fatigue result in poor quality of life.

(2) The model of genetic grounds of patient-reported quality-of-life (Wilson and Cleary, 1995) focuses on the genetic grounds of quality of life, but the author does not exclude the connection between QoL domains, biological mechanisms and genetic components, which would also comprise physical, social and psychological facets.

(3) The model of the relationship between upper-body morbidity following breast cancer treatment and QoL (Hayes et al., 2010) suggests that perceived upper-body function at both baseline and eighteen months post-surgery, reveals strong associations with quality of life.

(4) The model tested by Dawes et al. (2008) showed that the paths between comorbidity and disability, pain and disability, volume and physical function aspect of HrQoL, and disability and HrQoL were significant.

3.2.2. Integrative models of QoL

(1) An explanatory model of quality of life and valuation of life (Moss et al., 2007) aims to advance the importance of the relationship between positive experiences, behavioral and mental health outcomes.

(2) The power, uncertainty, self-transcendence and quality of life (Farren et.al, 2010) focuses on the positive experiences and the sense of growth and change women with breast cancer may have regardless of their demerits, as complex privy experiences may enhance their quality of life. Power, uncertainty and self-transcendence are independent predictors of quality of life.

(3) A third model postulated by Boehmer et al. (2007) postulated that self-efficacy promoted all domains of HrQoL and received support merely facilitated its emotional domain. Patients scoring high on received social support and satisfaction with support profited in terms of their emotional well-being. No direct associations between support and coping were noticed.

(4) Somjaivong and colleagues (2011) hypothesized a model where social support was the exogenous variable and symptoms, uncertainty, coping and HrQoL were endogenous variables. It was found that the direct effect of coping on HrQoL was nonsignificant, while uncertainty had a direct effect on HrQoL, but a non-significant indirect effect through coping.

(5) A more comprehensive model on QoL of 189 recurrent breast cancer women and their family members was postulated by Northouse (2002). The structural equation modeling revealed that self-efficacy, social support and family hardiness positively affected quality of life. Distress, concerns, hopelessness and negative appraisal of illness had negative effects. Patients with more advanced stages of disease reported more negative appraisal of their illness, more hopelessness and more uncertainty. Education was nonsignificant for the patient model. Little evidence supported the association between recurrent patients' and family members' quality of life.

(6) The sixth model, model tested by McLaughlin et al. (2013) on 192 breast cancer women suggested that participants with fewer concerns about their illness were less proactive if they deferred control to God. Additionally, lower levels of proactive coping resulted in poorer quality of life.

(7) Zwingmann et al. (2006) showed that the relationship between religious coping and psychosocial outcomes was completely mediated by nonreligious coping. Only depressive coping- and not active problem-focused coping proved to be a mediating variable.

(8) The last model in the list (Vos et al., 2004) aimed at estimating the connection between psychological adjustment in 87 newly diagnosed early stage breast cancer women and bio-demographic variables, coping and social support. The positive role of social support found in other studies on psychosocial adjustment could not be confirmed. The structural modeling revealed both direct and indirect associations between bio-demographic variables and psychosocial adjustment, in the sense that older women used a more optimistic coping style. Late stage of illness was linked with a reduction in recreational activities.

4. Predictors of HrQoL and Relationships between them: A Critical Literature Review

The main purpose of the review was to understand the various predictors of health-related quality of life of breast cancer survivors in both the short- and the long-term, and the relationships between them. The decade of 1980s was selected as the outset of the review, as it was defined as the early period of quality of life and cancer survivorship research (Meneses et al., 2010). One hundred and eighteen sources met the review criteria and were chronologically, thematically and methodologically analyzed according to three criteria adapted from Mols et al. (2005). Therefore, twenty nine reviews and eighty nine primary quantitative studies gave accounts of *weak*, *strong* and *inconclusive* evidence for the predictors of health-related quality of life of breast cancer women.

