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Care Transitions in Childhood Cancer Survivorship: Providers' Perspectives

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Purpose: Most adolescent and young adult (AYA)-aged childhood cancer survivors develop physical and/or psychosocial sequelae; however, many do not receive long-term follow-up (LTF) critical for screening, prevention, and treatment of late effects. To develop a health services research agenda to optimize care models, we conducted qualitative research with LTF providers examining existing models, and successes and challenges in maintaining survivors' connections to care across their transition to adulthood.

Methods: We interviewed 20 LTF experts (MDs, RNs, social workers, education specialists, psychologists) from 10 Children's Oncology Group-affiliated institutions, and analyzed data using grounded theory and content analysis techniques.

Results: Participants described the complexity of survivors' healthcare transitions. Survivors had pressing educational needs in multiple domains, and imparting the need for prevention was challenging. Multidisciplinary LTF teams focused on prevention and self-management. Care and decisions about transfer were individualized based on survivors' health risks, developmental issues, and family contexts. An interplay of provider and institutional factors, some of which were potentially modifiable, also influenced how transitions were managed. Interviewees rarely collaborated with community primary care providers to comanage patients. Communication systems and collective norms about sharing care limited comanagement capacity. Interviewees described staffing practices, policies, and informal initiatives they found reduced attrition.

Conclusions: Results suggest that survivors will benefit from care models that better connect patients, survivorship experts, and community providers for uninterrupted LTF across transitions. We propose research priorities, framing attrition from LTF as a public health concern, transition as the central challenge in LTF, and transition readiness as a multilevel concept.

Keywords: cancer care continuum, pediatric, survivorship, late effects, prevention, healthcare transition

Introduction

Preventing attrition from long-term follow-up (LTF) care requires a nuanced understanding of challenges providers face in caring for adolescent and young adult (AYA)-aged survivors of childhood cancer. To better understand current models of care and lay out a salient health services research agenda, we undertook exploratory qualitative research interviewing LTF providers.

In a great oncology success story, ~85% of children diagnosed with cancer survive beyond 5 years and many live into adulthood as long-term survivors.[1,2] By some estimates, however, only ~40% receive LTF care to address late effects.[3,4] In the Childhood Cancer Survivor Study cohort of over 14,000 survivors, two thirds had at least one chronic condition (e.g., second malignancy, premature cardiovascular disease, endocrinopathy) 25 years postdiagnosis;[3,5–8] about half develop a severe or disabling chronic condition.[2,9] Survivors are at increased risk of psychosocial distress (e.g., anxiety, depression, post-traumatic stress), and many have neurocognitive dysfunction.[2,10] Some, particularly those treated with cranial radiation, experience social isolation and struggle in school and the workplace.[5,6,11–13]

Thus the practice of LTF care has grown at pediatric oncology centers in recent decades.[14] Inherently multidisciplinary, LTF addresses survivors' mood, behavioral, and neurocognitive issues, school and vocational challenges, as well as physical health.[7,15–18] At different centers, LTF is

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offered during oncology clinic, on designated survivors' days in oncology clinic space, and in free-standing programs with their own space and staff.[19] Regardless of how it is structured, providing LTF is resource-intensive. Institutions' capacities are strained by the number of childhood cancer survivors, expected to reach 500,000 in the United States by 2020.[5,7,19–22] Elements of survivorship care are often transferred to community primary care providers (PCPs), but when and how these transfers occur vary across institutions.[16,19] Practically speaking, pediatric-trained clinicians cannot always manage adult survivors of childhood cancer, and survivors cannot conveniently return to the centers where their cancers were treated.[3,7,23–25]

