

Experience of Norwegian Female BRCA1 and BRCA2 Mutation-Carrying Participants in Educational Support Groups: a Qualitative Study

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Abstract Women identified as BRCA1 and BRCA2 mutation carriers are advised to manage their cancer risk through intensive screening programs and/or by undergoing risk-reducing surgery. The aim of this study was to explore and describe the experiences of female BRCA1/2 mutation carriers living with cancer risk and their experiences with participation in educational support groups (ESG). This qualitative study enrolled 17 (10 + 7) ESG participants in two different ESGs. The focus group interviews were performed immediately prior to and following two ESGs. The data were analyzed using John Knodel's (1993) practical approach. Three main themes were identified; the women's expectation and experience with ESG, the feeling of loneliness and isolation, and the feelings of living with "something else." In this paper we have focused on one of the main themes- the women's expectation and experience with ESG. This main theme presents four subthemes: the women's need for unambiguous, clear and unified information from health professionals, the need for social support, the important role of the patient representative, and increased knowledge potentially raising concern. Participation in an ESG for women with BRCA1 and BRCA2 mutations can provide relevant information and

support in the decision-making process related to risk-reducing surgery.

Keywords BRCA1 · BRCA2 · Hereditary cancers · Educational support group · Risk-reducing mastectomy · Risk-reducing oophorectomy

Introduction

In recent decades, genetic testing has become available for several hereditary diseases, including hereditary breast and ovarian cancers. Approximately 5–10 % of breast and ovarian cancers are caused by an inherited genetic mutation (Lux et al. 2006). The two genes most frequently involved in hereditary breast and ovarian cancer are the tumor suppressor genes Breast Cancer Gene 1 (BRCA1) and Breast Cancer Gene 2 (BRCA2) (Blackwood and Weber 1998). Female BRCA1 and BRCA2 gene mutation carriers face a lifetime risk of 56 % and 84 % of developing breast cancer and 54 % and 27 % for developing ovarian cancer, respectively (Kauff et al. 2008; Rebbeck et al. 2009). Variable risk estimates have been reported depending on whether the studies are family- or case-ascertained (Garber and Offit 2005). This hereditary cancer syndrome follows an autosomal dominant inheritance, with incomplete penetrance, giving children a 50 % risk of inheriting the mutated gene if one parent is a BRCA mutation carrier (Lux et al. 2006).

The decision to undergo genetic testing is very personal and complex (Di Prospero et al. 2001). Women identified with a BRCA mutation are advised to manage their cancer risk through intensive screening programs and/or by undergoing risk-reducing surgery (Bermejo-Perez et al. 2007; Eisen et al. 2005). These individuals are counseled to share the information with relatives, who themselves may subsequently face

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similar healthcare decisions (den Heijer et al. 2011; S. Kvale 1996). In Norway, women with mutations in the BRCA genes are offered annual mammography and magnetic resonance imaging (MRI) examinations from the age of 25 years (Eisen et al. 2005; Norwegian Breast Cancer Group 2011). However, there is evidence that mammography and MRI may not be sufficient to reduce the mortality in BRCA1-associated breast cancer (Moller et al. 2013). Therefore, these women are offered risk-reducing mastectomy. Research has indicated that prophylactic mastectomy can reduce the risk of developing breast cancer by 90 % in BRCA1/2 mutation carriers (Domchek et al. 2010; Salhab et al. 2010; Skytte et al. 2011). Meanwhile, ovarian screening has been shown to be ineffective in reducing mortality. Therefore, female BRCA mutation carriers are advised to remove healthy ovaries at 35–40 years of age (Domchek et al. 2010; Finch et al. 2014). It is estimated that prophylactic oophorectomy results in a relative risk reduction of approximately 80 % for ovarian cancer and reduces the risk of breast cancer by 50 % (Eisen et al. 2005; Finch et al. 2014).

