Exploring health behaviors and the feasibility of a lifestyle intervention for patients with multiple myeloma

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Abstract
Purpose Multiple myeloma (MM) is the second most common hematologic malignancy in the USA, with higher rates observed in older adults and African Americans (AA). Survivors experience fatigue, bone pain, reduced functioning, and obesity, highlighting the value of developing lifestyle interventions for this diverse group. This study explores lifestyle behaviors and supportive care needs to inform future programs tailored to the MM community.

Methods MM survivors, ≥ 100 days post autologous stem cell transplant (ASCT) with a BMI ≥ 20 kg/m², were recruited from two university hospitals. Diet, physical activity, and quality of life (QOL) were measured using validated measures. Qualitative interviews gathered information on survivorship needs and interests related to supportive interventions. Quantitative data was analyzed using descriptive statistics; qualitative data were analyzed using deductive strategies.

Results Seventy-two MM survivors participated (65% white, 35% black). Participants were 62.5 ± 15.8 years of age. Fifty percent were classified as obese and 65% were insufficiently active. Participants reported diets high in added sugars and saturated fats. QOL measures indicated clinically significant challenges in physical and sexual function. Most (87%) were interested in a lifestyle program. Predominant themes regarding survivors’ desires for a lifestyle program included social support, guided exercise, meal preparation support, and disease management information.

Conclusion This study demonstrates the need for and interest in lifestyle change support among a racially diverse sample of MM survivors. Interventions that are group-based, target knowledge gaps, social connections, accountability, and provide structured framework with professional instruction will best address the needs of this survivor population.

Keywords Multiple myeloma · Survivorship · Quality of life · Lifestyle · African American

Introduction

Multiple myeloma (MM) is the second most common hematologic malignancy in the USA, with higher rates observed in older adults and is twice as common in African Americans (AA) compared to other racial groups [1, 2]. Treatment advances, such as autologous stem cell transplant (ASCT) and a growing list of immunomodulatory drugs, have drastically improved survival rates. As a result, the disease has largely changed from being an imminently fatal condition to that of a chronic disease, with improvements in average 5-year survival rates increasing from 32 to 56% over the last two decades [3].

Despite improved survival, MM is associated with high morbidity from the disease process, which is then complicated by on-going treatment side-effects. Survivors often
experience fatigue, bone pain, sleep problems, and functional decline — all of which can impact physical, emotional, and social health [4]. Many MM survivors also have unfavorable body composition, specifically a high prevalence of obesity and sarcopenia, the latter reflecting a marked loss of skeletal muscle mass and function [5–7]. These body composition phenotypes may contribute to the decreased quality of life (QOL) seen in the MM population. Furthermore, several studies over the past decade have identified obesity as a risk factor both for the transformation of monoclonal gammapathy of undetermined significance (MGUS; MM’s precursor disease) to full-blown MM and for disease progression of MM itself [6, 8, 9]. Thus, it seems logical that lifestyle interventions aimed at improvements in body composition would reduce disease burden and improve QOL in MM survivors.

A growing body of evidence links positive changes in lifestyle behaviors with improvements in multiple aspects of survivorship [10–12]; however, these data are largely derived from studies involving solid tumors. Few studies have studied lifestyle behaviors (diet and physical activity) among MM patients [13], and there are limited data among diverse patient populations [14, 15]. Herein, we report the results of an exploratory study conducted across two urban sites. The study aimed to describe health behaviors (diet, physical activity), quality of life, and supportive care needs related to lifestyle among a diverse MM survivor community. We also sought to understand MM survivors’ interest in lifestyle programming and appropriate methodologies to meet their needs.

Methods

Study design and participants

This cross-sectional, mixed methods study was conducted at two academic cancer centers located in large urban areas of the Midwest (Milwaukee and Chicago). Study goals included the following: (1) to further our understanding of health behaviors and quality of life among AA and non-Hispanic white MM survivors and (2) to identify optimal methodologies that capture specific topic areas of interest, perhaps unique to population group, gender, or geographic areas. By design, most assessment tools and data points across the two sites were identical; however, differences were permitted due to varying resources and to inform future study procedures. Participants were recruited from two university hospitals with active stem cell transplant programs, reflecting cities with diverse patient populations. Patients were recruited from hospital oncology clinics, through recruitment letters and/or phone calls using contact information provided by medical oncologists (July, 2019–July, 2020). We intentionally sought a diverse study population with meaningful (goal of 50% of study population) representation of AA participants since MM impacts this population disproportionately. Gaining diverse perspectives on intervention needs and interests is critical to informing future studies [16]. Ethical approval was granted from the respective institutions prior to study initiation.

