


# Integrating online community support into outpatient breast cancer care: Mayo Clinic Connect online platform

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## Abstract

**Introduction:** Mayo Clinic Connect is an online community of over 100,000 members who support each other through sharing lived experience when facing and managing new diagnoses. The community is moderated by Mayo Clinic staff and volunteer patient mentors.

**Methods:** Mayo Clinic breast clinic patients undergoing evaluation received a binder of support resources including a brochure about Mayo Clinic Connect at visits between January and May of 2019. Surveys were distributed at subsequent visits between May and December of 2019 to assess patient awareness about the online resource, participation frequency, purpose of use, and benefits for members, as well as reasons for not joining (non-members). The primary aim was to assess patient resilience, coping, and self-management after joining the online community.

**Results:** Nine hundred surveys were distributed, and 102 participants completed surveys between May and December 2019. Forty-five percent ( $n=46$ ) had heard about Mayo Clinic Connect; 34% ( $n=15$ ) through a brochure. The remainder heard about the community from a Mayo Clinic provider (43%;  $n=19$ ) or other resources (22%,  $n=10$ ; no response  $n=2$ ). Twenty percent ( $n=20$ ) of survey participants registered as Breast Cancer group members, and most of this subgroup (55%;  $n=11$ ) reported understanding diagnosis, treatment plans, and finding peer support as reasons for joining. Seventy-five percent of Mayo Clinic Connect participants ( $n=15$ ) reported the community met or exceeded expectations.

**Conclusion:** This pilot study reveals the potential positive impact of introducing an online peer support group into clinical care plans for patients coping with a new and anxiety-provoking cancer diagnosis.

## Keywords

Breast cancer, online < General, online community, support group, coping

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## Introduction

Peer support is a crucial factor for patient self-management and quality of life when facing a life-altering diagnosis.<sup>1</sup> Online support groups help patients find others with similar diagnoses to augment their existing support system.<sup>2</sup> Unmonitored, online patient communities carry risk of inaccurate medical information or encouragement of malignant health habits; however, active, moderated communities may result in a higher quality exchange

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which can improve healthcare outcomes.<sup>3–6</sup> Though prior studies of these communities show positive impacts, they remain few in number.<sup>7</sup>

*Mayo Clinic Connect (Connect)* is a patient-led online community hosted, managed, and solely funded by Mayo Clinic with over 100,000 members.<sup>8</sup> Patients and family members support each other through sharing lived experience as they face new diagnoses, navigate treatment, and live with illness beyond the walls of healthcare institutions.<sup>9,10</sup> The community is open to all, regardless of Mayo Clinic patient status.<sup>11</sup> The Breast Cancer group is one of over 65 disease-related community groups.<sup>8</sup>

This pilot study introduced *Connect* to breast cancer patients at Mayo Clinic. We assessed resilience, coping, and self-management of registered members who utilized the platform. Secondary aims were evaluating: (a) perceived community benefits/limitations; and (b) awareness of *Connect* as a patient resource.

## Methods

All breast cancer patients evaluated in the Mayo Clinic breast clinic were eligible to participate in the study. The institutional review boards of the Mayo Foundation approved of this study. Patients were exempt from written or verbal consent as survey completion was voluntary for this quality improvement initiative. As such, limited demographic information was obtained during the study to encourage participation.

## Design

From January 2019 through May 2019 patients were provided a binder including support resources and educational material with information about *Connect* at multiple interdisciplinary visits to the Breast Clinic: diagnosis, surgical consultation, oncology consultation, and survivorship consultation. Brochures were also available in provider offices, and these were distributed and/or offered to patients at each visit if they had not previously heard about this resource. Paper surveys inquiring about patients' experience with *Connect* were distributed at each subsequent clinical visit by desk staff between May 15, 2019 and December 31, 2019. Given the distribution of surveys at multiple clinic visits, some breast cancer patients may have received surveys multiple times. Completed surveys were returned in a secure bin at each breast clinic reception desk and were entered in a secure electronic database, after which forms were securely discarded.

## Patient survey

Surveys included questions allowing for multiple answers regarding if and how: a) patients heard about *Connect*; b) they benefited from *Connect*; and c) the community

impacted resilience and self-management capacity in the setting of a new breast cancer diagnosis. Survey analysis also included patients who chose not to join the online community (non-members). Limited demographic evaluation of non-respondents was completed using available institutional data (Epic; SlicerDicer, Verona, WI).

