Development of the Functional Social Network Index for Adolescent and Young Adult Cancer Survivors

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Abstract

Background—Social network status in adolescent and young adult (AYA) cancer survivors has not been adequately studied. We developed and validated a functional social network index (FSNI) for AYA survivors, and compared its performance to two traditional indices (density and betweenness centrality).

Methods—102 AYA survivors and 102 age/sex/race-matched non-cancer controls were recruited from an internet panel. Each participant reported relationships with up to 25 of close friends/relatives. We developed a FSNI with reported marital status, contact frequency with friends/relatives, available resources for emotional and tangible support, and available resources for physical activity and weight management advice. Linear regression was used to analyze associations of FSNI with cancer diagnoses, treatments, and coping skills.

Results—Based on the FSNI, survivors had more available resources for emotional support (b=3.02; P=0.003), tangible support (b=4.17; P<0.001), physical activity advice (b=3.94;

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P<0.001), and weight management advice (b=4.10; P<0.001) than non-cancer controls. Lymphoma survivors had the largest FSNI, while CNS malignancy survivors had the smallest (b=2.77, P=0.02). Higher FSNI was associated with better coping skills: less denial (b=0.10, P=0.01), using emotional support (b=0.08, P=0.04), using instrumental support (b=0.12; P<0.001), less behavioral disengagement (b=0.08, P=0.04), venting of emotions (b=0.10, P=0.004), positive reframing (b=0.12, P=0.003), planning for the future (b=0.08, P=0.03), and religious engagement (b=0.16; P<0.001). Density and betweenness centrality indices revealed neither significant difference in social networks between survivors and controls (P's>0.05) nor significant associations with coping skills (P's>0.05).

Conclusions—FSNI appears to provide a better social network assessment for AYA cancer survivors than traditional indices.

Keywords

Adolescents and young adults; childhood cancer; coping skills; functional social network; survivorship

INTRODUCTION

Innovative therapies for pediatric cancers have increased the five-year survival rate from <30% in the 1960's[1] to >80% in the 2010's,[2] yet survivors are vulnerable to treatment-related late effects.[3] Although physical and psychological late effects have been well studied previously,[3–5] less attention has been given to social outcomes.[6] Childhood cancer survivors, particularly those who received central nervous system (CNS)-directed therapies, are less likely to graduate from college, be employed, be married, and live independently.[6, 7] Adolescents and young adults (AYAs) are at a unique stage of human development as they achieve independence from their parents, search for employment, and develop intimate relationships.[8–10] How cancer therapies and medical late effects affect AYA survivors' relationships with friends and their integration into society have not been adequately studied.

In the general population, maintaining good social relationships has been shown to benefit physiological/immunological functions,[11, 12] enhance mental[13, 14] and physical health conditions,[11, 15] and increase longevity.[16, 17] The presence of a social network, defined as the structure/web of social relationships around an individual featured by the type, frequency, and strength of the relationships, is a key component of social participation and integration.[18]

Several methodologies have been developed to measure social networks. Traditional measures (e.g., degree, density, betweenness centrality, closeness centrality, and homophily) focus on the objective degree of social connections among individuals.[19–22] In contrast, the Berkman-Syme Social Network Index (BSSNI) emphasizes social integration based on marital status, frequency of contact with friends/relatives, and membership in church and community organizations.[23] This index has been used to characterize social networks among breast cancer survivors.[24, 25] However, traditional measures and BSSNI may not be appropriate for AYAs because they capture the network structure rather than available resources that are critical for survivorship (e.g., emotional support, weight management

programs, and exercise guidance).[26–28] Developing a functional social network index (FSNI) by adding support-based social connections to facilitate life management for AYA survivors is warranted.

