Utilization of cancer survivorship services during the COVID-19 pandemic in a tertiary referral center

Bridget A. Oppong1 · Maryam B. Lustberg2 · Timiya S. Nolan3 · Theresa Relation4 · Ko Un Park1 · Erin Healy5 · Annie Trance6 · Dori L. Klemanski6

Received: 6 April 2022 / Accepted: 26 June 2022 / Published online: 27 July 2022 © The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

Abstract

Background All Commission on Cancer-accredited comprehensive cancer centers offer survivorship programs (SPs) to women upon completion of treatment. These SPs can include clinical and non-clinical programming such as physical rehabilitation, emotional and psychosocial support, nutrition, and exercise programming. Concern about the availability and access to these programs during the COVID-19 pandemic has been described in recent literature. We sought to identify the impact of the COVID-19 pandemic on participation in these supportive services for breast cancer patients within a single institution.

Methods The Ohio State University tertiary care center offers clinical and non-clinical breast cancer support services. Descriptive statistics were utilized to summarize referral and patient participation data from January 2019 through July 2021. Data from calendar year 2019 was used as a normative comparison for pre-COVID-19. In-person and telehealth use was tracked longitudinally.

Results During the lockdown due to the COVID-19 pandemic (March through May 2020), provider referrals to SPs declined by 10%, while the overall total for the calendar year modestly increased from 1195 in 2019 to 1210 in 2020, representing a 1.3% increase. Psycho-oncology referrals increased from 280 to 318 (13.5%). The most significant change of participation rates in non-clinical SPs during the pandemic was utilization of exercise content, which increased by 220% from 2019 to 2020. The total proportion of breast cancer participants choosing an exercise program increased from 16.8% in 2019 to 42.2% in 2021, making it the most selected program area overall. Previously, nutrition was the most selected program area as it comprised 42.5% of overall utilization in 2019.

Conclusion The pandemic’s potential to place barriers to participation in SPs is a legitimate concern. We found a modest decline in provider referrals to clinical services during the lockdown period, while patient-directed participation increased with more survivors engaging in exercise-based programs. Transitioning to virtual platforms served to maintain access for patients.

Implications for Cancer Survivors As we grapple with the COVID-19 pandemic, patients with cancer deserve increased attention due to the expected stressors associated with the diagnosis. Those in the survivorship stage utilize services for psychosocial support, and the observed increase in utilization of SPs suggests an elevated need for connectivity. To meet this need, telehealth platforms have been expanded to allow for continued participation. It remains to be seen whether this will be sustained post-COVID-19 or whether reduced human contact will create new needs for programming.

Keywords Breast cancer · Survivorship · Support services · COVID-19

1 Division of Surgical Oncology, Department of Surgery, The Ohio State University, Columbus, OH, USA
2 Department of Medical Oncology, The Ohio State University, Columbus, OH, USA
3 Martha S. Pitzer Center for Women, Children & Youth, College of Nursing, The Ohio State University, Columbus, OH, USA
4 MetroHealth Systems and Case Western Reserve University, Cleveland, OH, USA
5 Department of Radiation Oncology, The Ohio State University, Columbus, OH, USA
6 Cancer Support Services, The Ohio State University Comprehensive Cancer Center – James Cancer Hospital, Columbus, OH, USA
Background

The 2019 novel coronavirus disease (COVID-19) exacerbated already existing delays in cancer screening and potentially increased breast cancer-related mortality [1]. However, advances in surgical management and the discovery of new medical therapies have resulted in an overall 5-year relative survival of 90% for breast cancer, the most common cancer among women [2, 3]. This combined with aging of the US population has produced a rise in the number of breast cancer survivors, now estimated to be more than 3.8 million women [4]. Unmet supportive care ranges from psychological distress to deficits in physical functioning [5]. Previous reports on cancer survivors have described unique emotional needs related to anxiety, depression, fear of recurrences, sleep problems, physical limitations/fatigue, pain, sexual function and strains on family, interpersonal, employment, or financial needs. These may all have been exacerbated by the pandemic [6–15].

