Transition Readiness Assessment for Sickle Cell Patients: A Quality Improvement Project

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This article is the fourth in our Hemoglobinopathy Learning Collaborative series. See the related editorial by Oyeku et al in the February 2014 issue of JCOM. (—Ed.)

ABSTRACT

• **Objective:** To describe the use of quality improvement (QI) methodology to implement an assessment tool to evaluate transition readiness in youth with sickle cell disease (SCD).

• **Methods:** Plan-Do-Study-Act (PDSA) cycles were run to evaluate the feasibility and effectiveness of a provider-based transition readiness assessment.

• **Results:** Seventy-two adolescents aged 17 years (53% male) were assessed for transition readiness from August 2011 to June 2013. Results indicated that it is feasible for a provider transition readiness assessment (PTRA) tool to be integrated into a transition program. The newly created PTRA tool can inform the level of preparedness of adolescents with SCD during planning for adult transition.

• **Conclusion:** The PTRA tool may be helpful for planning and preparation of youth with SCD to successfully transition to adult care.

Sickle cell disease (SCD) is one of the most common genetic disorders in the world and is caused by a mutation producing the abnormal sickle hemoglobin. Patients with SCD are living longer and transitioning from pediatric to adult providers. However, the transition years are associated with high mortality [1–4], risk for increased utilization of emergency care, and underutilization of care maintenance visits [5,6]. Successful transition from pediatric care to adult care is critical in ensuring care continuity and optimal health [7]. Barriers to successful transition include lack of preparation for transition [8,9]. To address this limitation, transition programs have been created to help foster transition preparation and readiness.

Often, chronological age determines when SCD programs transfer patients to adult care; however, age is an inadequate measure of readiness. To determine the appropriate time for transition and to individualize the subsequent preparation and planning prior to transfer, an assessment of transition readiness is needed. A number of checklists exist in the unpublished literature (eg, on institution and program websites), and a few empirically tested transition readiness measures have been developed through literature review, semi-structured interviews, and pilot testing in patient samples [10–13]. The Transition Readiness Assessment Questionnaire (TRAQ) and TRxANSITION scale are non-disease-specific measures that assess self-management and advocacy skills of youth with special health care needs; the TRAQ is self-report whereas the TRxANSITION scale is provider-administered [10,11]. Disease-specific measures have been developed for pediatric kidney transplant recipients [12] and adolescents with cystic fibrosis [13]. Studies using these measures suggest that transition readiness is associated with age, gender, disease type, increased adolescent responsibility/decreased parental involvement, and adherence [10–12].

For patients with SCD, there is no well-validated measure available to assess transition readiness [14]. Telfair and colleagues developed a sickle cell transfer questionnaire that focused on transition concerns and feelings and suggestions for transition intervention programming from the perspective of adolescents, their primary caregivers, and adults with SCD [15]. In addition, McPherson and colleagues examined SCD transition readiness in 4 areas: prior thought about transition, knowledge...
about steps to transition, interest in learning more about the transition process, and perceived importance of continuing care with a hematologist as an adult provider. They found that adolescents in general were not prepared for transition but that readiness improved with age. Overall, most readiness measures have involved patient self-report or parent proxy report. No current readiness assessment scales incorporate the provider’s assessment, which could help better define the most appropriate next steps in education and preparation for the upcoming transfer to adult care.

The St. Jude Children’s Research Hospital SCD Transition to Adult Care program was started in 2007 and is a companion program to the SCD teen clinic, serving 250 adolescents aged 12 to 18 years. The transition program curriculum addresses all aspects of the transition process. Based on the curriculum components, St. Jude developed and implemented a transition readiness assessment tool to be completed by providers in the SCD transition program. In this article, we describe our use of quality improvement (QI) methodology to evaluate the utility and impact of the newly created SCD transition readiness assessment tool.

METHODS

Transition Program

The transition program is directed by a multidisciplinary team; disciplines represented on the team are medical (hematologist, genetic educator, physician assistant, and nurse coordinators), psychosocial (social workers), emotional/cognitive (psychologists), and academic (academic coordinator). In the program, adolescents with SCD and their families are introduced to the concept of transition to adult care at the age of 12. Every 6 months from 12 to 18 years of age, members of the team address relevant topics with patients to increase patients’ disease knowledge and improve their disease self-management skills. Some of the program components include training in completing a personal health record (PHR), genetic education, academic planning, and independent living skills.

