RIASE
REVISTA IBERO-AMERICANA DE SAÚDE E ENVELHECIMENTO
REVISTA IBERO-AMERICANA DE SALUD Y ENVEJECIMIENTO

HEALTH LITERACY:
THE REHABILITATION PROCESS IN BREAST CANCER

LITERACIA EM SAÚDE:
O PROCESSO DE REABILITAÇÃO NO CANCRO DA MAMA

ALFABETIZACIÓN EN SALUD:
EL PROCESO DE REHABILITACIÓN EN EL CÁNCER DE MAMA

Sara Vaz – Local Health Unit of Northern Alentejo EPE, Elvas, Portalegre, Portugal.
ORCID: https://orcid.org/0000-0002-7014-8356

Felismina Mendes – Department of Nursing, University of Évora. Comprehensive Health Research Centre (CHRC), Évora, Portugal.
ORCID: https://orcid.org/0000-0001-9518-2289

Corresponding Author/Autor Correspondente:
Sara Vaz – Local Health Unit of Northern Alentejo EPE, Elvas, Portugal. sarabaraovaz@hotmail.com

Received/Recebido: 2022-09-06 Accepted/Aceite: 2022-10-04 Published/Publicado: 2022-10-17

DOI: http://dx.doi.org/10.24902/r.riase.2022.8(2).567.274-307

VOL. 8 NO. 2 AUGUST 2022

ABSTRACT

Health literacy can be defined as the way people understand information about health and health care and how they apply this information to their lives, how they use it to make decisions and how they act based on this understanding. This concept becomes more relevant when we refer to vulnerable groups of the population, as is the case of the chronically ill, within this population were considered people with breast cancer. In Portugal, breast cancer is the most common tumor in women and, globally, is responsible for the greatest loss of healthy life expectancy compared to other types of cancer. Regarding the levels of health literacy in this population, it is thought that these are below sufficient. To respond to this reality, and from the reflection elaborated, it was built a plan to promote health literacy was developed, where measures and actions in the specific area of breast cancer rehabilitation are mentioned. The aim is to disseminate a proposed action plan and from it generate good health practices and a structured and planned care.
Keywords: Breast Neoplasms; Health Literacy; Rehabilitation.

RESUMO

A literacia em saúde pode ser definida como a forma que as pessoas compreendem a informação sobre a saúde, sobre os cuidados de saúde e como estas aplicam a informação à sua vida, como a usam para tomar decisões e como agem tendo por base esta compreensão. Este conceito toma maior relevância quando nos referimos a grupos vulneráveis da população, como é o caso dos doentes crónicos, dentro desta população foram considerados as pessoas com cancro de mama. Em Portugal, o tumor da mama é o mais frequente nas mulheres e, globalmente, é o responsável pela maior perda de esperança de vida saudável em comparação com os outros tipos de cancro. Relativamente aos níveis de literacia em saúde desta população pensa-se que estes serão abaixo do suficiente. Com o objetivo de dar resposta a esta realidade, e a partir da reflexão elaborada, foi construído um plano de promoção da literacia em saúde, onde são referidas medidas e ações, na área específica da reabilitação do cancro da mama. Pretende-se divulgar uma proposta de plano de ação e a partir do mesmo gerar boas práticas em saúde e uma prestação de cuidados estruturada e planeada.
Palavras-chave: Cancro de mama; Literacia em Saúde; Reabilitação.

RESUMEN

La alfabetización en salud se puede definir como la forma en que las personas entienden la información sobre la salud, sobre la atención médica y cómo aplican la información a sus vidas, cómo la usan para tomar decisiones y cómo actúan sobre la base de esta comprensión. Este concepto cobra mayor relevancia cuando nos referimos a grupos vulnerables de la población, como los enfermos crónicos, dentro de esta población se consideraron las personas con cáncer de mama. En Portugal, el cáncer de mama es el más frecuente en mujeres y, a nivel mundial, es responsable de la mayor pérdida de esperanza de vida saludable en comparación con otros tipos de cáncer. En cuanto a los niveles de alfabetización en salud de esta población, se piensa que estarán por debajo de lo suficiente. Para dar respuesta a esta realidad, y a partir de la reflexión elaborada, se construyó un plan de fomento de la alfabetización en salud, que incluye medidas y actuaciones en el ámbito específico de la rehabilitación del cáncer de mama. Se pretende difundir una propuesta de plan de acción y a partir de ella generar buenas prácticas de salud y una atención estructurada y planificada.