Dedicated efforts to address the diverse needs of the growing breast cancer survivor population are an ongoing focus of healthcare delivery models. Many cancer centers offer group coaching and counseling sessions on a variety of topics including psychological services, exercise counseling, and nutrition counseling along with formal prescription or motivation enhancement techniques to promote survivor engagement [6–8]. Areas of focus can include therapy through art, education, exercise, mind–body-spirit, music, nutrition, and addressing specific needs of young adult survivors. Each cancer center must craft a unique blend of these offerings based on available resources and the needs of specific patient populations.

Studies find that while interest in these survivorship programs (SPs) is generally high, there remains low participation. This phenomenon is due to a number of barriers including lack of time (82%), work/school (65%), and lack of information about wellness activities (65%) [8].

Efforts to enhance engagement in SPs were newly challenged with the emergence of COVID-19. The COVID-19 pandemic has led to further stressors on cancer survivors and healthcare systems with reductions in screening, delays in treatment, and reductions in in-person appointments [12, 16–18]. At the forefront initially was the concern over the medical implications of the virus on cancer survivors who may be susceptible due to the physical consequences of treatment [19, 20]. However, the psychosocial impact of the pandemic may also disproportionately affect this population [12, 16–20]. Many cancer centers were faced with challenges to continue delivery of survivorship services during the pandemic as social distancing and lockdowns created physical barriers [21]. The social isolation created by these restrictions was feared to compound the known stress associated with patients who have completed treatment but continue with surveillance or maintenance hormonal therapy. The supportive needs of breast cancer survivors during COVID-19 and whether the social distancing and lockdown of the healthcare system adversely affected access to SPs are not well described in literature. Herein, we aim to evaluate the impact of the COVID-19 pandemic on breast cancer survivorship program referrals and participation at a Midwest tertiary referral academic center.

Methods

The Stephanie Spielman Breast Care Center provides care for approximately 1000 analytic breast cancer cases per year. As a part of the Ohio State University Comprehensive Cancer Center – James Cancer Hospital (OSUCCC – James), a robust survivorship support service line for breast cancer patients (Fig. 1) is provided by physicians, advanced practice providers, psychologists, physical therapists, and social workers. Cancer Support Services is the overarching umbrella that includes both clinical and non-clinical support services for cancer patients. Non-clinical services are also widely available to promote holistic wellness and adjustment to life with cancer, including cancer and survivorship education, nutrition, exercise, expressive arts, family programming, mind–body-spirit practices, disease-specific support groups, and young adult programming. Survivorship clinic is provided by a nurse practitioner for assessment of health history, healthy lifestyle recommendations, and referrals as well as completing treatment summary and care plan. After completion of multimodal breast cancer treatment, patients receive the standard survivorship care plan (SCP) in-person or virtually from a nurse practitioner. In addition to a review of the treatments received, a needs assessment was performed. Patients were then referred by the oncology team based on requests and/or observed needs.

Data capture

The Cancer Support Service Line uses an institutional quality dashboard through a data visualization tool called Tableau to monitor clinical services. Data collection of patient demographics, referral patterns, utilization trends, and encounter volumes began in July 2014 (which was the start of the academic and fiscal year) and is updated monthly through present day. Data collected from participants who register and attend SPs were collected through Qualtrics and an internal database. Data is captured by
tracking registration, attendance, and post-program evaluations. Program evaluations querying demographic and program acceptability are emailed to all individuals who register and attend a program.

SPs are offered to cancer survivors and caregivers across all cancer sites. We evaluated the post-exposure program evaluations completed by women who self-identified as having a breast cancer diagnosis. This allowed capture of participants in the different program areas for the fiscal years 2019, 2020, and the first half of 2021 (encompassing January to July of the calendar year). Comparisons were made with the “pre”-COVID survivor engagement to the patterns emerging at the onset of the pandemic to identify patterns of utilization to better serve our patients.

