

# How to support patients with BRCA genetic mutation? Research review

Sylwia Michałowska

## Summary

**Objective:** According to research conducted so far, the detection of a genetic mutation that increases the risk of developing cancer may be associated with feelings of discomfort, anxiety and apprehension, so it is important to know the needs and expectations externalized by those patients who face the challenge of coping with information about cancer risk. This analyzes the results obtained on this subject in recent studies.

**Material and methods:** The results of 11 studies conducted in the years 2000-2018 were analyzed. To achieve this aim, the EBSCO, PubMed, PsychARTICLES and MEDLINE databases were searched through.

**Results:** The results obtained show that both male and female carriers of BRCA mutations have specific support needs. They usually look for valuable content, including information on the procedure for conducting the genetic test and the consequences of obtaining a positive result. Social as well as therapeutic support are also significant. Patients who participated in psychotherapy assessed this form of help as valuable and necessary, especially in relation to the decision making process regarding surgical treatment.

**Discussion and conclusions:** Support programs for patients with BRCA mutation implemented around the world have a chance to become an inspiration for the introduction of similar solutions tailored to the needs of patients in Poland, which could lead to an increase in their involvement or shall contribute to reduction of anxiety or distress resulting from having a genetic mutation.

**psychotherapy, support group, BRCA1, BRCA2, gene mutation**

## INTRODUCTION

Genetic counseling, belonging to informal groups or psychotherapy? What kind of support need patients undergoing genetic testing for BRCA1 and / or BRCA2 gene mutations? What do they expect? What do they find helpful when dealing with the test result and what actions could be the most appropriate form of help for them?

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Sylwia Michałowska<sup>1</sup>: <sup>1</sup> Department of Clinical Psychology, Institute of Psychology, University of Szczecin, Szczecin, Poland

Correspondence address: sylwiimichalowskiej@gmail.com

A positive genetic test result means that the genes multiply in an uncontrolled manner, which leads to an increased risk of developing breast or ovarian cancer. Research conducted in recent years has clearly shown that cancer patients need not only formal support in the form of reliable knowledge and information about the course of treatment, but also seek reinforcements among family and loved ones and use the help of specialists – a psychologist, psycho-oncology, or psychotherapist. The situation associated with the appearance of the disease can be a moment of imbalance and sometimes involves the search for various forms of support,

including psychological support, implemented, among others in the therapeutic process. A special type of disease are diseases with a negative prognosis, bearing the hallmarks of fatal diseases or largely associated with experiencing pain or complex and long-term treatment. Such diseases include cancer. A study conducted in 2013 by Pawlik and Karczmarek-Borowska showed, among others, that at the time of diagnosis of breast cancer as many as 92, 59% of the examined women did not accept the disease [1]. This may mean that adaptation to a new life situation, conditioned primarily by the experience of the disease, does not occur automatically, but rather is a process. The functioning of the ill person is subject to a number of changes. In addition, patients often struggle with chronic fatigue, which in turn contributes to a decrease in motivation to act or loss of interest. Many researchers focus on the protective function of support. Particular importance is attributed to social support, which according to it may affect the subjective experience of stress [2]. The effectiveness of psychotherapy as well-established method of treating patients struggling with mental crises is beyond doubt. More and more attention is currently being paid to the value that the therapeutic process in the relationship between the therapist and a somatically ill patient, especially an oncological patient, may bring. There are also discussions about the specifics of support that is provided to people suffering from cancer and the effectiveness and legitimacy of its use. It still seems important to come back to the question about the differences between a client of a psychotherapist and a client of a psycho-oncologist therapist [3].

Knowing that chronic somatic diseases, especially cancer, are associated with the need for additional social, therapeutic or psychotherapeutic support, it seems reasonable to verify whether similar needs apply also to those who have not yet been formally diagnosed, but they are aware of the significantly increased risk of getting sick. This concerns, among others, persons in whom BRCA 1 and / or BRCA 2 gene mutations have been detected. Inheriting a damaged copy of this gene causes an increased likelihood of developing breast cancer or ovarian cancer [4]. Indicated needs in such situation include providing appropriate support, especially to those pa-

tients whose positive genetic test result exceeds the perceived possibilities of coping with it [5].

