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**Predicting Effective Adaptation to Breast Cancer to Help Women
to BOUNCE Back**

Research and Innovation Action

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Personalised computer models and in-silico systems for well-being

Deliverable 2.1 and 2.2

WP2: Resilience Definition and operationalization

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0. Document Info

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¹ **R** = Document, report (excluding the periodic and final reports), **DEM** = Demonstrator, pilot, prototype, plan designs

² **PU** = Public, fully open, e.g. web, **CO** = Confidential, restricted under conditions set out in Model Grant Agreement

2. Executive Summary

This deliverable task (D2.1 and D2.2.) describes the definition of resilience, of related factors, and of aspired impact of the BOUNCE model. The aim of the BOUNCE project is to construct a measurement model of patient resilience to the physical and emotional challenges associated with breast cancer and with the burden incurred by associated treatments using data from the multicenter clinical pilot. The objectives of the project are: (1) to construct a conceptual model of multi-scale factors affecting individual resilience trajectories through diagnosis and treatments for breast cancer; (2) to identify expected personal, social and financial benefits of increased resilience in women recovering from breast cancer; (3) to address long-standing issues in the field of psycho-oncology regarding the dynamics of time-varying relationships between determinants of resilience and disease outcomes; and (4) to build a decision-support system that will be used in routine clinical practice in order to provide physicians and other health professionals with concrete, personalized recommendations regarding optimal psychosocial support strategies.

The purpose of WP2 is to (a) to delineate the evolution of resilience definition and to clarify the various ways this definition is conceptualized; (b) to suggest a working definition of resilience for BOUNCE project; (c) to provide literature review on resilience factors that were examined in the context of cancer or breast cancer research; (d) to suggest batteries of questionnaires for the repeated assessment of resilience construct. This document describes the suggested psycho-social instruments for the repeated assessment of resilience in breast cancer patients at baseline and after 3, 6, 12, 15 and 18 months from baseline assessment. Additionally, we will describe the process of decision making regarding the measurement of resilience and suggest several biomarkers of stress and resilience to be combined with the psychosocial factors.

Taken together and based on the literature review, our suggestion for working definition of resilience for Bounce - in the context of coping with breast cancer - is the following: *Resilience is a conglomerate of dynamic self-regulatory capacities that allow to mobilize and use internal and external resources over time in the face of adversity in order to maintain or promote wellbeing. The construct of resilience is used in three ways:* (a) *Resilience as a personal capacity or potential;* (b) *Resilience as an adaptive coping process or change trajectory;* (c) *Resilience as an outcome of maintaining healthy functioning and subjective well-being despite exposure to adversity. All these three aspects need to be measured.*

WP2: Resilience Definition and operationalization

3. Introduction

3.1. The BOUNCE project

Coping with breast cancer more and more becomes a major socio-economic challenge not least due to its constantly increasing incidence in the developing world. BOUNCE will bring together modelling, medical, and social sciences experts to advance current knowledge on the dynamic nature of resilience as it relates to efficient recovery from breast cancer. BOUNCE will take into consideration clinical, cancer-related biological, lifestyle, and psychosocial parameters in order to predict individual resilience trajectories throughout the cancer continuum and eventually increase resilience in breast cancer survivors and help them remain in the workforce and enjoy a better quality of life.

BOUNCE will deliver a unified clinical model of modifiable factors associated with optimal disease outcomes and will deploy a prospective multi-centre clinical pilot at four major oncology centres (in Italy, Finland, Israel and Portugal), where a total of 660 women will be recruited in order to assess its clinical validity against crucial patient outcomes (illness progression, wellbeing, and functionality). The advanced computational tools to be employed will validate indices of patients' capacity to bounce back during the highly stressful treatment and recovery period following diagnosis of breast cancer.

3.2. Literature review on the definition of Resilience

The term *Resilience*, used in psychological context, has been adopted from other disciplines. In Physics and Engineering resilience pertains to the capacity of material to absorb energy when deformed and to the rate at which it returns to its original condition. In Botany a resilient plant is one that bends but does not break or become uprooted. In the field of Math resilience is measured by the speed with which a material or system returns to equilibrium after displacement. These all relate to question of durability. In Ecology resilience relates to the persistence of relationships within a system; ability to absorb change and persist. Similarly, in Sociology, resilience is the ability of social units (communities, cities) to withstand external shocks to their infrastructure. These relate to the question of continued functioning (Windle, 2011).

Psychosocial resilience, inspired by these various definitions, is a complex construct that tends to be conceptually defined in multiple ways. Masten (2001) wrote that “Resilience does not come from rare and special qualities, but from the *everyday magic of ordinary*, normative human resources in the minds, brains, and bodies of children, in their families and relationships, and in their communities”. In this sense, being resilient does not necessitate a unique quality, rather a tapping in to resources which can produce resilience when facing adversity.

To date there is still a lack of clarity as to what resilience is. Does being resilient relate to an individual's *personal capacity or potential* (capacity to engage in adaptive coping processes), or to *an adaptive coping process or trajectory* (adaptive reactions to adversity), or to *an outcome of maintaining healthy functioning and subjective well-being despite exposure to adversity* (the final state achieved as the result of coping)?

Resilience as personal capacity or potential

Some understand resilience to be a pre-disposition, or potential, existing before facing an adverse situation. In this sense, *Resilience as Capacity* is the integration of internal and external resources available to the individual upon facing adversity that may influence the effectiveness of the coping process, e.g., optimism, humor, cognitive flexibility, cognitive explanatory style and reappraisal, acceptance, religion/spirituality, altruism, social support, role models, coping style, exercise, capacity to recover from negative events, and stress inoculation (Southwick, Vythilingam & Charney, 2005). Resilience as a potential is not a trait available solely to the individual, it can exist in groups as well. In a family, resilient

characteristics may take the form of a sense of solidarity, involvement or warmth towards other family members and cohesion among them (Mackay, 2003). A resilient community would be one to offer support of resources, and these may be based on a cultural context of resiliency reflected in the narratives, traditions or rituals of the individual or the community.

In our view, resilience capacity or potential can be perceived as a *formative construct*, namely, it is a total sum of all protective factors (vs. risk factors). A protective factor refers to anything that prevents or reduces vulnerability for the development of a disorder. Common protective factors for posttraumatic stress include the availability of social support and the use of healthy coping strategies in response to stress. In our view, resilience is as a multi-faceted concept that can include a wide scope of indicators: Medical/physiological (such as disease severity and additional medical conditions); socio-demographic (age, education, wealth); personal (intelligence and other cognitive skills, generalized affectivity, hardiness, optimism, self-control, self-efficacy, self-esteem); social/interpersonal (family and social support, emotional expressiveness). All these indicators are not a reflection of an underlying single construct (like syndromes reflect an illness or performance on intelligence tests reflects intelligence), but rather they define the resilience construct (like sum total of a person's assets, income, future inheritance, etc. define her wealth). In measurement theory terms, resilience capacity is a *formative, rather than a reflective*, construct. One of the consequences of this view is that we do not expect different indicators of resilience to be inter-correlated.

Resilience as an adaptive coping process or trajectory

Resilience was defined by APA (2018) as “the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress — such as family and relationship problems, serious health problems or workplace and financial stressors.” They further emphasize that being resilient does not mean that a person doesn't experience difficulty or distress and the road to resilience is likely to involve considerable emotional distress.

In 2002, resulting the terrorist attacks of September 11, 2001, the American Psychological Association launched a public education campaign “*The Road to Resilience*”. The campaign was designed to help the public learn ways to build resilience in the face of trauma and hardship and throughout daily life (Newman, 2005). Resilience is not a trait that people either have or do not have and can be seen as an adaptation processor as a post trauma

trajectory. It involves behaviors, thoughts and actions that *can be learned and developed* in anyone.

Resilience as an outcome of maintaining healthy functioning and subjective well-being despite exposure to adversity

Resilience represents the ability to maintain a stable equilibrium, healthy functioning and subjective wellbeing, and satisfactory quality of life despite exposure to trauma (Bonanno, 2004). Resilience is not merely the opposite of distress or the absence of psychopathology. Resilient individuals may experience transient perturbations in normal functioning (e.g., several weeks of sporadic preoccupation or restless sleep) but generally exhibit a stable trajectory of healthy functioning across time, as well as the capacity for generative experiences and positive emotions (Bonanno, Papa, & O'Neill, 2001). In this sense resilience is more prevalent than generally accepted, and there may be multiple ways of achieving resilience, e.g., hardiness, self enhancement, repressive coping, positive emotion and laughter (Bonanno, 2004). More recently, Bonanno (2012) defines resilience as *a stable trajectory of healthy functioning*, including “the following criteria: (1) The temporal bounds of the aversive event are clearly operationally defined, and (2) Resilience is explicitly categorized as a stable pattern of healthy adjustment following that event that is (a) more than the absence of diagnosable pathology, (b) based on measurements obtained at multiple points in time, and (c) with the initial measurement of outcome obtained relatively near to the occurrence of the aversive event (e.g., within several months or sooner).”

Resilience capacity as a formative construct

In our view, resilience capacity or potential is a total sum of all protective factors (vs risk factors), i.e., her personal and social capital. It is a multi-faceted concept that can include a wide scope of indicators: Medical/physiological (such as disease severity and additional medical conditions); socio-demographic (age, education, wealth); personal (intelligence and other cognitive skills, generalized affectivity, hardiness, optimism, self-control, self-efficacy, self-esteem); social/interpersonal (family and social support, emotional expressiveness). All these indicators are not a reflection of an underlying single construct (like syndromes reflect an illness or performance on intelligence tests reflects intelligence), but rather they define the resilience construct (like sum total of a person's assets, income, future inheritance, etc. define her wealth). In measurement theory terms, resilience capacity is a formative, rather than a

reflective, construct. One of the consequences of this view is that we do not expect different indicators of resilience to be inter-correlated.

Consensus Definition of Resilience

An effort to reach a consensus definition was made by Southwick and colleagues (2014), where a panel of prominent resilience experts agreed on the consensus definition. The concept of resilience includes *healthy, adaptive, or integrated positive functioning over the passage of time in the aftermath of adversity*. They further agreed that resilience is a complex construct and it may be defined differently in the context of individuals, families, organizations, societies, and cultures. With regard to the determinants of resilience, there was a consensus that the empirical study of this construct needs to be approached from a multiple level of analysis perspective that includes genetic, epigenetic, developmental, demographic, cultural, economic, and social variables. The empirical study of determinants of resilience will inform efforts made at fostering resilience, with the recognition that resilience may be enhanced on numerous levels (e.g., individual, family, community, culture).

Additionally, Kay (2016) argues that the ability or outcome of “bouncing back” from a stressful or chronic event is closely linked to the ability of the individual to cope with their emotions. In other words, there is a clear connection between resilience and emotion regulation, and this interrelation deserves more research.