Descriptores: Alfabetización en Salud; Cáncer de Mama; Rehabilitación.

INTRODUCTION

There is a growing interest in public health research on the concept of health literacy and how it can influence health service reform processes. Health literacy is now considered to be one of the essential factors and determinants of individual and health service user health[1].

Health literacy can be defined as how people understand health and health care information and how they apply the information to their lives, how they use it to make decisions, and how they act on this understanding. Health literacy is especially important because it shapes people's health, safety, and care quality[2].

There are two distinct components within this concept, individual health literacy and environmental health literacy. The first concept incudes the person's skills, knowledge, and ability to access, understand, and apply information to make effective decisions about health and health care and take appropriate action[2]. It is important that the person gathers a set of theoretical knowledge and is also able to put it into practice.

On the other hand, environmental health literacy relates to the infrastructure, policies, processes, materials, people and their relationships that constitute the health systems and how they impact the access, understanding, and application of health-related information and services. These two components influence how people perform certain tasks, such as: reading, understanding and acting on health-promoting messages, care plans, medication instructions and other health information, making informed decisions about health and health care, and knowing how to navigate health systems and services, among others[2].

Currently, there are not many studies in Portugal on the issue of cost-benefits associated with health literacy. However, it is known that with long-term conditions such as cancer, diabetes, and cardiovascular diseases being the most prevalent and costly for the health system, health literacy can play a central role in their prevention and adhering to treatment plans once diagnosed[3].

People living with this type of chronic disease are commonly in the position of needing to monitor their condition and/or adjust their therapy, so health literacy takes on a role of special relevance here. Individuals with lower levels of health literacy have fewer skills in understanding their illness, its symptoms, and how they should monitor it[4].

People living with a chronic illness are often designated as vulnerable[5]. This designation is used because the person confronted with the chronic disease acknowledges its own mortality and becomes more dependent on others, not only the closest ones, but also rely on the help of professionals which increases their levels of vulnerability[6]. Chronically ill patients can be considered physical vulnerabie, experience emotional distress, and their situation causes cognitive uncertainty[7].

Research on the phenomenon of vulnerability in health care has several dimensions, one of which states that vulnerability is an existential phenomenon that is understood as a basic condition of life, another considers it a contextual phenomenon that depends on the situation and the cultural context. Finally, it can also be described as a relational phenomenon where the relationship with others can increase or decrease the feeling of vulnerability[5].

From a phenomenological perspective vulnerability is related to our bodily condition and we become more vulnerable when exposed to danger[5].

Vulnerability is a multidimensional concept associated with a conceptual diversity related to the material and moral fragility of the most marginalized individuals or groups in society. This diversity involves internal conditions (which determine an individual's defenseless state against an adverse shock) and external conditions (which an individual

cannot cope with), when these two components come together, the individual faces an increasing difficulty in coping with adversity and accessing universal rights, either due to lack of resources or discrimination due to age, gender, or geographic location[8].

There is no "single, sound vulnerability", that is, this concept cannot be understood categorically, there are several layers that can condition it, such as difficulties related to informed consent, human rights violations, social circumstances, and the characteristics of the people involved[9].

In the case of the vulnerability of the chronically ill, it is important to understand how these types of conditions are defined. In this sense, chronic conditions can be defined as conditions of prolonged duration and slow progression[10].