The cancer risk of BRCA1/2 mutation carriers is generally well understood and can be communicated clearly to potential and known mutation carriers during genetic counseling (Meindl et al. 2011). Carriers must then contemplate risk and compliance with the recommended screening program (Bermejo-Perez et al. 2007; Salhab et al. 2010), which includes decisions concerning risk-reducing surgery and sharing information with offspring and other family members. These experiences may be followed by a sense of isolation and contribute to psychological and emotional distress (den Heijer et al. 2011; Esplen et al. 2004). Surgery may alter physical appearance, self-image, sexuality, and reproductive options, which might contribute to increased levels of distress both prior to and after surgery (Hallowell et al. 2012; Madalinska et al. 2006; McCullum et al. 2007). One study suggests that women in the absence of demonstrated mutations have a higher anxiety and depression levels than women with known mutation-carrier status (Geirdal et al. 2005). This is in conflict with later research that indicates that symptoms such as anxiety, depression, and stress are more prevalent in individuals with verified genetic mutations (Bosch et al. 2012; den Heijer et al. 2011). It is known that the medical and genetic information can lead to psychological-, social-, and health-related problems (Douglas et al. 2009; MacDonald et al. 2010). Several studies have indicated that providing women with increased knowledge and adequate information concerning their cancer risk may increase screening compliance and promote acceptance of risk-reducing surgery (Esplen et al. 2004; MacDonald et al. 2010; Visser et al. 2011), but this increased knowledge may also be perceived as overwhelming (Werner-Lin 2008).

There is currently little knowledge concerning female BRCA mutation carrier thoughts and experiences related to

clinical follow-up programs and risk-reducing surgery (Howard et al. 2011; Patenaude et al. 2008). Several studies have noted the need for more research within these areas (den Heijer et al. 2011; Di Prospero et al. 2001; Jeffers et al. 2014). Another key issue to explore is the need for educational support groups (ESGs) in connection with clinical follow-up programs (Dorval et al. 2013; Landsbergen et al. 2010; Patenaude et al. 2008). A Norwegian study by Austvoll-Dahlgren et al. (2011) presented positive effect on psychosocial outcomes such as mental health, coping and relationships, and on knowledge regarding own illness, by offering ESG to patients with chronic conditions. According to Landsbergen et al. (2010) educational support groups had a positive effect on the BRCA1/2 women's need for information, support and decision making regarding risk-reducing options.

According to oral sources the first ESG for BRCA1/2 mutation positive women in Norway was established as collaboration between a regional ESG and a University Hospital in Oslo in 2010. The concept of offering ESGs to Norwegian BRCA female carriers includes the provision of medical and genetic information targeted toward dealing with long-term health challenges. ESGs mostly engage in group activities in which patients and health professionals facilitate sessions and share their experiences and specialized expertise. In addition, patient representatives with relevant experiences act as spokespersons on behalf of the group (Edwards et al. 2008; Hvas and Thesen 2002; NKLMS (The Norwegian National Advisory Unit on Learning and Mastery in Health) 2013).

In Northern Norway, where this study was performed, the first ESG took place in December 2012, and included information from medical geneticists, genetic counselors, gynecologists, psychologists, surgeons, and sexologists. The aim of this study was to explore and describe the experiences of female BRCA1/2 mutation carriers living with cancer risk and their experiences with their ESGs (Table 1).

Methods

Participants and Procedure

Inclusion criteria were women with documented BRCA1/2 mutation and no previous history of cancer, over 18 years of age and fluent in Norwegian. The participants ranged in age from 27 to 67 years, and the study was conducted between 2 weeks and 15 years after the disclosure of the genetic test result. Twenty women were invited to participate in this study at the time they were invited to attend an ESG at a University Hospital in Northern-Norway. Written information about participation in the study clearly stated that the invitation to the ESG was independent of participation in the study. In accordance with Norwegian legislation, the women had all attended genetic counseling. Invitations were sent per mail to

Table 1 Information about the participants

Participant (numbered)	Age at the time of the ESG	Time since disclosure of test result	Time since risk reducing oophorectomy	Time since risk reducing mastectomy
Focus group I				
P1	27	3 years	÷	2 months
P2	28	6 years	÷	÷
P3	30	2 years	÷	1 month
P4	31	4 years	÷	÷
P5	32	2 weeks	÷	÷
P6	44	3 years	÷	÷
P7	49	8 years	8 years	÷
P8	50	2 years	2 year	÷
P9	57	5 years	5 years	1 year 6 months
P10	58	15 years	24 years (other reason)	12 years
Focus group II				
P11	28	2 years	÷	÷
P12	28	2 years	÷	÷
P13	29	1 year	÷	÷
P14	30	2 years	÷	5 months
P15	41	6 years	2 months	÷
P16	43	5 years	3 years	÷
P17	67	3 years	3 months	÷

