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**THE RIGHT TO LIFE AND QUALITY OF LIVING
OF WOMEN SUFFERING AND RECOVERED
FROM BREAST CANCER IN SERBIA¹**

The analysis of normative framework regulating health insurance and retirement as well as the findings of a qualitative empirical research confirm that women suffering and recovering from breast cancer in Serbia are facing a series of legal, social and practical obstacles that affect not only the quality of their lives, but their right to health as the essential aspect of the right to life too. In this paper, the aforementioned issue is addressed from two aspects: by analysing relevant national legal provisions pertinent to this field and by shedding the light on the experiences of women who passed through this struggle, with special focus on their problems and the providers of their support. As the result, suggestions are made regarding potential changes on legislative and practical level, which would improve the extremely vulnerable position of these women and strengthen the protection not only of their right to health but also of their mental and physical well-being.

Keywords: *the right to life, the right to health, health insurance, breast cancer, life quality*

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1. Introduction

The right to life, as a fundamental and indisputable human right, guaranteed by numerous international and national legislative sources, is inevitably related to a series of emotionally charged questions (Jovanović, 2020: 534). This particularly comes into focus in the context of the right to health as one of its crucial aspects and preconditions for its full enjoyment. Even more so, the right to health profoundly affects individual's quality of life not only on the medical but also on mental, social and economic level, which is the reason why it should be observed from a holistic perspective. Right to live and to health are intrinsically connected, and together with rights to physical and mental integrity, freedom, honor, reputation and personal identity form the basis of human dignity (Ljubičić, 2020: 406).

Unlike the medical conditions that have fatal outcome or those that do not leave permanent consequences on patient's physical and mental well-being, there are some diseases that cause long-lasting effects on various aspects of person's life throughout as well as after the treatment. Moreover, chronic diseases, such as cardiovascular diseases, cancer, diabetes and chronic respiratory diseases, tend to be the most frequent health issues in the modern society, especially in the developed world (World Health Organisation, 2020). Among these diseases, breast cancer represents the most common case in which patients survive, while still facing other obstacles affecting their full enjoyment of the right to live a life of good quality.

Being the fifth most frequent cause of cancer death, breast cancer is the most prevailing form of cancer and the primary cause of cancer-related mortality of women worldwide (Akram *et al.*, 2017; McPherson *et al.*, 2000). Latest World Health Organisation statistics show that there were 2,3 million women diagnosed with breast cancer and 685 000 deaths worldwide in 2020 (World Health Organisation, 2021). By the end of 2020, there were 7,8 million women alive who were diagnosed with breast cancer in the past 5 years, making it the world's most prevalent cancer (World Health Organisation, 2021). Breast cancer occurs in every country of the world in women at any age after puberty but with increasing rates in later life (World Health Organisation, 2021). Although breast cancer mortality rate did not vary significantly between the 1930s and the 1970s, the improvements in survival started in the 1980s in those countries that had early detection programmes together with various treatment modes designed to eliminate this disease (World Health Organisation, 2021). Nowadays, breast cancer stands for both - the cause of death as well as the factor that determines the quality of life of women.

The difference in breast cancer survival rates around the world, with an estimated 5-year survival varies between 80% in developed countries and below 40% in developing ones (Coleman *et al.*, 2008: 744-745). This indicates that there are many different factors contributing to the chance of survival, including, for example: social and economic circumstances, the general state of health system, the level of public awareness, education and sensitivity about this issue, the (un)equal position of women in a particular society and/or culture etc. Moreover, the rate of suicide among cancer patients is estimated to be twice higher than in general population, due to depression and feeling of hopelessness, which is particularly relevant in the context of the right to life (Anguiano, *et al.*, 2012: 14).

The quality of life is not a novel concept since it emerged at the beginning of the 20th century. It represents a complex multi-dimensional phenomenon that encompasses physical, mental, social and behavioural components (Čanković *et al.*, 2011:1). Health Related Quality of Life stands for a more specific concept that is focused on medical aspects (preventive health protection and medical interventions) of the aforementioned domains (Čanković *et al.*, 2011:1). The quality of life can be assessed from two different theoretical approaches: 1) standard one - based upon the needs, that perceives the quality of life as the level of fulfilment of universal needs; 2) psychological one - that dwell upon individual's evaluation of key personal aspects of life (Čanković *et al.*, 2011:3).