Care transitions are a major challenge for young people with complex health issues. Transition refers both to care transfers from one provider and/or setting to another and also to the processes through which adolescents and young adults take on responsibility for their own health and healthcare. Well-orchestrated transitions should help ensure that adolescents maintain continuity of care and are adequately prepared to self-manage their conditions.[26,27] How the healthcare community should orchestrate transitions, however, is not clear. In a 2002 consensus statement, a working group from the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians defined critical first steps to guide care and policy advocacy toward optimal transitions.[26,28] In 2011, the Got Transition initiative, led by the federal Maternal and Child Health Bureau and the nonprofit National Alliance to Advance Adolescent Health, operationalized the consensus statement as *Six Core Elements of Healthcare Transition* (Core Elements).[29] The Core Elements (summarized in Table 1) include the following: establishing a practice-wide transition policy; implementing a patient registry; assessing patients' readiness to transition; and carrying out comprehensive care planning reiteratively and collaboratively with patients and families.[29] Core Elements have not yet been widely implemented, however, and most youth with special healthcare needs still receive less than optimal transition support.[30] Evidence of how deliberate management of transitions affects patients' experiences and health outcomes is scarce.[26,31,32]

How to improve transition readiness is left to individual practices. Transition readiness, a multidimensional concept, some facets of which differ across diseases, has proven difficult to gauge.[33] Compared to youth with rheumatologic disease, diabetes, or cystic fibrosis, for a cancer survivor, transition readiness can have more to do with acquiring self-efficacy to prevent potential late effects, than with mastering immediate, tangible skills to manage existing problems. The Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) provides a framework for understanding, measuring, and intervening to improve transition readiness.[34] Intended to apply to AYA with disparate complex healthcare needs, the SMART model was developed and validated with 16–28 year old childhood cancer survivors, their parents, and healthcare providers.[35] It explains transition readiness as a function of the cultural, political, and healthcare system context (macrosystem and exosystem); reciprocal interactions among the patient, parents, and providers (microsystem); and patient, family, and providers' individual-level characteristics (mesosystem).[34] Schwartz et al. used the model to identify modifiable mesosystem-level factors, including parents' and providers' beliefs, as well as patients' knowledge, self-care skills, self-efficacy to navigate healthcare, and future expectations.[34]

Table 1. Summary of Six Core Elements of Healthcare Transition

1. **Transition policy**
   - Develop a practice-wide policy for handling transitions.
   - Discuss with patients and families starting in early adolescence.
2. **Transition tracking and monitoring**
   - Use a patient registry.
   - Track transition processes (e.g., readiness assessment, care planning) and outcomes.
3. **Transition readiness**
   - Assess self-care needs and goals starting at age 14, using transition readiness assessment tools.
4. **Transition planning**
   - Develop a comprehensive plan, addressing the following:
     - Subspecialty, legal, service referrals
     - Insurance
     - What patients should do in an emergency
     - Who is legally responsible for decision-making, who has access to personal health information
     - How to find, establish care with an adult provider if transfer needed
   - Update, discuss plan at regular intervals.
5. **Transfer of care**
   - Use checklists to confirm adherence to practice transition policy, and to ensure the following:
     - Appointments have been scheduled
     - Accepting providers have access to medical records
     - Patients and families have copies of summaries and care plans
     - Direct communication between pediatric and adult care provider has taken place
6. **Transfer completion**
   - Communicate with patients and receiving providers in follow-up.

Abbreviated, printed with permission from Transitioning Youth to an Adult Healthcare Provider: Six Core Elements of Healthcare Transition 2.0. Got Transition, Center for Healthcare Transition Improvement.[29]

Three basic care models of LTF described in the literature are largely distinguished by where care is managed as survivors transition into adulthood.[7,36] In the cancer center-based model, survivorship experts continue management.[37] This model offers continuity, but is costly.[3,23] In the community-based model, care is transferred to local providers. The Children's Oncology Group (COG) LTF guidelines are designed for use by PCPs as well as cancer center-based specialists.[38,39] However, most PCPs do not encounter childhood cancer survivors frequently enough to be familiar with the COG guidelines. Many feel unprepared to take on postcancer care independently.[40–42] In a hybrid model, PCPs share care with a cancer center team that provides guidance on cancer-related issues. No studies compare effectiveness of these models.[43] Shared care is described as the ideal and is hypothesized to be the most cost-effective; however, the degree to which it actually occurs in practice is not known.[7,15]

To develop a health services research agenda informing optimal care models, we conducted qualitative research with LTF providers to examine existing models, as well as successes and challenges in maintaining survivors' connections to care across their transitions to adulthood.

