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International and Interdisciplinary Identification of Health Care Transition Outcomes

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Abstract

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Author Contributions: Drs Fair and Ferris had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Fair, Sharma, Wiener, Gilleland-Marchak, Ferris.

Acquisition, analysis, or interpretation of data: Fair, Cuttance, Sharma, Maslow, Betz, Porter, McLaughlin, Gilleland-Marchak, Renwick, Naranjo, Jan, Javalkar, Ferris.

Drafting of the manuscript: Fair, Cuttance, Sharma, Maslow, Porter, McLaughlin, Gilleland-Marchak, Naranjo, Jan, Ferris.

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Statistical analysis: Cuttance, Sharma, Javalkar, Ferris.

Obtained funding: Ferris.

Administrative, technical, or material support: Cuttance, Betz, Naranjo, Javalkar, Ferris.

Study supervision: Fair, Sharma, Ferris.

Conflict of Interest Disclosures: None reported.

Group Information: The members of the International and Interdisciplinary Health Care Transition Research Consortium are listed in the eAppendix in the Supplement.

Supplemental content at jamapediatrics.com

IMPORTANCE—There is a lack of agreement on what constitutes successful outcomes for the process of health care transition (HCT) among adolescent and young adults with special health care needs.

OBJECTIVE—To present HCT outcomes identified by a Delphi process with an interdisciplinary group of participants.

DESIGN, SETTING, AND PARTICIPANTS—A Delphi method involving 3 stages was deployed to refine a list of HCT outcomes. This 18-month study (from January 5, 2013, of stage 1 to July 3, 2014, of stage 3) included an initial literature search, expert interviews, and then 2 waves of a web-based survey. On this survey, 93 participants from outpatient, community-based, and primary care clinics rated the importance of the top HCT outcomes identified by the Delphi process. Analyses were performed from July 5, 2014, to December 5, 2014.

EXPOSURES—Health care transition outcomes of adolescents and young adults with special health care needs.

MAIN OUTCOMES AND MEASURES—Importance ratings of identified HCT outcomes rated on a Likert scale from 1 (not important) to 9 (very important).

RESULTS—The 2 waves of surveys included 117 and 93 participants as the list of outcomes was refined. Transition outcomes were refined by the 3 waves of the Delphi process, with quality of life being the highest-rated outcome with broad agreement. The 10 final outcomes identified included individual outcomes (quality of life, understanding the characteristics of conditions and complications, knowledge of medication, self-management, adherence to medication, and understanding health insurance), health services outcomes (attending medical appointments, having a medical home, and avoidance of unnecessary hospitalization), and a social outcome (having a social network). Participants indicated that different outcomes were likely needed for individuals with cognitive disabilities.

CONCLUSIONS AND RELEVANCE—Quality of life is an important construct relevant to HCT. Future research should identify valid measures associated with each outcome and further explore the role that quality of life plays in the HCT process. Achieving consensus is a critical step toward the development of reliable and objective comparisons of HCT outcomes across clinical conditions and care delivery locations.

Health care transition (HCT) refers to “the movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems”^{1(p570)} and is a process that requires preparation along with periodic assessment of progress toward transition readiness. The assessment of HCT readiness involves the evaluation of indicators related to disease self-management, such as knowledge of illness, medications, and ability to communicate with health care professionals, that adolescents and young adults with special health care needs (AYA-SHCN) must have as they transfer to the adult-focused health care system.² Although there is broad agreement that preparation is needed to help AYA-SHCN transfer from pediatric- to adult-focused health care, there is no consensus regarding what constitutes successful HCT. Achieving consensus regarding HCT outcome metrics is a critical step toward reliable and objective comparisons across clinical conditions and health care delivery settings.

Studies examining the health of AYA-SHCN have looked at a wide range of outcomes from psychosocial to health outcomes. Findings include that some AYA-SHCN experience poor health issues, such as declines in disease self-management,³⁻⁶ increased health-related complications,⁷⁻⁹ deterioration of health status,¹⁰⁻¹³ graft loss in organ transplantation,¹⁴ emergence of secondary conditions,¹⁵ and treatment-related late effects as reported in survivors of childhood cancer.¹⁶⁻¹⁸ Other studies have focused on nonmedical aspects as outcomes. For example, Bloom and colleagues¹⁹ conducted a systematic review of HCT outcomes, and the included studies examined a variety of psychosocial outcomes in addition to medical outcomes: employment, life satisfaction, social development, mental health, education, access to health insurance, satisfaction with care, outcomes of care (eg, health care utilization and metabolic control), and quality of care (eg, having a usual source of care). A recent review²⁰ assessed the HCT literature through the lens of the Triple Aim of health care reform, examining outcomes of population health, patient experience, and cost. Despite the diversity of studies, much of this research has been limited by factors such as a lack of appropriate theoretically directed studies, small sample sizes, lack of appropriate control groups, and extensive focus on service and process measures rather than post-HCT outcomes for AYA-SHCN.¹⁹⁻³⁴

