Recovery from breast cancer: Investigating the role of resilience in breast cancer survivorship

Recovery from Breast Cancer

Investigating the role of resilience in breast cancer survivorship

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DOCTORAL DISSERTATION

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Abstract:

Breast cancer is a common event among women, one in ten women receiving a breast cancer diagnosis in their lifetime. The experience of breast cancer is a complex process that entails a multitude of interlinked potentially highly stressful events. It is thus evident that the manner in which one reacts to such stressors can have a substantial impact on both physical and mental health. Resilience is a construct that encompasses a positive adaptation to adverse events, and has been shown to be associated with both physical and mental health-related outcomes in breast cancer patients and survivors. Nevertheless, resilience is a complex construct which has been poorly operationalized in previous research. Additionally, there is a gap in research on how resilience changes over time, how these changes relate to the recovery process, as well as the lived experiences relevant for resilience in breast cancer survivors. The present thesis aims to address these gaps in knowledge. The general aim of this thesis was to better understand the role of resilience in recovery from breast cancer. The main aim of Study I was to elucidate the factor structure of the Connor-Davidson Resilience Scale (CD-RISC), the most widely used instrument for assessing resilience, as well as to determine its discriminant and predictive validity in the Swedish non-clinical setting. The aim of study II was to explore whether resilience changes from the time of receiving a breast cancer diagnosis to after treatment, as well as whether these changes in resilience mediate or moderate physical and mental health-related recovery from breast cancer. It also aimed to identify biopsychosocial risk factors for poor or slower recovery. Study III aimed to explore the lived experiences relevant for resilience among breast cancer survivors. Study I suggested that a 22-item unidimensional model of CD-RISC should be retained. It suggested that factors related to religion and spirituality may not play a role in resilience in this setting. Study I found that CD-RISC had good discriminant validity, being a separate construct from emotion regulation. Moreover, it had good predictive validity, as it predicted physical and mental health-related quality of life after adjusting for health and sociodemographic factors. Study II found that resilience was associated with both mental and physical health-related quality of life in breast cancer patients across time. However, resilience did not change substantially over time, and the process of recovery could thus not be explained by the changes in resilience. More resilient patients over time also did not have a faster recovery. Nevertheless, resilience was found to be protective, especially for mental health at diagnosis. Study II also identified a variety of clinical and sociodemographic factors which may be risk factors for poorer recovery, most notably ER negative and HER2 positive tumors, more advanced cancer at diagnosis, receiving adjuvant chemotherapy, and lower socioeconomic status. Study III identified three important aspects relevant for resilience in breast cancer survivors. Having agency in relation to one’s health, treatment procedures, feelings, thoughts, and daily functioning was one important aspect of resilience. Important others play a complex direct and indirect role in resilience in the context of breast cancer. Conceptualizing breast cancer as a closed chapter as opposed to a constant was an important aspect of resilience throughout survivorship. Overall, the studies included in this thesis suggest that resilience plays an important role in breast cancer survivorship, with implications for not only mental, but also physical health. Interventions aimed at enhancing resilience in breast cancer survivors may focus on increasing agency and social support, as well as changing beliefs about the finality of breast cancer.

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Illustrated on the front cover is a woman holding a bouquet of the Nootka lupines (*lupinus nootkatensis*). The plant is widespread in the north of Europe due to its resistance to cold and wet climates. It is especially dominant in Iceland, where it was first introduced to help with reforestation and to fight erosion. Since then, the plant has rapidly spread across Iceland and is now a defining feature of the Icelandic scenery. The Nootka lupine looks vibrant and striking in otherwise mostly monochromatic Icelandic landscape. Because of its vibrancy and ability to grow in the most difficult of circumstances, the Nootka lupine symbolizes resilience.

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To my siblings

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Abstract

Breast cancer is a common event among women, one in ten women receiving a breast cancer diagnosis in their lifetime. The experience of breast cancer is a complex process that entails a multitude of interlinked potentially highly stressful events. It is thus evident that the manner in which one reacts to such stressors can have a substantial impact on both physical and mental health. Resilience is a construct that encompasses a positive adaptation to adverse events, and has been shown to be associated with both physical and mental health-related outcomes in breast cancer patients and survivors. Nevertheless, resilience is a complex construct which has been poorly operationalized in previous research. Additionally, there is a gap in research on how resilience changes over time, how these changes relate to the recovery process, as well as the lived experiences relevant for resilience in breast cancer survivors. The present thesis aims to address these gaps in knowledge. The general aim of this thesis was to better understand the role of resilience in recovery from breast cancer. The main aim of Study I was to elucidate the factor structure of the Connor-Davidson Resilience Scale (CD-RISC), the most widely used instrument for assessing resilience, as well as to determine its discriminant and predictive validity in the Swedish non-clinical setting. The aim of Study II was to explore whether resilience changes from the time of receiving a breast cancer diagnosis to after treatment, as well as whether these changes in resilience mediate or moderate physical and mental health-related recovery from breast cancer. It also aimed to identify biopsychosocial risk factors for poor or slower recovery. Study III aimed to explore the lived experiences and aspects of resilience among breast cancer survivors.

Study I suggested that a 22-item unidimensional model of CD-RISC should be retained. It suggested that factors related to religion and spirituality may not play a role in resilience in this setting. Study I found that CD-RISC had good discriminant validity, being a separate construct from emotion regulation. Moreover, it had good predictive validity, as it predicted physical and mental health-related quality of life after adjusting for health and sociodemographic factors. Study II found that resilience was associated with both mental and physical health-related quality of life in breast cancer patients across time. However, resilience did not change substantially over time, and the process of recovery could thus not be explained by the changes in resilience. More resilient patients over time also did not have a faster recovery. Nevertheless, resilience was found to be protective, especially for mental health at diagnosis. Study II also identified a variety of clinical and sociodemographic factors which may be risk factors for poorer recovery, most notably ER negative and HER2 positive tumors, more advanced cancer at diagnosis, receiving adjuvant chemotherapy, and lower socioeconomic status. Study III identified three important aspects relevant for resilience in breast cancer survivors.

Having agency in relation to one’s health, treatment procedures, feelings, thoughts, and daily functioning was one important aspect of resilience. Important others play a complex direct and indirect role in resilience in the context of breast cancer. Conceptualizing breast cancer as a closed chapter as opposed to a constant was an important aspect of resilience throughout survivorship.

Overall, the studies included in this thesis suggest that resilience plays an important role in breast cancer survivorship, with implications for not only mental, but also physical health. Interventions aimed at enhancing resilience in breast cancer survivors may focus on increasing agency and social support, as well as changing beliefs about the finality of breast cancer.

Sammanfattning på svenska

Bröstcancer är vanligt förekommande bland kvinnor, en av tio kvinnor får en bröstcancerdiagnos under sin livstid. Upplevelsen av bröstcancer är en komplex process, som innebär ett flertal sammanlänkade stressfulla händelser. Det är därför tydligt att sättet personen reagerar på sådana stressorer kan ha en betydande påverkan på både fysisk och psykisk hälsa. Resiliens är ett konstrukt som innefattar en positiv anpassning till skadliga händelser, och har visat sig vara associerat med både fysiska och mentala hälsorelaterade utfall bland bröstcancerpatienter och överlevare av bröstcancer. Trots detta är resiliens ett komplex konstrukt som i tidigare forskning har varit bristfälligt operationaliserat. Vidare, finns det i forskningen begränsad kunskap kring hur resiliens förändras över tid, hur dessa förändringar förhåller sig till återhämtningsprocessen, och bröstcanceröverlevares levda erfarenheter relevanta för resiliens. Den föreliggande avhandlingen syftar till att adressera dessa kunskapsluckor. Det övergripande syftet är att bättre förstå vilken roll resiliens spelar i återhämtning från bröstcancer. Det huvudsakliga syftet med Studie I var att klargöra faktorstrukturen av the Connor-Davidson Resilience Scale (CD-RISC), det mest använda instrumentet för att mäta resiliens, och att utvärdera dess diskriminanta och prediktiva validitet i en svensk icke-klinisk kontext. Syftet med studie II var att undersöka om resiliens förändras från tidpunkten då bröstcancerdiagnosen ställs, till efter behandling, och huruvida förändring i resiliens medierar eller modererar fysisk och psykisk hälsorelaterad återhämtning från bröstcancer. Studien syftade även till att identifiera biopsykosociala riskfaktorer för sämre eller långsam återhämtning. Studie III syftade till att undersöka levda erfarenheter relevanta för resiliens bland bröstcanceröverlevare.

Studie I indikerade att den endimensionella modellen av CD-risk med 22 items bör bibehållas. Studien indikerade även att faktorer kopplade till religion och spiritualitet inte har betydelse för resiliens i den undersökta kontexten. Studie I fann att CD-RISC har god diskriminant validitet, resiliens är ett separat konstrukt från emotionsreglering. Vidare fann studien att instrumentet hade god prediktiv validitet, då det predicerade fysisk och mental hälsorelaterad livskvalitet, efter kontroll för hälso- och sociodemografiska faktorer. Studie II fann att resiliens var associerat med både psykisk och fysisk hälsorelaterad livskvalitet bland bröstcancerpatienter över tid. Resiliens förändrades däremot inte på ett substantiellt sätt över tid, och återhämtningsprocessen kunde därmed inte förklaras av förändringen i resiliens. Patienter med högre grad av resiliens hade inte en snabbare återhämtning över tid. Dock fann studien att resiliens var en skyddande faktor, särskilt för mental hälsa vid diagnostillfället. Studie II identifierade även en rad kliniska och sociodemografiska faktorer som kan utgöra riskfaktorer för försämrad återhämtning, där de mest noterbara var ER-negativa och HER2-positiva tumörer, mer framskriden cancer vid diagnostillfället, att få adjuvant kemoterapi, och lägre socioekonomisk status. Studie

III identifierade tre betydelsefulla aspekter relevanta för resiliens bland bröstcancerpatienter. Att ha agens i relation till sin egen hälsa, sina behandlingsprocedurer, känslor, tankar, och sitt dagliga fungerande var en viktig aspekt av resiliens. Betydelsefulla andra spelar en komplex direkt och indirekt roll för resiliens inom kontexten av bröstcancer. Att konceptualisera bröstcancer som ett avslutat kapitel jämfört med att se det som något konstant, var en viktig aspekt av resiliens genom överlevandeskapet.

Sammantaget tyder studierna inkluderade i den föreliggande avhandlingen på att resiliens spelar en viktig roll i överlevandet av bröstcancer, med implikationer för inte bara psykisk, utan även fysisk hälsa. Interventioner som syftar till att stärka resiliens bland bröstcanceröverlevare kan fokusera på att öka agens och socialt stöd, samt att förändra uppfattningar kring bröstcancerns slutgiltighet.

List of Papers

Paper I

Velickovic, K., Rahm Hallberg, I., Axelsson, U., Borrebaeck, C.A.K., Ryden, L., Johnsson, P., & Månsson, J. (2020). Psychometric properties of the Connor-Davidson Resilience Scale (CD-RISC) in a non-clinical population in Sweden. *Health and Quality of Life Outcomes, 18,* 132. doi:10.1186/s12955-020-01383-3

Paper II

Velickovic, K., Borrebaeck, C.A.K., Bendahl, P-O., Hegardt, C., Johnsson, P., Richter, C., Ryden, L., & Hallberg, I. (2022). One-year recovery from breast cancer: Importance of tumor and treatment-related factors, resilience, and socio-demographic factors for Health-Related Quality of Life. *Frontiers in Oncology,* 12. doi:10.3389/fonc.2022.891850

Paper III

Velickovic, K., Johnsson, P., Månsson, J., & Lundberg, T. (2022). ”You can't influence illness, but you can influence everything else”: Women's diverse experiences and aspects of resilience in the context of breast cancer. Manuscript in preparation.

Abbreviations

AIC	Akaike Information Criterion
BDNF	Brain-derived neurotrophic factor
CD-RISC	The Connor-Davidson Resilience Scale
CFA	Confirmatory Factor Analysis
CFI	Confirmatory Factor Index
COPD	Chronic obstructive pulmonary disease
CRH	Corticotropin-releasing hormone
CRHR1	CRH type 1 receptor gene
DERS-16	The Difficulties in Emotion Regulation Scale
EFA	Exploratory Factor Analysis
ER	Estrogen receptor
HER2	Human epidermal growth factor 2 receptor
HLoC	Health locus of control
HRQoL	Health-related quality of life
HPA	Hypothalamus-pituitary-adrenal
NPY	Neuropeptide Y
MCS	The Mental Health Component Summary Score
MDD	Major depressive disorder
PCS	The Physical Health Component Summary Score
QoL	Quality of life
RMSEA	Root Mean Square Residual
RS	The Resilience Scale
SCAN-B	Sweden Cancerome Analysis Network - Breast
SES	Socio-economic status
SF-12	The 12-Item Short Form Survey
SF-36	The Short Form 36 Health Survey
SRMR	Standardized Root Mean Squared Residual

Introduction

> “*I get so much anxiety, always, I feel that I have anxiety in my body that I haven’t had before, which is permanent. It is there all the time, it is there when I wake up at night, it is there when I wake up in the morning, and it is like cancer-fear, anxiety that I will discover something more myself, or that someone from my family will get sick. No, I don’t believe it will ever calm down, I believe that some people can drop it and leave it behind, but not me.*”
>
> - NC, breast cancer survivor

Breast cancer is an illness that can be extremely disruptive to one’s physical, emotional, and social functioning. It is characterized by not merely one single stressful event, but a series of stressful processes and ongoing uncertainty. The first stressful experience along the breast cancer continuum occurs during the **prediagnostic** phase. A woman[1] discovers a lump in the breast herself, or receives news that an anomaly was found at regular mammography screening. Both screen-detected and symptomatic women are faced with uncertainty whilst waiting for the diagnostic decision, feeling stunned and having to handle their distress (Morse et al, 2014). Soon after screening, a woman receives the result of the diagnostic procedures. Receiving a breast cancer **diagnosis** is unsurprisingly characterized by intense reactions, such as physical shock and emotional chaos (Landmark & Wahl, 2004).

Almost immediately after, the **treatment** plan is constructed and an often long and multimodal treatment process begins. Most women receive partial or full mastectomy, but may also receive chemotherapy, radiotherapy, endocrine, antibody, bisphosphonate therapy, or a combination of these. Aside from various consequences breast cancer treatment can entail in terms of physical health (Condorelli & Vaz-Luis, 2018; Hansel, Kropshofer, Singer, Mitchell, & George, 2010; Jackson, Freeman, Szlamka, & Spiegelhalter, 2021), its psychosocial effects are numerous and often highly disruptive (Syrowatka et al., 2016). After treatment is completed, the extended and permanent **survivorship** phase commences (Mullan,

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[1] The vast majority of diagnoses occurs in women, but it should be noted that, albeit very rarely, men also get breast cancer.

1985). Cancer survivorship ends with the end of life and is a process of living after being diagnosed with cancer (Zebrack, 2000). At this stage, women are sometimes left without formal support and very often worry that the cancer will come back (Simonelli, Siegel, & Duffy, 2016; Crist & Grunfield, 2012). Every year, they go to a check-up to find out whether they need to withstand the experience again.

Still, despite the numerous stressors along the breast cancer continuum, most breast cancer survivors seem to bounce back in terms of mental and emotional health in the long-term (Wade & Lee, 2005). Serious mental health problems such as PTSD are rare among breast cancer survivors, whereas post-traumatic growth is common (Parikh et al., 2015). Post-traumatic growth entails positive psychological changes resulting from highly disruptive life events such as breast cancer (Tadeschi & Calhoun, 2004). Breast cancer survivors may experience an increased perception of own strength and newly found will to live (Landmark & Wahl, 2002), alongside other positive changes.

It is evident that the experiences and reactions of breast cancer survivors are varied. Whereas a minority of individuals experience serious psychosocial problems as a result of their breast cancer, others seem to report no short-term or long-term emotional problems. Further, whereas certain negative psychosocial consequences are common, the majority of breast cancer patients seem to recover after sufficient time has passed. Therefore, it is of high importance to investigate why such distinct trajectories occur among breast cancer patients and survivors, and what characteristics allow one to overcome the challenging breast cancer experiences. One concept that can help elucidate this problem is **resilience**.

What is resilience?

Experiencing mildly or significantly stressful events is a common occurrence for most people. The majority of people experience at least one highly disruptive event in their lives (Ozer, Best, Lipsey, & Weiss, 2003). Nevertheless, people react differently to such events. Whereas some people seem to find highly stressful events debilitating, others recover after a while, and some seem not to be strongly affected by even the most challenging circumstances. This differential ability to handle highly stressful events is reflected in the concept of psychological resilience. Psychological resilience (further referred to as only resilience) has been defined in various ways over the years. Nevertheless, all definitions include two elements, the presence of a significant stressor or adversity, and positive adaptation in spite of this adversity (Garmezy, 1990; Fletcher & Sakar, 2013).

