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Decision-making Tools for Postmastectomy Breast Reconstruction: A Scoping Review

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Background: Breast reconstruction is an essential consideration for patients with breast cancer undergoing a mastectomy. Patients commonly report inadequate education as an important cause of dissatisfaction with breast reconstructive care. Information sources for breast reconstruction vary in quality, accuracy, and validity. We sought to determine what academic and nonacademic resources exist supporting decision-making for patients undergoing breast reconstruction.

Methods: A search was conducted of both academic literature and nonacademic social media sources. Three academic databases and 5 social media platforms were searched using keywords. Three independent reviewers performed the selection and data extraction of sources that met the inclusion criteria.

Results: A total of 1172 academic articles and 1419 nonacademic records were screened, with 14 and 9 included for final review, respectively. Of the 5 nonacademic mediums searched, none were included from TikTok and Instagram. One decision-making tool (DMT) was included from Twitter, 4 from YouTube, and 4 from Google. Overall, the quality of available DMTs was very good. The one included academic DMT had a mean DISCERN score of 5, whereas the 4 DMTs from Google and Twitter had a median DISCERN score of 4. YouTube videos were ranked using the modified DISCERN tool with a median score of 5.

Conclusions: Accessibility was found to be a significant barrier for patients in academic and nonacademic platforms with significant knowledge required to effectively search these platforms for resources. Efforts must be made to improve accessibility and awareness of these DMTs, as such tools are essential in shared decision-making. *(Plast Reconstr Surg Glob Open 2025;13:e6710; doi: 10.1097/GOX.0000000000006710; Published online 21 April 2025.)*

INTRODUCTION

Breast cancer is the second most common cancer among Canadian women, with an estimated 75 new diagnoses daily.[1] Although breast cancer accounts for approximately 25% of all new cancer cases in women, most have a good prognosis, with an 88% 5-year survival rate. Total or partial mastectomy is a mainstay treatment for breast cancer.[2] Despite its curative intent, a total mastectomy may have detrimental effects on body image, femininity, sexuality, intimate relationships, and self-esteem.[3–5] Postmastectomy breast reconstruction can reduce these harmful psychosocial effects.[6–8]

Patients face complex decisions regarding type (autologous, alloplastic) and timing (immediate, delayed) of reconstruction. Factors including the patient's baseline health, preferences, and cancer diagnosis can make the decision process overwhelming.[9]

Unfortunately, many experience decisional regret due to unfavorable outcomes.[10] A quarter report dissatisfaction with either their cancer or reconstructive care, the most common source being inadequate education regarding their options.[11,12] Patients report that explanations of their reconstructive options, including risks, benefits, and alternatives, are frequently rushed, leaving them with an incomplete understanding of their choices.[13] This

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decision is further complicated by the emotional distress of a cancer diagnosis, anxiety of multiple procedures, and concerns about the impact on their health and physical appearance.[14]

Confidence in treatment decisions reduces decisional regret.[11,15–18] Due to time-limited consultations, many feel they cannot engage in extensive decision-making conversations with their surgeons and thus rely on online resources, such as Google, YouTube, Instagram, and other forums.[19,20] These resources are often incomplete or inaccurate and can negatively impact decision-making.[21,22] Previous systematic reviews investigated the feasibility of decision-making tools (DMTs) for improved decision-making; however, they have been limited to academic databases and did not assess the online resources (forums, social media) that patients report using.[3] Shared decision-making between patients and providers as well as DMTs have been proven to reduce decisional regret.[23–25] There are several DMTs that exist for postmastectomy breast reconstruction, including BRECONDA, BREASTChoice, and Considering Breast Reconstruction after Mastectomy.[26–28] Therefore, there is a growing need to understand the availability and accessibility of breast reconstruction DMTs to help patients make informed decisions and optimize patient satisfaction. This scoping review evaluated current DMTs available for postmastectomy breast reconstruction, assessing the accessibility, quality, and impact of educational materials from academic, nonacademic, and social media sources.