This study aimed to develop and validate a FSNI for AYA cancer survivors, and compare performance of the FSNI to two traditional indices (density and betweenness centrality). We chose betweenness and closeness centrality as comparisons of FSNI because these indices evaluate network status for individual participants, and information derived from these measures provides implications for personalized interventions. We validated the FSNI through analyzing associations of AYA's social network status with a measure of social coping skills for addressing life difficulties. We hypothesized that a higher FSNI would be significantly associated with better coping skills, while this assumption would not apply to the traditional indices. We also aimed to identify risk factors of a poor FSNI in AYA survivors. We hypothesized that survivors of CNS malignancies would have a poorer FSNI than survivors of other cancers (e.g., leukemia, lymphoma, or solid tumors) because compared to survivors of other cancers, CNS malignancy survivors are more likely to develop neurocognitive deficits, which can impact social communication.[6, 7] Additionally, we hypothesized that survivors who received chemotherapy and/or radiotherapy would have a poorer FSNI than those who did not receive these treatments because exposures to cancer therapies are associated with various late effects, which can impact social functioning.[3–5]

METHODS

Study Sample

The study participants included 102 AYA cancer survivors and 102 age/sex/race-matched non-cancer controls who were recruited from a national internet survey panel maintained by Opinions 4 Good (Op4G) (Portsmouth, NH). In this study, Op4G identified a random sample of AYA cancer survivors from the enrollment database, and selected non-cancer controls by matching the distribution of age, sex, and race similar to AYA survivors. Enrollment criteria for survivors included: age between 18 and 30 years at the time of study, diagnosis of cancer between 15 and 30 years of age, five or more years from completion of cancer treatment, and sufficient English literacy to complete surveys. Enrollment criteria for controls included: age between 18 and 30 years at the time of study, no history of cancer, and sufficient English literacy to complete surveys. This study was approved by institutional review board of St. Jude Children's Research Hospital.

Data Collection

Data collection occurred in the spring of 2015. Eligible participants who agreed to take part in this study were asked to complete a self-administered survey via a secure website. Data used in this study for analysis was comprised of socio-demographics, cancer diagnosis/ treatment exposures, social relationships, and coping skills. We utilized the ego-centric approach for collecting social network data. Each participant was asked to identify up to 25 of close friends and/or relatives he/she most frequently contacted within the past two years, and to indicate if any of those friends/relatives knew each other. This design allowed to create the social tie data for up to 5,100 observations from 204 study participants. From each

friend/relative identified, participants were asked to report the type of relationships (e.g., immediate family members, friends at work), type of communication used (e.g., face-to-face, social media), and frequency of contact (e.g., daily, once per week, couple times per month, once per month, couple time per year). Participants were asked to report available resources for emotional support, tangible support, physical activity advice, and weight management advice from each of their friends/relatives.

Measures

Three social network indices were calculated: two traditional indices (density and betweenness centrality) and the FSNI. Density represented the ratio for the existing relationships/connections within a network to all possible relationships/connections.[29] Betweenness centrality represented the ratio for the number of the existing shortest paths between two friends/relatives that pass through the study participants to the shortest possible paths between two friends/relatives.[29]

The FSNI consists of six items (six domains): two items from the BSSNI and four items from this study. Two BSSNI items were marital status and contact frequency for friends/relatives identified by each participant. Four items created by this study were available resources for health support/advice, including emotional support, tangible support, physical activity advice, and weight management advice. An example of support item is: How would you characterize the tangible support (e.g., taking on extra responsibility, lending money, driving you somewhere) you receive from [person listed]?

Marital status was coded as 1 for "married" or "living with a partner as married;" otherwise, coded as 0. Each friend/relative that a participant contacted at least once per month was coded as 1; otherwise, coded as 0. The numbers were summed (maximum score of 25) for each participant, and ranked across all participants. The ranked scores were then divided into tertiles, and each tertile was assigned a score from 1 to 3, with 1 representing the fewest friends/relatives contacted per month and 3 representing the most. Each support/advice item used a 5-point Likert scale (very negative support/advice; somewhat negative support/advice; neutral support/advice; somewhat positive support/advice; and very positive support/advice), with a response to the last two levels coded as 1, and a response to the first three items coded as 0. For each of the four items, the scores for individual friends/relatives of each participant were summed (maximum score of 25), and ranked across all participants. The ranked scores were divided into tertiles, and each tertile was assigned a score from 1 to 3, with 1 representing participants with fewer support/advice resources for that domain, and 3 representing a higher level of support/advice. For each participant, the marital status score, tertile-based contact frequency score, and tertile-based available resources of support/advice score were summed to create the FSNI.

