Université de Montréal

Exploration de la préparation à la transition chez les adolescents et jeunes adultes ayant une maladie chronique à l'aide du *Transition Readiness Assessment Questionnaire* (TRAQ)

Exploring transition readiness in adolescents and young adults with chronic medical conditions using the Transition Readiness Assessment Questionnaire (TRAQ)

par

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Essai doctoral d'intégration présenté en vue de l'obtention du grade de Doctorat en psychologie (D. Psy.), option psychologie clinique

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Résumé

Cet essai doctoral porte sur la préparation à la transition des soins pédiatriques aux soins pour adultes des adolescents et jeunes adultes (AJA) souffrant de diverses maladies chroniques. Jusqu'à maintenant, l'outil ayant le meilleur soutien empirique quant à l'évaluation de cette préparation à la transition est le *Transition Readiness Assessment Questionnaire* (TRAQ).

Le premier objectif de l'essai doctoral était d'identifier des éléments qui contribuent au développement d'habiletés spécifiques liées à la préparation à la transition des AJA ayant des diagnostics de maladies chroniques variés. La première étude porte donc principalement sur les réponses des AJA aux items du TRAQ, ainsi qu'à la contribution de différentes caractéristiques sociodémographiques, médicales et psychosociales sur celles-ci. Les résultats suggèrent que l'acquisition d'habiletés liées à la préparation à la transition était influencée par l'âge, le sexe, ainsi que le fonctionnement psychosocial des AJA. En effet, les AJA qui avaient davantage commencé à développer des compétences liées au TRAQ étaient plus âgés, de sexe féminin, et déclaraient un meilleur bien-être émotionnel, social et scolaire/professionnel.

Le deuxième objectif de l'essai doctoral était d'explorer les liens entre le niveau de préparation à la transition des AJA survivants d'un cancer pédiatrique (SCP) et leurs buts auto-rapportés dans une clinique de suivi à long terme en oncologie. Malheureusement, étant donné des difficultés imprévues, le processus de recrutement a été interrompu et seulement un début de travail a été effectué sur cet objectif initial. Cependant, cet objectif a été révisé afin d'identifier les facteurs qui ont entravé sa réalisation. Par conséquent, le deuxième objectif de l'essai doctoral étaient plutôt d'identifier les barrières et les facilitateurs de l'utilisation systématique du TRAQ dans une clinique de suivi à long terme pour les AJA SCP. Ainsi, la deuxième étude porte principalement sur les facteurs entravant et facilitant l'implantation du TRAQ tels qu'identifiés par le personnel de soins

de la clinique de suivi à long terme en oncologie. Les résultats relèvent plusieurs barrières et facilitateurs de l'implantation du TRAQ, notamment au niveau de l'outil-même (c.-à-d., du TRAQ), de ceux qui l'administrent (c.-à-d., du personnel de soins), de ceux qui se le font administrer (c.-à-d., des AJA SCP) et du contexte (p. ex., de la pandémie du coronavirus). Des stratégies et moyens pour favoriser une implantation réussie ont également été proposés.

En bref, cet essai doctoral contribue à la recherche scientifique en identifiant des caractéristiques liées à une moins bonne préparation à la transition des soins pédiatriques aux soins pour adultes chez les jeunes souffrant de maladies chroniques variées (c.-à-d., les AJA plus jeunes, de sexe masculin, et rapportant un bien-être émotionnel, social et scolaire/professionnel plus faible). L'identification de ces facteurs de risque pourrait encourager le développement d'interventions ciblées visant à augmenter le niveau de préparation à la transition des AJA. De plus, l'échec rencontré quant au deuxième objectif initial de cet essai doctoral met en lumière la pertinence d'élaborer un plan d'implantation du TRAQ afin de faciliter son utilisation clinique systématique, particulièrement auprès des AJA SCP.

Mots-clés : psychologie clinique, pédiatrie, transition, adolescents, jeunes adultes, maladies chroniques, survivants d'un cancer pédiatrique, science de l'implantation, barrières, facilitateurs

Abstract

This doctoral dissertation focuses on adolescents and young adults (AYA) with various chronic medical conditions and their readiness to transition from pediatric to adult healthcare settings. To date, the tool with the best empirical support for assessing transition readiness is the Transition Readiness Assessment Questionnaire (TRAQ).

The first objective of this doctoral dissertation was to identify constructs contributing to the development of specific transition-readiness skills in AYAs with varying chronic condition diagnoses. Therefore, the first study focuses on AYAs' responses to the TRAQ items, as well as on the influence of various sociodemographic, medical, and psychosocial characteristics on their level of transition readiness. The results suggest that the acquisition of specific transition-readiness skills was influenced by AYAs' age, sex, and psychosocial functioning. Indeed, AYAs who were more likely to have started developing TRAQ-related skills were older, female, and reported better emotional, social, and school/work well-being.