Takeaways

Question: Our study aimed to assess the availability and accessibility of decision-making tools (DMTs) for postmastectomy breast reconstruction across academic and nonacademic sources.

Findings: We found limited DMTs across academic and nonacademic platforms, with accessibility posing a significant barrier for patients. Among included DMTs, quality varied, with YouTube providing high-quality resources.

Meaning: Patients facing postmastectomy breast reconstruction decisions lack accessible and comprehensive DMTs, hindering informed choices. Efforts to improve awareness and accessibility of high-quality DMTs are crucial for empowering patients in this complex decision-making process.

METHODS

This scoping review was based on the Arksey and O'Malley[29] framework. The protocol was registered on Open Science Framework under the identifier (FJX5A) https://doi.org/10.17605/OSF.IO/FJX5A.

Academic Search

An academic literature search strategy was developed with a University of British Columbia (UBC) medical librarian, informed by the search parameters by Berlin et al.[30] A combination of MeSH headings and keywords were used to search the CINAHL, MEDLINE (OVID), and EMBASE literature databases on April 28, 2023. (**See table, Supplemental Digital Content 1**, which displays the academic search strategy, **http://links.lww.com/PRSGO/D967**.) Handsearching of reference lists was also done to identify resources not captured in the database search.

Covidence (Veritas Health Innovation, Melbourne, Australia) was used to remove duplicates, facilitate screening, and store findings. Titles and abstracts were reviewed by 3 independent reviewers (S.S., C.F.I., and L.R.), with discrepancies resolved through discussion. If needed, an additional reviewer (E.N.) was consulted. Included studies focused on breast cancer patients undergoing breast reconstruction following mastectomy who used any DMT (eg, questionnaire, checklist). Randomized controlled trials and prospective, retrospective, cross-sectional, and cohort studies were included, whereas studies not focused on postmastectomy breast reconstruction patients or DMTs relevant to breast reconstruction were excluded. Inclusion and exclusion criteria are listed in Table 1.

Following title and abstract review, eligible studies underwent full-text review by 2 independent reviewers. Included studies underwent data extraction by 2 coders (S.S. and L.R.), with conflicts addressed by a third coder (E.N.). Certain metrics included authors, year of publication, study location, study population, and DMT format and efficacy.

The DISCERN tool, a 16-questionnaire validated instrument to judge the quality of written consumer health information, was used to appraise the DMTs extracted.[31] Two independent coders (S.S. and L.R.) ranked each DMT, and the Cohen kappa was used to determine inter-rater reliability. (**See table, Supplemental Digital Content 2**, which displays the DISCERN tool, **http://links.lww.com/PRSGO/D968**.)

Table 1. Academic Search Inclusion and Exclusion Criteria

	Included	Excluded
Diagnosis	Breast cancer	Nonbreast cancer diagnosis or prophylactic treatment
Procedure	Breast reconstruction following mastectomy	No mastectomy, mastectomy only, chemotherapy only, radiation only
DMT	Any tool (questionnaire, checklist, etc.) aimed to help with surgical decision-making for breast cancer patients	Tools unrelated to decision-making for breast cancer surgical decision-making
Study type	Prospective studies, retrospective studies, cross-sectional studies, cohort studies, randomized controlled trials	Review articles, abstracts, case reports, commentaries, editorials

Nonacademic Search of Social Media

The nonacademic social media search, conducted from April 26 to May 3, 2023, covered TikTok, Instagram, Twitter, Google, and YouTube, adapted from previous studies.[32,33] Search parameters, described in Supplemental Digital Content 3 (hashtags or search terms dependent on the medium searched), were developed in consultation with a UBC medical librarian and our patient advisory committee, comprised of patients with lived experience in breast cancer and reconstruction. (**See table, Supplemental Digital Content 3**, which displays the nonacademic search strategy, **http://links.lww.com/PRSGO/D969**.)