Eligible participants were required to be 18 years of age or older, at least 100 days post-ASCT, with a BMI ≥ 20 kg/m², a performance status of ECOG 0–1 or Karnofsky > 70, and life expectancy of at least 6 months. Prior to recruitment, participant eligibility was ascertained via the electronic health record and clearance from medical oncologists verifying clinical stability and appropriateness of inclusion.

Study procedures

Once deemed eligible, participants scheduled a time to complete informed consent, questionnaires, and a qualitative interview conducted either in-person or over the phone. Given resource allocation, body composition and physical performance were only collected at the Chicago site. At this site, the in-person visit was scheduled no more than 30 days after initial study eligibility and entailed ~90 min to complete questionnaires and/or physical measures. In March 2020, all in-person methodologies were stopped due to the impact of COVID19. Thereafter, recruitment and consent were conducted over the phone and data collection was restricted to phone or mailed questionnaires. Participants received a $20 gift card for their participation.

Demographics and medical information

Demographic data was collected through self-reported surveys and included age, gender, race/ethnicity, marital status, employment status, annual household income, household size, and education. Medical information on height, weight, co-morbid conditions, and treatments were collected using clinical oncology notes found in Epic electronic health records. Height and weight were used to classify normal weight, overweight, and obese, based on calculated BMI.

Body composition and physical performance (Chicago only)

Body composition was non-invasively measured using dual energy X-ray absorptiometry (DXA). A certified radiation technologist performed and analyzed participants using a Discovery W (Hologic Inc.) device, which was calibrated daily with manufacturer’s phantom. Applying the methods of Kaul et al. [17], android fat was automatically defined and measurements of abdominal and visceral fat were obtained from the android region. Sarcopenia was explored using...
appendicular skeletal mass (ASM)/height^2 using the cut-points of Baumgartner et al. [18] (7.26 for men and 5.45 for women). Cardiorespiratory fitness was assessed using a sub-maximum 6-min walk test on an indoor track [19]. The total distance was recorded and used to determine fitness level. Upper body muscle strength was measured using Jamar Hand Dynamometer following standard procedures [20]. Measures were obtained twice for each participant’s non-dominant and dominant hand. Scores of the dominant hand were averaged and the cut-point of <27 kg and <20 kg for men and women, respectively, was used to define compromised functioning [21]. Lower body muscle strength was measured by quantifying the number of “Chairs Stands” in 30 s [22]; <5 rises in 15 s was used to indicate compromised strength [21].

**Dietary intake**

Different dietary screeners were used at the two sites to compare participant burden and usefulness of resulting data. Both allowed for the evaluation of general trends in dietary intake with minimal burden and have been validated in diverse populations [23–25]. Participants at the Milwaukee site completed the validated Block Fat/Sugar/Fruit/Vegetable Screener [26]. This tool takes ~20 min to complete and queries about usual consumption and portion sizes of 55 food items. Analyses include estimates of total fat, saturated fat, added sugars, fiber, fruit, and vegetable intakes.

Participants at the Chicago site completed the Block Fruit/Vegetable/Fiber Screener [24], a 10-item on-line fruit, vegetable and fiber screener that ranks individuals with regard to their usual intake of fruits and vegetables [27]. Estimates of fruit, vegetables, and dietary fiber were generated.

**Physical activity**

The Godin Leisure Physical Activity Index asks about leisure time spent engaged in light, moderate, and strenuous activities over the past 7-day period [28]. Results are used to classify participants as sufficiently active (meets current physical activity guidelines of 150 min of moderate activity or 75 min of vigorous activity per week) or insufficiently active. Because current cancer survivorship guidelines recommend a minimum of twice weekly resistance exercise training (RET) [29], participants were also asked: (1) if they engage in RET and (2) if yes, how many times per week.

**Quality of life (QOL), symptom burden, and social support**

Symptom burden and functioning were measured using the Patient-Reported Outcomes Measurement Information System (PROMIS) [30]. Scores are reported using a common metric (T-score with a mean of 50 and standard deviation of 10) and have been normed to the US population. Higher scores represent more of that domain. The PROMIS-29 profile assesses seven health domains (physical function, anxiety, depression, fatigue, sleep disturbance, ability to participate in social roles and activities, pain interference). We used the 4-item short form for each domain. To further assess social relationships, we included PROMIS short forms measuring social isolation, companionship, and domains of social support. Short forms measuring self-efficacy in managing symptoms, cognitive function, and sexual function were administered, given these are frequent concerns in the MM population [4].