Data analysis

Descriptive statistics were utilized to summarize available data from January 2019 through July 2021. Data from calendar year 2019 was used as a normative comparison for pre-COVID-19. The distribution of participant characteristics was presented using frequencies and percentages for categorical data, and means and standard deviations for numerical data. Approval for use and publication of our institution’s internal quality data related to this study was granted by The Ohio State University Comprehensive Cancer Center (OSUCCC) – The James Quality and Patient Safety Committee (#08-18T10_43_27).

Results

We show the ambulatory referrals to provider-based SPs including adolescent and young adult (AYA), fertility, palliative care, psychosocial oncology, and survivorship in Table 1. In 2019, 1195 total referrals were made, while 1210 referrals were made in 2020. For 2021, only the first half of the year is included. Referrals to programs were based on the individual needs assessed at the survivorship clinic visit. Focusing on our psychosocial oncology program, from January 2019 to July 2021, a total of 814 referrals were made for patients with breast cancer (280 in 2019, 318 in 2020, and 216 in the first half of 2021) with 64%, 65%, and 66%, respectively, completing the referrals per year. The remaining patients who did not complete the referrals never formally scheduled, canceled the appointment, or did not show for the appointment. Patient referrals to psychosocial oncology by providers increased by 12%, and the cancelation and “no show” rates were similar to the previous year. During lockdown (March through May 2020), referrals dropped to 58 compared to 64 in 2019 (~10%). The AYA Program formally began in June 2019, with data capture beginning the following month. As a new service, internal outreach and education were
key on awareness of the program. The volume of AYA referrals from the breast service line increased in 2020 to 117 from 39 in 2019 (+300%) (Table 1) with the breast oncology service line accounting for 29% of all AYA referrals through December 2020.

Breast cancer survivor participation in the SPs is represented in Table 2 and shows 398 attendees for 2019, 462 in 2020, and 415 for 2021 (January to July). Table 2 also shows the program content area including art, education, exercise, family, mind–body-spirit, music, nutrition, and young adult survivor. Participation in exercise increased by 2.2-fold from CY19 to CY20 (Fig. 2). The total proportion of breast cancer participants choosing an exercise program area increased from 16.8% in 2019 to 42.21% in 2021. Nutrition was previously the most selected program area, with 42.5% in 2019 and dropping to 29.9% in 2021.

Support group attendance is shown in Fig. 3. During the state-mandated lockdown in Ohio spanning from March to May 2020, the meetings were transitioned to an all-virtual platform and have remained virtual to the present day.

### Discussion

While people living with a cancer diagnosis required concerted efforts to mitigate survivorship challenges pre-COVID-19 pandemic, such efforts are likewise required during the pandemic. In this analysis of breast cancer survivor referrals to and participation in supportive services, we show that COVID-19 did not adversely impact patient participation. There was only a transient drop in participation during March to May 2020 (when Ohio was in lockdown) compared to the previous year. Overall, patient referrals for 2020 were similar to the pre-pandemic 2019 numbers, while 2021 numbers are projected to surpass the last 2 years. Surprisingly, the cancelation and no-show rates remained unchanged during 2020 compared to the previous year, likely as a consequence of telehealth options. While the volume of AYA

### Table 1 Year-to-year comparison of ambulatory referrals to clinical resources in the Cancer Support Service Line

| Clinical resource                          | Total referrals | Completed referrals | %  | Total referrals | Completed referrals | %  | Total referrals | Completed referrals | %  |
|-------------------------------------------|----------------|-------------------|----|----------------|-------------------|----|----------------|-------------------|----|
| AYA                                       | 39             | 38                | 97.40 | 117            | 90                | 76.90 | 64             | 39                | 60.9 |
| Fertility preservation                    | 30             | 18                | 60  | 33             | 17                | 52  | 13             | 7                | 54  |
| Palliative care                           | 79             | 51                | 65  | 76             | 48                | 63  | 75             | 57                | 76  |
| Psychosocial oncology                     | 280            | 180               | 64  | 318            | 207               | 65  | 216            | 142               | 66  |
| Survivorship (survivorship, sexual health)| 767            | 574               | 75  | 666            | 503               | 76  | 328            | 257               | 78  |

