Promoting the Shared-Care Model for Adolescent and Young Adults With Cancer: Optimizing Referrals and Care Coordination With Primary Care Providers

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Abstract

Background: The “shared-care model” for patients with cancer involves care coordination between primary care providers (PCPs) and oncologists, with the goal of optimizing survivorship care. However, a high proportion of adolescent and young adult (AYA) cancer survivors do not have a PCP. Study objectives were to increase the percentage of AYAs with a PCP documented in the electronic medical record (EMR) via the use of a best practice advisory (BPA) or “stopgap” intervention; to increase communication between providers by the number of routed clinic notes; and to assess oncology providers’ attitudes/beliefs about the model and intervention. Methods: Data were collected for the 6 months before implementation of the BPA to determine the percentage of AYAs with a PCP and the number of notes routed to providers (time point 1 [T1]). The same data were collected at time point 2 (T2) after the BPA had been implemented for 6 months. Oncology providers participated in an education video module and an online survey at T1 and a survey at T2. Results: At T1, 47.1% of 756 AYAs had a documented PCP in the EMR. At T2, the percentage increased to 55.1% (P < .002). The number of routed notes did not change significantly from T1 to T2. Providers that completed the intervention survey agreed/strongly agreed that the shared-care model is a desirable model of care (T1 = 86%; T2 = 93%) and that a BPA is useful for facilitating PCP referrals (T1 = 76%; T2 = 39%). Conclusions: This BPA is feasible for increasing the percentage of AYAs with a PCP documented in the EMR and could potentially lead to increased PCP referral and communication among providers for the benefit of long-term survivorship care. Providers generally agree with the shared-care model; however, the BPA implementation requires modification.


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Submitted May 23, 2016; accepted for publication September 22, 2016.

The authors have disclosed that they have no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors.


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Background

Each year, approximately 70,000 people ages 15 to 39 are diagnosed with cancer. This patient population is termed “adolescent and young adult,” or AYA, and has been the focus of an evolving field of study for the last 10 to 13 years. In 2005, Dr. Archie Bleyer, a leader in the AYA movement, composed a monograph titled “The Adolescent and Young Adult Gap in Cancer Care and Outcome,” which highlighted the lack of relative improvement in 5-year survival rates in AYAs since 1986 compared with children or older adults. Despite the concerns about static 5-year survival rates, many AYA patients survive their disease, but perhaps at a cost to their health and quality of life. Close to 73% of pediatric, adolescent, and young adult survivors of childhood cancer develop chronic health conditions at...
30 years after cancer diagnosis, and 42% will develop severe, life-threatening, or disabling medical conditions. Recent studies have shown an increase in severe and disabling conditions as survivors of childhood, adolescent, and young adult cancer age into the fourth and fifth decades of their lives. With this in mind, “risk-based” medical care is essential for all cancer survivors, and especially for the AYAs with the potential to live many more decades postdiagnosis. This level of medical care includes an understanding of the cancer diagnosis, treatment history, and potential or actual late effects of therapy by the patient, primary care providers (PCPs), and oncology providers. The types of providers involved in this follow-up care and models of care delivery are issues being discussed in the literature and medical centers worldwide.

NCCN recently published the NCCN Clinical Practice Guidelines in Oncology for AYAs to help address specific needs of the AYA cancer population, make recommendations for interventions for care, educate providers regarding special considerations, and assist with patient management. The guidelines state that AYA patients should be managed by a multidisciplinary team of healthcare professionals well-versed in psychological and medical issues pertaining to this patient population.

The shared-care model refers to patient care shared by ≥2 clinical providers of different specialties (Figure 1). This model has demonstrated improved outcomes in patients with chronic illnesses, such as diabetes mellitus and chronic renal disease. Although this model for cancer survivor care needs to be studied further for key outcomes, it includes points of personal communication and a periodic transfer of knowledge and information between the specialist and PCP during and after cancer treatment. PCPs and advanced practice providers (APPs; ie, nurse practitioners and physician assistants) play an important role in cancer survivor care. Their comfort and expertise with this growing population of patients will be increasingly important as the number of medical oncologists decreases in the next decade due to an aging workforce, and as the population of survivors grows.

This study was developed in an effort to better serve a growing number of AYA survivors at all stages of their cancer journey. We aimed to proactively encourage care coordination among providers using the framework of the shared-care model. Study objectives were to promote this model by (1) increasing the percentage of AYA survivors with a PCP documented in the electronic medical record (EMR) via the use of a best practice advisory (BPA) or “stopgap” intervention; (2) increase communication between providers by the number of routed clinic notes; and (3) assess oncology providers’ attitudes/beliefs about the shared-care model and BPA intervention.

