



Predicting Effective Adaptation to
Breast Cancer to Help Women to

BOUNCE Back

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BOUNCE NEWSLETTER



THE BOUNCE PROJECT AT A GLANCE: MEETING THE CHALLENGE OF A MULTINATIONAL PROSPECTIVE STUDY ON RESILIENCE

By Dr Paula Poikonen-Saksela, MD,
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The ultimate goal of the BOUNCE project is to provide adaptive decision-support algorithms and a digital tool to measure resilience of early breast cancer patients throughout oncological treatments and during the rehabilitation period. Optimally this would help clinicians to plan targeted psychosocial interventions customized to the needs of each patients at optimal timepoints during the course of treatment and recovery.

We are now just over the halftime of the project and an important milestone is reached since the 660 patients for the prospective clinical pilot study were recruited by December 2019. The interest and selfless dedication of participating women form the cornerstone of this study providing valuable information for the modelling of resilience and for developing the decision-support tool. In parallel with data collection, various stakeholder groups have been interviewed to develop a better understanding of how the decision-support tool could be implemented at hospitals and various other clinical environments and scenarios.

Many of the factors affecting resilience in breast cancer are common worldwide since they are related to personal and medical factors. In BOUNCE, we will also assess cross-cultural differences as participating centers vary from the public healthcare system of Finland to the hospitals of Southern Europe and Israel including also private hospitals.

Alongside resilience digitality is an important theme in BOUNCE as we are developing an IT tool for future use by clinicians but also as three out of four clinical study centers use the Noona tool for registering patient responses to various questionnaires and medical data. Noona was originally developed in Finland to support communication between patient and oncological professionals and to ensure timely reporting of oncological treatment side-effects-among other functionalities. Developing a massive questionnaire battery for Noona in several languages was a substantial effort in the beginning of BOUNCE and of course when developing something new some technical challenges have occurred. However pilot centers including the centers without any prior experience of Noona in Milan and Lisbon have used Noona without any major problems.




Coping with breast cancer is a major challenge. Thus, it is necessary for health professionals to help patients increase their psychological resilience toward better and faster recovery.

The BOUNCE project will explore the factors that influence breast cancer patients' resilience and their ability to resume a normal everyday life through cost-efficient clinical tools for patient empowerment.

BOUNCE develops and deploys advanced computational tools to validate indices of patients' capacity to bounce back during the highly stressful treatment and recovery period following diagnosis of breast cancer. Elements of a dynamic, predictive model of patient outcomes are incorporated in building a decision-support system to be used in routine clinical practice providing oncologists and other health professionals with concrete, personalized recommendations regarding optimal psychosocial support strategies.





The first set of data, recorded at baseline (i.e., following cancer diagnosis but before the onset of oncological treatments) and after 3 and 9 months, is now being analyzed by our team statisticians and modellers, who are expected to report preliminary results as early as at the end of this month. Dissemination of study results will accelerate accordingly as BOUNCE experts will participate in several symposiums and conferences and start composing research reports for health psychology, psycho-oncology and medical informatics journals. During the next eighteen months the data

collection in BOUNCE will continue as we will follow up participating women through their, hopefully successful, crucial recovery period. Longitudinal data is essential to facilitate mathematical modelling of individual patients' trajectories throughout this challenging period. As more data become available, the modelling team will continue their work with predictive models of resilience. These models are incorporated into the BOUNCE platform where they can be implemented and tested for specific cases by the team's clinicians.

PSYCHOSOCIAL PROFILES WOMEN UNDERGOING TREATMENT FOR BREAST CANCER THROUGH ADAPTIVE ALGORITHMS

By Georgios C. Manikis, MSc, Konstadina Kourou, MSc, Prof. Evangelos Karadimas, PhD, & Prof. Panagiotis Simos, PhD, University of Crete and Foundation for Research and Technology-Hellas (FORTH), Herakleion, Greece