The present study used a Delphi method to define outcome indicators for successful HCT and examined the relative priority of these outcomes with international and interdisciplinary collaborators (primary care vs specialists and medical vs psychosocial professionals). In-person and online surveys were conducted to develop outcome indicators for HCT.

Methods

The study was approved and deemed exempt by the institutional review board at the University of North Carolina-Chapel Hill. Participants did not receive financial compensation and informed consent was waived. The study started on January 5, 2013, and ended July 3, 2014. Analyses were completed by December 5, 2014. The identification of HCT outcomes occurred in 3 phases using a modified version of the iterative Delphi consensus method,³⁵ as depicted in the Figure. The Delphi process involves repeated surveys to gather previously unknown information from a group of people with expertise in a particular area.³⁶ Participants in the Delphi process are typically given a large number of items that need to be rated, ranked, or otherwise categorized. The subsequent iterations of each stage of the Delphi process are designed to reduce the number of items based on analyses of participant responses so that the final product is more concise and represents the consensus of the included experts.

To identify outcome criteria for successful HCT, we conducted a 3-stage modified Delphi process relying on the expertise of an international and interdisciplinary group of AYA-SHCN, parents and caregivers of AYA-SHCN, and clinicians and researchers who were members of the Health Care Transition Research Consortium (HCTRC), as well as health care professionals and researchers involved in the field of HCT who attended a special interest group (SIG) associated with an international pediatric conference, as detailed below. The HCTRC members represent a wide range of interdisciplinary health care professionals, including those working within pediatric and adult primary and specialty care medicine,

social work, occupational therapy, physical therapy, nutrition, nursing, speech and language, rehabilitation, and psychology. The AYA-SHCN and their family members who are involved in activities of the HCTRC also play a critical role in the consortium.

Stage 1

On January 5, 2013, a literature search of HCT-related outcomes was completed using the terms *health care transition, adolescent transition, patient transfer, chronic disease, or transition* in the PubMed database, and an exhaustive review of the existing HCT websites was conducted. Initially, 187 English-language articles were identified, 28 of which discussed potential outcomes. An extensive list of youth-related outcomes for successful transition was extracted from the articles reviewed and HCT websites. The list was shared with several members of the HCTRC, who categorized similar outcomes into broad themes.

In addition, 14 in-depth interviews were completed with experts who had published articles on HCT, including an AYA patient and 2 parents of AYA-SHCN. The primary interview question centered on what constitutes a successful HCT. No further interviews were conducted when data saturation was achieved.

Outcomes were further refined during stage 1 at the 2013 SIG on Self-management and Health Care Transition meeting embedded in the annual Pediatric Academic Society/Society of Pediatric Research Conference in Washington, DC. At the meeting, a facilitator distributed note cards to participants who were asked to list the 5 most important HCT outcomes. Next, participants were given the list of previously identified HCTs and asked to rank them from most to least important. They were asked to rate the importance of each and comment on other outcomes to allow the inclusion of themes and outcomes not listed as part of the literature review. Finally, the facilitator engaged the participants in dialogue about HCT outcomes during a 60-minute discussion. All 39 participants who attended the SIG participated in the Delphi process. Participants included consumers (AYA-SHCN or a family member) and individuals representing a wide variety of health care professionals, including pediatric specialists, primary care physicians, nurses, rehabilitation specialists, social workers, and psychologists. More detailed demographic information was not collected from participants at this time. The research team used the results from the ratings, rankings, and open-ended responses to create a refined list of potential outcomes to be used in the next iteration of the Delphi process.

Stage 2

Following the conference, a survey was distributed to the entire HCTRC using the web-based platform Qualtrics.³⁷ In a process similar to that used in stage 1, participants were asked to rate the importance of the newly refined list of outcomes (from 1 to 10, with 1 being the least important) and offer suggestions for additional outcomes. Those who attended the SIG did not complete the online survey so as to prevent duplicative responses. Survey responses were tallied; means for each outcome were calculated, and members of the HCTRC categorized open-ended responses. Ten members of the HCTRC from multiple disciplines (including C.F., J.C., K.J., and M.F.) coded the open-ended responses by

identifying the recurrent themes after detailed instructions were given. Two coinvestigators (C.B. and M.F.) resolved all discrepant responses.