## METHOD

This work is an analysis of research aimed at verifying the level of satisfying the needs related to patient support in various contexts – such as genetic counseling, belonging to informal support groups, participation in psychotherapy or emotional support provided by family members and friends.

In order to include in the review the most important for the described topic studies, some elements of the systematic review method were used. The application of the method was limited to specific research stages, such as formulation of research questions, development of a strategy for searching literature on the subject and databases, selection of research based on predefined criteria for inclusion and exclusion from review, analysis and interpretation of data. The method omits data synthesis using the meta-analysis method. This was due to the lack of homogeneity of the studies that were included in the review, which prevented quantitative synthesis of the results. The research questions posed in the review were: Do patients undergoing genetic testing or carrying the BRCA genetic mutation have specific support needs? How they assess the effectiveness of the assistance received and the use of individual forms of support? What are their expectations for genetic counseling?

The results of 11 studies conducted in the years 2000-2018 were analyzed. The EBSCO, PubMed, PsychARTICLES and MEDLINE databases were searched. The following key words were used for the analyzed area: “BRCA1”, “BRCA2”, “psychotherapy”, “support group”, “support needs”. Only studies that met the following criteria were selected:

- participants were patients with a BRCA genetic mutation or considering undergoing genetic testing due to an increased cancer risk arising from family history,
- the studies took into account the individual, personal perspective of patients regarding the needs and expectations of psychosocial and / or formal-information support from medical staff,

- included a group of at least 9 people,
- participants were between the ages of 18 and 70,
- have been published in the English language.

The review includes interviews and questionnaire methods studies. Studies that described the same form of support, involved too few people (<9), did not take into account the individual perspective of patients, or did not clearly identify the form of either informative support (from doctors, medical caregivers) or psychosocial / emotional support (from

the family, partners, friends, psychologists, psychotherapists, psycho-oncologists) were excluded. Research analyzes were made on the basis of full-text articles. The following information has been specified: author / authors of the publication, year of publication, country in which the study was conducted, research method, the studied group taking into account age, sex, presence of the BRCA (+) genetic mutation, personal cancer history or lack thereof.

Table 1 provides a detailed summary of the data analyzed.

**Table 1.** Summary of studies assessing the need for support in patients undergoing genetic testing for BRCA mutations or who are carriers of a mutation

No.	Authors	Country/area	Studied group	Procedure of the study	Conclusions
1.	Werner-Lin	Eastern and Western Europe	BRCA (+) n= 22 without personal cancer history, women	Interview method. The researcher and participant jointly constructed a family genogram of at least three generations, focusing on experiments with cancer and genetic testing. All interviews were conducted by the researcher, lasted about 2 hours and were conducted in the place chosen by the participant, often in their homes. Participants received compensation for their time in the form of gift cards worth USD 25.00. All interviews with recordings were rewritten for analysis.	<ul style="list-style-type: none"> <li>– the need for psychosocial / emotional support</li> <li>– the need for formal and informational support,</li> <li>– psychotherapy assessed as significant support in the decision-making process regarding further treatment</li> </ul>
2.	Mendes, ChiquelhoSantos i Sousa	Portugal	BRCA (+) n= 9, Women= 8 Men= 1	4 multi-family sessions lasting 120 minutes and a focus group one month after the last multi-family session lasting 90 minutes	<ul style="list-style-type: none"> <li>– the need for psychosocial / emotional support</li> <li>– the need for formal and informational support,</li> </ul>
3.	Myklebust, Gjengedal i Strømsvik	Norway	BRCA (+) n= 17, Women	A qualitative study with participants from two different educational support groups (ESG) and focus group interviews conducted immediately before and after two ESG sessions.	<ul style="list-style-type: none"> <li>– the need for formal and informational support</li> <li>– the need for psychosocial / emotional support</li> </ul>