**Qualitative data**

Using open-ended questions in interviews (Milwaukee) and written prompts (Chicago) on the survey, information regarding (1) post diagnosis changes in health behaviors, (2) post diagnosis changes in general health, (3) unmet needs, and (4) interests related to a lifestyle intervention were gathered.

**Statistical analysis**

Data analyses were performed for quantitative and qualitative data. For quantitative data, categorical data were described using percentages, while continuous data were presented using means and standard deviations. PROMIS scores were reported on the T-distribution, which has been normalized to the US population, so that 50 corresponds to the US average with a standard deviation of 10. Higher scores represent more of that domain. Based on recent work by Jensen et al., a 3-point difference in T-score was considered clinically significant when comparing our study population to the US population not affected by cancer [31]. Qualitative data analysis relied on inductive strategies with thematic coding [32]. Several authors independently reviewed participant responses to open-ended questions to identify key topics areas and codes within each topic area. Subsequently, coders met to group codes into themes and to resolve discrepancies. Quantitative and qualitative data were stratified to examine racial, gender, and site differences.

**Results**

**Study participants**

At the Milwaukee site, 95 MM survivors met eligibility criteria; 47 did not respond to recruitment efforts, 11 declined due to scheduling conflicts and/or lack of interest, and 37...
enrolled. At the Chicago site, 53 MM survivors met the eligibility criteria; 9 did not respond to recruitment efforts, 9 declined due to lack of interest, and 35 enrolled. Between the two recruitment sites, 72 MM survivors participated (65% white, 35% black, 56% male, 44% female). Participants were 62.5 ± 15.8 years of age. The majority were married or living with a partner, retired, and earning $40,000 to $79,999 annually. Common comorbidities included arthritis, hypertension, hyperlipidemia, and chronic kidney disease.

### Quantitative data

Mean BMI was 30.6 ± 5.4; 32% were classified as overweight and 50% as obese (Table 1). Thirty-five percent reported physical activity levels considered sufficiently active (minimum of 150 min of moderate or 75 min of vigorous activity weekly) and 34% met the recommended twice weekly resistance exercise training guidelines (Table 2). The majority (65%) were insufficiently active. For dietary patterns, participants reported diets high in added sugars, saturated fats, total fat, Protein, fiber, fruits, and vegetables were low. Furthermore, AA participants reported a statistically significant lower fiber intake compared to white participants.

### Biometrics

In total, 13 individuals at the Chicago site completed the physical measures prior to COVID lockdown. Using DXA output, median percent body fat was 30.4% (28.0–35.9% IQR), and no participants were classified as sarcopenic. However, 50% and 40% of participants scored below age and sex-adjusted norms for chair stands and handgrip strength, respectively, indicating some degree of impaired muscle strength. The median number of meters walked in 6-min was 565 (529–587 m IQR).

### PROMIS (QOL)

PROMIS measures indicated clinically significant challenges (≥3 points below US mean of 50) within physical function and sexual function domains [31]. Pain interference was also an area of concern but fell short of being clinically meaningful (≥3 above mean of 50). When compared to the US norms for the general population, survivors felt less depressed, had greater companionship, and were better supported (≥3 above mean of 50). Between sites, Chicago participants reported higher ability to participate socially (p = 0.003). Social support, assessed only at the Milwaukee site, revealed gender differences, with women reporting having greater companionship and support in the informational, emotional, and instrumental domains compared to men (Table 3).

### Qualitative data

Qualitative data was summarized into three primary themes:

#### Changes and challenges with health behaviors (diet, physical activity, etc.) post-diagnosis

One prevalent theme among respondents was lifestyle impact post-diagnosis. Common issues include low physical functioning, symptom burden (sleep problems, pain, fatigue), fear, anxiety, impaired cognition, and a reduction in social activity. “I was forced to slow down” and “The fatigue has limited my ability to play with [my] grandchildren” were common sentiments among survivors. While some participants reported worse lifestyle habits secondary to complications from MM, many attempted self-directed lifestyle changes with the goal of improving QOL and regaining physical function. Most efforts focused on eating healthier and improving exercise habits. For example, some reported that they “tried to control sodium intake” and “don’t drink alcohol anymore.” With regard to exercise, one individual stated, “I used to try walking around my neighborhood but… I have lost self confidence in my physical ability.”