Resilience was first investigated in the field of developmental psychology, as it became evident that some children adapted well to stressful environmental conditions as compared to other children (Werner & Smith, 1977). In the 1970s it became clear that certain individuals with schizophrenia showed good adaptation at work and social life (Masten et al., 1970). Moreover, it was noted that some children of schizophrenic mothers had better adaptation than others (Garmezy, 1974; Masten et al., 1990). The scope of research soon expanded to children exposed to various high-risk environments, such as urban poverty (Luthar, 1999) and maltreatment (Moran & Eckenrode, 1992). Resilience had not been conceptualized as such at the time, but this early research helped to refocus the attention of scientific inquiry from maladaptive functioning and risk factors to protective factors and successful adaptation (Luthar, Cicchetti, & Becker, 2000). The aim of this early research on resilience was to uncover the protective factors and attributes of the children that displayed positive adaptation to significant risks and stressors. The focus was placed on the attributes of the children themselves, family attributes, as well as the attributes of the environment that facilitated good adaptation (Luthar, Cicchetti, & Becker, 2000). Later on, the focus has shifted towards uncovering the specific elements of resilience, i.e. the processes that underlie successful adaptation. Subsequently, investigation of resilience expanded from developmental psychology to other fields, such as adaptation to work-related stressors, bereavement, and serious physical conditions (Molina et al., 2014; Min et al., 2013; Strauss et al., 2007).

Inherent in both the concept of resilience and breast cancer is adversity. Resilience has in recent years been brought into the clinical oncology setting and there is sufficient evidence that resilience can serve as a protective factor against distress in the breast cancer population. Still, there is a lot to be learned about the role resilience has in handling breast cancer-related stressors. For instance, it is unknown whether resilience can change as a result of breast cancer-related stressors, or whether these changes can serve as a mediator or a moderator of recovery in breast cancer survivors. Specific lived experiences underlying a resilient response in breast cancer survivors are also unclear. These questions will be approached in this thesis, whilst opening up new areas of inquiry.

Structure of the thesis

This thesis explores the role of resilience in breast cancer survivors. It employs the psychosocial definition of survivorship, which characterizes survivorship as a process that begins with the diagnosis and ends with the end of life (Mullan, 1985). However, the term “breast cancer patients” will sometimes be used to ease understanding, and it will be used to refer to individuals undergoing the acute treatment phase. First, the conceptualization of resilience with its biopsychosocial components will be discussed. This is important as resilience is a complex construct and there is a lot of variety in how it has been conceptualized over the years. To be able to interpret the findings of the studies included in this thesis, it is necessary to understand how resilience was conceptualized and measured. Therefore, I will continue by describing the instruments used to measure resilience and place a special focus on the Connor-Davidson Resilience Scale (CD-RISC), the instrument used in the present studies. Further, the focus will be placed on the psychosocial consequences and reactions to the breast cancer experience. This will provide a background for understanding the specific stressors entailed in the breast cancer continuum. Then, I will focus on the role of resilience in cancer survivorship, whilst placing a special focus on breast cancer. Correlates of resilience as well as aspects and models of resilience in cancer and particularly breast cancer literature will be discussed, whilst highlighting knowledge gaps in the area. Subsequently, the main goals of this thesis will be described, and followed by a summary of the three studies included in the thesis. Further, the discussion of the studies and implications for future research and practice will be presented. I will discuss target areas for interventions and questions that arose from the studies that require further investigation. Ethical considerations, strengths, limitations, conclusions, and acknowledgements will follow. Finally, the three papers included in this thesis will be presented.

Conceptualizing resilience

"In the depth of winter, I finally learned that
within me there lay an invincible summer."

\- Albert Camus

Through the years, research on resilience has bloomed and expanded to a variety of areas of investigation. The plethora of research on resilience as well as the complexity of the construct has led to several authors rethinking the concept and highlighting problems that exist in its conceptualization. One of the seminal articles in the field by Luthar, Cicchetti, and Becker (2000) elucidated some of the concerns relating to the theoretical and empirical investigations of resilience. Overall, little consensus exists on the definitions of resilience. As previously mentioned, two defining elements of resilience are significant adversity and positive adaptation (Garmezy, 1990). However, Luthar, Cicchetti, and Becker posit that these two elements have been defined and measured in varying ways in the resilience literature (2000). Significant adversity can be conceptualized as one significant highly disruptive event (e.g. loss of a child), or a set of multiple mildly stressful events (e.g. stressors at work), measured as aggregates across different events (Luthar, Cicchetti, & Becker, 2000). Additionally, there seems to be great inconsistency in what is implied in good adaptation. It is unclear whether to infer resilience one must exhibit excellent functioning, or whether normal, i.e. average functioning is sufficient. Moreover, there is disagreement on whether one should excel in only one life domain (Luthar, 1991), or whether average or good functioning is needed in a variety of life domains (Tolan, 1996) to infer resilience. In another critique of the concept, Kaplan noted that these inconsistencies can lead one to wonder whether research on resilience indeed focuses on the same entity, or whether researchers are measuring entirely different phenomena (1999). Nevertheless, it is important to note that there has been an overall agreement in protective factors found in different studies in resilience research, suggesting that such strong criticisms are probably unfounded (Luthar, Cicchetti, & Becker, 2000).

Another point of confusion in resilience literature is whether resilience should be seen as a more or less stable trait or as a dynamic process (Luthar, Cicchetti, & Becker, 2000). If conceptualized as a trait, resilience entails a set of personal characteristics and resources that enables an individual to overcome difficult life situations without significant disturbance. To infer resilience, therefore, no significant adversity needs to be present in the given moment. Conversely, if conceptualized as a process, resilience may entail a set of mechanisms of achieving good adaptation, only when a significant adversity is present. Resilience has also been measured as an outcome (Molina et al., 2014), i.e. inferred when good adaptation (e.g. in terms of quality of life or wellbeing) is present. In this way, resilience could be criticized as a circular concept. Nevertheless, it can be argued that all operationalizations have their merits, depending on the study design. It is, however, important that the authors clearly state where they position themselves in relation to how they define and measure resilience in a given context.

Resilience as conceptualized in this thesis

To be able to draw comparisons between studies, it is essential to describe how resilience was operationalized and defined in a given study, i.e. 1) which specific adversity was considered and how many stressful events were implied; 2) what was considered as positive adaptation; 3) whether resilience was perceived as a trait, a process, or an outcome. In this thesis, adversity was viewed as a set of stressful experiences, given that the breast cancer continuum consists of numerous, albeit interlinked stressors. Furthermore, positive adjustment was seen as the level of physical and mental health-related functioning equivalent to or around the Swedish norm values. Finally, resilience was explored as both a more or less stable trait and a dynamic process. More specifically, in the first two studies in the thesis, resilience is measured using a quantitative scale for assessing resilience (CD-RISC, Connor & Davidson, 2003), which will be discussed in more detail in the sections below. The scale assesses a set of personal and interpersonal characteristics and resources that enable an individual to maintain average or above average levels of functioning and generate positive emotions and experiences in face of adversity (Connor & Davidson, 2003). The third study explored resilience as both a set of internal and external characteristics and dynamic processes which enable an individual to handle adversity, from receiving a breast cancer diagnosis to the present day. In conclusion, in this thesis, I conceptualize resilience as a set of qualities and processes that enable an individual to maintain good functioning in face of adversity. Such good functioning (e.g., average or high mental and physical health-related quality of life) is thus seen as an outcome of resilience.

Differentiating resilience from related concepts

Given the prevalent issues in how resilience has been conceptualized, it is important to discuss how a resilient trajectory differs from other trajectories following a highly disruptive event. In health research, it is of importance to discuss the resilient trajectory versus the **recovery trajectory**. Bonanno insists on making a distinction between resilience and recovery (2004) as two distinct trajectories. In this distinction, the process of recovery is characterized by a traumatic or highly disruptive event causing normal functioning to drop below threshold levels, sometimes consisting of psychopathology (e.g. depressive or anxiety symptoms). After this, the process of recovery entails functioning levels to increase again to normal levels. The time it takes for functioning to return to normal can vary depending on the nature of the stressor. Conversely, the resilience process encompasses maintaining stable functioning over time, despite the presence of a highly disruptive event. According to this view, resilience does not necessarily entail a lack of negative emotions or psychopathology symptoms, as it can encompass periods of disrupted functioning, but is characterized by not being severely affected by highly stressful events and a general ability to generate positive experiences and emotions even in face of such events (Bonanno, 2004).

Another concept sometimes conflated with resilience is that of **coping**. Some authors view coping as one of the comprising attributes of resilience (e.g. Gillespie et al., 2007; Lin et al., 2013; Windle, 2011). However, other authors view resilience and coping as similar but different constructs. For example, Wu and colleagues (2020) posited that resilience and coping have different effects on behavioral changes. Whereas coping is related to emotional, behavioral, and cognitive strategies used to manage demands that are perceived as exceeding one’s resources (Folkman & Lazarus, 1985), resilience refers to one’s adaptive capacity to maintain good functioning in spite of such events. The relationship between coping and resilience has been investigated in several studies, yielding inconsistent results. Some studies suggested that coping mediates the relationship between resilience and wellbeing (Thompson, Fiorillo, Rothbaum, Ressler, & Michopoulos, 2018; Chen, 2016), whilst other suggest that resilience mediates the relationship between coping and wellbeing (Chen, Xu, Mao, Sun, Sun, & Zhou, 2019; Chen, Yang, & Chiang, 2018). The inconsistencies in results may reflect the notion that resilience has been operationalized in vastly different ways across studies. In this thesis, resilience is perceived as a broader concept than coping, and involves a set of qualities and resources that help an individual maintain positive functioning. Coping itself would thus be only one attribute of resilience.

Lastly, the interplay between resilience and **emotion regulation** is another complex distinction. Emotion regulation relates to the processes of shaping the emotions we experience, when and how we experience emotions, as well as how they are expressed (Gross, 1998). As one of the two key elements of resilience is the presence of a highly stressful situations laden with strong negative emotions, it is evident that emotion regulation is a key process in a resilient versus non-resilient response. There is evidence that highly resilient individuals utilize more adaptive emotion regulation strategies (Troy & Mauss, 2011). If resilience is operationalized as a trait or a process, emotion regulation may be viewed as one of constituents of resilience. If resilience is defined as an outcome, emotion regulation might be perceived as a mediator between a stressful event and a resilient outcome (Troy & Mauss, 2011). In this thesis, emotion regulation is perceived as one element of resilience.

Interface between the mind and the body

The **biopsychosocial model of health** has been replacing the biomedical model of health over the last decades, at least in academic and institutional contexts (Alonso, 2004). The biomedical model of health stems from the Cartesian division of the mind and the body, where an illness primarily relates to the body, and health is defined as an absence of illness. Conversely, the biopsychosocial model of health posits that health, as well as illness, is a result of an interplay between biological, social, and psychological factors (Alonso, 2004). It has become increasingly clear that psychological and physical/medical difficulties are often interlinked and that it is important to take a person's psychological, biological, and social factors when providing treatment and engaging with them (Molyneux, 2022). The biopsychosocial model of health thus provides a more holistic view of the person as a whole organism which is simultaneously influenced by many factors. This thesis adopts the biopsychosocial model of health in two ways. First, breast cancer will be explored whilst taking biological, psychological, and social factors into account. Second, biopsychosocial nature of resilience itself will be recognized and discussed in the section below.

Resilience research originated in psychology and the dominant focus in the field has been the exploration of psychosocial components, antecedents, and outcomes of resilience, depending on how resilience was operationalized. However, inherent in resilience is the experience of stress, which is both a physical and psychological experience. It is thus not surprising that, in recent years, scientific advances have given way to the investigation of biological processes underlying resilient trajectories (Charney, 2004). In this area of research, resilience is viewed as a set of adaptive physiological and psychological stress responses, i.e. psychobiological allostasis (Feder, Nestler, & Charney, 2009). Conversely, psychobiological allostatic load refers to a failure to adequately shut down a stress response (Cathomas et al., 2019). Animal models of resilience are of importance as they allow for the investigation of behavioral, molecular, and neurobiological mechanisms that underlie resilience in well-controlled experimental conditions, which is not possible in studies with human subjects (Feder, Nestler, & Charney, 2009). A biopsychosocial perspective of resilience is necessary as it broadens the pathways of potential interventions to enhance resilience. An overview of psychosocial and biological components of resilience follows.

Psychosocial components of resilience

A variety of psychosocial factors that contribute to resilience and a successful adaptation to stress have been identified. For example, active coping strategies (e.g., planning and problem solving) and cognitive flexibility were associated with a better ability to handle stressful situations in a range of populations (Southwick, Vythilinga, & Charney, 2005). Spirituality and religion were also found to be important in some studies, as well as having a sense of purpose in life (Allim et al., 2008; Southwick, Vythilinga, & Charney, 2005). Hope, optimism and ability to experience positive emotions are often described as core elements of resilience (Ong, Bergeman, Bisconti, & Wallace, 2006). Resilient individuals further tend to utilize certain emotion regulation strategies in stressful situations, such as cognitive reappraisal and positive reframing, as they facilitate perception of these situations as less threatening (Southwick, Vythilinga, & Charney, 2005). In terms of social factors, social support has consistently been identified as a key resource among resilient individuals, as well as being open to social support and exhibiting social competence (Levine, 2003; Southwick, Vythilinga, & Charney, 2005). Relating to behavioral aspects of resilience, rodent models helped identify certain behavioral patterns which may translate to humans. Non-resilient rodents were found to display extreme responses to stress, namely "fight or flight" response or submission and freezing (Korte, Koolhaas, Wingfield, & McEwen, 2005).

Biological components of resilience

The exploration of the biological factors that underlie a resilient response to stress is extremely varied. The focus has thus far been placed on hormones, neuropeptides, and neurotransmitters involved in the stress response, genetic and epigenetic mechanisms, neural circuitry of resilience, the role of the innate and adaptive immune system, gut microbiota, and the blood-brain barrier (Cathomas et al., 2019; Feder, Nestler, & Charney, 2009). For example, the corticotropin-releasing hormone (CRH) is produced as a response to stress, further inducing the activation of the hypothalamus-pituitary-adrenal (HPA) axis and the release of cortisol. Early life stress can result in chronically high levels of CRH, indicating that low levels of the hormone can promote a resilient response to stress (Heim & Nemeroff, 2001). Overall, resilience seems to be associated with the efficient termination of the stress response by constraining the increases in CRH and cortisol (de Kloet, Joels, & Holsboer, 2005). Further, neuropeptide Y (NPY) is believed to facilitate cognition during stressful situations and might be implicated in resilience (Sajdyk, Shekhar, & Gehlert, 2004).

Little is known about the role of genetics in resilience. The dominant perspective is that one's genetic make-up and exposure to stressors determine how adaptable one's neurochemical stress response systems become (Feder, Nestler, & Charney, 2009). A number of genes have been identified as potentially contributing to resilience, including the CRH type 1 receptor gene (CRHR1), promoter of the human serotonin transporter gene (5-HTTLPR), and the gene that encodes the brain-derived neurotrophic factor (BDNF) (Ising et al., 2008; Munafo, Durrant, Lewis, & Flint, 2009; Krishan et al., 2007). In a review, Feder, Nestler, and Charney argued that it is epigenetic mechanisms that seem to play an especially important and interesting role in resilience (2011). Epigenetics refers to the changes in gene expression that do not imply a change in a DNA sequence. It seems as though early life adversity may induce epigenetic changes that influence behavior later in life, with a purpose of preparing an individual for possible life-long challenges (Feder, Nestler, & Charney, 2009).

Neural circuitry of fear is another area of interest in the field. It seems as though resilient individuals might have a well-functioning neural circuitry of fear, which can prevent over-generalization from certain conditioned stimuli, and an enhanced ability of the medial prefrontal cortex to inhibit amygdala responses, important for fear extinction (Liberzon & Sripada, 2008). Furthermore, it is well established that repeated exposure to stress causes severe peripheral immunological changes, similar to the effect of pathogen exposure, chronic stress giving way to an increase in certain inflammatory cells (Cathomas et al., 2019). The relationship between stress, resilience, and the immune system is interesting to consider when reflecting on how resilience may relate to physical health.

An important finding from biological explorations of resilience is that the resilient response to stress does not imply a lack of maladaptive changes, but a series of unique, adaptive changes. In a review, Cathomas and colleagues argue that, in fact, a resilient response seems to involve more activity than the low-resilient response (2019). This suggests that resilience is an active process and not just an absence of pathology. Therefore, resilience might be promoted by facilitating protective factors.

Assessing resilience

The complexity of resilience as a construct has given way to varied approaches to operationalizing and measuring resilience. In a review, Vanderbilt-Adriance and Shaw found that estimates of the prevalence of resilient subgroups vary between 25% and 84%, even among similar populations with similar experienced adversities (2008). This is problematic as it diminishes the ability to compare prevalence rates across studies. A plethora of scales to measure resilience have been constructed. Some of them include the Resiliency Attitudes and Skills Profile (Hurtes & Allen, 2001), the Resilience Scale (Wagnild & Young, 2001), the Resilience Scale for Adults (Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003), the Dispositional Resilience Scale (Bartone, 2007), Psychological Resilience (Windle, Markland, & Woods, 2008), the Brief Resilience Scale (Smith, Dalen, Wiggins, Tooley, Christopher, & Bernard, 2008), and the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003).

