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The impact of an online support group on patients' awareness of pregnancy-and lactation-induced osteoporosis

Sansin Tuzun¹ and Eren Aygun^{1*}

Abstract

Background Pregnancy and lactation-induced osteoporosis (PLO) is a serious and rare condition, which causes substantial physical and emotional distress. The rarity of PLO highlights the importance of alternative information sources such as online patient groups. This study aims to explore the experiences of PLO among members of a WhatsApp patient group and to analyze how participation in the group impacts members' knowledge about their condition, psychological well-being, and healthcare decisions.

Methods This cross-sectional study included forty-six members of the "Smile Please" WhatsApp patient group, diagnosed with PLO. A 9-item survey assessed membership duration, sources of group awareness, knowledge improvement, changes in fears and concerns, and impacts on treatment decisions. Data were collected through structured survey questions for quantitative analysis and an open-ended question to capture qualitative insights.

Results The average age of participants was 33.8 ± 4.8 years, with a mean BMI of 23.2. Their group membership duration was 15.3 ± 16.8 months. Increased knowledge was reported by 46.3% regarding symptoms and diagnostic tools, 75.6% on treatment options, and 41.5% on side effects. Half the participants experienced decreased fear of the disease, and 41.9% reported reduced concerns about treatment side effects. The thematic analysis showed that participants received substantial emotional support from peers in the online support group, which alleviated feelings of isolation and provided motivation. They also gained insights into treatment options, especially medications, improving the decision-making process. Furthermore, they received practical coping strategies that fostered acceptance and positively impacted their overall well-being.

Conclusions Online patient groups provide a unique platform where members can openly share their knowledge and experiences, thereby influencing their emotional well-being and healthcare decisions. These groups should be encouraged, especially for chronic and rare diseases like PLO.

Keywords Pregnancy, Lactation, Osteoporosis, Online patient group

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Introduction

Osteoporosis, a condition characterized by reduced bone density and increased risk of fractures, is a significant public health concern [1]. While postmenopausal women are at greater risk, the condition can also affect individuals of any age and gender [2]. One segment of the population that may be vulnerable to osteoporosis is pregnant and lactating women, who undergo significant physiological changes that can impact bone health.

Pregnancy and lactation-induced osteoporosis (PLO) is a rare condition characterized by fragility fractures, typically vertebral, occurring during late pregnancy or early postpartum period [3]. Despite its rarity, it can cause a serious fracture cascade in young women. Understanding the pathophysiology, risk factors, and optimal management strategies for PLO is crucial for preserving maternal skeletal health and preventing long-term complications [3–5]. On the other hand, the rarity of PLO complicates information gathering and hinders the development of a standardized approach, thereby highlighting the importance of alternative information sources. The advent of social media has revolutionized communication, allowing the formation of virtual patient groups where individuals can share experiences, seek advice, and support one another [6]. These groups are crucial in disseminating information and providing emotional support, particularly for those dealing with rare or chronic conditions [7]. Likewise, obtaining information from online surveys

and social media patient groups has become a popular method among PLO patients recently [8, 9].

This study aims to explore the experiences of PLO among members of a WhatsApp patient group and to analyze how participation in the group impacts members' knowledge about their condition, psychological well-being, and healthcare decisions.

Methods

This cross-sectional study was conducted among members of a WhatsApp patient group called "Smile Please" in January 2024, within a 10-day period. The study included a total of 46 participants who were diagnosed with PLO. A novel 9-item survey (Table 1) was developed to gather data on the following aspects: duration of membership, how members learned about the group, areas of increased knowledge, changes in fears and concerns, and impacts on treatment decisions. The survey, designed to be user-friendly and easy to complete within a short time frame, was hosted on Google Forms for easy distribution and collection of responses. The link to the survey was sent to participants through their patients' WhatsApp group. Informed consent was obtained from all participants before they completed the survey.