AYA adolescent and young adult

### Table 2 Breast cancer participant data — CY2019–CY2021 July

| Program area                      | Breast cancer participants CY2019 | Breast cancer participants CY2020 | Breast cancer participants CY2021 Jan to July |
|-----------------------------------|----------------------------------|----------------------------------|-----------------------------------------------|
| Art                               | 25 (7.0%)                        | 24 (5.2%)                        | 10 (2.4%)                                     |
| Education                         | 44 (12.3%)                       | 45 (9.7%)                        | 34 (8.2%)                                     |
| Exercise                          | 60 (16.8%)                       | 171 (37.0%)                      | 175 (42.2%)                                   |
| Family, teens, children           | 14 (3.9%)                        | 5 (1.1%)                         | 3 (0.7%)                                      |
| Mind, body, spirit                | 48 (13.4%)                       | 75 (16.2%)                       | 62 (14.9%)                                    |
| Music                             | 7 (2.0%)                         | 4 (0.9%)                         | 4 (1.0%)                                      |
| Nutrition                         | 152 (42.5%)                      | 132 (28.6%)                      | 124 (29.9%)                                   |
| Young survivors                   | 8 (2.2%)                         | 6 (1.3%)                         | 3 (0.7%)                                      |

Total # of attendees:
- CY2019 = 398
- CY2020 = 462
- CY2021 through July = 415

*Based on program evaluations — participants self-identified as breast cancer diagnosis
referrals from the breast service line increased in 2020, it was likely due to increased programmatic awareness and a longer time period of data capture in 2020 (12 months) than 2019 (6 months). Furthermore, patient selection focus shifted from nutrition content to exercise as the most utilized program. After lockdown, our SPs were converted to virtual content, and currently, there are hybrid options with in-person options if preferred. Telehealth, by reducing the burden of travel and transportation, may have broadened access to support services.

Before the onset of the COVID-19 pandemic, utilization of telehealth and telemedicine in the USA was limited [22, 23]. Telemedicine growth had been encumbered by lack of uniform coverage policies across insurers and states, and hurdles to establishing telemedicine in health systems (e.g., high startup costs, workflow reconfiguration, clinician buy-in, and patient interest) [24, 25]. The COVID-19 pandemic resulted in social distancing mandates which created a massive need for remote patient encounters. Telemedicine platforms enabled care continuity and demand rapidly increased [22]. While transitioning to digital platforms has been one of our healthcare system’s strategies to limit the disruption of many patient services, this poses some emerging challenges. There are reports of digital access inequalities in both the ability to access and to use telemedicine within local, regional, national, and global populations [23, 26–28]. Access to telemedicine may be particularly challenging for low-income patients and patients in rural areas, who may not have reliable broadband access [27, 29–32]. Recent data from the Pew Research Center shows that while internet non-adoption is linked to a number of demographic
variables including income, age, and educational attainment, no statistically significant differences exist in non-internet use by gender or race and ethnicity [33]. However, internet use is strongly connected to age, with older Americans continuing to be one of the least likely groups to use the internet with 25% of adults ages 65 and older reporting never going online [14, 23–25, 33, 34].