Windle, Bennett, and Noyes conducted a methodological systematic review of existing scales used to measure resilience utilizing a set of quality assessment criteria, namely criterion, content, and construct validity, internal consistency, floor and ceiling effects, reproducibility, responsiveness, and interpretability (2011). They found that none of the scales received a score higher than moderate. However, they found that the scales with best psychometric properties were CD-RISC, the Brief Resilience Scale, and the Resilience Scale for Adults. Moreover, they noted that most existing scales are useful to measure the process that yields a resilient outcome by assessing whether an individual has resources and assets that enhance resilience. This indicates that most scales can be used by in clinical practice to evaluate the absence or presence of these attributes (Windle, Bennett, & Noyes, 2011).

The Connor-Davidson Resilience Scale

One of the scales with best psychometric properties as found by Windle, Bennett, and Noyes (2011) is the Connor-Davidson Resilience Scale (CD-RISC). CD-RISC was developed by Connor and Davidson (2003) and is one the most widely used scale to measure resilience. The development of the scale was guided by a review of existing literature on resilience and recovery from life-threatening situations, as well as by research on protective factors found in resilient individuals (e.g. Rutter, 1985). The authors utilized concepts found to be closely related to resilience, such as hardiness (Kobasa, 1979). Some of the characteristics used to guide the development of the scale are close personal relationships, self-efficacy, and strengthening effects of stressful situations (Connor & Davidson, 2003).

CD-RISC comprises 25 items, rated on a five-point Likert scale ranging from 0 (“Not true at all”) to 4 (“True nearly all the time”). Theoretical scores therefore range from 0 to 100. In their psychometric investigation, Connor and Davidson evaluated the scale in both general and clinical populations, namely a typical American community, persons with post-traumatic stress disorder, persons with anxiety disorders, general psychiatric patients, and primary care outpatients (*N* = 550, Mean age = 44 years; Connor & Davidson, 2003). They found support for the test-retest reliability, internal consistency, and divergent and convergent validity of the scale. Nevertheless, they did not investigate psychometric properties of the scale in older populations, i.e. in individuals over the age 60.

In an exploratory factor analysis, Connor and Davidson found that CD-RISC was multidimensional, items corresponding to five factors. The first factor refers to having high competence, standards, and tenacity (eight items). The second factor reflects trusting one’s instincts, perceived strengthening effects of stress, and tolerance of negative affect (seven items). The third factor refers to having secure relationships and a positive attitude towards change (five items). The fourth factor reflects perceived control (three items). The fifth factor refers to spirituality and religion (two items). Two example items for each factor are presented in Table 1.

Table 1.
Example items from the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) and their corresponding proposed factors

Item	Proposed Factor
I do my best no matter what the outcome may be. I think I can achieve my goals, even if there are obstacles.	Personal competence, high standards, and tenacity
I try to see the humorous side of things when I face problems. When dealing with the problem of life, one must sometimes act on a hunch without knowing why.	Trust in one's instincts, tolerance of negative affect, strengthening effects of stress
I can adjust when changes occur. I have at least one close and secure relationship that helps me when I'm stressed.	Positive acceptance of change, secure relationships
I have a strong sense of purpose in life. I feel like I am in control of my life.	Control
When there are no clear solutions to my problems, fate or God can sometimes help. I think most things happen for a reason, whether it's good or bad.	Spiritual influences

It is evident that the proposed factors exhibit high thematic heterogeneity, as well as that the fourth and fifth factor contain only three and two items respectively. Structural validity of the scale was explored in multiple studies, yielding varying results. The consensus across studies was that the original five-factor model could not be replicated. Most of the psychometric explorations of the scale revealed a unidimensional model (Burns & Anstey, 2010; Arias Gonzalez et al., 2015; Gonzales, Moore, Newton, & Galli, 2016; Campbell-Sills, Cohan, & Stein, 2006). Others found two-factor models (Green, Hayward, Williams, Dennis, Bryan, & Taber, 2014), three-factor models (Yu & Zhang, 2007; Karairmak, 2010), or four factor models (Wu, Tan, & Liu, 2017, Lamond et al., 2009). Overall issues found in regards to the scale were items loading on no factors, a factor consisting of too few items, inconsistent loading across EFAs, and thematic heterogeneity of the factors. Campbell-Sills and Stein addressed these issues by proposing a unidimensional 10-item version of the scale (2010), which is now widely used in resilience research and is attractive due to its brevity. The factor structure as well as the psychometric properties of CD-RISC are thus important to explore when the scale is used in new contexts and populations.

Adapting to breast cancer

"Cancer has metamorphosed into a lethal shape-shifting
entity imbued with such penetrating metaphorical,
medical, scientific and political potency that cancer is
often described as the defining plague of our generation."

- Mukherjee Siddhartha, "The Emperor of all Maladies: A
Biography of Cancer"

One in ten women in Sweden will be diagnosed with breast cancer in their lifetime (Regional Cancer Centers, 2019). Breast cancer is thus a very common event among women, and is the most prevalent type of cancer among women (Swedish Cancer Registry, 2018). Breast cancer can also affect men – out of 10,359 breast cancer diagnoses made in 2017 in Sweden, 40 were among men (National Board of Health and Welfare Sweden, 2019). Fortunately, due to improved screening and treatment practices and procedures, the ten-year survival has increased from 60% to around 90% (Engholm et al., 2014). The increased number of breast cancer survivors has given way to the research focus shifting towards examining the psychosocial aspects of breast cancer. The breast cancer process comprises a series of potentially traumatic events and processes which can cause great amounts of stress and long-term psychosocial consequences in survivors (Molina et al., 2014). Thus, to better understand how resilience may play a role in breast cancer-related experiences, it is important to describe how stress might be conceptualized in the context of breast cancer.

The transactional theory of stress and coping

According to Lazarus and Folkman's transactional theory of stress and coping (1984), stress is defined as being exposed to stimuli which are appraised as threatening, challenging, or harmful (i.e. stressors), and available coping strategies are perceived as insufficient to resolve the stressor. Distress caused by a stressor initiates coping strategies aimed either at the stressor itself, or the emotions associated with the stressor. In breast cancer, the stressor itself is uncontrollable, limiting one's coping possibilities to deal with the stressor. Within the theory, this cognitive process of identifying and evaluating one's coping resources, styles, and situational variables, is named secondary appraisal. If an individual perceives their coping capabilities as insufficient to resolve the stressor, negative emotions are elicited and one is provoked to further cope, aiming to reach resolution (Lazarus & Folkman, 1984). According to the theory, it is therefore not the event itself, but the perception of the event and one's ability to cope which influences the stress reaction.

One important aspect of the theory is that, if a stressor is deemed as a challenge, rather than a threat or harm, and coping resources as sufficient, it can give way to positive emotions and growth (Cooper & Quick, 2017). In the revised version of the theory, Susan Folkman reconceptualized the role of positive emotions in the stress process (1997). Whereas in the original theory positive emotions were only elicited when the stressor was not resolved, in the revised theory Folkman posited that unsuccessful coping and distress can trigger a different type of coping, namely meaning-focused coping. This type of coping refers to reflecting on one's beliefs, goals, values, and ascribing positive meaning to stressful events, especially when the stressor is aversive and perceived as uncontrollable. This type of coping can further elicit positive emotions and provide an individual relief from the stress (Folkman, 2008). This is particularly interesting for breast cancer as qualitative investigations suggested that finding meaning, changing priorities in life, changed values, and growth are commonly reported among breast cancer survivors (Beatty, Oxlad, Koczmara, & Wade, 2008; Landmark, Strandmark, & Wahl, 2001; Landmark & Wahl, 2002).

The breast cancer continuum

> *"It did not occur to me while I was acutely ill or for some time afterward that the simple concepts of sickness and cure were insufficient to describe what was happening to me… It was survival – an absolutely predictable but ill-defined condition that all cancer patients pass through as they struggle with their illness."*
>
> \- Fitzhugh Mullan

The breast cancer experience is characterized by a series of interlinked events and processes. In a seminal essay, a physician and cancer survivor Fitzhugh Mullan posits that a defining characteristic of cancer is the unpredictability and uncertainty of feeling "cured" (1985). Whereas one individual can be "cured" of the disease soon after treatment, another can live disease-free for many years whilst having a covert disease and experience a relapse soon after. When can a patient thus safely claim victory? Mullan describes "seasons" of survival and defines survivorship as a process that begins at diagnosis. The first season of survival refers to the period between the diagnosis and treatment, and is named acute survival. Extended survival is the second season, it starts after treatment is completed, and fear of recurrence is the most acute. Permanent survival refers to the period when one has lived disease-free sufficiently long for the fear of recurrence to be decreased (Mullan, 1985).

In another classification of the breast cancer process, Molina and colleagues describe the process as the breast cancer continuum, which additionally covers the screening phase (2014). The breast cancer continuum begins with screening or discovering a symptom of breast cancer and ends with the end of life. Along the continuum lies a series of potentially stressful events, related to diagnosis, treatment, and the extended and permanent survivorship itself (Molina et al., 2014). To understand the complexity of women's experiences related to breast cancer, it is necessary to elucidate both the clinical process that starts with screening, as well as the physical and psychosocial consequences of related events. Whilst acknowledging the difficulties of defining breast cancer survivorship and separating the breast cancer experience into distinct events and processes, in this section the four phases of the breast cancer continuum will be described, namely the prediagnostic, diagnostic, treatment, and (extended and permanent) survivorship phases.

The prediagnostic phase

All women in Sweden aged between 40 and 74 are invited for screening for breast cancer, namely a mammography. If an anomaly is discovered, or if a woman discovers a symptom herself, she is invited for another, clinical mammography, sometimes complemented or supplemented by a breast ultrasound or biopsy (National Board of Health and Welfare Sweden, 2019). Women are faced with an uncontrollable stressor and have to cope with the experienced distress (Morse et al, 2014). Strong negative emotions (Dore et al., 2012), anxiety (Montgomery & McCrone, 2010) are common during the waiting period. Pineault has found that around 51% of women experience moderate or high anxiety during this period (2007). Flory and Lang found that waiting, accompanied by uncertainty, may be even more stressful than the diagnostic procedures themselves (2011). Experiences of screen-detected and symptomatic women may also slightly differ. On one hand, discovering a change in the breast can be shocking and may indicate worse prognostic and predictive tumor characteristics (Hofving et al., 2015). On the other hand, discovering an anomaly through regular screening is unpredictable and unexpected, thus inducing anxiety and shock in women (Brett, Bankhead, Henderson, Watson, & Austoker, 2005; Miles, Wardle, & Atkin, 2003; Gibbons, Groarke, Curtis, & Groarke, 2017).

The diagnostic phase

Receiving the diagnosis itself can induce a variety of reactions, including shock, anger, self-blame, fear, and distress (Beatty, Oxlad, Koczmara, & Wade, 2008). Landmark and colleagues conducted two qualitative studies focusing on this phase of the continuum (2001; 2002), aiming to identify the main issues women experience at diagnosis, the meaning ascribed to the experience, as well as the potential benefits. They found that the diagnostic phase is characterized by changed perceptions of the future and life expectations, fight against death, religion, increased will to live, finding an unknown strength, emotional chaos, and struggling with the female identity (Landmark, Strandmark, & Wahl, 2001; Landmark & Wahl, 2002).

At diagnosis, one also receives the results of the pathological examination, including type of tumor, stage, and histologic grade, as well as the implications these tumor characteristics have on cancer severity and treatment. Some studies indicated that women with a more advanced breast cancer at diagnosis might experience higher distress (Syrowatka et al., 2016) and suicidal ideation (Kim et al., 2013) post-treatment, whereas others found no differences in distress (Rakovitch et al., 2003; van Gestel et al., 2007). Tumor characteristics that have a large influence on treatment and prognosis are whether a tumor is estrogen receptor (ER) positive or negative, and if it has an overexpression of the human epidermal growth factor 2

(HER2) receptors. Most breast cancers are ER positive (Buijs, de Vries, Mourits, & Willemse, 2007) which indicates higher survival rates (Jamil et al., 2009). Moreover, 15-20% of breast cancers are HER2 positive, which might indicate a worse prognosis (Burstein et al., 2019). Thus, varying tumor characteristics can have a differential effect on quality of life and need to be considered when assessing needs among patients.

The treatment phase

Only 28 calendar days after breast cancer is suspected, treatment commences (National Board of Health and Welfare Sweden, 2019). Treatment for breast cancer is complex and often multimodal. Studies focusing on psychosocial aspects of the treatment phase have identified unique experiences and consequences on different types of treatment. Overall, women can experience fear of death, adverse effects of treatment and suffering, fear that the disease will spread, as well as the social consequences of treatment (Remmers, Holtgräwe, & Pinkert, 2009). They can feel isolated, helpless, depressed, or lacking control of the situation (Beatty et al., 2008).

Most patients receive partial (i.e. breast conserving) or full mastectomy as the main line of treatment (National Board of Health and Welfare Sweden, 2019). Surgery can negatively impact body satisfaction and health-related quality of life (HRQoL) and can cause pain and fatigue (Montazeri, 2008; Parker et al., 2007). Denford and colleagues found that women struggle going back to normality post-mastectomy, which includes looking normal, reconstructing the meaning of normality, having normal health, and looking normal (2010). Unsurprisingly, full mastectomy is associated with lower body satisfaction and HRQoL compared to breast conserving surgery (Zehra, Doyle, & Barry, 2020; Ng et al., 2019). Fortunately, most patients can avoid having axillary lymph node dissection, associated with side effects such as swelling, numbness, and pain, as well as lymphedema (Brar, Jain, & Singh, 2011). Lymphedema is one of the complications of surgery, a condition caused by damage in the lymph vessels and nodes (National Board of Health and Welfare Sweden, 2019). Greenslade and House described a sense of existential aloneness patients with lymphedema can experience, as they feel isolated and abandoned in their experience (2006).

Before or after surgery, patients can receive additional treatment. Some of the main treatment options include chemotherapy, radiotherapy, endocrine therapy, antibody therapy, and bisphosphonate therapy (National Board of Health and Welfare Sweden, 2019). One of the treatment options with most burdensome side effects is chemotherapy, shown to be an especially great risk factor for distress (Syrowatka et al., 2016; Montazeri, 2008; Galalae et al., 2005). Patients who receive chemotherapy may struggle to recover longitudinally (Galalae et al., 2005). Endocrine treatment plays a fundamental role in breast cancer treatment for hormone sensitive breast cancer (Buijs et al., 2008). It comprises a variety of uncomfortable side effects, including hot flashes, mood disturbance, weight grain, and loss of sexual function (Buijs et al., 2008; Condorelli & Vaz-Luis, 2018). Overall, side-effect profiles vary greatly across different types of endocrine therapy, though HRQoL measures seem to be quantitatively similar (Buijs et al., 2008). It is recommended to be taken for five years (Burstein et al., 2019), highlighting long-term burden this line of treatment might have on survivors. Main treatment strategy for HER2 positive tumors is antibody therapy, which can have short-term but potentially serious side-effects, such as cardiotoxicity (Hansel et al., 2010). Finally, in a recent review, Jackson and colleagues described main side effects of bisphosphonate therapy, which encompass fatigue, back pain, neurosensory problems, and flu-like symptoms (2021). Considering the variety of breast cancer treatment modalities, all having different side-effect profiles, it is important to explore the potentially varying impact they may have on physical and psychosocial recovery.

Extended and permanent survivorship phase

Zebrack described the experience of cancer as a process that involves identity construction (2020). He posits that traumatic events such as cancer change the process of identity formation. He discusses this process of identity construction as an integration of the cancer experience into one’s self-concept, which may give way to a new sense of self. Further, this renewed sense of self interacts with the environment and changes the way one interacts with others and carries out social roles. This way, cancer survivorship is a dynamic process that involves living after and beyond cancer, and interacts with other areas of life (Zebrack, 2020). However, specifying cancer survivorship is difficult. There are multiple possible trajectories of cancer survivorship, depending on whether recurrences took place, and whether a second primary cancer occurred. Psychological survivorship has been defined as a process starting at diagnosis and continuing until the end of life. In this way, survivorship can be divided into acute, extended, and permanent phases (Mullan, 1985). Therefore, certain studies on breast cancer survivorship were conducted with patients soon after diagnosis. Nevertheless, studies conducted after treatment have aimed to identify both negative and positive aspects of having gone through the breast cancer experience, as well as common needs, issues, and fears experienced post-treatment.

Among negative experiences post-treatment, different studies have identified struggling finding meaning and loneliness (Rosedale, 2009), regaining normality (Lam & Fielding, 2003), as well as fears of recurrence, impaired body image, and sexual dysfunction (Thewes, Butow, Girgis, & Pendlebury, 2003). However, there is also evidence of post-traumatic growth, such as gaining a new perspective and appreciation of life, prioritizing oneself, and improved relationships (Beatty et al., 2008). One study has explored needs of survivors, and has shown they are plentiful, including psychological, informational, everyday life-related, and vocational needs, as well as those relating to services, relationships, and sexuality (Thewes, Butow, Girgis, & Pendlebury, 2003). Breast cancer treatment can also have detrimental effects on one’s sexuality and self-concept. The way in which women experience and understand the illness and their body post-treatment is influenced by the discursive construction of sexuality and femininity (Wilmoth, 2001). In a review, Emilee and Perz have found that many women experience a variety of physical changes in their sexuality after treatment. These include decreased sexual desire, chemically induced menopause, negative body image, loss of femininity, fear of losing sexual attractiveness and fertility (2011). Considering the lasting physical and psychosocial effects that treatment for breast cancer has, it is necessary for support to be provided throughout the breast cancer continuum.