The data collected from the 9-item survey were analyzed using both quantitative and qualitative methods. The quantitative data were exported from Google Forms into a spreadsheet and analyzed using descriptive statistics to summarize the responses, employing IBM SPSS

Table 1 The 9-item survey

Q1. How many months have you been a member of this WhatsApp patient group?	
Q2. How did you hear about the group?	<ul style="list-style-type: none"> o Social Media or Online Forums o Word of Mouth (Family, Friends, etc.) o Doctor or Healthcare Professional o Other
Q3. In which specific areas has being a member of this group increased your knowledge? (You can choose multiple options)	<ul style="list-style-type: none"> o Symptoms of the disease o Diagnostic methods o Therapeutic options o Adverse effects of treatments o Disease progression during the follow-up
Q4. Has your fear of the disease changed since becoming a member of the group?	<ul style="list-style-type: none"> o My fear has increased o My fear has not changed o My fear has decreased
Q5. Have your concerns related adverse effects of your medical treatment changed since becoming a member of the group?	<ul style="list-style-type: none"> o My concerns have increased o My concerns haven't changed o My concerns have decreased
Q6. Have you sought out any extra diagnostic tools (QCT, DXA, or MRI) after joining the group?	<ul style="list-style-type: none"> o Yes, QCT o Yes, DXA o Yes, MRI o No
Q7. Has your self-management of the disease changed since becoming a member of the group?	<ul style="list-style-type: none"> o Yes o No
Q8. Are you also a member of other social media patient platforms (e.g., Facebook)?	<ul style="list-style-type: none"> o Yes o No
Q9. In your opinion, what are the most beneficial features of the WhatsApp group you're in?	

Statistics Version 26. Each question was analyzed as follows: The membership duration of participants (Q1) was shown using the mean, standard deviation, and range. Participants' responses regarding how they heard about the group (Q2) were categorized and tallied to identify the most common sources of awareness. Frequencies and percentages were calculated for each category, as well as for the areas where participants reported increased knowledge (Q3), to highlight the most significant aspects of learning. Participants' responses regarding changes in their fear of the disease since joining the group (Q4) were categorized as 'increased,' 'decreased,' or 'no change.' Frequencies and percentages were calculated for each category. Similarly, responses to the question about changes in concerns regarding the adverse effects of their medical treatment since becoming members of the group (Q5) were categorized and analyzed in the same way. For the remaining three questions (Q6, Q7, and Q8), responses were categorized as "yes" or "no," and the frequencies and percentages were calculated.

In analyzing the impact of membership duration on knowledge, awareness, and emotional responses,

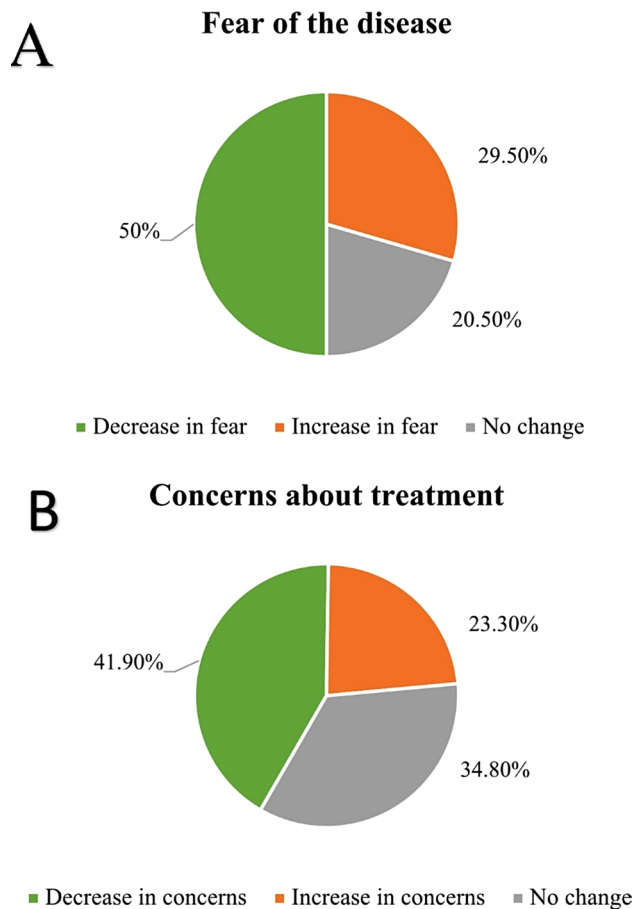


Fig. 1 Participants' proportions in terms of changes in their fear of the disease (A) and their concerns related to adverse effects of their medical treatment (B) since joining the group

participants were divided into two subgroups based on how long they had been members of the WhatsApp support group: Subgroup 1, with less than one year of membership, and Subgroup 2, with more than one year.