The use of BPAs in clinical practice is becoming more common. There is limited literature on the efficacy of BPAs in changing clinical outcomes and most literature to date is descriptive. EMRs are being used for prescribing medications using clinical decision supports. Other examples include use of BPAs to alert practitioners to order vaccines, refer for obesity counseling, screen for falls, and to streamline orders for public health outbreaks. To our knowledge, this study is the first to use a BPA for referral to
PCPs while also examining change in outcomes (eg, documented PCP) and BPA user satisfaction.

**Methods**

**Procedures**

**Patient Data:** Data for this study were collected from an NCI-Designated Comprehensive Cancer Center housed within a large tertiary care medical center. Patient data were obtained using Northwestern University's Enterprise Data Warehouse after the study received Institutional Review Board approval. Data were extracted for patients aged 18 to 39 years who completed an outpatient visit within the cancer center over two 6-month time periods (time point 1 [T1] = August 16, 2014 to February 15, 2015; time point 2 [T2] = February 16, 2015 to August 15, 2015). Patients with a cancer diagnosis, defined by ICD-9 diagnosis codes 140–239 (eliminating 210–229, benign neoplasm), and seen in medical, gynecologic, and neuro-oncology at the cancer center were included in the analysis. AYAs from the entire cancer care continuum were examined, including those who were newly diagnosed, currently on treatment, or being seen for routine follow-up posttreatment. For patients who had multiple visits during that period, only the last encounter was counted. The following data points were extracted at each time point: patient demographics, insurance, diagnosis, PCP status (ie, on file or not), number of letters and clinic notes sent by oncology providers (oncologists and APPs) to other providers, and number of AYAs that made new patient appointments in primary care at our institution.

**BPA Intervention:** The BPA or “stopgap” alert consists of a question that must be addressed during an encounter before the encounter can be closed in the EMR. All providers (ie, PCPs and specialists) in our outpatient tertiary care medical center use EPIC as their EMR. One of the main objectives of this project was to assess the feasibility of using a BPA as a means to a more complete and accurate PCP documentation in the EMR, and also referral to PCP practices either within our general medicine network or a provider of patient’s choice. The BPA “Does the patient have a primary care provider?” was designed to prompt the oncology provider to encourage an outpatient clinic appointment while in the patient’s EMR (Figure 2). For purposes of this study, the BPA was designed to fire no more than every 24 hours for patients aged 18 to 39 years, and only if the patient did not have a PCP listed in their EMR. The BPA included 4 options for providers to choose from to address the question. If the providers chose “NO (the patient does not have a PCP),” they were instructed to discuss the importance of shared care between the oncologist and PCP for all patients, and then continue with the referral process through an EPIC SmartSet. A SmartSet was developed as an option for providers to click on and electronically sign, which then opens a list of all of our institutions’ primary care practices. This list prints on the patient’s after-visit summary and is provided to patients during the checkout process after their oncology appointment. This BPA intervention was implemented after patient data were collected at T1, and ran for 6 months, at which time patient data were pulled for T2.

**Provider Survey:** Oncology providers (medical oncologists, gynecologic oncologists, neuro-oncologists, and APPs) at our cancer center were invited to participate in the study by completing a 28-item online survey. The T1 survey was administered 2 weeks before implementation of the BPA into practice and assessed provider demographics, such as age, sex, and years in practice. Five-point Likert scales assessed providers’ knowledge of and attitudes toward the shared-care model and the perceived usefulness of stopgap questions in practice.

The T1 survey included watching a 10-minute video education module developed by the primary investigator. The module was developed to educate providers on issues in AYA cancer nationally, lack of assigned PCPs at our institution, details of the shared-care model, BPA intervention, and goal of improving care coordination for AYA survivors. At T1, a select set of questions were asked before and after the video education module to assess for change in responses. The survey data was blinded to protect participant’s privacy and was collected using REDCap (Research Electronic Data Capture). Six months after administration of the T1 survey, a 13-item survey of similar questions (T2) was administered to providers who completed the T1 survey to assess for change 6 months after using the BPA in clinical practice. Provider type (oncologist vs APP) was the only demographic variable attained at T2 in an effort to keep the survey length at a minimum and
to minimize participant burden (see supplemental eAppendix 1 for T1 and T2 survey questions, available with this article at JNCCN.org).

**Statistical Analysis**
Continuous variables were compared between time points using the Kruskal-Wallis test, and Fisher's exact test and Chi-Square analysis were used to compare categorical variables. For patients seen at both time points, listing of a PCP was compared between times using McNemar's test.

**Results**

**Patient Data**
Patient data at T1 included 2,354 outpatient visits with a total of 756 unique AYA patients. T2 included 3,236 outpatient visits and 800 unique AYA patients. T1 and T2 patients were not significantly different with regard to age (mean, 32.3 years [SD, 5.1] vs mean, 32.5 years [SD, 5.1]; \( P=0.44 \)), sex (61.3% vs 62.5% female; \( P=0.64 \)), ethnicity (77.0% vs 75.7% non-Hispanic/Latino; \( P=0.32 \)), or diagnosis (\( P=0.41 \)).

