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Clinic Reported Facilitators and Barriers to Pediatric Cancer Survivor Care Delivery among Survivorship Clinics: A Fishbone Analysis

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Abstract

Background: Childhood cancer survivors need regular, long-term survivor care. The Children's Oncology Group (COG) recommends that pediatric patients receive ongoing, evidence-based surveillance for late effects beginning two years after the completion of cancer therapy. However, at least a third of survivors are not engaging in long-term survivorship care. This study assessed facilitators and barriers to follow-up survivorship care through the perspectives of pediatric cancer survivor clinic representatives.

Methods: As part of a hybrid implementation-effectiveness trial, a representative from 12 participating pediatric cancer survivor clinics completed a survey about site characteristics and a semi-structured interview on facilitators and barriers to survivor care delivery at their institution. Interviews were grounded in the socio-ecological model (SEM) framework and utilized a fishbone diagram to understand what facilitates and impedes survivor care. We ran descriptive statistics and conducted thematic analyses of the interview transcripts to create two meta-fishbone diagrams.

Results: All participating clinics (N=12) have existed for at least five years (mean=15, median=13, range=3–31), and half (n=6, 50%) reported seeing >300 survivors annually. In the fishbone diagram, the top facilitators were in the SEM domain of organization, specifically with familiar staff (n=12, 100%), resource utilization (n=11, 92%), dedicated survivorship staff (n=10, 83%), and clinic processes (n=10, 83%). Common barriers were across the domains of organization, community, and policy which included distance/transportation to the clinic (n=12, 100%), technology limits (n=11, 92%), scheduling issues (n=11, 92%), and insufficient funding/insurance (n=11, 92%).

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Conflicts of Interest

There are no conflicts of interest to be disclosed.

Conclusion: Clinic staff and provider perceptions are instrumental in understanding multilevel contextual issues related to survivor care delivery for pediatric cancer survivor clinics. Future research can aid in developing education, processes, and services to promote cancer survivor follow-up care.

Keywords

pediatric cancer; survivorship; care delivery; clinic level; SEM; fishbone

Introduction

The 5-year survival rates for the most common childhood cancers have increased from 58% during the mid-1970s to 85% in 2021.¹ The Children's Oncology Group (COG) developed evidence-based clinical practice guidelines for this growing population of survivors and recommends ongoing surveillance for late-effects beginning two years after the completion of cancer therapy.² However, there is low adherence to this recommendation; 30–60% of childhood cancer survivors do not receive long-term follow-up care focused on late effects.^{3–5} Dedicated cancer survivorship clinics are critical in ensuring long-term follow-up and continuity of care, yet, challenges exist such as resource limitations and a lack of knowledge of the importance of survivorship care among survivors and their caregivers.⁶

Research has been conducted to understand characteristics of the patient that facilitate or hinder adherence to follow-up survivorship care. Factors influencing engagement in survivorship follow-up care fall under three interrelated themes: 1) micro-level patient factors (e.g., due diligence, anxiety), 2) meso-level support factors (e.g., family, friends), and 3) macro-level system factors (e.g., appointments, healthcare providers).⁷ Studies have evaluated patient characteristics at diagnosis and their association with follow-up care and found that being diagnosed at a younger age, having insurance at diagnosis, being diagnosed with leukemia or lymphoma, being white, and enrolling in a therapeutic clinical trial were associated with adhering to follow-up.^{4,8,9} Additionally, survivors who received care at programs with multi-disciplinary coordinated care, flexible scheduling, and from providers with knowledge about childhood cancer have increased rates of follow-up.^{4,9} Survivors were less likely to engage in survivor care when their providers did not recommend it or when they lived in an under-resourced area, especially rural areas far from the clinic. Patients' fear of recurrent cancer diagnosis, desire to move on with life, competing life responsibilities, and lack of perception of the need for a visit due to having no symptoms or secondary cancer effects have also been found to be barriers to follow-up.^{9–13} Although much research has been conducted with patients, it is crucial to understand the facilitators and barriers to returning for follow-up care from the clinic staff and provider perspectives to have a comprehensive understanding of survivor care delivery.