Although the psychosocial oncology literature is comprehensive, significant limitations and unanswered questions remain open for further exploration. *Inconclusive evidence* was identified for the relationship between health-related quality of life and the following predictors: age, marital status, education, illness stage, time since diagnosis, subdomains of social support,

religious coping and personality. *Strong associations* between type of treatment and health-related quality of life were described in several papers. More research needs to be conducted for the relationship between area of residence and religious denomination and health-related quality of life, as the evidence for these predictors was *weak*. However, the majority of studies published to date were correlational, thereby constraining precise conclusions in the sense that they could not test any relation of causality.

5. Research Methods and Approaches

Due to the short space allowed in this abstract, descriptions of the methods related to each research chapter of the thesis are briefly presented in Table 5.1.

5.1. Data collection: sensitive research and ethical implications

A promising strategy to protect the vulnerable participants in the current research project was the use of the *ethics-as-process* (Ramcharan et al., 2001) and *process consent* (Munhall, 1991) approaches, through which ethical dimensions of the research were negotiated. This pragmatic ethical strategy followed the ethical principles set out by the Department of Health in the United Kingdom (2001: 8): ‘dignity, rights, safety and well-being’. Full consent was received from partner institutions in the field in Romania and the UK and from the Ethical Committee at Loughborough University.

5.2. Measures

(1) EORTC QOL-C30 (EORTC Quality of Life Group)

(2) Five Factor Model Rating Form (FFMRF) (Baer et al., 2010).

(3) Illness Perception Questionnaire Revised (IPQ-R) (Weimann et.al, 2005)

(4) The COPE Inventory (Carver et.al, 1994)

(5) Berlin Social Support Scale (BSSS) (Schwarzer et.al, 2000)

Table 5.1. Outline of the research chapters in the current thesis

Outcome	Source	Design	Aims	Data collection	Participants	Measurements	Data analysis	
Background Analyses	Critical literature review	Chapter 4	Narrative Report	To critically analyze the literature related to predictors of HrQoL of breast cancer survivors.	Quantitative studies and reviews	Not the case	See Appendix 4A1 (Protocol)	Descriptive report
	Analysis One	Chapter 6	Meta-Analyses	To perform meta-analyses of studies describing predictors of HrQoL and the relation between them	Quantitative studies and primary data	Not the case	See Appendix 4A1	Comprehensive Meta-Analysis (version 2, Biostat, Englewood)
	Analysis Two	Chapter 7	Cross-sectional	To examine the differences in HrQoL, if any, between the Romanian and the UK research groups	Questionnaire and online survey method	481 from Romania and UK.	Self-reported rating forms EORTC QLQ-30	IBM SPSS Statistics version 21
	Analysis Three	Chapter 8	Structural equation model	To test a comprehensive model of HrQoL of breast cancer women	Questionnaire and online survey method	138 breast cancer women in Romania	EORTC QLQ-30, Berlin Social Support Scale, Five Factor Rating Form	LISREL 9.1. Student
	Analysis Four (1)	Chapter 9	Descriptive, cross-cultural	To give an in-depth account of the concept of <i>breast cancer survivorship</i> .	Written or face to face semi-structured interviews	42 Romania 33 UK	Open-ended questions about experiences with breast cancer	Thematic analysis
	(2)		Cross-sectional	To validate the qualitative data	Online survey method	18 Romania 16 UK	Self-rating forms	IBM SPSS Statistics 21
	(3)		Descriptive	To explore the trajectory through cancer survivorship	Written and face to face interviews	3 cancer survivors	Open-ended questions Biographical data	Descriptive report Thematic analysis

6. Analysis One: Moderator Analyses in Meta- Analyses

Aim	To statistically explore the relation between diverse predictors of HrQoL in breast cancer women and the relationship between them
Research Questions	(1): Is there any difference between the levels of HrQoL of women diagnosed with breast cancer assessed before treatment and at a follow-up expanded to six weeks? (2): Is there any difference between the levels of HrQoL of women diagnosed with breast cancer assessed at baseline and at follow-up expanded to one year?
Hypotheses	1: Women with breast cancer will report different mean scores of HrQoL at baseline and at follow-up (up to six weeks and at one year after treatment completion) 2: Demographics (age and education) and illness-related variables (illness phase) are moderators of the relation between HrQoL and medical treatment.