Psychosocial support and rehabilitation

The Swedish national cancer strategy recognizes practical, emotional, and social challenges breast cancer patients may experience as a result of their illness or treatment procedures (Regional Cancer Centers, 2019). To help with these challenges, every patient is assigned a contact nurse, who has an overall responsibility for both the patient and their relatives throughout the entire process. The role of the contact nurse includes, among others, to inform the patient about each upcoming step in care and treatment, to be available to the patient, to make evidence-based assessments of the patient’s needs, and to provide support to the patient and their close ones, either themselves or by mediating contact with other professionals.

Cancer rehabilitation is also offered throughout the process, with the need for rehabilitation being assessed regularly (Regional Cancer Centers, 2021). The goal of rehabilitation is to reduce the social, psychological, and existential consequences of cancer and its treatment. The national care program for breast cancer specifies that the patient and their relatives must be given information on which interventions are offered. Professionals included in the cancer rehabilitation program are counsellors, physiotherapists, occupational therapists, dieticians, psychologists, but also other doctors and dentists. The program also recommends that patients and their close ones with complex needs should be assigned to a specialized psychosocial team. The psychological assessment is recommended to be made continuously, especially when changes in the process occur, such as progression of cancer or during transition from curative to palliative care.

The role of resilience in breast cancer

> *”No, it is just to look ahead, you must not go and bring yourself down, because if you go and bring yourself down, then it gets even worse, and one becomes sick in a whole different way. I am not the type that brings myself down so much, I can of course also feel depressed, but not in such a way.”*
>
> - BD, breast cancer survivor

Inherent to resilience is an experience of significant adversity. Breast cancer-related experiences encompass a series of potentially life-changing and traumatic events. It is thus evident that exploring the role of resilience when coping with breast cancer-related stressors is an important area of inquiry. Accordingly, in recent years, the concept of resilience has attracted significant interest in the oncology context. Empirical research on outcomes and predictors of resilience, as well as protective factors and mechanisms of resilience in survivors of all types of cancer has blossomed. Nevertheless, there is great variability in how these research aims have been addressed in literature. In quantitative studies, resilience was sometimes conceptualized as a stable trajectory of low distress, sometimes it was measured as a trait, utilizing a scale aimed at measuring resilience, whereas other times it was measured through protective factors supposed to comprise resilience, such as optimism, hardiness, or hope (Eicher, Matzka, Dubey, & White, 2015; Molina et al., 2016). It is also often unclear whether researchers defined resilience as a dynamic process, an outcome, or a trait facilitated by a set of personal and environmental characteristics. In a systematic review, Tan, Beatty, and Koczwara have found that researcher definitions of resilience in the oncology context are also rare in qualitative research. Namely, out of 32 studies, only eight provided a definition of resilience (2019). They conclude that *“resilience is poorly defined and potentially poorly understood and may be one of the factors contributing to the varying effects of resilience as reported in extant literature”* (Tan, Beatty, & Koczwara, 2019, pp. 52). An additional difficulty is that many studies were conducted on survivors of a variety of cancer types, inhibiting the possibilities to draw conclusions on specific types of cancer. Breast cancer has its unique stressors and characteristics, and elements of resilience therefore may vary as compared to other types of cancer. In this section, an overview of research on resilience in the oncology setting will be provided, whilst giving special attention to breast cancer.

Correlates of resilience in the oncology setting

Within the clinical oncology setting, resilience has been investigated along all phases of the cancer continuum, in a variety of types of cancer. There are two reviews of resilience in adult cancer care to date (Eicher, Matzka, Dubey, & White, 2015; Molina et al., 2016). In their paper, Molina and colleagues undertook a review of 57 studies in the area and concluded that most of the studies focus on the treatment and survivorship phases (14% and 72% respectively), research on the screening and diagnostic phases lacking (2016). Moreover, comparison of studies is challenging as the way resilience was conceptualized and assessed varies greatly among studies. Eicher and colleagues conclude in their review that, although several instruments for measuring resilience have been developed, studies in the clinical oncology setting used only two, namely the Resilience Scale and CD-RISC (Eicher, Matzka, Dubey, & White, 2015). Another issue lies in the studied cancer populations. The majority of studies utilized a broad sample of cancer patients, and only a few focused on a specific type of cancer. Nevertheless, there is sufficient evidence that, in a variety of types of cancer, resilience and its factors are associated with a range of health-related outcomes.

A few studies focused on factors commonly associated with resilience, such as hope, optimism, and perceived internal strength or hardiness. For example, at the screening phase, these may play a role in members of families with genetic susceptibility to various types of cancer. In one study, baseline hope was associated with lower distress among individuals with hereditary colorectal cancer (Ho et al., 2010). Further, resilience factors at diagnosis may be associated with health-related outcomes after treatment. Several studies addressed this in the breast cancer population. Kenne Sarenmalm and colleagues conducted a longitudinal study in breast cancer patients and found that greater internal strength at baseline was associated with reduced distress and an enhanced quality of life at follow-up among breast cancer patients (2013). Lam and colleagues found that optimism at diagnosis was associated with lower distress at follow-up among breast cancer patients (2010). Further, Carver and colleagues found that baseline hope and optimism were associated with adjustment and growth in a later stage of breast cancer survivorship (2006).

A few studies investigated resilience whilst utilizing available instruments for assessing resilience. Associations with positive outcomes, such as quality of life and growth, but also negative outcomes, including psychiatric comorbidities, have been reported. Several studies used the Resilience Scale (RS; Wagnild & Young, 2001) to assess resilience. In a study conducted in a German sample of cancer patients, Schumaher and colleagues investigated correlates of resilience as measured by RS. They found that it was positively associated with self-efficacy, quality of life, emotional, cognitive, and physical functioning, and quality of life, and was negatively associated with anxiety and depression (2013). Brix and colleagues conducted two studies using RS in German cancer patients with unspecified type of cancer. In the first study, they found that more resilient patients were in less need of social support as compared to less resilient patients (Brix et al., 2008). In the second study, they found that RS predicted fatigue in cancer patients (Brix et al., 2009). The relationship between resilience and fatigue was found in another study that used RS to assess resilience, conducted on a Chinese sample (Tian & Hong, 2013). Resilience may also serve as a protective factor at a secondary diagnosis. In a study conducted on an American sample of individuals with a variety of types of cancer, Gotay and colleagues found that resilience was associated with more successful coping with a secondary diagnosis (2007). Gotay, Isaacs, and Pagano also found that RS predicted physical functioning and quality of life (2004), as well as vitality, sexual adjustment, existential wellbeing, lower anxiety, and depression in American cancer patients (Gotay et al., 2007).

Several studies used CD-RISC to assess resilience. For instance, Min and colleagues investigated the relationship between resilience as measured by CD-RISC and emotional distress among patients with various types of cancer. They found that resilient patients had less emotional distress as compared to non-resilient ones, after adjusting for age, metastasis, gender, and perceived social support (2013). Sharpley, Wootten, Bitsika, and Christie also assessed resilience using CD-RISC in an Australian sample and found that it was negatively associated with depression (2013). Scali and colleagues explored the relationship between CD-RISC and psychiatric diagnoses among breast cancer patients. They found that patients scoring higher on resilience had a lower chance of having current generalized anxiety disorder. Interestingly, they were also more likely to report history of trauma (2012). Resilience measured with CD-RISC has also been associated with higher quality of life and with lower distress among breast cancer patients cross-sectionally (Harms et al., 2018; Ristevska-Dimitrovska et al., 2015).

Nevertheless, all of the studies on resilience in the clinical oncology setting assessed resilience cross-sectionally. There is a gap in literature on whether resilience can change over time, including among adult cancer populations. Downes and colleagues estimated that 80% of resilience research is cross-sectional (2013). No studies thus far investigated whether resilience can change following cancer diagnosis and treatment, characterized as highly challenging events. There have also been no studies investigating whether changes in resilience can serve as a mechanism of recovery, i.e. whether resilience mediates or moderates the process of recovery in the clinical oncology setting.

Models of resilience in the oncology setting

Given that resilience is often viewed as a process, there have been several attempts to develop models of resilience, describing how various protective factors contribute to handling cancer-related stressors in a dynamic way. Some of the models were developed as conceptual frameworks based on literature reviews, whereas other were based on qualitative methods or structural equation modelling. A brief description of the models is presented in this section.

Seiler and Jenemin developed a conceptual framework of resilience among cancer patients after conducting a literature review on factors which promote resilience (2019). Their conceptual framework comprises two pathways of resilience, namely a direct and an indirect pathway. The direct pathway promotes resilience and buffers distress via personality traits such as optimism, hope, sense of coherence, positive illusion, and spirituality. The indirect pathway decreases suffering through changing the individual’s self, influenced by one’s ability to make sense of the cancer experience and one’s capacity to find benefit from the experience. Other factors they describe which may affect resilience are one’s social context, coping strategies, and cancer-related variables (Seiler & Jenemin, 2019).

Another conceptual model of resilience in cancer patients was developed by Deshields and colleagues (2016). They posit that resilience is both a dynamic process and an outcome. According to this model, one’s baseline attributes (including personal characteristics and environmental factors) affect how one reacts to the stressor, in this case cancer, as well as the coping response one utilizes. This can further increase one’s resilience, or lead to distress (Deshields, Heiland, Kracen, & Dua, 2016).

Ye and colleagues utilized structural equation modelling to develop a model of resilience among breast cancer survivors (2018). They found that four protective factors, namely self-efficacy, social support, courage, and hope for the future, directly accounted for resilience. They also described risk factors which indirectly affect resilience by affecting the protective factors, namely emotional distress, physical distress, and intrusive thoughts (Ye et al., 2018).

Li and colleagues developed conducted a qualitative study on Chinese lung cancer survivors and developed a model of resilience (2020). Their model describes resilience as a process consisting of three stages: (1) initial stress, which most patients experience; (2) adaptation to the disease; and (3) personal growth. They also described protective factors that contribute to resilience, including psychological qualities such as gratitude, willpower, and optimism, social support, exercise and lifestyle factors, participating in social activities, and Chinese medicine (Li et al., 2020).

Aspects of resilience in the oncology setting

Since early days of resilience research, the main focus has been placed on describing protective factors found in resilient individuals, which buffer against stress (Luthar, Cicchetti, & Becker, 2000). Recently, this research area has been brought into cancer populations. Few qualitative studies examined the specific aspects of resilience among cancer survivors, investigations focusing on the breast cancer population being even sparser. Recently, Tan, Beatty, and Koczwara conducted a review of studies aiming to identify characteristics and attributes that contribute to resilience among cancer survivors (2018). However, most studies did not have identifying aspects of resilience as the main focus, instead aiming to explore coping strategies or overall lived experiences of cancer patients, whilst briefly touching upon resilience, or not providing a definition of resilience. In the review, they concluded that four overarching themes emerged from the studies, namely (1) coping; (2) social support; (3) spirituality; and (4) growth. In this section, common aspects of resilience among cancer survivors identified in previous qualitative research will be presented.

The overarching theme of coping included several subthemes that cover a broad range of coping strategies, but also hardiness, optimism, and other attributes that have previously been suggested as psychosocial components of resilience (e.g., Southwick, Vythilinga, & Charney, 2005). Some of the coping subthemes identified in the review included perseverance, normality, denial, change of lifestyle or mindset, hope, altruism, goal-based coping, and change in perspectives (Tan, Beatty, & Koczwara, 2018). For example, in a study on older survivors of breast cancer, Pieters found optimism, hope for rehabilitation, self-reliance, and perseverance to be contributing characteristics of resilience (2016). Kennedy and Rollins conducted a study among African American breast cancer survivors and identified keeping positive, pragmatism, self-attunement and having a voice as some of the qualities promoting resilience (2016). Further, Zhang and colleagues identified hardiness, optimistic attitude towards the illness, gratitude, mastery, hope for rehabilitation, and confidence as attributes of resilience among breast cancer patients (2018).

Social support is commonly found as one of the contributing characteristics or resources of resilience among cancer survivors, and encompasses support from friends and family, healthcare workers, and the community (Tan, Beatty, & Koczwara, 2018). For instance, in a study on American prostate, lung, and digestive system cancer patients, Pentz found that non-resilient individuals were characterized by their significant lack of social support, whereas resilient individuals perceived social support as one of the key resources allowing them to cope with the experience (2005). The importance of close others and stable personal relationships was found as an important element of resilience in other investigations (Pieters, 2016; Guruge et al., 2011; Lam et al., 2016).

Spirituality is sometimes found as an important aspect of resilience among cancer patients, and is in some studies characterized by religious beliefs, and in others as broader spirituality (Tan, Beatty, & Koczwara, 2018). In a study conducted on a sample of older Norwegian cancer survivors, Haug and colleagues found that existential meaning-making and growth to be contributing to resilience, within both atheism and traditional Christian faith (2016). Kennedy and Rollins further identified spirituality as one of the elements of resilience among African American breast cancer survivors (2016).

Finally, growth was often found as one of the overarching themes of resilience characteristics and refers to positive changes which occurred as a result of cancer (Tan, Beatty, & Koczwara, 2018). In a study conducted in veterans with cancer, Jahn and colleagues found changes in worldview, social relationships, and faith occurred among resilient patients (2012). Baker and colleagues described attaining new values and becoming someone new among cancer survivors, which in result can lead to becoming more resilient (2016). Nevertheless, it is possible that researchers used the terms growth and post-traumatic growth interchangeably with resilience, despite them often being classified as two separate constructs. Post-traumatic growth implies a positive change resulting from significant adversity (Tadeschi & Calhoun, 2004), whereas resilience in many definitions, including the one accepted in this thesis, refers to returning to at least baseline functioning (Bonanno, 2004). It is thus important to differentiate these concepts in future studies, although they might be related.

However, very few qualitative studies aimed at identifying important aspects of resilience among cancer patients were conducted on subsets of highly resilient and low resilient patients, identified using a validated scale. One study by Zhang and colleagues was conducted on patients who had a high score on a Chinese resilience scale (2016), but did not include low resilient patients. Only one study was conducted in such comparative manner. Lam and colleagues compared patients with persistent distress and those with low distress trajectories (2016). They explored differences in illness meaning between the two subgroups of patients. They found that patients with the persistent distress trajectory were characterized by having an already difficult life, a cancer diagnosis being only one in a series of difficult life events. They had intrusive thoughts, bias for assessing physical symptoms, displayed thought suppression, and hopelessness. Patients with low distress, on the other hand, managed distress by taking charge, living in the present, acceptance, and having supportive family (Lam et al., 2016). No studies thus far investigated aspects of resilience by comparing breast cancer survivors with low and high resilience scores, as measured by a validated scale for assessing resilience.

General and specific aims of the thesis

As evidenced, resilience seems to play an important role in reacting to and handling breast cancer-related stressors. Nevertheless, resilience is a complex construct and issues related to the conceptualization of resilience overall and in the breast cancer context are plentiful. To be able to uncover the role of resilience in the breast cancer context, resilience in itself needs to be addressed from multiple perspectives. The overarching aim of the thesis is to uncover the role of resilience in physical and mental health-related recovery from breast cancer, starting from diagnosis and into extended and permanent survivorship.

The specific aims of the three studies can be illustrated using a metaphor of a *tree* with its roots, trunk, and branches. The first study represents the *roots* of the tree as it aims to determine whether resilience can be measured as a trait, i.e. a set of characteristics and resources, in the relevant, Swedish context. It aims to explore the psychometric properties of CD-RISC in the non-clinical Swedish population, namely its construct validity, internal consistency, discriminant, and predictive validity. The second study represents the *trunk* of the tree, as it aims to elucidate the nature of the relationship between resilience and health-related quality of life in breast cancer survivors from diagnosis to one year after diagnosis. It takes a biopsychosocial approach, by exploring the role of clinical, sociodemographic, and psychological factors in recovery from breast cancer. Another aim of this study was to help understand whether resilience should be a target for psychosocial interventions aimed at breast cancer patients and survivors. The third study represents the *crown* of the tree, as it aims to explore the lived experiences and aspects of resilience among breast cancer survivors. Using a qualitative approach, it aims to identify experiences from diagnosis to the present day by employing purposive sampling to obtain maximum variability in resilience scores. This study also aims to identify target areas for interventions in this population.

Summary of the studies

The general aim of this thesis is to increase understanding of the role of resilience in breast cancer survivorship in the Swedish context. The approach taken in the studies was to explore resilience from both a quantitative (Studies I and II), and a qualitative angle (Study III). All studies utilized CD-RISC to assess resilience or identify low and high resilient survivors. CD-RISC is a measure of characteristics of resilient people, including tenacity, personal competence, acceptance of change, spirituality, coping with negative emotions, and control (Connor & Davidson, 2003). Study I focused on understanding the factor structure and other properties of CD-RISC in the Swedish context. Study II then addressed the relationship between CD-RISC and health-related outcomes in breast cancer survivors from diagnosis to one year later, whilst also addressing clinical and socio-demographic factors. Finally, Study III elucidated the important lived experiences of women who had breast cancer from diagnosis to the present day and aspects of resilience in this context. In the section below, the background, specific aims, methods, results, and contributions of the three studies are provided. The aim of this section is to highlight key elements of the three studies included in this thesis.