For each platform, the search strategy optimized results based on each platform's functionality. For example, TikTok searches can be sorted by highest overall ranking, recency, or likes. Each platform's default setting was used, assuming that most users would defer to default settings. The first 30 results for each search were reviewed, assuming most users would not go beyond this due to information fatigue.[34] Duplicates were removed, and items were screened according to the inclusion and exclusion criteria described in Table 1.

The included resources underwent data extraction and charting by 2 coders (S.S. and L.R.). Altmetric data were collected, including total search yield, tool format (video, infographic, and interactive), creator, inclusion of cited sources, likes, comments, shares, and whether the creator had a medical background.

The modified DISCERN tool, a 15-question ranking tool, was used, adapted from the DISCERN tool, to assess the quality of these tools.[35] Two independent coders (S.S. and L.R.) ranked each tool, and the Cohen kappa was used to determine inter-rater reliability. (**See table, Supplemental Digital Content 4**, which displays the modified DISCERN tool, **http://links.lww.com/PRSGO/D970**.)

Statistical Analysis

Descriptive statistics were used to summarize data as counts, percentages, mean ± SD, or median (interquartile range). Comparisons between groups were conducted using a one-way analysis of variance or the Mann-Whitney *U* test with a significance level of α equal to 0.05. Analyses were done using SigmaPlot software (version 11.0; Systat Software, Inc., Chicago, IL). Content analysis and qualitative synthesis were also performed on DMTs to assess the quality of tools and draw comparisons between existing resources.

RESULTS

Academic Search

The search strategy returned 1694 results (Fig. 1).[36] After removing 522 duplicates, 1172 were screened for inclusion, 1118 were excluded following title and abstract review, and 54 went on to the full-text review, where a further 40 were excluded. Fourteen studies met the inclusion criteria and were included in the qualitative synthesis.

Supplemental Digital Content 5 summarizes study and DMT characteristics, with data from 3 distinct patient populations: North American (n = 10), Chinese (n = 2), and Taiwanese (n = 2) patients, 25–83 years of age. (**See table, Supplemental Digital Content 5**, which displays the characteristics of included studies from academic databases, **http://links.lww.com/PRSGO/D971**.) The studies, conducted between 2008 and 2019, included sample sizes ranging from 8 to 276 patients. Eight studies assessed predeveloped DMTs, whereas 6 studies developed and tested their own. DMTs included Pink Journey (n = 2), BRECONDA (n = 2), Emmi Decide, BREASTChoice, BRAID, Post-Mastectomy Delayed Breast Reconstruction Options Decision Aid, Considering Breast Reconstruction After Mastectomy video and personal decision worksheet, and 5 others unnamed. Among the 14 studies, only 2 had provided accessible DMTs, both using BRECONDA, with the efficacy assessed differently in each study. One study conducted a randomized control trial to evaluate its impact on decisional conflict, satisfaction, and regret,[37] whereas the other used a qualitative thematic analysis.[38] Both found BRECONDA beneficial in decision-making and satisfaction (**Supplemental Digital Content 5**, **http://links.lww.com/PRSGO/D971**).[37,38]

The remaining academic studies involved inaccessible DMTs, preventing DISCERN ranking.[39–45] However, metrics such as decisional conflict, regret, body image, anxiety, and depression were evaluated. Two Taiwanese studies on Pink Journey found it reduced decisional conflict and regret; 1 study also reported a decrease in body image distress.[46,47]

Among the other studies with inaccessible DMTs, similar metrics were explored. The studies on BRAID and BREASTChoice indicated that both tools effectively increased patient knowledge and awareness regarding reconstruction options.[14,27] However, BREASTChoice did not significantly impact decisional conflict. A summary of the characteristics of the included academic studies is provided in Supplemental Digital Content 6. (**See table, Supplemental Digital Content 6**, which displays the characteristics of included DMTs, **http://links.lww.com/PRSGO/D972**.)