The qualitative data from the open-ended question (Q9) were analyzed using thematic analysis. First, all responses were carefully read multiple times to ensure thorough familiarity with the data, while initial ideas and significant points were noted. The dataset was systematically coded using both MaxQDA and Excel software to label meaningful segments of text, with each code representing a distinct concept or insight expressed by the participants. The codes were then reviewed and grouped into potential themes based on commonalities and relationships among them. Once the preliminary themes were identified, they were refined and named to ensure that each theme was distinct and accurately represented the data.

Results

The average age was 33.8 ± 4.8 years, with a mean BMI of 23.2. Excluding founding members (4 participants); the average membership duration of the online patients' support group was 15.3 ± 16.8 months ($n=36$, min 1 month, max 72 months). The majority of patients ($n=28$, 77.8%) stated that they heard about this group through the internet; social media platforms such as Facebook and Women's Club were reported as major sources. Twenty-one patients (45.7%) are also members of Facebook patient groups.

Nineteen patients (46.3%) reported increased knowledge about disease symptoms and diagnostic methods. Thirty-one patients (75.6%) gained better understanding of therapeutic options and disease progression, and 17 patients (41.5%) indicated a better understanding about treatment adverse effects.

Twenty-two patients (50%) felt less fearful about the disease, while 13 patients (29.5%) reported increased fear, and 9 patients (20.5%) felt no change in fear level. Regarding changes in their concerns related to adverse effects of their medical treatment, 18 patients (41.9%) reported that their concerns decreased, while 10 patients (23.3%) said their concerns increased, and 15 patients (34.9%) said their concerns remained unchanged (Fig. 1).

Twenty-one patients (47.8%) stated that they sought additional diagnostic methods based on the shared information in the patients's WhatsApp group. All participants underwent dual-energy X-ray absorptiometry (DXA) scans; fifteen of them (32.6%) reported having undergone DXA measurements through the WhatsApp group. Eleven patients (24.4%) reported that this patient group has had an impact on their disease management, such as using non-pharmacological and complementary methods alongside their medical treatment.

Based on membership duration in the WhatsApp group, Subgroup 1 included 21 patients with less than one year of membership, while Subgroup 2 consisted of 19 patients with more than one year. Statistical analysis revealed no significant differences between these subgroups in terms of increased knowledge or awareness of their condition. Although newer members tended to report increased fear and concerns more frequently, this difference was not statistically significant.

The thematic analysis of responses to the open-ended survey question identified four key themes: Emotional and Psychological Support, Information Sharing and Learning, Diagnosis and Treatment Awareness, and Acceptance and Coping with the Condition. Each theme comprises several codes, derived from participants' experiences, reflecting the diverse ways in which peer support influenced their health journey (Fig. 2).

Emotional and psychological support

The emotional and psychological support provided by the online group is vital for members coping with the challenges of living with PLO. The shared experience of facing similar health struggles creates a sense of community, helping individuals feel less isolated. As one participant shared, “Knowing that I am not alone because it is a rare disease and being able to talk about it whenever I want has provided psychological relief.” The group also fosters morale and motivation, with members supporting each other through shared experiences and stories of progress. “We support each other,” one participant noted, highlighting the collective effort to offer practical advice and emotional reassurance. While the group provides a sense of belonging, it also brings mixed emotions. Hearing about others' progress can inspire hope, but can also lead

to moments of panic or sadness. “Friends who mentioned getting better over time gave me morale, though sometimes I panicked when they shared their experiences.”

Information sharing and learning

One of the group's most important functions is information sharing, allowing members to stay informed and learn from each other's experiences. By exchanging knowledge about treatment methods, medications, and disease progression, members feel better equipped to manage their health. As one participant noted, “I learned about different treatment methods and doctors working in this field. I gained more information on what I could do.” The online group provides access to information that may not always be available through traditional medical sources. Peer-to-peer learning is central to this theme, as many members benefit from the collective knowledge of the group, learning from others who have tried various treatments or navigated similar challenges. One participant summed it up simply as “information sharing,” capturing the collaborative spirit that underpins the group's success.