Chronic conditions are health problems that require continuous management over a period of years or decades. From this perspective, "chronic conditions" encompass a very broad and disparate category of health conditions. However, persistent communicable diseases (e.g. HIV/AIDS) and non-communicable diseases (e.g. cardiovascular diseases, cancer, and diabetes), psychiatric conditions (e.g. depression and schizophrenia), and ongoing changes in structure (e.g. amputations, blindness, and joint disorders), although seemingly different, can all fit into the category of chronic disease[10].

The transformation of cancer from a rapid and fatal disease to a condition that can be managed over time has transformed the definition of cancer as a chronic disease[11].

In 2020, 2.3 million women were diagnosed with breast cancer and 685.000 died from the condition globally. By the end of 2020, there were 7.8 million women alive who had been diagnosed with breast cancer in the past 5 years, making it the most prevalent cancer[12].

In Portugal, breast cancer is the most common tumor in women – 7373 new cases per year and the incidence rate increases considerably with age until 70, with about 60% of cases occurring between the ages of 45 and 69[13].

Treatment for this condition involves surgery, radiation therapy, lymph node removal, and systemic therapies (chemotherapy, hormone therapy, and in some cases biologic therapy). Globally, breast cancer accounts for the greatest loss of healthy life expectancy compared to other types of cancer[12].

After completing treatment most patients have a high number of side effects such as fatigue, weight gain, loss of functional capacity[14], lymphedema[15] or pain, all these sequelae have a great impact on the quality of life[16].

Upper limb morbidity following breast cancer treatments affects 70% of patients, physical therapy can reduce the incidence of prolonged pain and physical activity can reduce long-term functional disabilities[17]. Timely and appropriate rehabilitation is vital to the recovery of breast cancer surgery patients[18].

Thus, considering all the above this condition benefits from an informed and correct management by the individuals themselves so it is important to understand the levels of health literacy in this population. In a study conducted in the Portuguese population, 61.4% of the respondents had a problematic or inadequate level of general health literacy. Regarding gender, 16.4% of women were found to have inadequate literacy and 4.9% were found to have problematic literacy. When the analysis is performed considering the age group it was found that from 46-55 years the health literacy level is inadequate in 18.8% of the population and problematic in 52.1%, from 56-65 years it was considered inadequate in 26.2% and problematic in 41.5% and among 66-75 years, 25% is inadequate and 41.5% problematic[3].

Crossing the most frequent characteristics of breast cancer patients (gender and age) with the data on health literacy in the Portuguese population, it is expected that, overall, this population has a lower than sufficient level of health literacy. This is a problem to be considered since this population, being considered chronically ill, needs to have the necessary skills to manage their condition and the sequelae originated by it. It is also of interest to the Portuguese population that there is an intervention in this context, since one of the objectives of the National Health Plan is to increase the healthy life expectancy at 65 years of age by 30%. For this they suggest a focus on the 50-60 age group, namely for the disability-related disease burden[19].

In response to this reality, a plan for the promotion of health literacy was developed, which includes measures and actions in the specific area of breast cancer rehabilitation. This article aims to present a contribution to health literacy in vulnerable people about the rehabilitation process in breast cancer patients and simultaneously disseminate an intervention plan and from it generate good health practices and a structured and planned rehabilitation care.

STRATEGIC AXES

The strategic axes are intended to guide the intervention with the final objective of improving the quality of life, function, and well-being of people with breast cancer. For their definition, the ICF conceptual model was used as a basis. The ICF is a taxonomy and classification system that leads professionals to identify environmental factors (facilitators and barriers) that will influence the patient's ability to carry out the therapy session, will support interventions and will allow the user to use knowledge outside the formal therapy sessions[20]. In the context of breast cancer, the morbidity associated with the disease and its treatments may leave physiological, psychological, or behavioral sequelae, which potentially cause limitations in the ability to perform certain tasks and in social participation (Figure 1↗)[21].

Thus, three strategic axes were defined: health (related to the functions and structures of the body), social and work context (related to participation), and training and research (related to environmental factors) (Figure 2↗).