4.	White, Farrelly, Meiser, Jefford, Young, Winship, Ieropoli & Koehler	New South Wales and South Australia	BRCA (+) n= 216, Women 44,0% (n = 95) with a personal cancer history	Baseline study included a 16-point scale assessing the unmet support needs, such as coping with fear of cancer development, the desire to be ensured that the experienced feelings are normal and talking with others in a similar situation. Women were asked to indicate their level of needs over the past month on each item using the Likert 5-point scale.	<ul style="list-style-type: none"> <li>– the need for psychosocial / emotional support</li> <li>– the need for formal and informational support,</li> </ul>
5.	Farrelly, White, Young, Jefford, Ieropoli, Duffy, Winship, Meiser	Australia	N=105 BRCA (+) n=74, Women Peers / volunteers n= 31	Participants from BRCA1 / 2 were matched with a trained volunteer peer (also a carrier of the mutation) to hold regular phone calls for more than 4 months. Then they completed surveys assessing satisfaction with the program.	<ul style="list-style-type: none"> <li>– the need for psychosocial / emotional support</li> </ul>
6.	Kajula, Kääriäinen, Moilanen, Kyngäs	Finland	BRCA (+) n= 35, Men	Data were collected from Clinical Genetics Departments at 5 Finnish university hospitals. The exploratory study project was conducted using a 51-point questionnaire based on a previously developed counseling model that was analyzed using nonparametric tests and basic content analysis.	<ul style="list-style-type: none"> <li>– the need for formal and informational support,</li> <li>– the need for psychosocial / emotional support</li> </ul>
7.	Underhill, Crotser	USA	BRCA (+)= 23, Women	Interpretation, secondary analysis of qualitative phenomenological narratives collected in 2008-2010. Women described the experience of breast and ovarian cancer risk, health recommendations and decisions as well as personal values based on life situation.	<ul style="list-style-type: none"> <li>– the need for formal and informational support (permanent, long term)</li> <li>– the need for psychosocial / emotional support</li> </ul>
8.	Thompson, Valdimarsdottir, Duteau-Buck, Guevarra, Bovbjerg, Richmond-Avellaneda, Amarel, Godfrey, Brown, Offit	USA	N= 76, Women, without personal cancer history	Based on the acceptance or refusal to use genetic counseling services, participants were divided into groups: (a) rejection of genetic counseling associated with BRCA (GC-); b) participation in genetic counseling and refusal to conduct genetic testing (GC + GT-); or (c) participation in both genetic counseling and testing (GC + GT +).	<ul style="list-style-type: none"> <li>– the need for formal and informational support</li> <li>– participants who rejected counseling had much less knowledge of the genetics of breast cancer than those who accepted both counseling and testing.</li> </ul>

9.	Farrelly, White, Meiser, Jefford, Young, Ieropoli, Winship, Duffy	Australia	BRCA (+) n= 279, Women	Surveys assessing the need for support regarding 16 information and forms of assistance were used. The impact of the scale of events assessed the suffering associated with the performance of the genetic test	– the need for psychosocial / emotional support
10.	Grimmett, Brooks, Recio-Saucedo, Armstrong, Cutress, Gareth, Evans, Copson, Turner, Meiser, Wakefield, Eccles, Foster	Wielka Brytania	BRCA (+) n= 29, with a personal cancer history	In-depth interviews have been conducted with women who have recently been diagnosed with breast cancer (<4 years). Patients' preferences regarding the way information was presented and their content were examined.	– the need for formal and informational support
11.	Gavaruzzi, Tasso, Franjuk, Varesco, Lotto	Włochy	N= 302, Women	Participants read the information brochure and responded to an ad hoc questionnaire assessing the usefulness of information for making decisions, intention to undergo testing and understanding of content (perception, general and risk understanding; open questions).  A comparative analysis of 2 groups – young women (18-24 years) and adult women (30-45 years) was performed. Differences in interpretation, understanding and perception of the risk associated with a positive BRCA test result were analyzed	– the need for formal and informational support