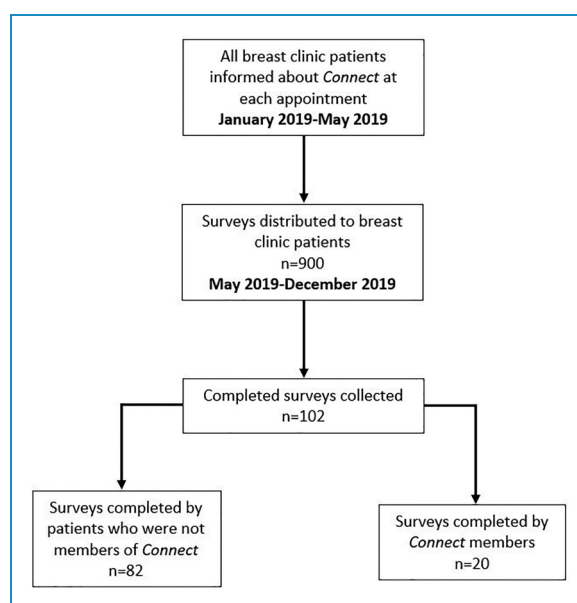
## Statistical analysis

Survey response analyses were conducted using Microsoft Excel and JMP statistical software, version 14.1 (SAS Institute).

## Results

### Demographics of survey participants

A total of 1097 breast cancer patients were diagnosed and evaluated at the Mayo Clinic Breast Clinic in 2019, and 790 office visits occurred during the survey period. Approximately 900 surveys were distributed to Mayo Clinic breast cancer patients, and 102 surveys were completed and returned (response rate 11.3%; Figure 1). Limited demographic data was similar between survey respondents and non-respondent breast clinic patients with breast cancer diagnosis (Table 1). Survey participants were noted to be significantly younger than non-respondents ( $p = 0.0002$ ). Of the survey participants, 45% ( $n = 46$ ) had heard about *Connect*—34% ( $n = 15$ ) through a brochure in the provider's office or in their educational binder. The remainder heard about *Connect* through a Mayo Clinic provider (43%;  $n = 19$ ) or through other sources such as family, friends, or internet searches



**Figure 1.** Study flow diagram of survey distribution and response.

**Table 1.** Demographic information of breast cancer patients at the Mayo Clinic breast clinic from May to December 2019.

Characteristic	Total Breast Cancer Patients Evaluated (n = 790)	Survey Respondents (n = 102)
Average Age (SD)†	64 (13)	59.2 (12.1)
Sex (%)	784 (99.2)	102 (100)
White (%)	728 (92.2)	n/a <sup>a</sup>

† $p = 0.0002$ .

<sup>a</sup>data not collected in surveys.

Abbreviations: SD-standard deviation.

(23%,  $n = 10$ ; no response  $n = 2$ ). Twenty percent ( $n = 20$ ) of surveyed patients were members of *Connect* and were, on average, five years older than non-member breast cancer patients (63.5 vs. 58 years;  $p = 0.04$ ).

### Activity of registered members of connect

Most members (65%;  $n = 13$ ) accessed their *Connect* account less than one time per week, and all but one of these members posted less than once per week. Members spent an average of 1 to 3 h on *Connect* when they visited the online community.

### Impact of connect on registered members

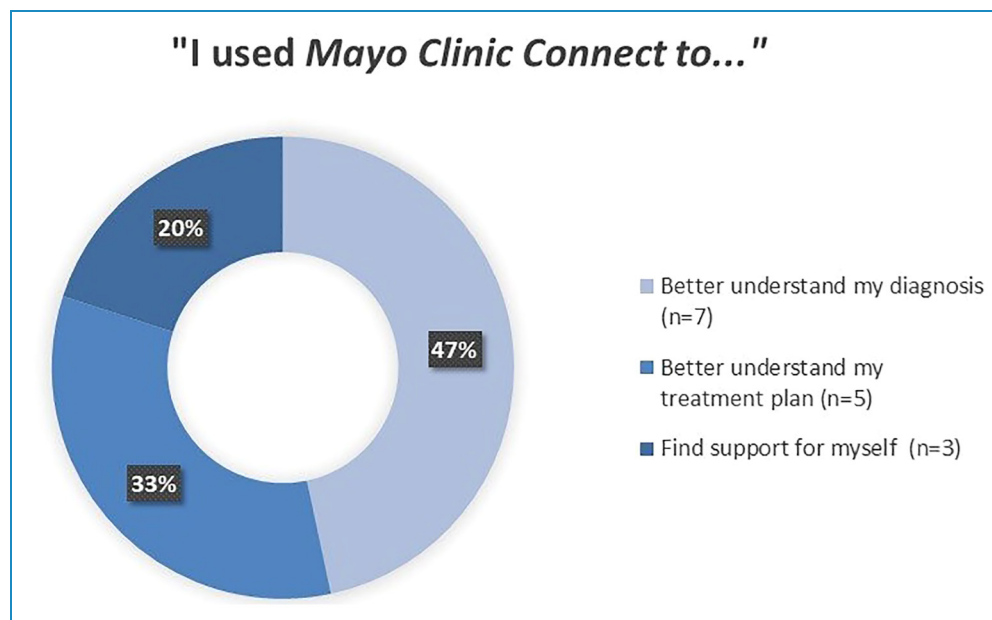
Fifty-five percent of members ( $n = 11$ ) reported understanding of diagnosis, treatment plans, and finding peer support