The second objective of this doctoral dissertation was to explore the associations between AYA childhood cancer survivors (CCS)' level of transition readiness and their self-set goals at a long-term follow-up (LTFU) oncology clinic. Unfortunately, due to unforeseen difficulties, the recruitment process was interrupted and only a preliminary work was done toward this initial objective. However, the objective was revised to identify the factors that hindered its achievement. As a result, the second objective was to identify the barriers and facilitators to the systematic use of the TRAQ in a LTFU clinic for AYA CCS. Thus, the second study focuses on the factors hindering and facilitating the implementation of the TRAQ as reported by the oncology LTFU clinical staff. The results identify a number of barriers and facilitators to TRAQ implementation related to the tool itself (i.e., the TRAQ), those who administer it (i.e., the healthcare staff), those

to whom it is administered (i.e., AYA CCS), and the context (e.g., the coronavirus pandemic). Strategies and means to promote a successful implementation were also suggested.

In sum, this doctoral dissertation contributes to the scientific literature by identifying characteristics associated with lower readiness to transfer from pediatric to adult healthcare settings for youths with a variety of chronic conditions (i.e., AYAs who are younger, male, and who report poorer emotional, social, and school/work well-being). Identifying these risk factors could lead to the development of targeted interventions aimed at increasing AYAs' level of transition readiness. Furthermore, the failure to meet the initial second objective of this doctoral dissertation highlights the need to devise an implementation plan for the TRAQ in order to facilitate its systematic clinical use, particularly with AYA CCS.

Keywords: clinical psychology, pediatrics, transition, adolescents, young adults, chronic conditions, childhood cancer survivors, implementation science, barriers, facilitators

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Liste des sigles et des abréviations

α – Cronbach's alpha

AJA – Adolescents et jeunes adultes

ANOVA – Analysis of Variance

AYA – Adolescent and young adult

c.-à-d. – C'est-à-dire

CCS – Childhood cancer survivors

CI – Confidence interval

COVID-19 – Coronavirus 2019

df – Degrees of freedom

e.g. – Exempli gratia

F – *F*-value

HCP – Healthcare provider

i.e., – Id est

LTFU – Long-term follow-up

M – Mean

MENA – Middle Easterner and North African

n – Number of respondents

p. ex. – Par exemple

p – *p*-value

PedsQL – Pediatric Quality of Life Inventory™ version 4.0

SCP – Survivants d'un cancer pédiatrique

SD – Standard deviation

SE – Standard error

SJUHC – Sainte-Justine University Health Centre

TRAQ – Transition Readiness Assessment Questionnaire

TRAQ-FR – French version of the Transition Readiness Assessment Questionnaire

χ^2 – Chi-squared

Dédicace

À mes parents que j'aime tant, Hermel Chapados et Suzanne Corneau.

Article 1

Title: Transition Readiness Assessment Questionnaire: Skill gaps and psychosocial predictors of transition readiness among adolescents and young adults with chronic medical conditions

Running head: Skill gaps and psychosocial predictors of transition readiness

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Abstract

Background: Transferring from pediatric to adult care can be challenging. Adolescents and young adults (AYAs) with chronic health conditions need to develop a specific set of skills to ensure life-long medical follow-up due to the chronicity of their condition. The Transition Readiness Assessment Questionnaire – French version (TRAQ-FR) is a 19-item questionnaire measuring such skills. The aims of the study were to 1) describe participant characteristics and 2) identify constructs related to, and predictors of, having learned domain-specific transition readiness skills.

Methods: Participants included 216 AYAs aged 14-20 years (M=15.93; SD=1.35; 54.1% male) recruited from five outpatient clinics in a Canadian tertiary hospital. AYAs completed the TRAQ-FR, the Pediatric Quality of Life Inventory 4.0 (PedsQL), and a sociodemographic questionnaire. Descriptive, bivariate, and binary logistic regression analyses were conducted.

Results: Overall, participants reported significantly higher scores on the Talking with Providers, Managing Daily Activities, and Managing Medications subscales than on the Appointment Keeping and Tracking Health Issues subscales (F[4,1075]=168.970, p<.001). At the item level, median scores (on a 5-point Likert scale) suggest that AYAs had begun practicing 5 of the 19 skills (median scores ≥4; "Yes, I have started doing this"), while a median score of 1 ("No, I don't know how") was found for one item ("Do you get financial help with school or work?"). At the subscale level, TRAQ-FR skills and skill gaps were related to AYAs' age, sex, and PedsQL scores (ps<.05).

Conclusion: Older and female AYAs were more likely to have begun practicing specific TRAQ-FR subscale skills. Better psychosocial functioning was also related to having learned specific transition readiness skills. AYAs show several gaps in transition readiness. Targeted intervention in transition readiness skill development could take into account AYAs' age, sex, and psychosocial functioning for a successful transfer to adult care.