6.1. Method

Data were analyzed under a *random effects model*. For each study the standard error, variance, Z value, p value, lower and upper levels of effect sizes were calculated. The coefficient *Hedges's g* (unbiased) was used to compute the overall size effects. The effect sizes could be represented by the difference in means; a null difference suggested no difference between groups.

6.2. Results

(a) Follow-up between one week and one year

Fifteen studies were grouped in the first category. The statistical tests for the null hypothesis revealed a p value of .598 with 14 degrees of freedom, which recommended the acceptance of the null hypothesis ($g = -0.093$, 95 % CI [-0.437; 0.252], $Z = -0.528$, $p = .598$). The difference between groups was then not statistically significant.

(b) Follow-up between one and six weeks

Nine studies were regrouped in this category. The statistical tests for the null hypothesis revealed a p value of .921 with nine degrees of freedom, which recommended the acceptance of the null hypothesis ($g = .022$; 95 % IC [-.409; .453]; $Z = -.099$, $p = .921$).

(c) One year follow-up

Five studies met the criteria to be included in the third meta-analysis. Under the random effect model, the mean size effect ($g = -.050$, 95 % IC [-.822; .722], $Z = -.127$, $p = .899$) was statistically nonsignificant.

(d) The moderating effect of age

After the descriptive statistics were screened for homogeneity, 9 studies met the criteria for inclusion in the meta-analysis, among which 7 included postmenopausal (>55 years) and other 2 examined premenopausal women (< 55 years). Overall data did not support a moderating effect of the variable of age to explain variance in observed effect sizes.

(e) The moderating effect of illness phase

Eleven studies were encompassed in the analysis, as they included homogeneous samples in terms of illness phase. Overall, illness phase did not have a moderating effect.

(f) The moderating effect of education

Only two studies included homogeneous samples in terms of education (Arraras et al., 2008; Taira et al., 2011), but only the level of 'lower than bachelor' could be analyzed. Results were statistically significant supporting partially the hypothesis that educational level acted as a moderator. In these two studies, breast cancer women with a degree lower than bachelor level reported better QoL at follow-up.

7. Analysis Two: A Pilot Study

Aims	(1)To investigate the effect of country of provenience, area of residence, time since diagnosis and medical condition on the QoL of breast cancer women in Romania and the UK. (2)To compare the HrQoL levels reported by controls in Romania and the UK.
Main Research Question	What is the difference, if any, in the scores reported by research participants in Romania and the UK for quality of life domains, based on location, country of provenience and period since being diagnosed?
Hypotheses	1:Non-neoplastic women in rural areas in the UK will report higher mean assessed levels of HrQoL and its subordinated domains over the Romanian control group in rural regions. 2: Breast cancer survivors in Romania will rate lower levels of their HrQoL (and subordinated domains) comparing with those in the UK. 3: Breast cancer women will report higher rates of HrQoL in a long term than in a short term or active treatment. 4: Romanian and UK breast cancer women will report lower levels of HrQoL than non-neoplastic women. 5: Breast cancer women receiving primary medical treatment will report higher rates of HrQoL comparing with women receiving extended medical treatment.

7.1. Data analysis

Demographics and illness-related data were analyzed by using descriptive statistics and χ^2 statistics. To test Hypotheses 1, 2, 4 and 5, 2x2x2 between-subjects multivariate analyses of variance (MANOVA) were performed. After conducting the three-way MANOVA, comparisons between the UK and the Romanian research groups were run with a series of two-group MANOVA. Hypothesis 3 was tested with one-way MANOVA (active vs. short-term, active vs. long-term and short-term vs. long- term).