## RESULTS

The need for support in ontologically ill people has been repeatedly analyzed. Increasing public awareness of genetic risk, however, meant that researchers began to focus attention also on those people who were not diagnosed with cancer, but genetic tests confirmed that they are at increased risk. Werner-Lin in 2008 analyzed the formal and informal needs of support in carriers of BRCA mutations and indicated that high risk of cancer is associated with great

er need for support [6]. The study was conducted on 22 women who were carriers of the mutation, but did not have their own history of cancer. The women were not pregnant at the time of the examination. They were between 21 and 36 years old. 12 of them had husbands and children, 1 person was engaged, 5 women declared that they were in a long-term relationship. Analysis of the collected data showed that among the surveyed women there was a need for informal support in the form of support for family, friends and partners or husbands. Participants

in long-term, committed relationships relied primarily on their partners and drew emotional support from them. Women who were not involved in relationships were determined to find a partner who could cope with the burden of diagnosis, and thus could in the future co-create a support system. Several participants had carers or friends working in the area related to mental health who were able to provide them with qualified help. None of the participants in study, however, could have all their needs fulfilled only in relationships with friends. The analyzes also allowed clear confirmation that mutation carriers also show a need for formal support, such as the need for information from medical personnel.

Genetic counselors, doctors and other healthcare professionals were the main source of information support for the study participants. However, it turned out that the content transmitted may not be sufficient, as most participants in the study supplemented information received from healthcare professionals using the Internet or searching for them in medical journals. This may also be relevant for families in which some women are just planning to carry out a genetic test, and at the same time they have concerns about the possibility of getting a positive result. Although psychotherapy as a method of supporting carriers of BRCA mutations is still not given enough attention, the Werner-Lin study found that participants who started psychotherapy found it very helpful in ordering important elements of the experience related to cancer risk and assessed this support as significant for taking specific actions, such as a decision to continue research or a decision related to the performance of an operation. This is of great practical importance for planning genetic counseling activities, in particular for those patients who are considering surgical procedures, including preventive mastectomy.

In addition to individual psychotherapy, in some countries there are also psychoeducation groups, which, in apart from having significant substantive value, also have a therapeutic dimension. Psychoeducational groups offered to families in which genetic mutations have been detected are of particular importance. This form of support makes it possible to talk in a secure atmosphere at a time and place that was previ-

ously planned. Meetings of this type of group also have a fixed structure. They are time-limited (from four to six sessions) and their purpose is to help families adapt and cope with the requirements and uncertainty of the disease, enabling support for people who share experience and alleviate the sense of isolation associated with a positive genetic test result [7]. The importance of psychoeducational support groups for families with high genetic risk has been confirmed by studies by Mendes, Chiquelho, Santos and Sousa [8]. Researchers have created a multi-family discussion group program that includes four semi-structured sessions coordinated by two facilitators trained in family medical therapy and experienced in working with family groups of cancer patients. In the course of the study, one group was created with the participation of three families and nineteen people. All participants were women relatives, including sisters, daughters, grandmothers and aunts. All participants underwent genetic testing and received a positive result, indicating an increased risk of breast and / or ovarian cancer. The only exception was one patient's husband, who participated in the last of the sessions. The program was evaluated by participants on the basis of a partially structured group interview.

Studies have shown that all participants considered the functional aspects of the program adequate (number of sessions, duration and frequency) because they prevented distraction while not burdening the personal and family life of the participants. The content of the session was assessed as useful because it focused on specific topics and encouraged the involvement of all participants in the discussion. According to the respondents, the main benefits considered the group experience of sharing their own thoughts and feelings, which allowed to reduce beliefs about the inadequacy of these thoughts or feelings and also prevented isolation. A multi-family psycho-educational group has also proved to be significant in making decisions about further treatment. Two women reported improved confidence in undergoing a risk reduction procedure of ovariectomy and subcutaneous mastectomy. In order to improve the program, participants suggested, inter alia, the need to involve other specialists in providing medical information in the fields of plastic surgery, radi-

otherapy and gynecology and / or obstetrics. It is worth paying attention to the variety of forms of support that are offered to patients. Some countries, such as Norway, offer mutation carriers to participate in educational support groups (ESGs). A qualitative analysis of interviews conducted with 17 participants of this type of groups made in 2016 by Myklebust, Gjengedal and Strømsvik [9] has led to the identification of a number of practical conclusions. The analysis made it possible to identify three main topics in the patient's narrations: the expectation and experience of participating in ESG group meetings, the feeling of loneliness and isolation, and the feeling of living with "something different". Studies have confirmed the need to receive unambiguous, clear and harmonized information from healthcare professionals, the need for social support and a desire to deepen knowledge on aspects of patients' concerns. Participation in educational support groups, such as ESG, organized for women with BRCA1 and BRCA2 mutations, as well as participation in multi-family psychoeducational groups can be significant in the decision-making process related to operations that reduce the risk of cancer.