Methods

We conducted semistructured interviews with multidisciplinary LTF providers. This research was deemed exempt by the Institutional Review Board at the University of North Carolina-Chapel Hill. We used the COG Late Effects Directory of Services and medical centers' websites to find LTF-focused providers at COG member institutions within ~300 miles of eastern North Carolina, as well as major national centers in the eastern United States, to which patients and families might travel from our state for care.[44] We recruited participants by email. We then snowball sampled, asking index participants to recommend care team colleagues. Purposive sampling of children's oncology centers with a range of patient volumes and catchment areas, followed by snowball sampling of team members allowed us to interview medical and psychosocial clinicians with disparate roles, practicing LTF in a variety of settings, including regular oncology clinics, self-standing programs within children's and adult hospitals, and outpatient clinics remote from affiliated cancer centers. Participants' centers were diverse in that some were major research institutions and others were not; some served patients primarily from their metropolitan areas and surrounding counties; some had patients from across their state; some drew regionally from several states; and other centers treated patients from across the country.

Twenty providers from 20 institutions were initially invited; 10 from 10 institutions agreed to participate. Six index participants referred us to 10 additional providers from their institutions. Participants included the following: nine physicians, from pediatrics, pediatric oncology or other pediatric subspecialty, and family medicine; two nurse practitioners; five social workers; two psychologists; and two educational consultants (Table 2). Interviews were conducted between August and December 2015.

Interview guides covered clinic organization, care coordination and transition management, survivors' quality of life, and participants' research interests. For nurses and physicians, we probed on clinic processes and the medical aspects of LTF. For social workers, psychologists, and educational consultants, we probed more on psychosocial care. After training to standardize how we used the interview guides, two coauthors (M.S.M., E.A.W.) conducted interviews by phone and in person. Interviews lasted 25–70 minutes and were recorded and transcribed. We managed data with ATLAS.ti qualitative analysis software (Version 7.5.10, Berlin).

Table 2. Participants

Center	*Participants' roles*
1	MD, Psy, SW
2	MD, SW
3	MD, SW
4	NP, SW
5	MD, MD, SW
6	NP, EC, MD, Psy
7	MD
8	MD
9	MD
10	EC

EC, education consultant; NP, nurse practitioner; Psy, psychologist; SW, social worker.

Using techniques from grounded theory and content analysis,[45,46] we developed a codebook starting with topics from the interview guide and adding emergent codes through iterative readings and comparison of interviews. As the complexity of childhood cancer survivors' care transitions became apparent, we compiled a second, transition-focused codebook. Team members independently applied codes to transcripts and discussed coding patterns.

While coding, we identified provider-level and institutional-level factors as important determinants of care models. To examine factors at each level, we carried out two analyses in parallel: for a provider-level analysis, we used the software's code output function to review segments of text-coded *transitions*, *communication*, *ideal practice*, *teamwork*, and *relationships with care team* as these concepts emerged as prominent themes across the interviews. Reviewing the output, we asked what made care transitions problematic for childhood cancer survivors in particular, and what did the interviewees do individually to facilitate transitions. For an institutional-level analysis, we considered how characteristics of cancer centers and the healthcare system shaped LTF models, and what systems were in place to facilitate transitions. We created a quotation matrix to compare centers' structural characteristics, survivorship care processes, and participants' different roles on care teams. We used the matrix to develop case studies of what LTF and transitions looked like at each center, and compared case studies to the models of care described in the literature. Synthesizing the two analyses, we considered how provider- and institutional-level factors interacted to influence LTF, as well as implications for research and practice.