7.2. Results

The 2x2x2 MANOVA revealed a non-significant multivariate effect for area of residence, country of provenience and research group, $\lambda = .97$, $F(1, 462) = 1.38$, $p > .05$. Analyses for area of residence and country of provenience, $\lambda = .98$, $F(1, 462) = .98$, $p > .05$ and for area of

residence and research group, $\lambda = .97$, $F(2, 462) = .78$, $p > .05$ did not reveal any significant interaction effects. Statistically significant interaction effect between country and research group was found, $\lambda = .90$, $F(2, 462) = 4.78$, $p < .01$ for the following dependent variables: physical, emotional, cognitive and social functioning and fatigue. The analysis revealed statistically significant main effects for country of provenience [$\lambda = .88$, $F(1, 462) = 7.62$, $\eta_p^2 = .11$, $p < .01$] and research group [$\lambda = .71$, $F(2, 462) = 10.54$, $\eta_p^2 = .15$, $p < .01$]. The main effect for area of residence was statistically non-significant, $\lambda = .97$, $F(1, 462) = 1.56$, $p > .05$. Results are reported for each hypothesis, as follows, stressing on significant findings.

(a) Hypothesis 1: The results partially supported the *comparison between non-neoplastic controls in rural areas in RO and UK*. The UK control group in rural areas reported higher scores over the Romanian group on the following QoL scales:

Physical function, $F(1, 103) = 27.31$, $p \leq .006$;

Role function, $F(1, 103) = 15.71$, $p \leq .006$;

Cognitive function, $F(1, 103) = 8.57$, $p \leq .006$;

Emotional functioning $F(1, 103) = 11.68$; $p \leq .006$.

The scores of post-hoc statistical power ranged from .78 to .99, which suggested a very good magnitude of the study and less than 22% probability of committing a type II error. The Romanian control group mean score was approximately one standard deviation below the mean score of the UK control group on physical functioning ($d = 1.10$). Overall, the magnitude of the effect sizes ranged from medium to very high.

(b) Hypothesis 2: The results partially supported the *comparison between RO and UK survivors*. The two-group MANOVA revealed a better *cognitive*, $F(1,108) = 8.23$, $p \leq .006$ and *social functioning*, $F(1,108) = 9.92$, $p \leq .006$, for the Romanian survivor group over the UK group. The probability of making a type II error was less than 20%, as the statistical power ranged from .81 to .87. The magnitude of the effect sizes was medium, which indicated that the Romanian survivor group outperformed the UK group by approximately two quarters of a standard deviation.

(c) Hypothesis 3: The results partially supported the *comparison between Romanian breast cancer women with different medical conditions (active vs. short- vs. long-term)*. Poorer *physical functioning* was reported for the Romanian active treatment group over the survivor group, $M_D = 1.83$, 95% CI = [.45; 3.21], $p < .006$, $d = .45$. The survivor group outperformed the active treatment group on physical function by almost two quarters of a standard deviation. Higher mean scores of *fatigue* were found for active treatment over survivor condition, $M_D = 1.59$, 95% CI = [.37; 2.35], $p < .006$, $d = .50$. Women under active treatment had a poorer *role functioning* comparing with both short-term, $M_D = -2.06$, 95% CI = [-3.22; -.89], $p < .006$, $d = -1.07$ and long-term survivors, $M_D = -1.49$, 95% CI = [-2.61; -.37], $p < .006$, $d = 2.06$. Active treatment group had a poorer *social functioning* comparing with short-term, $M_D = -2.27$, 95% CI = [-3.50; -1.03], $p < .006$, $d = -.94$ and long-term survivors, $M_D = -1.78$, 95% CI = [-2.96; -.59], $p < .006$, $d = -.69$. Short-term survivors had a lower level of *fatigue* comparing with the active treatment group, $M_D = -2.13$, 95% CI = [-3.67; -.58], $p < .006$, $d = -.68$. The values of post-hoc statistical power ranged from .84 to .99, implying less than 16 % probability of committing a type II error. The Romanian active treatment group outperformed the short-term survivor group by approximately a standard deviation on role and social function scores. The long-term survivors were outperformed by the active treatment group by two standard deviations on role functioning. The magnitude of the rest of the difference in means ranged from .45 to .68, suggesting medium effect sizes. No differences in mean scores for QoL were found when comparisons between short-term and long-term survivors were made. The values of post-hoc statistical power for the difference in means ranged from .12 to .38, which suggest that the findings related to the comparison between the short- and long-term survivors needs to be interpreted with caution (Onwuegbuzie et al., 2004).