Taken together and based on the literature review, our suggestion for working definition of resilience for Bounce - in the context of coping with breast cancer -is the following:

Resilience is a conglomerate of dynamic self-regulatory capacities that allow to mobilize and use internal and external resources over time in the face of adversity in order to maintain or promote wellbeing. The construct of resilience is used in three ways:

(a) Resilience as a personal capacity or potential; (b) Resilience as a post trauma adaptive process or trajectory; (c) Resilience as an outcome of maintaining healthy functioning and subjective well-being despite exposure to adversity. All these three aspects need to be measured.

References:

American Psychological Association (2018, February 5). “The Road to Resilience”.

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- Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, 21(2), 152-169. doi:10.1017/S0959259810000420

In Table 1 we summarize the literature on resilience organized by the definitions of the concept as potential, process or outcome (see pages 12-21).

In table 2 we summarize the protective factors for posttraumatic distress that appear in the literature as related to the concept of resilience, the suggested measures for these factors and the reference to recent studies which tested these factors in the context of breast cancer research (see pages 22-26).

In table 3 we summarize the potential outcome measures for the assessment of quality of life (see pages 26-27).

Table 1: Summary of the definitions of Resilience conceptualized as potential, process or outcome			
Source		Conceptualization of Resilience	Measures
(1) Campo, R. A., Wu, L. M., Austin, J., Valdimarsdottir, H., & Rini, C. (2017). Personal Resilience Resources Predict Post-Stem Cell Transplant Cancer Survivors' Psychological Outcomes through Reductions in Depressive Symptoms and Meaning Making. <i>Journal of Psychosocial Oncology</i> , (just-accepted), 00-00.	Potential	Personal resilience resources (Optimism, Self-esteem & Mastery) as predictors of adverse Cancer effects (PTSD symptoms, depressive symptoms, reason for illness) and purpose in life. Greater personal resilience resources may promote better psychological adjustment after a difficult cancer treatment.	Personal resilience resources: Optimism (10-item Life Orientation Test-Revised); Self-esteem (10-item Rosenberg Self-Esteem Scale); Mastery (7-item Mastery Scale).n=254
(2) Diehl, M., & Hay, E. L. (2013). Personality-related risk and resilience factors in coping with daily stress among adult cancer patients. <i>Research in human development</i> , 10(1), 47-69.	Potential	Psychological Well-Being as a Resilience factor to help battle the daily stressors of cancer.	2-3 hours individual baseline session, followed by 30 consecutive daily assessments, consisting of an evening phone interview (5-30+ minutes) and a diary (15-20 minutes to complete). Psychological Well-Being assessed with Ryff's Short Psychological Well-Being Scales (note: there are other variables assessed in study, such as self-esteem, stress and others) n=55
(3) Hou, W. K., Law, C. C., Yin, J., & Fu, Y. T. (2010). Resource loss, resource gain, and	Potential?	Describes 4 trajectories of coping with cancer, the forth bring the 'resilient trajectory'.	Psycho-social resources assessed:

psychological resilience and dysfunction following cancer diagnosis: a growth mixture modeling approach. <i>Health Psychology</i> , 29(5), 484.		Resilience denotes maintenance of healthy levels of psychological functioning in the face of highly disruptive or life-threatening events, not only at a single point in time but also as a stable trajectory across time.	The 14-item Chinese Hospital Anxiety and Depression Scale (HADS); Physical functioning, a 9-item checklist; The 6-item Chinese Revised Social support assessed by 3 items; Life Orientation Test (C-LOT-R); The Social Relational Quality Scale (SRQS) n=234
(4) Markovitz, S. E., Schrooten, W., Arntz, A., & Peters, M. L. (2015). Resilience as a predictor for emotional response to the diagnosis and surgery in breast cancer patients. <i>Psycho-Oncology</i> , 24(12), 1639-1645.	Potential	Resilience as proposed by Rutter: people with high resilience are not immune to emotional distress, but they manage to maintain emotional stability despite this intrinsically negative experience. Results favor a protective model of resilience on pathological effects of emotional distress. Finding suggests that resilience may be a relatively stable trait rather than a state triggered by a stressful event. Adversity did not seem to have an impact on the level of resilience, but we found resilience to be a crucial contributor to the emotional response after adversity.	25-item Connor–Davidson Resilience Scale; Hospital Anxiety and Depression Scale; Positive and Negative Affect Schedule (shortened version) n=464 (253 breast cancer patients and 211 control subjects)
(5) Ong, A. D., Zautra, A. J., & Reid, M. C. (2010). Psychological resilience predicts decreases in pain catastrophizing through positive motions. <i>Psychology and aging</i> , 25(3), 516.	Potential	psychological resilience as an important trait that may account for the adaptive ways in which life stressors are encountered, managed, and transformed	The Ego-Resiliency Scale (Block & Kremen, 1996); And open questions rating daily pain intensity and positive and negative emotions.

			And items about pain catastrophizing based on previous study. n=95
(6) Pan, C. J., Liu, H. C., Liang, S. Y., Liu, C. Y., Wu, W. W., & Cheng, S. F. (2017). Resilience and Coping Strategies Influencing the Quality of Life in Patients with Brain Tumor. <i>Clinical Nursing Research</i> , 1054773817714562	Potential	Resilience is defined as the resistance, recovery, or rebounding of psychological and physical health after a challenging life event. It is considered an important trait or ability of individuals that sustains well-being in the face of the many stresses that individuals encounter in their lives.	European Organization for Research and Treatment of Cancer QOL Questionnaire–Brain Cancer Module (EORTC QLQ-BN20); Resilience Scale (RS); Coping scale (Ways of Coping Checklist–Revised [WCC-R]); n=95
(7) Popa-Velea, O., Diaconescu, L., JidveianPopescu, M., & Trușescu, C. (2017). Resilience and active coping style: Effects on the self-reported quality of life in cancer patients. <i>The International Journal of Psychiatry in Medicine</i> , 52(2), 124-136.	Potential	The aim of the study was to evaluate the distinct contribution of active coping strategies and resilience to the self-reported QOL at cancer patients.	Brief COPE Questionnaire RS-14 Resilience Scale; Rotterdam symptom checklist n=178
(8) Shilling, V., Starkings, R., Jenkins, V., & Fallowfield, L. (2017). The pervasive nature of uncertainty—a qualitative study of patients with advanced cancer and their informal caregivers. <i>Journal of Cancer Survivorship</i>	Potential	Resilience is not the focus of the study. Rather it is mentioned as a personal factor resilience together with higher sense of coherence as factors that may be associated with coping with and/ or accepting feelings of uncertainty associated with extended survival and may potentially be amenable to intervention.	Qualitative interviews n=24 (patient-caregiver dyads)
(9) Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back.	Potential?	Scale Presentation	Brief Resilience Scale (BRS)

International journal of behavioral medicine, 15(3), 194-200			
(10)Wu, W. W., Tsai, S. Y., Liang, S. Y., Liu, C. Y., Jou, S. T., & Berry, D. L. (2015). The mediating role of resilience on quality of life and cancer symptom distress in adolescent patients with cancer. <i>Journal of Pediatric Oncology Nursing</i> , 32(5), 304-313.	Potential	The study looks at cancer symptom distress, QoL, and resilience in adolescents with cancer and to determine whether resilience is a mediating variable	Cancer Symptom Distress Scale; The Resilience Scale; Minneapolis-Manchester Quality of Life Scale n=40
(11)Aydin, E. (2008). Trauma and Resilience in Women Diagnosed with Breast Cancer: A Transactional Analysis Perspective. <i>Transactional Analysis Journal</i> , 38(4), 323-334.	Process	A process which can be developed, based on psychological defenses, that can help woman cope and perhaps grow from their traumatic event (having Cancer).	Biographic Narrative Interpretative Method (interviews) n=6
(12)Bonanno, G.A. (2004). Loss, Trauma, and Human Resilience Have We Underestimated the Human Capacity to Thrive After Extremely Aversive Events? <i>American Psychologist</i> 59(1), 20–28.	Process	Resilience represents a distinct trajectory from the process of recovery, that resilience in the face of loss or potential trauma is more common than is often believed, and that there are multiple and sometimes unexpected pathways to resilience.	N/A Theoretical Paper
(13)Chmitorz A., Kunzler A., Helmreich I., Tüscher O., Kalisch, R., Kubiak T., Wessa, M. & Lieb, K. (2018). Intervention studies to foster resilience – a systematic review and proposal for a resilience framework in future intervention studies. <i>Clin Psychol Rev.</i> 59:78-100.	Process	Resilience is not a stable trait, but a dynamic process; Resilience can be conceptualized as mental health in relation to stressor load. Resilience as a dynamic process of adaptation can potentially be trained	Review - Theoretical Paper
(14)Infurna, F. J., & Luthar, S. S. (2016). Resilience to major life stressors is not as common as thought. <i>Perspectives on Psychological Science</i> , 11(2), 175-194.	Process	Resilience is operationalized as stable healthy levels of well-being and the absence of negative outcomes during or following potentially harmful circumstances— is the prototypical trajectory following exposure to potentially traumatic events	N/A Replication Study * Previous study used Closed questions formulated for the study, for example: “How

			satisfied are you with your life, all things considered?" using a 0 (totally unsatisfied) to 10 (totally satisfied) rating scale.
(15)Luthar, S. S., Crossman, E. J., & Small, P. J. (2015). Resilience and adversity. In R.M. Lerner and M. E. Lamb (Eds.). <i>Handbook of Child Psychology and Developmental Science</i> (7th Edition, Vol. III, pp. 247- 286). New York: Wiley.	Process	Resilience is a phenomenon or process reflecting relatively positive adaptation despite significant adversity or trauma. Because it is a superordinate construct subsuming two distinct dimensions—adversity and positive adaptation— resilience is never directly measured, but instead is indirectly inferred based on evidence of the two subsumed constructs.	N/A Theoretical Paper
(16)Southwick, S. M., Sippel, L., Krystal, J., Charney, D., Mayes, L., & Pietrzak, R. (2016). Why are some individuals more resilient than others: The role of social support. <i>World Psychiatry</i> , 15(1), 77-79.	Process	Resilience is dependent on multiple individual-level systems which can be fostered by environmental/caregiving conditions during childhood and later on in life. Social support from one's community can also help foster resilience in the individual.	N/A Theoretical Paper
(17)Casellas-Grau, A., Ochoa, C., & Ruini, C. (2017). Psychological and Clinical Correlates of Posttraumatic Growth in Cancer. A Systematic and Critical Review. <i>Psycho-Oncology</i> .	Outcome	Resilience refers to the capability of maintaining stable levels of psychological functioning when being exposed to a potentially stressful event, especially when it lasts for a long period, as the case of chronic illnesses and cancer. Also defined as a positive reaction triggered by an oncological illness.	N/A Literature review
(18)Corzine, E., Figley, C. R., Marks, R. E., Cannon, C., Lattone, V., & Weatherly, C. (2016). Identifying Resilience Axioms: Israeli Experts on Trauma Resilience. <i>Traumatology</i> . Advance online publication. http://dx.doi.org/10.1037/trm0000094 et al., 2016	Outcome	Resilience can relate to the individual or to a larger group, or a community. The importance of a strong sense of purpose, of being connected to others, individual characteristic contributed to trauma resiliency. From the aspect of community- resiliency is the capacity of a community to deal with a major crisis by adapting and growing while minimizing casualties and preserving a fair quality of life for all its citizens and maintaining its core values and identity.	N/A Theoretical Paper
(19)Luthar, S.S., and Eisenberg., N. (2017). Resilient Adaptation Among At-Risk	Outcome?	Resilient adaption deal with fostering the well-being of caregivers via regular support, reduction of	N/A Theoretical Paper