Keywords: Pediatrics, Patient transfer, Adolescent, Young adult, Quality of life

Introduction

It is estimated that 10-20 million children and adolescents are living with a chronic condition in the United States [1]. Due to recent medical and technological breakthroughs, more than 90% of youth diagnosed with a chronic medical condition are expected to survive into adulthood [2,3,4]. However, many will require lifelong medical follow-up because of the chronicity of their condition and the risk of late effects [5]. Therefore, it is essential that these youths develop transition readiness skills [2,4,6]. Transition is an essential process supporting youth in acquiring self-care, self-advocacy, and the knowledge necessary to pursue care in adult care settings [7].

Notably, guidelines for transition care have recommended routine assessment of transition readiness [8]. To this end, a number of assessment instruments have been developed, and systematic reviews have concluded that the Transition Readiness Assessment Questionnaire (TRAQ) had the greatest empirical support to date [9,10]. The TRAQ is a condition-neutral, self-administered questionnaire, and its final version consists of 20 items divided into five subscales [4]. The TRAQ has been translated and validated into several languages [11,12,13,14,15,16,17,18], including French (TRAQ-FR) [19].

As pediatric long-term follow-up care programs begin to implement transition readiness assessment, it is important to understand the specific gaps in AYA transition readiness skills to inform care targeted to the needs of AYAs with chronic conditions. Typically, studies using the TRAQ have reported the total score, which allows for a broad idea of AYA transition readiness, but does not allow for a clear understanding of specific skill deficits. Although some studies reported differences in total TRAQ score in AYAs prior to age 18, none reported transition readiness skills only in pretransfer AYAs (≥18 years old). In theory, the age limit for pediatric services is 18, after which patients are assigned to adult care; however, in practice, patients may

continue to be treated in the pediatric care system after age 18 depending on their healthcare needs [20,21,22,23].

Thus far, lower overall transition readiness has been associated with younger age [4,11], being male [14,19], cognitive impairment [3], and lower health literacy beliefs [24]. Beyond global scores, few studies identified predictors of transition readiness at the subscale level [4,16], and several factors associated with transition readiness have yet to be assessed, such as AYAs' psychosocial functioning [16,25]. Identifying AYA transition readiness skills and skill gaps, both in general and at transfer age, could be a valuable means of promoting a successful transition to the adult care system. The use of evidence-based screening measures such as the TRAQ may offer a helpful basis from which transition psychoeducation and tools can be delivered consistent with individual patient needs and skill levels [26].

This study consists of secondary analyses of the baseline data reported by Chapados and colleagues (2021). In their study, the authors' focus was on determining the psychometric properties of the TRAQ-FR in a French-speaking population. Analyses included identifying predictors of *overall* transition readiness to evaluate the tool's criterion validity [19]. Study findings suggested that AYA patients' age and sex were predictors of their *global* transition readiness, whereas their psychosocial functioning was not [19,25]. However, because psychosocial functioning includes very distinct components (e.g., physical and emotional well-being) [27], an aggregated psychosocial functioning score may be of limited significance in relation to overall transition readiness, and a *subscale*-level analysis is warranted. As pediatric long-term follow-up care programs begin implementing the TRAQ in clinical care worldwide, it is essential to identify AYAs' *specific* challenges. In order to address these gaps in the literature, the aims of the study are to 1) describe item-level transition readiness skills and skill gaps of AYAs with chronic medical

conditions, both in the overall sample and in the pretransfer subgroup, and 2) examine predictors of transition readiness skills at the TRAQ subscale level.

Methods

Participants

Inclusion criteria for AYAs were 1) being between 14-20 years old, 2) having a diagnosis of chronic condition and being followed annually at either the hematology-oncology, diabetes, cystic fibrosis, epilepsy, or nephrology clinic of a tertiary pediatric hospital, and 3) speaking and reading French.

Procedure

The study protocol was approved by the local research ethics committee (#2016-1220). Participants were recruited from October 2016 to January 2018. Eligible AYAs were told about the study either over the phone or in person by a research assistant or a healthcare professional. For those who agreed to participate, consent was obtained from both AYAs and their accompanying caregivers regardless of AYAs' age [19]. Patients then consecutively received an identification number as they were recruited at the outpatient clinics. They were given the option to complete the questionnaires at the clinic or at home, and the latter received a stamped self-addressed envelope. Participants were instructed to complete the self-reported questionnaires individually and to answer them to the best of their knowledge in a way that best reflected their reality.

Measures

Sociodemographic and medical questionnaire. The following sociodemographic and medical data were collected from participants: age, sex (female, male), race/ethnicity (Black, Latinx, Middle Easterner and North African [MENA], White, Other), education level (high school, college), and chronic medical condition (cancer, cystic fibrosis, diabetes, epilepsy, kidney disease).