(d) Hypothesis 4 *Comparison between survivors and controls in each country, separately*
2 x 2 (UK vs. RO) / (control vs. survivors) MANOVA revealed a statistically significant interaction between country of provenience and research group, $\lambda = .90$, $F(1, 380) = 3.32$, $p < .01$. The effect size was estimated at $\eta_p^2 = .09$, which implied that 9% of the variance in the dependent variables was accounted by the interaction effect between the two independent variables. As seen in Table 7.1, statistical results supported partially the hypothesis. Romanian

survivor group performed better than the control group on *fatigue*. The UK control group outperformed the survivor group on *social, cognitive* and *physical function*. The scores of post-hoc statistical power ranged from .84 to 1.00 for the UK group, suggesting less than 16% probability of committing a type II error. The differences in means for the UK samples ranged from medium to very high values.

Table 7.1 Significant results for the mean difference between research groups

QoL dimensions	RO (control vs BC)**				UK (control vs BC)**			
	M _D	F(1,243)*	p	Cohen's d	M _D	F(1,137)*	p	Cohen's d
Fatigue	1.37	12.65	< .006	.48				
Social function					-.57	39.86	< .006	-1.06
Cognitive function					-3.21	8.92	< .006	-.52
Physical function					-2.68	18.47	< .006	-.73

** N (controls) =175, (BC) =70 ** N (controls) =101, (BC) =36

*Mean effect of *research group* variable

(e) **Hypothesis 5:** Statistical results did not support the *comparison between primary and extended treatment groups*. No differences in means were found for breast cancer women undergoing primary treatment and those receiving extended medical regimens. The observed post-hoc power was low, ranging from .05 to .40. According to Onwuegbuzie et al. (2004), statistically nonsignificant results in a study with low power imply a degree of ambiguity in interpreting the findings.

8. Analysis Three: Structural Equation Model

Aim	To test a mediating structural equation model of HrQoL in breast cancer women.
Main Research Question	What is the predicting and mediating role of person factors, personality traits, social support, illness perception, religious coping and perceived illness timeline in the understanding of HroL in breast cancer women?
Hypotheses	1a: Advanced illness phase and older age are negative predictors of global QoL. 1b: High educational level, urban area of residence and marital status are positive predictors of QoL. 2a: Neuroticism and Extraversion are negatively associated with religious coping. 2b: Openness to experience is a positive predictor of religious coping. 3a: Advanced illness phase and perceived illness consequences positively predict perceived acute/ chronic timeline. 3b: Perceived support and treatment control negatively predict perceived illness timeline. 4: Religious coping is a positive predictor of global QoL. 5: Perceived acute/ chronic timeline negatively predicts global QoL.

8.1. Preliminary analyses

Data were preliminarily analyzed by using descriptive statistics, Pearson's correlations and standard multiple regression. As strong correlations between variables (e.g., bivariate correlation $> .85$; tolerance level ≤ 0.1) result in similar estimation problems in SEM as in multiple regressions, data were checked for multicollinearity. Before running the main analyses, the researcher examined the differences, if any, between active treatment and survivor groups in terms of studied variables, by running a series of Z tests. The variables were examined, by running Principal Component Analyses and reliability tests. The structural equation model included only variables with high alpha reliabilities. Before running the LISREL analysis, the suggestion of Tabachnick et al. (2006) was used for the model identification. As fourteen manifest variables were included in the model, the number of data points was $14 \times 15/2 = 105$, which suggested that the model was 'over-identified' and that the path analysis could be run.

8.2. Results

The hypothesized model had a good fit, with the values of the Goodness of Fit Index (GFI) of 0.97. The Maximum Likelihood Ratio Chi-Square had a value of 29.17, $p > .05$ (.13), with 22 degrees of freedom. According to Tabachnick et al. (2006), a χ^2/df ratio less than 2 is a criterion for good fit. The current model had a χ^2/df ratio of 1.32. Additionally the model-data fit was assessed by examining other indices, as follows.