Another theme was the lack of direction/lifestyle support post-diagnosis. Only 17% of participants were aware of the American Cancer Society’s nutrition and physical activity guidelines and 56% reported no one from their oncology team had discussed lifestyle recommendations with them since transplant. Those who did have lifestyle discussions felt “it was too long ago” and that they “did not remember any of the specific recommendations.”

#### Unmet survivorship needs

Discussions of unmet needs centered on living with MM and the need for a “well-rounded program that addresses all the issues of cancer survivors.” Specific requests were noted for support groups and opportunities to connect with other survivors. For many survivors, the social aspect of the program was considered critical to keep them engaged with behavioral change and to build accountability. Furthermore, participants acknowledged the value of addressing healthy eating and exercise, relating they would like professional assistance to make changes tailored to their needs and abilities. There were specific requests for access to dieticians to advise on healthy eating. Instructor support to guide physical activity was also requested given a general lack of knowledge and fear of injury, with the latter being especially prominent among women. One individual specifically stated, “I need a coach to tell me what [harmful exercises] I shouldn’t do.”
Table 1 Characteristics of multiple myeloma cancer survivor participants

| Variable                        | Overall N (%) = 72 | Milwaukee site n (%) = 37 | Chicago site n (%) = 35 |
|---------------------------------|-------------------|--------------------------|------------------------|
| **Race**                        |                   |                          |                        |
| White                           | 47 (65.3)         | 20 (54.1)                | 27 (77.1)              |
| Black or African American       | 25 (34.7)         | 17 (45.9)                | 8 (22.9)               |
| **Gender**                      |                   |                          |                        |
| Male                            | 40 (55.6)         | 17 (45.9)                | 23 (65.7)              |
| Female                          | 32 (44.4)         | 20 (54.1)                | 12 (34.3)              |
| **Variable**                    | Overall Mean (SD) or N (%) | Milwaukee site Mean (SD) or n (%) | Chicago site Mean (SD) or n (%) |
| Age                             | 62.5 (15.8)       | 60.4 (19.8)              | 64.7 (9.8)             |
| Time since MM Diagnosis (months)| 51.36 (35.58)     | 43.73 (32.85)            | 59.42 (37.02)          |
| Time since ASCT (months)        | 39.19 (31.72)     | 32.79 (28.94)            | 45.95 (33.50)          |
| Body mass index (BMI)           | 30.6 (5.4)        | 29.8 (5.8)               | 31.4 (4.9)             |
| % obese                         | 36 (50.0)         | 17 (45.9)                | 19 (54.3)              |
| % overweight                    | 23 (31.9)         | 11 (29.7)                | 12 (34.3)              |
| % normal weight                 | 13 (18.1)         | 9 (24.3)                 | 4 (11.4)               |
| **Marital status**              |                   |                          |                        |
| Married or living with partner  | 52 (74.3)         | 26 (74.3)                | 26 (74.3)              |
| Single                          | 7 (10.0)          | 3 (8.6)                  | 4 (11.4)               |
| Divorced or separated           | 6 (7.6)           | 3 (8.6)                  | 3 (8.6)                |
| Widowed                         | 5 (7.1)           | 3 (8.6)                  | 2 (5.7)                |
| Missing                         | 2                 | 2                        | 0                      |
| **Education**                   |                   |                          |                        |
| College graduate                | 31 (43.7)         | 17 (45.9)                | 14 (41.2)              |
| High school graduate or GED     | 16 (22.5)         | 8 (21.6)                 | 8 (23.5)               |
| Graduate or professional degree | 13 (18.3)         | 6 (16.2)                 | 7 (20.6)               |
| Associate degree or 2-year certificate | 7 (9.9)        | 3 (8.1)                  | 4 (11.8)               |
| Some high school                | 2 (2.8)           | 1 (2.7)                  | 1 (2.9)                |
| Other                           | 2 (2.8)           | 2 (5.4)                  | 0 (0.0)                |
| Missing                         | 1                 | 0                        | 1                      |
| **Income**                      |                   |                          |                        |
| $80,000 or more                 | 26 (39.4)         | 8 (25.0)                 | 18 (52.9)              |
| $40,000–$59,999                 | 16 (24.2)         | 9 (28.1)                 | 7 (20.6)               |
| $60,000–$79,999                 | 12 (18.2)         | 7 (21.9)                 | 5 (14.7)               |
| $20,000–$39,999                 | 7 (10.6)          | 4 (12.5)                 | 3 (8.8)                |
| Less than $20,000               | 5 (7.6)           | 4 (12.5)                 | 1 (2.9)                |
| Missing                         | 6                 | 5                        | 1                      |
| **Employment**                  |                   |                          |                        |
| Retired                         | 41 (56.9)         | 21 (56.8)                | 20 (57.1)              |
| Employed (full-time or part-time)| 20 (27.8)       | 7 (18.9)                 | 13 (37.2)              |
| Disabled                        | 7 (9.7)           | 6 (16.2)                 | 1 (2.9)                |
| Other                           | 2 (2.8)           | 2 (5.4)                  | 0 (0.0)                |
| Homemaker                       | 1 (1.4)           | 1 (2.7)                  | 0 (0.0)                |
| Out of Work                     | 1 (1.4)           | 0 (0.0)                  | 1 (2.9)                |
| Missing                         | 1                 | 0                        | 1                      |
| **Comorbidities**               |                   |                          |                        |
| Arthritis                       | 35 (48.6)         | 16 (43.2)                | 19 (54.3)              |
| High blood pressure             | 31 (43.1)         | 16 (43.2)                | 15 (42.9)              |
| High cholesterol                | 23 (31.9)         | 9 (24.3)                 | 14 (40.0)              |
| Kidney disease                  | 13 (18.3)         | 8 (22.2)                 | 5 (14.3)               |
| Asthma                          | 12 (16.7)         | 5 (13.5)                 | 7 (20.0)               |
| Diabetes                        | 8 (11.1)          | 4 (10.8)                 | 4 (11.4)               |
Participants were acutely aware of how MM and associated bony lesions placed them at increased risk of fractures.