TRAQ-FR. The TRAQ-FR consists of 19 items divided into five subscales: Managing Medication (4 items), Appointment Keeping (6 items), Tracking Health Issues (4 items), Talking with Providers (2 items), and Managing Daily Activities (3 items) [4,19]. The item "Do you apply for health insurance if you lose your current coverage" was removed as it did not culturally apply to several French-speaking communities worldwide [19]. Each item is rated on a five-point Likert scale ranging from "No, I don't know how" to "Yes, I always do this when I need to," with higher scores indicating higher transition readiness. The TRAQ has shown high reliability and good validity in patients diagnosed with a variety of chronic medical conditions [4]. In this study, good reliability was found for the TRAQ-FR total score and the "Appointment Keeping" subscale (α=.84 and α=.80, respectively). The other subscales showed lower reliability estimates, with αs ranging from .44-.62 [28]. For binary logistic regression analyses, TRAQ-FR item scores were coded dichotomously: scores ≤3 ("No, but I am learning to do this") corresponded to unlearned skills, whereas scores ≥4 ("Yes, I have started doing this") represented emerging or acquired skills.

Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL). The PedsQL is an assessment instrument that measures health-related quality of life in a pediatric population [27]. In this study, the validated French versions of self-reports for AYAs ages 13-18 and 18-25 were used [29]. Scores were reverse-coded and transformed into percentages (0=100, 1=75, 2=50, 3=25, 4=0), with higher scores indicating better quality of life [27]. In this study, the PedsQL scale showed good internal consistency [28].

Statistical analysis

Statistical analyses were conducted using the Statistical Package for the Social Sciences version 26, and *p*-values <.05 were considered statistically significant [30]. To determine whether data was missing at random, we performed Little's Missing Completely at Random test

(χ^2=352.957, *df*=382, *p*=.854; missing data rate=1.67%). Because data was missing at random, we used multiple imputation analysis to reduce bias and retain as many cases as possible in our final sample [31,32,33]. A one-way ANOVA examined differences between TRAQ-FR subscale and item scores across medical conditions, using Bonferroni post-hoc tests for significant results. Bivariate analyses between AYAs' TRAQ-FR dichotomous variable (on average, skills begun versus not begun) and their medical diagnosis, sex, age, and PedsQL scores consisted of Fisher *z*-statistics, chi-square tests, and independent-samples *t*-tests, respectively. Finally, we performed binary logistic regression analyses to ascertain the effects of demographic, medical, and quality of life variables on the likelihood that AYAs had, on average, begun versus not begun transition readiness skills for each TRAQ-FR subscale.

Results

The final study sample consisted of 216 AYA patients. Sociodemographic and medical data are presented in ***Table 1***. Participants were on average 15.9 years (*SD*=1.4), most of them were White (89.4%) and male (53.7%). The majority of participants were in high school (81.3%) at the time of recruitment. Patients were recruited at the following outpatient clinics of the Sainte-Justine University Health Centre (SJUHC): hematology-oncology (41.2%), diabetes (19.4%), cystic fibrosis (16.2%), epilepsy (15.3%), and nephrology (7.9%) clinics. 34 participants (15.7%) had at least one missing value on the TRAQ-FR. Patients with missing values significantly differed from those who did not in terms of sex and race/ethnicity, with greater missing values on the TRAQ-FR associated with being female versus male (χ^2[1]=9.577, *p*=.002) and with patients identifying as visible minority versus White (χ^2[1]=7.037, *p*=.008). Participants' missing values did not significantly differ in terms of chronic conditions, age, and education level.

Table 1. Sociodemographic and medical data (*n*=216)

AYA patients (*n*=216)	*n* (%)	Mean ± *SD*	Range
Sex			
Female	100 (46.3)		
Male	116 (53.7)		
Age		15.9 ± 1.4	14 – 20
Race/ethnicity			
White	193 (89.4)		
MENA	8 (3.7)		
Black	5 (2.3)		
Latinx	5 (2.3)		
Other	5 (2.3)		
Education (*n*=208)			
High school level	169 (81.2)		
College level	39 (18.8)		
Clinics			
Hematology-oncology	89 (41.2)		
Diabetes	42 (19.4)		
Cystic fibrosis	35 (16.2)		
Epilepsy	33 (15.3)		
Nephrology	17 (7.9)		

Note. AYA=adolescent and young adult; MENA=Middle Eastern and North African; *n*=number of respondents; *SD*=standard deviation.

Aim 1: Describing transition readiness skills and skill gaps.

TRAQ-FR subdomain skill scores in the overall group. A long-to-wide format one-way ANOVA indicated significant differences in average skill ratings by TRAQ-FR subdomain (F[4,1075]=168.970, p<.001). Bonferroni post-hoc tests indicated significantly higher mean scores on the subscales of Talking with Providers (*M*=4.49; *SD*=0.77; all *p*s<.001), Managing Daily Activities (*M*=4.10; *SD*=0.78; all *p*s<.001), and Managing Medications (*M*=3.65; *SD*=0.96; all *ps*<.001). No statistically significant mean differences were found between the Appointment Keeping (*M*=2.74; *SD*=1.07) and Tracking Health Issues subscales (*M*=2.62; *SD*=1.04; *p*=1.000; ***Table 2***).