÷ = did not have risk-reducing surgery

prospective participants through a regional Medical Genetics clinic in Norway. They included written information about the study, ESG information, written consent forms, and an attendance form. The participation was voluntary, and no reminders were sent. Of the 20 women who received an invitation, 17 participants provided written consent back to the clinics. (10 + 7) females participated in two different focus group interviews. The interviews were performed immediately prior to and following two ESG seminars. In the first focus group, 10 women participated prior to the ESG, and 9 after. One woman had to leave due to practical reasons. At the second focus group, conducted five months later, 7 women participated in the interview prior the ESG and 6 women participated after the ESGs. One participant left early due to her early transportation home. Approval for this study was obtained through a Regional Research Ethics Committee.

Data Collection

This study used focus groups to explore and describe the experiences of female BRCA1/2 mutation carriers. The focus group interviews were performed immediately prior to, and following two ESGs. The participants were encouraged to discuss the broad, key questions in an interview guide, created by the third author and included the following; personal

reactions after being identified as mutation carriers, experiences with the risk management program, decision-making and experiences regarding risk-reducing surgery, group expectations and experience participating in the ESG. In addition, the participants were encouraged to emphasize the topics important to them. The first interview explored their experiences of living with cancer risk, and their expectations with ESG. The second interview mainly focused on their experiences with the ESG. In addition, information and unclear statements from the first interview were verified. A genetic counselor with long standing experience, who also had counseled some of the participants at an earlier stage, had primary responsibility for the project and directed the interviews. A PhD nurse was observing and made field notes during the interviews. She had no prior contact with any of the participants. Both researchers have long standing experience with qualitative research. All of the interviews were audio recorded, lasted approximately sixty minutes on average and occurred at the ESG location.

Data Analysis

Following the verbatim transcription, all of the data from this study were analyzed together using John Knodel's (1993) practical approach. He described four steps for analyzing focus groups interviews (Morgan 1993). First, it was important to obtain a sense of the entire material by listening to the audiotapes and repeatedly reading the transcripts and by mapping and coding the transcripts. Next, the data were coded and grouped under the main subjects regarding the interview guidelines. The themes that were collected, but were not a part of the interview guide, were also included. In the third step, preliminary themes were transformed into a descriptive abstract of the group discussion. Finally, upon considerations of the differences and similarities, the smaller themes were combined with larger themes. All three female co-authors participated in the analysis, and the content of the themes were discussed. After analyzing the focus group interviews, three main themes were identified. The data program Nonnumerical Unstructured Data Indexing, Searching, and Theorizing (NUD*IST) was used to organize and analyze the focus group interview transcripts. Prior to the analysis, the personal identifiers were removed from the transcripts, and the participants were numbered.

Results

Seventeen female BRCA1/2 mutation carriers participated in the study. Three main themes were identified in the analysis; the women's expectations and experience with ESG, the feeling of loneliness and isolation, and the feelings of living with "something else". To limit the extent of this paper in this current study, we have focused on one of the main themes-

the women's expectation and experience with ESG. We present four subthemes; the women's need for unambiguous clear and unified information from health professionals; the need for social support; the important role of the patient representative, and increased knowledge potentially raising concerns. These subthemes are illustrated in excerpts from transcripts in which the participants talk about their experience with the ESG. The remaining two main themes will be introduced in other publications.

The Need for Unambiguous, Clear, and Unified Information from Health Professionals

The first subtheme addresses the participants' need for unambiguous, clear and unified information from health professionals. In consultations regarding risk-reducing surgery, participants had received different information from various doctors. Some of the women stated that they had canceled their scheduled surgery for risk-reducing removal of breasts and ovaries because they had received conflicting and confusing information from their surgeons. These women described feelings of frustration with their health professionals, whom they deemed lacked sufficient insight about the patient's point of view, and they felt these providers prevented them from learning important information related to risk-reducing options.

"I was here with some doctor who I felt didn't know enough about it [risk-reducing options]. And he said, you could choose, yes, you can do this or you can do that, or that, or that, and you need to decide what you want to do. You don't need to decide right now, but call me tomorrow and let me know your decision. It was a bit like that. So I felt that the information was really, really bad."