Results

Participants collectively described LTF as an evolving transdisciplinary specialty, one that encompasses both highly focused and whole-person preventive care, and in which transitions are a central challenge. Their clinics were more than a convenient arrangement by which patients could see several providers in one visit. The teams functioned synergistically, beyond the sum of their parts. Providers collaborated to see the big picture and provide holistic, supportive care focused on all-around quality of life and patient empowerment. Provider-level findings centered around the complexity of AYA-aged childhood cancer survivors' transitions and educational needs, and tailoring care transfers for individual patients. Overall, there were not prominent differences in responses by types of provider, although physicians and nurse practitioners expressed strongest preferences to continue managing patients long term. Institutional-level findings clarified how structural factors influence transition management. We describe provider-level and institutional-level findings in turn, then, interviewees' insights about attrition from care.

Provider-level findings: unique complex transitions

Educational needs. Providers described AYA-aged childhood cancer survivors' transitions as complex in that survivors had pressing educational needs, many lived remotely, and some had impaired development. Transitions could require multiple transfers, from cancer treatment teams to survivorship-focused providers, pediatric to adult settings, and/or cancer centers to communities. Survivors and families needed information and skills in several domains to navigate each (Illustrative quotes, Box 1).

Participants reported that engaging survivors in preventive lifestyle and healthcare behaviors was a primary goal and a major challenge, as late effects may not have developed by adolescence/young adulthood. They explained that if patients understood potential implications of their medical histories, it could motivate healthy behaviors and keep them connected to care across transitions. However, survivors who had been diagnosed as young children might not know details of their cancer course and first needed to learn their own histories. Interviewees expected survivors' knowledge of late effects risks to fill in for what future PCPs would be unlikely to know. Thus to prepare for transfers, patients needed to be empowered to advocate for themselves, as well as access community resources and navigate insurance and unfamiliar organizations.

Patient education was generally felt to be a major focus and major strength of LTF. Participants said educating survivors was their responsibility and key to supporting patients through transitions. Nurses, nurse practitioners, and social workers did the majority of patient education. They worked flexibly with patients and families during clinic time as needed.

Care transfers. Participants preferred timing transfers on a case-by-case basis (Box 2, quotes 1 and 2). They described how the work of helping to shift healthcare responsibility from parent to child was highly tailored, taking into account families' socioeconomic situations and capacity to work with health systems, as well as patients' health status and complexity of care. In transfers of survivors with cognitive impairment, social workers and psychologists provided crucial guidance for family caregivers with respect to caregivers' future roles in working with adult-oriented providers.

Participants often framed care transition as a developmental milestone. Many, however, conveyed the belief that care transfer was an unfortunate necessity. They generally acknowledged that survivors at low risk for late effects should be able to be managed in a primary care setting, and those without adult medicine training said continuing to see patients indefinitely was not ideal. Several of the medical providers we interviewed acknowledged that they were not necessarily the best person to care for adult patients with adult chronic disease; yet many served as *de facto* PCPs and were reluctant to send even low-risk patients elsewhere unless they, personally, could remain in charge of cancer-related follow-up (Box 2, quotes 3 and 4).

The significance of providers' relationships with patients and their families was a recurrent theme. Interviewees valued these relationships not only because they were personally meaningful but also because knowing patients' stories and contexts, not just their medical histories, contributed to ef-

Box 1. AYA-Aged Childhood Cancer Survivors' Educational Needs for Transitions

Health behaviors

Helping people understand how they can modify their behaviors in a good way, and educating them about the risks and going over that over and over again…That really is the key…Getting people to change their behaviors and improve their diet and exercise and lifestyle, those are hugely challenging. But those are very, very important. —Pediatric subspecialist

Health insurance

We have an individual who's in their 20's and I ask over the phone, "What's your health insurance?" And they sort of say, "Hold on a second." You can hear them say, "Mom!?" —Social worker

Medical histories

They come to us with their parents having been…the archival memory of the whole history and so we're getting young adults coming who really have very little knowledge about their cancer history,…what they were treated with, and particularly what the late effects of those treatments might be. —Social worker