Table 2. Bonferroni post-hoc tests for the 5 TRAQ-FR subscales mean scores (*n*=216)

TRAQ-FR subscales		Mean Difference (I–J)	SE	95% CI	
Subscale (I)	Subscale (J)			Lower Bound	Upper Bound
Managing Medications	Appointment Keeping	.917***	.090	.664	1.169
	Tracking Health Issues	1.034***	.090	.781	1.287
	Talking with Providers	-.838***	.090	-1.091	-.586
	Managing Daily Activities	-.452***	.090	-.705	-.200
Appointment Keeping	Tracking Health Issues	.118	.090	-.135	.370
	Talking with Providers	-1.755***	.090	-2.008	-1.502
	Managing Daily Activities	-1.369***	.090	-1.622	-1.116
Tracking Health Issues	Talking with Providers	-1.872***	.090	-2.125	-1.620
	Managing Daily Activities	-1.486***	.090	-1.739	-1.234
Talking with Providers	Managing Daily Activities	.386***	.090	.133	.639

Note. CI=confidence interval; *n*=number of participants; SE=standard error; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.
***$p<.001$

Specific TRAQ-FR skills and skill gaps in the overall group. Descriptive statistics for transition readiness skills by chronic medical conditions are presented in ***Table 3***. No statistically significant mean differences were found for TRAQ-FR subscale and item scores, with the exception of item 18 ("Do you keep home/room clean or clean up after meals?"; (F[4,211]=2.967, p=.021). The Bonferroni post-hoc tests indicated that AYAs with epilepsy reported significantly higher scores on item 18 than AYAs with diabetes (p=.032). Aggregating scores across chronic conditions, 5 items had mean scores above the threshold of emerging skills (M=4; "Yes, I have started doing this"). Mean scores on the remaining 14 TRAQ-FR skills (73.6%) indicated that the majority of participants had, on average, not begun learning these skills. Importantly, a median

score of 1 ("No, I do not know how") was found for one item ("Do you get financial help with school or work?"). The quartile and median scores of AYAs' TRAQ-FR ratings suggest that older AYAs tend to have developed transition readiness skills to a greater extent than younger AYAs, with the exception of those aged 19 and 20 (***Figure 1***).

Specific TRAQ-FR skills and skill gaps in the pretransfer subgroup. Descriptive statistics for transition readiness skills for AYAs aged 18 years and older are presented in ***Figure 2***. Aggregating across chronic conditions, 9 items had mean scores above the threshold of emerging skills. However, mean scores on the remaining 10 TRAQ-FR skills (52.6%) indicated that the majority of participants had, on average, not begun practicing these skills.

Aim 2: Examining factors associated with TRAQ-FR subscale skills.

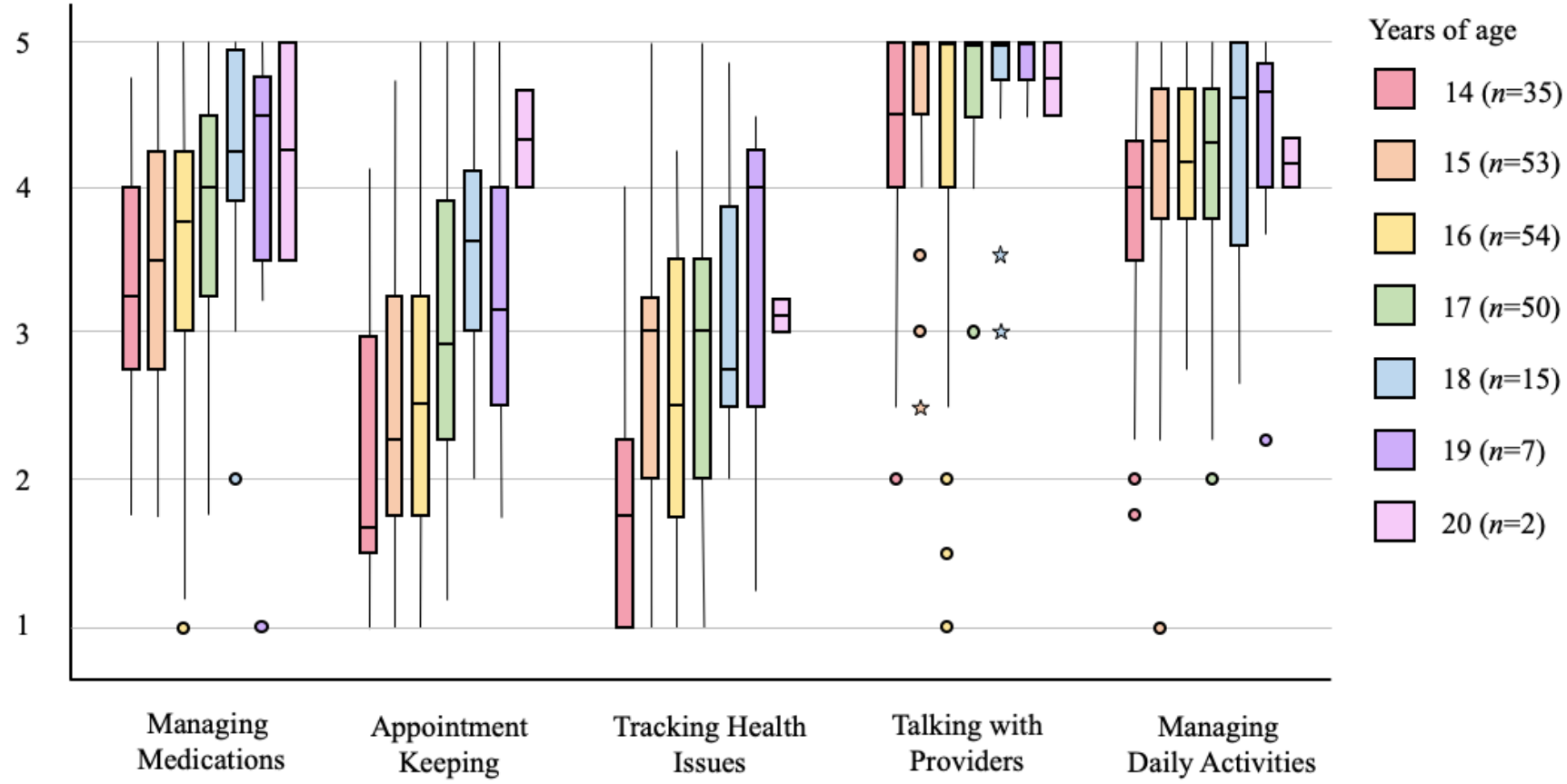
Binary logistic regression analyses were performed to ascertain the effects of medical, demographic, and quality of life variables on the likelihood that AYAs had, on average, begun versus not begun transition readiness skills for each TRAQ-FR subscale (***Table 4***). In the logistic regression models, a greater likelihood of having learned Managing Medications skills was associated with being female, older age, and higher emotional well-being (all *p*s<.05). Being female and older age were also associated with a greater likelihood of having acquired Appointment Keeping and Tracking Health Issues skills (all *p*s<.05). Being female and higher social quality of life were associated with a greater likelihood of having acquired Talking with Providers skills (all *p*s<.05). Finally, a greater likelihood of having learned Managing Daily Activities was only associated with better school/work functioning (*p*<.05).