Coping skills were assessed using the Brief COPE[30] which encompasses 14 domains with two items corresponding to each domain. Items were measured using a 4-point Likert scale ("I haven't been doing this at all" to "I have been doing this a lot"). Domain scores were calculated by summing responses for each pair of items, with higher scores for better coping skills. To validate the FSNI, eight domains (denial, use of emotional support, use of instrumental support, behavioral disengagement, venting of emotions, positive reframing,

planning for the future, and religious engagement) hypothesized to be the most relevant to social network status were used.

Statistical Analysis

Chi-square tests were used to examine differences in socio-demographic characteristics between survivors and controls. T-tests were used to examine differences in individual domains of the FSNI between survivors and controls. T-tests were also used to examine differences in individual social network indices (density, betweenness centrality, and FSNI) between survivors and controls (Model 1 in Table 3). Covariates (age at study participation, sex, race/ethnicity, education, etc.) were not included in the comparisons because they were well-balanced between survivors and controls (Table 1). As a sub-analysis, multiple linear regression models were used to compare the difference in individual social network indices associated with the type of cancer diagnoses (Model 2 in Table 3) and the type of therapeutic regimens (Model 3 in Table 3). To validate the FSNI, multiple linear regression models were used to test associations of density, betweenness centrality, and FSNI with each of the eight coping skill domains. In all linear regression analyses, age at study participation, sex, race/ ethnicity, and education background were adjusted to remove confounding effects.

RESULTS

Socio-demographic characteristics

Table 1 presents characteristics of study participants. Similar to controls, the majority of AYA survivors were between 18 and 25 years of age (63%), female (51%), and non-Hispanic white (68%). The distributions of socio-demographic characteristics between two groups were similar (P's>0.05), with the exception of marital status (P=0.046). Among survivors, 41% were diagnosed with a solid tumor, 27% with leukemia, 24% with lymphoma, and 9% with CNS malignancies.

Individual Domains of FSNI between AYA Survivors and Controls

Table 2 presents differences in FSNI for each domain between survivors and controls. Survivors had more available resources from friends/relatives regarding emotional support (P=0.003), tangible support (P<0.001), physical activity advice (P<0.001), and weight management advice (P<0.001) than controls. However, survivors had equivalent contact frequency compared with controls (P=0.21).

Social Network Indices Associated with Socio-Demographic and Clinical Factors

Table 3 presents associations of clinical factors with three individual social network indices, adjusting for socio-demographic factors when appropriate. AYA survivors had higher FSNI scores than controls (P=0.002; Model 1); however, the scores of density and betweenness centrality indices were not significantly different (P=0.80 and P=0.93, respectively) between survivors and controls. A sub-analysis based on survivors suggests that the FSNI scores differed significantly among the four cancer diagnosis groups (Model 2). Compared to CNS malignancy survivors (the reference group), leukemia (P=0.03), lymphoma (P=0.02), and solid tumor (P=0.047) survivors had higher FSNI scores, after adjusting for age at study participation, sex, race/ethnicity, and educational attainment. Survivors treated with

chemotherapy had higher FSNI scores than those who were not (P=0.03; Model 3). In contrast, density and betweenness centrality scores were not different among four diagnosis groups nor among chemotherapy and radiotherapy groups (P's>0.05).

Multivariable Associations of Social Network Indices with Coping Skills

Table 4 presents associations between the three social network indices and coping skills. Results indicating higher FSNI scores were associated with higher coping skills, including less denial (b=0.10, P=0.01), use of emotional support (b=0.08, P=0.037), use of instrumental support (b=0.12, P<0.001), less behavioral disengagement (b=0.08, P=0.04), venting of emotions (b=0.10, P=0.004), positive reframing (b=0.12, P=0.003), planning for the future (b=0.08, P=0.03), and religious engagement (b=0.16; P<0.001). In comparison, scores for density and betweenness centrality indices were not associated with coping skills (P's>0.05).