Nonacademic Search

Figure 2 demonstrates the search strategy for TikTok, Instagram, Twitter, YouTube, and Google, yielding 360 TikToks, 196 Instagram posts, 292 tweets, 360 YouTube videos, and 360 Google searches.[36] A total of 1419 materials were screened after removal of duplicates, with 1212 excluded for lack of DMT, 185 for irrelevance, 11 for non-English language, and 2 for inaccessible links. One tweet, 4 YouTube videos, and 4 Google searches were included for qualitative synthesis, with the characteristics discussed in Table 2. No TikTok videos or Instagram posts were included. One Instagram post was initially included, with a link in the caption section referring patients to a DMT; however, both reviewers could not access the link, so this Instagram post was also excluded.

The included tweet was from a North American breast cancer association. Similarly, YouTube videos

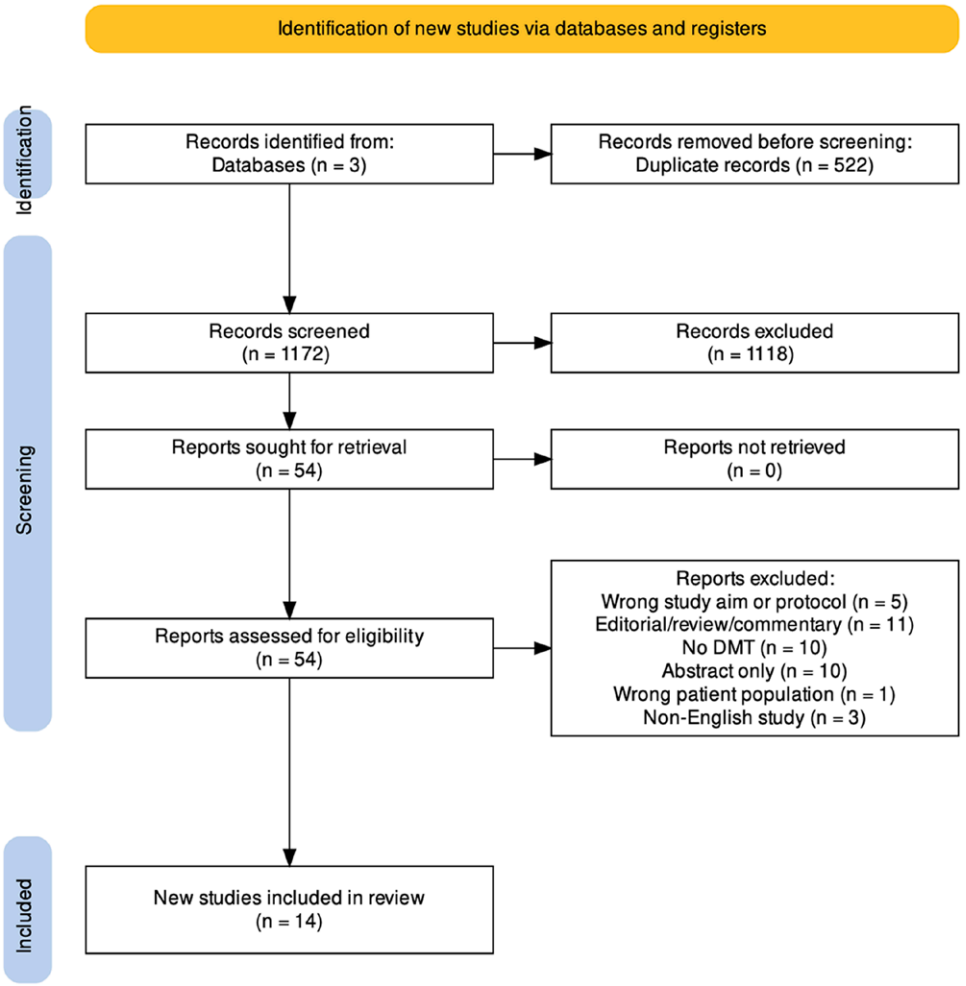

Fig. 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram.[36]

were exclusively made by North American creators with medical backgrounds, affiliated with a university, cancer center, or nonprofit organization, and ranged in length from 8:17 to 23:38 minutes. Google searches came from Canada, the United States, the Netherlands, and Australia.