For the RMSEA the model revealed a value of .049, $p > .05$, with 90% CI of [.0; .09]. The Estimated Non-Centrality Parameter (NCP) was 7.17, with 90% CI of [.0; 25.36].

In specific, age ($\xi \rightarrow \eta$; $\gamma = .14$), education ($\xi \rightarrow \eta$; $\gamma = -.19$), marital status ($\xi \rightarrow \eta$; $\gamma = .05$), location ($\xi \rightarrow \eta$; $\gamma = -.02$) and illness phase ($\xi \rightarrow \eta$; $\gamma = .01$) influenced global QoL. Only the standardised path coefficient between education and global QoL was statistically significant at the .05 level or less and indicated a negative association. The standardised path coefficients between neuroticism ($\xi \rightarrow \eta$; $\gamma = .13$), extraversion ($\xi \rightarrow \eta$; $\gamma = -.02$), openness to experience ($\xi \rightarrow \eta$; $\gamma = -.04$) and religious coping were statistically nonsignificant. The standardised path coefficients between illness phase ($\xi \rightarrow \eta$; $\gamma = .03$), treatment control ($\xi \rightarrow \eta$; $\gamma = -.19$) and perceived illness timeline were not statistically significant. In turn, perceived support ($\xi \rightarrow \eta$; $\gamma = -.09$) and illness consequences ($\xi \rightarrow \eta$; $\gamma = .55$) were significantly associated with perceived acute timeline at two-tailed $p < .05$ and $p < .01$, respectively. Poorer perceived support and higher levels of illness consequences were associated with increased perception of illness timeline. As perceived support was not significantly associated with global QoL (see Table 10.5), the variable was a partial mediator of the relation between perceived illness timeline and global QoL.

Two directional relations between two of the endogenous variables were observed in the model. Religious coping influenced both global QoL ($\eta \rightarrow \eta$; $\beta = .08$), but the path coefficient was not statistically significant. The standardized path coefficient between perceived acute timeline and global QoL was statistically significant ($\eta \rightarrow \eta$; $\beta = -.25$), at two-tailed $p < .01$. PSI (Ψ) indicated indirect relationships between endogenous variables' error terms: Religious coping ($\Psi = .98$), Perceived acute timeline ($\Psi = .68$) and global QoL ($\Psi = .87$).

Results showed that both illness consequences ($\xi \rightarrow \eta$; $\gamma = -.04$, $p < .05$) and global QoL were negatively associated with perceived acute timeline so that poorer perception of illness consequences and quality of life were related to higher scores of perceived illness timeline. As these relationships were statistically significant, this implied that the relation between illness consequences and global QoL was mediated by perceived illness timeline. An alternative mediation model postulating a direct path between global QoL and illness consequences had a nonsignificant chi-square (28.54, $df=21$, $p=.12$, $RMSEA=.051$), suggesting that a model which postulated a partial mediation of the relationship between global QoL and perceived illness consequences provided a satisfactory fit to the data. The chi-square difference between the two models was very small ($\chi^2_1 - \chi^2_2 = .57$, $df_1 - df_2 = 1$). The size of the relation between global QoL and perceived timeline did not show significant change when the variable of illness consequences was controlled ($\gamma_1 - \gamma_2 = .04$).

To conclude, results supported completely H5 and partially H3b. Contradictory results were found for H1b and H3a, in the sense that education was reported as a negative predictor of global QoL; perceived illness consequences were negatively associated with perceived acute/ chronic timeline.

9. Analysis 4A: *Breaking the Silence*. Results

The aim of the pieces of analysis, from which this chapter drew, was threefold:

- | | |
|---------|--|
| Phase 1 | To explore insights into sensitive issues related to breast cancer survivorship. |
| Phase 2 | To validate the results of the thematic analysis through the method of ‘respondents checking’. |
| Phase 3 | To illustrate alternatives to cancer discourses (autopathography, autobiography and diary) through three case studies. |

9.1. The methods in brief

The first section was concerned with thematic analyses of the recollections of breast cancer survivors during the interviews in regard to aspects related to their diagnosis. In the second unit the researcher used the ‘respondents checking’ method to ensure the external validation and transparency of the results derived from the thematic analysis. The third section advanced three case studies through which the concepts of autopathography, autobiography and diary were illustrated to further expand on the concept of survivorship. Model cases, which were taken up as exemplary of modes of the narration of cancer, displayed exemplifications of alternative discourses to cancer in Romania and the UK..