Children: Harnessing Science Toward Maximizing Salutary Environments. <i>Child Dev.</i> 88(2):337-349		maltreatment while promoting positive parenting, and strengthening emotional self-regulation of caregivers and children	
(20)Morin, R. T., Galatzer-Levy, I. R., Maccallum, F., & Bonanno, G. A. (2017). Do multiple health events reduce resilience when compared with single events?. <i>Health Psychology</i> , 36(8), 721.	Outcome?	The study investigated whether experiencing multiple major health events diminishes rates of resilience and increases rates of mortality using a large population-based prospective cohort, and concludes that multiple major stressors do not reduce rates of resilience.	Health events (cancer, stroke, heart disease, or lung disease); Center for Epidemiologic Studies–Depression (CES-D); Death records n= 1,395 from database
(21)Radina, M. E., & Armer, J. M. (2004). Surviving breast cancer and living with lymphedema: Resiliency among women in the context of their families. <i>Journal of Family Nursing</i> , 10(4), 485-505	Outcome	Resiliency refers to the positive ways in which families and individuals function under and are changed by stressful or adverse circumstances. Results categorized 3 types of pathways to family coping: adjustment, adaptation (considered by authors as resilient categories), and crisis.	Qualitative dataset: interviews with survivors, n = 6 interviews with health professionals, n = 2 observations of a support group, n = 3 field notes
(22)Sippel, L., Pietrzak, R., Charney, D., Mayes, L., & Southwick, S. (2015). How does social support enhance resilience in the trauma-exposed individual?. <i>Ecology and Society</i> , 20(4).	Outcome (process?)	Resilience is a complex phenomenon that, for each individual, may have specific meaning that varies by phase and domain of life and may, but does not always, lead to the absence of psychopathology. Resilience in the individual is dependent on multiple layers of society, and the authors promote individual resilience to stress and trauma through social networks. They argue that resilience in the individual is highly dependent on social systems that provide positive support, and that these systems enhance resilience through a variety of psychosocial and neurobiological mechanisms.	N/A Theoretical Paper
(23)Deshields, T. L., Heiland, M. F., Kracen, A. C., & Dua, P. (2016). Resilience in adults with cancer: development of a	Outcome (Process)	Authors Propose a model of resilience in cancer survivorship, viewing resilience as response to cancer.	N/A Theoretical Paper

conceptual model. <i>Psycho-Oncology</i> , 25(1), 11-18.		Resilience is seen as a fluid and dynamic process, which personal attributes may foster, but may be nurtured, learned, and practiced, thus leading to a resilient response (on the Resilience–distress continuum).	
(24)Kazantzaki, E., Koumakis, L., Kondylakis, H., Renzi, C., Fioretti, C., Mazzocco, K., ... & Pravettoni, G. (2017). Current trends in Electronic Family Resilience Tools: Implementing a tool for the cancer domain. In <i>EMBECE & NBC 2017</i> (pp. 29-32). Springer, Singapore	Process, Outcome	Resilience is the ability of an individual, a family or a specific group of people to overcome adversities, misfortunes or suffering situations. This recovery is achieved through processes that enforce individual or collective strengthening, empowerment, and rehabilitation. Resilience is conceived as the ability to be less vulnerable to environmental experiences, to overcome the consequent stress due to an adversity and to gain an as good as possible outcome despite adversities.	N/A Reviews existing resilience promotion programs
(25)Southwick, S. M., Pietrzak, R. H., Tsai, J., Krystal, J. H., & Charney, D. (2015). Resilience: An update. <i>PTSD Research Quarterly</i> , 25(4), 1050-1835.	Process/ Outcome	There is no one accepted definition of resilience. “the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of threat”. “a stable trajectory of healthy functioning after a highly adverse event; the capacity of a dynamic system to adapt successfully to disturbances that threaten the viability, the function, or the development of that system” Humans are endowed with natural protective systems that help them adapt to change and adversity. However, in order for these protective systems to develop and operate effectively individuals need basic social and material resources, and, ideally, healthy family and community environments	Connor-Davidson Resilience Scale; Response to Stressful Experiences Scale; Resilience Scale for Children and Adolescents
(26)Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: interdisciplinary	Process/ Outcome	A concept of healthy, adaptive, or integrated positive functioning over the passage of time in the aftermath of adversity.	N/A Theoretical Paper

perspectives. <i>European journal of psychotraumatology</i> , 5(1), 25338.		Resilience is a complex construct and it may be defined differently in the context of individuals, families, organizations, societies, and cultures.	
(27)Bonanno, G. A., Romero, S. A., & Klein, S. I. (2015). The Temporal Elements of Psychological Resilience: An Integrative Framework for the Study of Individuals, Families, and Communities. <i>Psychological Inquiry</i> , 26(2), 139-169	Potential, Process, Outcome	Psychological resilience in terms of four basic temporal elements: baseline or pre-adversity adjustment, the actual aversive circumstances themselves, post-adversity adjustment or resilient outcomes, and predictors of resilient outcomes.	N/A Theoretical Paper
(28)Greup, S. R., Kaal, S. E., Jansen, R., Manten-Horst, E., Thong, M. S., van der Graaf, W. T., ... & Husson, O. (2017). Post-Traumatic Growth and Resilience in Adolescent and Young Adult Cancer Patients: An Overview. <i>Journal of Adolescent and Young Adult Oncology</i> .	Potential, Process, Outcome	Resilience is described as the process of finding or developing resources to manage stressors and reach positive outcomes, it is described as a balance of several factors, including stress and coping, goals, optimism, finding meaning, connection, and belonging. Resilience was found to be a mediator in the relationship between symptom distress and Health Related QoL.	N/A Literature review However, the two most commonly used in Qal. Studies were the Resilience in Illness Model and its adolescent version.
(29)Helmreich, I., Kunzler, A., Chmitorz, A., König, J., Binder, H., Wessa, M., & Lieb, K. (2017). Psychological interventions for resilience enhancement in adults. <i>The Cochrane Library</i> .	Potential, Process, Outcome	Psychosocial resilience factors that are well-evidenced according to the current state of knowledge and are thought to be modifiable include meaning or purpose in life, sense of coherence, positive emotions, hardiness, self-esteem, active coping, self-efficacy, optimism, social support, cognitive flexibility (including positive reappraisal and acceptance) and religiosity or spirituality or religious coping. Resilience has been conceptualized as a multidimensional, dynamic and variable process, characterized by either a trajectory of undisturbed mental health during or after adversities or temporary dysfunctions followed by successful recovery. Resilience as the outcome of an interaction between the individual and his or her environment, which may be	N/A Literature review

		influenced through personal or environmental resources.	
(30)Hobfoll, S. E., Stevens, N. R., & Zalta, A. K. (2015). Expanding the science of resilience: Conserving resources in the aid of adaptation. <i>Psychological inquiry</i> , 26(2), 174-180.	Potential, Process, Outcome	Resilience is a process that stands in contrast to psychopathology or breakdown, thus having many facets. The Authors add additional concepts to Bonanno's definition (here, 2015) including toughness, resistance to breakdown, and plasticity.	N/A Theoretical Paper
(31)Infurna, F. J., & Luthar, S. S. (2016). Resilience has been and will always be, but rates declared are inevitably suspect: Reply to Galatzer-Levy and Bonanno (2016). <i>Perspectives on Psychological Science</i> , 11(2), 199-201.	?	The authors argue that definition of Resilience changes based on measurements and therefore "it is wrong to make any definitive declarations about rates of resilience". "Besides varying significantly by data analytic techniques as we described in detail, we also discussed briefly how labels of resilience can differ greatly based on measurements used to define resilience; it is practically impossible to make definitive "diagnoses of resilience" because of the range of plausible adjustment difficulties that must be ruled out."	N/A Theoretical Paper
(32)Masten, A. S. (2015). Pathways to integrated resilience science. <i>Psychological Inquiry</i> , 26(2), 187-196.	Discusses and debates the types of resilience	Resilience can be broadly defined as the potential or manifested capacity of a dynamic system to adapt successfully to disturbances that threaten the function, survival, or development of the system... This definition can be applied to an individual, a family, an economy, or other systems at more micro or macro levels.	N/A Theoretical Paper
(33)KenneSarenmalm, E., Mårtensson, L. B., Andersson, B. A., Karlsson, P., & Bergh, I. (2017). Mindfulness and its efficacy for psychological and biological responses in women with breast cancer. <i>Cancer medicine</i> , 6(5), 1108-1122.		This is a randomized controlled trial was to determine the efficacy of a mindfulness-based stress reduction (MBSR) intervention for mood disorders in women with breast cancer. Does not use the term Resilience	3 groups RCT: Socio-demographic data were collected through chart review and interviews. Hospital Anxiety and Depression scale (HADS); Memorial Symptom Assessment Scale (MSAS);

			Short Form Health Survey (SF-36); Sense of Coherence scale (SOC); Five Facets of Mindfulness Questionnaire (FFMQ–Swedish version); Posttraumatic Growth Inventory (PTGI); Lymphocyte distribution in peripheral blood; NK-cell activity n=177
(34)Shim, E. J., Lee, J. W., & Min, Y. H. (2017). Does depression decrease the moderating effect of self-efficacy in the relationship between illness perception and fear of progression in breast cancer? <i>Psycho-Oncology</i> .		Fear of progression (FOP) is a prevalent concern among breast cancer patients affecting their adjustment to disease. The study examined whether self-efficacy moderates the effect of illness perception (IP) on FOP and whether the moderating effect of self-efficacy depends on the level of depressive symptoms. Does not use the term Resilience	Fear of Disease Progression Short Form (FOP-SF); Brief Illness Perception Questionnaire (BIPQ); General Self-Efficacy Scale; Center for Epidemiologic Studies Depression Scale; Menopause Rating Scale (MRS) n=254
(35)Werner, H. M., Mills, G. B., & Ram, P. T. (2014). Cancer systems biology: a peek into the future of patient care? <i>Nature reviews Clinical oncology</i> , 11(3), 167-176.		Systems biology approaches will be vital for developing and implementing effective strategies to deliver personalized cancer therapy. Does not use the term Resilience	N/A

