Review

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Transition readiness measures for adolescents and young adults with chronic health conditions: a systematic review

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Abstract

Background: Transition from pediatric to adult health-care for adolescents with chronic health conditions has emerged as a critical period influencing health outcomes. Suitable transition readiness measures are necessary to facilitate effective planning. Currently, there is little consensus about well-validated transition readiness measures. The purpose of this systematic review was to identify best practices in transition readiness measurement for adolescents and young adults with chronic health conditions.

Data sources: Academic databases searched included PubMed, Cumulative Index to Nursing and Allied Health Literature, Google Scholar and Athabasca University Library's Discover.

Study selection: Articles were included that discussed the development and psychometric properties of transition readiness measures for adolescents and young adults (11–25 years) with chronic health conditions and/or that utilized a previously developed measure.

Data extraction: The primary and secondary reviewers extracted data from the selected articles as per the data extraction tool developed for this review.

Results: Forty-eight articles, representing 19 tools, were included in the review. Ten of the tools were disease-specific; nine were disease-neutral. According to the Cohen criteria, eight measures were “well-established assessments”. The Transition Readiness Assessment Questionnaire was deemed the best measure of transition readiness available. The literature search included only articles published in peer-reviewed journals; measures nearing completion or awaiting publication were not included. In addition, only English manuscripts were included, many from North America.

Conclusions: Despite national practice guidelines and ongoing policy development, there is slow movement towards achieving a gold standard or best-practice measure of transition readiness.

Keywords: adolescents and young adults; best practice; chronic health conditions; measurement; systematic review; transition readiness.

Introduction

Healthcare advancements have improved the survival of chronically ill children into adulthood [1]. Transfer from the specialized pediatric to specialized adult care is challenging for adolescents and young adults (AYA), their parents, and the receiving healthcare providers who may be ill-prepared for this newly emerging population. Without adequate support, many AYA are unable to transfer to adult healthcare successfully [2]. Transition readiness measures have been developed to identify the key aspects of health independence and to track, for clinical and research purposes, AYA through the transition process which is the period before, during and after transfer to specialized adult care. In addition, these measures identify AYA at risk of loss to follow-up [3]. However, the development of measures to facilitate the transition for AYA with chronic health conditions are in the early phases, and there is a link between poor patient outcomes and a lack of transitional care and support [2].

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For a successful transfer, self-management of chronic health conditions is crucial and influences health outcomes in adult life [2, 4, 5]. A successful transition process facilitates empowerment and self-management, whereas poorly executed transitions may lead to inappropriate healthcare utilization, non-adherence to medical treatments and difficulty establishing a connection with an adult healthcare provider [4].

Currently, there is little consensus in the literature about well-validated tools that measure the readiness of AYA to transition from pediatric healthcare to adult healthcare. Three literature reviews were published in 2014 [4–6]. In these reviews, transition readiness measures published up until 2013 were analysed. All three reviews demonstrated the diversity of transition measures, and recommended the ongoing development of new measures and further validation of current measures. Contributions to scholarly knowledge of transition readiness were evident in each review. Stinson et al. [5] included measures of transition readiness and transfer satisfaction in their review and acknowledged that the review was limited to measures that reflected the conceptual definition of transition satisfaction they developed as there was no standard definition available. Zhang et al. [6] concluded that the Transition Readiness Assessment Questionnaire (TRAQ) was the most reliable transition readiness measure. Both Zhang et al. [6] and Stinson et al. [5] identified similar limitations in the literature, especially the difficulty establishing criterion validity because there was no gold standard measure of transition readiness. Finally, Schwartz et al. [4] utilized well-developed inclusion criteria, resulting in the review of ten measures. They offered recommendations and considerations for future researchers, including grounding measures in theory, testing measures with diverse populations, and testing psychometric properties with appropriate sample sizes. These previous syntheses provided the impetus for our review.

The purpose of this knowledge synthesis was to identify the best practices in transition readiness for adolescents and young adults with chronic health conditions. A systematic review of current literature was the best methodology fit for this purpose. The research question guiding our systematic review was: What are the strengths and limitations of validated and non-validated transition readiness measures in the published peer-reviewed literature since 2014? The Cohen criteria [7] is a three-level ranking system employed in this study to evaluate the methodological quality of each tool based on 1) the number of publications that cite the tool; 2) accessibility of the tool; and 3) psychometric evaluation. The aim of this evaluation was to classify

each measure into one of three categories, listed here in descending quality: “well-established assessment,” “approaching well-established assessment,” and “promising assessment.” The Cohen criteria was straightforward to apply and was consistent with the previous systematic review on this topic which determined methodological quality [5]. The strengths and limitations of each measure were then evaluated to make recommendations for future research and measure development.