This qualitative study aimed to explore clinic staff and providers' perspectives on facilitators and barriers to return for follow-up care for pediatric cancer survivors through fishbone analyses. We applied the social-ecological model (SEM) to understand the multilevel determinants of health that affect individuals' health behaviors through a fishbone diagram.¹⁴ The results can inform the development of multilevel strategies to increase

adherence to survivorship care and increase patient and family activation for using these services.

Methods

Study Design

This study utilized data collected as part of a larger hybrid type 1 effectiveness-implementation, clustered randomized trial (NCT03543852). The parent study evaluates the implementation of Cancer SurvivorLink™ (www.cancersurvivorlink.org),¹⁵ an electronic personal health record, at COG pediatric cancer survivor clinics and the impact of its use on patient engagement in care and clinical outcomes.¹⁶ COG clinics with a designated pediatric cancer survivor clinic were sent an email invitation describing the study with a link to an interest form collecting eligibility characteristics of the clinic. To participate in the study, the interested clinics had to provide survivorship care plans to all patients as defined by the National Cancer Institute (NCI), see at least 100 survivors annually, agree to the clinical use of SurvivorLink, and commit to enrolling 75 survivors.¹⁷ Twelve clinics were selected for participation, were matched and randomized pairwise. This study was approved by Emory University's IRB board (IRB00101506).

Study population and Recruitment

Clinic representatives were either a provider (MD, NP, PA) or the program coordinator (RN) of the survivorship clinic. Clinic representatives completed an enrollment questionnaire to provide information about clinic metrics and patient populations and participated in a baseline interview describing their program, readiness to adopt SurvivorLink, and their perspectives on return for follow-up cancer survivor care.

Data Collection

A trained interviewer followed a semi-structured guide to interview clinic staff and providers. Specifically, this analysis focused on questions regarding staff and provider's perceptions of cancer survivors' knowledge about cancer survivorship, and facilitators and barriers related to engagement in survivor care at all levels of the SEM framework: individual and intrapersonal, organizational, community, and societal/policy (Table 1). Interviews lasted 1–1.5 hours and were conducted via video call, digitally recorded, and transcribed by a HIPAA-certified transcriptionist.

Data Analysis

The interview guide was used to create a fishbone diagram, also known as the Ishikawa diagram, to understand what facilitates and impedes follow-up care in childhood cancer survivors at each level. It consists of the “mouth” of the fish representing the issue and the “bones” that display various categories as possible causes. The fishbone diagram allows the identified causes to be observed simultaneously.^{18,19} We created an a priori codebook on the fishbone and socio-ecological levels and coded in Microsoft Word 2019.²⁰ We then conducted a thematic analysis for each clinic to create 24 fishbone diagrams,²¹ with each site having two diagrams (i.e., facilitators and barriers to return for survivor care). Each diagram had seven bones or categories of causes: survivors and family, patient

education, clinic providers and staff, management and processes, technology, community or environment, and policy. Two trained research staff reviewed the transcripts and utilized deductive coding to identify SEM facilitators and barriers. Overarching themes were placed as categories to summarize and present the data. Categories were chosen based on the frequency of mentions from the representatives. Any disagreements in coding were discussed among the research team, and codes were refined and added as needed. The data were then compiled into two meta-fishbone diagrams across the 12 sites, using the main themes that emerged with at least six clinics.

Results

A clinic representative from each of the 12 pediatric cancer survivor clinics participated in the study. Table 2 illustrates clinic characteristics. Fig. 1 illustrates the meta-fishbone diagram of reported facilitators for returning for follow-up survivor care. Across clinics, the most common facilitators were positive and familiar staff (n=12, 100%), clinic-level resource utilization (i.e. satellite clinic, a local clinic for lab work, non-profit organization funding, social worker, space for support group) (n=11, 92%), survivorship dedicated staff (n=10, 83%), and an efficient workflow and defined processes (n=10, 83%). Fig. 2 represents the most noted barriers, which were distance/transportation (n=12, 100%), scheduling issues for both the survivor (i.e., school, work, childcare for other children, transportation during clinic hours) (n=11, 92%) and the clinic (n=11, 92%), lack of funding/insurance coverage (n=11, 92%), and lack of technology (n=11, 92%). These facilitators and barriers are further discussed by SEM level with quotes included as supportive illustrations below in Table 3.