3.5. Table 2: Protective factors after exposure to trauma /adversity

Protective Factors	Name of the Questionnaire	Reference to the paper describing the questionnaire	Reference relevant to breast cancer
Social support	Perceived social support - Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1990)	Zimet G, Powell S, Farley GK, Werkman S, Berkoff KA. 1990. Psychometric characteristics of the multidimensional scale of perceived social support. <i>Journal of Personality Assessment</i> 55:610–617 doi:10.1207/s15327752jpa5503&4 17.	Perceived social support and coping strategies in advanced cancer patients Adelaida Zabalegui, Esther Cabrera, Montserrat, Navarro María & Isabel Cebria <i>Journal of Research in Nursing</i> , 2011 Vol 18, Issue 5, pp. 409 - 420
Positive feelings	the Positive and Negative Affect Scale (PANAS)	Watson D, Clark LA, Tellegen A. Development and validation of brief measures of positive and negative affect: The PANAS scales. <i>J Pers Soc Psychol.</i> 1988;54(6):1063–1070.	Moreno, P. I., Moskowitz, A. L., Ganz, P. A., & Bower, J. E. (2016). Positive Affect and Inflammatory Activity in Breast Cancer Survivors: Examining the Role of Affective Arousal. <i>Psychosomatic Medicine</i> , 78(5), 532–541. http://doi.org/10.1097/PSY.0000000000000300
Optimism	Life Orientation Test – Revised (LOT-R)	Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A re-evaluation of the Life Orientation Test. <i>Journal of Personality and Social Psychology</i> , 67, 1063-1078	* Optimistic Personality and Psychosocial Well-Being During Treatment Predict Psychosocial Well Being Among Long Term Survivors of Breast Cancer Carver, Smith, Antoni, Petronis, Weiss, and Derhagopian 2005 *Optimism, mental health, and quality of life: A study among breast cancer patients Deborah A. Colby & Kim Shifren. <i>Psychology, Health & Medicine</i> Vol. 18 , Iss. 1,2013
Self-efficacy	The Cancer Behaviour Inventory (CBI, version-2) (Merluzzi et al., 2001) assesses self-efficacy for	Merluzzi TV, Nairn RC, Hegde K, Sanchez MAM, Dunn L. 2001. Self-efficacy for coping with cancer: revision of the cancer behavior inventory (Version 2.0). <i>Psycho-</i>	Exploring the Role of Self-Efficacy for Coping with Breast Cancer: A Systematic Review Omaieh Borjalilu, Ahmad Kaviani, Sanaz Helmi, Mojgan Karbakhsh, Mohammad Ali Mazaheri. <i>Archives of Breast Cancer</i> ; Vol 4, No 2: May 2017

	coping with cancer	Oncology 10:206–217 DOI 10.1002/pon.511.	
Self esteem	The Rosenberg Self-Esteem Scale (RSES)	Rosenberg, M. (1979). <i>Conceiving the Self</i> . New York: Basic Books.	Markopoulos et al., (2009). Impact of Breast Cancer Surgery on the Self-Esteem and Sexual Life of Female Patients. <i>Journal of International Medical Research</i> , 37(1) 182 - 188
Personality	Neuroticism-Extraversion-Openness Five Factor Inventory (NEO-FFI)	Costa PT, Jr, McCrae RR. NEO-PI/FFI manual supplement. Odessa, FL: Psychological Assessment Resources; 1989	Van der Steeg, A. F. W., De Vries, J., & Roukema, J. A. (2010). Anxious Personality and Breast Cancer: Possible Negative Impact on Quality of Life After Breast-Conserving Therapy. <i>World Journal of Surgery</i> , 34(7), 1453–1460. http://doi.org/10.1007/s00268-010-0526-0
Flexibility	Perceived Ability to Cope with Trauma (PACT) scale	Bonanno, G. A., Pat-Horenczyk, R., & Noll, J. (2011). Coping flexibility and trauma: The perceived ability to cope with trauma (PACT) scale. <i>Psychological Trauma: Theory, Research, Practice, and Policy</i> , 3, 117–129. http://dx.doi.org/10.1037/a0020921	Pat-Horenczyk, R., Saltzman, L. Y., Araz, Y., Perry, S., Ginat-Frolich, R., & Stemmer, S. M. (2016). Stability and transitions in posttraumatic growth trajectories among cancer patients: LCA and LTA Analyses. <i>Psychological Trauma: Theory, Research, Practice, and Policy</i> .8(5)541-549
Sense of coherence	Life Orientation SOC-29	Antonovsky A. The structure and properties of the sense of coherence scale. <i>SocSci Med</i> 199336725–733.	Kenne Sarenmalm E, Browall M, Sense of coherence in women diagnosed with breast cancer as key to health Ewa Kupcewicz, Aleksandra Tołoczko. <i>Hygeia Public Health</i> 2017, 52(1): 64-70 Persson L-O, Fall-Dickson J, Gaston-Johansson F. Relationship of sense of coherence to stressful events, coping strategies, health status, and quality of life in women with breast cancer. <i>Psychooncology</i> . 2013;22(1):20–27.
CERQ	The cognitive emotion	Garnefski, N. & Kraaij, V. (2006). Cognitive emotion	Hamama-Raz, Y., Pat-Horenczyk, R., Perry, S., Ziv, Y., Bar-Levav, Y.,

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	regulation questionnaire (CERQ)	regulation questionnaire: Development of a short 18-item version (CERQ-short). <i>Personality and Individual Differences</i> , 41, 1045–1053. doi:10.1016/j.paid.2006.04.010	&Stemmer, S. M. (2016). Cognitive emotion regulation with breast cancer patients: two-year follow up of a group intervention study. <i>Integrative Cancer Treatments</i> 15(2) 175–182
Life satisfaction	Satisfaction with Life Scale (SWLS).	Diener et al. (1985) The Satisfaction with Life Scale. <i>Journal of Personality Assessment</i> 49(1), 71-75	Tate, D.G. & Forchheimer, M. (2002). Quality of Life, Life Satisfaction, and Spirituality: Comparing Outcomes Between Rehabilitation and Cancer Patients. <i>American Journal of Physical Medicine & Rehabilitation</i> , 81(6), 400-410
Meaning in life	The Life Attitude Profile (LAP)	Reker, G. Peacock, T., Edward J (1981). The Life Attitude Profile (LAP): A multidimensional instrument for assessing attitudes toward life. <i>Canadian Journal of Behavioral Science</i> 13(3), 264-273	Thompson P. (2007). The relationship of fatigue and meaning in life in breast cancer survivors. <i>Oncol Nurs Forum</i> . 34(3):653-60.
Sense of happiness	Oxford Happiness Questionnaire (OHQ)	Michael Argyle and Peter Hills (2002) The Oxford Happiness Questionnaire: a compact scale for the measurement of psychological well-being <i>Personality and Individual Differences</i> , 33 1073–1082	Ahmadidarrehshima et al. (2016). An Evaluation of Happiness and Factors affecting it in Patients Diagnosed with Breast Cancer. <i>Der Pharmacia Lettre</i> , , 8 (13):305-310 (http://scholarsresearchlibrary.com/archive.html)
Gratefulness	GRATITUDE QUESTIONNAIRE- GQ-6	McCullough, M. E., Emmons, R. A., & Tsang, J. (2002). The Grateful Disposition: A conceptual and Empirical Topography. <i>Journal of Personality and Social Psychology</i> , 82, 112-127.	Ruini , C. & Vescovelli, F (2013). The Role of Gratitude in Breast Cancer: Its Relationships with Post-Traumatic Growth, Psychological Well-Being and Distress. <i>Journal of Happiness Studies</i> 14(1), 263–274
Clarity of emotions	the short version of Clarity subscale from the Trait Meta Mood Scale (TMMS;)	Salovey, P., Mayer, J. D., Goldman, S. L., Turvey, C., & Palfai, T. P. (1995). Emotional attention, clarity, and repair: Exploring emotional intelligence using the	Schmidt, J. E., & Andrykowski, M. A. (2004). The role of social and dispositional variables associated with emotional processing in adjustment to breast cancer: an internet-based study. <i>Health Psychology</i> , 23(3), 259.

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		Trait Meta-Mood Scale. In J. W. Pennebaker (Ed.), <i>Emotion, disclosure and health</i> (pp. 125-154). Washington, D.C.: American Psychological Association	
Mindfulness	The Five Facet Mindfulness Questionnaire (FFMQ) in cancer patients <u>or</u> The Mindful Attention Awareness Scale (MAAS)	Piet, J., Würtzen, H., & Zachariae, R. (2012). The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: A systematic review and meta-analysis, <i>Journal of Consulting and Clinical Psychology</i> , 80, 1007-1020 <u>or</u> The Mindful Attention Awareness Scale (MAAS) in cancer patients: Carlson, L. E., & Brown, K. W. (2005). Validation of the Mindful Attention Awareness Scale in a cancer population. <i>Journal of Psychosomatic Research</i> , 58, 29-33.	Piet, J., Würtzen, H., & Zachariae, R. (2012). The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: A systematic review and meta-analysis, <i>Journal of Consulting and Clinical Psychology</i> , 80, 1007-1020 <u>or</u> The Mindful Attention Awareness Scale (MAAS) in cancer patients: Carlson, L. E., & Brown, K. W. (2005). Validation of the Mindful Attention Awareness Scale in a cancer population. <i>Journal of Psychosomatic Research</i> , 58, 29-33.
Body awareness	The body awareness questionnaire	Shields, S. A., Mallory, M. E., & Simon, A. (1989). The body awareness questionnaire: reliability and validity. <i>Journal of personality Assessment</i> , 53(4), 802-815.	There are no published papers that report body awareness among cancer patients

Table 3: Outcome Measures

Quality of life: Specific to breast cancer	The Satisfaction with Life Domains Scale for Cancer (SLDS-C)	The World Health Organization Quality of Life assessment instrument. Geneva: WHO; 1995.	Baker, F., Curbow, B., & Wingard, J. (1992). Development of the Satisfaction with Life Domains Scale for Cancer (SLDS-C). <i>Journal of Psychosocial Oncology</i> , 10(3), 75–90.
	QLQ-BR23	Breast cancer specific module	Matthews et al., (2002). Health status and life satisfaction among breast cancer survivor peer support volunteers. <i>Psycho Oncology</i> . 11(3),199-211.
Quality of life In general	WHOQOL-100	World Health Organization Quality of Life assessment instrument-100 (WHOQOL)	Van der Steeg., De Vries & Roukema (2010). Anxious Personality and Breast Cancer: Possible Negative Impact on Quality of Life After Breast-Conserving Therapy. <i>World Journal of Surgery</i> , 34(7), 1453–1460. http://doi.org/10.1007/s00268-010-0526-0
	QLQ-C30	EORTC quality of life questionnaire Sprangers et al. (1996) The European Organization for Research and Treatment of Cancer breast cancer-specific quality-of-life questionnaire module: first results from a three-country field study. <i>J Clin Oncol</i> 14(10), 2756–2768.	Aaronson NK, Ahmedzai S, Bergman B, <i>et al.</i> The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. <i>J Natl Cancer Inst</i> 1993; 85 (5):365–376.
Post Traumatic Growth	Posttraumatic Growth Inventory	Tedeschi & Calhoun (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. <i>Journal of Traumatic Stress</i> 9,455–471.	Pat-Horenczyk, et al. (2015). Posttraumatic growth in breast cancer survivors: Constructive and illusory aspects. <i>Journal of Traumatic Stress</i> , 28, 214-222.