Diagnosis and treatment awareness

This theme highlights how members raise awareness about their diagnoses and treatment options within the group. The group becomes an essential resource, especially for those newly diagnosed. Members frequently share insights into diagnostic processes, enabling others to recognize similar symptoms or seek out important tests. As one participant noted, “I noticed my hip pain, had an MRI, and was diagnosed with sacroiliitis, thanks to the group.” Another key aspect is the sharing of various treatment approaches, including therapies, medications,

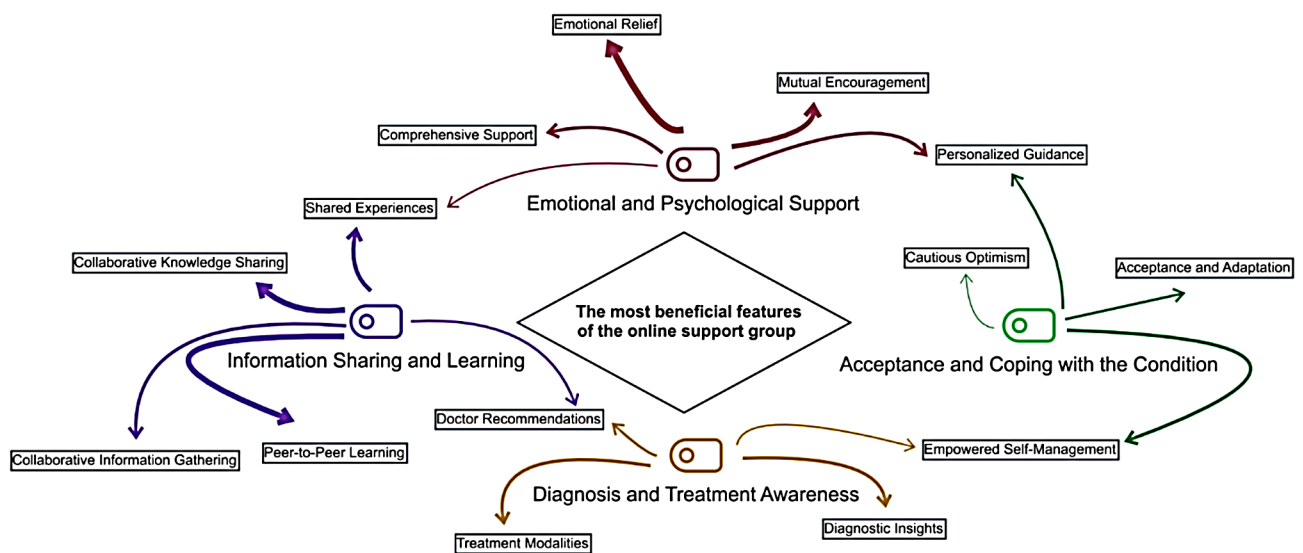


Fig. 2 The most beneficial features of the online support group, according to participants

and exercises, which are vital for disease management. *“There are over 50 people from different cities, visiting different doctors and sharing their opinions with us,”* one member explained, underscoring the value of diverse perspectives. As another member put it, *“We help each other with many issues, such as diagnosis and treatment,”* reflecting the group’s role in providing both emotional support and valuable healthcare guidance.

Acceptance and coping with the condition

The group plays a crucial role in helping members cope with the emotional challenges of living with a rare disease. *“Most importantly, friends who mentioned getting better over time gave me hope,”* shared one participant, highlighting how members learn from each other’s experiences. Those facing setbacks often adjust their expectations, accepting that a definitive solution may not be achievable. *“When I realized that women who have been searching for treatment for years still haven’t found a solution, I decided to let the disease take its course,”* one member explained. Some members take a proactive approach to managing their care, while others stick to treatment plans. As one member noted, *“I comply with the treatment planned by my doctor.”* The group provides a space for shared learning and emotional support, helping individuals adapt to their condition while offering morale and motivation.

