



Evidence Report

Models of Care That Include Primary Care for Adult Survivors of Childhood Cancer: A Realist Review

Evidence Summary



Main Points

- Our program theory describes how survivor and provider characteristics and facilitators/barriers may interact to produce intermediate and final outcomes and the potential role of models and resources in these interactions.
- The program theory variables seen most consistently in the literature include oncology care versus primary care, survivor and provider knowledge (e.g., survivor risks and needs), provider comfort treating childhood cancer survivors, communication and coordination between and among providers and survivors, and delivery/receipt of prevention and surveillance of late effects of original cancer treatment.
- We developed seven hypotheses about the relationships between *context*, *mechanism*, and *outcomes* (CMO) that could be associated with effective survivorship care models that include primary care.
- Care delivered outside of the specialty setting needs to include communication of knowledge to both survivors and primary care providers; our program theory provides guidance on the ways this knowledge could be shared.



Background and Purpose

Childhood cancer survivors are at increased risk for life-long chronic morbidities owing to their cancer and its treatment. There is no practical taxonomy for survivorship models of care. There is also a lack of clarity about which models are appropriate for whom and in what circumstances, as well as how resources (e.g., education, support groups, care plans, and care management processes) can support quality survivorship care.

The key decisional dilemmas for providers, survivors, caregivers, and health systems are (1) what models of childhood cancer survivorship care that include primary care may improve short- and long-term outcomes, for which survivors, and under what circumstances, and (2) what tools, trainings, processes, and other resources can promote quality survivorship care across the various models?





Methods

We addressed Contextual Questions about the different types of models of care and resources through review of literature and discussions with Stakeholders. For the purposes of this project, the term “resources” includes long-term followup guidelines; educational materials; trainings; survivor care documents (e.g., survivorship care plans); survivorship care management processes (e.g., expedited routes of contact for consultation); and survivor supportive tools and services (e.g., support groups).

We addressed the decisional dilemmas by conducting a realist review. We interviewed Stakeholders (survivor advocates, providers, researchers) and conducted targeted and iterative searching to (1) identify models of survivorship care and analyze the program theories (underlying ideas and assumptions) about how they are intended to work; and (2) identify available tools, training, and other resources for childhood cancer survivorship care and analyze the program theories underlying how they are intended to be implemented. Finally, we refined the identified program theory and developed hypotheses about context, mechanism, and outcomes through review of quantitative evidence and discussions with Stakeholders.



Results

There are many models of survivorship care with no practical taxonomy. We identified four differentiating factors across models: (1) the inclusion of survivorship expertise (whether via a specialized primary care provider or oncologist; or a physician, nurse practitioner/physician assistant, or multidisciplinary team); (2) the role of the primary care provider (e.g., main provider of survivorship care, provides survivorship care under the guidance of survivorship expert, provides primary care with no particular attention to survivorship); (3) degree of access to academic/cancer center support for survivors and/or providers; and (4) delivery of consultative versus longitudinal care. In practice, what is seen in the literature (and experienced by survivors) are more often patterns of care that occur not by design but owing to circumstance. We identified 40 resources freely available to both survivors and providers: 23 survivor-specific, 12 provider/researcher-specific, 5 for both. Discussions with Stakeholders suggested that resources are most helpful if they are easy to access, user-friendly, known to survivors and providers, from trustworthy sources, and valued by survivors and their families.

At the most basic level, models of care that include primary care need to ensure that survivors and providers have the necessary information to obtain/deliver appropriate care, and resources are a key mechanism in providing this information. The program theory variables seen most consistently in the literature include oncology care versus primary care, survivor and provider knowledge (i.e., survivor risks and needs), provider comfort treating childhood cancer survivors, communication and coordination between and among providers and survivors, and delivery/receipt of prevention and surveillance of

late effects of the original cancer treatment. In turn, these variables played the most prominent role in hypothesizing what works for whom and in what circumstances. The provider health practices and survivor health services use/behaviors represent the intermediate outcomes for survivors and providers as described by the Stakeholders: “Survivors feel confident about sharing their history, know their risks, recognize symptoms and problems, understand the care they need, are aware of the resources available to help them, and can access relevant care and services” and “PCPs understand a survivor’s history, know the survivor’s risks, recognize symptoms and problems, understand the care survivors need, are aware of the resources available to help them, and can access relevant care and services.” Our program theory illustrates how, within an environment, survivor and provider characteristics and facilitators/barriers, may connect through models of care and resources to achieve these intermediate outcomes for survivors and providers, ultimately leading to survivors living longer and feeling better (Figure A).