Stage 3

During the final phase of the process, a list of the outcomes refined in stage 2 was distributed at the SIG on HCT at the Pediatric Academic Society/Society of Pediatric Research 2014 Conference in Vancouver, British Columbia, Canada, and electronically to the HCTRC members who did not attend the conference, using the same web-based platform as in stage 2. In keeping with the methods used by Elwyn et al,³⁵ participants were asked to rate the importance of the remaining HCT outcomes from 1 to 9, with 1 being the least important.

Statistical Analysis

Comments from the survey submitted by participants at stage 2 and stage 3 were analyzed from July 5, 2014, to December 5, 2014, using traditional qualitative data analyses approaches.³⁸ Three coders used open coding to generate themes and closed coding to identify whether the comments described outcomes already listed. We came to a consensus on the codes. For stage 3, based on the methods of Elwyn et al, we established a threshold for retaining transition outcomes based on the overall level of agreement among participants in stage 3. We determined that “participants ‘disagreed’ if 30% or more of the ratings were in the lower third (ratings 1-3) and 30% or more of the ratings were in the upper third (ratings 7-9).”^{35(p5)} Outcomes were viewed as important if they had a mean of 7 to 9 (without disagreement). Outcomes rated 4 to 6 were considered equivocal, and those rated 1 to 3 were rated as not important. Comparisons between the ratings of outcomes by country of practice, type of service, and type of practice were conducted for the importance scores from stage 3 using SPSS, version 21.³⁹ Analyses comparing responses of pediatric vs adult care professionals were not completed owing to the small number of adult care professionals. A Mann-Whitney test was performed to determine significance since the scores were not normally distributed. Dependent variables were ordinal, independent variables contained 2 or more categories, and independence of observations between groups was observed, all rendering a Mann-Whitney test as the appropriate statistical approach.⁴⁰

Results

During stage 1, the literature review conducted by the study team resulted in a list of 18 outcomes (Figure). After analyzing the expert interviews and the data collected during the SIG, the 18 outcomes were used as part of the Delphi process in stage 2. During stage 1, some outcomes were split into more than 1 part. For example, adherence was split into 3 separate categories (adherence to medications and/or other treatments, attending medical appointments, and adhering to diet restrictions). Other outcomes were eliminated at this stage, including process and readiness categories such as communication and records transfer and understanding of the transition process.

For stage 2, the 18 outcomes received importance ratings from 117 members of the HCTRC ranging from 1 to 10, with 1 indicating the least importance. Table 1 provides details

regarding the sample; most were from the United States (102 [87.9%]) and were specialists (those who work in a specialty clinic; 58 [58.6%]) as opposed to primary care (8 [8.1%]) or others (33 [33.3%]), such as transition coordinators, parents, youth, and researchers. More than half of the participants were health care professionals (52 [53.1%]); of the 117 participants, 80 (68.3%) were pediatric professionals. Importance scores from stage 2 are presented in Table 2. Quality of life, understanding the characteristics of the conditions and complications, knowing the names and purposes of medications, adhering to medications and/or other treatments, and self-managing one's condition were the top 5 outcomes at this stage. As a result of the scores and other elements of the stage 2 Delphi process, 4 outcomes were eliminated: having hobbies/pastime activities, being enrolled in a college or training program, having a steady job, and having a significant other.

Forty-two participants provided qualitative comments about the outcomes, which supported the inclusion of the 13 outcomes in the stage 3 survey. In addition, the coders noted that special importance was placed on the types of outcomes for AYA-SCHN with cognitive disabilities and how the types of outcomes for these individuals might differ from those for individuals without cognitive disabilities. For example, 7 of 42 participants (16.7%) who offered comments noted that "living independently" may not be a realistic outcome. The AYA-SCHN with cognitive disabilities, as well as other participants, suggested that another set of outcomes should be created for this group.