Methods

Procedure

Electronic searches were completed in PubMed, Cumulative Index to Nursing and Allied Health Literature, Athabasca University Library’s Discover, and Google Scholar. With previous systematic reviews of measures of transition readiness ending their searches between October 2012 and December 2013, this systematic review included literature published from January 1, 2014 to March 31, 2018. Each database was searched using pre-determined search terms including transition concepts, chronic health condition concepts, and survey and questionnaire concepts.

Inclusion criteria included: 1) published in a peer-reviewed journal between 2014-01-01 and 2018-03-31; 2) developed, discussed or assessed measures of transition readiness in AYA aged 11–25 with chronic health conditions, before or after the transfer from pediatric to adult care; and 3) discussed the development and psychometric properties of the measure. There continues to be no standardized definition of transition readiness; therefore, to prevent limiting the studies included in the review, articles were included that directly and indirectly measured transition readiness. The following types of publications were excluded from the review: guidelines, dissertations, reports, commentaries, integrative reviews, systematic reviews, literature reviews and abstracts. Articles not available in English were excluded; articles translated into English were included.

The systematic review was conducted using a search strategy developed by the first author in consultation with the third author, an academic reference librarian as recommended in the literature [8]. The reviewers, first, second and last author, worked independently of each other. The primary reviewer was responsible for the overall conduct of the review, ensuring rigour and timeliness, and applying the inclusion and exclusion criteria. Phase 1 involved screening by titles only by the primary reviewer. In Phase 2

at least two reviewers worked independently to screen articles by titles and abstracts. This screening phase began once there was at least an 80% level of reliability between the primary reviewer and secondary reviewers as per published recommendations [9]. Articles identified as eligible by both the primary and secondary reviewers had their full text reviewed in Phase 3. As recommended [9], the three reviewers discussed disagreements until consensus was reached; eligible articles were moved to Phase 4, data extraction; ineligible articles were excluded. Before completing Phase 2, 3, and 4, ten percent of the articles were reviewed by at least two reviewers to ensure inter-rater reliability.

The Cohen criteria [7] were used to evaluate the methodological quality of each measure by identifying the evidence supporting the psychometric testing of the transition readiness measure. Each measure was compared to the others included in this review to identify the best-validated measure as the current best practice in the field. Additionally, a list of recommended generalizable best practices for future research and practice were drawn from the evaluated measures.

Results

A total of 1851 articles were identified via the electronic searches from which 164 duplicate articles were removed and ten articles identified through other sources, such as Google Scholar and reference lists, were added. Of these 1697 articles, 1617 were excluded following screening Phases 1 and 2. From the 80 remaining articles, a further 32 were excluded after screening Phase 3, a review of the full-text. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [10] protocol was used to depict the flow of information through the different phases of the review process. Forty-eight articles remained for inclusion in this systematic review (see Figure 1).

Characteristics of measures

Nineteen transition readiness tools were identified among the 48 articles included in this systematic review (see Table 1). Only four of the 19 tools used in the included articles were developed prior to 2014 [11, 32, 37, 43]. Of the 15

Figure 1: PRISMA flow diagram.

Table 1: Characteristics of transition readiness measures.