We developed seven hypotheses about the relationships of context, mechanisms, and outcomes (Tables A and B) for how models of care that include primary care, and resources, could be effective in providing care to adult survivors of childhood cancer.

We hypothesized that four mechanisms would be associated with higher levels of the survivor intermediate outcome:

1. Linking resources with information that survivors can themselves use and also share with their primary care provider (PCP),
2. Identifying perceived/actually healthier survivors who have perceived/actually lower needs for survivorship-specific care,
3. Connecting survivors’ engagement in the health system with increased knowledge about survivorship care, and
4. Suggesting that survivors with greater confidence in their PCPs would be more willing to transition their care.

We hypothesized that three mechanisms would be associated with higher levels of the provider intermediate outcome:

1. Linking resources with information to guide the PCP in delivering survivorship care,
2. Identifying the shared care model as a way to obtain the needed support from oncologists, and
3. Suggesting the PCPs with more experience caring for childhood cancer survivors would have greater comfort and expertise in doing so.



Limitations

Evidence on adult survivors of childhood cancer was limited leading us to consider studies of adult survivors of adult cancer. There was a lack of formal evaluations of models of care and data on final outcomes, particularly mortality, are sparse. A challenge was conducting a realist review of multiple ill-defined patterns of care rather than one intervention or model of care. Our review was also limited by the relatively short amount

of time available, precluding the depth and number of iterative searches, syntheses, and refinement of theory typical in a realist review.



Implications and Conclusions

If care for adult survivors of childhood cancer is to be delivered outside of the specialty setting, there needs to be communication of knowledge about survivorship care to both survivors and primary care providers. Our program theory provides guidance on the ways this knowledge could be shared. Our context, mechanism, and outcome hypotheses suggest how the relationships illustrated in our theory could be associated with survivors living longer and feeling better through high-value care.

Future research is needed to address two essential research questions related to this review: (1) who needs to be seen in specialty care and who can be followed in their own community; and (2) for those followed in the community, how can the knowledge that survivors and PCPs need to receive/deliver quality care be effectively transferred?