A. Health – Promotion of interventions that aim the integration of people with breast cancer into health services, decrease their physical sequelae, and that promote increased health literacy about their condition and self-management, enhancing their functionality.

B. Social and Work Context – Support initiatives aimed at increasing the social participation of these people and promoting safe work environments adapted to their needs.

C. Training, Research and Monitoring – Encouraging the strengthening of pre- and post-graduate training curricula on the topic of health literacy and its potential in clinical practice. Encourage the development of community intervention projects, scientific research projects and monitoring of results within the area of rehabilitation of people with breast cancer.

Strategic Axis – Health

Within the strategic axis of health there are two guidelines, the first, Health Care Management that aims to explore how people with breast cancer should manage themselves within health care and the entire management of their clinical process. The second guideline, Rehabilitation, refers to their physical recovery (Table 1↗, Table 2↗).

Strategic Axis – Social and Work Context

This strategic axis aims to promote the increase of social and professional participation of this group of individuals, this only has a guideline that aims to enhance the skills and overcome any functional limitation that remains. The measures and actions suggested are aimed at the individuals themselves, but also at their support network, namely family and social circle (Table 3↗).

Strategic Axis – Training, Research and Monitoring

The third and last axis, although it does not have an immediate consequence for people with breast cancer is central to maintaining the quality of services provided to any population. It is necessary to safeguard the monitorization and evaluation of health interventions so that they maintain their dynamic and evolving character. It is necessary to keep in mind that it is the obligation of health services to provide care based on the best available scientific evidence (Table 4↗).

EVALUATION AND MONITORING

The successful implementation of this type of plan requires the involvement and work of various entities. Therefore, all those that are important for the success of the intervention should be involved.

To ensure the proper implementation of this plan, it is imperative that it is subject to periodic evaluation, it is suggested that this be done quarterly, through those responsible for the project, and that it includes outcome indicators related to health professionals and the population to which the intervention is directed.

FINAL CONSIDERATIONS

Health literacy has been a very explored concept, which allows the acquisition of skills by the population on all dimensions of their health. This theme takes on special relevance when associated with populations considered vulnerable, in this case people with chronic diseases.

The presented intervention plan facilitates the acquisition of skills to enhance the functionality of breast cancer patients and also creates strategies for them to cope with their situation and be autonomous in their own management.

It also promotes health literacy on the importance of breast cancer rehabilitation in vulnerable populations and on the importance of actions and structured interventions in health, among health professionals and the general population. This integrated intervention plan allows all protagonists, individual and collective, to be involved so that the objectives of literacy and recovery are achieved and people with breast cancer resume their lives with the highest possible degree of autonomy. Increasingly, in health care, this is the most necessary and effective type of intervention.

In the case of people with breast cancer we considered three dimensions of priority intervention, health, social and work context and training, research and monitoring, which must be intervened based on health literacy, since it is expected that they will provide this population a full integration in society, avoiding costs and burdens to health services.

A limitation of this intervention plan is the fact that it was not discussed in a multidisciplinary context. The contribution of multiple health professions and the patients themselves would make it more complete. It is also extremely important that, at the end of the execution of this plan the results be public. This is important to understand whether or not they are in fact a good practice and an added value in health, and also to be aware of the necessary redefinitions.

Authors' contributions

SV: Study design, data collection, data storage and analysis, review and discussion of results.
FM: Study design, review and discussion of results.
All authors read and agreed with the published version of the manuscript.

Ethical Disclosures

Conflicts of Interest: The authors have no conflicts of interest to declare.
Financing Support: This work has not received any contribution, grant or scholarship.
Confidentiality of Data: The authors declare that they have followed the protocols of their work center on the publication of data from patients.
Protection of Human and Animal Subjects: The authors declare that the procedures were followed according to the regulations established by the Clinical Research and Ethics Committee and to the 2013 Helsinki Declaration of the World Medical Association.
Provenance and Peer Review: Not commissioned; externally peer reviewed.

Responsabilidades Éticas

Conflitos de Interesse: Os autores declaram a inexistência de conflitos de interesse na realização do presente trabalho.