There are several studies comparing the quality of life of the breast cancer survivors on the one side, and general population on the other, confirming that the first have lower quality of life than the former (Lee *et al.*, 2011; as cited in: Lee *et al.*, 2012: 449; Schou *et al.*, 2005 as cited in: Lee *et al.*, 2012: 449). There are several reasons for such discrepancy and that is why the purpose of this paper includes: identifying main factors that contribute to lower quality of life of breast cancer patients; highlighting key obstacles that breast cancer patients in Serbia are facing nowadays; mapping the most important sources of support that breast cancer patients receive throughout their diagnosis, treatment and recovery; holistic insight into respondents' quality of life from their personal perspective, which represents a sublimation of challenges, obstacles and sources of support. Finally, the purpose of the research also included making suggestions and guidelines that are intended to contribute to the improvement of current situation in this field in Serbia.

2. Methodology

The complex and multi-faceted nature of the issue that is analysed in this paper required a multi-disciplinary approach to its various layers and aspects. For that reason, several methods were applied including the following: 1) doctrinal or “black letter” method; 2) case study; and 3) focus group interview.

Doctrinal or “black letter” method (Smits: 2009: 46) was used for the purpose of the analysis of relevant international and national legislative provisions (including international declarations, constitutional norms, laws, bylaws and strategic documents) relevant to the protection of the right to health in the Republic of Serbia with particular focus on the rights of breast cancer patients.

Focus group interview, as a qualitative research method refers to moderated group discussions of participants that are gathered around similar characteristics and experiences with the intention to discuss the issues relevant to the research topic (Đurić, 2007: 22). Focus groups include group discussions about a broader topic, problem or issue, which are guided and directed by a moderator (Ignjatović, 2020: 52).

Case study approach was used with the intention to highlight specific characteristics of patients’ association “Let’s be together”. Namely, the sample of this qualitative research includes only 7 women all of which are the members of the aforementioned association. That is the reason why it provides qualitative findings that are supposed to be interpreted solely as examples, without pretensions to be used as premises for any kind of generalisations or predictions in this field. Patients’ association “Let’s be together” was established in December 2010 as a humanitarian non-governmental and non-profit organisation that gathers individuals who have been affected by breast cancer as well as their family members, friends and other interested persons. The purpose of the association is to provide information and psychological support to women who have been diagnosed with breast cancer in order to facilitate their prompt return to normal life as well as to their families. The association actively promotes breast cancer prevention and education of women about the necessity of preventive and regular medical examinations.²

² For further information see: <https://budimozajedno.rs/o-nama>, accessed on 31.07.2021.

3. Identity and Narratives of Breast Cancer Patients

Concerning the specific identity of breast cancer patients, it is crucial to note that dichotomies are an important factor in socio-genesis of any kind of identity in general. Drawing symbolical boundaries between “Us” and “Them” or “normal” and “deviant” tend to produce stable sense of belonging to one group, together with feelings of solidarity towards its members and, under particular conditions, of hostility towards outsiders (Elias, Scotson, 1997).

Difference between the state of “illness” and “health” is on the other hand, much more dynamic in its nature (Ljubičić, 2016: 59-61). As it was already mentioned before, chronic diseases such as the breast cancer are considered as permanent, even in cases where patients have managed to overcome its consequences. Some female patients reproduce this notion by accepting this part of their self³, while others tend to see themselves as former patients. Third group, as it was reported, reject the very fact that they have cancer, and try to hide their health status (“I was trying really hard to appear as perfectly healthy women”), or even to persuade others that they don’t have this particular disease, or that they have some other (unknown) disease different than cancer (“A woman came here who underwent chemotherapy, radiation therapy, surgery... And she said: I don't know what I'm suffering from. How this can be possible!/? She doesn't want to accept it - she won't, she refuses”; “Women don't feel ready to face this problem... They don't want to hear about it... As if you have... plague”).

Although stigmatization of medical patients (from leprosy to AIDS), especially those who suffer from non-contagious conditions like cancer seems to belong to past centuries and pre-modern social conditions, women report that stigma is present to some degree:

“While I was undergoing chemotherapy, I experienced situations like this - when my neighbour saw me in front of her door, she grabbed her child and ran inside her apartment to avoid me. This really hurt my feelings... As if I was contagious. So, I told her - listen, darling, I am ill, but I am not infectious. If I was, I would have kept my own child away from me”

Unfortunately, this is not an isolated experience. Other respondents have confirmed that they have faced similar unpleasant reactions of random individual, particularly while

³ Sometimes with slight, but revealing semantic variations in discursive reproductions “I simply can’t say that I have *rak* (meaning literally cancer or crayfish in Serbian). It sounds so terrible. I prefer to tell that I have cancer - I feel that this is more acceptable”.

participating in public events for breast cancer awareness raising campaigns: “When we go out on public spaces - and she (passer-by) says - Shoo, shoo, don’t put a hex on me. I might get it from you! Keep it for yourself!”. This impression is even more evident in the following words: “When we present ourselves as women who were being cured, and hopefully healed from breast cancer, they (passers-by) return the flyers to us, as if they could get infected”.