At T1, 47.1% of patients had a PCP listed in their EMR, 42.5% did not, and 10.4% had an oncologist listed as their PCP. Within the T2 cohort, 55.1% had a PCP listed in their EMR, 30.5% did not, and 14.4% had an oncologist listed as their PCP. After 6 months of BPA implementation, Fisher's exact test found the percentage of patients with a PCP listed to have increased significantly (T1=47.1% vs T2=55.1%; \( P=0.002 \)), whereas those without a PCP decreased (T1=42.5% vs T2=30.5%; \( P<.001 \)). There was also an increase in those having an oncologist listed as their PCP (T1=10.4% vs T2=14.4%; \( P=0.02 \)). A secondary analysis was completed for 498 patients who had appointments in both time periods. Of those, 48.0% had a PCP in T1 and 54.6% had a PCP in T2 (\( P<.001 \)).

**Provider Communication and BPA Utilization:**
The number of letters and copied clinic notes sent by oncology providers to other providers showed modest improvement from T1 (1,484 of 2,354 total encounters; 63%) to T2 (2,102 of 3,236 total encounters; 65%), and was not statistically significant (\( P=0.14 \)). The BPA fired a total of 890 times during the 6 months of intervention.

**Provider Survey**
Table 1 demonstrates the provider breakdown and survey participation rates. Demographic information was attained during the T1 survey and the providers named their primary oncology specialty by diagnostic category (eg, brain, breast, leukemia), with a breadth of diagnostic specialties being captured and many listing >1 specialty. Most providers were aged <40 years (75.6%), female (76.7%), of white race (88.4%), and had <5 years in practice (64.3%). An additional 9.5% had 21 to 30 years in practice, and 4.8% had >30 years in practice.

**Video Module and Provider Knowledge:** Provider knowledge of the shared-care model increased from a mean of 1.81 (SD, 0.93) to 3.21 (SD, 0.94; \( P<.001 \)) on a 5-point Likert scale after administration of the video education module at T1. T2 data with a mean of 3.07 (SD, 0.85; \( P=.70 \)) indicate that this knowledge was retained over the 6-month period. Additionally, participants of the T1 survey were asked about the impact of the video education module on their knowledge and on future patient care. Most of the

**Table 1. Provider Survey Participation**

<table>
<thead>
<tr>
<th>Position</th>
<th>Number Invited at Time 1</th>
<th>Number Completed at Time 1</th>
<th>Number Invited at Time 2</th>
<th>Number Completed at Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oncologist</td>
<td>27</td>
<td>14 (51.9%)</td>
<td>14</td>
<td>9 (64.3%)</td>
</tr>
<tr>
<td>APP</td>
<td>34</td>
<td>29 (85.3%)</td>
<td>29</td>
<td>19 (65.6%)</td>
</tr>
<tr>
<td>All providers</td>
<td>61</td>
<td>43 (70.5%)</td>
<td>43</td>
<td>28 (65.1%)</td>
</tr>
</tbody>
</table>

Abbreviation: APP, advanced practice provider.
participants (79.1%) stated they obtained new information (knowledge) as a result of completing the module; 67% of the participants said the module will change the way they practice and made comments such as “100% communication with PCP (sending all notes to the PCP) and referring all patients to a PCP” and “Ensuring bridge between specialty and PCP.”

**Attitudes Regarding Shared-Care Model and BPA:** A summary of provider survey results can be found in Table 2. Providers generally agreed that the shared-care model is a desirable model of care. Because communication between providers is an important component of this model, providers were asked how routinely they send clinic notes to their patient’s PCP, with 42.8% to 48.8% reporting they often or always send clinic notes after every oncology encounter. Interestingly, most providers (82.1%–86.1%) reported that they never or rarely receive a summary of the patient’s past “noncancer” medical care history from the patient’s PCP. There were no significant differences across time points on these items. However, providers’ attitudes regarding the usefulness of the BPA showed a significant decrease from T1 to T2.