Needs Assessment

Prior to initiation of the project, members of the transition program met monthly to informally discuss the progress of patients who were approaching the age of transition to adult care. We found that adolescents did not appear to be ready or well prepared for transition, including not being aware of the various familial and psychosocial issues that needed to be addressed prior to the transfer to adult care. We realized that these discussions needed to occur earlier to allow more time for preparation and transition planning of the patient, family, and medical team. In addition, members of the team each has differing perspectives and did not have the same information with regard to existing familial and psychosocial issues. The discussions were necessary to ensure all team members had pertinent information to make informed decisions about the patient’s level of transition readiness. Finally, our criteria for readiness were not standardized or quantifiable. As a result, each patient discussion was lengthy, not structured, and not very informative. In 2011, a core group from the transition team attended a Health Resources Services Administration–sponsored Hemoglobinopathies Quality Improvement Workshop to receive training in QI processes. We decided to create a formal, quantitative, individualized assessment of patients’ progress toward transition at age 17.

Readiness Assessment Tool

The assessment is divided into 4 domains based on the disciplines represented on the team: medical, psychosocial, emotional/cognitive, and academic (Table). Each discipline developed transition readiness items based on the transition curriculum content. The pediatric hematologist, midlevel provider (physician assistant), and nurse case managers developed the medical domain checklist to assess disease literacy, self-management, organ and dysfunction screening. The psychosocial domain checklist was developed by the social workers to assess patients’ understanding of information related to independent living and adult rights (eg, advance directives), emotional concerns related to transition, self-advocacy skills, and completion of a personal health record, a document designed to assist adolescents in learning about their medical history.

The emotional/cognitive domain checklist was developed by the pediatric psychologist and pediatric neuropsychologist. Because the psychology service is set up to see patients referred by the medical team and is unable to see all patients coming to hematology clinic, the emotional/cognitive checklist is based on identifying previous utilization of psychological services including psychotherapy and cognitive testing and determining whether initiation of services is warranted. The academic domain checklist was developed by the academic coordinator who serves as a liaison between the medical team and the school system. This checklist assesses whether the adolescent is meeting high school graduation require-
ments, able to verbalize an educational/job training plan, on track with future planning (eg, completed required testing), knowledgeable about community educational services, and able to self-advocate (eg, apply for SSI benefits).

Items within each domain have equal value (ie, each question on the checklist is worth 1 point) and the sum of points yields the quantifiable assessment of how well patients are performing in each area of their health. Assessment meetings occur monthly when eligible patients are discussed. Domains are evaluated by the health care provider responsible for his/her own domain (eg, social worker completes the psychosocial domain, the academic coordinator completes the academic domain, etc.).

**PDSA Methodology**

PDSA (Plan-Do-Study-Act) methodology was utilized to develop and evaluate the assessment tool. PDSA is a QI method that utilizes small-scale changes to a process, primarily within health care environments [16]. PDSA is executed in cycles and as changes are made, the process acted upon is improved. Changes are tested on a small scale and barriers are identified. Adjustments are made in subsequent cycles and as needed.

For the QI project, 3 PDSA cycles were completed for the development and implementation of the assessment tool (Figure 1). We established a goal of completing an assessment for 80% of eligible patients (Figure 2). We used the clinical database to track this goal for each PDSA cycle. The period of data collection was August 2011 through May 2013. All adolescents receiving medical care in the SCD teen clinic aged 17 and 18 years were eligible for evaluation. From August 2011 to June 2013 we assessed 72 patients (53% male), median age 17.04 years. The following sickle cell genotypes were represented: 40 HbSS, 19 HbSC, 8 HbSβ⁺, 3 HbSβ⁰, and 2 HbS/HPFH. The data were collected for this report with institutional review board approval.

**Cycle 1**

The objective of the first cycle was to assess feasibility and acceptability of the assessment tool. Patients were assessed during the month of their 17th birthday. Fourteen out of 16 eligible patients (87.5%) were assessed: 1 patient was lost to follow-up, and 1 patient inadvertently was not included in the assessment due to an administrative error. Feedback from the first cycle revealed that some items on the emotional/cognitive domain checklist were not clearly defined, and there was some overlap with the psychosocial domain checklist. Additionally, some items were not readily assessed by psychology based on the structure of psychology services at the institution. Not all patients are seen by psychology; patients are referred to psychology by the team and appointments occur in the psychology clinic.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Number of Items</th>
<th>Items</th>
<th>Readiness Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>12</td>
<td>Disease literacy, Disease self-management, Organ and dysfunction screening</td>
<td>12 = ready for transition, 6–11 = probably ready but plan of action needed, ( \leq 5 ) = not ready for transition</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>5</td>
<td>Understanding of necessary resource information, Identification of concerns related to transition, Ability to self-advocate, Completion of Personal Health Record</td>
<td>5 = ready for transition, 3–4 = probably ready but plan of action needed, ( \leq 2 ) = not ready for transition</td>
</tr>
<tr>
<td>Emotional/Cognitive</td>
<td>2</td>
<td>History of emotional/behavioral concerns, History of cognitive concerns</td>
<td>2 = ready for transition, 1 = probably ready but plan of action needed, 0 = not ready for transition</td>
</tr>
<tr>
<td>Academic</td>
<td>5</td>
<td>On target for graduation requirements, Have educational/job training plan, Have completed steps in future planning, Knowledge of community educational services, Ability to self-advocate in educational/vocational matters</td>
<td>5 = ready for transition, 3–4 = probably ready but plan of action needed, ( \leq 2 ) = not ready for transition</td>
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**Table. Domain Checklists and Scoring**