Fontes de Financiamento: Não existiram fontes externas de financiamento para a realização deste artigo.

Confidencialidade dos Dados: Os autores declaram ter seguido os protocolos da sua instituição acerca da publicação dos dados de doentes.

Proteção de Pessoas e Animais: Os autores declaram que os procedimentos seguidos estavam de acordo com os regulamentos estabelecidos pelos responsáveis da Comissão de Investigação Clínica e Ética e de acordo com a Declaração de Helsínquia de 2013 da Associação Médica Mundial.

Proveniência e Revisão por Pares: Não comissionado; revisão externa por pares.

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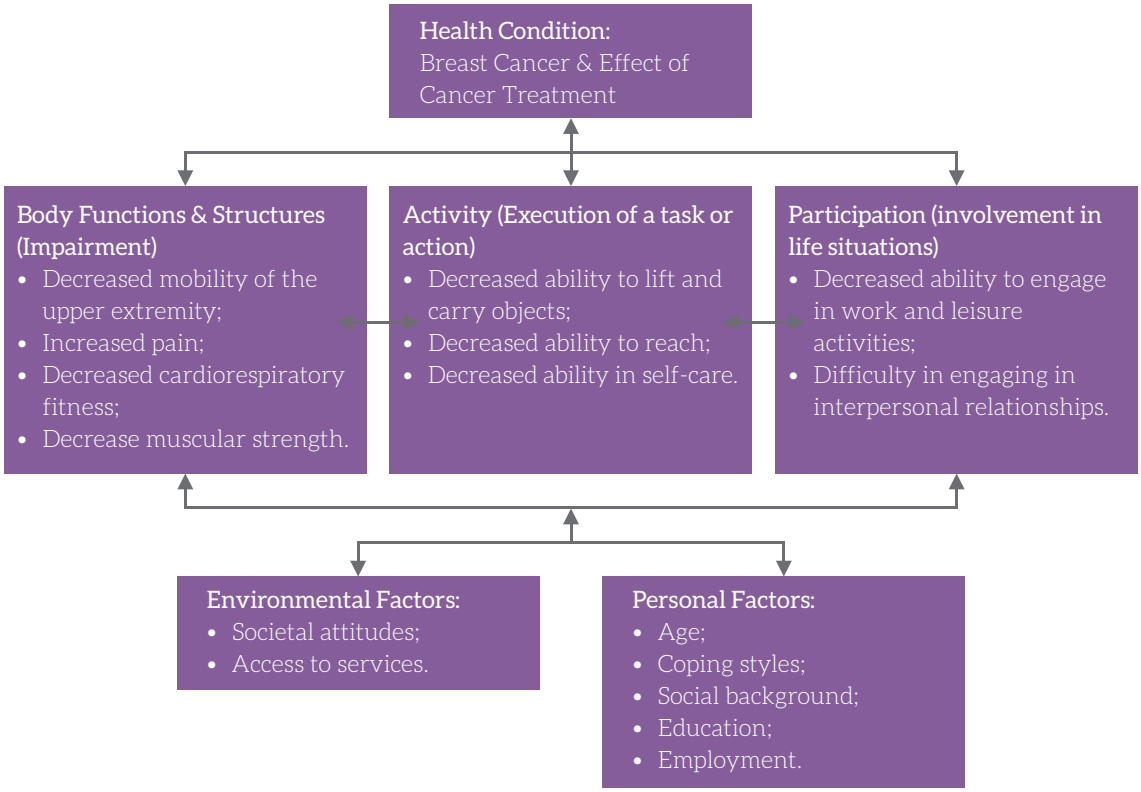

Figure 1 – A prospective model of care for breast cancer rehabilitation: Function[21].