Study I

Background

The aim of the first study was to investigate psychometric properties of CD-RISC in a non-clinical population in Sweden to determine its utility in clinical settings. The main aim was to explore whether the five-factor structure found by Connor and Davidson (2003) would be replicated in the Swedish context. This would help us better understand the characteristics of the resilience construct in the Swedish population. The second aim was to explore discriminant validity of CD-RISC by investigating its independence from a measure of emotion regulation. Resilience and emotion regulation are closely related, but distinct constructs, resilience encompassing a range of biopsychosocial components. Further, resilience has consistently been found to be associated with a range of outcomes, including health-related quality of life (HRQoL). The third and final aim of Study I was to explore the predictive validity of CD-RISC in relation to physical and mental HRQoL.

Methods

Participants and procedure

Study I was a cross-sectional survey study. Data was collected in 2018 within the BIG3, an ongoing project that aims to explore various health variables in the region of Skåne (Region Skåne, 2019). Data collection within the project was conducted in three rounds. A total of 57,107 randomly selected individuals in Skåne were invited to take part in the first round, out of which 11,083 agreed to participate. Age ranged between 45 and 75 years. The second round also included a randomly selected subsample (*n* = 5,230), except that it was geared to include a substantial percentage of smokers (25%) and former smokers (50%). Finally, the third round included 3,724 randomly selected participants. Data included in this study was collected in the third round, retention rate being 69.9%. Data was collected online.

Measures

Resilience. The Swedish version of the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) was used to measure resilience. We received permission from the authors of the scale to use it in this study. Scores range from 0 to 100, higher scores indicating higher resilience. Respondents state to which extent they agree to 25 statements (see Table 1 for examples) on a 5-point Likert scale.

Emotion regulation. Emotion regulation was assessed using the Swedish version of the Brief Version of the Difficulties in Emotion Regulation Scale (DERS-16; Bjureberg et al., 2016). This scale assesses emotion dysregulation, i.e. the difficulties in various elements of regulating emotions. It comprises 16 items, rated on a 5-point Likert scale (1 corresponds to “Almost never”; 5 corresponds to “Almost always”). Scores range from 16 to 80 and higher scores correspond to higher emotion dysregulation. Some of the aspects of emotion regulation assessed by the scale are impulse control (e.g., “When I am upset, I feel out of control”), goal-directed behaviors (e.g., “When I am upset, I have difficulty focusing on other things”), different strategies for emotion regulation (“When I am upset, I believe that I’ll end up feeling very depressed”). The scale had high internal consistency in the sample ($\alpha = .92$).

Health-related quality of life (HRQoL). HRQoL was assessed using the Swedish version of the 12-Item Short Form Survey (SF-12; Ware, Kosinski, & Keller, 1996). It consists of 12 items aiming to measure perceptions of different aspects of health. Two scores are derived from the scale, namely the Mental Health Component Summary Score (MCS12) and the Physical Health Component Summary Score (PCS12).

Socio-demographic and health measures. Other variables included in the study were gender, age, highest level of education, and socio-economic status (SES), which was assessed by participants estimating how often they have difficulties paying their bills. Health-related variables included smoking habits, as well as diagnoses of 18 health conditions, self-reported by the participants.

Data Analysis

Construct validity of CD-RISC was investigated via Exploratory Factor Analyses (EFA) and Confirmatory Factor Analysis (CFA) conducted on three randomly derived subsamples ($n1 = 866$, $n2 = 866$, $n3 = 867$) extracted from the total sample (N = 2,599). EFAs were conducted on the polychoric correlation matrices on first two subsamples to explore the factors that emerged. They were compared between the two subsamples to investigate the stability in factor structure. As factors were expected to correlate, Principal Axis Factoring and promax rotations were utilized (Costello & Osborne, 2005). EFA extraction was guided by Parallel Analysis (Horn, 1965). The acquired model was then tested with a CFA on the third subsample. The model was assessed using standard Goodness-of-Fit Indices criteria (RMSEA <.08; SRMR <.05; CFI > .90). Variances of latent variables were fixed to one. Given that data were not normally distributed, the Sattora-Bentler scaled test statistic was used as a correction.

Discriminant validity of the acquired model was assessed with a CFA in relation to DERS-16. The same Goodness-of-Fit indices were used, as well as the AIC scores for both models. Predictive validity was assessed using two hierarchical multiple regression analyses. Sociodemographic and health variables were included into the model in the first step, and CD-RISC was included in the second step. Dependent variables were MCS12 and PCS12 derived from the SF-12 scale.

Results

EFAs resulted in a 22-item unidimensional model of CD-RISC. Three items did not load on the extracted factor, namely item 3 (“When there are no clear solutions to my problems, fate or God can sometimes help.”), item 9 (“I think most things happen for a reason, whether it's good or bad.”), and item 20 (“When dealing with the problems of life, one must sometimes act on a hunch without knowing why.”). Both absolute and relative Goodness-of-fit indices suggested that the unidimensional model fit the data well. Therefore, the CFA supported the 22-item unidimensional model of CD-RISC. Internal consistency was high (α = .91). The 22-item CD-RISC was also found to be independent from DERS-16, giving evidence for its discriminant validity. Finally, two hierarchical multiple regression analyses suggested CD-RISC predicted both physical and mental HRQoL, over and above sociodemographic and health variables, giving evidence for the instrument’s predictive validity.

Contributions

The main contribution of this study was that the Swedish version of CD-RISC does seem to have good psychometric properties and might be used in research and clinical contexts in Sweden to assess resilience as defined by the authors of the scale. The investigation of factor analyses conducted in this study suggested that resilience, as measured by CD-RISC, seems to be a unidimensional construct, rather than a collection of interlinked factors. We utilized an oblique rotation method in our investigation, as opposed to an orthogonal rotation, used in the original investigation by Connor and Davidson (2003). An oblique rotation is recommended when factors are assumed to correlate (Costello & Osborne, 2005). This study further helped us better understand the nature of resilience in the Swedish cultural context. Three items that did not load on the extracted factor related to spirituality and “acting on a hunch”, giving support to the notion that spirituality and religion may not be important aspects of resilience in the Swedish context. Most of the items that were retained, especially those with highest factor loadings, reflect one’s perceived self-efficacy in handling difficult situations and being able to deal with difficult situations. Another interesting finding of the study was that resilience, as measured by CD-RISC, had a higher association with physical HRQoL than a plethora of health-related variables, such as diagnoses of a variety of chronic diseases and smoking habits. Interestingly, patients with chronic obstructive pulmonary disease had significantly lower resilience as compared to those without the disease. The relationship between resilience and physical health is a fascinating new area of research which deserves to be examined more closely, from a biopsychosocial perspective.

Study II

Background

The aim of this study was to uncover whether changes in resilience mediate or moderate the changes in HRQoL among breast cancer patients from diagnosis to one year after diagnosis. Resilience has thus far only been investigated cross-sectionally in clinical oncology settings. A plethora of studies suggested that resilience does seem to be an important predictor of QoL long-term, but no studies thus far investigated whether resilience can change after a cancer diagnosis and treatment, highly stressful and potentially traumatic events. Moreover, no studies thus far investigated whether the physical and mental health recovery from breast cancer can be explained by changes in resilience that occur, or whether more resilient patients over time have a quicker recovery. Additionally, this study utilized a biopsychosocial model of health, aiming to uncover how a range of tumor and treatment-related factors, as well as sociodemographic factors are associated with the recovery process. This would further help identify risk factors for slower recovery or worsened outcomes among breast cancer patients and survivors. In this study, we explored a range of tumor- and treatment-related variables (listed further below), as well as age, socioeconomic status (SES), and living arrangement.

Methods

Participants and procedure

Study II was a prospective longitudinal study conducted within the SCAN-B Resilience project (Axelsson et al., 2018), which is a part of the Sweden Cancerome Analysis Network - Breast (SCAN-B). SCAN-B is a population-based study that included approximately 90% of all patients with breast cancer in Skåne (Saal et al., 2015). Breast cancer patients from the abovementioned study sites were also invited to participate in SCAN-B Resilience, a project that aims to identify biological markers of resilience. The inclusion rate for this study was approximately 70% of all newly diagnosed breast cancer patients (Axelsson et al., 2018). Therefore, the majority of individuals with breast cancer in the region were included in SCAN-B Resilience. Data collection at time point one occurred on the day of receiving the diagnosis, two to three weeks after the diagnostic procedures took place. Patients filled in the study questionnaires on paper or electronically. One year after diagnosis, the data collection for time point 2 occurred. Patients received the questionnaires via post. A total of 980 participants took part at baseline, whereas 780 took part at follow-up.

Measures

Resilience. The Swedish version of the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) was used to measure resilience. The description of the scale is provided in the Methods section for Study I above.

Health-related quality of life (HRQoL). HRQoL was assessed using the Swedish version of the Short Form 36 Health Survey (SF-36; Ware, Kosinski, & Keller, 1994). It consists of 35 items that correspond to eight domains, namely physical functioning, role limitations to due physical and emotional problems, general health, bodily pain, social functioning, mental health, and vitality. Aside from eight scores derived for eight domains, two additional scores are calculated, the mental health component score (MCS) and physical health component score (PCS). An additional, 36th item, measures perceived changes in current health as compared to one year ago. Scores are calculated using specialized software and range from 0 to 100, higher scores indicating more optimal functioning.

Clinical variables. Clinical variables included in the study were: Mode of detection of breast cancer, menstrual status, TNM stage, ER status, HER2 status, histologic grade, type of surgery, axillary surgery, adjuvant chemotherapy, radiotherapy, bisphosphonate, endocrine, and antibody therapy. Clinical data were extracted from the national breast cancer registry (Regional Cancer Centers, 2019), which includes close to 100% of all breast cancer cases in Sweden.

Sociodemographic variables. Participants also reported their highest level of education, SES, living arrangement, and age. SES was assessed by assessing whether they would be able to pay an unexpected bill of 11,000 SEK.

Data Analysis

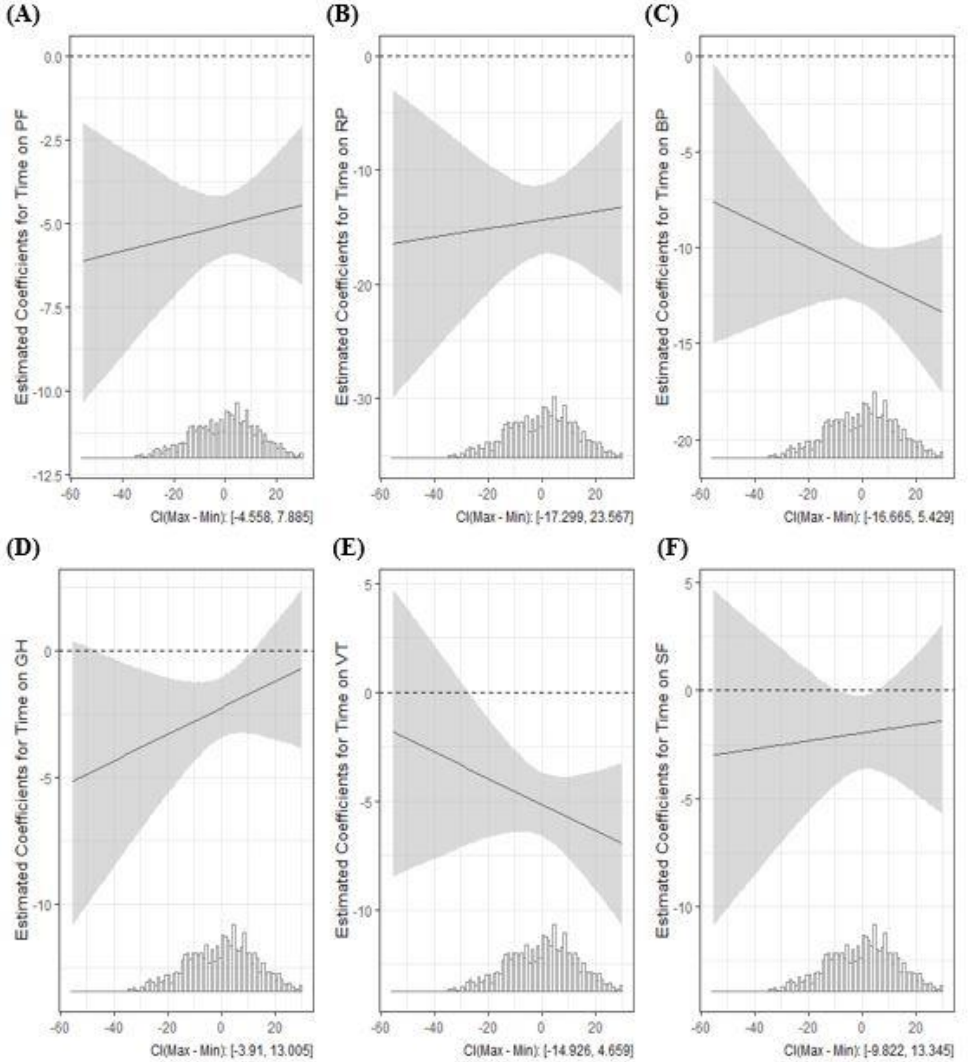
Data were analyzed using mixed model regression analysis, considering the two-level nature of the data. In the study, data were nested within person. The data had two levels: 1) the within-subject factor named *time*, i.e. the estimations of ten SF-36 subscores and CD-RISC at two time points; 2) between-subject factors, namely clinical and sociodemographic variables. These between-subject factors served as potential predictors or moderators to the change in SF-36 subscores over time. In the analyses process, first only time and random effects of intercepts were included in the model. Subsequently, main and interaction terms of variables of interest were included into the model. In all models, between-patient variability, namely the differences in intercepts of individual units, explained large amounts of variance. Tumor characteristics were also controlled for the effects of therapy.

Resilience was explored as a covariate. The moderating effect of a variable, including resilience, was assumed in cases where there was an interaction between time and the variable of interest. Significant interactions were explored using simple slopes at -1SD, Mean, and +1SD, slopes being adjusted for covariates. All covariates were mean-centered. The mediating role of resilience was inferred when the adjusted effect of time was weaker after including resilience into the model. Resilience at baseline was also investigated.

Respondents were compared to non-respondents using t-tests for independent samples, $\chi 2$ tests of independence for categorical variables, and the Mantel–Haenszel test of the trend for ordinal variables, to investigate attrition.

Results

Results revealed that mental HRQoL improved over time, whereas physical HRQoL deteriorated over time. Changes in resilience did not mediate nor moderate the changes in HRQoL, although changes in resilience were positively associated with changes in all HRQoL outcomes, especially mental health and general health. Therefore, HRQoL did not improve more among participants with higher resilience. Marginal effects of time across observed values of resilience are represented in Figure 1.


(A)
Estimated Coefficients for Time on PF
0.0
-2.5
-5.0
-7.5
-10.0
-12.5
-60
-40
-20
0
20
CI(Max - Min): [-4.558, 7.885]
(B)
Estimated Coefficients for Time on RP
0
-10
-20
-30
-60
-40
-20
0
20
CI(Max - Min): [-17.299, 23.567]
(C)
Estimated Coefficients for Time on BP
0
-5
-10
-15
-20
-60
-40
-20
0
20
CI(Max - Min): [-16.665, 5.429]
(D)
Estimated Coefficients for Time on GH
0
-5
-10
-60
-40
-20
0
20
CI(Max - Min): [-3.91, 13.005]
(E)
Estimated Coefficients for Time on VT
5
0
-5
-10
-60
-40
-20
0
20
CI(Max - Min): [-14.926, 4.659]
(F)
Estimated Coefficients for Time on SF
5
0
-5
-10
-60
-40
-20
0
20
CI(Max - Min): [-9.822, 13.345]

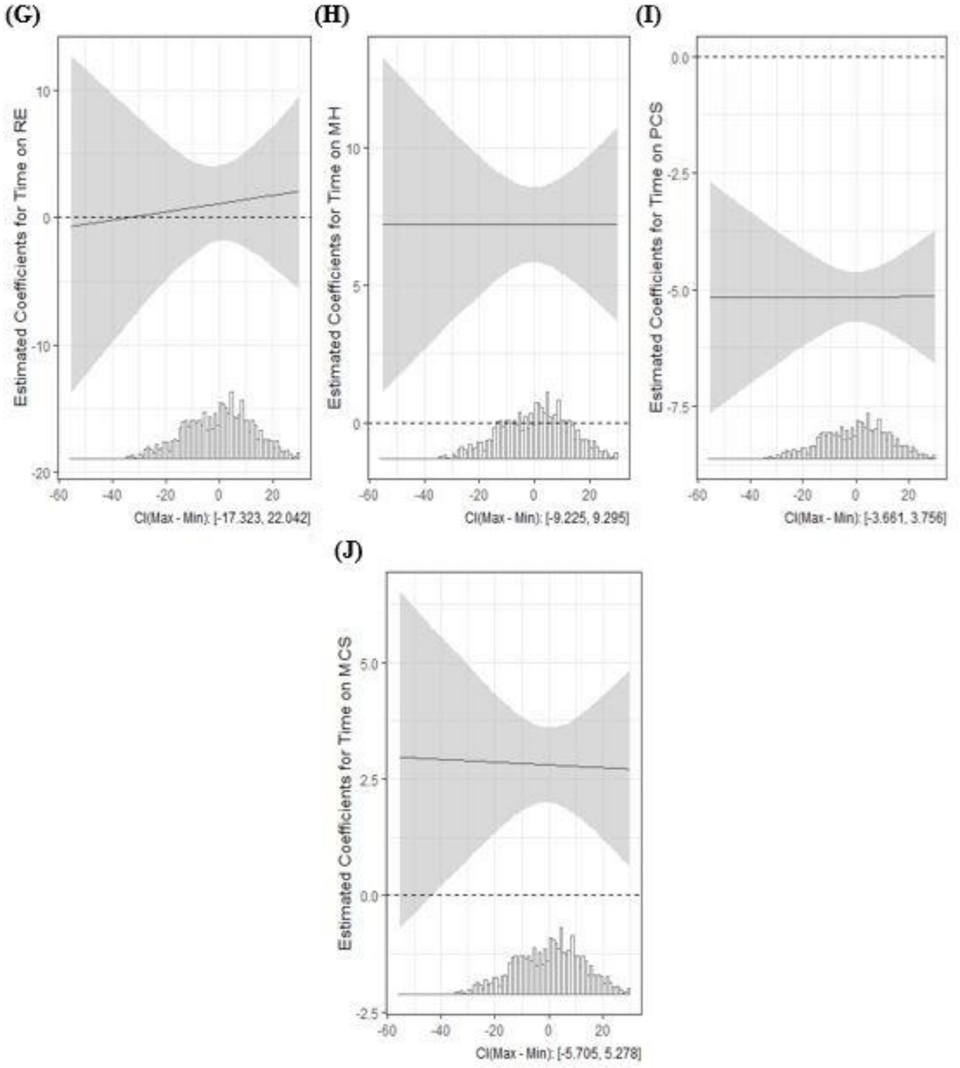


Figure 1.

