Continuity and Coordination of Care for Childhood Cancer Survivors with Multiple Chronic Conditions: Exploratory Cross-Sectional Data from the Childhood Cancer Survivor Study

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Background: Childhood cancer survivors with multiple chronic conditions require care from a variety of providers, but the coordination and continuity of their care is understudied. We explored continuity and coordination of care, and associated characteristics, in Childhood Cancer Survivor Study (CCSS) participants to inform future research and interventions.

Methods: Between April and June 2022, 800 CCSS participants with 2+ chronic conditions (≥1 severe/life-threatening/disabling) were invited to complete the “Patient-Perceived Continuity of Care from Multiple Clinicians” (CC-MC) survey. The CC-MC measures care coordination at 3 levels: main provider, across multiple providers, patient-provider partnership. Summary scores for each of these levels served as independent variables. The CC-MC also includes 6 items to assess discontinuity (how well care is organized, having to organize your own health care, feeling like no one is in charge, feeling abandoned by health care system, going to emergency room for care, physical/mental health suffering because of poorly organized care). For 4 of the 6 items, respondents are asked to specify reason(s) for the discontinuity (see Table). A composite binary outcome of discontinuity (yes/no), defined as reporting poor care on ≥1 of the 6 discontinuity items, served as the dependent variable. Chi-square tests assessed associations between discontinuity and socio-demographics (White non-Hispanic vs. other race/ethnicity; private vs. non-private insurance; age 25-39, 40-49, 50+ years; college graduate or more vs. less than college education; male vs. female). Logistic regression models estimated odds ratios for the risk of discontinuity associated with 10% improvements on the summary scores for the 3 levels of care coordination.

Results: Of the 800 CCSS participants invited, 377 (47%) responded (mean age 48, 67% female, 88% non-Hispanic White, 67% employer-insured, 73% college graduate+). Among respondents, 147 (38%) reported discontinuity. Younger age ($p=0.02$) and less education ($p=0.07$) were related to discontinuity. Common reasons for discontinuity were provider not knowing personal health situation, no one in charge of care, providers not knowing what other providers had done or said, too difficult/long to be seen by specialist, regular provider not being available, and not knowing what to expect or next steps (see Table). Improved scores on the summary measures of coordination at all 3 levels were associated with lower discontinuity risk (OR; 95%CI): main provider (0.58; 0.46-0.73), across multiple providers (0.56; 0.49-0.65), patient-provider partnership (0.71; 0.64-0.79) (all $p<0.0001$).

Conclusion: These findings reveal reasons and risk factors for discontinuity of care. The results will inform future work to investigate and promote continuity and coordination of care among long-term childhood cancer survivors.

Table: Reasons Selected Among Those Who Reported Discontinuity

	Were there times when it felt like no one in the health care system was really in charge of your health care? (N=163)		Were there times during or between health care visits when you felt abandoned by the health care system or left too much to your own resources? (N=133)		Did you go to a hospital emergency room for health care? (N=103)		Were there times when your physical or emotional health suffered because your health care was poorly organized? (N=95)	
Reason	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Because I do not have a regular provider or clinic	29	17.5	19	14.2	7	6.6	13	13.6
Because my regular provider was not available	26	15.7	22	16.6	46	46.2	20	21.1
Because it was too difficult or too long to be seen at my regular clinic	34	20.6	24	18.1	16	15.4	19	20.1
Because it was too difficult or too long to be seen by a specialist or another person I had been referred to	46	29.6	47	35.6	13	14.9	31	32.9
Because the person I saw didn't really know my personal health situation	56	33.8	46	34.7	8	7.5	33	34.9
Because no one seemed to be in charge of my health care	65	39.4	54	40.5	5	4.9	32	33.5
Because the provider didn't seem to know who was in charge of my health care	17	10.3	19	14.4	1	1.1	11	11.7
Because the provider I saw didn't know what others had done or told me	58	34.8	43	32.4	1	1.1	26	27.6
Because I didn't know what to expect about my health condition or the next steps in my care	35	21.2	36	27.2	12	11.8	29	30.8
Because when things went wrong or changed, I could not get answers or advice quickly	25	15.1	24	18.1	15	14.3	26	27.4
Because the providers I saw gave me different information	32	19.4	24	18.1	5	4.9	19	20.1
Because I didn't have the information I needed to cope with my health between appointments	10	6.1	13	10.0	5	4.9	17	18.2