Discussion

PLO can cause substantial physical and emotional distress in young women [3]. Our findings indicate that online platforms facilitating the instant flow of information among patients are invaluable in managing rare conditions like PLO and can be beneficial for other rare diseases as well. These groups serve as essential information sources, enhancing members’ knowledge about their conditions and therapeutic options. Additionally, they offer psychological support, alleviating fears and concerns for many patients. The social interaction within these groups helps members feel less isolated and more understood, which is particularly important for those with rare or chronic conditions [7, 10].

This study represents a demographic of young to middle-aged adults, generally within the normal BMI range. This profile aligns with the typical age and physical characteristics of PLO studies [4, 9, 11]. The fact that the majority of our patients found the online group through the internet and social media highlights the role of digital platforms in connecting individuals with rare or less publicly discussed conditions, as also shown recently by Chang et al., who demonstrated that digital tools are essential in the lives of individuals with rare diseases and their caregivers [12]. This underscores the importance of social media as a tool for enhancing accessibility to peer

support, particularly for younger or middle-aged adults like our patients. Nearly half of our patients were also members of Facebook PLO patient groups. This suggests a trend where patients, as with other rare genetic diseases [13], seek knowledge and support from multiple sources, possibly due to the information gap between healthcare providers and patients diagnosed with PLO.

Half of our patients reported feeling less fearful about PLO as a result of being in the online group. This decrease in fear likely stems from the informational support and emotional reassurance they receive from peers who have faced similar challenges. Their general thought concerning the group was that it has been a significant source of emotional and psychological comfort. Many members emphasized psychological relief and a sense of community. The emotional support provided by this online patient group for patients with PLO is similar to what is described in the literature for other patient groups with different diseases [14, 15]. Furthermore, shared experiences and peer education may reduce the feeling of uncertainty, giving patients improved acceptance of the disease and increased optimism [13]. However, nearly a third of our patients experienced increased fear. This could be due to exposure to others’ challenging experiences or adverse outcomes, which may amplify anxiety, especially for those newly diagnosed or less familiar with the disease. This increase in fear points to the complexity of support groups, where the sharing of unfiltered information may raise anxiety, particularly if the information pertains to severe cases or potential complications. Similarly, Mo et al. demonstrated the dual nature of online patient groups, offering both support and, at times, anxiety for individuals living with HIV/AIDS [16].

Approximately 41.5% of our patients reported a greater awareness of potential treatment side effects—an area that may not always be thoroughly addressed during healthcare visits. Many participants also reported a decrease in concerns related to adverse effects of their medical treatment, possibly due to the shared experiences through which patients can gain insights into the side effects they might encounter. On the other hand, some participants reported increased concerns, as hearing about peers’ experiences with side effects might make risks feel more immediate or personal, thereby prompting a heightened awareness of potential adverse effects.

In contrast to postmenopausal osteoporosis, the management of PLO is challenging due to limited options and a lack of clinical guidelines [17]. This lack of evidence-based treatment approaches likely contributes to the fear and anxiety experienced by these women, as they face uncertainty about managing their condition effectively. One study also highlighted that patients with PLO had a reduced quality of life and increased fear of fractures and falls compared to a control group [9].

The online patient groups provide a different platform where patients can share their knowledge and experiences without any authoritative influence. They play a crucial role in raising awareness about both diagnostic tools and therapeutic options [6, 18]. Nearly half of our patients (46.3%) reported an enhanced understanding of the disease's symptoms and diagnostic methods. This reflects the online support group's role in providing initial awareness that may help patients recognize symptoms earlier, possibly leading to a more informed approach to seeking medical care [19]. Approximately one-third of our patients specifically credited the WhatsApp group for influencing their decision to undergo DXA scanning, a key diagnostic tool for osteoporosis. This peer-to-peer learning is a good example of empowering patients and preparing them for medical appointments, particularly in the case of rare conditions like PLO, where individuals may initially feel isolated or unsupported by general healthcare providers. For those new to the condition, the shared knowledge and peer guidance can offer reassurance and motivate them to take proactive steps in managing their own care.