Elderly patients are a concerning population in which telemedicine solutions may be less feasible. Because older patients are at higher risk for severe symptoms of coronavirus and in general require more frequent primary care, they may benefit greatly from telehealth to reduce in-person risk of exposure [12, 16–18]. However, many seniors may not feel comfortable with or be able to use these technologies [29–34], although there has been improvement in this area. While 86% of adults ages 65 and older did not go online in 2000, today that figure has fallen to just a quarter [34]. Still when it comes to telemedicine, a recent study by Walker et al. found that patients aged 60–69 (45.3% difference, \( p < 0.001 \)) and those over age 70 (36.7% difference, \( p = 0.04 \)) used the inpatient portal less than patients aged 18–29 [35]. In such cases, alternative routes of communication such as telephone conversations can be potentially helpful for survivorship care [7, 19, 20]. Data shows the pandemic increased use of telehealth platforms, whether virtual or web-based or telephone, comprising 30.2% of healthcare visits [26]. A systematic review on patient satisfaction with telemedicine found that patient satisfaction can be associated with the modality of telehealth, but factors of effectiveness and efficiency are mixed with patients’ expectations being met when providers delivered healthcare via telehealth method [36]. A randomized trial, Comparing Modes of Telehealth Delivery: Phone vs. Video Visits (ASSIST), will assess patient satisfaction with visit time as primary endpoint which will provide important insights [37].

There are many limitations in this study. Primarily, data utilized herein was abstracted from our institutional quality database which contains limited variables. For example, participant’s race, ethnicity, other sociodemographic details, and satisfaction with services are not captured. As a result, these data limit our ability to characterize women categorized as cancelation or no-show for scheduled visits or programming. This information could guide further programming to better serve different subgroups of women during the pandemic and beyond. To inform further investigation and result in program changes, more detail is needed. Additionally, this study is situated in the context of a comprehensive and well-resourced institution. This aids in demonstrating possible interventions for other institutions; however, not all institutions may be able to implement the same breadth of interventions. A customized approach to each institution is needed to best serve patients. Nonetheless, we show that during these challenging times, there is sustained interest in supportive services, and especially ones focused on exercise given the physical restriction in place to reduce COVID-19 infection rates. Transitioning to telehealth to deliver our SPs has permitted continued access for our patients.

Conclusions

We show the utilization patterns of survivorship-focused programming in patients with breast cancer comparing the year before the emergence of the COVID-19 pandemic to the year after. Despite concerns about decreased access due to restrictions placed on patient visits within our healthcare center, participation is maintained and actually on track to exceed pre-pandemic rates. Many offerings were transitioned to a virtual format which likely helped the patients continue participation. Future analysis of patient needs and preferences are planned with a focus on patient reported satisfaction.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

References

1. Alagoz O, Lowry KP, Kurian AW, et al. Impact of the COVID-19 pandemic on breast cancer mortality in the US: estimates from collaborative simulation modeling. J Natl Cancer Inst. 2021;113(11):1484–94. https://doi.org/10.1093/jnci/djab097.
2. Breast Cancer Statistics | How common is breast cancer? Accessed March 3, 2022. https://www.cancer.org/cancer/breast-cancer/about/how-common-is-breast-cancer.html
3. Cancer Statistics Review, 1975–2015 - Previous Version - SEER Cancer Statistics Review. SEER, Accessed March 3, 2022. https://seer.cancer.gov/archive/csr/1975_2015/index.html
4. Miller KD, Nogueira L, Mariotto AB, et al. Cancer treatment and survivorship statistics, 2019. CA Cancer J Clin. 2019;69(5):363–85. https://doi.org/10.3322/caac.21565.
5. Wong EC, Kaplan CP, Barulich M, Melisko M. Assessing preferences for receiving supportive care resources among patients seen at a Breast Care Center. Breast Cancer Res Treat. 2020;183(2):381–9. https://doi.org/10.1007/s10549-020-05786-0.
6. O’Malley DM, Davis SN, Amare R, et al. User-centered development and patient acceptability testing of a health-coaching intervention to enhance cancer survivorship follow-up in primary care. J Cancer Educ Off J Am Assoc Cancer Educ. Published online October 7, 2020. https://doi.org/10.1007/s13187-020-01883-2
7. Harrington C, Hansen J, Moskowitz M, Todd B, Feuerstein M. It’s not over when it’s over: long-term symptoms in cancer survivors—a systematic review. Int J Psychiatry Med. 2010;40:163–81. https://doi.org/10.2190/PM.40.2.c.
8. Szuhan KL, Malgaroli M, Riley G, et al. Barriers and engagement in breast cancer survivorship wellness activities. Breast Cancer Res Treat. 2021;188(1):317–25. https://doi.org/10.1007/s10549-021-06279-4.