Several of the participants attended the ESG to gain insight to the experiences of other mutation carriers. One of the women decided to participate because of sparse information from her GP and surgeon:

"I didn't get the information that I needed. That's why it is interesting to talk to others who have had the surgery [mastectomy], I think, in order to know."

Other participants felt pressure from health care providers to opt for risk-reduction surgery. One patient expressed feeling abandoned by her doctor in her decision-making process: The doctor called her two days prior to the planned operation and told that he had changed the planned mastectomy into a different procedure without consulting her:

"And I couldn't go through with it [the "new" procedure] right...this is one and a half year ago, and I have

still not heard anything [for my surgeon]. I've been in surveillance, but nothing from the department. So I think that's pretty bad".

The women stated that one of the reasons they underwent genetic testing was to be included in a clinical follow-up program to help them make decisions about risk-reducing surgery. Some of the women expressed concerns that they had waited a long time to receive relevant information, but they were now pleased to be included in an ESG.

"I wish I had had it [information about risk-reducing mastectomy] a long time ago. But I have known it [the mutation] for about 7 or 8 years already. I have wondered about the BRCA mutation for quite a while and known very little actually. I just knew what dad and others told me. And the little I have read, I am a bit careful about what I read on the internet, and where the information comes from. So, yes, and in terms of the operation I had [oophorectomy], I think there was not much information on the internet. There was information about how the operation was done, but very little about what happens after that."

The Need for Social Support

This theme addressed the participants' descriptions of how they had benefited from meeting other mutation carriers to discuss and share their knowledge and experiences. The women were satisfied with the opportunity to ask health professionals questions about risk-reduction surgery, and to share experiences with other participants at the ESG. One woman described it as follows:

"Yes, I feel that I am very happy... I think that all my expectations I had [about the ESGs]. Because I thought that I wanted to learn about this a bit. I wanted to meet someone I could ask, someone who had had the operations [mastectomy and oophorectomy] and things like that. And I have absolutely done that, seen boobs and everything." (laughter)

The Important Role of the Patient Representative

The patient representative played an essential role in the participant interaction, and all the women experienced her contribution as positive. She promoted discussion amongst the participants by sharing personal history, asking health professionals questions that the participants did not have the knowledge or courage to ask. She showed them the results from her own risk-reducing surgery. One of the women recognized

herself when the patient representative expressed that her breasts did not mean so much to her and that she therefore could remove them.

The patient representative gave practical advices that seem to be of great value for the participants. It was also positive that she was present during the entire ESG.

“I think that it’s been good that the patient representative has been here. Because she has the experience [of being a mutation carrier], so she has asked some questions that maybe others haven’t thought of, but that we actually wanted the answer to, but didn’t think of.”

Many of the women had several questions regarding the results after risk-reducing breast surgery and, during the course, the participants had the opportunity to see the “new” breasts of the patient representative.

“On my part, I have really wondered about how it is [the results] if you have such a breast surgery. So it was so good that the patient representative was here and could show them [her breast]..”

Increased Knowledge may also Raise Concern

It seems that the new information the women received at the ESG might lead to concerns for some of the women in relation to their decisions about implementing risk-reducing surgery. For others, the new knowledge had not led to any changes in relation to previous decisions of not performing risk-reducing removal of the breasts.

“I am not sure if I am any closer to doing it [mastectomy]. But anyway, it seems totally harmless. But I don’t know if I am quite there. I think it is ok with the surveillance now.”

Several participants had become more conscious of their choices regarding risk-reducing surgeries.

” I am, well, I’ve thought this way from the first moment, that I would first remove my boobs and then the ovaries. And then yesterday I realized I have actually decided. You remember we talked about setting an age or a date. And I have actually done that. I realized that yesterday”
 “But then, it’s a little like. It’s ok to have this course because I had sort of forgotten the whole thing. So it’s ok with more information. I have now received more information that makes me think more about risk-reducing surgery I am a bit more conscious.”

One of the participants had not been offered risk-reducing mastectomy.