INDIVIDUAL AND INTRAPERSONAL

Survivors and family—As reported by clinic representatives, two of the most significant perceived patient-level facilitators for follow-up for survivors and their families were having strong support systems (n=9, 75%) and trust in familiar care teams (n=8, 67%). Interviewees mentioned that involved family members ensured that patients attended all necessary survivor appointments. This support system helped to keep families organized and adhere to their appointments. Patient and caregiver understanding of long-term care and the importance of ongoing engagement were vital in keeping up with appointments. In addition, a care team already familiar with the patient facilitated the transition to survivorship care and helped families, especially patients, feel more comfortable if issues arose again.

Clinic representatives reported that scheduling issues (n=11, 92%) were the most common patient-level barrier to returning for follow-up visits. Many families could not or did not want to miss school or work to attend weekday appointments. Additional survivor and family barriers included perceived lack of patient motivation (n=8, 67%), poor relationship with clinic staff (n=6, 50%), ability to self-manage their health (n=6, 50%), and emotional triggers (i.e., return to cancer treatment facility) (n=6, 50%).

Patient education—Personalized patient education was reported by clinic representatives as a facilitator when done well (n=7, 58%) and a barrier when lacking or poorly implemented (n=6, 50%). Verbal explanations about survivorship visits emphasizing the

importance of follow-up care and educational materials specific to the patient's visit and incorporating the patient's interests and worries improved the return for follow-up care. Information packets that patients could take and share with their non-oncology providers surfaced as a facilitator, in addition to the translation and personalization of risk factors in the patient's individualized survivorship guidelines.

Interviewees acknowledged the lack of personalized information and materials in patients' preferred mode of learning as barriers to follow-up care. They noted that information provided to cancer survivors and their families appeared generic and redundant. If follow-up care is needed, sometimes the contact information for specific departments or information on scheduling appointments was not covered consistently in the materials. Several mentioned a lack of online resources to provide educational materials. In addition, materials supplied in Spanish may not have been of the right reading level.

ORGANIZATIONAL

Clinic staff and providers—In terms of clinical personnel factors, all interviewees (n=12, 100%) perceived that the patient's familiarity with the staff was a facilitator. Other facilitators included having a dedicated survivorship team (n=10, 83%) that is multidisciplinary (n=7, 58%), low staff turnover rates (n=7, 58%), and personalized patient communication (n=6, 50%). Representatives commented that patients who had consistent and positive interactions with their oncology and survivor care teams were more likely to return. Having staff with strong communication skills, expressing a positive outlook on patients' future, and empowering patients by listening and responding to their concerns helped facilitate return for follow-up care. Some providers gave patients direct contact information if they had questions and personally contacted those with abnormal tests, rather than having their nurses call with the results. Combined with low turnover rates, having dedicated survivorship staff, including schedulers, was instrumental in patients returning for care as they were knowledgeable about cancer survivorship and the appointments needed. Multidisciplinary teams were vital because they provided more comprehensive patient care. Lastly, having in-person language interpreters helped to ease language barriers.

Miscommunication with patients (n=8, 67%), understaffing (n=8, 67%), and simple errors (n=8, 67%) were barriers representatives indicated as to why patients did not return for survivor care. Most miscommunication issues raised involved Spanish-speaking patients and a lack of Spanish-speaking doctors or staff. Other common miscommunication occurred between front desk and care team staff which often delayed the completion of clinic follow-up tasks. With turnover, representatives reported untrained or non-tech-savvy staff were prone to more errors.

Management and processes—Under management, the most cited facilitators were adequate use of clinic resources (n=11, 92%), efficient workflow with defined processes (n=10, 83%), patient outreach (n=9, 75%), and flexible scheduling in advance (n=8, 67%). Having and using additional resources, such as a satellite clinic or telehealth, gave patients options closer to home and clinics flexibility in scheduling and providing follow-up care. For example, a patient could have their labs completed at a local clinic with the results

sent to the survivorship clinic for the provider to review with the patient during a telehealth visit. Procedures that allowed front desk staff to follow up with patients before the end of their visit to schedule follow-up visits were ideal. Interviewees also discussed that staff persistently reached out until patients responded and contacted those lost to follow up. In addition, social workers and other multidisciplinary team members that helped coordinate and acquire funding and transportation made it more likely that patients could afford and arrive at their follow-up visits.

