

Increasing Access to Psychosocial Care for Adolescents and Young Adults with Cancer by
Integrating Targeted Navigation Services
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Running head: Access to Psychosocial Care for Young Adults with Cancer

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1 **Key Points**

- 2 • This study assessed the impact of integrating AYA-specific clinical navigation at a large,
3 urban, adult-focused cancer center.
- 4 • Information about social work encounters was extracted from electronic medical records
5 for the ten months prior to and following integration of an AYA navigator.
- 6 • Compared to pre-integration, the number and proportion of overall and office visit
7 encounters increased post-integration.
- 8 • The AYA Cancer Program increased its reach without increasing burden on oncology
9 social work services.
- 10 • Results suggest that integrating an AYA-specific clinical navigator led to increased
11 access to psychosocial care, and likely improved adherence to NCCN biopsychosocial
12 assessment guidelines, without increasing the burden on oncology social work services.

13 **Introduction**

14 Nearly 90,000 adolescents and young adults (AYA) ages 15-39 are diagnosed with cancer
15 annually in the United States.¹ AYAs face unique psychosocial challenges related to being
16 diagnosed with cancer at a time of great socio-developmental transition.²⁻⁵ In recognition of this,
17 the National Comprehensive Cancer Network (NCCN) released Clinical Practice Guidelines in
18 Oncology specifically for AYAs in 2012,⁶ which recommend that all AYAs with cancer undergo
19 a comprehensive biopsychosocial assessment at diagnosis. Such assessments are related to
20 increased quality of life, decreased symptom burden, improved continuity of care, enhanced
21 communication, and decreased mortality.⁷ Oncology social workers, the primary providers of
22 cancer-related psychosocial services, often complete these assessments.⁸ Unfortunately, many
23 medical centers are under-resourced to meet this NCCN recommendation. Patient navigation is
24 increasingly being used to improve access to psychosocial care for AYAs.⁹ As part of ongoing
25 AYA Cancer Program development, the Robert H. Lurie Comprehensive Cancer Center
26 (RHLCCC) of Northwestern University, a large, urban, adult-focused cancer center, recently
27 integrated an AYA-specific clinical navigator into oncologic care. Among other responsibilities,
28 the AYA navigator proactively identifies newly diagnosed AYAs and completes an initial
29 biopsychosocial assessment. Depending on the results of this assessment, the navigator may
30 check in with the AYA on occasion during and following anti-cancer treatment, provide regular
31 follow-up psychosocial care (e.g., counseling), or refer the AYA for services from another
32 provider (e.g., dietician, psychologist, social worker). Non-English speaking AYAs can meet
33 with the navigator with support from a medical interpreter. To better understand the impact of
34 integrating AYA-specific navigation, we evaluated 1) AYA access to psychosocial care, 2)
35 burden on the social work service, and 3) implied biopsychosocial assessment completion before
36 and after the integration of navigation services.

37
38 **Methods**

39 As part of a quality improvement initiative, we conducted a retrospective electronic medical
40 record (EMR) review for AYAs seen at RHLCCC during the ten months prior to (T1) and
41 following (T2) navigator integration. We identified total social work encounters during this
42 timeframe as a proxy for AYA access to psychosocial care and burden on the social work
43 service. At RHLCCC, all encounters with the AYA navigator and with oncology social workers
44 are categorized as social work encounters, as the navigator is a licensed clinical social worker.
45 Additionally, outpatient office visit encounters were identified as a proxy for biopsychosocial
46 assessment completion, as these assessments are exclusively completed during office visits.
47 Importantly, at the time of analysis the navigator was only seeing AYAs aged 15-30 with
48 sarcoma, brain, or blood cancers. Thus, EMR review was restricted to AYAs who met these
49 criteria. Variables extracted from the EMR included: 1) the number of navigation-eligible AYAs
50 seen at RHLCCC, 2) the number and type (i.e., office visit, inpatient/hospital, documentation
51 only, telephone, patient message, infusion, other) of social work encounters, both per patient and
52 of the total number of encounters, and 3) the number and type of encounters with the AYA
53 navigator, both per patient and of the total number of encounters (post-integration only). Each
54 type of extracted encounter is categorized differently in the EMR, thus enabling us to distinguish
55 encounter types in analyses, and encounters were classified as having occurred with the AYA
56 navigator or an oncology social worker by identifying the name of the provider who completed
57 the encounter. All oncology social worker encounters were grouped for analysis. We used

58 descriptive statistics, t -tests, and χ^2 tests to compare the frequency and nature of social work
59 encounters before and after integration of AYA navigation.