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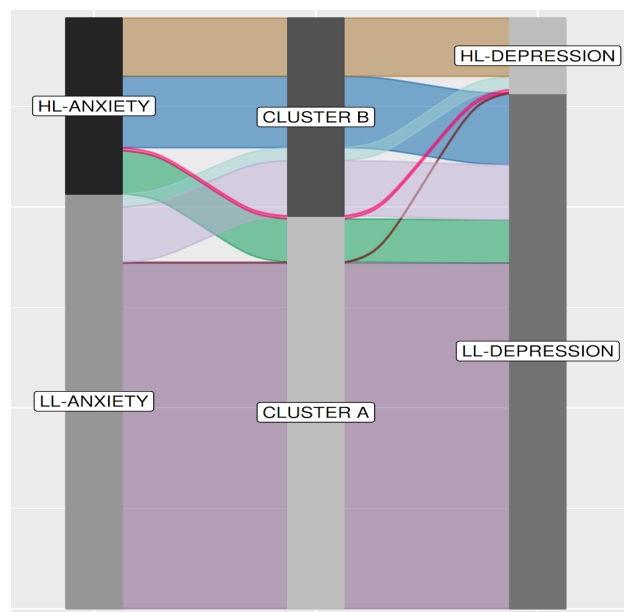
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Unsupervised clustering is one application of adaptive algorithms, whereby machine learning

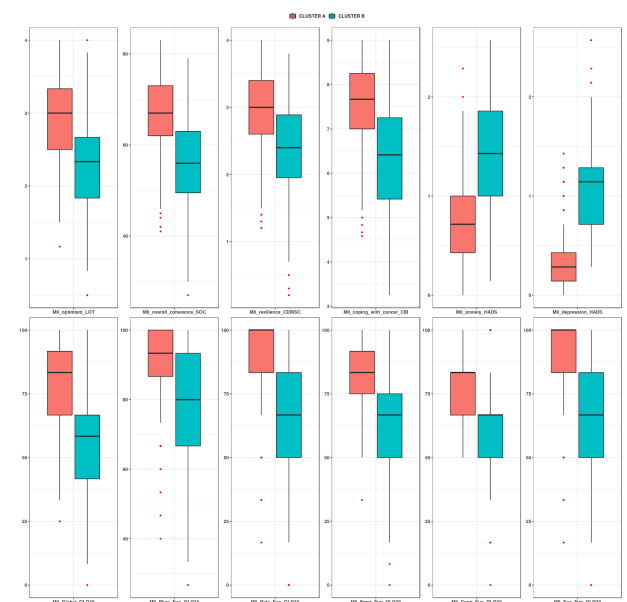
procedures are used to test the ability of exhaustive combinations of measured variables to group persons without a priori specification of neither the number of groups (or clusters) or the subset of variables that will contribute most to this “blind” grouping. Determining the optimal number of clusters is one of the most fundamental issues in cluster analysis and highly subjective to the criterion used for assessing clustering quality. Herein, models run multiple times over a loop with varying number of cluster choice and the optimal number of clusters was given using several internal validation criterion values.

Several unsupervised clustering techniques were applied to the baseline data (i.e., from Month 0 of the BOUNCE clinical pilot) from the four clinical sites, including partitioning based, hierarchical, fuzzy, and model-based. Twelve variables were fed into the models (including optimism, belief of events as predictable, overall self-perception of resilience capacity, anxiety and depression symptoms, perceived quality of life in physical, emotional, cognitive, social, and relational contexts). Several metrics were used to quantify the goodness of the clustering structure, including the Calinski-Harabasz, Dunn’s and Silhouette index, which converged in solutions of **two subgroups/clusters** present in the data set. The sparsity-based partitioning clustering technique (K-POD) was chosen for this cohort as it has shown slightly better results compared to other methods applied to the same dataset. K-POD relies on k-means clustering providing an analysis framework capable of handling various types of missing data distributions and sources. Clinical validation of clustering results was initially performed against clinically established cutoffs on the depression and anxiety symptom scales. [The adjusted rand index \(ARI\) was used under a permutation scheme to test the null hypothesis of random agreement between the cutoffs and the generated clusters.](#)

As shown in the figure below, Cluster B consisted of women demonstrating significant symptoms indicative of both anxiety and depression, whereas nearly all women in Cluster A reported non-clinically significant symptoms.