Part of explanation why the identity of cancer, and especially breast cancer patients, is partially generated by an external stigma can be explained in the framework of Elias’ theory presented in his late study *The Loneliness of the Dying* (Elias, 2001, first time published in 1983). Elias proves, based on extensive historic and literary data and in the broader theoretical context of civilizing process, that in the past people were much more in direct touch with dying individuals, and with the very notion of death itself. Even though medically incompetent family members and friends were unable to offer adequate help, they still were deeply involved in the process and would do everything they could to save dying individual. In the case of failure, funeral and other rites were again performed primarily by relatives and close individuals. Development and specialization of medical profession, although drastically enhancing chances of survival, also has one latent and unforeseen consequence as well. Individuals have become more and more excluded from offering help to their close dying ones and the topic of death is more frequently considered a taboo. Lacking everyday familiarity with it, individuals tend to avoid other people who are in the risk of dying, regardless of the risk of infection. This altogether generates the rejection and the feeling of loneliness for the people who are (stigmatized as) dying. Like some of the respondents have confirmed in their own words:

“People are convinced that cancer means death. Like, you know, that cancer is not a curable illness, but death. That is where patients’ fear of rejection comes from. And that is mostly the reason why they hide their medical condition. Their families could reject them, and colleagues as well. Reasons are taboos and the lack of information”

“People are so fed up with their own sad lives, that they don't want to hear another sad story from some Vesna out there, who survived the hell of chemotherapy, surgery...”

Having in mind the fact that breast cancer is predominantly considered a female illness and life condition, some gender related issues should be tackled in this context. Some respondents reported that they are familiar with the cases where husbands rejected their

wives. Some of them left their partners, while others tried to deter them from surgery, or even suggested them to wear bra implants immediately after the surgery.

Since the majority of breast cancer patients are middle aged or elderly women it is important to draw a differentiation between health issues that are related to patients' age on the one hand and breast cancer as their primary disease, on the other. Two respondents pointed out that their quality of life is negatively affected by their general health issues, which appear as a consequence of their age, and not of breast cancer as their primary disease. On the other hand, some respondents intuitively and immediately relate their other health problems (headaches, spine and bone ache, fatigue, swelling, drastic weight and appetite variations etc.).

The fact that the majority of breast cancer patients are elderly women may produce ambivalent consequences on the quality of their lives. While some of them are close to an end of their professional carrier, have grown up and employed children, grandchildren as motivation and the source of everyday joy and so on, others lack this kind of material and emotional support. In some cases, cancer patients have to take care of their family members or to share their already insufficient incomes, which is the reason why they have to keep working, despite their disease. One respondent reported that she is familiar with the cases where women who receive chemotherapy go to work straight after the treatment, and give their best to look healthy, so that their colleagues would not notice that they are ill.

Besides the problems generated from the linear passing of time (women's biological and social life phases) certain problems arise for particular temporal circles, which are shared by all patients with chronic diseases, especially those with high risk of remission. In the case of breast cancer patients passing through regular medical examinations after the treatment (every six months at the beginning and annually later on) requires extensive engagement and sometimes serious financial expenses. Besides that, these time frames between one medical check-up and another generate a constant feeling of fear and uncertainty. As one of the respondents describes: *"We all live from one check-up to another. And we all have fear inside ourselves and she who says that she doesn't have it, doesn't tell the truth. The most important thing is not to allow this fear to take control over us, to overpower us, because then we have a problem."*

4. The Rights of Cancer Patients in the Republic of Serbia – Normative Framework and Practical Challenges for its Implementation

4.1 *International Standards regarding Health Protection and their Implementation in the Republic of Serbia*

Adequate, comprehensive, detailed but at the same time sufficiently flexible, normative framework regulating health protection represents the first step towards full enjoyment of the right to health and appropriate life quality that comes within. In the Republic of Serbia, normative framework regulating the right to health should be observed and analysed within a broader context, i.e., having in mind the obligation that our country has in accordance with ratified international agreements and as one of World Health Organization's (hereinafter: WHO) Member Countries⁴. However, one should also consider the fact that despite the normative framework there are some practical issues that the respondents tackled within this research, which undermine legislator's best intentions and actually represent obstacles for the application of essential normative standards in this field. For that reason, some of their statements are cited after the analysis of relevant legal provisions as a contrast between the normative and the practical aspect of the same topic - the right to health and quality of life.