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Resilience	The Connor-Davidson Resilience Scale (CDRISC)	Connor KM, Davidson JRT: Development of a new resilience scale: The Connor-Davidson resilience scale (CD-RISC). <i>Depress Anxiety</i> 2003, 18(2):76-82.	<u>Scali</u> et al. (2012). Measuring Resilience in Adult Women Using the 10-Items Connor-Davidson Resilience Scale (CD-RISC). Role of Trauma Exposure and Anxiety Disorders. <i>PLoS One</i> . 2012; 7(6): e39879. doi: 10.1371/journal.pone.0039879
PTSD	PCL PTSD Check-List (for DSMV)	Weathers, F.W., Litz, B.T., Keane, T.M., Palmieri, P.A., Marx, B.P., & Schnurr, P.P. (2013). The PTSD Checklist for <i>DSM-5</i> (PCL-5). Scale available from the National Center for PTSD at www.ptsd.va.gov .	Mulligan, et al. (2014). Cancer as a Criterion A Traumatic Stressor for Veterans: Prevalence and Correlates. <i>Psychol Trauma</i> . 6(Suppl 1): S73.S81. doi: 10.1037/a0033721
Anxiety and Depression	HADS Hospital Anxiety and Depression Scale	Zigmond & Snaith (1983).The hospital anxiety and depression scale. <i>Acta Psychiatr Scand</i> . 67(6),361-70.	Heim et al. (1999). Anxiety and depression in cancer patients — The HADS-questionnaire as screening instrument in cancer rehabilitation. <i>European Journal of Cancer</i> , 35, S281. doi: https://doi.org/10.1016/S0959-8049(99)81546-9
Fear of Recurrence	FCRI-SF Fear of Recurrence (short form)	Fear of Recurrence - (2015). Screening and comorbidity of clinical levels of fear of cancer recurrence. <i>Journal of Cancer Survivorship</i> 9 (3), 481–491.	short form

4. Related Concepts: Possible additional outcome measures?

In this section, we will elaborate on two relevant constructs to resilience in the face of exposure to life threatening illness such as cancer and other types of trauma. The interest in the concept of Post Traumatic Growth (PTG) is growing and there is a need to explore the interrelations between resilience and PTG. PTG can be also conceptualized in the BOUNCE study as an outcome measure or as one of the mediating or moderating factors in the course of post cancer adaptation process. The Fear of Cancer Recurrence (FCR) is a construct that appear to be central in the literature on coping with cancer. There is a lack of clarity as to whether these fears of recurrence reflect a type of posttraumatic distress manifested as “forward flashbacks”. The FCR can also serve as an outcome measure in the BOUNCE study throughout the adaptation process.

4.1. Posttraumatic Growth and Resilience

Another construct associated with the positive adaptation after traumatic adversity is Posttraumatic Growth (PTG). PTG is defined as the positive psychological change experienced as a result of the struggle with highly challenging life circumstances (Tedeschi& Calhoun, 2004). The growth, according to Tedeschi& Calhoun (1996) may be seen in five areas: appreciation of life, relationships with others, new possibilities in life, personal strength and spiritual change.

Resilience and PTG are both salutogenic factors, i.e. factors supporting human health and well-being (Antonovsky, 1987), which emphasizes the consideration of positive rather than pathological or negative factors in trauma. In light of these similarities, it has been debated whether PTG is a form of resilience, or superior to it (Bensimon, 2012). A primary source of confusion regarding the distinction between the two, is due to the fact that studies have often found a positive correlation between them (e.g., Connor & Davidson, 2003, Nishi, Matsuoka & Kim, 2010, and Ogińska-Bulik & Kobylarczyk, 2017). However, the existence of both constructs simultaneously, especially when both result in seemingly positive outcomes to traumatic adversity, strengthens the need to understand if and what are the differences between the two.

Carver (1998) and Tedeschi & Calhoun (1996) assumed that for PTG to occur, a person must display resilience and return to healthy functioning before moving towards more advanced functioning, which they saw as posttraumatic growth. Later Tedeschi &

Calhoun (1998) attempt to specifically distinguish between the two and argued that resilience differs from posttraumatic growth in that resilience implies *a return to prior levels of functioning* following a trauma, whereas posttraumatic growth is a significant, positive change in emotional and cognitive functioning that *supersedes previous levels of adaptation*, psychological functioning, or life awareness. In other words, while resilience may be perceived as *bouncing back*, PTG can be perceived as *bouncing forward*.

Further, resilience can act as a growth facilitator. Resilience is perceived as *a trait*, which later (post adversity) allows for the development (a *process*) of a *growth outcome*. However, a literature review following this idea could not distinguish between individuals who were low, moderate or high in resilience, and how these different levels of resilience related to PTG (Li, Cao, Cao & Liu, 2015). A similar notion was presented, whereby resilience is considered a personality trait, and PTG a mode of adjustment to traumatic events (Bensimon, 2012). Again, here *resilience would be considered a trait*, and *PTG as a process*. Whether resilience is a trait or process, and PTG a process or outcome, according to these understandings, resilience and PTG can be viewed as independent constructs, the same continuum, both potentially arising when faced with adversity.

An alternative line of thought has also been presented in the literature. Westphal & Bonanno's study (2007) showed that people presenting high resilience did not engage in cognitive processing to the extent necessary for PTG to occur. Therefore, they concluded, *resilient outcomes may provide little need or opportunity for PTG*. Much earlier, Taylor (1983) argued that growth stems from the trauma itself and in order for the individual to experience the growth process, PTSD symptoms must appear. According to this line of thought, resilience acts as *a protective factor* against development of PTSD, whereas *PTG can only occur if the trauma is experienced*. Meaning, growth stems from experiencing posttraumatic distress, which can be interpreted as a lack of resilience. Bensimon (2012) also adopted similar view and concluded that resilience should be seen as a reference to the *overall resistance to traumatic events* due to the presence of previous personal characteristics, whereas in his study *trauma increased PTSD and growth levels*. A different distinction was made by Levine and colleagues (2009) who stated that their findings showed that high levels of resilience, conceptualized as a lack of PTSD following adversity, were negatively associated with posttraumatic growth. They concluded that although growth and resilience are both salutogenic constructs they are *inversely related* (Levine, Laufer, Stein, Hamama-Raz, & Solomon, 2009).

Based on views presented here, while both resilience and PTG are conceptualized as positive outcomes to adversity, the relationships between them is not clear nor consistent. There is research evidence for positive, negative and no correlation between them. Will resilient individuals be less affected by a trauma? Or be able to withstand it better? or not express posttraumatic symptoms? Will PTG appear only among those individuals who were seemingly not resilient, therefore negatively affected by the trauma and presented PTSD, leading to a potential for developing PTG later on?

Applying more nuances, Nishi, Matsuoka & Kim (2010) proposed to related to PTG, not as one single outcome emerging post-trauma, but to PTG's five factors each with different properties. They found that personal strength, relating to others, and new possibilities, were positively correlated with resilience, whereas the factors, appreciation of life and spiritual change, were positively correlated with PTSD symptoms (Nishi, Matsuoka & Kim, 2010). Therefore, they hypothesized that essentially PTG has mixed properties and represents both coping effort, which they found to coexist with distress, and with coping success, associated with resilience (Nishi, Matsuoka & Kim, 2010). In this view there is some overlap between resilience and certain properties of PTG, whereas the remaining properties seem to contradict the presence of resilience.

Evidently, a more complex conceptualization of PTG and its relationship with positive adaptation distress, and coping is needed. Maercker & Zoellner (2004) differentiated between constructive and illusory aspects of PTG. According to their proposed model named "the Janus Face Model" growth is separated into two categories: constructive, which describes the functional aspect of PTG, and illusory, the dysfunctional or self-deceptive side of PTG. The model assumes that the two faces of PTG can coexist and are likely to have different trajectories. While constructive PTG is more likely to result in long-term positive adaptation, illusory PTG offers short-term relief, which is more likely decrease over time (Zoellner & Maercker, 2006)

In the context of coping with breast cancer, Pat-Horenczyk and her colleagues (2015) further operationalize this distinction between constructive and illusory PTG. Their findings showed that more than half the women (55.3%) showed an increase in PTG at 6-month follow-up while most of them 75% of the women reported constructive PTG (defined as an improvement in both PTG and coping). Further, in another study, Pat Horenczyk, et al. (2016) distinguished between four post cancer treatment adaptation profiles: (a) distressed, (b) resistant, (c) constructive growth, and (d) struggling growth. The majority of transitions between different adaptation profiles occurred between 6 and 12

months after treatment. The new profile of *struggling PTG* which is characterized by a high degree of struggle and distress differs from the construct of illusory PTG since it is characterized by high efforts of positive coping and higher reported distress. Illusory and struggling PTG may have similar clinical implications given both suggest non optimal adaptation. Moreover, the presence of struggling PTG may be a transitional state that over time may give way to *either* constructive or illusory growth. (Pat-Horenczyk, et al., 2016).

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4.2. Fear of Cancer Recurrence

In recent years, greater attention has been dedicated to ‘Fear of Cancer Recurrence’ (FCR), generally defined as ‘the fear or worry that cancer could return or progress in the same place or another part of the body’ (Butow, Fardell & Smith, 2015). This may be the result of improved medical care and higher rates of cancer survival. FCR has been found to be almost universal among cancer survivors, proving it difficult for those experiencing higher levels of FRC to reintegrate back into daily life routine and leading to a poorer quality of life (Butow, Fardell & Smith, 2015). Reports in the literature are of rates of FCR ranging 33-56% amongst cancer survivors (Siegel et al., 2012; Lebel et al., 2013). Younger survivors and those who experience more psychological distress have been shown to have greater symptom burden. In addition, FCR bares significant costs for family members and the society at large (Butow, Fardell & Smith, 2015).

FCR is often measured literally, simply by asking about the degree of worry or fear one has about ‘cancer coming back’ or being diagnosed with another type of cancer (Simonelli, Siegel & Duffy, 2017). Other measurements look at specific aspects, such as attention to symptom checking (e.g. concern that pain may indicate a recurrence), apprehension over future screening or diagnostic tests, anticipated physical health consequences of a recurrence (e.g. need for additional treatment, poor health, dying), and anticipated psychosocial consequences of a recurrence (e.g. emotional distress, the inability to fulfil important social role (Simonelli, Siegel & Duffy, 2017).