Tool name Country of origin <i>Disease-neutral-specific</i>	Included articles Author first name date	Original language <i>Translated language</i>	Target Population Age Condition	Measurement concepts/domains/factors	No. of Items	Who completes measure? What format?	Cohen Criteria; is the tool validated?
Well-established n = 8							
1. Transition Readiness Assessment Questionnaire TRAQ 4.1 [11] United States <i>Disease-neutral</i>	Grady 2018 [12] Hart 2016 [13] Huang 2014 [14] Jensen 2017 [2] Mackie 2014 [15] Mackie 2016 [16] Okumura 2014 [17] Stewart 2017 [3] Szalda 2017 [18]	English	Adolescents 16–26 years Special healthcare needs/wide variety of complex health conditions	1. Self-advocacy 2. Chronic disease self-management	29	AYA self-report; Likert scale	Well-established Validated
2. Transition Readiness Assessment Questionnaire TRAQ 5.0 [1] United States <i>Disease-neutral</i>	Anelli 2018 [19] Beal 2016 [20] Gonzalez 2017 [21] Kiziler 2017 [22] Klostermann 2018 [23] Little 2017 [24] Seeley 2017 [25] Wood 2014 [1]	English <i>Argentinian Spanish [21] Brazilian Portuguese [19] Turkish [22]</i>	Adolescents 14–21 years Special healthcare needs	1. Managing medications 2. Keeping appointment 3. Tracking health issues 4. Talking with providers 5. Managing daily activities	20	AYA self-report 5-point Likert scale	Well-established Validated
3. Self-Management and Transition to Adulthood with the Rx = Treatment STARx [26] United States <i>Disease-neutral</i>	Benson 2018 [27] Cohen 2015 [28] Eluri 2017 [29] Ferris 2015 [26] Johnson 2015 [30] Nazareth 2017 [31]	English	AYA 12–25 years Chronic health conditions	1. Medication management 2. Provider communication 3. Engagement during appointments 4. Disease knowledge 5. Adult health responsibilities 6. Resource utilization	18	AYA self-report Parent STARx-P ³⁹ Questionnaire	Well-established Validated
4. UNC TRxANSITION [32] United States <i>Disease-neutral</i>	Cantu-Quintanilla 2015 [33] Fenton 2015 [34] Javalkar 2014 [35] Javalkar 2016 [36]	English <i>Spanish [33]</i>	AYA Chronic health conditions	1. Type of illness 2. Knowledge about medications and adherence 3. Disease 4. Nutrition 5. Insurance 6. Reproductive health	33 English 32 Spanish	Health care provider Questionnaire	Well established Validated

Table 1 (continued)

Tool name Country of origin <i>Disease-neutral-specific</i>	Included articles Author first name (date)	Original language <i>Translated language</i>	Target Population Age Condition	Measurement concepts/domains/factors	No. of Items	Who completes measure? What format?	Cohen Criteria; is the tool validated?
				7. Disease self-management 8. Self-activation 9. New health care providers 10. Ongoing support			
5. Readiness to Transition Questionnaire RTQ [37] United States <i>Disease-neutral</i>	Gumidyala 2018 [38] Speller-Brown 2015 [59]	English	Adolescents 16–22 years Kidney transplantation	1. Teen or Parent RTQ-Overall Transition Readiness 2. Teen or Parent RTQ-Adolescent Responsibility 3. Teen or Parent RTQ-Parent involvement	22–26	AYA self-report Parent – paral- lel version 4-point Likert scale	Well-established Validated
6. Am I ON TRAC for Adult Care [39] Canada <i>Disease-neutral</i>	Gravelle 2015 [40] Moynihan 2015 [39]	English	Adolescents 12–19 years Chronic health conditions	1. Knowledge scale 2. Behaviour Index	26	AYA self-report 4-point Likert scale	Well-established Validated
7. Transition-Q [41] Canada <i>Disease-neutral</i>	Ekim 2018 [42] Klassen, 2015 [41]	English <i>Turkish</i> [42]	Adolescents 12–18 years Chronic health conditions	Self-management skills re: to one's health and healthcare	14	AYA self-report Likert scale	Well-established Validated
8. Responsibility and Familiarity with Illness Survey REFILS [43] United States <i>Disease-specific</i>	Annunziato 2018 [44]	English	Adolescents 9–17 years Liver transplantation	1. Perceived knowledge about the illness 2. Responsibility for medical management	13	AYA self-report Likert scale	Well-established Initial validation reported
Approaching well-established $n = 4$							
1. Transition Scales [45] Canada <i>Disease-specific</i>	Ishida 2016 [46] Klassen 2015 [45]	English <i>Japanese</i> [46]	AYA 15–26 years Childhood cancer survivors	1. 6-item Cancer worry scale 2. 15-item self-management skills scale 3. 12-item expectations scale	33	AYA self-report Likert scale	Approaching well-established Validated
2. Adolescent Assessment of Preparation for Transition ADAPT [47] United States <i>Disease-neutral</i>	Sawicki 2015 [47] Sawicki 2017 [48]	English <i>Spanish</i>	Adolescents 16–17 years Chronic health conditions	1. Counseling on transition self-management 2. Counseling on prescription medication 3. Transfer planning	26	AYA self-report Questionnaire	Approaching well-established Validated

Table 1 (continued)