DISCUSSION

This study developed and validated a new social network measure for AYA cancer survivors. We found that AYA survivors had a significantly larger FSNI than matched controls. Among cancer diagnoses, lymphoma survivors had the highest FSNI, while CNS malignancy survivors had the lowest. Larger FSNI was associated with better coping skills: less denial, use of emotional and instrumental support, less behavioral disengagement, venting, positive reframing, planning for the future, and religious engagement. However, the density and betweenness centrality indices did not distinguish between levels of social network status among survivors and controls, and these two indices were not associated with coping skills. These findings suggest that the FSNI has important utility for characterization of social networks for AYA cancer survivors compared to traditional indices. Our FSNI can be applied to other cancer populations as well (e.g., elderly or adult-onset cancer). Clinicians may use this tool to screen survivors' social connection problems for future interventions.

Although previous studies have reported effects of social networks on health outcomes in survivors of adult-onset cancers,[24, 25, 31, 32] none have evaluated social networks in AYA survivors. Our study is innovative because in contrast to the generic-based Berkman-Syme Social Network Index,[24, 25] the FSNI includes available resources for emotional/tangible support and physical activity/weight management advice. This addition provides useful information to be considered when designing clinical interventions for childhood cancer survivors who have a higher prevalence of psychological distress,[33, 34] physical inactivities,[35, 36] and overweight/obesity[37] than individuals without a cancer history. However, our FSNI did not include the concept of religious participation, which has been used in the Berkman-Syme index, as religious participation has gradually decreased among AYAs in the past 30 years.[38, 39] Instead of measuring religious participation, future studies may include the concept of spiritual supports (e.g., mindfulness) because spirituality affects how people cope with cancer from diagnosis through survival. Optimal spiritual well-being has also shown positive health outcomes.[40]

Adolescent cancer survivors have shown a desire for supportive relationships,[41] typically emotional support from friends,[42] to address unmet needs. The use of FSNI reveals that AYA

survivors had more available resources for emotional support, tangible support, physical health advice, and weight management advice than controls. Our validation analysis confirmed that available resources for support/advice were indeed associated with better coping in life. However, fewer survivors reported being married or living with a partner as married, than controls, which is consistent with findings from previous studies.[6, 7]

Among clinical factors, AYA survivors who received chemotherapy had a significantly higher FSNI than survivors who did not, which indicates the concern about treatment-related late effects among AYA survivors who require more informative support/advice to manage multiple chronic health conditions.[43, 44] As expected, CNS malignancy survivors had a significantly lower FSNI than leukemia, lymphoma, and solid tumor survivors. A possible interpretation is that CNS malignancy survivors experience greater impairment in neurocognitive functioning than non-CNS malignancy survivors and the general population, [45, 46] resulting in poor communication skills and social competency.[47]

AYA cancer survivors are in a transitory stage of independence from parents who have provided protection and support during childhood. Previous studies have reported that AYA survivors were more likely to experience suboptimal psychological functioning (including distress and loneliness) and social well-being compared to controls.[48, 49] Therefore, it is critical to longitudinally assess social network status, especially available supportive resources/advice for AYA survivors, to facilitate evaluating its impact on health outcomes. As a lack of social networks with friends is associated with poor quality of life,[25, 31, 32] risky behavior engagement (e.g., smoking prevalence,[50] obesity[19]), and premature death,[16, 17] collecting information about social relationships in conjunction with clinical data helps clinicians identify health risks for AYA survivors. Although interventions to improve social networks for cancer survivors are emerging,[51] convincing strategies (e.g., a web-based interface) that provide a platform for survivors to interact with each other are available and show promising initial efficacy.[52, 53]

This study has several limitations. First, study participants were recruited from an internet panel, which may bias the sample toward outgoing personality traits. Alternatively, eligible participants might refuse to participate if their social networks were exceedingly small. Second, the study design relies on an egocentric approach that precludes the collection of dynamic relationships between survivors and friends/relatives. Future research is warranted to use sociocentric approaches for investigating bidirectional interactions among members within a network. Third, we did not collect participants' living status and age of their friends/relatives. Some survivors may still live with their parents or interact with peers less frequently due to health strain or perceived isolation. Future studies are encouraged to collect living status and social network characteristics (e.g., age of friend/relatives) to understand the source of supports.