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and were not well-integrated within the hematology clinic visit.

**Cycle 2**
The second cycle addressed some of the problems identified during Cycle 1. The emotional/cognitive domain checklist was revised to reflect psychology clinic utilization (psychotherapy and testing) and a section was added where team members could indicate individualized action plans. Seventeen patients out of 18 eligible patients were assessed (94.4%): 1 patient was lost to follow-up. At the conclusion of this cycle, we found that several patients had not completed certain transition program components, such as genetic education or their PHR. Therefore, we decided that we needed to indicate this and create a Plan of Action (POA) to ensure completion of program components. The POA indicated which components were outstanding, when these components would be completed, and when the team would discuss the patient again to track their progress with program components (eg, 6 months later).

### Figure 1. PDSA cycles for implementation of readiness assessment tool. P = plan/develop; D = do/perform; S = study/learn; A = act/revise. Adapted from the Institutes for Healthcare Improvement (www.ihi.org).

<table>
<thead>
<tr>
<th>Cycle 1: Individualized Tool Implementation</th>
<th>Cycle 2: Tool Revision</th>
<th>Cycle 3: Adaptation</th>
<th>Cycle 4: Dissemination</th>
</tr>
</thead>
<tbody>
<tr>
<td>P – Each domain developed a checklist to document individualized assessment during month of patient’s 17th birthday</td>
<td>P – Developed revised checklists</td>
<td>P – Provided a POA for patients assessed as not ready for transition</td>
<td>P – Monthly assessment with information submitted in tracking database</td>
</tr>
<tr>
<td>D – Implemented readiness assessment checklists at meeting – 14/16 eligible patients assessed</td>
<td>D – Used revised checklists at readiness assessment meeting – 17/18 eligible patients assessed</td>
<td>D – Completed domain forms prior to meeting with POA if appropriate and results given during meeting – 20/22 eligible patients assessed</td>
<td>D – Continue use during subsequent monthly meetings with information submitted in tracking database – 21/21 eligible patients assessed</td>
</tr>
<tr>
<td>S – Determined overlap in checklists</td>
<td>S – Patient missing transition components</td>
<td>S – Observed improved assessment time and more detailed individualized assessment. Increased number of patients needing assessment</td>
<td>S – Process is focused on provider use but POA may be informative to the families</td>
</tr>
<tr>
<td>A – Revised checklist per observations</td>
<td>A – Added a plan of action (POA) section to checklists</td>
<td>A – Developed a tracking database to monitor tool scores and other transition components</td>
<td>A – Developing vehicle to inform families of readiness assessment discussions and POA</td>
</tr>
</tbody>
</table>

**Cycle 3**
Following a few months using the assessment process, each member of the team provided feedback about their observations from the second cycle. The third cycle of the PDSA addressed some of the barriers identified in Cycle 2 by adding the POA and timeline for reassessment. With this information, the nurse case manager was able to identify and contact families who had significant gaps in the learning curriculum. Additionally, services such as psychological testing were scheduled in a timely manner to address academic problems and to provide rationale for accommodations and academic/vocational services before patients transferred care to the adult provider. With the number of assessed patients increasing, it was determined that a reliable tracking system to monitor progress was essential. Thus, a transition database was created to document the domain scores, individualized plan of action, and other components of the transition program, such as medical literacy quiz scores, completion of pre-transfer visits to adult providers, and completion of the PHR. During this cycle, 20 patients...
were assessed out of a total of 22 eligible patients (90.9%); 2 patients were lost to follow-up.