Topics discussed in the sources were reviewed and are depicted in Table 3. All sources discussed implant and tissue-based reconstruction, whereas only 8 of 9 sources discussed the option of not pursuing reconstruction. Three sources discussed implant safety, 4 reconstruction timing, 6 complications, and 7 recovery time associated with each modality. YouTube and Twitter had high-quality sources, whereas quality was more heterogeneous among the Google searches included.

Quality

The academic literature, the included Google searches, and the singular tweet were scored using the DISCERN tool. The DISCERN, rather than the modified DISCERN, was used for the included Google and Twitter searches, as they linked to validated questionnaires rather than nonacademic content. For the included academic literature, 1 DMT was ranked with a mean DISCERN score of 5, whereas 4 DMTs were reviewed between the 5 included from Google and Twitter, with a median DISCERN score of 4.

YouTube videos were ranked for quality using the modified DISCERN tool. The median modified DISCERN score for the 4 videos was 5. Inter-rater reliability with the Cohen kappa was 0.78, demonstrating substantial agreement between the 2 reviewers.

DISCUSSION

Of 1172 academic and 1418 nonacademic records screened after duplicate exclusion, only 14 and 9 records were included, respectively. Of the 5 nonacademic mediums searched, none were included from TikTok and Instagram. One was included from Twitter, 4 from YouTube, and 4 from Google.

Overall, our results show few high-quality and accessible DMTs tailored to patients considering postmastectomy breast reconstruction. Only 2 of the 14 academic studies had an accessible DMT (BRECONDA), which was