61 **Results**

62 Of those eligible for navigation, 280 unique AYAs were seen at T1 and 298 were seen at T2.
63 Table 1 shows sample characteristics and Supplemental Table 1 summarizes key study results.
64 There were no statistically significant differences in sample characteristics between T1 and T2.

66 **Access to psychosocial care.** A larger proportion of navigation-eligible AYAs had any social
67 work encounter at T2 (47%, $n=139$) compared to T1 (33%, $n=93$; $\chi^2(1)=10.8$, $p<0.001$).
68 Additionally, the average number of social work encounters per patient increased from T1 to T2
69 (mean[M]=2.6, standard deviation[SD]=6.6 vs. $M=4.4$, $SD=8.3$, $t(576)=2.82$, $p=0.005$).

71 When considering just office visits per patient, 59 AYAs had an encounter with an oncology
72 social worker at T1. This decreased to 50 AYAs at T2. However, an additional 23 were served
73 by the navigator at T2, reaching a total of 73 AYAs and demonstrating increased access to care.

75 Additionally, of all encounters at T1, 10% ($n=76$) were office visits and 61% ($n=444$) were
76 inpatient/hospital encounters, which largely consist of discharge planning and acute case
77 management. At T2, the percentage of encounters that were office visits increased to 25%
78 ($n=328$) while only 38% ($n=496$) were inpatient/hospital.

80 **Implied completion of biopsychosocial assessments.** Of those who had at least one social work
81 encounter, a larger proportion had at least one office visit at T2 (64%, $n=89$) compared to T1
82 (46%, $n=43$; $\chi^2(3)=25.5$, $p<0.001$). Of the 89 AYAs with at least one office visit at T2, three-
83 quarters (75%, $n=67$) had a visit with the AYA navigator, who was specifically tasked with
84 completing biopsychosocial assessments at each AYA's initial office visit. The navigator was the
85 only social worker with whom 51 of these 67 AYAs (76%) had an office visit.

87 **Burden on the social work service.** The AYA navigator documented 571 total encounters at T2.
88 Comparatively, the three outpatient oncology social workers who saw navigation-eligible AYAs
89 documented a combined total of 155 encounters at T1 and 186 at T2. When considering just
90 office visits, the AYA navigator had 259 office visits at T2 while the three outpatient oncology
91 social workers who saw navigation-eligible AYAs had a combined total of 57 office visits at T1
92 and 48 at T2.

94 **Discussion**

95 We conducted a retrospective EMR review to evaluate the impact of integrating an AYA-
96 specific clinical navigator into oncologic services. We observed significant increases in the
97 proportion of AYAs who received psychosocial services, the number of encounters per patient,
98 the number of patients completing office visits, and the proportion of encounters that were office
99 visits as opposed to inpatient/hospital encounters. Thus, integrating an AYA navigator appears to
100 have increased patient access to psychosocial care, consistent with other recent work exploring
101 resource-limited settings.¹⁰

103 Oncology social workers provide expertise addressing the variable presentations typically

104 observed in a large, urban, comprehensive cancer center where the ratio of patient to providers is
105 quite large. This includes, but is not limited to, broad services such as discharge planning and
106 case management, serving adults of all ages. Conversely, the AYA navigator is specifically
107 trained to provide focused, comprehensive assessment, psychosocial care, and triage tailored to
108 meet the unique needs of AYAs. Thus, it stands to reason that integrating navigation not only
109 increased access to psychosocial care, but also depth of psychosocial care by proactively
110 providing these specialized services.

111
112 The observed increase in the number of AYAs completing office visits implied increased
113 completion of biopsychosocial assessments. Importantly, this increase was not proportional to
114 the typical per-provider load for the outpatient oncology social workers. Thus, this was likely not
115 a reflection of having added another provider, but rather of the targeted effects of AYA
116 navigation. In addition to improved adherence to national guidelines, such an increase in
117 biopsychosocial assessment suggests that a larger proportion of AYAs experiencing elevated
118 distress and other symptoms (e.g., depression, anxiety, pain, cognitive impairment) can be
119 identified and referred for treatment expeditiously. This in turn could improve self-management
120 of cancer-related symptoms and treatment side effects, as well as promote adherence to medical
121 recommendations. Future work would benefit from directly evaluating completion of
122 biopsychosocial assessments, identifying referrals for supportive care, and measuring patient-
123 reported symptom monitoring outcomes following integration of AYA navigation.