Navigating medical system, accessing community resources

Once they go back to their home community…they're responsible for adapting…and having to…seek these services on their own. So, even though I'm here to help…ultimately the families have to be responsible for kind of making that bridge. —Psychologist

Box 2. Individualized Timing of Transfers, Preference to Continue Managing Care

Delaying transfer for psychosocial reasons

1. *We may delay…We may give them a little bit more support. Some of our patients have developmental delays because of treatment late effects, and sometimes they stay with us longer because they're still dependent on a care-giver…Sometimes it's not even about developmental issues. It can be emotional and psychological issues too.* —Social worker

Delaying transfer for medical complexity

2. *A kid who went through treatment for a lymphoma…and had almost no complications, and they're still coming to us 15 years later and everything is going to be probably completely fine with them, you know, those kind of patients probably could have been transitioned to their primary care 10 years ago. But our brain tumor patients, who have all kinds of social and emotional and intellectual and hormonal and all those kinds of issues, you know, I'm scared to send them out when they're 30. I don't wanna send them.* —Nurse practitioner

Preference to continue managing care

3. *I would rather, as the oncologist and someone who does survivorship, be able to see the patients and order what I think is necessary for their follow-up, and follow up with it. I would rather be in control.* —Pediatric oncologist
4. *Probably 25% of the patients we see could really be seen exclusively in the community, and we could serve as a resource should they need some backup or expertise. But that doesn't happen…They leave us and go out into the real world where things are really bad and where they're very unlikely to get the care they need unless they're extremely proactive or extremely fortunate.* —Pediatric subspecialist

fectiveness of care. Reluctance to transfer also came across in what participants, in particular physicians and nurse practitioners, had to say about PCPs' readiness to manage complex patients and the atmosphere in adult medicine settings. Some perceived community providers to be generally unprepared for childhood cancer survivors because they rarely encountered such patients. PCPs were too busy, interviewees believed, to be expected to learn the COG guidelines. Adult care culture was said to be less nurturing, harder for patients and families to navigate. Adult clinic staff would probably not routinely call patients who missed appointments, they said. For these reasons, many of the providers we interviewed preferred to continue seeing patients as long as possible. They were more comfortable with transfers when they knew PCPs and were familiar with psychosocial resources, and could connect patients with them directly.

Institutional-level findings: cancer center and health system characteristics influencing transitions management

Structural factors, funding. Centers' catchment area, patient volume, affiliation with adult medicine, and funding-shaped LTF arrangements (Box 3, quotes 1–3). Patient distance from the cancer center was an important logistical consideration and figured into whether LTF providers were familiar with patients' local doctors, vocational rehabilitation programs, mental health providers, and school personnel. Providers at centers serving a statewide or national patient base could not be familiar with resources in patients' many-home communities. In such circumstances, participants sometimes found local services through local PCPs, but they also taught patients and families to make those connections themselves.

Box 3. Cancer Center and Health System Characteristics Influencing Transitions Management

Influence of clinic size, patient geography

1. *Because we're more local, our patients are more local, I think it helps to provide kind of that personal approach…knowing the local resources.* —Social worker
2. *People are coming in from all over. Our big focus is…to teach you to get the same level of care and comprehensive evaluations and attention to your health in your community, which is quite challenging.* —Pediatrician
3. *I have got a list of people whom I trust… I've got my hypertension go-to person. I've got my heart failure go-to person and I've got my skin cancer go-to person, etc. etc…But for somebody who lives 150 miles away, that's more challenging.* —Pediatric oncologist

Communication with primary care providers: Comanagement capacity and collective norms

4. *We never get back anything from the primary care provider. I mean I'm sure they're incredibly busy with droves of patients. So, that makes this kind of thing hard because we don't have any follow-up. So, we don't know when we send a kid out what's going on on the other side.* —Pediatric oncologist
5. *We actually send…patient-specific guidelines to the primary care physicians, but I'm not sure it's so well known or followed. And I think in a busy pediatrician's office, it's hard to slow down to look at that.* —Pediatric oncologist
6. *We very infrequently get calls from primary care physicians even after we send stuff out…There's…a handful of people where I have communication with the primary care physician.* —Pediatric oncologist
7. *I'm really big on the primary care doctors being within our system…continuity of care is so much better if everybody is on the same [electronic health record] system.* —Nurse Practitioner