In summary, FSNI is a more appropriate measurement of social network status for AYA cancer survivors than density and betweenness centrality metrics. AYA survivors had significantly larger FSNI than matched non-cancer controls. Among the different cancer diagnoses, CNS malignancy survivors had the smallest functional social networks compared to survivors of other diagnoses. The use of FSNI provides an opportunity to evaluate social

network status and associations with health and behavioral outcomes in AYA cancer survivors.

Acknowledgments

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Table 1

Participant Characteristics

	Cancer survivors (N=102)	Non-cancer controls (N=102)	X^2 (P-value)
Age at study participation			
18–25 years	64 (62.7%)	59 (57.8%)	0.512 (0.47)
26–30 years	38 (37.3%)	43 (42.2%)	
Sex			
Male	50 (49.0%)	52 (51.0%)	0.078 (0.78)
Female	52 (51.0%)	50 (49.0%)	
Race/ethnicity			
White, non-Hispanic	70 (68.3%)	71 (69.6%)	0.304 (0.96)
Black, non-Hispanic	13 (12.8%)	13 (12.8%)	
Hispanic	10 (9.8%)	11 (10.8%)	
Other	9 (8.8%)	7 (6.9%)	
Education			
High school	44 (43.1%)	31 (30.4%)	3.942 (0.14)
College	23 (22.5%)	32 (31.4%)	
Graduate	35 (34.3%)	39 (39.2%)	
Household income			
<$40,000	41 (40.2%)	29 (29.9%)	2.484 (0.29)
$40,000–$79,999	41 (40.2%)	48 (49.5%)	
$80,000	20 (19.6%)	20 (20.6%)	
Employment status			
Full-time	44 (43.1%)	49 (48.0%)	0.494 (0.48)
Not full-time	58 (56.9%)	53 (52.0%)	
Marriage status			
Not married	67 (65.7%)	53 (52.0%)	3.967 (0.046)
Married/living with partner as married	35 (34.3%)	49 (48.0%)	
Age at cancer diagnosis			
15–18 years	31 (30.4%)		
19–26 years	71 (69.6%)		
Cancer diagnosis			
Solid tumor	42 (41.2%)		
Leukemia	27 (26.5%)		
Lymphoma	24 (23.5%)		
CNS malignancy	9 (8.8%)		
Any chemotherapy			
Yes	63 (61.8%)		
No	39 (38.2%)		

	Cancer survivors (N=102)	Non-cancer controls (N=102)	X^2 (P-value)
Any radiotherapy			
Yes	30 (29.4%)		
No	72 (70.6%)		

Table 2

Difference between AYA Survivors and Controls by Individual FSNI Domains[†]

	Contact frequency with relatives and friends (N=204)		Available resources for receiving emotional support (N=204)		Available resources for receiving tangible support (N=204)		Available resources for receiving physical activity advice (N=204)		Available resources for receiving weight management advice (N=204)	
	Mean[‡] (SD)	T-statistic (P-value)	Mean[‡] (SD)	T-statistic (P-value)	Mean[‡] (SD)	T-statistic (P-value)	Mean[‡] (SD)	T-statistic (P-value)	Mean[‡] (SD)	T-statistic (P-value)
Cancer survivors	1.97 (0.84)	−1.246 (0.21)	2.26 (0.82)	3.023 (0.003)	2.23 (0.73)	4.174 (<0.001)	2.25 (0.71)	3.944 (<0.001)	2.18 (0.71)	4.097 (<0.001)
Non-cancer controls	2.118 (0.85)		1.90 (0.84)		1.78 (0.78)		1.82 (0.81)		1.75 (0.79)	