Table 3. Descriptive statistics and ANOVAs for transition readiness skills by chronic conditions (*n*=216)

TRAQ subscales and items	Hemato-Oncology *M* (*SD*)	Diabetes *M* (*SD*)	Epilepsy *M* (*SD*)	Cystic Fibrosis *M* (*SD*)	Nephr-ology *M* (*SD*)	*F-value*
Managing Medications						**.572**
1.Do you fill a prescription if you need to?	3.15 (1.53)	3.55 (1.49)	2.85 (1.44)	2.86 (1.44)	3.35 (1.69)	1.466
2. Do you know what to do if you are having a bad reaction to your medications?	3.36 (1.63)	2.99 (1.59)	3.03 (1.74)	3.31 (1.71)	3.94 (1.30)	1.297
3. Do you take medications correctly and on your own?	4.66 (0.75)	4.76 (0.53)	4.55 (0.87)	4.63 (0.60)	4.65 (0.70)	.451
4. Do you reorder medications before they run out?	3.42 (1.57)	3.89 (1.43)	3.89 (1.56)	3.20 (1.62)	3.18 (1.47)	1.757
Appointment Keeping						**.490**
5. Do you call the doctor's office to make an appointment?	2.46 (1.34)	2.72 (1.48)	2.45 (1.44)	2.06 (1.28)	2.41 (1.46)	1.082
6. Do you follow-up on any referral for tests, check-ups or labs?	2.61 (1.41)	2.79 (1.65)	2.24 (1.44)	2.19 (1.45)	2.59 (1.54)	1.158
7. Do you arrange for your ride to medical appointments?	3.26 (1.58)	3.24 (1.68)	3.19 (1.79)	2.55 (1.66)	2.94 (1.75)	1.299
8. Do you call the doctor about unusual changes in your health (For example: allergic reactions)?	2.37 (1.35)	2.62 (1.50)	2.47 (1.47)	2.37 (1.54)	2.12 (1.36)	.450
9. Do you know what your health insurance covers?	2.20 (1.39)	2.93 (1.73)	2.41 (1.48)	2.66 (1.51)	2.76 (1.52)	1.971
10. Do you manage your money & budget household expenses (For example: use checking/debit card)?	3.58 (1.55)	3.14 (1.63)	3.36 (1.69)	3.63 (1.37)	3.18 (1.55)	.831
Tracking Health Issues						**.629**
11. Do you fill out the medical history form, including a list of your allergies?	3.57 (1.58)	3.60 (1.62)	2.91 (1.59)	3.20 (1.66)	3.41 (1.66)	1.315
12.Do you keep a calendar or list of medical and other appointments?	2.87 (1.65)	3.12 (1.64)	2.77 (1.53)	2.37 (1.46)	2.71 (1.31)	1.141
13. Do you make a list of questions before the doctor's visit?	2.37 (1.56)	2.43 (1.42)	2.50 (1.56)	2.40 (1.59)	2.41 (1.42)	.045
14. Do you get financial help with school or work?	2.03 (1.52)	1.67 (1.28)	1.73 (1.51)	1.86 (1.52)	1.58 (1.16)	.724
Talking with Providers						**2.058**
15. Do you tell the doctor or nurse what you are feeling?	4.31 (1.07)	4.17 (1.32)	3.70 (1.63)	4.03 (1.38)	4.41 (0.80)	1.712
16. Do you answer questions that are asked by the doctor, nurse, or clinic staff?	4.93 (0.25)	4.74 (0.63)	4.76 (0.79)	4.71 (0.52)	4.88 (0.33)	1.982
Managing Daily Activities						**1.991**
17. Do you help plan or prepare meals/food?	3.97 (1.17)	3.62 (1.45)	3.76 (1.23)	3.69 (1.18)	3.12 (1.32)	1.889
18. Do you keep home/room clean or clean-up after meals?	4.11 (1.15)	3.57 (1.23)	4.30 (0.88)	4.17 (0.79)	4.24 (0.75)	2.967*
19. Do you use neighborhood stores and services (For example: grocery stores and pharmacy stores)?	4.65 (0.85)	4.40 (1.13)	4.39 (1.03)	4.40 (0.91)	4.41 (1.06)	.890