“...and I’ve never been informed or offered it [risk-reducing surgery] either. So I am thinking, why...? Why is only somebody asked? A cousin of mine, she removed her breasts. And we want to know why? I thought, ok, I have small ones, maybe there is nothing to remove.” (laughter)

The women agreed that the information they received from health professionals in the ESG was helpful. But, on the other hand, some were left with other questions for the health professionals.

“I think I have received more information [about mastectomy surgery], but I still have some new questions too. I’ve removed my ovaries, but not my breasts. And I am a bit uncertain. Sometimes I think, no, I won’t remove my breasts. I have become unsure [after the ESG]. Now I have some new questions in that regard.”

The participants were pleased that they had received consistent information from health professionals during the ESG, particularly regarding age indications for when to remove healthy breasts and ovaries.

Discussion

Findings from the present study have revealed some of the issues these women faced after being identified as carrying a BRCA1/2 mutation. The participants described the need for unambiguous, clear and unified information and the need for social support. The patient representative in the ESG played an important role. The increased knowledge also raised concerns. To view these issues, we have based our discussion on Antonovsky’s perspective on coping and health promotion. According to the Norwegian National Advisory Unit on Learning and Mastery in Health (NK LMH), Antonovsky’s work is central precisely because it emphasizes on our ability to cope with what happens in life. These women had received different and conflicting information from various providers. This inconsistency may have contributed to feelings of frustration and uncertainty. It is said that health care providers need to strive for better communication among them to send a unified message to patients (Aujoulat et al. 2007; Edwards et al. 2008; Rosas-Blum et al. 2007). The participants in our study experienced doubt when information was insufficient, which may be a crucial factor when the women have to make important decisions such as whether to undergo risk-reducing surgery. It is said that by strengthening patient’s own power, their resources will be strengthened (Edwards et al. 2008;

Hvas and Thesen 2002; K. Kvale 2007). Antonovsky suggests that to experience meaningfulness, it is important for individuals to feel that they have control over their own health and disease. Meaningfulness is essential for people to shape their own future (Antonovsky 1979, 1987; Lindström and Eriksson 2010). Previous literature has indicated that information concerning health recommendations is of great importance to patients to address their own life situations (Austvoll-Dahlgren et al. 2011; Di Prospero et al. 2001; Landsbergen et al. 2010). Strengthening a women's own resources by providing her with more information and knowledge through participation in ESGs might provide a feeling of control over her own health and disease.

Some of the participants expressed concerns that the surgical risk-reduction decisions were sometimes forced upon them. Among the women who had undergone surgery, several reported that pressure from either a family member or a physician was the main rationale for undergoing surgery. This observation is consistent with previous studies on women with a personal or family history of breast cancer who underwent risk-reducing surgery (Lodder et al. 2002; Patenaude et al. 2008). A relevant factor that was mentioned in the women's statements was that one of the reasons for undergoing genetic testing was to be included in a clinical follow-up program. Some of the women expressed concerns that they had waited a long time to receive information about risk-reducing surgery, and they were satisfied to be included in the ESG. Antonovsky's concept of manageability suggests that if clients can identify available resources, the future may be more manageable (Antonovsky 1987). Some of the participants were identified as mutation carriers many years prior to the inclusion in the ESG. According to Rosas-Blum et al. (2007), incorrect timing when communicating important information may lower the utility value. Medical and genetic information should ideally be provided when patients are ready to make independent choices and decisions on their own life situations (Rosas-Blum et al. 2007).

Some women stated that they had canceled their scheduled surgery for risk-reducing surgery because they had received limited, conflicting and confusing information. These women described feelings of frustration with their health professionals, whom they deemed lacked sufficient insight into the patient's point of view. It is said that health care professionals might need to place more emphasis on the patient's perception of living with a disease, in addition to factual and scientific information (Rosas-Blum et al. 2007). According to Langeland et al. (2007), it is necessary that health professionals use a holistic approach to gain a more in-depth perspective and understanding of the patient's situation. It has also been reported in studies that mutual support and information from health professionals may improve coping (Esplen et al. 2004; Landsbergen et al. 2010; Patenaude et al. 2008).