Although larger centers were often described as having more resources, services, and types of providers, higher patient volumes and full clinics limited how long patients might continue to be seen and the degree of flexibility in timing transfers. Some clinics had strict age limits because of patient volumes. In contrast, participants from smaller institutions reported more flexibility in transfers both from treating oncologists to survivorship-focused providers and from cancer center providers to community PCPs. They could more easily time transfers on a case-by-case basis.

Resource allocation for LTF varied across sites and was not entirely dictated by pediatric oncology volume. Some clinics were self-supported, others were supported by philanthropic or research grants, and some received direct funding from the cancer centers. Funding influenced staffing, particularly for those professionals who did not bill directly for services. At some centers, for example, social workers and educational consultants were entirely dedicated to LTF, but at other centers, they shared their time with active treatment clinics. These arrangements were generally felt to be effective; however, they influenced time available to focus on transitions because these staff members played key roles in patient education, connecting patients to community resources, and advocacy with schools.

Communicating with PCPs. Some participants contacted PCPs at receiving practices in advance of care transfers, while others relied on survivorship care plans (SCPs) and treatment summary documents. Such documents were widely used and generally considered standard of care. Participants had varying opinions of their effectiveness, however. Typically they described SCPs as static documents that were not actively incorporated into electronic health records (EHRs). They were time-consuming to produce. It was difficult to include enough individually tailored information to be useful, without making the documents overly lengthy. Patients lost them, and PCPs did not always recognize their value. Finally, systematic feedback as to whether PCPs saw or followed care plan recommendations was usually not available.

Participants generally found the lack of regular communication with PCPs about shared or transferred patients unremarkable. Limited communication was the norm (Box 3, quotes 4–6); a majority of our participants seemed resigned to having little direct contact with community providers. Communication systems limited comanagement capacity. Where PCPs were in the same healthcare organization such that their practices' EHRs were connected, comanaging care was a practical option (Box 3, quote 7). Coordinating with providers outside their systems through faxed documents and phone calls required time and effort. There was more mention of PCPs' presumed time constraints than participants' own time constraints, however.

Box 4. Attrition

Attrition a challenge to measure

It's hard to know how many patients we're losing…It's impossible to really know…We've done a few studies where we actually call back and say, "Did you make your follow-up appointment?" But it's not easy to do that kind of work, because if they went for a cold, does that count?…It's not that straightforward. —Pediatric oncologist

Gaps in care common

Eventually what happens is people come back around. So, you may not see someone for years and then something happens. They remember me…They make a phone call and they're back in the fold…They may have a lump or a bump or a scare, or someone they know relapses. —Nurse practitioner

Insurance. Most participants mentioned insurance. They helped young adults navigate insurance systems, obtain and understand coverage, and find in-network providers especially for mental health needs. Insurance sometimes influenced LTF models, for example, in requiring screening tests to be ordered by PCPs rather than at the cancer center, and/or by adult-oriented rather than pediatric providers. Many said coverage was problematic as young adults aged out of parents' policies or public programs, and charity care was less available for care during survivorship than for active treatment. Participants were generally optimistic about the Affordable Care Act's potential to reduce this barrier, but acknowledged that its long-term impact remains to be seen. Young adults' lack of insurance was cited as a cause of attrition.

AYA-aged survivors' attrition from care

Participants saw attrition as a problem nationally, and challenging to measure (Illustrative quotes, Box 4). Because care gaps were common, it was difficult to sort out who was taking a break, who had gone to college, who had moved and found providers elsewhere, and who had fallen out of care entirely. Overall, however, most participants felt attrition was not a major issue at their own centers. They said patients tended to return with symptoms or before getting married or starting a family.