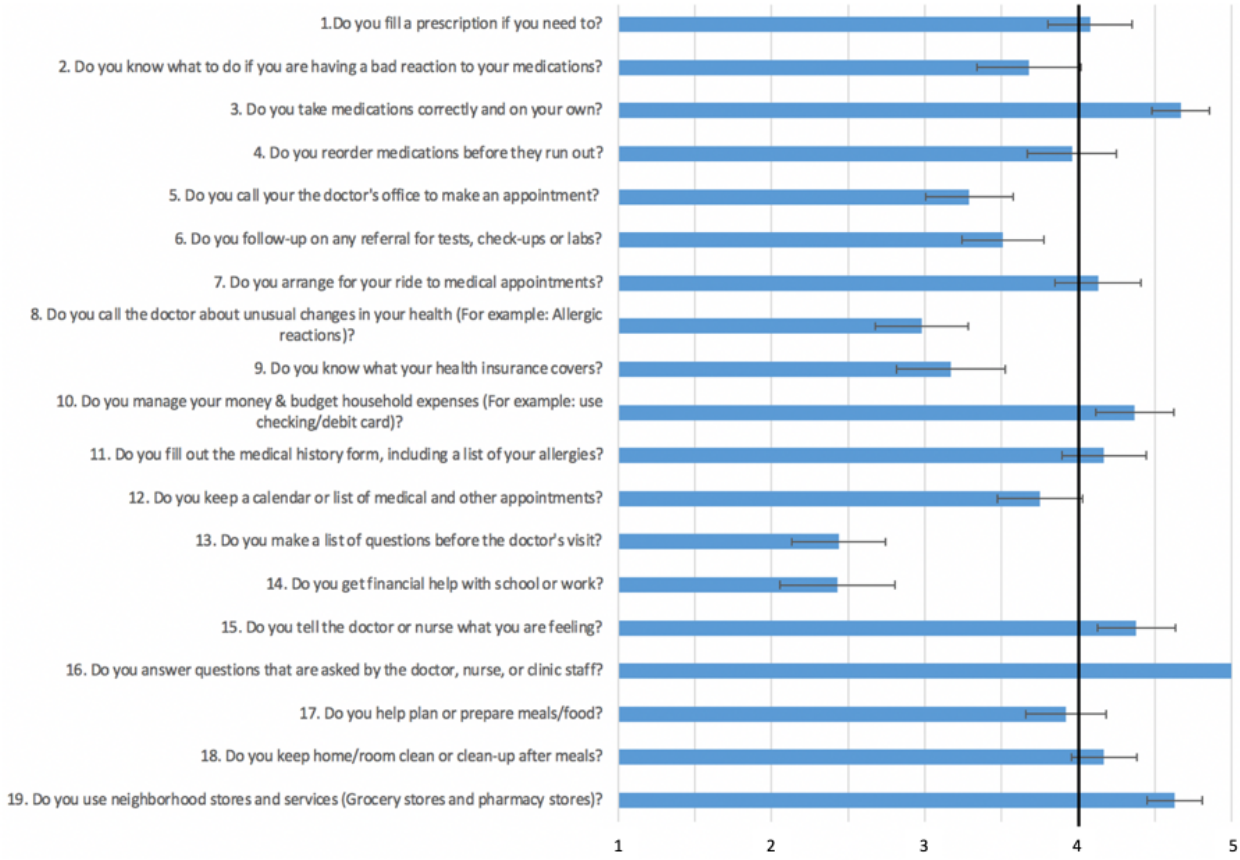
Note. ANOVAs=analysis of variance; *F-value*=ANOVA results; *M*=mean; *n*=number of individuals; *SD*=standard deviation. Scores of 1, 2, 3, 4, and 5 represent the following TRAQ-FR answer options respectively: "No, I do not know how," "No, but I want to learn," "No, but I am learning to do this," "Yes, I have started doing this," and "Yes, I always do this when I need to."
* $p<.05$