The majority of the barriers reported by the clinic representatives were related to their clinic processes, with 11 noting clinic scheduling issues (92%), 8 stating that there are staff errors (67%) and long visits (67%), and 7 reporting a lack of defined processes (58%). Some of the barriers under management and processes mirror those in clinic staff and providers. The key difference is the processes that clinics use for care. Scheduling issues such as inefficient rescheduling processes, having limited days available for survivorship care, lack of coordination between the different sub-specialist appointments a survivor needs, and general scheduling issues impeded the survivor's return for care. Requiring patients to call to schedule their scans was highlighted as a barrier. Long clinic visits, extended duration between the end of treatment and survivorship follow-up, and inefficient use of available resources negatively affected follow-up care outcomes. Lack of patient care coordination, inefficient workflows leading to long patient wait times, and burdensome chains of communication impeded patients from returning.

Technology—Using technology to communicate with patients in a variety of methods, including automated reminders (n=8, 67%) and scheduling technology (n=8, 67%), were given as top facilitators for return for follow-up care. Interviewees mentioned providing patients with diverse options for communication with their provider, such as using an electronic medical record portal for patient care questions, requesting appointments, and accessing lab results, as well as maintaining social media presence, were ideal. Scheduling technology was essential – having designated schedulers who used digital templates to organize patient calls and reminders facilitated follow-up even more. Internal communication in the online system was beneficial for the physician to inform the front desk staff to stop the patient at check out to schedule their follow-up appointment. Simply having telehealth options and digital appointment reminders also helped patients adhere to their appointment times while balancing their personal schedules.

While technology can be used to remind patients and improve scheduling issues automatically, the lack of technology (n=11, 92%) to do such things, including telehealth, and its inherent limits (n=8, 67%) were considered barriers. Additionally, the limited interoperability of electronic health record systems was noted as a barrier when patients were transferring care to their institution. Interviewees stated that patients must bring in or fax physical copies of their health records, creating a burden on the patient. When transferring from one clinic to another, the online medical records programs may have differed between clinics, making it more difficult for the patients to provide their new physicians with their medical history records. Interviewees also mentioned problems with the translation technology for those who speak Spanish, as sometimes video call translators lacked proficiency in the interpretation language.

COMMUNITY

Beyond the clinic level, the primary facilitator on the community or environment level was comprehensive support resources (n=7, 58%), including low-cost transportation (n=6, 50%). Having transportation funding, vouchers from social work to support transportation, and access to low-cost transportation options, such as low-cost public transportation or Medicaid-provided transportation, were helpful for return for follow-up visits. Additionally, support groups for adolescents and young adults and having liaisons for school reintegration were all instrumental in enabling long-term care.

While some solutions in place are facilitators, they are not sufficient, as all 12 representatives (100%) mentioned distance and transportation issues as barriers to returning for follow-up care. There were logistical and financial issues with rural patients traveling long distances to clinics. Other transportation challenges were the ability to afford transportation, not having a vehicle, the inability to drive, and lack of Medicaid transportation.

SOCIETY/POLICY

Interviewees stated that having financial resources (n=9, 75%) and insurance policies that cover certain benefits, such as transportation (n=6, 50%) was helpful to patients. Clinics, non-profit organizations, or other organizations with policies for financial programs to cover medical expenses not covered by insurance, including gas, travel and household utilities, and allowing patients to have a flexible payment plan were all instrumental in encouraging follow-up visits. It is also deemed crucial to have institutional and extramural funding for a survivorship clinic. Other facilitators involve insurance policies that cover transportation, such as an online ride-sharing service providing free rides to clinics, and social workers who assist families without insurance by helping them navigate and understand the available resources.

Interviewees highlighted the lack of survivorship funding or insurance coverage as one of the overarching barriers to follow-up care (n=11, 92%). Cancer survivors and their families would either not have enough funding to cover the cost of follow-up care or lack insurance coverage. Some Medicaid patients lose their coverage and thus lose free transportation to and from appointments, which negatively affects access to follow-up visits. Clinics without financial assistance programs or other ways to ease patient costs voiced this as a barrier to returning for care.