The women wanted to attend the ESG to gain insight into the experiences of other mutation carriers and to discuss and

share their own knowledge and experiences. We found that women indicated that they received mutual support from participating in the ESG and through interacting with other mutation carriers. According to Antonovsky, social support may help increase a person's health and well-being (Antonovsky 1987). Previous research has documented the importance of social support (Langeland and Wahl 2009; Langeland et al. 2007). Both health professionals and like-minded people can contribute to a patient obtaining a secure and predictable future. It is said that if the patients have the opportunity to share thoughts, feelings, and reactions, the emotional pressure can be released, which will provide a better treatment outcome (Esplen et al. 2004). This aspect of health benefits has also been found in more recent research (den Heijer et al. 2011; Douglas et al. 2009; Landsbergen et al. 2010).

In the present study, the patient representative seemed to play an essential role in participant interactions. This finding suggests that the interaction between the patient representative and participants satisfied the women's need for mutual support and in-depth knowledge. Further, the interaction seems to have had an impact on some of these women's decision processes regarding implementing risk-reducing surgery. This is consistent with the literature that refers to patient representatives as central in the ESG because they act as spokespersons on behalf of the women, resulting in a collective interaction between the participants and health professionals (Crawford et al. 2002; NKLMS (The Norwegian National Advisory Unit on Learning and Mastery in Health) 2013). Research has indicated that most of these women are anxious about making such choices (Bresser et al. 2007), particularly because it can affect physical appearance, self-image, sexuality, and reproductive ability (Lodder et al. 2002; Wainberg and Husted 2004). More knowledge might ease acceptance, thereby aiding in the decision concerning risk-reducing surgery (MacDonald et al. 2010; Patenaude et al. 2008).

We also found that participation in the ESG generated new questions for the participants regarding their risk of developing cancer. The women received new information in the course; this new information may be a new source of concern in relation to decisions about screening methods and implementing risk-reducing surgery. Some sources of concern might be that new research has indicated that mammography and MRI might not be sufficient to reduce mortality in BRCA1-associated female carriers (Moller et al. 2013) and that it is proven that screening of the ovaries has been shown to be ineffective in reducing mortality (Domchek et al. 2010; Finch et al. 2014).

The participants were pleased that they had received consistent information regarding risk-reducing oophorectomy during the ESG. This result is interesting because the women obtained information concerning recommendation to remove the ovaries at 35–40 years of age both orally and in writing, during the genetic counseling sessions. The findings might

suggest that these women have a lack of ability to process, retain, or accept such information at the disclosure of their test results. Studies have shown that accurate information and knowledge can help increase screening behavior and acceptance of surgical procedures among women (MacDonald et al. 2010; Visser et al. 2011). This result can be reflected in Antonovsky's theory that one must focus on identifying patient health resources and capacity within the patient's interior as much as in the patient's environment, rather than the actual disease (Antonovsky 1987).

Study Strengths and Limitations

In this study, two focus group interviews were performed prior to and after the ESG course, allowing us to assess women's experiences with the ESG, contributing to the findings in the study. The data collection and analysis were performed by several researchers and might have strengthened the objectivity of this study. The participants in this study varied according to age and timeframe after identification of mutation status and risk-reduction surgery. The fact that the principal investigator had counselled some of the participants may have enhanced the communication in the interviews. However, it was important to avoid too close interpersonal interactions with the participants to maintain a professional researcher's view in the focus group interviews. The number of participants was limited, and the study was performed only in rural areas in Northern Norway and the results may not be representative of all BRCA positive women.

Implications for Practice

Participation in an ESG can provide relevant information and social support, and should ideally be provided shortly after the women have received their positive test results. Health care providers need to strive for better and uniform communication. It is important to involve patient representatives in future planning of clinical interventions to provide important insight into the perceived needs of these women.

Conclusions and Research Recommendations

The information received at the ESG has made these women more independent, and more aware of their options for care and choices regarding risk-reducing surgical methods. It is also evident that providers need to strive for better communication among them to send a unified message to patient. Our findings imply that these issues should be addressed. Further investigations should be conducted in other populations of women who are BRCA1/2 mutation carriers to assess the potential benefit of participation in supportive expressive groups, using both qualitative and quantitative study designs.

More studies should also be conducted regarding the important role of the patient representative in ESG.

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Compliance with Ethical Standards

Conflict of Interest Marion Myklebust, Eva Gjengedal and Nina Strømsvik declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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