As one of the most essential components of the right to life and, the right to health is proclaimed in several international documents, including **Universal Declaration of Human Rights** adopted in 1948⁵ (hereinafter: UDHR). This fundamental and inalienable human right is also confirmed by numerous activities conducted under the auspices of the UN General Assembly directed towards its worldwide promotion (Čiplič *et al.*, 2010: 771). According to Article 25 of UDHR:

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in

⁴ WHO Office in Belgrade, Serbia was first established in 1992 as a humanitarian aid office providing public health advice to United Nations agencies and humanitarian aid to vulnerable groups during the conflicts in the former Yugoslavia. On the grounds of a formal agreement between Ministry of Foreign Affairs of the Republic of Serbia and WHO, made in 2002, this office became a full country office and the focal point for all WHO activities in Serbia, WHO Regional Office for Europe, Serbia, <https://www.euro.who.int/en/countries/serbia>, accessed on 30.07.2021.

⁵ UN General Assembly, Universal Declaration of Human Rights, 10 December 1948, 217 A (III), <https://www.refworld.org/docid/3ae6b3712c.html>, accessed on 12.05.2021.

the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.”

In this provision of UDHR, it is actually proclaimed that the right to life is inseparable not only from the right to health (in the sense of being provided with adequate medical care) but also from the right to well-being, as a much broader concept, prescribing higher standards than mere „survival “and „health maintenance”. In the context of breast cancer patients, this is of crucial importance since it actually represents an international guarantee of their right to maintain or even upgrade the quality of their life, both - during as well as after their medical treatment, not only via means that they are given as the necessary minimum in compliance with the laws, but also in other disposable and recommended ways. To be more exact, this international legal provision provides space for breast cancer patients to claim support from relevant stake holders throughout the entire process of diagnosis, treatment and recovery, particularly in the spheres where the decline of the quality of their life is most strongly felt. For example, if interpreted broadly enough and in the favour of breast (as well as other) cancer patients (which, of course is in compliance with the very essence and the purpose of UDHR) the right to well-being should include their right to be provided with adequate, professional, continuous and free psychological support throughout the entire healing process and even after their recovery in purely medical sense.

4.2 The Right to Health as a Constitutional Right in the Republic of Serbia

The broader interpretation of the aforementioned international legal document is in accordance with Article 8 Paragraph 3 of the **Constitution of the Republic of Serbia**⁶ (hereinafter: CRS), prescribing that the provisions pertinent to human and minority rights are to be interpreted in the favour of the improvement of the values of a democratic society, in harmony with international human and minority rights standards as well as in accordance with the practice of international institutions in charge of their application (Article 8, Paragraph 3, CRS).

When it comes to constitutional guarantees of the right to health on the national level, it should be mentioned that Paragraph 1 of Article 68. of CRS proclaims that everybody has got the right to the protection of their physical and mental health (Article 68, Paragraph 1 CRS). Paragraph 2 of the same Article contains the list of the categories of citizens who are provided with health protection from public incomes unless they are accomplishing it

⁶ Constitution of the Republic of Serbia, *Official Gazette of the Republic of Serbia*, No. 98/2006.

otherwise, in accordance with the law. This refers to: children, pregnant women, mothers during their maternity leave and elderly citizens (Article 68, Paragraph 2, CRS). Moreover, in Paragraph 4 of the same Article, it is emphasized that the Republic of Serbia supports the development of health and physical culture (Article 68, Paragraph 4, CRS). Although these constitutional provisions are rather broad and do not explicitly mention cancer patients, they are crucial for appropriate interpretation of all other legal document pertinent to the protection of health and the promotion of patient's rights not only in the process of diagnosis and treatment but also within and after the period of recovery.

4.3 Law on Health Protection as Umbrella Law for the Protection of the Right to Health in the Republic of Serbia

The organisation of health protection system of the Republic of Serbia, citizens' health protection, general interest in the field of health protection and other issues related to the organisation and accomplishment of health protection as well as the monitoring of legality and regularity in this area in the Republic of Serbia are all regulated by the **Law on Health Protection**⁷ (hereinafter: LHP) (Article 1, LHP). In that sense, LHP proclaims key principles and standards in the area of health protection in our country and sets fundamental organizational framework for the functioning of medical institutions. In Article 3, LHP admits the right to the protection of health in accordance with the law to all citizens of the Republic of Serbia, as well as to foreign citizens and stateless persons with temporary or permanent residence in our country, obliging them at the same time to maintain and improve their own and other citizens' health and the appropriate conditions of living and working environment (Article 3, LHP). Again, although this provision might seem rather general and does not address directly the rights of breast cancer patients, it is worth mentioning due to its importance for the correct interpretation of all other legal provisions (contained in laws or sublegal documents such as bylaws, instructions, decisions etc.) regulating these issues.