The emotional aspect of the lives of people with a positive genetic test result also includes social interactions and the impact of diagnosis on the future of the family. White and colleagues [10] examining women aged 18 to 70 who had obtained a positive BRCA1 / 2 mutation test in the last 4 years showed that among the most frequently indicated needs (moderate to very high) were: "dealing with uncertainty about the future" (42%), "dealing with the impact of a defective gene on the family" (40%) and "dealing with fears of developing cancer" (39%). The value of support activities based on interaction with other people struggling with the burden of diagnosis has been confirmed in research by Farrelly and colleagues [11]. Researchers described the process of implementing a mutual assistance program aimed at reducing the level of distress experienced by carriers of the BRCA1 and / or BRCA2 mutations. In the Farrelly study, participants with the BRCA 1/2 mutation were matched with a trained peer volunteer (also the mutation carrier) to conduct regular telephone conversations for a period of 4 months. Then, participants completed evaluation question-

naires, which covered the topics discussed, the number of conversations and the time spent on the conversation. Studies have shown that the peer support program is not only feasible, but is also positively evaluated by participants. Satisfaction with the program was high for both parties. Conclusions from the research indicate that to encourage peers and recipients to further engagement, a greater flexibility of the method is needed, possible through the use of e.g. text messages and / or e-mails. Mixed intervention, in which recipients can adapt the communication method to their needs, can be effective, although this would require testing. The use of modern communication channels could in the future become a strategy complementing the traditional intervention model and at the same time fulfill the need for support externalized by people with a positive genetic test result. This was also confirmed by Vigdis Stefansdottir [12] proving that modern technologies can be helpful in the support process also because they give the opportunity to create informal support groups using social media. Supporting online communities operate around the world, also in Poland. These include groups created on Facebook such as BRCA Breast Cancer Gene Community, or BRCA1 – BRCA2 – Nazionale Italiano. In addition, mutation carriers also share their experiences on online forums. It is worth considering whether the importance of the groups functioning in this way could not be strengthened if they encouraged medical service employees or volunteers trained in substantive matters to participate in the discussions conducted there, including simultaneously an educational element.

Although most of the researchers' attention is focused on the quality of support provided to carriers of the BRCA1 / 2 mutation, it should not be forgotten that genetic counseling also applies to men who have been found to have the mutation. In 2015 [13], a study was carried out in Finland to determine the quality of genetic counseling offered to male mutation carriers and to identify their support needs. Satisfaction with genetic counseling has proved to be high, especially with regard to the content of counseling. However, the results showed that only 49% of male carriers believe they have received sufficient social support. Attention was paid to individual psychosocial support as a factor that

may contribute to improving the quality of genetic counseling. Carriers of mutations decided to use counseling primarily for educational purposes – they were looking for information, so they highly rated the way of conducting counseling in which valuable substantive content appears. However, these results clearly show that the need for psychosocial support does not only apply to women, but also manifests in the expectations of men who have a positive genetic test result. In addition, despite the fact that decisions resulting from receiving a positive test result are mostly personal ones made directly by the carrier of the mutation, their consequences often affect the whole family system. What's more, these decisions are not always taken once in a binding way, but sometimes the decision-making process must be repeated regularly, even in the case of cyclical research. The analysis carried out by Underhill and Crotser [14] confirmed this fact. Data was collected in 2008-2010, using 23 accounts of women who were carriers of the BRCA1 or BRCA2 mutation. Researchers have shown that decisions made by people with a positive genetic test result are more than just deciding whether to perform surgery or undergo medical care. It has been proven that the decisions taken include complex factors related to the person, their family, specific procedures and the healthcare system. The emotional and physical consequences of these decisions, both real and potential, were important to the decision-making process and turned out to require constant, long-term support also from healthcare professionals.