Marginal Effect of Time across Observed Values of Resilience on Physical Functioning (A), Role Limitations due to Physical Problems (B), Bodily Pain (C), General Health (D), Vitality (E), Social Functioning (F), Role Limitations due to Emotional Problems (G), Mental Health (H), PCS (I), MCS (J). Y axis represents centered scores on resilience. Histograms on the y axis represent the distribution of observed scores on resilience. Gray areas represent confidence intervals for the marginal effect, which is significant whenever the lower and upper margins are below or above the zero line. Confidence intervals for marginal effects are provided below each panel.

Moreover, changes in HRQoL could not be explained by changes in resilience over time. Interestingly, patients with higher baseline resilience had less of an increase in mental health over time, and a steeper decline in bodily pain and vitality, possibly due to ceiling and floor effects. Another possible explanation for this is regression to the mean. Figure 2 portrays the simple slopes for baseline resilience on bodily pain, vitality, and mental health over time. Yellow line represents Swedish norm values (Sullivan, Karlsson, Taft, & Ware, 2002), suggesting that resilient individuals stayed around or above the norm values at both time points.

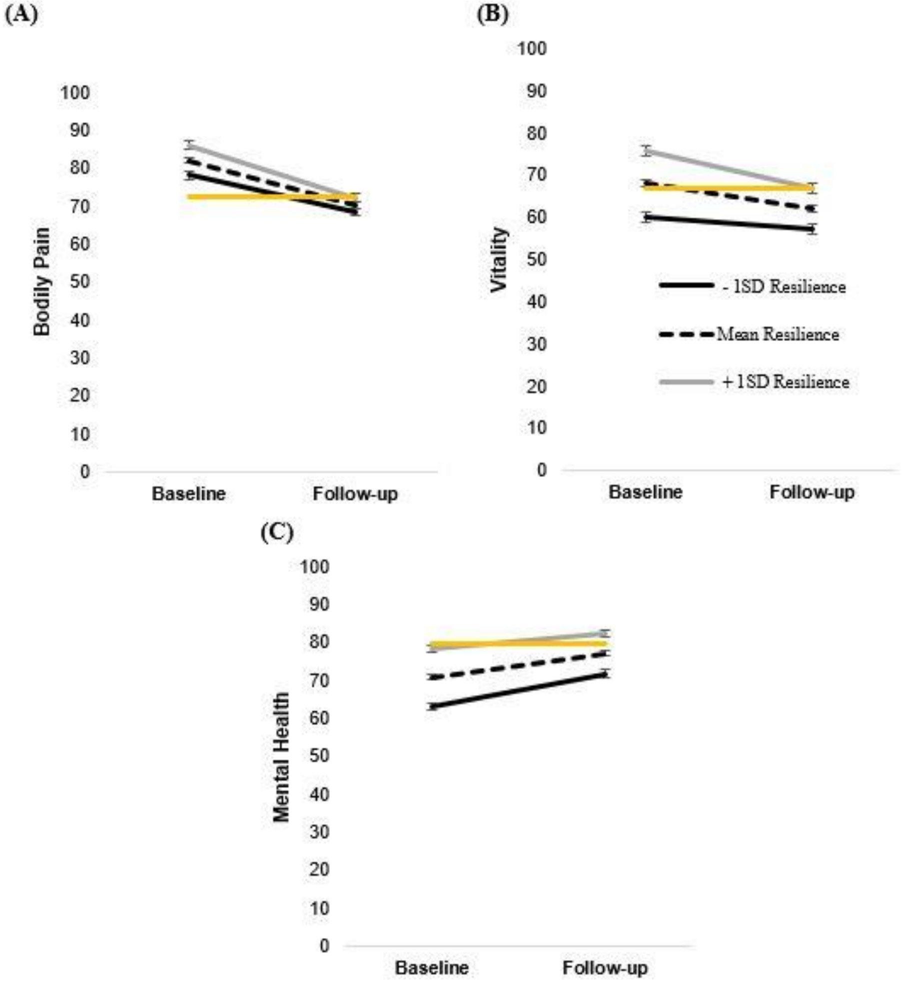


Figure 2.

Simple Slopes of the Moderating Effect of Baseline Resilience on Changes in Bodily Pain (A), Vitality (B), and Mental Health (C). Higher scores on outcome variables indicate better functioning, i.e. less bodily pain, more vitality, and better mental health. Yellow lines represent Swedish norm values. Error bars show standard errors.

Among the clinical variables that facilitated the recovery process were lower TNM stage and histologic grade, ER2 positive status, HER2 negative status, as well as not having adjuvant chemotherapy, bisphosphonate, or antibody therapy. Interestingly, antibody therapy and HER2 status seem to be especially important for mental health-related outcomes, whereas other clinical variables seem to matter more for physical health. Lower socioeconomic status was associated with lower HRQoL outcomes across time.

Contributions

The main contribution of this paper to resilience literature is that it increases understanding of how resilience changes and interacts with physical and mental health-related recovery from breast cancer, starting from diagnosis to one year after diagnosis. It revealed that resilience does not seem to change substantially after experiencing potentially life-changing events. Mental and physical recovery thus do not seem to be mediated nor moderated by changes in resilience, although longer term investigations are needed to draw more solid conclusions. Baseline resilience, however, did seem to be a protective factor, with highly resilient participants exhibiting remarkably little drops in functioning at diagnosis. This study thus tells us more about the resilient trajectory among breast cancer patients and survivors. Additionally, this study highlighted the clinical and sociodemographic factors which seem to indicate worse functioning or a steeper decline in functioning in this population. The findings of this study can thus help identify patients in special need of support throughout the diagnostic and treatment processes, as well as shortly after treatment.

Study III

Background

The main aim of Study III was to explore the lived experiences and aspects of resilience among breast cancer survivors. Existing research that aimed to investigate aspects of resilience in clinical oncology settings lacks methodological and conceptual rigor in terms of how resilience was defined and explored. To the best of our knowledge, only one qualitative study studied resilience among patients with low and high distress trajectories (Lam et al., 2016). Their study, however, defined resilience as an outcome. In this study, we defined resilience as a set of dynamic qualities, resources, and processes that facilitate successful adaptation to breast cancer-related stressors. We used CD-RISC to identify women who had very low and very high scores on resilience and thus obtain the maximum variation of resilience scores in the sample. This would further give way to designing more specific intervention for breast cancer patients and survivors.

Methods

Participants and procedure

This study was a qualitative study that consisted of semi-structured in-depth interviews. We utilized purposive sampling in the study, building on results from SCAN-B Resilience (Axelsson et al., 2018). Women who scored very high (+2SD) and very low (-2SD) on CD-RISC at diagnosis were asked to take part in the study. They were contacted via post. Inclusion criteria included having completed treatment at least six months before, in order to include the extended survivorship phase (Mullan, 1985). Other inclusion criteria included no cancer recurrence or a second primary cancer diagnosis to enhance homogeneity, as well as speaking Swedish fluently. Two co-authors of the study, who are licensed clinical psychologists, conducted interviews by telephone. They were blind to the CD-RISC score of each interviewee. The interview guide was developed to include main experiences from diagnosis into survivorship, their thoughts, emotions, and social responses to such experiences, as well as strategies and resources they relied on. Interview questions covered all phases of the breast cancer continuum (Molina et al., 2016).

We conducted a total of 25 interviews. Interviewees were breast cancer survivors residing in southern Sweden. Out of 25 women, 14 had a high resilience score, whereas 11 had a low resilience score at diagnosis. The two groups were similar in terms of clinical and sociodemographic characteristics. Most women received a combination of adjuvant therapy and surgery.

Data Analysis

Interviews were tape recorded and transcribed verbatim. We used the critical realist perspective (Jackson, 2016) as we acknowledged the interpretative, subjective, and contextual ways in which humans make sense of their lived reality. The interpretative nature of our analysis process was thereby also recognized. We used thematic analysis as the method of analysis (Braun & Clarke, 2006) as it can help extract both shared meanings and experiences as well as differences across different groups. Whilst analyzing the transcripts, we were blind to the groups to which the transcript belonged to minimize bias. After familiarizing ourselves with the data and coding, initial themes were extracted. At this point, we compared and contrasted the codes between and within resilience scores. This process was repeated until consensus was reached between the authors. In the end, the themes and subthemes were more closely defined and named.

Results

We identified three overarching themes, each containing several subthemes. The themes and subthemes are presented in Table 2.

Table 2.
Themes and subthemes

Themes	Subthemes
"I will try to keep the spirits up": Struggling with agency in the face of uncontrollability	Navigating uncertainty when cancer is the agent Maintaining normalcy to be able to deal with illness Exercising agency in relation to thoughts and feelings Taking charge of one's health
"You know that you are not alone": Social support and collective survivorship for better and for worse	Dealing with illness with or without social support Being "on the same bus" with others with breast cancer Reliving past occurrences of breast cancer in the family
"I try to leave that behind me": Conceptualizing cancer as a closed chapter or a constant	Understanding cancer as removed or as constantly lurking Returning to your normal (better) self or as a weaker self

The first theme, namely *"I will try to keep the spirits up": Struggling with agency in the face of uncontrollability*, referred to the agency relating to different aspects of having breast cancer. Having or not having agency was one of the defining experiences relevant for resilience, with those who had higher resilience scores seemed to express more agency. The illness itself is uncontrollable. Breast cancer can be invisible and unpredictable, which seemed to have given way to intense worry and anxiety in all women. Nevertheless, women with higher resilience scores were interpreted as having agency relating to other aspects of the breast cancer experience. For instance, they expressed being able to maintain normalcy in regards to their daily functioning and routines. Disruptions in normalcy occurred in women with low resilience scores, who expressed having difficulties adapting to changes that arose, e.g. bodily changes that come with breast cancer treatment. Further, women with higher resilience scores expressed having agency relating to their thoughts and feelings. They perceived worrying as useless and maintained a positive attitude. They also seemed to have exhibited agency in relation to their health, which enabled them to perform activities that helped them feel physically and mentally better throughout the experience. The second theme, namely *"You know that you are not alone": Social support and collective survivorship for better and for worse*, referred to the complex role of important others in breast cancer-related experiences. In a multitude of ways, others play a beneficial practical and emotional role. Having close friends and family to speak to was important to all women, irrespective of resilience scores. However, some women with lower resilience scores expressed not having close others to rely on. Seeking support from women who once had, or currently have breast cancer, was also an important resource for all women. Nevertheless, caring for others can express itself as burdening in women with breast cancer, as many had breast cancer in the family and expressed worry for their daughters and granddaughters. The third theme, *"I try to leave that behind me": Conceptualizing cancer as a closed chapter or a constant*, refers to the ways in which women conceptualize the finality of breast cancer and in which they relate to breast cancer as an invisible, yet potentially life-threatening illness that may come back at any point. Women with higher resilience scores seemed to have interpreted breast cancer as removed with surgery, which helped them move on with their daily lives after treatment. They described leaving their breast cancer behind and returning to their normal self. Conversely, women with lower resilience scores seemed to have conceptualized breast cancer as a threat that is constantly lurking, which lent itself to being highly sensitive to warning signs of breast cancer and not being able to leave the experience behind. They described feeling weaker, having problems concentrating, and not being the same person as a result of their breast cancer.

Contributions

This study helped illuminate relevant aspects of resilience in breast cancer survivors. By utilizing purposive sampling and obtaining high variation in resilience scores, we were able to compare and contrast survivors with high and low resilient score profiles, thereby being able to investigate a complex construct such as resilience. Having agency relating to one's emotions, thoughts, daily functioning, health, and wellbeing was interpreted as one important aspect of resilience. Future quantitative studies should further explore the relationship between agency and resilience, the concept of health locus of control (HLoC; Norman & Bennett, 1996) being a potential useful tool to achieve so. The findings of this study supported the notion that resilience does not seem to comprise a lack of negative emotions, which were commonly experienced by both groups of women, but having agency relating to such emotions. Breast cancer itself is uncontrollable, which can inadvertently give rise to negative reactions. Nevertheless, highly resilient women seemed to have agency relating to their health and wellbeing, which seemed to have further driven them to utilize the resources and strategies available to them. The findings of this study may thus inform target intervention areas for women with low resilience profiles.

Discussion

The overarching aim of this thesis was to deepen our understanding of the role of resilience among breast cancer survivors. Study I served as the foundation of the thesis, clarifying that CD-RISC can be used in the Swedish context, exhibiting good psychometric properties. Exploring the factor structure of CD-RISC also added to our understanding of elements of resilience as measured by CD-RISC in the Swedish context. Study II investigated the role of resilience as measured by CD-RISC in the process of breast cancer recovery. It investigated whether resilience changes over time during the breast cancer trajectory, and whether these changes in resilience mediate or moderate mental and physical health-related recovery. Doing so, Study II indicated that CD-RISC can be used to identify patients in need of additional psychosocial support, as well as that it may be most useful at the time of diagnosis itself, but also further in the breast cancer recovery trajectory. Finally, Study III deepened our knowledge on the specific areas where support may be needed in low resilient breast cancer survivors. Thereby, it added to the literature on specific aspects of resilience in this population.

Integrating main findings with previous literature

In this section, I aim to discuss the main findings of the three studies included in this thesis whilst comparing it with the existing literature on resilience among breast cancer survivors. Doing so, I will discuss how the current findings add to existing empirical research in the area, as well as how they add to the broader conceptual discussion of the construct of resilience.

The Connor-Davidson Resilience Scale

CD-RISC is perhaps the most widely used scale to assess resilience and its psychometric properties have previously been investigated in a variety of contexts. Study I contributed to the breadth of knowledge in this area by proposing a 22-item unidimensional model of CD-RISC in the Swedish general population. It suggested that resilience, as measured by CD-RISC, is a unidimensional construct. This is in line with some other previous research which also arrived at a one-factor model in different populations (Burns & Anstey, 2010; Arias Gonzalez et al., 2015; Gonzales, Moore, Newton, & Galli, 2016; Campbell-Sills, Cohan, & Stein, 2006). It is possible that the differences in outcomes can be contributed to utilizing different rotations when performing EFAs, namely oblique versus orthogonal rotations, as done in the original exploration by Connor and Davidson (2003). Given that the authors of the scale developed the instrument drawing from a variety of protective factors found to be associated with resilience (e.g. close interpersonal relationships, emotion regulation, hardiness), this result is rather surprising. Nevertheless, some the items that had highest factor loadings are the ones broadly relating to the concept of hardiness, i.e. having a purpose of life, a sense of agency, and growing from stressful life experiences (Kobasa, 1979). Interestingly, the factors that did not load on the proposed factor relate to the factor labeled as “Spirituality” by Connor and Davidson, and refer to both religion and more broadly defined spirituality. These items were also excluded in Australian and Spanish contexts (Burns & Anstey, 2010; Arias Gonzalez et al., 2015), so it is possible that the role of religion and spirituality in resilience is largely context-dependent. This was corroborated in Study III, as spirituality and religion did not emerge in any themes or subthemes among breast cancer survivors.

The results of this factor analysis bring into question the conceptual nature of resilience, as measured by CD-RISC, and thus employed in this thesis. Connor and Davidson developed the scale whilst relying on previous research on factors that were found to protect an individual from experiencing strong negative reactions and outcomes to adverse events. However, as described above, most items of the scale refer to one’s perceived ability to handle, overcome, and grow from stressful experiences. Very few items relate to more specific protective factors. It is thus not surprising that those items (e.g. items relating to social support and spirituality) had lower factor loadings. The scale could therefore be criticized that it perhaps misses out on some important components of resilience which might be of importance for one’s ability to handle adverse events. Nevertheless, although this could be the case, investigation of the scale’s discriminant and predictive validity gives some evidence for the utility of the scale in research and clinical settings.