Another general provision of LHP is very important for the promotion of the right to health, especially when it comes to cancer and particularly breast cancer patients: Article 8 of LHP prescribing the obligation of the Republic of Serbia, autonomous province and municipal units to provide so called "social care for citizens' health". According to Article 8 of LHP, "social care for citizens' health" includes a series of explicitly enumerated measures and activities such as: 1) health maintenance and improvement, prevention, revealing, suppression and control of risk factors contributing to the emergence of

⁷ Law on Health Protection, Official Gazette of the Republic of Serbia, No. 25/2019.

illnesses, 2) education of citizens about healthy lifestyle, 3) prevention suppression and early detection of diseases, 4) prompt diagnostics, timely, efficient and effective treatment, health care and rehabilitation of ill and injured persons, 5) informing citizens about the facts that are necessary for their responsible conduct and accomplishment of health care protection.

Some of these measures, which are supposed to be applied on the level of the Republic of Serbia are of particular relevance for cancer patients, not only in the phase of treatment but also in the period of recovery, since they include: (Article 9 and 10, LHP) 1) making priorities, planning, adopting special health protection programs and legal documents regulating this field, 2) application of measures within tax, economic, educational and cultural policies that are aimed to enhance the development of healthy living habits; 3) providing preconditions for the adoption of knowledge about and the practice of healthy lifestyle; 4) enabling the development of integrated healthcare information system in the Republic of Serbia; 5) developing scientific research in the field of health protection and 6) facilitating additional expert education of medical professionals.

Finally, Article 11 of LHP is also worth mentioning in the context of breast cancer patients' health protection since it emphasizes that social care for health is fulfilled through providing health protection for the citizens that are exposed to higher health risk, prevention, suppression, early detection and treatment of the diseases that are of greater relevance for public health as well as through health protection of socially disadvantaged citizens under equal conditions on the territory of the Republic of Serbia (Article 11, Paragraph 1 LHP). Moreover, is of particular importance to highlight that this type of health protection is guaranteed for the citizens who are more than 65 years old as well as for the citizens who have to be provided with special preventive medical examinations such as screening in accordance with appropriate national programs such as National Breast Cancer Early Detection Program, which is discussed in the section dedicated to future development of health protection in the Republic of Serbia.

Despite legislator's intention to regulate the area of health care in a precise and comprehensive manner, the experiences of the respondents who participated in this research indicate that there are still some practical issues that undermine full accomplishment of its key standards and principles. According to their statements, the most vulnerable point is the moment when therapy is over and the woman stays alone. As one of them said: *"When you finish with hospital treatment, you are transferred to the ambulance level. And then, you can't do any analysis at your local health care centre although you need to undergo a medical check-up every three months at the beginning.*

As soon as you finish with one control, you have another. That is the moment when you feel completely helpless. Until then, someone used to take care of you, and what now?"

4.4 Law on Patients' Rights as the Ground for Guarantees of Patients' Rights Protection in the Republic of Serbia

Law on Patients' Rights⁸ (hereinafter: LPR) promulgates a series of general patients' rights, some of which are of particular relevance for breast cancer patients, including the right to: 1) accessibility of health protection (Article 6, LPR), 2) relevant data (Article 7, LPR), 3) preventive measures (Article 8, LPR), 4) health service quality (Article 9, LPR), 5) safety (Article 10, LPR), 6) being informed about the fact that are necessary for decision making about the application of a proposed medical measure (Article 11, LPR), 7) freedom of choice (Article 12, LPR), 8) second expert opinion (Article 13, LPR), 9) privacy and confidentiality (Article 14, LPR), 10) decision-making (Article 15, LPR), 11) insight into medical documentation (Article 20, LPR), 12) confidentiality of data related to his/her medical condition, 13) leave medical institution on his/her own responsibility (Article 27, LPR), 14) relief of pain and suffering (Article 28, LPR), 15) respect of his/her time (Article 29, LPR), etc. On the other hand, LPR also stipulates some duties and obliges the patient to maintain a responsible approach to his/her health, other medical services beneficiaries, medical workers and other employees in public or private medical institutions, as well as to respect relevant normative acts regulating the conduct in this field (Article 32, LPR). In addition, LPR suggests that a patient should play an active role in the process of the accomplishment of his/her health protection by: 1) actively participating in the protection, preservation and improvement of his/her health, 2) providing medical workers in charge with complete and accurate information about his/her health condition and 3) following the instructions and implementing the measures prescribed by relevant medical experts (Article 33, LPR).