Figure A. Refined program theory

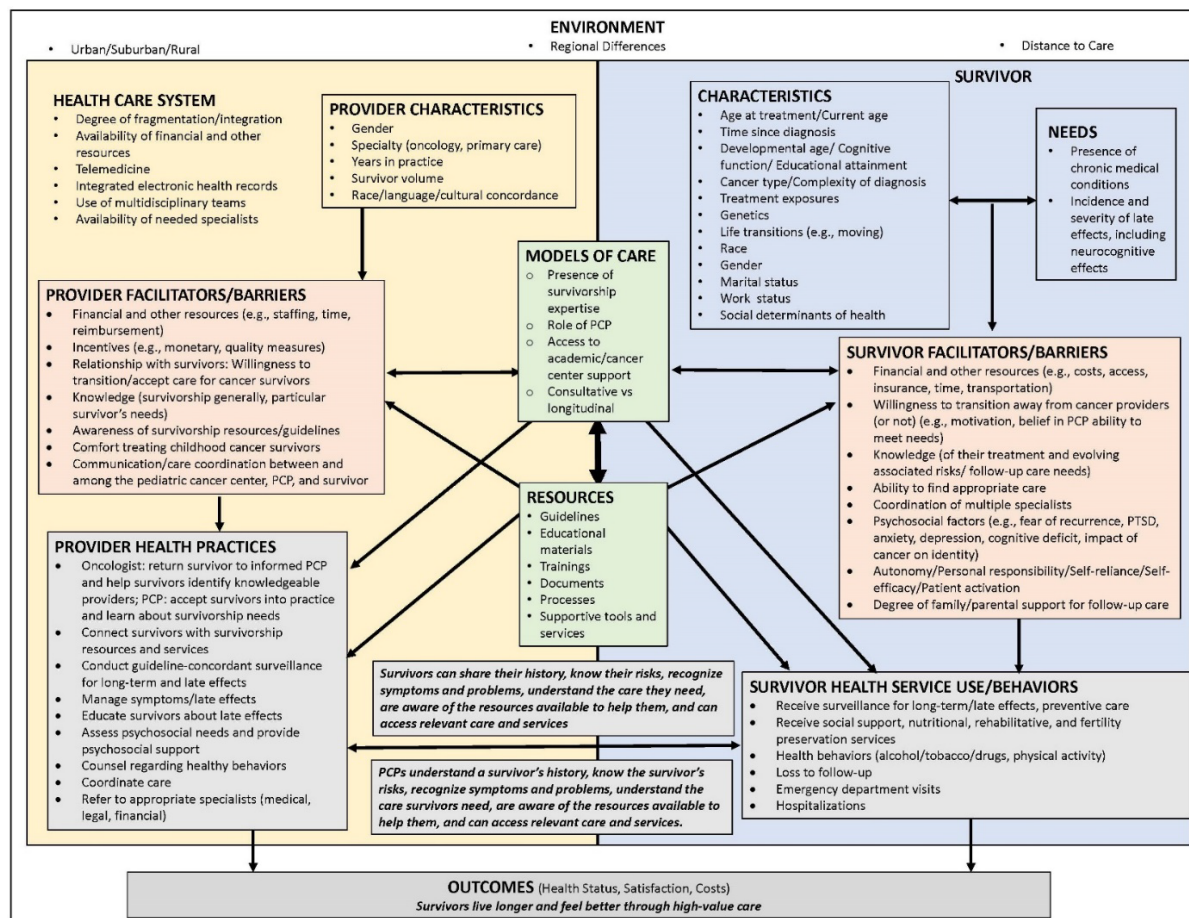


Table A. Context-mechanism-outcome hypotheses regarding how models of care that include primary care could be effective, focusing on intermediate outcomes for the survivor

| In the CONTEXT of | This MECHANISM ... Produces | OUTCOME (Intermediate) | OUTCOME (Final) |
|---|--|--|--|
| A) the availability of survivorship care plans, guidelines, and other resources | A1) improved survivor knowledge A2) information available to share with PCP to inform delivery of survivorship-related care | Survivors can share their history, know their risks, recognize symptoms and problems, understand the care they need, are aware of the resources available to help them, and can access relevant care and services. | Survivors live longer and feel better through high-value care. |
| B) healthier survivors (perceived or actual) | B) less perceived/actual need for survivorship-related care | Survivors can share their history, know their risks, recognize symptoms and problems, understand the care they need, are aware of the resources available to help them, and can access relevant care and services. | Survivors live longer and feel better through high-value care. |
| C) survivors engaged in healthcare system | C) improved knowledge | Survivors can share their history, know their risks, recognize symptoms and problems, understand the care they need, are aware of the resources available to help them, and can access relevant care and services. | Survivors live longer and feel better through high-value care. |
| D) survivor confidence in PCPs | D) willingness to transition care | Survivors can share their history, know their risks, recognize symptoms and problems, understand the care they need, are aware of the resources available to help them, and can access relevant care and services. | Survivors live longer and feel better through high-value care. |

PCP = primary care provider

Table B. Context-mechanism-outcome hypotheses regarding how models of care that include primary care could be effective, focusing on intermediate outcomes for the primary care provider

| In the CONTEXT of | This MECHANISM ... Produces | OUTCOME (Intermediate) | OUTCOME (Final) |
|---|---|---|--|
| A) the availability of survivorship care plans, guidelines, and other resources | A) information available to guide the PCP in delivering survivorship-related care | PCPs understand a survivor's history, know the survivor's risks, recognize symptoms and problems, understand the care survivors need, are aware of the resources available to help them, and can access relevant care and services. | Survivors live longer and feel better through high-value care. |
| B) PCP shared-care with oncologist | B) support from the oncologist to aid the PCP in delivering survivorship-related care | PCPs understand a survivor's history, know the survivor's risks, recognize symptoms and problems, understand the care survivors need, are aware of the resources available to help them, and can access relevant care and services. | Survivors live longer and feel better through high-value care. |
| C) more experience caring for childhood cancer survivors | C) greater comfort caring for childhood care survivors | PCPs understand a survivor's history, know the survivor's risks, recognize symptoms and problems, understand the care survivors need, are aware of the resources available to help them, and can access relevant care and services. | Survivors live longer and feel better through high-value care. |

PCP = primary care provider

Full Report

Snyder C, Yuan CT, Wilson RF, Smith K, Choi Y, Nathan PC, Zhang A, Robinson KA. Models of Care That Include Primary Care for Adult Survivors of Childhood Cancer: A Realist Review. Evidence Report. (Prepared by the Johns Hopkins University Evidence-based Practice Center under Contract No. 75Q80120D00003.) AHRQ Publication No. 22-EHC003. Rockville, MD: Agency for Healthcare Research and Quality; February 2022.

DOI: [10.23970/AHRQEPREALISTMODELSCARE](https://doi.org/10.23970/AHRQEPREALISTMODELSCARE). Posted final reports are located on the Effective Health Care Program [search page](#).

