Brief Communication

“Najia” Story: A WhatsApp Support Group For Patients With Breast Cancer

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Social media is becoming an essential part of every aspect of life. Different media platforms exist, and each has different features; however, all platforms provide the opportunity to interact, engage, and share. The use of social platforms has extended to the medical field. Online support groups for several medical conditions have progressively evolved with the expansion of Internet use.[1–4] A Cochrane review evaluated the effect of online breast cancer support groups on women's emotional distress, uncertainty, anxiety, depression, and quality of life. It included online support groups in six trials that lasted 6 to 30 weeks and included eight to 15 members. Because the included trials were small and of low quality, the review did not find robust evidence to show whether participation in online support groups was beneficial for women with breast cancer. Also, they did not specify the specific online platform in the reviewed trials.[5] An abstract from India reported a 14-week program that was created to provide physical and psychological interventions by doctors, nurses, and social workers for groups consisting of six to 10 women with metastatic breast cancer on WhatsApp. The intervention was short-lived, but the authors concluded that such groups might replace physical meetings.[6]

Saudi Arabia is considered one of the countries with rapidly increasing social media engagement. Sixty-eight percent of the Saudi population consists of active media users with an average use of 3 hours daily. Interestingly, Saudi Arabia ranked first among Arab countries and second worldwide in the use of Snapchat and WhatsApp and Facebook had the top rates of social networking platforms use.[7]

From our experience, many patients in Saudi Arabia prefer to keep silent about their cancer diagnosis or perhaps prefer to maintain anonymity while participating in an online group. Although the desire to engage and share with similar patients and caregivers is present, such barriers may present difficulties and challenges, especially to women who grew up in a conservative culture.[8] Moreover, a reliable native language platform is not easily found. On consultation and discussion with the author's patients about online platforms, many expressed their desire to be part of a trusted group to connect, exchange experiences, and obtain psychosocial support. It is essential to know that real-time support groups do not exist in our country for the same reasons that hinder open social participation.[9,10] After considering these barriers, in 2016 a WhatsApp support group for women with breast cancer was created. It is called Najia, which is Arabic for “A lady survivor” and has an artistically designed turtle as a group logo to symbolize the endurance and persistence of patients with breast cancer during their treatments and wish for posttreatment longevity. The group is moderated and supervised by the author, making sure it serves its intended purpose. It is a shared partnership with patients. Each one of the women is an administrator in addition to being a member and has the right to add or modify the goals of the group. The group has gained popularity over time. It was intended to connect and support the patients who the author manages. Unexpectedly, it has expanded to include women with breast cancer, both survivors and those undergoing active treatments at different hospitals and from different regions across Saudi Arabia. On invitation, other female oncology physicians joined the group and help supervise and provide trusted knowledge. The Najia WhatsApp group was initiated with 10 members. Currently, it is hosting more than 160 members and continues to grow.

Many participants find the experience of participation empowering and educating according to their own statements. For instance, experience exchange between group members regarding the potential side effects of treatments and how to effectively deal with them form their perspectives. Such sharing gives reassurance to those starting the treatment journey that these treatments are bearable and tolerable. Challenging survivorship issues, such as sexual dysfunction and others, are
discussed openly and willingly as the group provides a secure and trusted space made by and for women. Moreover, these women provide psychological support to each other; the feeling of mutual understanding that they exchange as a result of similar disease experience allows them to connect and relate to each other's feelings. It is admirable how some women are naturally talented in dealing with their peers' feelings and recommending coping strategies. It has helped to correct misconceptions and myths about breast cancer and cancer-related treatments. After receiving a cancer diagnosis, many women receive messages from family members and friends advertising miracle cures or specific diets leading to subsequent confusion and sometimes deferring effective treatments for false claims. Najia has become a hub for fact-checking, demystifying incorrect messages, and explaining the truth. With such use, each member of the group is equipped with the correct knowledge to combat the false claims. Hence, we are creating exponential awareness; each member shares her knowledge with all other people in her surroundings (Table 1).

From a physician's and author's personal perspective, it is educating as it opens a window to the thoughts of these women, draws attention to their concerns, and lays emphasis on their unspoken fears. Hence, it is strengthening the physician–patient relationship. Furthermore, the author knows places that sell local quality wigs, scarves, headwear, and underwear for women with cancer. This knowledge surely has led to more resourcefulness when dealing with patients newly diagnosed breast cancer.

Nonetheless, several challenges have been faced with respect to maintaining group integrity and cohesiveness over the years. Initially, each one of the women was made an administrator and had the right to add other new members; however, a woman advertising herbal supplements to reduce the cancer risk was inadvertently added to the group. She was added by one of the group members as she claimed that her sister is a breast cancer survivor, and she was willing to help her sister by sharing others' experience. Subsequently, the administrator privilege is now restricted to personal knowledge, emphasizing the criteria for joining the group that was previously agreed on. This incident necessitates the development of delegates who help to maintain the group's objectives and ensure that it serves its intended purpose. Their ability to maintain the group was tested during the summer of 2017 when a 4-month sick leave was required for the administrator, and they successfully succeeded in managing the group. Sending out unrelated broadcasts and news to the group that spam or obscure the more relevant discussion is a recurring encounter, and is usually done by nonactive group members. Therefore, periodic reminders in general and introductory messages to new members are sent. However, a few members who could not repeatedly comply with the group's goals were removed.

The group is primarily dedicated to supporting and empowering patients with breast cancer through all stages of their disease; thus, patients with metastatic breast cancer are included. Nevertheless, the news of them worsening or dying leaves a negative impact on other earlier stage disease survivors. Fortunately, such a negative impact is transient, as observed by the author. Some members redirect the sad news as God's will, which is an effective and soothing method in a spiritual society such as ours.

Misunderstanding and interpersonal conflicts among the group members occur on different occasions as a result of the typed communication being devoid of emotions. Such incidents were contained with conversation and further clarification of each party prospect. During the first year of the group, a disruptive member falsely claimed that the goal of the group is to gather women and use them for experiments, such as is done with laboratory animals. Unfortunately, she was known and added personally by one of the female physicians to the group. When she was approached about her statements, it became obvious how angry she was with the diagnosis, which might have reflected on her judgment. Although she chose to leave the group, the administrator was able to gain the members' trust and prove that the group is solely dedicated to supporting and empowering them.

The group introduces members to each other; some members have made new friendships and others organize social gatherings and volunteer in breast cancer-related activities. Several real-time meetings enthused by the desire to meet in person and further discuss issues that arose on the virtual platform were organized. Time and effort to organize meetings limit the constancy. Nevertheless, the virtual support group is available at any time and is flexible for participation.
Although WhatsApp-based interventions for health-related issues covering weight loss coaching, healthy lifestyle tips, smoking cessation, plus other topics have been described, a professional-led cancer support group using WhatsApp is not among them.[11–13] Lea et al.[14] highlight the need to develop resources that support the holistic needs of patients with cancer and recommend that this should be done in collaboration with them. Therefore, the Najia support group is unique for creating professional-patient partnership on one hand and patient-patient partnerships on the other hand, leading to a productive multifunctional support group (Table 1).

Moreover, the constant expansion and the positive feedback that has received indicate that it is functioning effectively. This group was formed to share, empower, and advocate. Najia aims to use innovation and advances in technology to progress to a larger multidimensional online platform led by and for women to fill the gap between medical treatment and the much-needed support for breast cancer survivors.

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