Apart from promulgating general rights and duties of patients, LPR also provides a mechanism for their protection, by prescribing that patients' rights are provided on the level of local administration units (Article 38, LPR) through the activities of patients' rights counsellors – jurists who passed necessary exams for working in state administration bodies, who are familiar with legislative framework regulating the area of health protection and who have at least 3 years of working experience in the field (Article 39, LPR). It is also important to note that LPR prescribes adequate administrative offences

⁸ Law on Patients' Rights, *Official Gazette of the Republic of Serbia*, No. 45/2013 and 25/2019.

and appropriate punishments for the activities that represent the violations of patients' rights (see for example: Article 44, 45, 46 and 47, LPR)

4.5 Disability Pension and its Challenges for Breast Cancer Patients in the Republic of Serbia

Law on Pension and Disability Insurance⁹ (hereinafter: LPDI) is also relevant for the protection of health and life quality of breast cancer patients, particularly having in mind the fact that the majority of them have to leave their employment and go to disability pension due to their medical condition.

In accordance with Article 21 of LPDI, disability emerges when an individual's complete lack of working capability is determined due to the changes in his or her medical condition caused by: injury at work, professional illness, injury that was not caused at work or illness that cannot be cured by medical treatment or rehabilitation (Article 21 LPDI).

According to Article 25 of LPDI, it is possible to receive disability pension up until the age required to realize the right to old age pension. In cases where complete lack of working capability is determined, provided that: 1) the reason for disability is injury at work or professional disease, regardless of the length of pensionable service 2) the disability is a consequence of disease or injury unrelated to work, in which case at least five years of pensionable service are required. However, in accordance with Article 26 of LPDI, the aforementioned requirements are not applied to individuals who became disabled before the age 30: 1) for individuals aged 20, at least one year of pensionable service is required; 2) for individuals aged 25, at least two years of pensionable service are required and 3) for individuals aged 30, at least three years of pensionable service are required.

The procedure for the accomplishment of rights on the basis of disability is initiated upon the request of the individual, based upon the proposal made by his or her chosen doctor for the determination of disability and in accordance with the law (Article 94, LPDI). Nevertheless, an individual who is entitled to receive disability pension may lose this right if the circumstances on the basis of which he or she obtained this right changed. The changes that affect the right to disability pension are determined in a special procedure

⁹ Law on Pension and Disability Insurance, *Official Gazette of the Republic of Serbia*, No. 34/2003, 64/2004, 84/2004, 85/2005, 101/2005, 63/2006, 5/2009, 107/2009, 101/2010, 93/2012, 62/2013, 108/2013, 75/2014, 142/2014, 73/2018, 46/2019, 86/2019 and 62/2021.

that can be initiated either upon the request of the individual who this right was given to or *ex officio* (Article 96, LPDI; see also: Article 115, LPDI).

The fact that the patient may lose his/her right to disability pension depending on the circumstances might also cause some serious problem in practice. The respondents who participated in the research the results of which are presented in this paper, agreed that once their disability is confirmed, they have to quit their job, which is logical since they start receiving disability pension. However, if the circumstances change after some time and they manage to fully recover, they might lose the right to receive disability pension. But, at the same time, if they lose the right to disability pension, they are not automatically returned to their former employment, which actually means that in such cases, they might remain without any sources of income. As one of the respondents described: “At one moment, you are officially declared as disabled, and then, in a couple of years you are not disabled anymore”.

According to respondents’ impressions, disability pension has got both – advantages as well as disadvantages, depending on individual’s overall economic, social, marital and family status. One of key disadvantages of disability pension that breast cancer patients have to face is the decrease in their monthly incomes. This becomes particularly challenging if one takes into consideration the expenses of treatment and recovery of breast cancer patients, as well as the fact that a significant number of them are left on their own, without family members who could provide them with financial support. As one of the respondents reported:

“Disability pensions are really small and most women barely make ends meet. Plus, there are medical examinations... I don’t have this problem, since my family members provide me with financial support, but I give my best not to take advantage of that.”

On the other hand, some of the respondents saw numerous advantages in disability pension, primarily due to the fact that it provided them with a lot of leisure time that they could dedicate to themselves, their physical and mental recovery and personal growth. One of the respondents described this in the following manner:

“I am really satisfied. I am very active in various fields, not to mention all the things I do. I practice rowing and shooting sport. and I attend our association’s meetings twice a week. I also go out, as much as it is possible due to COVID situation. But all that is possible thanks to the fact that I have disability pension. And I have taken disability pension thanks to my

illness. It sounds strange but it is true. I can thank to my illness for disability pension and the abundance of time that I have now, for all the activities I'm interested in. And I find that rather pleasant."