Closer examination of the distributions of scores on the 12 measures employed by the clustering algorithm, displayed in the figure below, indicated that in addition to anxiety and depression symptoms the two clusters displayed minimum overlap on the belief that life events are predictable and controllable (coherence), and perceived quality of life (mainly relational-social, and cognitive). Based on their psychological profiles, Cluster B was characteristic of **negative adaptation**, at least in this early stage of the illness, whereas Cluster A comprises women who display characteristics of **positive adaptation** to the illness.



Inspection of other cluster characteristics—not considered by the clustering algorithm—reveals that negative adaptation was more characteristic of women who **did not engage in regular physical exercise, were not in a relationship, and had experienced two or more significant life stressors in the past six months.** Interestingly,

adaptation at this stage of illness was not related to any other sociodemographic, life style, or psychological characteristic (of the several measured in the BOUNCE study). Taken together these findings highlight the **importance of**

integrating measurements over two or more successive time points spanning six or more months of the crucial early period of cancer treatments in order to make reliable personalized assessments of resilience capacity.

ENGAGING STAKEHOLDERS FOR A MORE SUSTAINABLE OUTPUT

By Riikka-Leena Leskelä, D.Sc, Ira Haavisto, PhD, Anna-Maria Hiltunen, M.Sc, RN, Suvi Karvinen, M.Sc, Nordic Healthcare Group, Helsinki, Finland

One of the principal goals of the BOUNCE project is to develop a decision support system that can predict the resilience trajectories of breast cancer patients. Understanding stakeholders' needs is crucial for the BOUNCE consortium – without that it would be challenging to develop a platform, which could become a routine tool in clinical practice. Only through a platform which is applicable in real world contexts, can the ultimate goal of benefiting as many breast cancer patients and health care professionals become reality.

Stakeholder feedback has been gathered during the autumn and winter of 2019/2020 in order to gain in-depth understanding of stakeholder needs and to assess the sustainability of the BOUNCE platform. To do this, the consortium has conducted workshops, and dissemination events and discussed with over 40 stakeholders (patients, IT professionals, health care professionals, patient organizations, and external business stakeholders) in Finland, Italy, Israel, and Portugal.

The feedback collected from patients and health care professionals confirms the unmet need for a tool that can predict a patient's resilience potential. Professionals treating breast cancer patients have stated repeatedly in discussions how

they would benefit from such a tool. However, they also voiced that extra attention should be aimed at the validation of the risk prediction algorithm, and the usability of the platform. Thus, care needs to be put into making the interface user friendly and visually compelling. Furthermore, the resilience prediction itself can only lead to increased value for the patients and professionals, if the service portfolio available to the patients is developed to include resilience-building interventions, and the professionals educated to utilize them. The consortium will continue to engage in discussions and develop the BOUNCE platform together with key stakeholders throughout the rest of the project.

The consortium wants to ensure the sustainability of the BOUNCE results and is currently working on the updated version of BOUNCE business plan. The aim of the business plan is to understand how the results could best reach potential end-users outside of the BOUNCE consortium. The market for predictive algorithms designed for clinical settings is still underdeveloped. Therefore, the market and business sustainability analysis currently conducted in BOUNCE will pave the way for other similar projects and innovations in the future.

BEYOND SCIENCE: HOW TO EMPOWER WOMEN WITH BREAST CANCER

By the HUJI Dissemination team

Empowering women battling with breast cancer is widely recognized as a crucial step toward a successful recovery. Emphasis on empowerment represents a growing trend worldwide aspiring to place the patient at the center of health care. Amidst various definitions of this concept a number of key components are universally recognized, including knowledge and skills (of the patient) and available procedures in the health care system that would enable the person to take control over their health care needs. Experts further stress the need to actively engage persons most likely to benefit in the process of defining empowerment. The breast cancer survivors who attended the BOUNCE

dissemination event at the Hebrew University, Jerusalem in Sept 2019, expressed their desire to be empowered by their physicians and other health providers by receiving timely information that would allow them to participate in decision making based on their capacity to understand. They acknowledged that having more detailed information of their health status, treatment options and alternative medical paths would be essential for empowerment. They also voiced the importance of an empathic approach by health professionals. The role of primary care physicians in the course of the illness and also in the more chronic care management was also emphasized.