**Interest in lifestyle program intervention and suggested format and content**

There was considerable interest in a dual component diet and exercise program with 87% of participants reporting they would join or consider joining such a program. Reasons for joining included the desire to incorporate healthy diet and exercise habits into daily routines while simultaneously building connections with other survivors. The majority of those not interested were already engaged in other support programs.

Related to the intervention structure and content, survivors expressed interest in learning practical information (e.g., “how many calories to eat,” “how much red meat is too much”) to facilitate behavioral change. The majority preferred having in-person group sessions to build a sense of comradery and accountability, although some expressed interest in an individualized, home-based program. Participants envisioned the exercise component to be led by an older instructor who could relate to an aging population and provide guidance on how to exercise safely. Preferred exercise modalities were aerobics, weight training, and yoga. Dietary components included cooking classes, healthy recipes that are affordable and convenient, and access to a dietitian to inform development of meal plans.

Additional desired components included sessions on MM disease information where participants could have their questions answered by health care providers. Furthermore, participants were open to using technology-based tools such as activity monitors and text messages for motivation and reminders.

In terms of location, participants preferred the program to be based at a community fitness center (e.g., YMCA) or at a medical facility. Regarding timing, the morning or early afternoon was favored by those who identified as retired or...
Discussion

The benefits of nutrition and physical activity interventions on QOL and body composition in patients living with cancer are gaining recognition. However, the MM population has been understudied in this field due to concerns of fractures and pain. Contrary to this belief, a limited number of studies have demonstrated that personalized exercise programs are not only safe but also improve QOL in MM survivors, particularly related to fatigue and weakness [13, 14]. Considering the benefits of exercise and the potential contribution of adverse body composition on MM survivorship, the present study was designed to inform the development of a lifestyle intervention tailored to the needs of the diverse MM population, making it one of the first to do so.

This study’s findings highlight the QOL challenges MM survivors face post-diagnosis and the obstacles they encounter while learning to live with the disease. Using a combination of PROMIS measures and free responses, we learned our MM survivor population has numerous limitations. Decreased physical function, fatigue, sleep problems, and sexual dysfunction are just some examples. Given these constraints on daily life, it is understandable that some survivors perceive a decline in their lifestyle habits. However, our results show many participants making self-directed attempts to improve QOL and regain physical function through healthy eating, and to a lesser extent, increased physical activity. Despite these attempts, MM survivors were found to have suboptimal dietary patterns (high intakes of sugar and fat, low intakes of fiber, fruits, and vegetables). Furthermore, only 35% were sufficiently active. Both factors likely contribute to the high prevalence of overweight and obesity seen in our sample; 82% of our participants were overweight or obese, which was markedly higher than the national average of 69% for cancer survivors [33].