A large majority of our patients (75.6%) reported a better understanding of therapeutic options and the progression of PLO. This suggests that the online group serves as a valuable source of information about treatments and fosters a realistic understanding of the disease's progression. Online patient communities can assist patients in making more informed treatment decisions and managing their symptoms, as demonstrated by Wicks et al. in their study [20]. In the present study, nearly a quarter of participants indicated that the online group influenced their management strategies, including the incorporation of non-pharmacological and complementary approaches, such as dietary changes, physical therapy, and alternative therapies. This underscores the potential for online support groups to expose members to a broader range of options beyond conventional treatments. Aligning with the present study, there is growing literature indicating that online support groups can influence treatment decisions. For example, participation in an online support group led 29.2% of prostate cancer patients to revise their initial treatment decisions [21].

The average membership duration of 15.3 months, with a wide range from 1 to 72 months, reflects varying levels of engagement within the group. This variation suggests that members may have different experiences and levels of familiarity with group dynamics and information sharing. Both short-term and long-term members reported similar levels of understanding and insight into their diagnosis and treatment options, indicating that the exchange of information and the group's resources were equally accessible and effective, regardless of membership duration. Interestingly, while increased fear and

concerns were more frequently observed among newer members, this difference was not statistically significant. This trend may reflect an adjustment period, where newly joined members initially feel overwhelmed by the volume of information, potential complications of the condition, and the stories shared by others. These factors could lead to increased anxiety or fear at first. Over time, however, it appears that prolonged engagement with the group may help alleviate these concerns, perhaps due to greater familiarity with the information, reassurance from other members, and the gradual development of coping mechanisms.

The strength of this study lies in its data collection process, which spanned only a 10-day period, allowing for timely insights. The collection of both quantitative and qualitative data provided a comprehensive view of participant experiences. Furthermore, participants offered perspectives that were not influenced by authority, contributing to the authenticity of the findings. However, this study also has several limitations that should be considered when interpreting the results. Firstly, data were collected through a self-reported survey, which introduces the potential for recall bias. Additionally, responses to some survey questions, such as those regarding fear and concerns, may not completely fit within the three suggested options (increased, decreased, no change). Therefore, a more comprehensive set of options is needed in future studies to better capture the nuances. The cross-sectional design limits the ability to draw conclusions about how participation in the group may affect participants' knowledge over time, as no longitudinal data were collected. Lastly, while the sample size appears adequate for this rare condition, it remains relatively small compared to other studies involving online patient groups in the literature, which often include larger populations [14, 21].

In conclusion, online patient groups can play a vital role in rapidly disseminating information to women with PLO, serving as a unique platform for members to share knowledge and experiences. These groups positively impact emotional well-being and healthcare decisions, making them valuable resources, particularly for patients facing rare and chronic diseases like PLO.

Abbreviations

PLO	Pregnancy and Lactation induced osteoporosis
BMI	Body Mass index
DXA	Dual energy X-ray absorptiometry
MRI	Magnetic resonance imaging

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Author contributions

S.T. and E.A. wrote the main manuscript text, prepared the tables and figures, and reviewed the manuscript together.

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Data availability

The datasets used and/or analyzed during the current study available from the corresponding author on reasonable request.

Declarations**Ethics approval and consent to participate**

The study adhered to the principles outlined in the Declaration of Helsinki. The study was approved by the Medical Ethics Committee of the Istanbul University - Cerrahpasa (IUC-83045809-604.01-1069180). The questionnaire included a statement indicating that completing it would be considered consent to participate, allowing for an exemption from requiring a signed consent form.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