4.6 Future Prospects of Health Protection of Breast Cancer Patients in the Republic of Serbia - Program and Strategic Documents

One of national programs for social health protection is the **National Breast Cancer Early Detection Program** (hereinafter: NBCEDP), announced by a special Regulation in 2013¹⁰. NBCEDP introduces a series of guidelines and instructions for the implementation of activities aimed at the improvement of health, minimization of mortality caused by breast cancer and enhancement of life quality of women (Article 1, Regulation on NBCEDP). Key goal of NBCEDP is the minimization of mortality caused by breast cancer in the Republic of Serbia, whereas its specific goals include: 1) raising awareness of women on the importance of regular medical examinations and early breast cancer detection as well as on the importance of screening; 2) strengthening the capacities of medical institutions for the application of screening in the terms of sufficient number of trained professionals and adequate equipment; 3) establishing a system of data collection and management during the screening process; 4) providing services' quality control throughout the screening process; and 5) including local self-government units and citizens' associations in the application of screening (NBCEDP, Sections 3.1. and 3.2.).

Public Health Strategy of the Republic of Serbia 2018-2026¹¹ (hereinafter: PHSRS) mentions breast cancer in the context of prevention and suppression of diseases and leading health risks (Section 4.3. PHSRS). To be more exact, PHSRS stipulates continuous improvement of health protection programs in several areas, including prevention, suppression and early detection of colorectal, cervical and breast cancer (Subsection 4.3.3.3. PHSRS). PHSRS is also familiar with screening and considers it a measure of secondary prevention directed towards early detection of disease, together with self-examinations and preventive medical examinations (Section 1. PHSRS).

¹⁰ Regulation on National Breast Cancer Early Detection Program, *Official Gazette of the Republic of Serbia*, No. 73/2013.

¹¹ Public Health Strategy of the Republic of Serbia 2018-2026, *Official Gazette of the Republic of Serbia*, No. 61/2018.

5. Key Sources of Support for Breast Cancer Patients in Serbia

Apart from institutional (at first place medical) support which is regularly conducted within the norms prescribed by previously described legislative framework, another kind of support appears to be crucial for breast cancer patients – throughout the treatment as well as within the recovery process: the emotional support of persons around them including: family, friends, colleagues, neighbors as well as the entire community.

The majority of respondents agreed that they received the strongest support from their family members. However, this statement should be interpreted with certain limitations. First of all, all members of patients' association "Let's be together" who participated in the research (apart from one participant) have families and have been receiving their support throughout the entire process of breast cancer diagnosis, treatment and recovery. Moreover, according to the statements of the respondents, the support provided by each family member was of a different kind and sometimes it did not appear to be as helpful as it was genuinely intended to be.

For example, one of the respondents described the response of her family members to the fact that she was undergoing breast cancer therapy in the following way:

"My husband used to close himself in the bathroom and cry when they told him I had cancer. Because we all had this scenario in our heads, because we all watch movies, when she receives chemotherapy, she gets bold, loses weight and dies. For the first month or so, my husband was crying all the time. I could not rely on him at all. On the contrary, my daughter was very strong. When I lost my hair, she used to call me 'messy-haired', she accompanied me to chemotherapies, medical check-ups... she went everywhere with me. Of course, my whole family supported me – parents, brother, entire family."

In certain cases, however, the respondents perceived the fear and anxiety of their family members as a burden. As one of them said: *"I had to fake that I'm OK in front of my mother. After finding out that I had cancer, we spent two hours at a coffee shop, trying to figure out how to tell my parents about it. I was more focused on the intention to protect them."* Similarly, one of them explained: *"We are the ones who had to stay in our position. We got what we got, so let's fight it. And those around us had only fears and the question – What will happen?"*

On the other hand, exaggerated care and attention of family members was perceived as almost offensive by some respondents. For example, one respondent described that she

perceived the offers of her relatives to help her with house chores as too assertive or even pushy and that it made her feel as if she was incapable of doing anything by herself. That was the reason why she kindly rejected them, with the excuse that she would call them if necessary. Like she said: *“When my relatives offered me their help, to bake something, I told them – don’t make a disabled person out of me. I will call you in case I cannot make it.”*

In some situations, the support of close persons or family members was missing, which deeply affected the respondents, making them feel disappointed and offended. For example, one of them described with sadness and disbelief: *“When I was making plans for the holidays, my best maid told me – Keep quiet and stay where you are – you don’t know if you will survive until summer and you are still planning vacation.”*

The respondents agreed that, apart from their family members, the greatest source of psychological and emotional support for them was (and still is) their association “Let’s stay together”. As they said: *“A woman enters the room and you can see that she’s completely lost... The woman who enters the room and the one who leaves it is not the same person.”* One of the respondents described, the most inspirational moment for her at the association was when she met a woman who was undergoing chemotherapy 14 years before. It really encouraged her and inspired her to help other women and when they asked how much time has passed from her chemotherapy, she proudly says – 18 years.