The value of genetic counseling in the context of stress reduction by expanding knowledge about mutations, was already demonstrated in 2002 by Hayley S. Thompson and colleagues [15]. The study involved 76 African American women participating in a longitudinal study analyzing the psychological and behavioral effects of genetic counseling and genetic testing on patient functioning. To qualify for the study, patients had to identify themselves as African American, be over 18, had at least one first degree relative who was diagnosed with breast cancer. Also, the patients had to be able to read and write in English, never received a diagnosis of breast cancer, and gave informed consent to participate in the study. Research data

were collected in the years 1996–2000. The results revealed that participants who did not express a desire to use counseling had much less knowledge about the genetics of breast cancer than those patients who accepted both counseling and agreed to take tests. The conclusions of the studies described clearly emphasized the need to improve information and intervention measures that both increase awareness of genetic counseling and testing for the presence of BRCA mutations among African-American women, and provide relevant information to those considering the possibility of performing such tests.

The very procedure of performing genetic tests can be a difficult experience for patients. A study conducted in 2013 by Farrelly and colleagues [16] in Australia assessed the suffering associated with performing a genetic test. The analyzes used the Impact of Events Scale to measure disorders resulting from the effects of strong stressors [17]. Farrelly and colleagues showed that 21% of subjects experienced moderate distress and 13% struggled with elevated distress. Needs for support were also analyzed. Higher results in the analysis of unmet needs were achieved primarily by younger people who had no one to confide in, and the time that has passed since they received the genetic test result was short. A greater number of unmet needs was associated with a greater likelihood of moderate to high levels of distress [16]. Considering the results of modern research, one cannot ignore the fact that the need for support does not apply only to patients with a mutation. The very decision making process regarding the performance of the genetic test may be so difficult that it will require additional support. In 2018, Grimmert [18] and colleagues tested the utility of a tool whose purpose was to support decisions regarding the performance of a genetic test. At the testing stage, in-depth interviews were conducted with 29 women under the age of 50 who have recently been diagnosed with breast cancer. Patients' preferences regarding the presentation of information and content of the message were examined. The results allowed for the identification of specific needs, such as a precise presentation of both the advantages and disadvantages of the genetic test, its course, and family implications resulting

from the test. It has been proven that the decision support tool is widely used as an add-on to genetic counseling or in busy oncology clinics where formal genetic counseling may be unavailable or significantly reduced.

In addition to the fact that the situation associated with the need to perform a genetic test for many patients may be associated with the feeling of stress, it is also worth paying attention to another differentiating factor, which is age. This was confirmed by research carried out in Italy by Gavaruzzi and colleagues [19]. During the analysis, a group of young women (18-24 years) was compared with a group of adult women (30-45 years) in order to examine differences in their interpretation, understanding and perception of the risk associated with obtaining a positive result of a genetic test. The conclusions revealed that younger women surveyed achieved results indicating a lower level of understanding of important information regarding BRCA mutations and that it was more difficult for them to identify the risk of cancer. In addition, younger patients more often showed errors in answering open questions, while presenting a positive attitude towards the genetic test. In the face of the collected data, it seems particularly important to constantly increase public awareness about the high cancer risk groups.

The constant development of communication, through the use of modern technologies, as well as changes in genetic counseling and focusing on the real needs of people who undergo genetic testing for the presence of BRCA mutations, give an opportunity to expand the possibilities of support offered to patients. Support groups seem to be of particular importance, including both educational and therapeutic aspects.

## DISCUSSION

Analysis of previous studies shows that patients undergoing genetic tests, regardless of their sex, cancer history and test result, have needs related to various forms of support. Based on the experience presented by researchers from other countries, it would be worth considering the possibilities of improving the current system supporting patients with cancer risk implemented in Polish conditions. This would require the implemen-

tation of practical, sometimes innovative solutions that can bring satisfactory results. Bearing in mind the opportunities offered by the development of modern technologies and the evolution of social attitudes towards informal support groups, it would be worth considering their practical use. Perhaps some patients would decide to belong to newsgroups or informal support groups, but they do not, because they are not aware that such groups exist and are positively evaluated by their users.