Current cancer models propose that obesity promotes MM development in those with MGUS and furthers progression in those with MM through dysregulation of insulin, sex hormones, and inflammatory cytokines [34]. Furthermore, a recent study by Fairfield et al. [35] demonstrates a bidirectional interaction between bone marrow adipocytes and MM cells and proposed targeting of bone marrow adipose cells as a novel therapeutic target. Thus, it is crucial that obesity be addressed when considering MM survivorship.

One possible explanation for the high prevalence of overweight and obesity among our sample is the lack of guided lifestyle change. Many participants reported attempting self-directed lifestyle changes; however, knowledge was a stated barrier. Interest in receiving specific instructions and guidance by professionals was common in our sample and likely stems from a lack of discussions regarding healthy lifestyles with their medical team. Examples of expressed knowledge gaps included how to conduct exercises, how to avoid injury, and how to determine what foods are healthy. The lack of motivation and desire for support and accountability were also related. Our participants were looking for programs that would provide structure and guided instruction, keep them engaged and allow them to establish relationships with other survivors. As a solution, we propose the implementation of a lifestyle intervention program for MM survivors targeting both physical exercise and healthy eating. This program should be tailored to addressing the needs and preferences of the MM community to motivate initiation and maintenance of positive behavioral change in a group setting. Ultimately, the goal of the program would be to help survivors achieve a QOL worthy of being described as “thriving, not surviving.”

To our knowledge, a program of this kind, developed with firsthand input from a diverse sample of MM survivors does not exist at this time. Such a program could be implemented in association with major cancer centers, with patients referred to the program by their providers. However, we acknowledge, that this may not be feasible for all cancer centers or communities. Alternatively, our results inform the need for clearer lifestyle recommendations from medical staff as participants transition from active treatment to maintenance/surveillance treatment. Providing sufficient information about healthy diet and exercise recommendations specific to cancer survivors may not fit into one clinic visit. Perhaps, a dedicated appointment with a dietician and/or physical therapist should be offered, if not recommended, to survivors.

Our study is not without its limitations. First, to be approached for the study, patients were required to appear clinically stable; thus, an inherent selection bias is present. As a result, our findings may not be generalizable to the entire MM community; however, we purposefully recruited participants who were capable of and appropriate for participating in lifestyle programs. Soliciting feedback from patients at the end of life is not practical, as these patients are not appropriate or intended targets of our work. Furthermore, participants who elected to join our study tended to have a high level of education (e.g., college) which may have affected perceptions regarding the need for survivorship programming. Second, while all study measures were validated, many surveys relied on self-report data (e.g., dietary screeners, physical activity measures). In this circumstance, more
comprehensive quantitative data would be more informative. Given funding restrictions and the confines of COVID19, these opportunities, such as the collection of biometric data, were diminished. Finally, our goal was to recruit a racially diverse patient population. Although we achieved 35% AA participation, we aimed for 50% given the disproportionate burden this population faces, as well as the higher likelihood of poor access to healthy eating and exercise resources [16, 36, 37]. Regardless, our sample does reflect the 24% of MM survivors who identify as AA.

Conclusion

Given the rising incidence rates of MM among the aging US population and the efficacy of modern therapies, this survivor population is rapidly growing. Unfortunately, these survivors experience comorbidities and QOL challenges. Thus, it is imperative that survivorship programming be implemented to proactively address these concerns. Here, we propose the development of a program tailored to the MM community. Interventions that are group-based, target knowledge gaps, social connections, accountability, and provide a structured framework with professional instruction will best address the needs of this survivor population.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s00520-022-07385-9.

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Author contribution All authors contributed to the study conception, design, and/or funding acquisition. Material preparation, data collection, and analysis were specifically performed by Allen Hodge, Patricia Sheean, Paula O’Connor, Kiley Tyler, Abby Kerschner, Alexis Williams, Kathleen Jensik, Alexis Visotcky, and Melinda Stolley. The first draft of the manuscript was written by Allen Hodge, Patricia Sheean, Abby Kerschner, and Melinda Stolley. All authors read and approved the final manuscript.

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Declarations

Ethics approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Bioethics Committee of the Medical College of Wisconsin and Loyola University Chicago.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Competing interests The authors declare no competing interests.

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