When developing the Fear of Cancer Recurrence Inventory (FCR), Simard and Savard (2009), found seven trigger situations for FCR: conversations about cancer, knowing someone who is ill, media references to cancer, attending funerals or reading obituaries, appointments with health professionals, examinations and procedures, and feeling sick. Other possible triggers may be physical symptoms such as aches, pain, and fatigue, and the anniversary of the diagnosis can also be triggers (Simonelli, Siegel & Duffy, 2017).

According to Simonelli, Siegel & Duffy (2017), there are no established criteria regarding the frequency, duration and severity of symptoms that would constitute clinically significant FCR. However, they stated that the majority of studies included in their review suggest FCR is relatively stable over time, for example: Savard and Ivers (2013), reported prevalence rates of clinically significant FCR of 44–56% with highest levels at a peri-operative baseline, persisting over time. Koch and colleagues (2013), found in their review,

that most cancer survivors experience FCR which remains stable over time. Simonelli, Siegel & Duffy do note there were a couple of studies showing a decrease in FCR over time (Simonelli, Siegel & Duffy, 2017). At the end of their review they reach two conclusions; The first, that the degree of FCR does not appear to be proportional to prognosis or survival statistics; The second, that FCR does not necessarily resolve or even diminish with the mere passage of time; instead, it can be stable for years (Simonelli, Siegel & Duffy, 2017).

In low levels, FCR may be somewhat beneficial by encouraging survivors to maintain a healthy life style, keep vigilance towards concerning physical symptoms warranting medical attention, and ensuring routine follow-ups as advised. However, in higher levels, FCR ceases to be adaptive since it causes high levels of distress, thus disrupting quality of life. These high levels of distress can manifest as an anxiety disorder, trauma or stressor related disorder, somatic symptom disorder and subclinical distress or may exacerbate pre-existing psychological conditions. Common clinical diagnoses observed in the context of FCR include post-traumatic stress disorder(PTSD), generalized anxiety disorder (GAD) and adjustment disorder (Simonelli, Siegel & Duffy, 2017).

Fear of Cancer Recurrence and Posttraumatic Stress

What is the relationship between FCR and clinically diagnosed disorders, specifically PTSD? Abbey et al. (2015) suggest that there may be over inflated rates of cancer related PTSD, caused by artefacts of drugs, medical conditions, and the realistic fears of cancer recurrence. This confusion can be explained by a certain overlap in symptom presentation that may lead to a confusion regarding FCR and cancer related PTSD. FCR, like PTSD, may also interfere with daily life, by causing intrusive thoughts about cancer and its recurrence, leading for relationship conflicts, preoccupation with health, and an inability to plan for the future (Kewley, 2016). Previously it was thought that intrusive thoughts in cancer survivors were associated with traumatic events related to past cancer or treatment resulting in PTSD, however it is now believed the intrusive thoughts are more frequently related to future orients fears such as FCR (Simard, Savard & Ivers ,2010).

Coping with cancer involves continual attention to the potential threat from internal cues. Thus FCR may lead to hypervigilance, another characteristic that may be similar to posttraumatic symptoms, taking shape in the form of excessive checking for signs that the

cancer has returned (Koch et al., 2014). In many cases, the hypervigilance is to physical symptoms which contribute to misinterpretation that cancer has returned. However, unlike other cases of PTSD where the focus is usually on external stimuli, reminiscent of past threats, in instances of FCR the stressor is usually internal and focused on future oriented threats (Kangas, Henry & Bryant, 2002). This is an important difference between the two conditions and may contribute to a better understanding of the unique attributes of FCR which may be misdiagnosed as cancer related PTSD. Simonelli, Siegel & Duffy, (2017) add that in light of the future-oriented and catastrophic nature of FCR, worry may be of particular importance in FCR cases, as it relates to the presentation, measurement and treatment of FCR.

Despite similarities, to date there is no evidence of a causal relationship between FCR and posttraumatic stress symptoms (Simonelli, Siegel & Duffy, 2017). There have been a few studies noting the correlations between the two. For instance, Custers et al. (2016), found that survivors with high levels of FCR experienced significantly more general distress ($t(73)=-5.4$, $p<0.001$) and cancer specific distress ($t(26.5)=-3.9$, $p=0.001$) characterized by post-traumatic stress symptoms including significantly more intrusive ($t(31.3)=-3.8$, $p=0.001$) and avoidant ($t(27.2)=-4.6$, $p<0.001$) phenomena after the traumatic experience of cancer, than did survivors with low levels of FCR. Three other studies including ovarian and breast cancer survivors reported that PTSD symptoms were positively associated with FCR ($r=.42$ to $.71$) (Simard&Savard, 2015).Skaali and colleagues (2009), reported higher rates of cancer-related intrusions and avoidance among testicular cancer survivors who reported greater levels of FCR.

Looking at the literature, it seems that all though connections have been found between FCR and PTSD, much remains to be learned about causality or the order in which they appear. As mentioned above, cancer survivors reporting high levels of FCR are more likely to experience mental health issues including PTSD (Simonelli, Siegel & Duffy, 2017). However, it has also been shown that a common risk factor for FCR include a history of trauma and possible preexisting PTSD. For example, among survivors of gynecologic cancer, anxiety, post-traumatic stress and functional and emotional well-being accounted for over 40% of variance in FCR (Urbaniec, Collins, Denson & Whitford, 2011). Does PTSD lead to higher potential for FCR, or do high levels of FCR put the survivors at risk for cancer related PTSD?

Resilience definition and operationalization

It also remains unclear whether internal stimuli (e.g. physical symptoms and side effects) or external stimuli (e.g. cancer-related media, medical follow-up), which raise FCR levels can or should be considered as part of a cancer related PTSD diagnosis, raising the question regarding over-diagnosis of cancer related PTSD.

Another relevant question for consideration is whether being diagnosed with cancer should be considered as a traumatic event warranting a PTSD diagnosis (as often presented in the literature), or whether a more specific traumatic event (such as a ICU hospitalization or considerably low white blood cell count levels) needs to exist for a complete PTSD diagnosis, thus creating an additional possible way to distinguish between the two conditions. Although various hypotheses have been raised to distinguish between the two conditions, there is a need in further research to address these questions. When focusing on everyday challenges of the survivors, the similarities, and perhaps the overlap in symptoms, need to be considered.

It should be noted, however, that fear of cancer recurrence, in moderate levels, can also be considered as a resource leading to higher compliance with follow-up treatment and self-monitoring. Since the source of threat may reside inside the body, rather than being a threat coming from outside, the level of self-awareness, bodily awareness and a moderate level of concern may be adaptive. The ability to adaptively tolerate the fear of cancer recurrence is based on self-awareness and emotion regulation capacities.

In sum, Champagne, Ivers & Savard (2018) summarized their review on utilization of health care services in cancer patients that elevated FCR was related to a greater utilization of health care services indicating that health-related anxiety generated significant costs for the health care system. They further highlighted the need to assess the magnitude of the costs entailed for the health care system and the patients themselves due to FCR specifically, the importance of early detection of FCR, and the need to develop and offer interventions that effectively treat it.

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5. Operationalization and measurement of Resilience

5.1. Initial specification of pool of measures

The processes of defining the instruments for the BOUNCE study started with a list of about 50 relevant concepts and their measures (see Appendix A). The initial pool of relevant measures was determined based on: (1) literature review; (2) the initial document on resilience definition discussed at the kick-off meeting (see Appendix 0 Part 1) and (3) preliminary proposals prepared by a focus group of experts from four clinical sites of BOUNCE (Italy, Portugal Finland and Israel) as a result of a meeting held in Milan in February 2018, see notes for that meeting in Appendix 0 Part 2). The expert group was comprised from psycho-oncologists, health psychologists, social workers, and psychometricians. The following criteria were proposed for choosing the measures:

- Sound psychometric properties (reliability and construct validity).
- Divergent validity in context of the present research (low overlap with other measures).
- Proven usefulness in research on breast cancer patients.
- Ability to predict important outcomes in RCT's or in longitudinal studies (controlling for initial levels of the outcome measures).
- Preferably short.

5.2. Experts panel

Following the initial identification of the study's constructs and measures, the representatives of the five clinical teams met in Milan (February 2018) and conducted an intensive discussion of the measures, relying on their clinical experience and acquaintance with relevant research literature. In the process of this discussion, the following steps were taken:

- The broad conceptual domains to be covered in the BOUNCE study were discussed and refined;
- The list of appropriate measures was changed to include instruments that correspond better to the selection criteria (reliability, construct, predictive and research-specific divergent validity, and user-friendliness);
- The periodicity with which each one of the measures had to be delivered was discussed and determined.

As a results of this experts' panel discussion, the variable list was reduced from about 50 to about 20 major research constructs (Appendix B).

Following the meeting in Milan, several rounds of e-mail discussions were held in order to refine the measures details, create new measures where there was a lack of existing scales, identify the exact sources of each existing scale and its availability in local languages of the countries participating in the project. An effort was made to find out the legal status of each existing scale – whether it was in public domain or permission was needed for using it, and determine the details of copyright holders. The subset of instruments was determined for use at each measurement occasion (baseline, monthly brief measurement, tri-monthly, half-year, yearly measurement, etc). See Appendix C for this version of instruments proposal.

It should be noted that in this version, two baseline measurement waves were specified. The first one is done at the first possible opportunity, within about one month – 6 weeks after the first patient's meeting with her oncologist. At this wave, only non-cancer-specific measures are delivered (like personality). The first time that cancer-specific measures can be delivered should take place at a later stage, when the Pt has already had some meaningful experience with the illness, coping with it, etc.

5.3. The advanced proposal

After the version of measurement plan was made explicit (see Appendix A), it became clear that it had several flaws:

- Two measurement waves had almost 400 items, two – over 200. We felt that it was unrealistic to deliver so many items in a single wave.
- WP2 coordinators from the Israeli team, specialists in psycho-oncology and oncology, all with experience in similar longitudinal research programs, strongly doubted the feasibility of asking the Pts to answer 20+ questions on a monthly basis (for that matter, asking to answer any number of questions monthly).
- The periodicity with which we were supposed to deliver different questionnaires did not follow a clear rationale and we felt that a better logic could be proposed.

Therefore, an advanced measurement plan was proposed (Appendix C). At the time of submission of the WP2 summary, this is a tentative proposal under discussion. Finalizing the decision on the measurement plan is scheduled for the meeting of all national teams in June in Crete.

Resilience definition and operationalization

The main difference between the two proposals is in the measurement timing. Three assumptions led the choice of timing in the latest version/proposal.