Stage 3 included 93 participants, with most from the United States (78 [83.9%]); others were from Canada, Switzerland, and the United Kingdom. Of 88 participants who reported on their service, most were specialists (66 [75.0%]), including hematology/oncology, adolescent medicine, and cardiology, and medical (67 [76.1%]) and psychosocial (20 [22.7%]) professionals (eg, social workers and psychologists). Participants rated quality of life as the most important HCT outcome across groups, followed by disease self-management (Table 3). Adhering to diet restrictions, living independently, and appropriate emergency department use were removed from the list because they did not meet the threshold of 70% agreement.⁴¹

The eTable in the Supplement presents the 10 outcomes and the difference between importance scores based on country of practice, type of practice, and type of professional. Quality of life was rated the most important HCT outcome across groups, followed by disease self-management and adherence to medications and/or other treatment. Participants in the United States rated the importance of understanding insurance options significantly higher compared with those from other countries ($P = .04$). No other significant group differences were found.

Discussion

As a result of a Delphi process conducted in 3 waves, our study refined a list of 10 transition outcomes that were broadly acceptable to a diverse group of HCT experts. In addition, the qualitative examination of comments from participants did not yield additional HCT outcomes except that there is a need to develop a set of outcomes specific to AYA-SHCN with cognitive disabilities. The findings of this study align with our current understanding of

HCT outcomes, including the conceptual model developed by Betz and colleagues⁴² from the HCTRC. Their conceptual model views HCT as a process that involves individual, social, and health service domains. The results of the present study are consistent with this conceptual model since the outcomes fit within these domains, including individual outcomes (quality of life, knowledge of medication, self-management, adherence to medication, dietary adherence, understanding health insurance, and understanding the characteristics of the conditions, and complications), social outcomes (having a social network), and health services outcomes (attending medical appointments, having a medical home, and avoidance of unnecessary hospitalization). Other factors within each level of the conceptual model can affect HCT outcomes. For example, number of hospitalizations can be influenced by individual factors, such as disease severity, or health care system factors, including access to primary care. Grouping these outcomes by level may allow researchers to conduct focused evaluations of current processes and more detailed evaluation of interventions.

The identification of quality of life as the most important factor is a unique feature of this study. Suris and Akre⁴³ also used a Delphi process to examine key elements and indicators of HCT. However, their findings emphasized continuity of care rather than outcomes associated with quality of life, such as social and educational opportunities. The authors noted that the primary focus on health outcomes was somewhat surprising given that AYA-SHCN are at increased risk for poor educational attainment and low incomes in adulthood.^{44,45} Incorporating quality of life as an aspect of transition may facilitate a more holistic approach to HCT that, in turn, could facilitate more effective transition to adult care for vulnerable populations. Similar to the study of Suris and Akre, the present study included international participants who primarily worked in pediatric specialty clinics.

The present study adds to the efforts under way to generate a standard set of HCT outcomes that can be evaluated across conditions and settings, which has been largely neglected in literature discussing disease-specific chronic illness. In addition, our results can be used to guide individual patient care and program priorities for AYA-SHCN. In particular, the health services outcomes are consistent with the findings from the 2007 Survey of Adult Transition and Health. To determine HCT outcomes, Oswald and colleagues⁴⁶ defined successful HCT as having a usual health care source, having a professional providing adult care, having health insurance, having at least one preventive health care visit, being satisfied with health care, and not having delayed or forgone necessary health care services. The specific medical outcomes that are important for individual conditions were not a part of the HCT outcomes generated by the Delphi process in the present study; however, these outcomes are important to consider for specific conditions and for evaluating the success of transition for AYA-SHCN. Future research should focus on more disease-specific differences, including individuals with cognitive disabilities.

Limitations of the study are that it used a Delphi process to measure and develop consensus on outcomes for HCT. Results are limited to the opinions of respondents; owing to the anonymity of the web-based contributions, we are not able to directly compare characteristics of respondents and non-respondents. For example, patients and families who have withdrawn from the transition process are of significant interest to clinicians and

researchers, and the perspectives of such patients and families have often been represented by proxy respondents who provided services to them and were informed of their HCT needs and future planning.^{47,48} The inclusion of an interdisciplinary and international consortium, SIG sessions at pediatric meetings attended by international researchers, and a web-based survey platform attempted to maximize access and minimize participant costs to improve involvement. However, some terms, such as *medical home*, may not be universally applicable.

Another limitation of the present study is the low representation of AYA-SCHN and their family members beyond stage 1. The HCTRC membership includes AYA-SCHN and families; however, they either did not participate in the online surveys or did not self-identify as such when they completed the survey. Furthermore, we did not plan to recruit a panel of parents and young people. Future research should include a focus on the perspectives of AYA-SCHN living with chronic conditions as well as their families.