Study I gave evidence to the discriminant and predictive validity of CD-RISC in the Swedish context. CFAs revealed that resilience as measured by CD-RISC is a separate construct from a measure of emotion regulation. It would be interesting to explore discriminant validity of CD-RISC in relation to other related concepts such as coping and post-traumatic growth. CD-RISC also predicted physical and mental HRQoL over and above health-related and sociodemographic measures. It was an especially important predictor of mental HRQoL, explaining 18% of additional variance. Utilizing different methodologies, all three studies included in the thesis support the notion of resilience being highly important for mental HRQoL, in both non-clinical population as well as the breast cancer population.

Resilience and cognitive functions

Aside from providing some insight into whether CD-RISC can be used in research and clinical settings, Study I can help us better understand the components of resilience as measured by the scale. It is interesting to more closely investigate the content of the items which had the highest factor loadings in the factor analyses. Those items seem to thematically encompass perceiving oneself as able to exert various cognitive processes, perform successful problem solving, and thus handle difficult situations. For example, item 14 assesses the ability to maintain and sustain focus, item 17 assesses one's perceived strength when dealing with difficult events, item 5 measures learning from the past to meet new challenges and difficulties, item 11 relates to one's perceived ability to achieve one's goals despite difficulties, and item 23 refers to liking challenges. It thus might be interesting to reflect on the role of cognitive processes in resilience.

Parsons, Kruijt, and Fox proposed a cognitive model of resilience (2016), which suggests that cognitive functions might play an important role when dealing with adversity and stress, thus resulting in a resilient response. It asserts that resilient responses are dependent on a flexible utilization of cognitive and affective systems. This is noteworthy as, if one applies Lazarus and Folkman's definition, it is not the event itself, but how one interprets the event which affects the stress response (1984). Therefore, the initial appraisal of the event, which is a cognitive process, is crucial in producing a resilient response. Further, Parsons, Kruijt, and Fox argue that selective allocation of attention to negative cues is a key cognitive characteristic of anxiety, and might play a role in responding to a stressful situation. In addition, experienced anxiety and stress can further inhibit executive function abilities. Interestingly, the findings of Study III suggested that an aspect of lower resilience profiles included experiencing lingering worry, self-blame, and rumination, potentially giving way to cognitive effects such as troubles concentrating and memory problems. In the cognitive model of resilience, rumination, self-blame, and catastrophizing would encompass a lack of ability to exert cognitive control, a form of emotion regulation, as well as psychological flexibility, i.e. the capacity to use a range of cognitive and behavioral strategies to enhance adaptation (Parsons, Kruijt, & Fox, 2016).

According to Lazarus and Folkman, secondary appraisal is initiated when a certain situation is perceived as stressful, and refers to assessing one's coping capabilities to deal with the stressor (1984). In line with the cognitive model of resilience, the responses initiated in this process can be assimilative or accommodative. Assimilative responses reflect actively changing the situation itself, whereas accommodative responses refer to aiming to change the subjective evaluation of the event or downgrading the importance of goals affected by the stressor (Parsons, Kruijt, & Fox, 2016). Authors of the model note that perceived controllability of adversity seems to be crucial in determining the initiated cognitive responses. If the adverse event is deemed uncontrollable (such as breast cancer), accommodative coping responses seem to be more efficient. According to this model, resilience would encompass a flexible utilization of assimilative versus accommodative responses depending on whether the stressor is controllable or uncontrollable. Therefore, changing the subjective evaluation of breast cancer may be a part of a more resilient response. An important aspect of resilience identified in Study III relates to how survivors conceptualized the finality of breast cancer. Women with higher resilience scores seemed to perceive breast cancer as only one chapter in their lives, perceiving its finality once the tumor has been surgically removed. Moreover, they often perceived adjuvant treatment as a way of preventing the recurrence, thus reframing the meaning of breast cancer treatment. This is in line with some previous research which suggested that resilient individuals tend to utilize cognitive reappraisal and positive reframing, thus perceiving these situations as less threatening (Southwick, Vythilinga, & Charney, 2005).

Looking at the cognitive models of resilience, findings of Study I and Study III together, it is possible that resilient individuals are able to make difficult decisions, solve problems, sustain focus, adapt to a changing environment, in an efficient and flexible manner. They may utilize coping strategies flexibly, depending on the nature of the stressor. Furthermore, they may be able to successfully regulate their emotions by using adaptive emotion regulation strategies, such as cognitive reappraisal. Humorous cognitive reappraisal is an emotion regulation strategy that has been suggested to result in higher wellbeing by perceiving the situation in a less threatening way (Perchtold et al., 2019), and is reflected in one of the items of CD-RISC (item 6). Interventions aimed at enhancing cognitive processes may thus be useful for facilitating resilience.

Resilience and agency

Study III suggested that agency was a defining aspect of resilience in breast cancer survivors. Women with higher resilience scores seemed to have more agency relating to their health, treatment, daily routines during treatment, thoughts, and emotions. They were interpreted to, as a result of agency, be able to fulfill their need for normalcy and perform activities that in turn made them feel better. However, the breast cancer itself was uncontrollable and the notion of breast cancer also being an agent was burdening for all women.

The concept of agency is not new in literature. Bandura (2006) described agency as intentionally handling one’s circumstances and functioning. Agency as such comprises several elements. First, intentionality in making action plans and manners of executing them. Second, forethought in goal-setting and anticipation of outcomes. Third, it involves executing these intentions in concrete actions. Fourth, it includes self-reflection of own thoughts and actions. Bandura’s examination of agency may serve as a useful tool to describe concrete elements women with breast cancer who are highly resilient employ when reacting to breast-cancer related stressors. They seemed to exhibit intentionality and forethought in planning and executing activities and strategies, whilst anticipating a desired outcome. For example, this included taking charge of certain treatment procedures, rescheduling their routines to adapt to their treatment plans, and even striving not to worry about the uncontrollable outcomes of breast cancer treatment. They also seemed to have exhibited self-reflection and self-reactivity in that they were able to describe this process and reasoning behind the decisions they made. Acting as an agent in relation to breast cancer thus could be one of the key aspects of resilience in this context.

The concept of agency identified in Study III is similar to a few other concepts proposed in literature, which could be useful to discuss. First, perceived behavioral control is a concept described by Ajzen (2006). Ajzen argued that perceived behavioral control can be considered a unitary latent factor consisting of two correlated, albeit distinct factors, namely perceived self-efficacy and perceived controllability. Perceived self-efficacy refers to the ease or difficulty in performing a certain behavior, whereas perceived controllability refers to whether the actor has control over their own behavior (Ajzen, 2006). Defined more broadly, perceived self-efficacy also refers to beliefs about one's capacity to exert control over one's own level of functioning or other events. Important to note is that, according to Ajzen, perceived self-efficacy does not necessarily have basis in internal factors, and perceived controllability in external factors. A person may have high perceived self-efficacy and controllability over both internal and external factors. Another distinction is made between efficacy expectations and outcome expectations. Efficacy expectations reflect one's perceived ability to perform a certain behavior, whereas outcome expectations refer to the perceived likelihood that performing a behavior will result in a certain outcome (Ajzen, 2006).

Whilst reinterpreting the findings of Study III in these terms, more resilient survivors may have high perceived self-efficacy, i.e. they may hold beliefs that they can exert control over their level of health and wellbeing, as well as behaviors aimed at maintaining health and wellbeing. In terms of perceived controllability, they may believe that they themselves have control over such behaviors. They may also have high outcome expectations, i.e. they may hold beliefs that there is a high likelihood that performing certain behaviors will lead to feeling good. They might also have high efficacy expectation, or perceive their ability to perform such health-directed behaviors as high.

Another useful concept related to this notion is the concept of health locus of control (HLoC). HLoC refers to one's beliefs about whether it is external or internal factors that control one's health (Norman & Bennett, 1996). Internal HLoC refers to the belief that the individuals themselves have control over their health, whereas external HLoC reflects the belief that their health is affected by external factors, namely 'powerful others' and 'chance' (Devin, Ghahramanlou, Fooladian, & Zohoorian, 2012). Relying on powerful others, namely medical staff, was notable among low resilient patients. The relationship between internal versus external HLoC and resilience has not yet been studied.

Resilience and recovery from breast caner

Study II adds to the existing literature on resilience in clinical oncology populations. A notable finding of Study II is that breast cancer patients with higher baseline resilience maintained good physical and mental health-related quality of life throughout diagnosis and treatment, their scores on all subscales of SF-36 staying around or above Swedish norm values at both times of measurement. Conversely, low resilient patients were more affected in terms of mental health at diagnosis, but recovered after one year. These trajectories can be reflected upon in relation to Bonanno's view on the resilient versus recovery process. According to Bonanno, the resilient trajectory is characterized by maintaining stable functioning after experiencing a traumatic event, unlike the recovery trajectory, which is characterized by a decline in functioning and followed by a return to normal levels over time. Study II confirmed that resilience might indeed protect an individual against experiencing a decline in at least physical and mental health-related functioning following a highly stressful event. Important to note is that we do not have data on functioning prior to the breast cancer diagnosis, which could have been substantially higher. However, it is notable that it was equivalent to or higher than the Swedish norm values, despite the experienced event being potentially traumatic.

On a conceptual level, the findings of Study II suggest that the question of whether resilience should be measures as a trait, process, or an outcome may thus solely depend on the choice of the authors. In Study II, resilience was measured as a trait, and it was positively associated with a stable trajectory of mental and physical health-related outcomes. It is thus possible to view resilience as a trait that led to the development of such outcomes, but it might have also been possible to identify patients with such stable trajectory of outcomes over time, and label them as resilient. Despite there being great inconsistency in relation to how resilience has been defined over the years, the question of whether authors have been measuring the same phenomena may be unwarranted. This notion is also supported by there being an overall agreement in protective factors identified in resilience research (Luthar, Cicchetti, & Becker, 2000).

Multiple studies have found resilience to be associated with a variety of health-related outcomes, including QoL (e.g., Schumaher et al., 2013; Kenne-Sarenmalm et al., 2013; Gota, Isaacs, & Pagano, 2004). However, most previous studies investigated resilience at one time point only and explored its associations with health-related outcomes measured either at the same measurement occasion (e.g., Harms et al., 2018; Ristevska-Dimitrovska et al., 2015) or after a certain period of time, usually after treatment (e.g., Lam et al., 2013; Kenne Sarenmalm et al., 2013). Overall, research on resilience has mostly been cross-sectional (Downes et al., 2013), longitudinal studies on the topic lacking. Study II therefore adds to the existing body of knowledge by suggesting that resilience may not change substantially between a breast cancer diagnosis and the end of treatment. Exploring resilience in this time frame is uniquely important, as it represents a period when multiple potentially highly stressful events occur, including diagnosis of a potentially life threatening illness, surgery, and a multitude of adjuvant treatment procedures. The results of Study II thus indicate that resilience may be more or less stable over time, even though investigations over longer periods are needed. This does not imply, however, that resilience cannot be enhanced with interventions. Additionally, Molina and colleagues found that most studies in the area focused on treatment and survivorship phases (2016), Study II thus added to the existing body of knowledge by focusing on the diagnosis phase as well as the treatment phase.

The role of resilience in physical health

A compelling finding of Study I and Study II relates to the relationship between resilience as measured by CD-RISC and physical HRQoL as well as a number of health conditions. The relationship between resilience and components of physical health such as physical functioning among clinical oncology populations has been previously reported (Schumaher et al., 2013; Gotay, Isaacs, & Pagano, 2004; Tian & Hong, 2013). This was confirmed in Study II, as resilience was associated with all subscores of SF-36 across time. Resilience thus seems to be associated with not only mental health, but also physical health. Interestingly, one of the strongest associations found in this study was that between resilience and general health, as self-reported by participants. This relationship is perhaps not surprising, as previous studies have suggested that a resilient response may imply an efficient termination of the stress response, mediated by constrained increases in CRH and cortisol (de Kloet et al., 2005). Experiencing chronic stress may in turn lead to a multitude of changes, including an increase in certain inflammatory cells (Cathomas et al., 2019). It is important, however, to mention that the association between resilience and physical HRQoL is much weaker than that between resilience and mental HRQoL. Still, it is interesting to reflect on the potential relevance of resilience for physical health outcomes.

Some of the health conditions were also associated with resilience in Study I, namely hypertension, having high cholesterol, having experienced a stroke, blood clots in the brain or cerebral hemorrhage, and chronic obstructive pulmonary disease (COPD). Most of the effect sizes were small, with the exception of COPD (Cohen's d = .43). COPD is a progressive chronic inflammatory lung disease with symptoms such as shortness of breath, chest tightness, lack of energy, chronic cough, and chest tightness (Barnes, 2000). No studies thus far have explored the role of resilience in COPD. One study found that resilience may be negatively associated with symptom severity in individuals with COPD (Kyoung-Ran & Eun-Nam, 2015). Naturally, it is possible that individuals with COPD perceive themselves as less resilient due to the severity of their symptoms and consequent disruptions to their daily functioning. Interestingly, COPD is an inflammatory disease that involves several types of inflammatory cells, such as T-lymphocytes, B-lymphocites, neutrophils, and macrophages (Barnes, Shapiro, & Pauwels, 2003). Studies on the role of immune cells in resilience are thus far limited, but suggest that psychosocial stress has an effect on the adaptive immune system, which influences the outcomes of exposure to future stress, with T-lymphocytes having an important pro-resilient effect (Cathomas et al., 2019). Anti-inflammatory therapies have previously been found as potentially useful for individuals with MDD (Kohler et al., 2014) and one can only speculate whether they may be useful in enhancing resilience to stress. The role of the immune system in resilience to stress is a fascinating new area of study which requires further exploration.

Aspects of resilience in breast cancer survivorship

By adopting a qualitative approach, Study III adds to the body of knowledge on lived experiences and aspects relevant for resilience among breast cancer survivors. Some of the aspects identified in this study have been previously described. For instance, positivity, optimism, and hope are commonly described in resilience literature, including that in clinical oncology populations (e.g., Pieters et al., Kennedy & Rollins, 2016; Zhang et al., 2018). The subtheme of the Taking charge of one’s health identified in Study III comprised a set of strategies and resources, including exercise, meditation, and hobbies. Exercise and lifestyle factors have previously been included in a model of resilience among lung cancer survivors (Li et al., 2020). Nevertheless, Study III proposes that these aspects are subordinate to a more general sense of agency relating to one’s breast cancer experience. In this way, Study III adds to the body of knowledge by providing a more interpretative rather than descriptive approach. It suggests that having agency in relation to one’s health, wellbeing, treatment procedures, daily functioning, thoughts, and feelings may be closely interrelated with maintaining activities that may enhance one’s health and wellbeing, as well as successfully maintaining normalcy during treatment and survivorship. Agency has not been previously reported in qualitative explorations of resilience among breast cancer survivors. One model of resilience in breast cancer survivors described a similar factor, namely self-efficacy (Ye et al., 2018).

However, breast cancer is also an agent. Study III helped identify time points that are crucial for providing psychosocial support regardless of women’s resilience profiles. Namely, the anticipatory worry while waiting for a diagnosis and results of the yearly check-ups after treatment are uniquely stressful for both high and low resilient women. This finding is not surprising as it corroborates previous investigations which found that approximately 51% of women experience anxiety during the prediagnostic phase (Pineault, 2007). Short waiting times should thus be prioritized in health care, and support should be provided at these stages of the breast cancer continuum. It is encouraging that the protocol for rehabilitation for cancer survivors does recognize the need to conduct psychological assessment continuously, and especially when changes in the process occur (Regional Cancer Centers, 2021). Study III proposes that waiting for the diagnosis and yearly check-ups after formal treatment are some of the periods which may be especially challenging.

Social support is another commonly described external resource of resilience (Tan, Beatty, & Koczwara, 2018). Study III further informs that close others play a more complex role than previously thought. It confirms the notion of sharing one's experiences and having close others to rely on as highly beneficial, and an important aspect of resilience. In this manner, it suggests the notion of resilience being a set of not only psychological, but also social elements. Nevertheless, Study III suggests that other people play another, more indirect role in breast cancer. Breast cancer being very common in the population seemed to be a double-edged sword for survivors. On one hand, it aided connectedness to others and thus contributed to women's wellbeing. On the other hand, when breast cancer was a part of women's family history, women felt the burden of not only their breast cancer, but also that of their female relatives.

Practical implications

The goal behind the studies included in this thesis was to ultimately help breast cancer survivors obtain better physical and mental health, starting from screening and into survivorship. Most of the practical implications emerging from this thesis are based on Study III. Nevertheless, Study I and Study II laid the groundwork for these implications. Study I suggested that CD-RISC may be used in the clinical context to identify patients in need of more support. Study II implied that low resilient patients are in special need of mental health-related support immediately at diagnosis. After treatment, special attention should be paid to physical functioning and problems in maintaining everyday activities. Study II further identified clinical and sociodemographic factors that may indicate the need for more support, including ER negative and HER2 positive status, higher TNM stage of cancer, adjuvant chemotherapy, bisphosphonate therapy, antibody therapy, as well as lower SES. HER2 positive status and accompanied antibody therapy especially seem to be relevant for mental health-related functioning.