- The first assumption was that the most frequent feasible measurement is tri-monthly.
- The second one was that the timing should be guided by the dynamics of the Pts' illness. The main "stations" are baseline (say, M0 for general traits, M3 for cancer-specific measures), M9/M12, and M12/M15 months. This is based on the assumption that treatments usually last between 9-12 months. We aim to test at baseline and then towards the end of the treatment (M9/M12), at which time the Pts are confronted with a new reality and thus they need to exercise or adjust their coping skills. After that – we measure at M12/M15, when the active phase of treatment and coping is over and the Pt had the opportunity to integrate the experience and assess it in retrospective.
- The third assumption was that, where possible, measuring hypothesized causes we should be performed before measuring hypothesized outcomes, as time precedence of causes over outcomes is one of the accepted conditions of causality; and also in order to divide questionnaires between two waves to minimize the burden for the Pts. Therefore, for example, PACT, CERQ and Social Support will be measured at M0, M9, M15 – while PTSD, adherence to doctors' recommendation, and PTG will be measured at M3, M12, M18 and can be examined as a temporary (and repeated) outcome measure or as a moderating factor.

Relying on this logic, the latest version was prepared by the Israeli clinical team and discussed and refined with the psychometric specialists from Forth.

It should be noted that the M24 measurement appearing in this proposal is only an optimistic, probably not realistic, possibility – in case that necessary money is saved or becomes available. In this proposal, it is recommended to omit several measures with the aim to make the batteries used at each wave as short as possible:

- Big Five, LOT, Sense of Coherence, and CBI (self-efficacy) are supposed to be relatively stable. Their main role is as predictors and moderators of resilience. Assessing changes over time in them can be interesting academically, but of little practical use.
- FACIT spirituality – is probably not the most important measure, and an aspect of spirituality is measured with the spirituality coping visual bar.

Resilience definition and operationalization

- Satisfaction with hospital care – at least in Israel, these items are redundant, as all hospitals and all health-care providers are similar and of acceptable quality. The relevance of this measure to other countries
- The two IPQ items for frequent measurement are adapted from the brief version of IPQ (see below re: the full version).
- Suicidal ideation – probably will be too sensitive to be asked within the research.
- Physical functioning scales – in a short form, all the domains are covered in QLQ, the more detailed reports are probably not.

On the other hand:

- It was proposed to use the full IPQ, including the part that assesses perceived reasons for the illness, as there are important findings in recent literature that the perceived reasons are a valid and unique predictor of coping and of outcomes.
- Assessing the most important outcomes: quality of life, HADS, and PANAS at every measurement, as these will allow to calculate the trajectories of change in a sensitive manner. This makes the use of single QoL and distress items redundant.

As the result of these changes, significantly shorter batteries at each measurement wave (132-192 items) were created.

Summary

In this work package we reviewed the literature on the evolution of the concept of resilience and mapped the various resilience factors. The process of operationalizing of the concept of resilience in the context of coping with breast cancer was based on selecting the theory informed factors and their validated research instruments that have been demonstrated to be reliable and useful in prior studies with cancer patients.

We refined the list of proposed instruments through an interactive process of group discussions of psychologists and psycho-oncologists of BOUNCE that resulted in a consensus battery of questionnaires (see Appendix D). The comprehensive measure includes 20 measures that assess various domains of predicting variables (such as personality or available social support) and of outcomes (such as quality of life or distress). The majority of these measures are available in the languages of the four clinical sites of BOUNCE, and the rest of the questionnaires will be translated and back-translated following a pre-defined formal process.

6. Appendices (4 excels files are attached)

Appendix 0 - Part 1: Resilience - Document prepared for the kick-off meeting in Helsinki (Jan 11-12, 2018)

Appendix 0 - Part 2: Notes from the meeting in Milan (Feb 15, 2018)

Appendix A: The initial list of constructs and selected measures (towards Milan meeting, February 2018).

An excel file: Available upon request from: ruth.pat-horenczyk@mail.huji.ac.il

Appendix B: The concepts and measures list (resulting from Milan meeting, February 2018)

An excel file: Available upon request from: ruth.pat-horenczyk@mail.huji.ac.il

Appendix C: A revised proposal

An excel file: Available upon request from: ruth.pat-horenczyk@mail.huji.ac.il

Appendix D: The advanced measures proposal (towards the meeting in Heraklion (June 15-16, 2018)

Attached. An excel file: Available upon request from: ruth.pat-horenczyk@mail.huji.ac.il (see pages 48-52)

Appendix 0: Part 1

Document prepared for the kick-off meeting in Helsinki (January 11-12, 2018) Resilience from an interdisciplinary perspective: Theory and clinical implications

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First draft - November 26, 2017

OVERVIEW:

1. The evolving theoretical definitions of the construct of Resilience. We base upon extant definitions of this concept and view it as comprised of three distinct components:
 - a. Resilience as a potential / capacity / pre-disposition
 - b. Resilience as a process / trajectory
 - c. Resilience as an outcome
 - d. Temporal aspects of resilience
 - e. Contextual and cultural aspects of resilience
2. Biological underpinning of resilience
 - a. Biological mechanism (PAH): Stress hormones (e.g. cortisol)
 - b. Hedonistic system: Dopamine system (e.g. oxytocin)
 - c. Inflammatory (i.e, C-reactive protein, tumor necrosis factor receptor-II, NGF1
 - d. Immunological bio markers
3. The interrelationship between Trauma PTSD and Resilience
4. Resilience in the context of breast cancer
5. Operationalization and measurements
 - a. Identifying resilience/ protective factors
 - i. Life-style (i.e., exercise, social connectivity)
 - ii. Environmental
 - b. Selecting the most appropriate measures
 - c. Beyond self-reports
 - d. Repeated measures blood tests. Paper and pencil/ Internet technologies
6. Evidence based intervention studies on resilience as an outcome measure
7. Combining analytic and biological methods in assessing resilience the clinical setting
8. New tools and technologies for enhancing resilience
9. Dissemination of knowledge Sustainability
10. Evaluation of building resilience intervention for breast cancer patients and assessment of cost effectiveness

Individual Resilience is a complex construct that tends to be conceptually defined in multiple ways that often confuse between an individual's potential (capacity to engage in adaptive coping processes), process (adaptive reactions to adversity), and outcomes (the final state achieved as the result of coping). An effort to reach a consensus definition was

made by Southwick and colleagues (2014), a panel of prominent/leading resilience experts who agreed on the consensus definition that the concept of resilience includes “healthy, adaptive, or integrated positive functioning over the passage of time in the aftermath of adversity.” They further agreed that resilience is a complex construct and it may be defined differently in the context of individuals, families, organizations, societies, and cultures. With regard to the determinants of resilience, there was a consensus that the empirical study of this construct needs to be approached from a multiple level of analysis perspective that includes genetic, epigenetic, developmental, demographic, cultural, economic, and social variables. The empirical study of determinates of resilience will inform efforts made at fostering resilience, with the recognition that resilience may be enhanced on numerous levels (e.g., individual, family, community, culture).

“

We will adopt the working definition of resilience distinguishing between three aspects of the manifestation of the construct (i.e., resilience potential, resilient coping process, and positive outcomes).

Resilience capacity/potential:

Resilience capacity is the integration of internal and external resources available to the individual upon facing adversity that may influence the effectiveness of the coping process; e.g., self-esteem and optimism.

Resilient coping processes:

Executing/ showing healthy and flexible regulation in different domains of functioning, including physical, emotional, cognitive and interpersonal regulation over period of time; e.g., improvement in coping flexibility and self-regulation strategies.

Positive outcomes:

Maintaining healthy functioning, subjective wellbeing, and satisfactory quality of life despite exposure to trauma; e.g., high quality of life, positive affectivity, low level of fear of illness recurrence.

Resilience capacity as a moderating variable

In our view, resilience capacity is a factor which potentially moderates the relationship between exposure to adversity and outcomes by initiating resilient coping processes. High resilience capacity will contribute to lower impact of the stressful events and /or to the maintenance of healthy functioning and to subjective wellbeing and satisfactory quality of life in the aftermath of adversity.

Resilience capacity as a formative construct

In our view, resilience capacity or potential is a total sum of all protective factors (vs risk factors), i.e., her personal and social capital. It is a multi-faceted concept that can include a wide scope of indicators: Medical/physiological (such as disease severity and additional medical conditions); socio-demographic (age, education, wealth); personal (intelligence and other cognitive skills, generalized affectivity, hardiness, optimism, self-control, self-efficacy, self-esteem); social/interpersonal (family and social support, emotional expressiveness). All these indicators are not a **reflection** of an underlying single construct

(like syndromes reflect an illness or performance on intelligence tests reflects intelligence), but rather they **define** the resilience construct (like sum total of a person's assets, income, future inheritance, etc. define her wealth). In measurement theory terms, resilience capacity is a *formative*, rather than a *reflective*, construct. One of the consequences of this view is that we do not expect different indicators of resilience to be inter-correlated.

Specificity of resilience outcomes definition

Resilience manifests in response to adversity. Different forms of adversity call for specific manifestations of resilience. Although there are universal dimensions of resilience, we will pay special attention to its particular aspects in coping with breast cancer and its outcomes (e.g., body image or sexual functioning). We shall start our search for resilience capacity and resilient coping processes indicators from the end: by clarifying (via literature search and our own experience with patients) the exact list of relevant outcomes, including recovery, fatigue, depressive symptoms, growth, and overall quality of life.

Importance of both stable and malleable indicators

Indicators of resilience capacity can be stable or malleable. For example, age or disease stage cannot be altered by intervention, while life style or coping strategies can be changed. The goal of the BOUNCE project is to create effective interventions that would help breast cancer patients to cope with the illness, once we have a predictive model of resilience. For intervention purposes, only the malleable indicators are useful. However, we want to include both types of indicators in the conceptual model, in data collection, and in analyses – for two reasons. One is another important product of our work: knowledge dissemination – helping the involved parties to correctly assess the risk and choose the optimal ways of dealing with the disease. The other reason is that the stable indicators will serve as control, as well as moderating, variables in the statistical model. For example, we would like to know, to what extent psychological variables determine outcomes beyond the background or medical indicators. Therefore, data on all relevant risk/protective factors should be collected and analysed.

Importance of sample heterogeneity

Right at the start, we should specify, who is our target population in terms, for example, of ages, stage of disease, and recovery prospects. Once this is done, we should collect data on as heterogeneous a sample as possible, representing all the relevant sub-groups in the target population. We mention this, since researchers may seek to control for background heterogeneity by creating homogeneous **samples**. We believe that it is preferable in our case to rather use **statistical** control.