[†]Covariates were not adjusted in the analysis because they were balanced between survivors and controls (see Table 1)

[‡]Values represent tertile-based scores

Table 3

Multivariable Associations of Social Network Indices with Clinical Factors

	Density		Betweenness		FSNI	
	Mean (SD)	T-statistic (P-value)	Mean (SD)	T-statistic (P-value)	Mean (SD)	T-statistic (P-value)
Model 1: For survivors and controls (N=204) [†]						
Survivors	0.42 (0.17)	−0.060 (0.802)	0.50 (0.26)	−0.010 (0.929)	11.22 (2.95)	10.20 (0.002)
Controls	0.43 (0.18)		0.51 (0.27)		9.85 (3.14)	
	Beta	95% CI (P-value)	Beta	95% CI (P-value)	Beta	95% CI (P-value)
Model 2: For survivors by cancer diagnoses (N=102) [†]						
Diagnosis						
CNS malignancy	Ref	Ref	Ref	Ref	Ref	Ref
Leukemia	0.057	−0.073, 0.188 (0.39)	−0.089	−0.295, 0.117 (0.39)	2.542	0.269, 4.815 (0.03)
Lymphoma	0.057	−0.075, 0.190 (0.39)	−0.099	−0.309, 0.111 (0.351)	2.765	0.451, 5.080 (0.020)
Solid tumor	0.030	−0.094, 0.153 (0.63)	−0.052	−0.247, 0.143 (0.60)	2.178	0.025, 4.331 (0.047)
	Beta	95% CI (P-value)	Beta	95% CI (P-value)	Beta	95% CI (P-value)
Model 3: For survivors by therapeutic regimens (N=102) [†]						
Chemotherapy						
Yes	−0.009	−0.079, 0.060 (0.80)	−0.033	−0.143, 0.077 (0.55)	1.362	0.139, 2.585 (0.03)
No	Ref	Ref	Ref	Ref	Ref	Ref
Radiotherapy						
Yes	0.050	−0.022, 0.122 (0.17)	−0.083	−0.196, 0.031 (0.15)	0.493	0.773, 1.759 (0.44)
No	Ref	Ref	Ref	Ref	Ref	Ref

[†] Adjusted for age at study participation, sex, race/ethnicity, and education background in Models 2 and 3, but not in Model 1 as these covariates were balanced between survivors and controls (see Table 1)

Table 4

Multivariable Associations of Social Network Indices with Coping Skills[†],[‡]

	Less denial	Use of emotional supports	Use of instrumental supports	Less behavioral disengagement	Venting of emotions	Positive reframing	Planning for future	Religious engagement
	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)
Density	−0.070 (−1.55, 1.41)	−0.031 (−1.51, 1.45)	−0.389 (−1.80, 1.02)	−0.660 (−2.01, 0.69)	−0.902 (−2.14, 0.33)	0.221 (−1.24, 1.68)	−0.376 (−1.79, 1.04)	−0.139 (−1.80, 1.52)
Betweenness	−0.348 (−1.30, 0.60)	0.056 (−0.90, 1.01)	−0.072 (−0.98, 0.84)	0.258 (−0.62, 1.13)	0.417 (−0.38, 1.22)	−0.516 (−1.46, 0.42)	0.109 (−0.81, 1.02)	−0.489 (−1.56, 0.58)
FSNI	0.101 * (0.02, 0.18)	0.084 * (0.01, 0.16)	0.121 *** (0.05, 0.20)	0.078 * (0.01, 0.15)	0.097 ** (0.03, 0.16)	0.118 ** (0.04, 0.20)	0.084 * (0.01, 0.16)	0.164 *** (0.08, 0.25)

[†] Coefficients represent the results of 24 regression analyses where each analysis included one of the three social network indices as an independent variable and one of the eight coping skill domains as a dependent variable

[‡] Adjusted for age at study participation, sex, race/ethnicity, and education background

*
P<0.05;

**
P<0.01;

***
P<0.001