Our sample contained many specialists and was almost entirely composed of pediatric health care professionals. For this reason, the outcomes may not fully represent the HCT outcomes that primary care or adult-focused health care professionals view as important. This factor is a limitation, but it provides an opportunity for an important next step. These 10 outcomes could be presented to groups of adult-focused and primary care health care professionals through a Delphi process and thus be further refined. The methods allow multiple viewpoints to emerge and, simultaneously, limit the emergence of a dominant individual or perspective that might lead to the exclusion of other important components.⁴⁹

Conclusions

Our study was designed to be inclusive of diverse input with a transparent selection process and clearly defined acceptable levels of consensus. The results highlight the importance of identifying meaningful elements that go beyond an individual's readiness for HCT. The Delphi process lays the groundwork for future research to define and operationalize the measurement of these outcomes. Health care transition is a complex process with a wide range of potential end results. It is important to identify the associations between variables, such as HCT readiness and adherence, that are stepping stones toward more patient-centered outcomes, such as quality of life. The HCT outcomes identified in the present study at each stage are general concepts. Next, it will be necessary to define (both for research and clinical practice) and identify valid measures associated with each outcome. We hope that, by identifying and developing interventions targeting such proximate outcomes, we can improve the more distal patient-centered outcomes and ensure success broadly defined for AYA-SCHN.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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At a Glance

- There is a need to define outcomes for the process of health care transition among adolescents and young adults with special health care needs.
- This study describes a 3-stage Delphi process designed to identify health care transition outcomes with members of the Health Care Transition Research Consortium.
- Final outcomes identified included individual outcomes (quality of life, understanding the characteristics of conditions and complications, knowledge of medications, self-management, adherence to medication, and understanding health insurance), health services outcomes (attending medical appointments, having a medical home, and avoidance of unnecessary hospitalization), and a social outcome (having a social network).