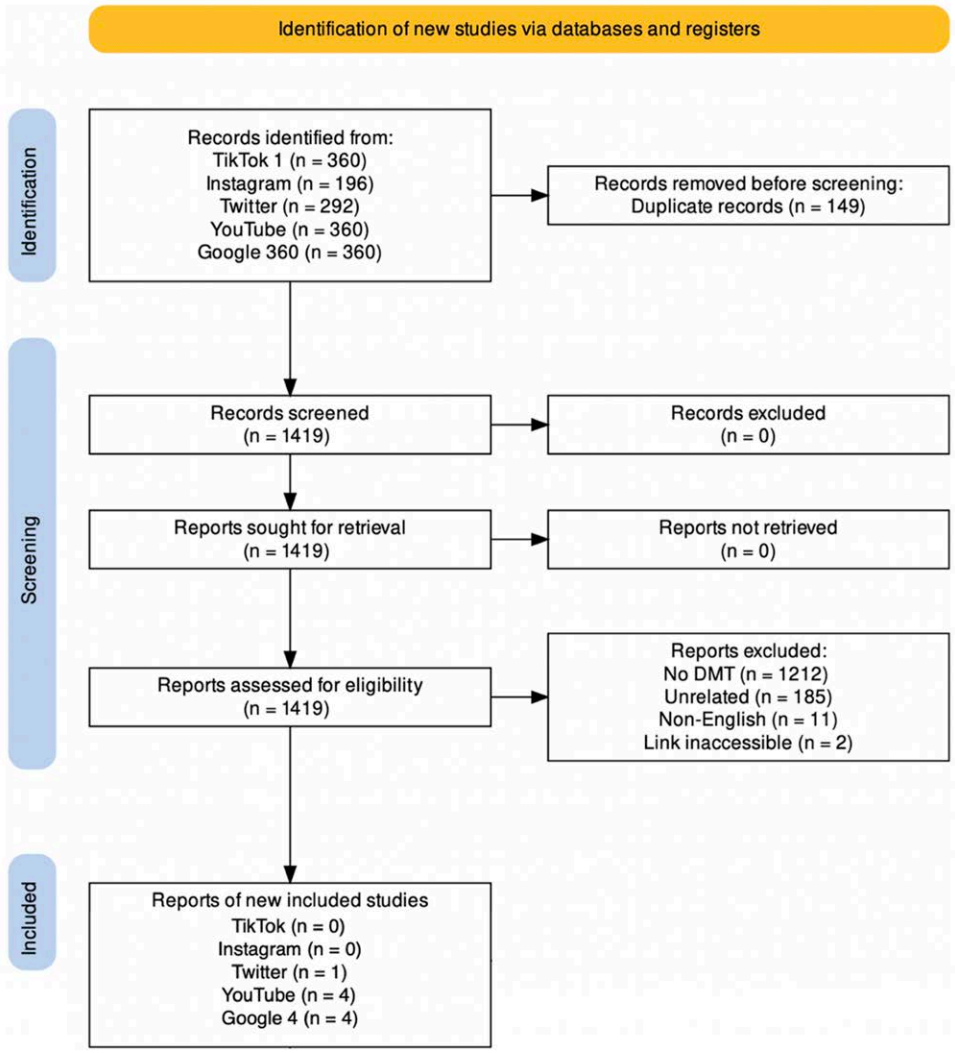

Fig. 2. Nonacademic search strategy.[36]

the same tool as 2 of the 9 included nonacademic materials. Of the available sources, they were difficult to access, even more so for patients of nonacademic backgrounds who may not know what keywords to search or what platforms to access. Further, only 5 of the 14 included studies were open access, making private access costly. This is a clear issue, as these tools provide essential information, guidance, and support to help patients navigate complex choices and make informed decisions aligning with their preferences and needs.[30,48] Of the 14 academic DMTs, 8 assessed the efficacy of preexisting DMTs, whereas 6 tested their own developed DMT. The inclusion of preexisting tools is valuable because they provide context to the evolution and scope of DMTs available to patients and providers. Understanding the historical and developmental landscape provides insight into the progression, trends, and gaps in the field.

DMTs provide comprehensive and reliable information about breast reconstruction, including surgical techniques, risks, benefits, and long-term outcomes, while personalizing decisions based on factors such as age, overall health, cancer stage, body shape, and desired outcomes.[30,49,50] They also offer emotional support through testimonials, access to support groups or counseling resources, and shared decision-making, empowering patients and garnering confidence in their decision-making.[49] By providing a clearer picture of the potential outcomes, these tools enable patients to align their decisions with their personal values, lifestyles, and goals.[9]

DMTs are valuable adjuncts, not replacements, for the provider–patient consultation. They help facilitate informed decisions by providing additional information, whereas personalized advice from the provider ensures further clarity; this collaborative approach facilitates informed and confident decision-making. Given the complexity of breast reconstruction, it is essential that DMTs are of high quality and comprehensive to complement this process.

In the academic literature, all DMTs were not accessible or were not included within the journal article, except for

Table 2. Characteristics of Included Tools From Gray Literature

Database	Creator	Healthcare Professional or Organization	DMT Name (Video Title)	Views	Length	Likes	Comments	Retweets	DMT Format	DMT Accessibility	Mean Overall Modified DISCERN
Twitter	BCNAPinkLady	Yes	BRECONDA	N/A	N/A	1	0	1	Web-based decision aid	Easily accessible, requires the creation of an account so the process can be saved	5
YouTube	Johns Hopkins Medicine	Yes	Exploring Your Options for Breast Reconstruction	11,871	18:35	97	5	N/A	Live video with animations	Easily accessible on YouTube	5
YouTube	MD Anderson Cancer Center	Yes	Considering Breast Reconstruction After Mastectomy	4465	23:38	52	10	N/A	Animation and voiceover	Easily accessible on YouTube	5
YouTube	Yerbba—Breast Cancer	Yes	Which Type of Breast Reconstruction Surgery Is Best for Me?	5806	8:17	235	20	N/A	Live video with pop-up animations	Easily accessible on YouTube	5
YouTube	Breast Cancer School for Patients	Yes	Mastectomy Breast Reconstructions Options	62,594	15:37	818	54	N/A	Live video	Easily accessible on YouTube	5
Google	MyHealthAlberta	Yes	Healthwise: Breast Cancer: Should I Have Breast Reconstruction After a Mastectomy?	N/A	N/A	N/A	N/A	N/A	Web-based interactive decision aid	Easily accessible, requires the creation of an account so the process can be saved	4
Google	Ohio State University Medical Center	Yes	Breast Reconstruction: Decision Making Tool	N/A	N/A	N/A	N/A	N/A	Informational sheet	Easily accessible, can be downloaded	2
Google	Breast Cancer Network Australia	Yes	BRECONDA	N/A	N/A	N/A	N/A	N/A	Web-based interactive decision aid	Easily accessible, requires creation of account so process can be saved	5
Google	Dutch Breast Cancer Research Group	Yes	PatientPlus Decision Aid	N/A	N/A	N/A	N/A	N/A	Web-based interactive decision aid	Easily accessible, initially asks for insurance information, but this can be bypassed if Dutch insurance is not available	4