- Cauley JA. Public health impact of osteoporosis. *J Gerontol Biol Sci Med Sci*. 2013;68(10):1243–51. <https://doi.org/10.1093/gerona/glt093>.
- Gourlay ML, Brown SA. Clinical considerations in premenopausal osteoporosis. *Arch Intern Med*. 2004;164(6):603–14. <https://doi.org/10.1001/archinte.164.6.603>.
- Scioscia MF, Zanchetta MB. Recent insights into pregnancy and Lactation-Associated osteoporosis (PLO). *Int J Womens Health*. 2023;15:1227–38. <https://doi.org/10.2147/IJWH.S366254>.
- Qian Y, Wang L, Yu L, et al. Pregnancy- and lactation-associated osteoporosis with vertebral fractures: a systematic review. *BMC Musculoskelet Disord*. 2021;22(1):926. <https://doi.org/10.1186/s12891-021-04776-7>.
- Kovacs CS. Osteoporosis presenting in pregnancy, puerperium, and lactation. *Curr Opin Endocrinol Diabetes Obes*. 2014;21(6):468–75. <https://doi.org/10.1097/MED.000000000000102>.
- Conrad P, Bandini J, Vasquez A. Illness and the internet: from private to public experience. *Health (London)*. 2016;20(1):22–32. <https://doi.org/10.1177/1363459315611941>.
- Delisle VC, Gumuchian ST, Rice DB, et al. Perceived benefits and factors that influence the ability to establish and maintain patient support groups in Rare diseases: a scoping review. *Patient*. 2017;10(3):283–93. <https://doi.org/10.1007/s40271-016-0213-9>.
- Kondapalli AV, Kamanda-Kosseh M, Williams JM, et al. Clinical characteristics of pregnancy and lactation associated osteoporosis: an online survey study. *Osteoporos Int*. 2023;34(8):1477–89. <https://doi.org/10.1007/s00198-023-06793-9>.
- Peltz-Sinvani N, Raz HM, Klein P, et al. Pregnancy- and lactation-induced osteoporosis: a social-media-based survey. *BMC Pregnancy Childbirth*. 2023;23(1):311. <https://doi.org/10.1186/s12884-023-05639-w>.
- Rollman BL, Herbeck Belnap B, Rotondi AJ. Internet support groups for health: ready for the Affordable Care Act. *J Gen Intern Med*. 2014;29(11):1436–8. <https://doi.org/10.1007/s11606-014-2884-z>.
- Carsote M, Turtorea MR, Valea A, et al. Bridging the gap: pregnancy-and Lactation-Associated osteoporosis. *Diagnostics (Basel)*. 2023;13(9):1615. <https://doi.org/10.3390/diagnostics13091615>.
- Chang A, Huang SD, Benjamin DJ, et al. Exploring the role of digital tools in rare disease management: an interview-based study. *J Genet Couns*. 2024 May;13. <https://doi.org/10.1002/jgc4.1908>.
- Ashtari S, Taylor AD. The internet knows more than my physician: qualitative interview study of people with Rare diseases and how they use online support groups. *J Med Internet Res*. 2022;24(8):e39172. <https://doi.org/10.2196/39172>.
- Muhammad S, Allan M, Ali F, et al. The renal patient support group: supporting patients with chronic kidney disease through social media. *J Ren Care*. 2014;40(3):216–8. <https://doi.org/10.1111/jorc.12076>.
- Medina EL, Loques Filho O, Mesquita CT. Health social networks as online life support groups for patients with cardiovascular diseases. *Arq Bras Cardiol*. 2013;101(2):e39–45. <https://doi.org/10.5935/abc.20130161>.
- Mo PK, Coulson NS. Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering processes of participation within HIV/AIDS-related online support groups. *Int J Nurs Stud*. 2014;51(7):983–93. <https://doi.org/10.1016/j.ijnurstu.2013.11.006>.
- Herath M, Cohen A, Ebeling PR, et al. Dilemmas in the management of osteoporosis in younger adults. *JBMR Plus*. 2022;6(1):e10594. <https://doi.org/10.1002/jbm4.10594>.
- Chretien KC, Kind T. Social media and clinical care: ethical, professional, and social implications. *Circulation*. 2013;127(13):1413–21. <https://doi.org/10.1161/CIRCULATIONAHA.112.128017>.
- Hu X, Bell RA, Kravitz RL, et al. The prepared patient: information seeking of online support group members before their medical appointments. *J Health Commun*. 2012;17(8):960–78. <https://doi.org/10.1080/10810730.2011.650828>.
- Wicks P, Massagli M, Frost J, et al. Sharing health data for better outcomes on PatientsLikeMe. *J Med Internet Res*. 2010;12(2):e19. <https://doi.org/10.2196/jmir.1549>.
- Huber J, Maatz P, Muck T, et al. The effect of an online support group on patients' treatment decisions for localized prostate cancer: an online survey. *Urol Oncol*. 2017;35(2):37e. 19–37.e28.

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