Many of the participants' clinics maintained spreadsheets of patients to contact those who were overdue for visits. One physician said their LTF team held meetings to discuss missed appointments, and how to bring patients back into care. One participant's center had used registry data to identify correlates of not coming to appointments. Few of the participants' centers had formal registries, however, and even fewer institutions quantified their no-show rates precisely.

Participants described several strategies, suiting their different practice contexts, they employed to keep survivors engaged in care across transitions. One LTF team was developing an in-system shared care model. Other strategies included staffing practices, policies, and informal initiatives that increased patients' transition readiness, maintained patient/provider relationships, and facilitated patient/provider and provider/provider communication. Exemplar strategies are described in Table 3.

Discussion

This study suggests an intersection of LTF-focused health services research and the growing field of transitions, both critical for AYA-aged survivors of childhood cancer. We found transitions were individually tailored such that, even within cancer centers, LTF did not fit neatly into any one care model described in earlier research.[7,43] There was inherent tension around whether and when transfer would result in the best care for their patients. These findings support recommendations of flexible models that suit different contexts and

Table 3. Practice Strategies That Facilitated Childhood Cancer Survivors' Care Transitions

Transition readiness appointments	One or more formal pretransition visits for adolescents/young adults were scheduled at least a year in advance of anticipated care transfer. These visits were dedicated time for talking about patients' medical histories, navigating adult-oriented clinics, and choosing community providers.
Gradual care transfer	To make transfer less abrupt for patients and families, office visits to the new adult-oriented provider were for a time interspersed with appointments with the familiar pediatric-oriented provider. In one center, this arrangement also facilitated transfers from active treatment to the survivorship clinic.
Outpatient navigation	A designated point person served as a contact for current and former patients. Patients and families knew they could reach out as needed to a known individual (typically a social worker or nurse) in between visits or after transfer to community-based care. These point people scheduled appointments, sent out medical records, contacted community physicians, and identified local social and educational services and financial resources as needed.
Staffing a medicine/pediatrics-trained liaison	Having nurse practitioners, family physicians, and providers dually trained in internal medicine and pediatrics on LTF teams made transfer timing more flexible. In some centers, a provider trained to care for all ages could "bridge both sides" across transitions, seeing patients at pediatric and adult sites.
Engaging with local PCPs	At one center, the LTF team was developing an in-system hybrid care model. They had identified a group of PCPs amenable to taking on local adult survivors' medical needs and learning about survivorship and the Children's Oncology Group Guidelines. The LTF team would refer patients to these PCPs, but continue to provide psychosocial care and consult with the PCPs on cancer-related screening, surveillance, and late effects management.

LTF, long-term follow-up; PCPs, primary care providers.

accommodate patient preferences and medical needs,[15,47] and suggest that the ideal model would allow movement between cancer center-based, community-based, and shared care as needed over time. The provider, patient, and health system-related factors that shaped transition management in our study are consistent with existing frameworks depicting how such factors intersect to influence longitudinal care,[48] postcancer morbidity,[5] and healthcare transitions.[34] Our study extends those frameworks by describing the interplay among those factors, including across contextual levels. An understanding of this interplay is likely necessary to envision, and then build, a flexible model that keeps AYA-aged survivors connected across transitions.

The SMART model acknowledges the influence of context, but frames contextual factors as immutable, while individual-level patient, parent, and provider knowledge, skills, and beliefs are targeted to improve transitions.[34] Our findings identify promising points of intervention farther out the social ecologic framework. We conceptualize transition readiness as a clinic and health system level, as well as an individual level, variable. In our study, institutional factors sometimes worked counter to interviewees' practice preferences. Some factors (e.g., centers' clinic volumes, affiliations with adult medicine) were structural; however, flexibility in timing transfers and comanagement capacity are potentially modifiable. Understanding that these dimensions of care relate to providers' expectations and decisions about transfer, LTF teams can consider what systems, technologies, and processes (e.g., Table 3 strategies) would most effectively increase flexibility and comanagement capacity in their practice contexts. It will also be important to consider what training might better prepare PCPs and specialists for shared care.