Tool name Country of origin <i>Disease-neutral-specific</i>	Included articles Author first name (date)	Original language <i>Translated language</i>	Target Population Age Condition	Measurement concepts/domains/factors	No. of Items	Who completes measure? What format?	Cohen Criteria; is the tool validated?
3. Transition Intervention Program Readiness for Transition TIP-RFT [49] United States <i>Disease-specific</i>	Treadwell 2016 [49] Treadwell 2016 [50]	English	AYA Sickle Cell Disease	1. Healthcare Knowledge and Skills 2. Education and Vocational Planning 3. Social Support Skill set 4. Independent Living Skills	22	AYA self-report Questionnaire	Approaching well-established Validated
4. Transition Readiness Inventory item pool TRI [51] United States <i>Disease-specific</i>	Schwartz 2017 [51]	English	AYA Childhood cancer survivors	<i>Pre-existing factors:</i> 1. Socio-demographics/culture 2. Access/insurance 3. Medical status and risk 4. Neurocognitive/IQ <i>Modifiable variables:</i> 5. Knowledge 6. Skills/self-efficacy 7. Beliefs/expectations 8. Developmental maturity (patient only) 9. Goals/motivation 10. Relationships/communication 11. Psychosocial/emotions	81 AYA 85 Parent	AYA self-report Parent Likert scale	Approaching well-established Not validated
Promising assessment n = 4 1. Healthcare Needs Scale for Youth with Congenital Heart Disease HNS-CHD [52] Taiwan <i>Disease-specific</i>	Chen 2017 [52]	Mandarin	Adolescents 15–24 years Congenital heart disease	1. Health management 2. Health policy 3. Individual and interpersonal relationships	25	AYA self-report Likert scale	Promising assessment Initial validation reported

Table 1 (continued)

Tool name Country of origin <i>Disease-neutral-specific</i>	Included articles Author first name (date)	Original language <i>Translated language</i>	Target Population Age Condition	Measurement concepts/domains/factors	No. of Items	Who completes measure? What format?	Cohen Criteria; is the tool validated?
2. CHD Readiness transition Assessment [53] United States <i>Disease-specific</i>	Uzark 2015 [53]	English	Adolescents 13–25 years Parents of children 13–18 years Congenital heart disease Heart transplantation	1. Perceived knowledge domain 2. Self-management 3. Self-efficacy	28–30 based on gender and medications	AYA self-report Parent Online administration Likert scale	Promising assessment Initial validation reported
3. On your own feet transfer experience scale OYOF-TES [54] <i>Disease-neutral</i> The Netherlands	VanStaa 2017 [54]	English	Adolescents 18–25 years Chronic health conditions	1. Perceived alignment and collaboration between PC and AC 2. Experienced preparation for transfer including readiness, timing, and co-decision making	18	AYA self-report Likert scale	Promising assessment Not validated
4. No title- from Moving On binder [55] United States <i>Disease-specific</i>	Polfuss 2015 [55]	English	Adolescents Diabetes Parents	1. Diabetes knowledge 2. Adolescents diabetes self-efficacy 3. Family members perceptions of how important specific knowledge or skills were in preparing the adolescent for transition to adult care 4. Perceptions of 8 areas of adolescent preparation for transition and their ability to self-manage diabetes 5. Evaluation of specific aspects of the program	59	AYA self-report Parent Likert scale	Promising assessment Not validated
Does not meet Cohen criteria n = 3 1. Sickle cell transition intervention program skills checklists [56] United States <i>Disease-specific</i>	Sobota 2014 [56]	English	Adolescents 18–22 years Sickle Cell Disease being seen in a transition program	<i>Five knowledge skill sets:</i> 1. Medical 2. Educational/Vocational 3. Health Benefits 4. Social 5. Independent Living <i>Psychological checklists:</i> 1. Self-efficacy 2. Sickle cell stress 3. Feelings about transition	85	AYA self-report Checklist 54 questions 4 point Likert 31 questions	Does not meet Cohen criteria Not validated

Table 1 (continued)

Tool name Country of origin <i>Disease-neutral-specific</i>	Included articles Author first name (date)	Original language <i>Translated language</i>	Target Population Age Condition	Measurement concepts/domains/factors	No. of Items	Who completes measure? What format?	Cohen Criteria; is the tool validated?
2. The Adolescent Autonomy Checklist SCD-AAD [57] United States <i>Disease-specific</i>	Abel 2015 [57]	English	Adolescents 13–21 years Sickle Cell Disease	1. Kitchen 2. Nutrition 3. Laundry 4. Housekeeping 5. Emergency 6. Personal skills 7. Health care skills 8. Sexual development 9. Money management 10. Leisure skills 11. Vocational skills 12. Living arrangements	100	AYA self-report Checklist	Does not meet Cohen criteria Not validated
3. No title-Fontan procedure in-house questionnaire [58] Australia <i>Disease-specific</i>	Du Plessis 2017 [58]	English	Adolescents 15–18 years Congenital heart disease – Fontan Parents	Health knowledge Medication management Experiences of pediatric healthcare services (including engagement with cardiologists) Readiness for transition.	NR	AYA self-report Parent Questionnaire	Does not meet Cohen criteria Not validated