Discussion

Through interviews with clinic staff and providers, we were able to understand the different levels of facilitators and barriers to follow-up survivor care. The facilitators and barriers are complex and interrelated. Our results revealed that the most common facilitators of survivors' follow-up care were having positive and familiar staff, utilizing clinic-level resources, having dedicated survivorship staff, and establishing efficient workflows and processes. These facilitators were often at the organizational level, while barriers were across all levels of the fishbone diagram but concentrated at the organizational,

community, and policy levels. The most frequently reported barriers were related to lack of transportation, inadequate insurance coverage, lack of funding for survivorship healthcare, technology limits to assist with scheduling follow-up care, and cancer clinics' and survivors' scheduling issues.

Our study found that at the organizational level technology and scheduling were important factors in facilitating follow-up cancer care. Multiple communication methods, such as phone and electronic clinic portal allowed patients to communicate in their preferred way. These findings are similar to previous research that shows the importance of scheduling reminders and various communication methods.^{9,12,13} A recent meta-analysis found that patients who received automated text reminders were 23% more likely to attend their outpatient clinic visit.²² Scheduling technology and flexible clinic schedules can help coordinate the multiple appointments that survivors often have. Clinics can also recommend the use of electronic personal health records, such as SurvivorLink, to allow patients to manage and electronically share survivorship and other health records across institutions.²³ Any technology changes are often driven by the institution and require significant support to implement. Ensuring staff are trained in existing software and utilizing it to its fullest extent may benefit clinic efficiency without large investments.

Most of the top barriers that impede the return for follow-up care were focused on the organizational, community, and policy levels. A recent scoping review found 27 published interventions aimed at overcoming barriers and disparities in survivorship care; most addressed barriers at the patient level.²⁴ Social determinants of health assessment or screening may be helpful as a tool to ascertain barriers at other levels from the provider, health system, and community to policy as it relates to surveillance care for pediatric cancer survivor patients. If available, survivor clinics may offer alternative options for the location of care, such as telemedicine or a satellite clinic to lessen the transportation issues. Additionally, integrating social work and financial counselors into the multi-disciplinary survivor team could help clinics assess for financial burdens after cancer and assist eligible patients in navigating options for financial assistance.²⁵ These organizational changes could help survivor clinics address and reduce barriers to follow-up cancer care.^{26,27} Future research could evaluate higher-level interventions at the pediatric cancer survivor clinic level to improve surveillance.

Overall, we found that there are themes related to the staffing, operations, and patient support in survivorship clinics that were barriers to the return for follow-up survivorship care. Through understanding the interrelatedness of the facilitators and barriers, clinics can design and pilot solutions to improve the return for follow-up care. Survivorship programs have an opportunity to improve care by addressing organizational factors, such as the scheduling process, and by urging policymakers to increase funding and insurance coverage for long-term follow-up survivorship care.

Strengths and Limitations

We interviewed representatives from 12 pediatric cancer survivor clinics to discern facilitators and barriers to follow-up survivorship care. We chose COG clinics from different areas of the U.S. with various patient populations to gain a diverse understanding of return

for follow-up survivor care; however, these findings may not reflect all pediatric cancer survivor clinics, particularly survivor clinics with smaller patient populations. Additionally, the data collection instrument and analyses were grounded in theory and guided by the fishbone diagram process and the SEM allowing for the visualization of results at each level. Limitations of the study include the number of COG clinics participating, data based on only one representative from each clinic, time constraints for the duration of the interviews, and subjective responses based on the participants' perceptions and knowledge, specifically about policy and survivor and family barriers. In addition, although the interview was semi-structured, they responded with varying depth to their explanations.

Conclusion

From clinic staff and provider's perspectives, there are facilitators and barriers to receiving survivor care at all levels, from the individual and organization to the community and health policies. Understanding the inter-relatedness is essential when determining where to focus resources to improve engagement in long-term survivor care. There may be some organizational limitations that would require significant institutional support to implement (i.e., funding to implement electronic scheduling systems), while others are individual, such as providers building a relationship with a new survivor and their family. Future research should build on these findings to expand our understanding of the factors associated with return for follow-up cancer care across socio-ecological levels. Future research could also lead to services and interventions to promote better healthcare utilization and improve the quality of life of pediatric cancer survivors.