9. Reed SC, Bell JF, Miglioretti DL, Nekhlyudov L, Fairman N, Joseph JG. Fear of cancer recurrence and associations with mental health status and individual characteristics among cancer survivors: findings from a nationally representative sample. J Psychosoc Oncol. 2020;38(2):125–42. https://doi.org/10.1080/07347332.2019.1649338.

10. Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment. CA Cancer J Clin. 2018;68(2):153–65. https://doi.org/10.3322/caac.21443.

11. Aaronson NK, Mattioli V, Minton O, et al. Beyond treatment — psychosocial and behavioural issues in cancer survivorship research and practice. EJC Suppl EJC Off J EORTC Eur Organ Res Treat Cancer AL. 2014;12(1):54–64. https://doi.org/10.1016/iejcexpup.2014.03.005.

12. Massicotte V, Ivers H, Savard J. COVID-19 pandemic stressors and psychological symptoms in breast cancer patients. Curr Oncol Tor Ont. 2021;28(1):294–300. https://doi.org/10.3390/currenconcl28010034.

13. Kim SY, Kim S. Do COVID-19-related treatment changes influence fear of cancer recurrence, anxiety, and depression in breast cancer patients? Cancer Nurs. 2022;45(2):E628–38. https://doi.org/10.1097/CNJ.0000000000001934.

14. Sirintrapun SJ, Lopez AM. Telemedicine in cancer care. Am Soc Clin Oncol Educ Book Am Soc Clin Oncol Annu Meet. 2018;38:540–5. https://doi.org/10.1200/EDBK_200141.

15. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Pianta AL. Digital health for geriatric oncology. JCO Clin Inform. 2018;2:1–12. https://doi.org/10.1200/CCI.17.00159.

16. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Pianta AL. Digital health for geriatric oncology. JCO Clin Inform. 2018;2:1–12. https://doi.org/10.1200/CCI.17.00133.

17. Garutti M, Cortiula F, Puglisi F. Seven shades of black thoughts: exploring uncertainty upon uncertainty: supportive care for cancer patients. J Natl Cancer Inst. 2021;113(8):955–61. https://doi.org/10.1093/jnci/djaa200.

18. Soklodev E, Shahrokni A. Digital health for geriatric oncology. JCO Clin Inform. 2018;2:1–9. https://doi.org/10.1200/CCI.17.00133.

19. Ensuring the growth of telehealth during COVID-19 does not exacerbate disparities in care | Health Affairs. Accessed March 3, 2022. https://www.healthaffairs.org/do/https://doi.org/10.1377/forefront.20200505.591306/full/.

20. Huerta TR, McAlearan AS, Rizer MK. Introducing a patient portal and electronic tablets to inpatient care. Ann Intern Med. 2017;167(11):816–7. https://doi.org/10.7326/M17-1766.

21. Lewis K. COVID-19: preliminary data on the impact of social distancing on loneliness and mental health. J Psychiatr Pract. 2020;26(5):400–4. https://doi.org/10.1097/PRA.0000000000000560.

22. Kerr KM, de Groot M, Wagner JA. Racial and ethnic disparities in diabetes complications in the northeastern United States: the role of socioeconomic status. J Natl Med Assoc. 2013;105(1):51–8. https://doi.org/10.1016/s0027-9684(15)30085-7.

23. Lin CCC, Dievler A, Robbins C, Sripipatana A, Quinn M, Nair S. Telehealth in health centers: key adoption factors, barriers, and opportunities. Health Aff Proj Hope. 2018;37(12):1967–74. https://doi.org/10.1377/hilthaff.2018.05125.

24. Garg S, Williams NL, Ip A, Dicker AP. Clinical integration of digital solutions in health care: an overview of the current landscape of digital technologies in cancer care. JCO Clin Cancer Inform. 2018;2:1–9. https://doi.org/10.1200/CC1.17.00159.

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.