**Cycle 4**
This cycle is currently underway and comprises monthly assessments of eligible 17-year-old patients with SCD. From January 2013 to May 2013 we have assessed 100% of the eligible patients (21/21). All information obtained through the assessment tool is added to the transition database. Future adjustments and modifications are planned for this tool as we continue to evaluate its impact and value.

**DISCUSSION**
The transition readiness assessment tool was developed to evaluate adolescent patients with SCD aged 17 years regarding their progress in the transition program and level of transition readiness. Most transition readiness measures available in the literature consider the patient and parent perspective but do not include the health care provider perspective or determine if the patient received the information necessary for successful transition. Our readiness assessment tool has been helpful in providing a structured and quantifiable means to identify at-risk patients and families prior to the transfer of care and revealing important gaps in transition planning. It also provides information in a timely manner about points of intervention to ensure patients receive adequate preparation and services (eg, psychological/neuropsychological testing). Additionally, monthly meetings are held during which the tool is scored and discussed, providing an opportunity for members of the transition team to examine patients’ progress toward transition readiness. Finally, completing an individualized tool in a multidisciplinary setting has the added benefit of encouraging increased staff collaboration and creating a venue for ongoing reevaluation of the QI process.

We achieved our objective of completing the assessment tool for 80% of eligible patients throughout the cycles. The majority of our nonassessed patients was lost to follow-up and had not had a clinic visit in 2 to 3 years. Implementing the tool has provided us with an additional mechanism to verify transition eligibility and has afforded the transition program a systematic way to...
screen and track patients who are approaching the age of transition and who may have not been seen for an extended period of time. As with any large program following children with special health care and complex needs, the large volume of patients and their complexity may pose a challenge to the program, therefore having an additional tracking system in place may help mitigate possible losses to follow-up. In fact, since the implementation of tool, our team has been able to contact families and in some cases have reinstated services. As a by-product of tool implementation, we have implemented new policies to prevent extended losses to follow-up and patient attrition.

Limitations
A limitation of the assessment tool is that it does not incorporate the perspectives of the other stakeholders (adolescents, parents, adult providers). Further, some of the items in our tool are measuring utilization of services and not specifically transition readiness. As with most transition readiness measures, our provider tool does not have established reliability and validity [14]. We plan to test for reliability and validity once enough data and patient outcomes have been collected. Additionally, because of the small number of patients who have transferred to adult care since implementation of the tool, we did not examine the association between readiness scores and clinical outcomes, such as fulfillment of first adult provider visit and hospital utilization following transition to adult care. As we continue to assess adolescent patients and track their progress following transition, we will be able to examine these associations with a larger group.

Future Plans
Since the implementation of the tool in our program, we have realized that we may need to start assessing patients at an earlier age and perhaps multiple times throughout adolescence. Some of our patients have guardianship and conservatorship issues and require more time to discuss options with the family and put in place the appropriate support and assistance prior to the transfer of care. Further, patients that have low compliance to clinic appointments are not receiving all elements of the transition program curriculum and in turn have fewer opportunities to prepare for transition. To address some of our current limitations, we plan to incorporate a patient and parent readiness assessment and examine the associations between the provider assessment and patient information such as medical literacy quizzes, clinic compliance, and fulfillment of the first adult provider visit. Assessment from all 3 perspectives (patient, parent, and provider) will offer a 360-degree view of transition readiness perception which should improve our ability to identify at-risk families and tailor transition planning to address barriers to care. In addition, our future plans include development of a mechanism to inform patients and families about the domain scores and action plans following the transition readiness meetings and include scores into the electronic medical records. Finally, the readiness assessment tool has revealed some gaps in our transition educational curriculum. Most of our transition learning involves providing and evaluating information provided, but we are not systematically assessing actual acquired transition skills. We are in the process of developing and implementing skill-based learning for activities such as calling to make or reschedule an appointment with an adult provider, arranging transportation, etc.

Conclusion
In conclusion, the provider transition readiness assessment has been a helpful tool to monitor progress of adolescents with SCD towards readiness for transition. The QI methodology and PDSA cycle approach has not only allowed for testing, development, and implementation of the tool, but is also allowing ongoing systematic refinement of our instrument. This approach highlighted the psychosocial challenges of our families as they move toward the transfer of care, in addition to the need for more individualized planning. The next important step is to evaluate the validity and reliability of the measure so we can better evaluate the impact of transition programming on the transfer from pediatric to adult care. We found the PDSA cycle approach to be a framework that can efficiently and systematically improve the quality of care of transitioning patients with SCD and their families.

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REFERENCES
1. Quinn CT, Rogers ZR, McCavit TL, Buchanan GR. Improved survival of children and adolescents with sickle cell