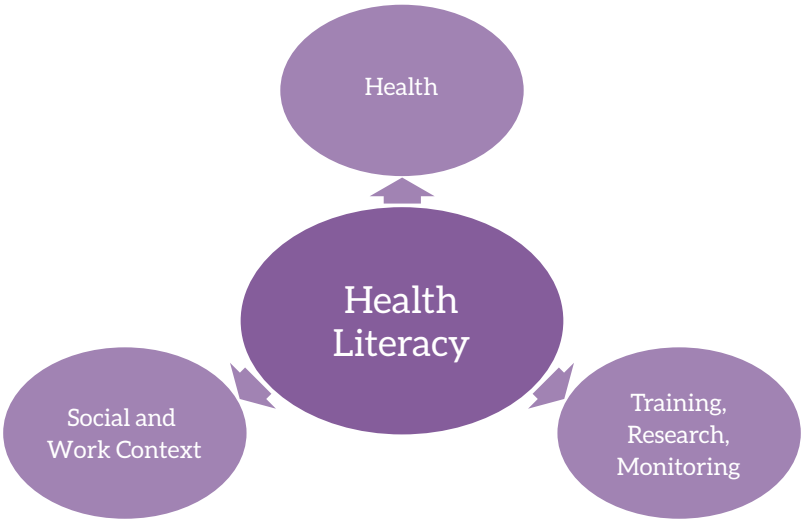

Figure 2 – Strategic Axes.

Table 1 – Health Care Management.

No.	Measure	Action
1	Guarantee the integration between the different levels of care and service provision with the goal of initiating interventions in a timely manner.	Create guidelines so that at the time of hospital discharge the person with breast cancer is referred for consultation with Physical Medicine and Rehabilitation; Build a system of positive differentiation based on vulnerability for these people so that they start treatment in time.
2	Promote the inclusion of clinical effectiveness indicators in care contracting programs.	Create indicators plan that encompasses functionality and quality of life.
3	Encourage specific training for health professionals in the area.	Develop a training plan for professionals that focuses not only on technical skills, but also on health literacy in this population.

Table 2 – Rehabilitation.

No.	Measure	Action
4	Promote the physical rehabilitation of the signs and symptoms resulting from breast cancer treatments.	Develop an intervention protocol based on evidence-based practice; Equip the Physical Medicine and Rehabilitation services with the human and material resources necessary for the intervention in people with breast cancer.
5	Encourage health literacy of these users so that they can recognize the warning signs and understand how to maintain the rehabilitation program in an autonomous way.	Insert moments of reflection/education about the condition of the user and his rehabilitation in all contacts with him.
6	Increase the functionality of the person with breast cancer.	Stimulate the performance of activities of daily living during the treatment sessions; Adapt the strategies used in clinical context for the daily life of the person with breast cancer.

Table 3 – Social and Labor Context.↖

No.	Measure	Action
1	Prevent social and work exclusion of people with breast cancer.	Programs for social interaction and sharing of experiences.
2	Encourage regular and adapted physical exercise.	Specific campaigns on physical exercise after breast cancer.
3	Facilitate work re-integration.	Define a training plan for companies, focusing on the adaptations necessary for the integration of people after breast cancer.
4	Decrease the risk of impairment of functionality due to altered clinical status.	Sensitize health professionals, family members and caregivers to the need for redirection.

Table 4 – Training, research and monitoring.↖

No.	Measure	Action
1	Promote continuous improvement of the quality of care.	Follow-up and monitoring of health gains; Prepare regular reports on the data collected.
2	Contribute to the improvement of the evaluation of the care provided.	Develop instruments that evaluate the impact of health literacy in the self--management of people after breast cancer; Promote the use of specific instruments for the area.
3	Encourage education about oncology and its rehabilitation.	Promote awareness actions to increase health literacy of the general population on oncological diseases, consequences, and rehabilitation.
4	Contribute to the increase of knowledge about rehabilitation in breast cancer with the aim of promoting evidence-based practice.	Development of scientific and multidisciplinary research projects on the subject; Define research priorities within the theme.
5	Promote the analysis and integration of the results of health gains in clinical practice.	Establishment of clinical guidelines on rehabilitation in breast cancer.