as reasons for joining (Figure 2). Seventy-five percent ( $n = 15$ ) reported *Connect* met or exceeded expectations having achieved goals of learning about diagnosis and treatment, learning from others, and becoming more confident about their personal health management skills (Figure 3). Members similarly reported improved coping and self-advocacy from their participation (Figure 3). Only 10% of members reported negative associations, such as increased anxiety and fear of what might occur while undergoing treatment. There did not appear to be a correlation between time spent on *Connect* and perceived benefit from the platform.

The majority of members (57%,  $n = 8/14$ ; no response  $n = 6$ ) would repeat their decision to join again if presented with this option. More than two-thirds (71%,  $n = 10/14$ ; no response  $n = 6$ ) of members would recommend the site to a friend or family member while the rest ( $n = 4$ ) were uncertain.

### Perceptions of survey participants who did not join connect

Of the patients who completed surveys in the Breast Clinic and did not join *Connect* (80%;  $n = 82$ ), most had not heard of *Connect* (65%;  $n = 53$ ) or elected not to join the community (35%;  $n = 29$ ). Though non-members reported lack of knowledge about *Connect* as the primary reason for not participating, many also cited already having a good support group, or general disinterest in using online forums as reasons for not participating (Figure 4). None of these non-member survey participants cited specific negative concerns about *Connect* as reasons for non-participation.



**Figure 2.** Mayo Clinic Connect in the context of clinical care plan.

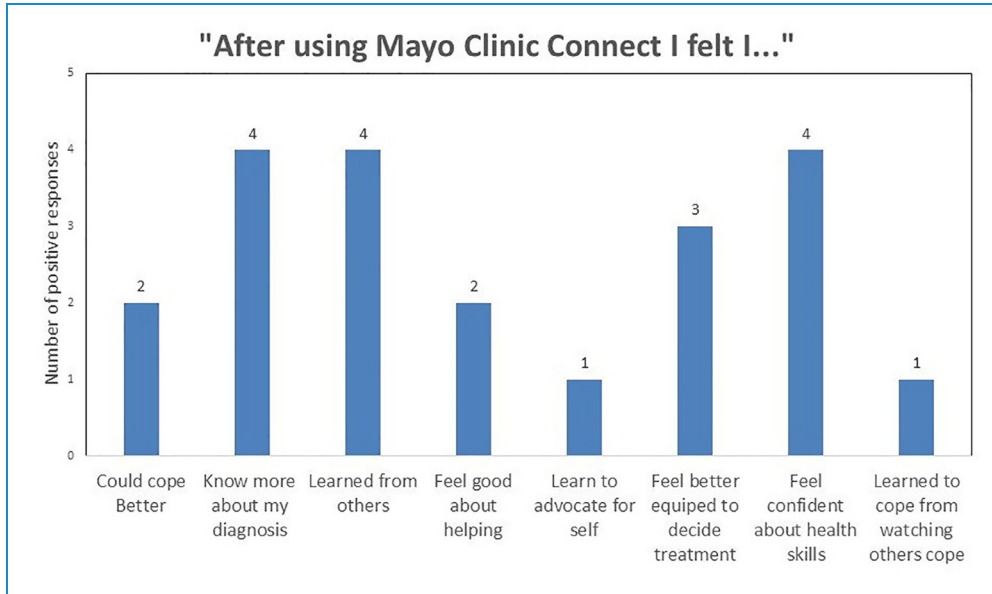


Figure 3. Perceived positive impact of Mayo Clinic Connect on registered members.

### Discussion

Novel introduction of *Connect*, an online, moderated patient-care platform, into the patient care journey had a positive impact on newly diagnosed breast cancer patients. Physician recommendation and informational brochures were vital in spreading word of the community, and patients utilizing *Connect* found the experience to be both educational and empowering during a new, anxiety-provoking diagnosis. Strikingly, negative feedback about *Connect* was almost entirely absent from both breast cancer patients who utilized the online platform and those who did not;

however, the low response rate (near 11%) and brevity of feedback from non-members may explain this absence.