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Abbreviations

COG	Children's Oncology Group
SEM	Socio-Ecological Model

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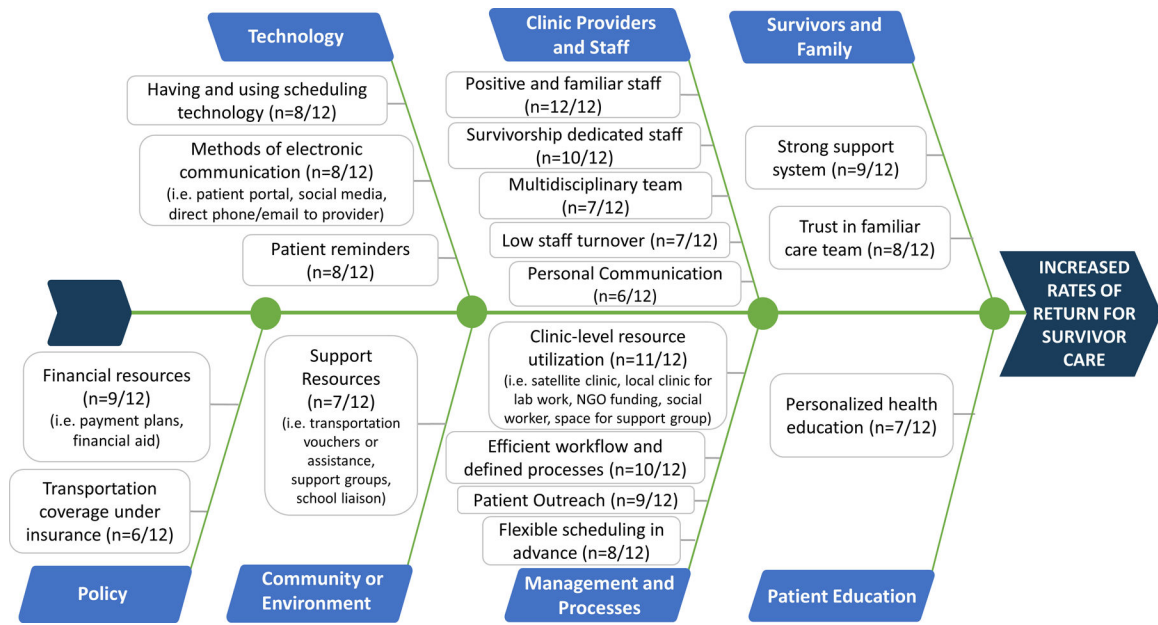


FIGURE 1. Meta-fishbone diagram of facilitators for returning to survivor care as reported by clinic representatives during in-depth interviews.