newly developed tools, 13 originated in the United States [11, 26, 32, 37, 43, 47, 49, 51, 53, 55–57], and among the 48 included, articles have been utilized in Argentina [21], Brazil [19], Canada [3, 15, 16, 23], Mexico [33], and Turkey [22]. Three tools originated in Canada [39, 41, 45] and have been utilized in Japan [46] and Turkey [42]. The remaining three tools originated in Taiwan [52], The Netherlands [54], and Australia [58]. Nine tools were disease-neutral [1, 11, 26, 32, 37, 39, 41, 47, 54] while 10 were disease-specific [43, 45, 49, 51–53, 55–58]. Of the 19 tools, the University of North Carolina (UNC) TRxANSITION was the only tool administered to the adolescent by a healthcare provider [32]; the other 18 were self-report. Twelve used a Likert-scale format [1, 2, 11, 37, 39, 41, 43, 51–55], five had a questionnaire format [26, 32, 47, 49, 58] and two were checklists [56, 57] (see Table 1). The REFILLS [37, 44] had the fewest items [i.e. 14] and The Adolescent Autonomy Checklist [57] had the most items, 100 items. All of the measures were designed for use with AYA; one measure, the STARx [26] had a parent version, the STARx-P [31].

Characteristics of study participants and sample sizes

All the articles involved both male and female AYA. The articles varied widely on the age of patients included in each study. The youngest age of patients studied ranged from 6 to 16 years (Mean: 12.2 years; SD 2.5) [30]; and oldest ranged from 23 to 36 years (Mean: 27.7 years; SD not specified) [18]. Eight studies reported the patient's age at transfer, ranging from 17 to 22, and reported the age of diagnosis, ranging from birth to 17. However, age of diagnosis for some conditions may have been assumed to be at birth or in infancy as is the typical etiology of the particular disease processes, such as, congenital heart disease, cystic fibrosis and sickle cell disease.

The ten disease-specific tools used in 12 of the articles included in this review were designed for and used with AYA who had: liver transplantation [44], childhood cancer survivorship [45, 46, 51], sickle cell disease [49, 50, 56, 57], congenital heart disease [52, 53, 58], and diabetes [55]. Among the remaining 36 included articles, all of the disease-neutral tools, except the ADAPT were used with a single disease population, in addition to use with samples of AYA from several disease populations within the given study.

The TRAQ 4.1, a disease-neutral measure, was used in six studies with AYA with a single disease population: congenital heart disease/pediatric heart transplantation [3, 12, 13, 15, 16], cystic fibrosis [17], and childhood cancer survival [18]; and in three studies with a diverse sample

of conditions ranging from four specified conditions [14] to 11 specified conditions [2]. The TRAQ 5.0 was used in five studies with AYA with a single condition, including chronic rheumatology conditions [19], diabetes [22, 24], inflammatory bowel disease [23], and spina bifida [25]. The STARx was used with one disease-specific population, eosinophilic esophagitis and gastroenteritis [29]. The UNC TRxANSITION was used with AYA with kidney disease [33–35]; the RTQ with AYA with inflammatory bowel disease [38], and sickle cell disease [59]; the ON TRAC with cystic fibrosis [40]; and the Transition Q with congenital heart disease [42]. In contrast, the ADAPT, a disease-neutral measure was in studies with mixed conditions only [47, 48].

The studies included in this review that used one of the disease-neutral tools with diverse populations, based on the number of chronic health conditions and sample size, were as follows: three studies that utilized the TRAQ 4.1, with one study listing nine health conditions in a sample of 71 AYA [13], another study three diseases in a sample of 81 AYA [14], and another specifying three condition groups in a sample of 89 AYA [2]. Sample sizes and numbers of conditions in studies that employed a disease-neutral tool increased over the review period. The TRAQ 5.0, that has 20 questions rather than 29 questions for the TRAQ 4.1, was used with a sample of 526 AYA from two transition clinics (i.e. University of Florida Jacksonville Health and Transition Services, and University of North Carolina STARx Program) and one cystic fibrosis clinic [1]. Another study with the TRAQ 5.0 had a sample of 163 AYA from five clinics [20]; and a third one had 191 patients from eight departments [21].