Community-based networks and centers, including family, spiritual places, yoga classes, mentoring and volunteer groups for other survivors, were identified as ideal sources of support and empowerment, but also for imbuing meaning in their daily life. Interestingly, these types of community support groups were not only culturally sensitive to the needs of the individual patient, but also provided a platform for cross-cultural interactions and experience sharing, which created a sense of purpose and contribution to society despite the cancer diagnosis. See for example the case of two of our patient participants: <https://www.lilith.org/articles/across-the-barrier/>.

Studies on the use of technological tools to empower patients have demonstrated that co-

production of ICT tools is paramount. The health literacy of patients is a key factor in translating knowledge into practice, helping to establish an optimistic view of daily living but also to effectively interact with the health care system and participate in co-decision.

There are also policy reforms that could enhance empowerment by making accessible and affordable community-based “enabling” spaces for cancer survivors, where they can engage in physical activity training, and practice mindfulness and yoga exercises, and provide volunteer opportunities in their local communities. These types of activities have been shown to build a sense of self-esteem and well-being, contributing to resilience over the life span.



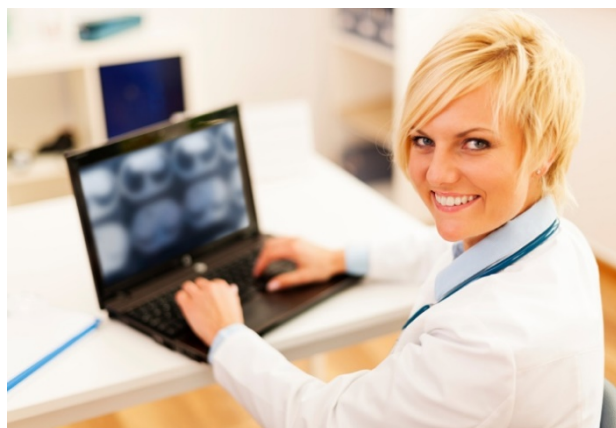
BOUNCE DISSEMINATION EVENTS

By the HUJI Dissemination team

The Jerusalem BOUNCE dissemination event focused on the sociocultural aspects of resilience. Cultural and religious beliefs concerning the causes and outcomes of breast cancer can have a strong effect on breast cancer patients' reactions to their illness and for their coping strategies. In particular, cultural values, customs, and norms greatly influence modifiable life style factors which, in turn contribute to building resilience. To introduce this important variable in the evaluation of resilience and the dissemination of the results of BOUNCE, we invited expert researchers to speak on how various cultural elements can impact on resilience. The event was attended by over 90 persons throughout Israel and Palestine, who closely followed special topics including:

- Physician Empathy and resilience in breast cancer patients
- The 'Steps to a Healthy Life'® project for healthy life style changes
- A round table Breast Cancer Survivors from various ethnic groups
- Bridging the gap for breast cancer persons – from health care system to the community
- From self- to dyadic-regulation: Chronic patients' efforts to understand and cope with illness and the role of their partners.





Ongoing activities by BOUNCE researchers in Israel

1. BOUNCE researchers are in the process of obtaining permission to create a dynamic end-user group of health professionals and breast cancer survivors from across the country. This highly motivated group will be invited to use the pilot version of the Decision Support tool to be built within BOUNCE in the context of both face to face workshops and on line Training Programs. This process will actively engage actual patients in the development of BOUNCE tool functionalities and interface elements.
2. Transcribed interviews with breast cancer survivors undergo qualitative analyses by social science experts toward a report on cultural elements of cancer survivors needs.
3. Training videos are known to have a great impact on both learning and motivation in health care. To address this need, BOUNCE experts in Israel are working with the Israeli National Cancer Society and other related NGO to develop teaching vignettes derived from videotaped presentations of health professionals involved in cancer care and cancer survivors.

BOUNCE PARTNERS



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