124
125 Importantly, integration of AYA navigation facilitated improved access to and depth of care for
126 patients without increasing burden on the oncology social work service. There was a more than
127 three-fold increase in overall encounters and a four-fold increase in outpatient office visits
128 following integration; however, the encounters and office visits completed by oncology social
129 workers remained relatively stable. Given that AYA navigation is intended to augment, not
130 replace, services provided by oncology social workers, this stability is not surprising. Moreover,
131 in addition to the aforementioned responsibilities, the AYA navigator provides a range of AYA-
132 targeted services including leading multiple support group and orchestrating peer meet ups and
133 AYA-specific events. Thus, the AYA Cancer Program increased its reach and breadth of services
134 provided without increasing burden on the oncology social work service.

135
136 Generalizability of results may be limited by the urban nature of the cancer center where this
137 work was conducted. Nonetheless, these data demonstrate that integrating an AYA-specific
138 clinical navigator led to increased access to and depth of psychosocial care, and likely improved
139 adherence to NCCN biopsychosocial assessment guidelines, without increasing burden on the
140 oncology social work service. Although AYA navigation at RHLCCC is currently provided by a
141 social worker, this role could be fulfilled by another allied health professional with appropriate
142 psychosocial training (e.g., psychologist, nurse). Next steps for our program are to expand
143 navigation eligibility to patients up to age 39 and with a broader range of cancer diagnoses, and
144 to pursue support for additional dedicated AYA cancer program clinical staff. Future work would
145 benefit from a health economic evaluation of the cost of integrating an AYA-specific navigator
146 relative to the benefits observed for clinical care. Our hope is that this work will continue to
147 improve access to psychosocial care for the underrepresented, underserved, and growing
148 population of AYAs with cancer.

149 **Table 1.** Sample characteristics

Variable	Pre-Integration	Post-Integration	Statistic
Age			$\chi^2=1.88, p = 0.37$
15–19 years	15 (5%)	20 (7%)	
20–24 years	72 (26%)	89 (30%)	
25–30 years	193 (69%)	189 (63%)	
Sex			$\chi^2=0.02, p = 0.88$
Male	142 (51%)	153 (51%)	
Female	138 (49%)	145 (49%)	
Relationship status			$\chi^2=2.30, p = 0.32$
Married	51 (18%)	47 (16%)	
Single	216 (77%)	229 (77%)	
Other or unknown	13 (5%)	22 (7%)	
Race			$\chi^2=3.98, p = 0.41$
White	204 (73%)	218 (73%)	
Black/African American	27 (10%)	18 (6%)	
Asian	11 (4%)	15 (5%)	
Other	20 (7%)	29 (10%)	
Declined	18 (6%)	18 (6%)	
Ethnicity			$\chi^2=0.10, p = 0.95$
Hispanic/Latinx	35 (12%)	35 (12%)	
Not Hispanic/Latinx	229 (82%)	245 (82%)	
Declined	16 (6%)	18 (6%)	
Language			$\chi^2=0.29, p = 0.87$
English	269 (96%)	288 (96%)	
Spanish	8 (3%)	8 (3%)	
Other	3 (1%)	2 (1%)	
Primary cancer diagnosis			$\chi^2=0.13, p = 0.99$
Brain/central nervous system	73 (26%)	79 (26%)	
Sarcoma	48 (17%)	51 (17%)	
Leukemia	53 (19%)	59 (20%)	
Lymphoma	106 (38%)	109 (37%)	

150

Supplemental Table 1. Social work encounters before and after integrating AYA navigation

	Pre-integration (<i>N</i> = 280 eligible AYAs)		Post-integration (<i>N</i> = 298 eligible AYAs)	
	<i>n</i> possible	<i>n</i> (%) observed	<i>n</i> possible	<i>n</i> (%) observed
Access to Psychosocial Care				
AYAs with any social work encounter	280	93 (33%)	298	139 (47%)
AYAs with 1+ social work encounter whose only encounters were with the navigator	--	--	139	54 (39%)
Social work encounters that were office visits	726	76 (10%)	1298	328 (25%)
Implied biopsychosocial assessments completed				
AYAs with 1+ social work encounter who had 1+ office visit	93	43 (46%)	139	89 (64%)
AYAs with 1+ office visit who were served by the navigator only	--	--	89	51(57%)
Navigator encounters that were office visits	--	--	571	259 (45%)
Burden on the social work service				
Oncology social work encounters that were office visits	155	57 (37%)	186	48 (26%)

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