According to analyzes conducted so far, genetic counseling is one of the most important elements in the process of providing assistance. It is also often the only form of support that the patients use. Narrations of people surveyed show that the value of such counseling is primarily based on receiving understandable content about the test procedure, the implications of obtaining a positive result, the possibilities and legitimacy of introducing various forms of prevention, including activities that require surgical interventions. Participants of the research whose results were presented in this work positively assess the genetic counseling they used. However, it is also worth remembering the practical conclusions from the analyzes. Patients who are under the influence of strong emotions at the time of receiving the result may not understand the information transmitted in a way that is too complicated, or in which typically medical phrases appear. The solution could be multi-stage counseling that would allow patients to gradually expand their knowledge of the significance of the result and the consequences it has. Considering the real time and personnel limitations connected with introducing this type of changes, it is worth referring to the model of mutual assistance tested by Farrelly and colleagues [11], provided by a trained peer volunteer, and to educational groups functioning in Norway, which describe Myklebust, Gjengedal and Strømsvik [9]. Perhaps in the future similar groups will be organized in Polish conditions. Considering the two types of needs indicated by patients, it would be worth taking into account the possibility of organizing educational and therapeutic groups that would allow to meet both the needs related to the information deficit and the needs related to psychosocial support.

## CONCLUSIONS

Patients undergoing genetic testing for the presence of BRCA gene mutations have specific needs such as the need for information (educational), social or therapeutic support. Obtaining a positive result of a genetic test, regardless of whether it concerns women or men, is associated with the need to receive a high quality genetic counseling. The effectiveness of counseling is based primarily on its substantive content and clarity of message. The traditional genetic counseling model does not always meet patients' expectations. Both formal and informal support groups turn out to be effective supplements. Modern information technologies and dynamic development of communication in the network allow for quick and easy access to information and the use of informal support groups, even in the form of activity in closed groups created on social networks or discussion groups on internet forums. However, high importance is still attached to the support provided by relatives – family and friends as well as partners of the mutation carriers. As it results from the analyzes described in this paper, support groups can not only affect the well-being of patients by reducing distress, but are also important from the perspective of making decisions related to treatment. If the need for support is clearly externalized in patient relationships in a way that can facilitate the decision-making process regarding e.g. surgery, it seems important to include this perspective in planning long-term activities aimed at increasing patient involvement in cooperation with medical staff and the process of supervising their health and possible treatment, also surgical procedures.

### Declaration of interest

*This manuscript has never been published reproduced or sent anywhere. The study was conducted in accordance with worldwide standards of Good Clinical Practice (GCP) and conform to accepted ethical standards as outlined by local requirements and the Declaration of Helsinki (World Medical Association, 1989).*

*The Authors declare no conflict of interest.*

*All experiments were performed with approval of the Ethics Committee of the University of Szczecin, Poland.*