Selecting the measures of resilience factors

We have already done some work in looking at potential instruments for assessing resilience capacity and outcomes. First, we noted that in many theoretical and operational definitions of resilience, different facets of the Quality of Life (QoL) concept surface up as its indicators. We searched the literature for QoL measures used in cancer research in general, and in breast cancer research, specifically. One of them is **WHOQoL-100** (WHOQOL Group, 1998), the general-purpose instrument developed by WHO, covering

numerous potentially relevant domains that also appear in different measures of resilience. This can be supplemented by **QLQ-C30** (Aaronson et al., 1993), a specific measure tailored for assessing cancer patients, and further supplemented by **QLQ-BR23** (Sprangers et al., 1996), a module created for breast cancer patients.

There are also numerous instruments for assessing overall resilience capacity. Relying on existing reviews, we located about 20 popular measures. Having checked them for theoretical and psychometrical soundness, we chose five "runners up". Finally, we checked the extent, to which each of these instruments has been used in research with cancer patients in general, and with breast cancer patients specifically. The most reliable and fitting to the purposes of the study seems to be **The Connor-Davidson Resilience Scale** (Connor & Davidson, 2003), the most popular scale which our team has used in the past. We will continue to search for additional instruments, but we assume that some combination of these scales will make its way to our proposal for research measures.

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Appendix 0 Part 2

Notes from the meeting in Milan (February 15, 2018)

Participants

FORTH

Evangelos C. Karademas
Akis Simos

HUJI

Ilan Roziner
Ruth Pat-Horenczyk

HUS

Saara Halme

CHAMP

Luzia Travado (by skype)
Berta Sousa (by skype)

IEO

Ketti Mazzocco
Gabriella Pravettoni
Greta Pettini
Virginia Sanchini
Marianna Masiero
Flavia Faccio
Chiara Crico
Elisabetta Munzone

Main points of discussion

1. The definition of resilience

Ilan has already circulate notes on the definition of resilience and a file with the psychosocial measures to be checked and eventually integrated by the other clinical partners.

In particular, IEO has to provide more precise measures on functional variables

As from Ilan's email, the definition of resilience has been discussed and we agreed on the following definition:

“Resilience is a conglomerate of dynamic self-regulatory capacities that allow to mobilize and use internal and external resources over time in the face of adversity in order to maintain or promote wellbeing. The construct of resilience is used in three ways: (a) Resilience as a personal capacity or potential; (b) Resilience as an adaptive coping process or change trajectory; (c) Resilience as an outcome of maintaining healthy functioning and subjective well-being despite exposure to adversity.

Cognitive assessment

We discussed about the possibility to collect objective cognitive data with neuropsychological testing as proposed by Berta Sousa from CHAMP. The main issue is the length in time of the testing that seems not to be feasible considering the time necessary for the self-reported questionnaires and considering that this is not the main purpose of Bounce.

Few items on cognitive functioning will be add to the main questionnaire, but as self-report measurement.

Each clinical partner can decide to collect data also on this topic, on top of the 200 patients (60 for CHAMP).

Suicidal ideation

Consider to insert a question on suicidal ideation, in order to actuate the right actions if needed.

Measures Time Frame

The description of the time point(s) of assessment are specified in the excel file provided by Ilan (HUJI)

A face-to-face encounter between the patient and the “experimenter” should be considered for the main time points.

More frequent measures will be collected using Noona device.

A proposal for maintaining patients’ adherence to the study (especially for using Noona so frequently) is to phone call patients in order to monitor and motivate them.

Use of Noona Interface

Noona will provide a new version in English of the interface specifically for Bounce. Each partner will be responsible of the translation in their language.

E-literacy becomes an implicit inclusion/exclusion criterion.

2. Intervention

After discussion, all partners agreed that no intervention will be implemented in BOUNCE project. The sample is not large enough to guarantee enough power. Moreover, it is not a purpose of Bounce project to test an intervention, rather to use the results of the bounce pilot to create recommendations that can turn into a coherent intervention.

However, if partners are interested in it, they can recruit a subgroup of patients on top of the 200 patients needed for BOUNCE clinical pilot.

For the partners who want to test an intervention, Ruth and her team have a good standardized intervention model, they are more than happy to share.

3. Retrospective data

After discussion, all clinical partners agreed that we will collect retrospective data only if accessible directly from databases. On the contrary, accessing personal patients' charts to extract the data would require resources that we do not have. IEO will circulate the ethical protocol of the retrospective data.

Appendix D - The advanced measures proposal towards June 2018 meeting in Crete

Domain	Abbreviation	Measure name
Personality	TIPi	Ten Item Personality Measure (brief "Big Five")
	LOT-R	Optimism/Pessimism
Meaning	SOC-13	Sense of Coherence
	FACT-Sp-12	Spirituality
Trauma Exposure	PCL-5	PTSD Check-List
		Recent negative life events
		Recent illness-related events
Coping	PACT	The Perceived Ability to Cope With Trauma (Flexibility in coping)
	CERQ short	Cognitive Emotion Regulation Questionnaire
		MAAS - Mindfulness
		Spirituality coping - a visual bar
Social Support	mMOS-SS	modified Medical Outcomes Study Social Support Survey
	F.A.R.E.	1.Communication and cohesion; 2.Perceived family coping subscales
		Instrumental/emotional perceived social support
Resilience	CD-RISC	Connor-Davidson Resilience Scale
		How much are you back to yourself?
Illness Perception & behaviors	IPQ	Illness Perception Questionnaire - Items I1-I38 and C1-C18 = 3 last
	B-IPQ	Items no 3 and 4 from B-IPQ
	mini-MAC	Mental Adjustment to Cancer
		Single item: what has done to cope (open question)
	CBi-8	Cancer Behavior Inventory (self-efficacy in coping with cancer)
		A general self-efficacy item
		Satisfaction with care quality
		Adherence to medical advice: item 5 from MOS Adherence scale
Quality of life	PTGI	The Posttraumatic Growth Inventory - short form
	QLQ-C30	EORTC quality of life questionnaire
		Item 29-36—overall health and QoL items from EORTC30
	QLQ-BR23	EORTC quality of life questionnaire breast cancer module
Distress	FCRI-SF	Fear of Recurrence - short form (severity scale of original FCRI)
	HADS	Hospital Anxiety and Depression Scale
		NGON-Onkios-level thermometer
	PANAS	Positive and Negative affectivity - short form
		Suicidal ideation
Sociodemographics and lifestyle		
Physical functioning	SHR	Pain
		work capacity—days absent due to somatic symptoms
	FACT Fatigue	Fatigue scale
	FSFI-BG	Sexual Functioning
	PSQI	The Pittsburgh Sleep Quality Index—questions 2, 4, 5, 6—
		IBCSG-patient-reported symptoms form

		# of number of items at each wave of data collecti							
Doc #	Items	M0	M3	M6	M9	M12	M15	M18	M24
1	10	10							
2	10	10							
3	13	13							
26	212								
4	20			20		20		20	
0.1	1	1	1	1	1	1	1	1	1
0.2	1		1	1	1	1	1	1	1
5	20	20			20		20		
6	18	18			18		18		
7	15	15				12			
0.15	1		1		1		1		
8	8		8		8		8		
9	12		12		12		12		
0.8	1	1	1	1	1	1	1	1	1
10	10	10			10		10		10
0.4	1			1	1	1	1	1	1
11	56			56		56		56	
12	2		2	2	2	2	2	2	2
13	29		29		29		29		29
0.6	1		1	1	1	1	1	1	1
14	12	12							
0.7	1								
15	4								
0.11	1		1	1	1	1		1	
16	10		10			10		10	
17	30		30	30	30	30	10	30	30
0.8	23								
18	23		23	23	23	23	23	23	23
19	9			9		9		9	9
20	14	14	14	14	14	14	14	14	14
0.9	21								
21	10	10	10	10	10	10	10	10	10
0.4	21								
22	22	22						11	
0.12	21								
0.13	21								
23	23								
24	25								
25	*13								
	*19								
# ITEMS	365	156	144	170	183	192	182	191	132

The source

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MD Anderson Center

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The ILO group

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Public

YES <http://www.midss.org/content/ten-item-personality-measure-tipi>

YES <http://www.midss.org/content/life-orientation-test-revised-lot-r>

NO, contact Dr Avishai Antonovski (the son): avishan@openu.ac.il

NO, permission: <http://www.facit.org/facitorg/questionnaires>

NO Should be ordered from the National Center for PTSD at www.ptsd.va.gov

YES

YES

YES

NO contact <https://www.universiteitleiden.nl/en/research/research-projects/social-and-behavioural-sciences/cognitive-emotion>

YES, but report results to <https://sirkawarrenbrown.vcu.edu/wp-content/scales/MAAS%20trait%20research-ready%20%20in>

YES

YES, but contact Cathy D. Sherbourne; Phone: (310) 393-0411, x7216; Email: Cathy_Sherbourne@rand.org

YES

YES

NO, contact <http://www.connordavidson-resilience.com/index.php>

YES

YES, see <http://www.uib.no/ipq/index.html>

YES, see <http://www.uib.no/ipq/index.html>

YES, but probably we should order and pay for the manual: <http://www.karelo.com/register.php?RID=618&RT=10&Ev=15869>

YES

Behavior Inventory (CBI-B). *Psycho-Oncology*, 20 (3), 302-312.

YES

YES (generic items)

YES

YES, but a copy of the report/article should be sent to L. G. Calhoun or R. G. Tedeschi, Department of Psychology - UNC Charlotte

NO, permission required, see address in the manual

NO, permission required, see address in the manual

NO, permission required, see address in the manual

NOT clear, write to Sébastien Simard sebastien.simard@criucpq.ulval.ca

YES, probably - it's an old measure?

?

YES, see <http://www.midss.org/content/panas-x-manual-positive-and-negative-affect-schedule>

YES

YES

YES

?

NO, permission: <http://www.facit.org/facitorg/questionnaires>

YES, but better ask for permission: <http://www.fsfquestionnaire.com/>

YES, but changes only with permission: <http://www.sleep.ait.edu/research/instruments.html>

Availability and legal status by language							
IT	Public	PT	Public	FI	Public	IL	Public
Y	N	Y		?		Y	N
Y	Y	Y		Y	Y	Y	Y
Y	Y	Y		Y	Y	Y	N
Y	N	Y	N	N		Y	N
N		?		Y		Y	?
N		N		N		Y	Y
N		Y		N		Y	N
Y	N	?		Y	Y	Y	Y
		Y					
Y	N	Y		N		Y	Y
Y	Y	N		N		N	
		Y					
Y	N	Y		Y	N	Y	N
Y	Y	Y		Y		Y	Y
Y	Y	Y		Y		Y	Y
Y	Y	Y		N		Y	Y
Y	N	Y		N		N	
		Y					
		N					
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Y	Y	Y		Y	Y	N	
		Y		Y	Y		
Y	Y	Y		Y	Y	N	
Y	N	N		N		N	
Y	Y	Y		Y	Y	Y	Y
Y	Y	Y					
N		Y				Y	Y
Y	N	Y	N	Y	N	Y	N
						N	
		Y				2	