### Self-empowerment and emotional wellbeing

In this quality improvement initiative, survey questions were specifically designed to qualify *both* patients' self-empowerment through education and emotional wellbeing by participating in *Connect*. This "journey to becoming informed" with a new cancer diagnosis is frequently too overwhelming to fully process during a single office

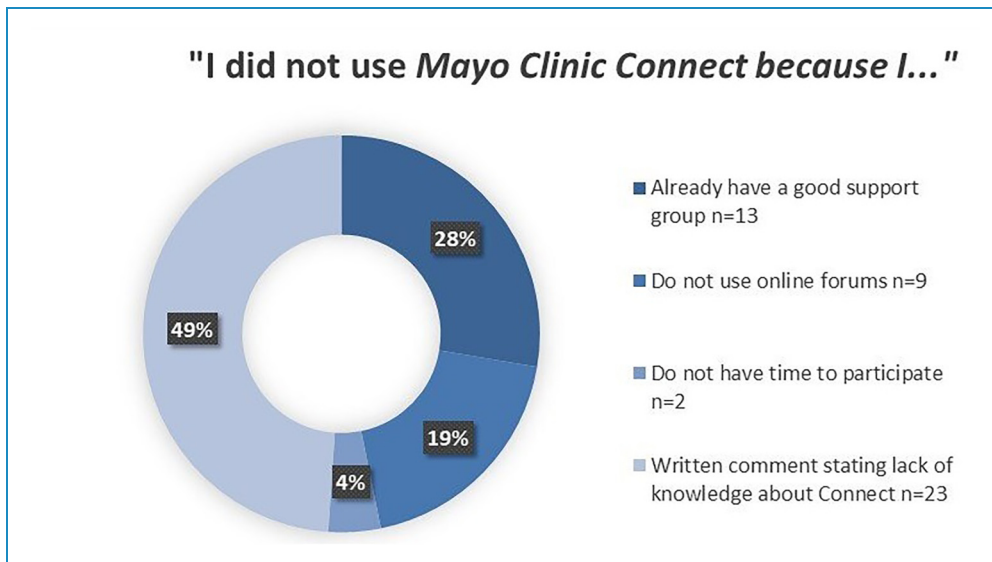


Figure 4. Non-members' reasons for lack of participation in Mayo Clinic Connect.

visit.<sup>12</sup> Though online patient communities are suggested as a beneficial patient education experience, prior evaluations of the benefits from forum participation do not fully capture patients' sense of self-empowerment or emotional well-being.<sup>8,13</sup> The *Connect* members indicated this community addressed *both* of these needs as they felt the community was firstly an educational and empowering experience and secondly an emotional, community-social support. As the *Connect* community grew by 10,497 members during our study's pre-survey period (from January – May 2019; grand total of 82,973 members May 2019), we believe patients are finding this educational, empowering experience in other disease-specific populations as well.

### Visit frequency: perceived benefits and pitfalls

Previous studies addressing frequency of online community participation and perceived benefit have provided mixed results.<sup>14,15</sup> From the *Connect* community we did not find significant correlation between time spent online and perceived emotional or empowerment benefits as nearly all survey participants visited or posted on *Connect* less than one time per week. Notably, multiple studies have described potential educational and emotional benefit from “lurking”—reading forum questions and responses without posting.<sup>12</sup> As *Connect* members reported high personal benefit from the community without prolonged visit time or frequent personal posting, this activity may reflect the benefits of lurking, though further investigation is needed to confirm this.

We observed that members of *Connect* who completed surveys were older than non-members who completed surveys ( $p = 0.04$ ). It is often assumed that members of online patient forums are younger and technology-focused. However, it is possible that *Connect* members of elevated age may have more limitations on identifying reliable, online resources independently and prefer trusted physician/institution-recommended resources. With assumed higher online literacy, younger patients may seek support within their known online networks or preferred technology platforms. Further study is necessary to further explain this user age gap.

Common criticisms of online forums were essentially absent from our study such as: a) opinions of questionable reliability; b) emotionally charged unrelated posts.<sup>12,16</sup> Though these characteristics did not appear in our analysis, our study had a limited number of members providing feedback. Further controlled investigation may help clarify if *Connect's* moderated system explains this absence of negative feedback.

### Limitations

This study was conducted at a single medical center with a specific breast cancer patient population using a single online platform, *Connect*. This study analyzed a small sample of outpatients with a low survey response rate prohibiting significant statistical analysis. As non-respondents

were not interviewed or assessed beyond limited demographic information, a true control group was also lacking, and patients who completed surveys likely represented a biased sample (i.e. highly motivated, younger, well-educated etc). Given these significant limitations, this pilot study must be interpreted with caution, and results may not be widely generalizable.

### Conclusions

*Mayo Clinic Connect*, an online, moderated community, may have a positive impact on the outpatient cancer patient experience by supplementing educational needs, empowerment, and peer support. Surveyed *Connect* members met their personal education goals and expectations from their participation.

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**Ethical approval:** The institutional review board of the Mayo Foundation approved of this study (ID 19-002840)


**Guarantor:** SP

**Author contributions:** DH, CY, and SP researched the literature and conceived the study. DH, MB, LA, and SP were involved in protocol development, gaining ethical approval, and data analysis. DH and CY wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved of the final version of the manuscript.

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