9.2. Summary of the results of the first unit of analysis

The results revealed that participants found the following experiences (called ‘themes’ in the analyses) as being the most representative while struggling with the diagnosis: (a) Ups and downs; (b) Experiences with mastectomy; (c) Experiences with hair loss; (d) Experiences with prostheses, breast reconstruction and clothing; (e) Hindrances to communication (see Table 10.1). The experiences mentioned in these categories were found to be outlined by twelve subthemes which could only be compendiously recapitulated and explained within the dynamics of the theme they refer to. All these themes and subthemes revolved around the organizing theme ‘Insights into breast cancer survivorship’.

The main theme ‘Ups and downs’ encapsulated six subthemes, as follows: The Breast, Alienation and isolation, Lack of value, Need for support, Lessons, and Fear of recurrence. The diagnosis of breast cancer determined women to question the symbolical meaning and the importance of their breasts and hair. Participants voiced that alopecia and changes in body image led them to avoid people, on the one hand, or to be avoided, on the other hand. Moreover, the perceived lack of value, the need for support and fear of recurrence exacerbated the intensity of the experiences with the illness. It is important to note that the illness had an empowering function for some women, in the sense that it taught lessons about life and self valuation.

The main theme ‘Experiences with mastectomy’ consisted of two subthemes, namely Body loss and Psychological growth. The results revealed that mastectomy was associated with physical

and psychological traumatic consequences accompanied by feelings of being ‘handicapped’ or ‘mutilated’. For some women, the body loss represented a means towards fulfillment and psychological growth; in other words, the experience with mastectomy oriented women towards reflection and self development.

The main theme ‘Experiences with hair loss’ comprised two subthemes: Use of cosmetic purchases and Isolation. Alopecia, as some participants described, was the main reason for self-isolation and devaluation. The use of cosmetic purchases in some cases camouflaged the physical imperfection, while in other cases led to unexpected and humiliating reactions from strangers in public places.

The analysis of the main theme ‘Prostheses, breast reconstruction and clothing’ revealed that a number of women had difficulties with finding proper clothes after the surgery. Others, although opted to wear the prostheses temporarily, described the inconveniences (e.g. dysmorphic body shape or inability to do sports) or the advantages (e.g. to retain the shape of the breast) associated with them. In Romania, none of the participants could follow breast reconstruction. Nevertheless, the very limited number of women that gave an account of their experiences within this theme was encouraging given the challenging life contexts that were revealed by participants. Breast reconstruction was found to play a significant role in body perception and self-esteem.

The theme ‘Hindrances to communication’ encompassed two subthemes, namely Lack of confidence and Lack of care. The findings showed that some women had difficulties in terms of getting information about their diagnosis or receiving proper care from health care professionals. Some of them voiced that felt ‘ignored’ or ‘bullied’ during hospitalization.

To summarize, overall findings have suggested that the majority of breast cancer women both in Romania and the UK experienced a couple of significant negative physical and psychological changes that affected their lives. A smaller number of women mentioned that the illness enabled them to understand better and value their lives more. Findings from the interviews indicated concerns surrounding inadequate and insufficient care provided in medical settings and a need for more ‘humanized’ medical practice.