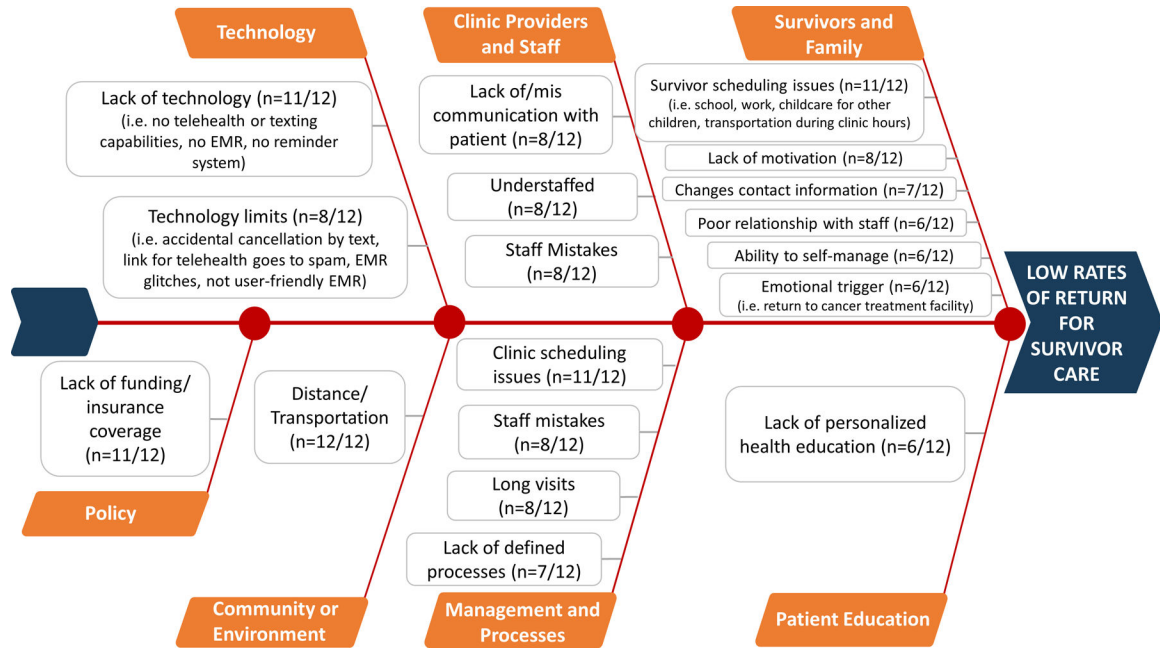


FIGURE 2. Meta-fishbone diagram of barriers to returning for survivor care as reported by clinic representatives during in-depth interviews.

TABLE 1.

Interview Questions associated with Each Level of the SEM

SEM Level	Interview Questions
Individual and Intrapersonal	<ul style="list-style-type: none"> • What survivor or family factors may facilitate survivors' return for ongoing survivorship visits? • What are some barriers that survivors and families face that may lead them to miss their annual follow-up visits?
Organizational	<ul style="list-style-type: none"> • What factors related to the providers or staff that support survivors in your clinic help enable survivors to return to your clinic for follow-up care visits? • What factors related to the providers or staff that support survivors in your clinic might lead survivors to miss their follow-up visits? • What factors related to technology may lead survivors to miss their visit? • What factors related to clinic operations that survivors or families face at pediatric cancer clinics facilitate a survivor's return for annual follow-up visits? • What factors related to clinic operations lead survivors to miss their visit?
Community	<ul style="list-style-type: none"> • What factors related to your survivors' community or environment might make it more likely that survivors miss their annual follow-up visit?
Societal/Policy	<ul style="list-style-type: none"> • What are some barriers that survivors and families face that may lead them to miss their annual follow-up visits? Prompt: insurance coverage

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TABLE 2.

Clinic Characteristics

Characteristic	Clinics (N=12) no. (%)
Clinic Location in the United States	
Northeast	4 (33%)
Midwest	4 (33%)
West	3 (25%)
South	1 (8%)
Estimated Survivorship Clinic Years in Existence	
1–10 years	3 (25%)
11–20 years	7 (58%)
21–30 years	1 (8%)
>30 years	1 (8%)
Estimated Number of Visits for Late Effects/Survivor Care in 2018	
201–300	6 (50%)
>300	6 (50%)
Estimated Race/Ethnicity of patient population	
> 50% Hispanic	2 (17%)
> 50% White, Non-Hispanic	8 (67%)
< 50% Any Race/Ethnicity	1 (8%)
Missing	1 (8%)
Estimated Percentage of Rural Patient Population	
0–19%	4 (33%)
20–39%	3 (25%)
40–49%	1 (8%)
50%	3 (25%)
Missing	1 (8%)
Job Title of Clinic Representative	
Physician	2 (17%)
Advance Practice Provider	7 (58%)
Nurse Program Coordinator (Registered Nurse)	3 (25%)

TABLE 3.