Practical implications arising from Study III relate to specific areas to target when providing support to breast cancer survivors. Importantly, beliefs about health and wellbeing being within one's control need to be challenged. Survivors can be encouraged to identify ways in which they can have a sense of agency in relation to their health and wellbeing, as well as activities which make them feel better, especially during treatment. Cognitive behavioral therapy (CBT) might be useful to challenge such beliefs. Support providers can help patients learn how to manage the treatment side-effects, thus developing a sense of agency relating to their treatment and wellbeing. This may facilitate the intention to perform positive health-related behaviors. Learning how to identify and manage negative emotions and thoughts that arise is another important area to target. Acceptance and commitment therapy (ACT) might be a useful tool to achieve this. Further, the need for normalcy was identified among both women with high and low resilience scores, but women with lower resilience profiles seemed to struggle to maintain normal activities during treatment. Contact nurses can help them do so by helping them adapt treatment schedules into their existing routines. Feeling of looking normal should also be addressed, self-compassion being potentially useful to accept changes that come with treatment for breast cancer (Przezdziecki et al., 2012). Social support was identified as an important external resource of resilience. Study III implied that social support can be found in other breast cancer survivors. It is therefore necessary for systems in place to encourage contact between breast cancer patients and survivors. One good example of such contact was mentioned in the study by several interviewees and relates to meeting other patients in buses that drive from smaller towns to hospitals in neighboring towns:

"... but then one could take that bus and we were four-five people in the same situation that we spoke to each other and some days we slept there in the patient hotel and met up when we ate there and talked in the evenings." (MB, breast cancer survivor)

Lastly, like in all types of cancer, breast cancer survivorship is a process that involves creating a new identity, it entails living during, after, and beyond breast cancer (Zebrack, 2020). When can one safely say one is cured from cancer? Because of this unique nature of cancer survivorship and possibility of relapse, it is important to help survivors cope with such uncertainty, especially during extended survivorship, when the risk of relapse is the highest (Mullan, 1985). Study III corroborated that anticipatory anxiety and fear of relapse are common in breast cancer survivors, implying that psychosocial support should be available well into survivorship. Study III also implied that highly resilient women might have a unique outlook on their breast cancer, perceiving it as "removed after surgery, everything after surgery being merely preventative". Oncologists can help patients incorporate such outlook by describing the treatment process in those terms, thereby facilitating the perception of finality of breast cancer.

Directions for future research

Taken together, studies included in this thesis add to the knowledge on the role of resilience in breast cancer survivorship. While it is possible that some of the results may apply to other cancer types, this requires further investigation. Namely, other types of cancer entail different types of treatment with different side effect profiles, which impacts the nature and speed of recovery. The recovery trajectory identified in Study II thus needs to be investigated in other cancer types. Moreover, some of the aspects of resilience identified in Study III may apply to all cancer survivors, particularly when taking previous studies into consideration. However, breast cancer is a uniquely female illness with a high prevalence rate, which likely gives way to unique lived experiences. Breast cancer surgery in particular has unique effects on one's quality of life and encompasses a specific set of needs and fears in breast cancer survivors. Importantly, Study III should be replicated in male breast cancer survivors.

In Study II, biopsychosocial factors were investigated in separate models in order to explore their differential associations with the mental and physical health-related recovery. Future studies should include the factors identified as potentially relevant into the model together and investigate to which extent they explain recovery in this population. This would give way to a more comprehensive biopsychosocial understanding of the recovery process from diagnosis to after treatment. Whether resilience, as measured by CD-RISC, interacts with clinical and sociodemographic factors is another interesting area of study which should be explored in future investigations. Additionally, as noted before, breast cancer recovery does not end after treatment. More longitudinal investigations on resilience as well as HRQoL are thus needed. Doing so would help further outline the trajectories of resilience and HRQoL well into extended and permanent survivorship. Moreover, Study II did not look into the impact of lymphedema, a common treatment side effect in breast cancer survivorship (Brar, Jain, & Singh, 2011). The influence of developing lymphedema on recovery should be further explored. Finally, future studies could explore whether some of the specific aspects of resilience identified in Study III, namely emotion regulation, exercise, social support, and maintaining normal activities predict resilience as measured by CD-RISC. Moreover, it would be interesting to investigate whether internal versus external HLoC mediates these relationships. This would help create a conceptual model of resilience in breast cancer survivors.

Ethical considerations

Two of the studies included in this thesis relate to breast cancer, which entails a series of highly stressful and potentially sensitive events for participants. Data collection for Study II in particular was conducted during a highly disruptive period, namely on the day of receiving the breast cancer diagnosis. Although this enables us to add to the breadth of knowledge in the field, doing so carries the risk of placing additional burden on the patient. At this time point, data collection for Study II was conducted as part of the SCAN-B project. Consent to participate in SCAN-B was needed in order to participate in SCAN-B Resilience. These patients were informed about the study and gave oral and written consent to participate in SCAN-B Resilience. They were informed that their participation was voluntary and that they could withdraw their consent at any point, including after filling out the questionnaires. Data from patients who withdrew their consent were removed from the database (n = 3). Participants could take part either on paper or electronically, and received help from nurses. Each patient received a unique ID-code, which the persons involved in data handling could not track to their personal information.

Study III entailed interviews with breast cancer survivors who were asked to participate as they previously gave consent for SCAN-B Resilience. They received invitations via post. It was of great importance to check whether the person was still alive at this time, which was manually checked for each invited individual. This study also comprised sensitive topics related to the breast cancer experience, which could cause strong negative emotions. Thus, the consent form the participants received contained a brief but comprehensive description of the interview guide. Participants gave their written consent to take part in this study and were informed they could cancel the interview at any point, as well as that the interviews themselves would be recorded. The interviews themselves were conducted by two licensed clinical psychologists, who gave space to the participants to ask any questions they may have at the end of the interviews. Interviewers did not note any strong negative reactions during the interviews. All interview transcripts received a unique ID-code which could not be tracked to any identifiable personal information.

An important ethical consideration related to Study III which should be discussed in more detail is that the participants were not informed they were asked to take part in the study due to their high versus low resilience score. The goal of the paper was to add to resilience literature by obtaining maximum variation in resilience scores in the sample. It was considered that this information might cause harm to the participants and would bias the results of the study. It was therefore considered that the benefits of not disclosing this information outweighed the potential risk. However, we recognize the drawback of not asking the women themselves to define what resilience means to them. Moreover, we were careful not to label participants as “resilient” or “not resilient” in the manuscript, but to use the terms of having “high versus low resilience scores”, as we deemed it more appropriate and correct.

Ethics approval was obtained from the Regional Ethical Review Board in Lund/ Swedish Ethical Review Authority for all three studies included in the thesis. Original ethics approval numbers as well as subsequent amendments for BIG3, SCAN-B, and SCAN-B Resilience are provided in respective manuscripts.

Strengths and limitations

The present thesis approached the topic of resilience in breast cancer survivorship using both quantitative and qualitative methods. The three studies taken together may thus help inform the needs in this population, as well as the critical periods when support may be needed. A common critique in both quantitative and qualitative research on resilience is vagueness of definitions and poor operationalization of resilience. In this thesis, resilience was operationalized using the framework of CD-RISC. Resilience was thus operationalized as a set of characteristics and resources which may lead to a positive outcome, and not as a positive outcome itself. Additionally, this thesis focused on breast cancer, unlike a plethora of previous studies which included samples consisting of a broad range of types of cancer. Different types of cancer entail widely different prognoses, treatment modalities and schedules. By focusing on breast cancer, this thesis aims to inform support for an illness that will affect one in ten women in Sweden.

Study I was conducted on a substantially large sample, which allowed for splitting it into three subsamples. Conducting EFAs on two subsamples and a CFA on the third subsample facilitated the stability of the extracted factor. Furthermore, as the study was conducted within a larger project, it allowed for identifying populations for which the scale might be most useful. Study II was also conducted on a relatively large population-based sample. Namely, the majority of newly diagnosed breast cancer patients in Skåne were included in the study. Having access to a variety of clinical data allowed for a comprehensive investigation of the risk factors for poor recovery from breast cancer. Adopting a biopsychosocial perspective further allowed for a broad overview of potential risk factors for poor recovery. Additionally, the first time measurement for Study II was conducted at the time of receiving the diagnosis. Despite this being a highly stressful event, it allowed for investigating resilience at a uniquely critical time. Investigating resilience longitudinally allowed for exploring the changes of resilience over time. Lastly, Study III investigated the lived experiences and aspects relevant for resilience using purposive sampling, which allowed for a deeper understanding of resilience. It covered all phases of the breast cancer continuum, allowing for identifying aspects and experiences relevant for each phase of the continuum. Nevertheless, the studies included in this thesis have several limitations, which will be discussed below.

Generalizability

The question of generalizability of findings on the three studies to the breast cancer population in and outside of Sweden, as well as other clinical oncology populations is an important one. In relation to the population of breast cancer patients and survivors in Sweden, it is important to note that the study sample for all studies came from a region in southern Sweden. It is unlikely that the sociodemographic characteristics of the samples (Studies I and II) differed significantly from that of other regions. Moreover, the protocol for breast cancer treatment is standardized across the country (Regional Cancer Centers, 2019). Therefore, the treatment schedules should not vary significantly across the country. It is thus possible that the findings of studies I and II may be generalizable within Sweden.

The question of the generalizability of study findings to breast cancer survivors outside of Sweden is a more difficult one. There are no significant differences in mortality rates between regions in Sweden, but there are differences internationally. Sweden has one of the lowest mortality rate from breast cancer as compared to other European countries as well as the United States (Engholm et al., 2014). Moreover, the treatment and screening protocols vary country to country, thereby probably resulting in differences in the speed of the recovery process, as well as psychosocial outcomes. The rehabilitation program and interventions offered within Sweden are also likely to differ from that in other countries. The relationship between resilience and physical and mental health-related recovery might depend on such treatment factors, although no such relationships have been previously found. There was also significant attrition from baseline to follow-up in Study II. Non-respondents had lower SES and physical functioning at baseline, which might have introduced some bias to the sample.

Importantly, the sample in Study I consisted of participants aged between 45 and 75. Mean age in the sample was 65.6, significantly higher than the mean age on the national level. Resilience was not associated with age. The study sample was also biased to include a higher proportion of smokers and former smokers (50%). As the project is aimed at investigating health conditions, it is likely that participants with poorer health were more interested to take part in the study. However, there is little reason to assume these variables would moderate the relationship between resilience and health-related outcomes included in the study. Further, the aim of Study III was not to generalize its findings to the population of breast cancer survivors, but to propose a series of experiences and aspects which might play a role in resilience in this population.

The question of generalizability of the study findings to other types of cancer is less obvious. Different types of cancer imply different treatment protocols, prognoses, and symptomatology. Moreover, breast cancer is a uniquely female disease, although men get breast cancer as well. It is important to note that male participants were not excluded from the sample in Study II but comprised less than 1% of the sample (n = 8). Still, there is no reason to assume that gender would moderate the relationship between resilience and health-related outcomes. Study III was conducted on only female participants and it would be interesting to explore the lived experiences and aspects of resilience in male breast cancer survivors, although gathering a big enough sample to do so would prove challenging.

Rigor in qualitative research

In Study III, we aimed to satisfy the recommended standards of trustworthiness, such as the "parallel criteria", which are comparable to internal and external validity, reliability, and objectivity found in quantitative research (Morrow, 2005). We also aimed to utilize verification strategies proposed by Morse and colleagues (2002) to ensure such criteria. For instance, to achieve credibility in our research, we utilized a prolonged engagement with study participants, negative case analysis, aimed to explain how the data was assessed, as well as provide a detailed and rich description of participants' experiences. Further, we aimed to provide sufficient information about the interviewers, characteristics of the study participants, their relationship, as well as the research context and processes to facilitate transferability. Methodological coherence between the research question and the chosen method was thought to be adequate, especially considering the purposive sampling we used to obtain the highest possible variation in resilience scores. Further, the data was collected and analyzed concurrently, enabling an interactive process between data collection and analysis.

Nevertheless, the question of the appropriateness of the sample in Study III needs to be discussed in greater detail. On one hand, all participants had either very high or very scores on CD-RISC at diagnosis, which was one of the most important criteria for the study. They were all breast cancer survivors with no secondary cancer diagnosis or relapse, which contributed to ensuring the invited participants best represented the research topic. However, participants did not fill in CD-RISC again at the time of the interviews. This was done due to the logistical difficulties at the time the interviews were collected, as well as not to place additional burden on the participants. As Study II indicated, however, resilience does not seem to change substantially over time, but this might have been the case for some of the participants. Further, participants with lower and higher resilience scores seemed to be similar in terms of sociodemographic and clinical characteristics. Still, severity of the diagnoses and treatment received might have varied between the interviewees, which could have introduced some bias.

Important to note is that the interviews were conducted through telephone, due to the data being collected during the COVID-19 pandemic. Invited participants were considered a particularly vulnerable group given their age and health status. The potential harm of conducting the interviews in person was thus considered to outweigh the benefits. Although there is evidence that telephone interviews are a viable method for collecting rich narrative data (Drabble, Trocki, Salcedo, Walker, & Korcha, 2016), it is possible that the interviewees were less comfortable sharing personal stories over the telephone, which might have influenced the study results. Finally, the subgroup of survivors with low resilience scores (n = 11) was smaller than that of survivors with high resilience scores (n = 14). This was due to low resilient survivors having a lower response rate. In fact, more survivors with low resilience scores were invited to participate than the ones with high resilience scores. The discrepancy in subgroup sizes is small, but it might have harmed the richness of information found in the low resilience score group.

Recall bias, effect sizes, and CD-RISC

A potentially confusing choice made in Study II was to utilize a 25-item CD-RISC, despite Study I suggesting a 22-item model of the scale. Although this seems to contradict the methodological thread proposed in this thesis, it was done to facilitate comparing the study results with investigations performed in other contexts. It is, however, an important limitation which needs to be recognized. Furthermore, the effect sizes found in Study II for the majority of clinical factors were small. Given the large size of the sample, it is reasonable to assume that some of the effects found were due to the sample size, increasing the likelihood of Type 1 error. This is recognized in the study, however, due to the potentially great clinical significance, it was considered appropriate to report all potential risk factors identified in the study. However, the results of the study should be taken with caution and replicated. Finally, Study III involved the participants recalling the events from a few years ago, which might have introduced recall bias. Some inconsistencies were noted between the treatment procedures reported by the participants and those registered in the Swedish national breast cancer quality registry. However, this may be due to participants not being aware of the correct terminology related to different treatment procedures, or them not deeming it important to mention all procedures they endured. Moreover, this was not the main focus of the study. Nevertheless, it would be useful to use diary studies in future investigations.

Conclusions

Resilience has been a construct of interest for several decades, research in the area moving from developmental psychology into a variety of arenas, including clinical oncology settings, and more specifically breast cancer. It seems evident that resilience with its factors is associated with a variety of health-related outcomes in this population. Despite there being numerous advances in understanding the role of resilience in breast cancer survivorship, existing research has been a target of critiques relating to how resilience has been operationalized and assessed. Existing scales were shown to have moderate psychometric properties at best, indicating a need for a closer investigation. Moreover, little is known about how resilience changes over time and interacts with the recovery process, and what experiences in particular play a role in the resilient trajectory of breast cancer survivorship.

The present thesis aimed to address such critiques and methodological flaws by applying a combination of quantitative and qualitative methodology to resilience research and focusing on CD-RISC, perhaps the most widely used scale to measure resilience. Resilience is sometimes criticized for its conceptual circularity, as it has been defined as both a trait that results in a certain positive outcome, and as the positive outcome itself. This thesis helped clarify that resilience may be conceptualized as a set of characteristics and resources that enable an individual to achieve positive outcomes in face of adversity. The findings of the studies presented in this thesis indicated that CD-RISC seems to measure a unidimensional construct consisting of a multitude of characteristics, corroborating the notion of resilience entailing different albeit related factors which together aid handling potentially stressful events. CD-RISC also seems to have good psychometric properties and can be used in research and clinical settings in Sweden. Items related to spirituality and religion, however, do not seem to be important for resilience in this cultural context, as suggested by Studies I and III. Further, resilience seems to be associated with mental and physical HRQoL in breast cancer patients, being especially important for mental HRQoL, at both diagnosis and after treatment. Resilience seems to be protective for mental HRQoL immediately after receiving a breast cancer diagnosis, and a resilient trajectory may be distinguished from a recovery trajectory. This thesis also indicated that resilience may be a stable construct which does not change substantially over time, at least short-term. The process of recovery from breast cancer cannot be explained by changes in resilience. Low resilient breast cancer patients and survivors are in need of additional psychosocial support, especially at diagnosis, but also throughout survivorship. Agency relating to various facets of breast cancer seems to be a defining aspect of resilience in handling breast cancer. Conceptualizing breast cancer as a closed chapter rather than a constant was another important aspect of resilience in this context. Having social support in form of close others and other breast cancer survivors was identified as another potential external resource of resilience.

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If this is the first section you are reading, welcome to my thesis. Getting a PhD takes a while. According to my rough calculations, I have spent approximately one seventh of my life thus far working towards it, and I have not spent that time isolated (if we discount for the few days leading up to the submission deadline, of course). The last four years have been filled with experiences and interactions with so many people who have helped me write this thesis - some more directly, others indirectly, by helping me stay sane throughout the process. I would like to dedicate the next few pages expressing my gratitude to these important people[2].

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*

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