9.3. Summary of the results of the second unit of analysis

In this section the researcher focused on the principle of confirmability to ensure the validation of the qualitative findings of the Analysis 4A. The current study's confirmability was aimed to be increased by using methods as member checking. The method involves the corroboration of research findings by seeking the feedback from study respondents or from a group with the same experience or characteristics. The main technique is to compare the researcher's interpretation of the participants' accounts to appreciate the level of correspondence between them. In order to avoid the redundancy bias which implied that the experiences described during the interviews were similar enough that all the participants would agree to the findings, the lead researcher located participants that did not take part initially in the research process. Therefore, the researcher used this strategy to examine whether there were differences between the Romanian and the UK samples in terms of the (sub) themes, on the one hand, and whether the data reliability could be attained by involving participants who did not initially take part in the study. The merit of the sample selection was that four categories of participants in Romania and the UK were involved in the validation process to ensure the accuracy of findings: breast cancer women, family members, health care professionals in oncological units and other.

Results were analyzed by using χ^2 statistics. As the percentage of observations for each category of participants was too small, the analysis comprised all the categories in each country. Common themes that emerged from the analysis of interviews with cancer patients, namely (1) Hindrances to communication, (2) Experience with hair loss (the subtheme of use of cosmetic purchases), (3) Experience with breast reconstruction and (4) Ups and Downs (the subthemes of isolation and lack of value) were included in the validation form.

The χ^2 test of independence revealed that participants in Romania and in the UK provided similar answers in terms of the information women with breast cancer received from the medical staff (about diagnosis, treatment and psychological support).

Different statistically significant answers were given in terms of the following subthemes: lack of communication, use of cosmetic purchases and experiences with breast reconstruction.

Theme: Hindrances to communication

In specific, participants reported that women with breast cancer in Romania had fewer appointments with health care professionals to discuss about difficulties that came across. Interestingly, more than 50% of participants in Romania reported that breast cancer survivors had no appointments with members of the health care team to discuss about their challenges. Almost 78% of medical staff mentioned that they had such appointments with their patients, while only one survivor out of six (17%) reported that outcome.

Experience with hair loss (the subtheme of use of cosmetic purchases)

In the UK, breast cancer survivors were perceived as having more chances to get free of charge wigs and breast prostheses. In Romania, 77% of the respondents mentioned that breast cancer women were not provided with this chance. None of the breast cancer survivors in Romania was provided with free wigs and prostheses; 56% of the health care team mentioned there were no such opportunities for the Romanian patients.

Experience with breast reconstruction

Differences were also reported in terms of the possibilities for breast cancer reconstruction. Whereas almost the same percentage of participants in Romania and the UK considered that survivors could easily get breast reconstruction, almost a double percentage of people in Romania, comparing with the UK, reported that there was no easy access to it. 67% of the breast cancer survivors in Romania mentioned they could not easily get breast reconstruction and other 33% said that the opportunity was *somehow* provided. None of the participants in this category gave a fully positive answer concerning this topic. In turn, 33% of the medical staff reported they could provide this chance and other 44% mentioned it was *somehow* possible.

Ups and Downs (the subthemes of isolation and lack of value)

Statistically significant differences were reported for the valuation of women with breast cancer. In Romania 83% of respondents reported that breast cancer women might have been less valued by their community, whereas in the UK only 31% made this estimation. In turn, 63% participants in the UK, and only 11% in Romania appreciated that women were not devalued. In Romania,

none of the breast cancer women felt completely devalued; all of them felt *somehow* devalued instead.

9.4. Summary of the results of the third unit of analysis

The narratives had diverse dimensions and powers. The autopathography challenged the medical knowledge by pointing out the failure of the medical practice, where the professional remained isolated from authentic engagement with the patient. The first case acknowledged the need to reconnect the medical professional to the patient through a bridge of common understanding of the illness.

The autobiography provided the chance to the survivor to redeem the link with identity. From the second case, the reader learns about a man's experience with cancer in a support group for breast cancer women. The group provides the chance for reciprocal fulfillment of intergenerational needs, where distrust, shame and guilt were likely to be experienced.

The diary valued intimate, unique, sensitive and hidden experiences with death and dying. One learnt from the narrative that the survivor was contrived to face her own mortality because of the breast cancer diagnosis. Through becoming a survivor, Maria struggled with a series of experiences, such as her husband's death, her illness recurrence, and preconception about cancer. Overall, these narratives become a modality of phenomenological and cognitive self-expression.

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