N/A, not applicable.

Table 3. Content of Included Tools From Gray Literature

Database	Creator	DMT Name (Video Title)	Implant-based Reconstruction	Tissue-based Reconstruction	No Reconstruction	Implant Safety	Timing of Reconstruction	Complications	Recovery
Twitter	BCNAPinkLady	BRECONDA	Yes	Yes	Yes	No	No	Yes	Yes
YouTube	Johns Hopkins Medicine	Exploring Your Options for Breast Reconstruction	Yes	Yes	Yes	Yes	Yes	Yes	Yes
YouTube	MD Anderson Cancer Center	Considering Breast Reconstruction After Mastectomy	Yes	Yes	Yes	No	Yes	Yes	No
YouTube	Yerbba—Breast Cancer	Which Type of Breast Reconstruction Surgery Is Best for Me?	Yes	Yes	Yes	Yes	Yes	No	No
YouTube	Breast Cancer School for Patients	Mastectomy Breast Reconstructions Options	Yes	Yes	Yes	No	Yes	No	No
Google	MyHealthAlberta	Healthwise: Breast Cancer: Should I Have Breast Reconstruction After a Mastectomy?	Yes	Yes	Yes	Yes	No	Yes	Yes
Google	Ohio State University Medical Center	Breast Reconstruction: Decision Making Tool	Yes	Yes	No	No	No	No	Yes
Google	Breast Cancer Network Australia	BRECONDA	Yes	Yes	Yes	No	No	Yes	Yes
Google	Dutch Breast Cancer Research Group	PatientPlus Decision Aid	Yes	Yes	No	No	No	Yes	Yes

the BRECONDA. All included studies were patient trials. DMTs were likely not included in the articles because the trials focused on assessing the efficacy and validity of the tools rather than public accessibility.[51,52] Moreover, intellectual property rights, proprietary considerations, and commercial interests may also play a significant role.[51,53] Some DMTs are integrated into electronic health records to assist in patient care and decision-making, limiting their availability beyond institutions where they were initially implemented.[54,55] Although this lack of public access is disappointing, it underscores the importance of such trials refining DMTs. Additionally, there is no standardized format or guidelines for DMT dissemination, though many of these articles discussed the need for further development and testing before release. This lack of accessible DMTs was further reinforced by our nonacademic search, wherein TikTok, Instagram, and Twitter severely lacked practical resources, whereas Google and YouTube had scarce resources.

This can be attributed to the format and algorithms of these platforms. TikTok primarily focuses on short videos and prioritizes trending content and entertainment over medical information, whereas Instagram is primarily a visual platform that focuses on sharing images where visually appealing content is prioritized.[56] Similarly, Twitter emphasizes brevity, reinforced by a character limit restricting the amount of information shared in a tweet.[57] As such, providing nuanced information required for complex decisions like breast reconstruction is challenging. Further, the nature of these platforms may not align with the informational nature of DMTs, making it challenging to gain visibility.[58] The limited interactive features on these platforms limit personalized interactive elements, which may be better suited for platforms that allow longer form content and in-depth discussions.