One respondent emphasized the importance of sharing the same experiences with other members of the association, but without the obligation to constantly discuss their medical conditions: *“It was a revelation for me to realise that we don’t talk about the disease here. And I learned so many positive things and some new skills and hobbies. You come back to yourself... We got closer, became friends. Like a family. Nobody can understand you as well as the one who has passed through all that stuff.”*

Another significant source of support are the sports activities, i.e., dragon-boat rowing that some of the respondents attend together. Apart from being beneficial for their physical condition, these activities offer possibilities for establishing new and strengthening existing social bonds among breast cancer patients, which larger contributes to their mental and emotional recovery as well. Team spirit and the support of the community boost their self-esteem and increase their motivation for further progress. As some of the respondents said:

“There (at the rowing club) we get everyone’s support. There are children who are less than 10 years old, but also those who are over 70. We really found warm welcome there. Not only by the club, but also by the rowing federation. We won gold medals, which for us... We received carbon paddles, which aren’t too heavy for us, free trainings, training kits, hanging out together, nature... Beautiful”.

The following suggestions made by respondents clearly depicts how much this kind of support means from the perspective: “This truly is a positive example that should be followed by other sports as well. And not only sports, but... Psychologists as well, like we discussed”. Other similarly good examples include free entrance to the Botanical garden, river cruising, free concert tickets, donations in basic cosmetic products, especially those that are safe for oncology patients etc. Another important source of support highlighted by respondents encompasses free individual and group session with a professional psycho-therapists. This is of particular importance since the official health system does not provide the scope of psychological assistance that is suitable for persons in this kind of life situation, and the patients often can not afford the services of private psycho-therapist.

One of the decisive moments within the process of breast cancer patients’ inner healing definitely is the point at which they start setting personal boundaries and claim their emotional autonomy. For example, one of them said: *“This disease has taught us to say - I don’t want to do that. Not to say - I can’t do that, but - I won’t do that. And to put ourselves first”*. Furthermore, they confirm that this insight has inspired them to introduce some profound changes into their everyday patterns of behaviour and thinking. As one of the respondents thoroughly explained:

“For me, leisure time is the most important thing. Not in the sense that I have given up life, but that I have the priorities that I find acceptable. I carefully weigh what suits me - where I stand in the entire situation. Before, I used to put myself on the last place. Now, I give my best to do what suits me, I adjust myself to my own possibilities and not to other persons’ aspirations. I don’t train endurance any more, like I used to and then I would collapse, but I also don’t give up easily. For me, time is the key thing after taking care of my health”.

6. Conclusions and Recommendations - Physical and Emotional Recovery as an Effort to Fully Enjoy the Right to Life

Despite the fact that both - academic community as well as general public are usually focused on its medical aspects, the consequences of breast cancer undoubtedly reach beyond the borders of medicine, making it a complex multi-faceted phenomenon that deeply affects all spheres of patients' lives and seriously threatens not only their survival, but also the quality of their everyday living. Physical, mental, emotional, social, financial, legal, gender and family issues all emerge as the repercussions of this disease, requiring a holistic approach not only to its medical treatment, but also to its general perception on individual and public level.

Timely, adequate and comprehensive support provided by relevant medical state institutions throughout the entire process of diagnosis, treatment and recovery of breast cancer patients represents a key precondition for the accomplishment of their constitutionally and legally guaranteed right to health, as one of the most important aspects of the right to life. However, although the analysis of current normative framework relevant to health protection indicates that this area is fully regulated and organised, the results of qualitative research that are presented in this paper show that there are some obvious lacks and discrepancies between the normative and the practical, causing serious problems for breast cancer patients and deeply affecting their quality of life on several different levels. Such situation requires a series of synchronised activities that would bring positive changes in all sectors relevant to this issue, including: health care centres and institutions, bodies in charge of the rights of patients, state institutions in charge of pension and health insurance, as well as other relevant stakeholders such as public health policy makers, the media, non-governmental organisations and, finally the entire community. Although such activities are planned within strategic documents that have been analysed in this paper, practical experiences of the respondents of this research suggest that they still have not resulted in some radical improvements.

The results of qualitative research presented in this paper imply that key source of problems in this area comes from the lack of knowledge and information about the problems and needs of breast cancer patients. Namely, ignorance raises fear and the feeling of discomfort, particularly among the members of the broader community. In some cases, this fear may induce prejudice, discrimination and stigma, all of which additionally decrease the quality of life of an already vulnerable group. In that context, the media should be considered a suitable channel for the distribution of relevant information and sensitisation of the broader public about this topic. That the reason why

raising awareness of all relevant subjects is of utmost importance for overcoming the aforementioned obstacles on their road to full recovery and (re)claiming the right to live their lives.

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