## REFERENCES:

1. Pawlik M, Karczmarek-Borowska B. Akceptacja choroby nowotworowej u kobiet po mastektomii. *Przegląd Medyczny Uniwersytetu Rzeszowskiego i Narodowego Instytutu Leków w Warszawie*. Rzeszów: 2013, 2: 203-211
2. Sęk H, Cieślak R. Wsparcie społeczne – sposoby definiowania, rodzaje i źródła wsparcia, wybrane koncepcje teoretyczne. W: Sęk H, Cieślak R (ed.). *Wsparcie społeczne, stres i zdrowie*. Wydawnictwo Naukowe PWN, Warszawa 2011; 11-28.
3. Jabłoński M, Kozaka J, Rachel W. Czy można mówić o specyfice psychoterapii i superwizji psychoonkologicznej? *Psychoonkologia*. Warszawa: 2015; 3: 97-103
4. Dębniak T, Lubiński J. Principles of genetic predisposition to malignancies. In: Lubiński J. ed. *Genetyka kliniczna nowotworów*. Lubiński J Print Group sp z o o, Szczecin 2016, 9–19.
5. Michałowska S, Samochowiec A, Jakubowska A. Komponenty funkcjonowania psychospołecznego nosicieli mutacji genów BRCA1 i/lub BRCA2. *Psychiatria* 2018, 15, 4: 234-240.
6. Werner – Lin A. Formal and Informal Support Needs of Young Women with BRCA Mutations. *Journal of Psychosocial Oncology*. 2008; 26(4): 111-133.
7. Gonzalez S, Steinglass P. Application of multifamily groups in chronic medical disorders. In: McFarlane W, editor. *Multifamily groups in the treatment of severe psychiatric disorders*. New York: Guilford; 2002.
8. Mendes A, Chiquelinho R, Santos T.A, Sousa L. Family matters: examining a multi-family group intervention for women with BRCA mutations in the scope of genetic counseling. *J Community Genet*. 2010; 1(4): 161–168.
9. Myklebust M, Gjengedal E, Strømsvik N. Experience of Norwegian Female BRCA1 and BRCA2 Mutation-Carrying Participants in Educational Support Groups: a Qualitative Study. *Journal of Genetic Counseling* 2016; 25, 6: 1198-1206.
10. White V, Farrelly A, Meiser B, Jefford M, Young M, Winship I, Ieropoli S, Koehler J. What are the unmet support needs of women with a known BRCA1/2 mutation? *Hered Cancer Clin Pract*. 2012; 10(Suppl 2): A54.
11. Farrelly A, White V, Young MA, Jefford M, Ieropoli S, Duffy J, Winship I, Meiser B. Implementing a telephone based peer support intervention for women with a BRCA1/2 mutation. *Fam Cancer*. 2015, 14(3):373-382.
12. Stefansdottir V, Experience of Social Media Support Group for BRCA Carriers. *J Genet Counsel*. 2016; 25:1342–1344
13. Kajula O, Kääriäinen M, Moilanen JS, Kyngäs H. The Quality of Genetic Counseling and Connected Factors as Evaluated by Male BRCA1/2 Mutation Carriers in Finland. *J Genet Couns*. 2016; 25(3):413-421.
14. Underhill ML, Crotser CHB. Seeking Balance: Decision Support Needs of Women Without Cancer and a Deleterious *BRCA1* or *BRCA2* Mutation. *J Genet Couns*. 2014; 23 (3): 350-362.

15. Thompson H, Valdimarsdottir H.B, Duteau-Buck CH, Guevarra J, Bovbjerg D.H, Richmond-Avellaneda C, Amarel D, Godfrey D, Brown K, Offit K. Psychosocial Predictors of *BRCA* Counseling and Testing Decisions among Urban African-American Women. *Cancer Epidemiology, Biomarkers & Prevention*. 2002, 11: 1579–1585.
16. Farrelly A, White V, Meiser B, Jefford M, Young MA, Ieropoli S, Winship I, Duffy J. Unmet support needs and distress among women with a *BRCA1/2* mutation. *Fam Cancer*. 2013;12(3):509-518.
17. Juszczynski Z, Ogińska-Bulik N. Pomiar zaburzeń po stresie traumatycznym – polska wersja Zrewidowanej Skali Wpływu Zdarzeń. *Psychiatria* 2009, 6, 1: 15-25.
18. Grimmett C, Brooks C, Recio-Saucedo A, Armstrong A, Cutress RI, Gareth Evans D, Copson E, Turner L, Meiser B, Wakefield CE, Eccles D, Foster C. Development of Breast Cancer Choices: a decision support tool for young women with breast cancer deciding whether to have genetic testing for *BRCA1/2* mutations, *Supportive Care in Cancer*. 2018; 27: 297 – 309.
19. Gavaruzzi T, Tasso A, Franjuk M, Varesco L, Lotto L. Are young women ready for *BRCA* testing? Comparing attitudes and comprehension of two age groups of healthy Italian women. *Patient Education and Counseling*. 2019. Online. <https://doi.org/10.1016/j.pec.2019.01.022>