Although TikTok, Instagram, and Twitter are not ideal for DMT access, they help raise awareness, provide emotional support, and allow patients to share personal experiences. It can be a space for individuals to connect with others, find resources, and discover reputable organizations offering DMTs outside the social media ecosystem.

A difference was found in content between Instagram and TikTok searches. On Instagram, the searches were more commercial, reflecting the platform's emphasis on influencer marketing. Market brands, healthcare institutions, and medical professionals use Instagram for service promotion; thus, many of these searches yielded advertisements and sponsored posts, contributing to a more commercialized experience.[59] TikTok leaned more toward supportive or shared experience narratives. This is in keeping with TikTok's format, with short videos that facilitate the sharing of personal experiences, emotional support, and the formation of supportive communities.[60] However, these observations are generalizations, and there can be overlap and variation in the content found on both platforms.

YouTube proved more fruitful in providing DMTs for patients, with 4 DMTs all scoring 5 out of 5 on the modified DISCERN. These tools, from medical institutions, offered diverse, detailed information. YouTube's format supports

sharing comprehensive content and a range of perspectives.[61] One benefit is the platform's search algorithm, which provides personalized recommendations based on the user's viewing history and preferences, helping patients find relevant videos based on their preferences.[62]

Google was the best platform for finding DMTs due to its comprehensive search engine, efficiency, and user-friendly interface.[63] The continually evolving algorithm prioritizes relevant and reliable resources, also considering user reviews, engagement, and authority, increasing the likelihood of finding high-quality DMTs.[64] Results often include links to trusted organizations, healthcare providers, and patient advocacy groups, ensuring access to reliable, evidence-based information. Of the 4 included Google search DMTs, the median DISCERN score was 4; all were derived from health institutions with varied quality. The BRECONDA tool was once again identified in this search, indicating its growing availability.

Social media engagement measured in the form of likes, comments, shares, or retweets was relatively sparse. This is likely reflective of the niche nature of the topic within the broader social media landscape. Some Twitter and Instagram posts had no engagement at all. The few tools that did demonstrate higher levels of engagement were found to be unrepresentative of the entire sample. These tools often had specific characteristics or were promoted in a certain context that was not generalizable to the broader set of tools identified, making it difficult to fully capture the current landscape of DMTs.

This study highlights the limited accessibility and quality of preexisting DMTs, underscoring the need for resources that are validated, user-friendly, and accessible. We recommend active involvement from the medical community in developing and promoting DMTs, encouraging surgeons to integrate DMTs within their practice. Another suggestion includes broadening the accessibility of these tools to encompass multiple platforms, including both online and mobile applications.

Future studies should explore the integration of artificial intelligence (AI) into patient education, particularly in enhancing DMT use. As AI advances, it may become a key resource in decision-making. This could be leveraged to develop a sophisticated tool in the future. One study by Boyd et al[65] investigated the use of AI as a triage tool in the perioperative period, finding currently available AI tools promising for fielding patient queries and providing recommendations.

This study was limited to English-language sources, excluding a broader range of DMTs. A standardized framework was used to ensure the replicability of results and minimize error; however, this resulted in the prioritization of certain aspects of the literature and nonacademic sources. Moreover, the dynamic nature of nonacademic mediums means this cross-sectional study only provides a snapshot of the information. Furthermore, the absence of online DMTs does not exclude the possibility that patients may be provided written or video information on DMTs by their providers. Finally, the conclusions of this study were drawn by healthcare professionals and may not be generalizable to the greater population.

CONCLUSIONS

Although limited, the available DMTs were generally of high quality. The most significant barrier for patients is not the availability of DMTs, but rather, accessibility, requiring knowledge of effective search methods and platforms. Efforts should focus on improving access and awareness, as such tools are essential in empowering patients, enhancing their understanding, and helping them make informed decisions that align with their unique needs and goals.

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DISCLOSURE

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ETHICAL APPROVAL

Under article 2.4 of the Tri-Council Policy Statement, this study was exempt from institutional review board approval because all data were gathered from published primary research and publicly available registries. Study results will not identify individuals or generate new forms of identifiable information.

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