Themes and selected example quotations

Theme Title	Summary of theme	Quotations
Survivors and family		
Strong support system	Family members are very involved with care.	<i>"...the micromanaging family members actually help our patients, I think, make sure. Especially our young adult population to get on board with their regular routine care."</i>
Patient Education		
Personalized health education	Health education is tailored to the patient's needs/wants and delivered at the time requested.	<i>"...if the patient came in and that day they asked about fertility ... that's when you hand them the paper on fertility rather than every single visit or, you know, giving them 20 sheets of paper that they weren't interested in."</i>
Lack of personalized health education	Health education is not tailored to patient's needs or wants.	<i>"I think that we would be better off if we could meet patients where they are. So much of our educational material is in written form, and it's printed with maybe a diagram of something... if we could talk to them in their own language, I think it would be much more effective."</i>
Clinic staff and providers		
Survivorship dedicated staff	Staff that is solely assigned to the survivorship clinic and is educated on survivorship care.	<i>"It was nice to have a dedicated scheduler who kind of understands like here's how you can book five things in a day and space it out correctly so the families can get everything done and not feel stressed out by that."</i>
Lack of/miscommunication with patient	Providers and/or staff members do not communicate adequately with each other and/or patient.	<i>"We don't have any Spanish-speaking providers. We can request an interpreter, but they're very expensive ... They prefer we use these little phones that are about six inches long, they go out, they don't hold a charge. You can't hear. I think it's sub-optimal at best."</i>
Management and Processes		
Clinic-level resource utilization	Providers and staff use resources that are available to the clinic (i.e. satellite clinics, local clinics for lab work, NGO funding, social workers, space for support group).	<i>"They can go locally and get their labs and their tests and have them faxed to us" "And then I also go to a satellite office in [a different city]. So, [different city]'s about an hour and a half from [here], hour, hour and a half depending on traffic, so I do go six times a year over to that clinic to see patients."</i>
Clinic scheduling issues	Scheduling processes are inefficient, not followed, and/or not defined.	<i>"My latest appointment is 3:00. I'm sure [patients would] prefer my latest appointment be more like 5:00." "Sometimes when we have not perfected when appointments moved, making sure all testing moves with them. And I think that's frustrating for families when their appointment has to move, and then they realize that when they come that they don't have the echo scheduled that they thought they did."</i>
Lack of defined processes	General clinic processes are inefficient, not followed, and/or not defined.	<i>"We have satellite clinics in [another area of the state]...but we don't hold the [survivorship] clinic in either of those locations. They have to come down to main."</i>
Technology		
Having and using scheduling technology	The clinic has and uses the scheduling technology available, such as for arranging telehealth or in-person visits.	<i>"There's a community...that is about two hours north of us, and we started a once-per-month half-day telemedicine clinic [there]. That one is nice, because they actually go into the clinic there. So, we get the vital signs, we get their height and weight. There's a lab there."</i>
Lack of technology	The means of current technology are not available to the clinic.	<i>"... [a] text reminder I think would be great, because I think we're such an electronic society now that if you don't recognize the phone number, you're not going to answer the phone."</i> <i>"I should be able to see what [previous clinic has] done to them, you know, like if they're transitioning care down to [this state], but right now I can't, so I have to get like physical paper records."</i>
Community or environment		
Support Resources	Community support resources available to the patient, such as transportation vouchers, support groups, or a school liaison.	<i>"... I would write letters to the school, ...and they would just totally ignore it because I wasn't speaking their language. I didn't say what they needed to hear. ... so [person hired] is now our school liaison, and that has been a godsend, so being able to specifically have people in place that can address the expected problems our kids have and have solutions to problems and ways to fix it."</i>

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Theme Title	Summary of theme	Quotations
Distance/ Transportation	Transportation challenges include distance and financial and logistical issues.	<i>“We are the only survivorship program in the state. We have a huge state...So it’s access to care. It’s transportation down here and being able to kind of coordinate all that.”</i>
Policy		
Financial resources	Availability of financial support for patients and/or survivorship clinic	<i>“Like any childhood cancer patients in our – at [the clinic], they don’t have a bill, because anything that the insurance doesn’t pay, [the NGO] pick(s) up”</i> <i>“We’ve been very lucky to over the past five years go from a part-time program coordinator to a full-time program coordinator, and to have that funding be taken on by the university ... because again, people respond better to a personal phone call...”</i>
Lack of funding/ insurance coverage	Absence or insufficient funding, including insurance coverage for patients and/or survivorship clinic	<i>“There is like a barrier to cost and what insurance companies think are appropriate or not.”</i> <i>“What I’m finding is that patients are, out of necessity, choosing high deductible, low monthly rate plans.”</i> <i>“When they were getting treatment, they met those high deductibles, so it didn’t matter in terms of them coming into a clinic visit, but now once a year a few scans, a couple years, they’re not meeting that high deductible.”</i> <i>“I find that there’s less foundations and less funds available for people who are off therapy.”</i>