Similarly the STARx, a tool developed during this review period was tested with large sample sizes, the originator of this tool having a sample of 996 participants with 19 conditions in phase 2 of tool development [26]. Other studies utilizing the STARx had samples of 245 AYA of 14 diagnosis types [27]; 351 AYA with one of 18 conditions [28]; 160 AYA with “different chronic conditions” [30] and 341 parents and 455 children with six diagnosis groups [31]. The UNC TRxANSITION was used with a sample of 511 AYA with nine different chronic health conditions [36]. The three previous systematic reviews included studies with considerably smaller sample sizes than those reviewed in the given study. The largest sample size for a development study was 226 in the Stinson review [5] and 192 in the other two reviews [4, 6].

The ADAPT, a measure that was developed during the review period, was the only disease-neutral measure that was used exclusively in studies with diverse health conditions by the originator of the tool [47, 48]. One study involved 1632 adolescents from both complex chronic

disease and noncomplex chronic disease categories as per health plan insurance designations, and from 10 difference clinics at Boston Children's Hospital [47]. One study had 1355 subjects including six chronic disease categories [48]. These two studies had the largest sample sizes among the articles included in this review.

AYA were the target population in most of the included studies. Eight studies however, elicited the parents' perspectives as well, using the utilized transition measure to assess both the AYAs' and parents' perspective of transition. Six of these studies provided a transition measurement tool to the AYA with a parallel version for parents to use. The STAR-x and parent version of the STAR-x, the STARx-P, was used in two studies [27, 31]. The RTQ was used with AYA/parent dyads in two studies [38, 59]. The CHD Readiness Transition Assessment [53], the measure from the Moving On binder [55], and the Fontan procedure in-house questionnaire [58] were also used with adolescents and parents. In one study [29] it is reported that the STARx was used for all participants, and although there is reference to patient-reported and parent-reported surveys, there is no reference to the STARx-P. The development of the TRI item pool, based on the social-ecological model of AYA readiness for transition (SMART) that involves a parallel parent version, is still in the early stages of validation and development [51]. None of the measures were used to elicit the perspectives of the healthcare providers.

Recommended best practices

As per the Cohen criteria [7], eight of the 19 tools achieved a ranking of "well-established assessment" [1, 11, 26, 32, 37, 39, 41, 43]. Four tools achieved a ranking of "approaching well-established assessment" [45, 47, 49, 51] and four achieved a ranking of "promising assessment" [52–55]. The three remaining measures [56–58] did not achieve a ranking in any of the categories, indicating that their psychometric qualities were inadequately reported or not reported at all. One measure, the TRAQ, emerged as the current best practice in comparison to the others included in this study. Five aspects of transition readiness measures emerged as best practices for clinical and research consideration.

Discussion

Review and synthesis of the literature included articles that met inclusion criteria since 2014 when three systematic reviews of transition readiness measures were completed simultaneously [4–6]. Compared to previous systematic reviews, the number of articles included in

this review, $n = 48$, was considerably higher than the 14 articles [5], 10 articles [4], and 10 articles [6] in the previous reviews. The inclusion criterion was similar across all four systematic reviews. In addition, like previous reviews, both validated and non-validated measures were included. Within the 48 articles included in this review, 19 tools were identified; ten of the 19 were validated and six were not; researchers reported initial validation of three tools while discussing future implications to include further validity and reliability studies. The large number of articles in our review demonstrates the increasing attention on the study of transition readiness measures, both new and previously developed. There is recognition that measures are still in the early stage and measures that have been rigorously tested with multiple patient populations and large sample sizes are needed.

The recent literature, however, including academic publishing, guidelines, and practices, shows only slow movement towards achieving a gold standard measure of readiness of adolescents and young adults to transition to adult healthcare units; a gold standard being a validated measure that may be used longitudinally, across cultures and countries, and among varied health settings and conditions. Regardless, six best practices emerged from this systematic review. Five are generalizable to future research and clinical practice. A sixth is the current best-validated measure of transition readiness.

Best practice 1: a measure grounded in theory

There is growing emphasis on grounding transition readiness measures in theory to support the validity [4]. A minority of the measures in this review, five of the nineteen (i.e. TRAQ 4.1 and 5.0, Am I ON TRAC for Adult Care, TRI item pool, and the transition readiness measure from the Moving On binder) were informed by theory, frameworks and models, including individual and self-management theory, stages of change model, the ON-TRAC framework, and social-ecological model of AYA readiness for transition (SMART). In addition, some argue that many tools do not capture socio-ecological factors that are theoretically important for transition readiness [18, 51]. The majority of the measures in this review focused on disease knowledge, disease self-management, medication management, and healthcare provider communication. Researchers agree measuring patient experience, as well as self-management and self-advocacy skills is needed. Sawicki argues that by measuring patient experience, healthcare providers will be able to evaluate and compare the quality of the transition preparation among clinical

programs or larger health systems [47, 48]. It is essential that future research focus on psychological characteristics affecting life-long successful self-management regardless of age, while also including the healthcare provider and family perspective [60, 61].