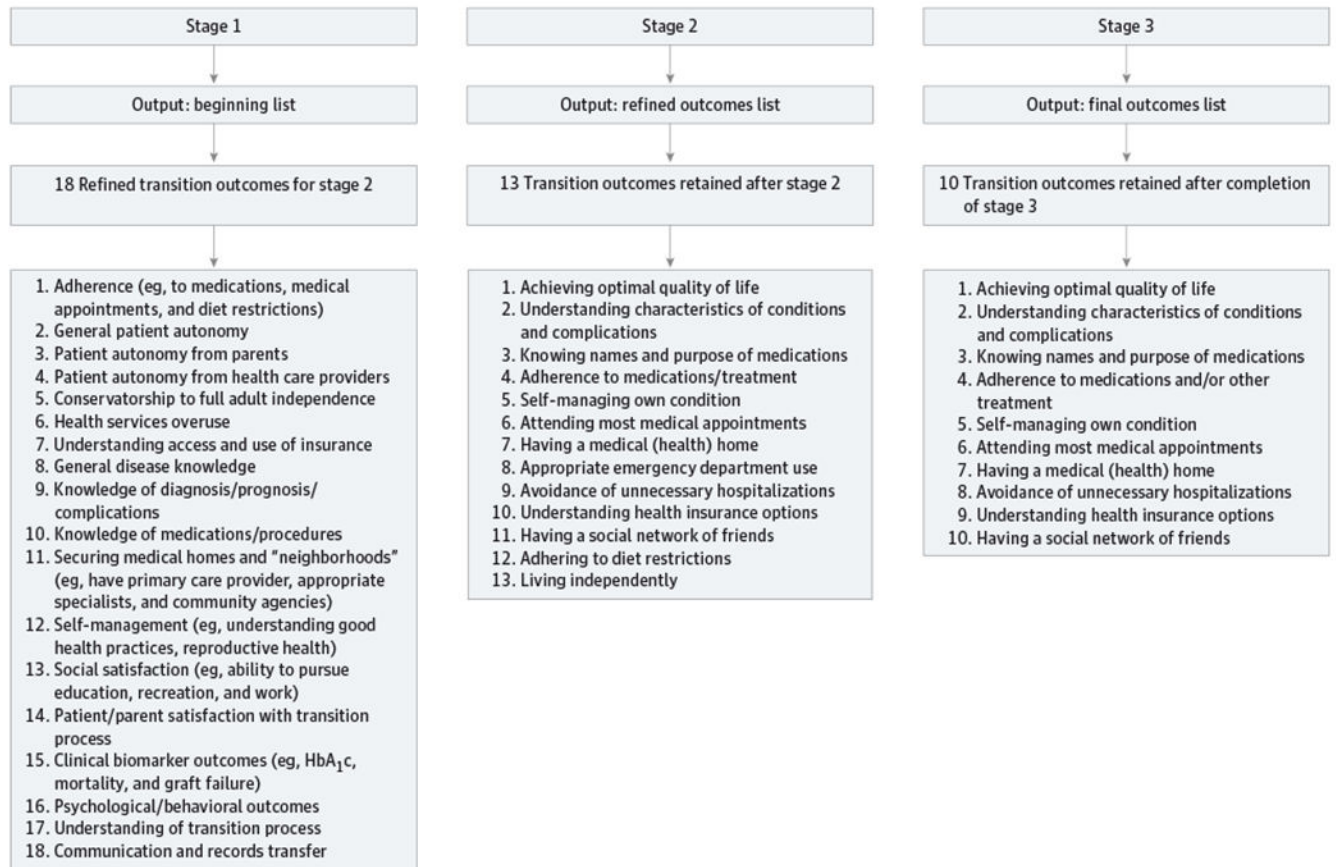


Figure. Summary of Activities Connected as Part of the 3-Stage Delphi Process for Defining Health Care Transition (HCT) Outcomes

Stage 1 included an initial list of transition outcomes generated by a literature review, interviews with experts, and facilitated discussions during the 2013 HCT special interest group at a pediatric conference. Stage 2 consisted of a survey sent to members of the HCT Research Consortium (HCTRC) in 2013; members were asked to rate the importance of each outcome from 1 to 10 and to provide free-text comments. Stage 3 involved a survey sent to members of the HCTRC in 2014; members were asked to rate the importance of each outcome from 1 to 9. The order shown here is linked to the outcomes in stage 2. Important items had scores from 7 to 9. HbA_{1c} indicates hemoglobin A_{1c}.

Table 1.

Demographics of Participants in Stages 2 and 3

Characteristic	No. (%) ^a	
	Stage 2 (n = 117)	Stage 3 (n = 93)
Country		
United States	102 (87.9)	78 (83.9)
Other	14 (12.1)	15 (16.1)
Type of practice		
Specialist	58 (58.6)	66 (75.0)
Primary care	8 (8.1)	10 (11.4)
Other	33 (33.3)	12 (13.6)
Type of service		
Medical	52 (53.1)	67 (76.1)
Psychosocial	38 (38.8)	20 (22.7)
Other	8 (8.2)	1 (1.1)

^aSome data were missing.

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Table 2.Mean Importance Ratings of Stage 2 Outcomes^a

Outcome	Importance Rating, Mean (SD)^b
Achieving optimal quality of life	9.2 (1.2)
Understanding characteristics of conditions and complications	9.1 (1.3)
Knowing names and purpose of medications	9.1 (1.3)
Adherence to medications and/or other treatment	9.0 (1.4)
Self-managing own condition	8.9 (1.6)
Attending most medical appointments	8.7 (1.4)
Having a medical (health) home	8.3 (2.4)
Appropriate emergency department use	8.2 (2.1)
Avoidance of unnecessary hospitalizations	8.2 (1.8)
Understanding health insurance options	8.0 (2.0)
Having a social network of friends	7.9 (2.2)
Adhering to diet restrictions	7.4 (1.8)
Living independently	6.5 (2.1)
Having a steady job	6.5 (2.1)
Identifying hobbies or past-time activities	6.4 (2.3)
Enrolling in postsecondary program (college, training program)	6.1 (2.4)
Have or had a significant other	5.7 (2.6)

^aSample of 117 participants.

^bRatings ranged from 1 to 10, with 1 indicating the least important outcome.

Table 3.Mean Importance Ratings of Stage 3 Outcomes^a

Outcome	Importance Rating, Mean (SD)^b
Achieving optimal quality of life	8.5 (1.0)
Self-managing own condition	8.2 (1.2)
Understanding characteristics of conditions and complications	8.1 (1.1)
Knowing names and purpose of medications	8.1 (1.1)
Adherence to medications and/or other treatment	8.2 (1.0)
Attending most medical appointments	7.9 (1.2)
Having a medical (health) home	7.9 (1.2)
Avoidance of unnecessary hospitalizations	7.9 (1.4)
Understanding health insurance options	7.5 (1.6)
Having a social network of friends	7.4 (1.5)

^aSample included 93 participants.

^bRatings ranged from 1 to 9, with 1 indicating the least important outcome.