### Table 2. Provider Survey Results

<table>
<thead>
<tr>
<th>Question/Scale</th>
<th>Time Point 1 (N=43) Agree or Strongly Agree</th>
<th>Time Point 2 (N=28) Agree or Strongly Agree</th>
<th>P Value (Fisher Exact Test)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stopgap questions (ie, questions within an EMR encounter that must be addressed in order to close the encounter) are useful approaches to ensure entry of important data into the electric medical record</td>
<td>74.4%</td>
<td>46.4%</td>
<td>.024</td>
</tr>
<tr>
<td>A stopgap question is a useful way to assist me in referring patients to a PCP if they do not already have one listed in their EMR</td>
<td>76.2%</td>
<td>39.3%</td>
<td>.0025</td>
</tr>
<tr>
<td>Implementation of a stopgap question to assist me in referring patients to PCPs has the potential to decrease the amount of time I spend meeting the patient’s primary care needs</td>
<td>60.4%</td>
<td>35.7%</td>
<td>.054</td>
</tr>
<tr>
<td>A desirable model of patient care is one in which a cancer patient receives consistent care from both a medical oncologist and a PCP</td>
<td>86.1%</td>
<td>92.9%</td>
<td>.47</td>
</tr>
<tr>
<td>When a patient has completed active treatment, PCPs have the skills to provide follow-up care related to the effects of cancer or its treatment</td>
<td>51.2%</td>
<td>46.4%</td>
<td>.81</td>
</tr>
<tr>
<td>How often do you receive a summary of the patient’s past “noncancer” medical care history from the patient’s PCP?</td>
<td>86.1% of the time</td>
<td>82.1% of the time</td>
<td>.74</td>
</tr>
<tr>
<td>Thinking of how you deliver cancer-related follow-up care for survivors, how often do you experience difficulties transferring patient care responsibilities between you and the PCP?</td>
<td>27.9% of the time</td>
<td>21.4% of the time</td>
<td>.59</td>
</tr>
</tbody>
</table>

**Discussion**

This study is the first to use a BPA in cancer care to facilitate referrals to PCPs. Our primary objective was to assess the feasibility of implementing a BPA to increase documentation of PCPs in the EMR and initiate referrals to PCPs for AYAs with cancer. Although it is premature to draw definitive conclusions about the efficacy of this BPA intervention, our data yield promising findings and are supportive of this intervention, because we were successful at implementing the BPA and results show an 8% increase in patients with a PCP listed in T2 compared with T1. This increase in PCP listing was verified to be 6.6% in a matched analysis of patients seen at both time points. An unexpected finding for the research team was the high percentage of patients with an oncologist listed as their PCP (10.4%) even before the option was given to them when using the BPA. For some patients (eg, those with advanced-stage disease), having an oncologist listed as the PCP may be most appropriate. However, further discussions about incorrect PCP documentation at our institution suggests we may also be able to improve by
educating our cancer center intake coordinators and patient service representatives regarding the role of a PCP versus an oncologist and how to properly document each in the medical record.

There is limited literature on the effectiveness of BPAs in clinical practice. One study looking at the associations between healthcare quality and the use of EMR functions in ambulatory care showed that intensive use of one EMR function was associated with increased adherence to recommended care as measured by the electronically reported “meaningful use” quality measures.25 Additionally, a number of studies suggest that the use of EMRs can be associated with quality improvement, which includes drug safety and administration, chronic illness management, and an improvement in ambulatory care preventive services.26–29 Other literature on the use of BPAs highlights “alert fatigue,” which occurs when providers are inundated with too many BPAs and ignore them or work around them.30,31 There was evidence of alert fatigue in our study based on the providers’ significant decrease in perceived usefulness of the BPA from T1 to T2, despite the observed increase in PCP documentation in the EMR. After analyzing the data, in an effort to reduce alert fatigue, we changed the frequency in which the BPA was set to fire from every 24 hours to no more than every 7 days.

Limitations of the study include using a convenience sample from one institution, so the data may not be generalizable to other settings. There was also a possible response bias at each time point. Lastly, there are a number of BPAs currently in use at our institution, some of which were implemented near the same time as our BPA, which may have led to alert fatigue and affected the responses of the participants. Future directions for examining the data could include assessing provider characteristics and patient disease classification that predict BPA use and PCP referral.

Conclusions
The importance of collaboration between oncology and primary care is commonly cited in the literature, recognized by large organizations such as ASCO, and often discussed in our clinical settings.32–36 According to Kovner and Knickman,37 the future of healthcare delivery in the United States will include putting more resources into primary care, public health, and prevention. This aligns nicely with the risk-based follow-up care that AYA cancer survivors need from practitioners in the community and cancer center settings.8,15 In many large organizations, such as major cancer centers, there are challenges in developing infrastructures to support quality improvement initiatives that can be analyzed and disseminated in a timely manner. However, EMRs will continue to be implemented widely, which can drive improvements in quality of care. According to a report from the Institute of Medicine, the increased use of EMRs and other digital tools has enhanced the ability to collect data routinely and also provides a means for pertinent results to be fed back into clinical practice quickly and efficiently.38 The statistically significant increase in PCP documentation after implementation of the BPA demonstrates that this project was feasible, showed preliminary effectiveness, and has potential for continued use in our cancer center for AYA and older patients. This study, which uses the patient’s EMR to promote shared-care for cancer survivors across the care continuum, is in line with the current culture of medical and nursing care in the United States, and these methods have potential to be implemented in cancer centers around the globe that use EMRs.38

References