Best practice 2: a measure using longitudinal design

Measurement of transition readiness over time, as part of developing more reliable evidence-based transition programs and transition processes, is necessary and slowly appearing in the literature. Guidelines provided by the American Academy of Pediatrics (AAP) and the American Academy of Family Physicians (AAFP) [62] recommended that healthcare providers regularly assess transition readiness using an objective measure [2]. However, of the 48 articles included in this review, only seven had a longitudinal design. This was highlighted as a need for future tool development in the previously published systematic reviews [4–6]; however, this continues to be an area for improvement. In this review the following four measures were used longitudinally in a total of seven of the reviewed articles; TRAQ 4.1 [14, 16, 17] and 5.0 [24, 25], STARx [30], and OYOF-TES [54]. Transition is not a one-time event; using a transition readiness measure over time may contribute to personalizing the transition process for AYA [5, 25]. Researchers agree that the transition process takes many years [24, 25]. Having the ability to assess transition readiness over time will lead to the introduction of interventions specific to an AYA's individual needs [1, 24, 63].

Best practice 3: a measure validated for patients under 16 years of age

Researchers agree transition interventions can begin at an early age [2, 24, 25, 41]. Previous studies have consistently demonstrated that patient age is one of the common predictors of transition readiness [30, 60]. Increasing age correlates with increasing transition related knowledge [16, 17, 20, 38, 59]; however, chronological age may not be the best indicator of transition readiness [24, 39]. Findings from two studies highlighted that age should not define readiness for transition; instead, readiness should develop over time as the adolescent achieves targeted psychosocial, educational and medical independence [13, 64]. It can take several years for patients to gradually assume responsibility for chronic disease management [24]. Assessing psychosocial maturity gives healthcare providers the ability to be flexible and client centered throughout the transition period. There is flexibility on the

lower age to begin introduction to the transition process; however, there may be a limit on the upper age to complete the transfer because of some funding restrictions once the AYA reaches 18.

Coordinated and supportive transition involves individualization and ongoing assessments of transition readiness. Individual studies have shown the value of beginning transition planning around the age of 12–14 years, allowing AYA time to master skills necessary to manage their own healthcare responsibly [25, 38, 47, 63]. To meet the needs of AYA and promote successful transitions, measures of transition readiness need to be done over time [12, 29, 65]. This research reinforces the need to engage AYA at an early age and throughout the transition process.

Best practice 4: a measure engaging multiple stakeholders

Planned strategies should engage AYA before the expected transition period and involve all members of the pediatric healthcare team. AYA and their parents should be engaged in the preparation for transition services beginning around the age of 12–14 years [27]. Previous systematic reviews recommended assessing transition readiness from multiple perspectives yet most measures continue to lack the view of parents or healthcare providers [4, 5]. Only eight of the 48 studies involved parents in the measures of transition readiness. Of the eight studies, six measured transition readiness by parents as well as AYA utilizing parallel parent versions (TRI item pool, STARx-P, RTQ); tools to be completed by healthcare providers were not evident in any studies. Parent assessment of transition readiness and healthcare provider recognition of transition knowledge and behaviour deficits will prompt interventions to promote successful transition to adult healthcare and maximize lifelong physical and psychosocial functioning [53, 56].

Patients' readiness for transition needs to be rigorously and regularly assessed by applying validated measurement tools [66]. The priority for healthcare providers of both pediatric and adult services is to develop a universally structured process and evidence-based transition program, utilizing validated tools, which are user-friendly to all patients and not disease-specific [66, 67]. An improved transition process that educates AYA involves parent perspectives. The process engages the healthcare provider to have the potential to improve quality of life and decrease the burden on the healthcare system [23, 34]. Measures from the parent perspective are crucial. There is an ever-changing balance between adolescent healthcare responsibility and parental involvement during the

transition process [27, 37, 51]. Research has recognized that parents and or caregivers incorrectly perceive their AYA's feelings about transition and comfort level with their healthcare providers [27]. This research reinforces the need to engage AYA and their parents at an early age and throughout the transition process. AYA should aim to incrementally increase their amounts of healthcare responsibility, as their developmental abilities allow and their parents become less involved.

Best practice 5: a measure with high methodological quality

The methodological quality of transition readiness measures was the basis of evaluation in this systemic review. Despite multiple national clinical guidelines for healthcare transition, deficiencies remain in the quality of transition readiness and transition preparation [48]. This review identified 19 measures of transition readiness used in studies published in peer-reviewed journals. Two measures in this review did not have titles [55, 58] and eight measures were published in one peer-reviewed journal only [51–58].