The team synergy rooted in the multidisciplinary providers' shared experience, expertise, and passion for working with childhood cancer survivors offered something unique to AYA patients and families. Community PCPs, however, were often not part of the synergy. Workable shared care will require more and improved means of communication between LTF experts and community providers. Ideally, care coordination would be better reimbursed; SCPs would be actively integrated into EHRs' encounter templates; and EHRs would link across systems to allow two-way communication. Any large-scale solution that improves communication among providers and patients will have to rely on more effective use of health information technology. Norms influence how providers use health information technology, and our findings suggest that a limiting factor in comanagement capacity may be medical providers' collective norms about actively sharing care. It is telling that these interviewees seemed resigned to having little interaction with PCPs, and did not emphasize the need for better communication systems. To drive technological and reimbursement innovations that would make collaborative care logistically and financially feasible, a shift in providers' collective expectations is needed. As pragmatic first steps, competencies in care transfer and shared care should be required of clinical trainees, and communication standards for care transfer and shared care should be incorporated into the COG guidelines. Future research could evaluate whether standards were being followed; PCPs' perspectives on how they might be better connected with LTF teams; as well as collective norms, individual providers' perceived norms, and their associations with provider/provider communication behaviors and shared care.

Finally, a transition research agenda should include the design of transition care quality metrics, evaluation of transition preparation, and measurement of attrition from care. We briefly elaborate on these agenda items below.

- Quality measures are needed not only to assess clinic quality improvement initiatives but also to further intervention research into whether deliberate transition management (e.g., using Core Elements) in fact reduces care gaps for AYA survivors and, ultimately, whether eliminating care gaps improves patient outcomes.[28] Our findings suggest transition care quality measures should assess degree of flexibility in transfers, comanagement capacity, and transition preparation effectiveness, as well as clinics' adherence to Core Elements.
- The providers we interviewed sought to empower AYA-aged survivors to self-advocate, navigate systems, and choose healthy behaviors, sometimes forging new ground where proven interventions are lacking. Tracking patient-reported outcomes in these domains would contribute important evidence of what works to prepare for transitions.
- To some extent, LTF staff coached patients and families one-on-one in similar skills and information. Transition preparation programs, ideally adapted from proven, theory-based disease self-management curricula, could address common needs, freeing LTF staff to focus on patients' and families' unique issues during limited clinical encounter time. Using standard programs could also allow group or web-based delivery, and facilitate evaluation.
- While many participants spoke of promising research to strengthen COG guidelines, few were gathering evidence of which eligible patients were receiving guideline-concordant care, or about the efficacy of strategies they employed to reduce attrition. Several clinics tracked patient follow-up rates as a quality metric. As the number of survivors grows, however, it is imperative to reframe survivors' attrition from care as a public health, as opposed to an individual clinic, issue. To this end, population-level attrition must be more accurately measured, with closer examination of variation in survivors' health services use, and health and quality-of-life outcomes, by race/ethnicity, socioeconomic status, and geography.

Given the increasing potential for long survival after childhood cancer and growing numbers of survivors, health and quality of life in survivorship are public health concerns. Equal attention should be paid to increasing the health system's transition readiness as to individual patients' transition readiness. Quality of life of adult survivors of childhood cancer has been shown to vary more by severity of chronic disease than by age at cancer diagnosis, cancer type, or treatment modality,[49] making prevention, self-management, and uninterrupted LTF care critical for this population. In this study, clinicians' perspectives provided insight into how medical, psychosocial, and preventive care could be maintained over time at the population level as childhood cancer survivors grow up. A key next step will be research contributing AYA survivors' descriptions of their transition experiences, particularly those who have experienced care gaps and those who live far from where they received cancer treatment. A research agenda informed by providers' and survivors' insights is vital to the design of a LTF care model that addresses care transitions, capitalizes on team synergy, includes community providers, and effectively prepares AYA survivors to manage their health and healthcare as adults.

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Disclaimer

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