Eight of the 19 measures (42%) achieved a status of “well-established assessment” according to the Cohen criteria [7]. This indicates that the measures were published in at least two peer-reviewed journals; that there was easy access to either the measure, manual or both; and detailed information about validity and reliability available. Four tools (21%) were classified as “approaching well-established” indicating the measures were published in at least two peer-reviewed journals by the same investigatory team; the researchers provided sufficient detail about the measure for replication and evaluation; and the tools validity and reliability were vaguely described. Finally, four tools (21%) were classified as “promising assessment”; indicating the measures were published in at least one peer-reviewed journal; validity and reliability were presented in vague terms or not presented at all; and there were limited details about the measure to allow for evaluation and replication. Three measures (16%) did not meet the Cohen criteria.

This represents an improvement in validity and reliability since the Stinson et al. systematic review, where no tools were classified as “well-established” and six out of 7 tools (86%) received a ranking of “promising assessments” [5]. In the other two systematic reviews methodological quality was not assessed [4, 6]. Researchers agree that a successful transition process requires a standard approach in assessing and facilitating the maturity

and self-management of an adolescent; however, there continues to be a lack of structured transition programs and operational definitions [63, 67].

Best practice 6: the transition readiness assessment questionnaire (TRAQ)

The final recommended best practice emerged from comparing the methodological qualities of the nineteen transition readiness measures included in this systematic review. The TRAQ was previously recommended or identified as the best-validated measure of transition readiness [2, 6]. Based on this systematic review, it is evident that the TRAQ, as a disease-neutral and theory-informed tool, remains the best-validated measure. The TRAQ has been utilized with multiple chronic disease populations, in both disease-specific and disease-neutral environments. The TRAQ is easy to administer, short to fill out, and easily available online to download and utilize. It has been implemented internationally. Use of the TRAQ with AYA with many different chronic health conditions has successfully shown positive longitudinal transition readiness scores over 6 years [30]. The TRAQ has been translated and validated to three languages. The TRAQ has not been validated in adolescents less than 16 [3]. Considering the strengths and weaknesses the TRAQ is currently the best-validated measure for transition readiness.

Limitations of the review

This review systematically identified and evaluated the current measures of readiness of AYA transitioning to adult care. The literature search included only articles published in peer-reviewed journals; therefore, measures nearing completion or awaiting publication were not included. A systematic review is a form of knowledge synthesis that summarises the results of healthcare studies and provides an overview of the effectiveness of healthcare interventions. It is however, up to clinicians and researchers to make conclusions about the evidence and inform recommendations for healthcare [68]. Additionally, only English manuscripts were included, and many of the studies originated in Canada or the United States. Due to the country of origin, many of the measures had questions directed to those living in North America, such as the TRAQ's questions about health insurance. These measures may need to be modified for use in other countries.

Conclusions

This review was timely given the proliferation of published articles in the field of transition. This review demonstrates the growing interest in measures of transition readiness. In the short time period of 4 years, 48 additional articles were identified, representing 19 tools, 15 that were not included in previous systematic reviews. An additional strength of this review is that it demonstrated advancement in the field of transition readiness measurement according to the Cohen criteria [7], which is consistent with the previous systematic review that determined methodological quality of the transition readiness measures [5]. Subsequent systematic reviews of transition readiness could utilize the Cohen criteria for continued consistency.

Five recommended best practices emerging from this systematic review are to use transition measurements which are based in theory, use longitudinal design, appropriate for patients under 16 years of age, engage multiple stakeholders, and meet high standards of methodological quality. Based on the literature reviewed in this study, the TRAQ remained the best measure of transition readiness. Utilized in 17 of the 48 articles, it remains the most reliable, valid, and widely used tool. The TRAQ's disease-neutral design has allowed researchers from countries across the world to utilize the tool, with little modification needed.

It was also demonstrated in this systematic review that few transition readiness measures are informed by theory. This was similar to findings of previous systematic reviews. Clinicians and researchers continue to create their own tools ad hoc instead of utilizing previously validated and well-established measures. Regardless of the chronic health condition, without a well-designed transition measure, such as the TRAQ, adolescents and young adults are at an increased risk for loss to follow-up during the challenging transfer period [2, 69–72]. Healthcare advancements have improved the likelihood of chronically ill children surviving into adulthood and with access to well-validated transition readiness measures clinicians and adolescents and young adults have the potential to feel more confident and be more successful with transitioning patients from specialized pediatric to specialized adult care.

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