Figure 1. TRAQ-FR subscale scores by age (14, 15, …20; *n*=216)



Note. n=number of respondents; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire. Scores of 1, 2, 3, 4, and 5 represent the following TRAQ-FR Likert scale answer options respectively: "No, I do not know how," "No, but I want to learn," "No, but I am learning to do this," "Yes, I have started doing this," and "Yes, I always do this when I need to." In the boxplot, circles represent outliers, whereas stars represent far outliers which are more likely true outliers. Outliers are observations that are far removed from other values in a dataset, which may affect the results of statistical analyses.

Figure 2. Ratings on the TRAQ-FR items for AYAs 18 years and older (*n*=24)



Note. *n*=number of respondents; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire. Scores of 1, 2, 3, 4, and 5 represent the following TRAQ-FR Likert scale answer options respectively: "No, I do not know how," "No, but I want to learn," "No, but I am learning to do this," "Yes, I have started doing this," and "Yes, I always do this when I need to."

Table 4. Predictors of TRAQ-FR subscale scores (means dichotomized as acquired versus not acquired; *n*=216)

	Managing Medications OR	**Appointment Keeping OR**	**Tracking Health Issues OR**	**Talking with Providers OR**	**Managing Daily Activities OR**
Diagnosis					
Hematology-Oncology (*n*=89)	0.85	1.47	2.56	2.54	0.30
Diabetes (*n*=42)	1.62	3.88	2.90	1.32	0.34
Cystic fibrosis (*n*=35)	1.01	1.14	3.54	1.57	0.21
Epilepsy (*n*=33)	0.84	3.25	1.24	1.37	0.16
Nephrology (*n*=17)	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)
Age	**1.50**	**1.82**	**1.78**	1.01	1.11
Sex					
Female	**1.91**	**3.36**	**6.84**	**2.16**	1.14
Male	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)
PedsQL Physical	0.99	1.03	1.02	0.97	0.99
PedsQL Emotional	**1.02**	1.00	0.99	1.00	0.99
PedsQL Social	1.00	1.03	0.99	**1.03**	1.01
PedsQL School/Work	0.99	0.99	1.02	1.02	**1.02**

Note. n=number of respondents; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire. Bolded values represent statistically significant results *(p*<.05). All variables are included in the models.

Discussion

In a sample of 216 AYA patients with various chronic medical conditions, we provided item-level descriptive statistics on the TRAQ-FR, including a particular focus on AYAs aged 18 and over, and identified factors associated with TRAQ-FR domain-specific skills and skill gaps, including psychosocial functioning.

Specifically, the transition readiness skills that AYAs rated as most developed were related to everyday activities. These are activities that AYAs have frequent opportunities to practice, such as answering questions from doctors (analogous to answering questions from teachers/work supervisors). Therefore, repeated exposure to such tasks may help AYAs gain a sense of self-efficacy and reduce potential anxiety associated with performing these tasks [34].

In contrast, the transition readiness skills that AYAs rated as least developed tend to relate to more complex constructs, such as "unusual changes in [their] health," and to relatively infrequent activities. On the one hand, AYAs may lack knowledge of their personal health risks and may not know what changes in their health to report to the medical team [35]. Poor follow-up on health changes may also be related to AYAs avoiding talking about the late effects of their chronic conditions for fear of becoming more vulnerable to them as a result [36]. On the other hand, healthcare providers may lack the ability to ask questions that encourage AYAs to report changes in their health [37]. For the finance-related items, including the only TRAQ item with a median indicating "No, I don't know how", AYAs' parents may take an active role in managing finances, which may affect their emerging financial autonomy. Usually, AYAs remain on their parents' health insurance coverage until they are no longer full-time students or reach the age of 26, at which point they need their own coverage [38]. Therefore, prior to age 26, AYAs may have limited knowledge of health insurance coverage or financial aid options.

Interpretation of pretransfer AYAs' transition readiness (18 years and older) requires caution given the small sample size (*n*=24) and the fact that they are still seen in pediatric care after reaching 18 years [20]. It may be that pretransfer AYAs who are still being treated in the pediatric care system have more behavioral, cognitive, and emotional problems [23], more demanding healthcare needs than younger AYAs [21], or parental overprotection which may impede youth taking greater control in disease management [39]. Notably, Jenkins and colleagues (2022) found that AYAs aged 15 to 30 years with at least 3 childhood-onset complex chronic conditions were more frequently treated in pediatric hospitals (15.5%) than in adult care settings with (9.1%) or without pediatric services (6.7%) [22]. Pretransfer AYAs' TRAQ-FR item-level scores, compared to AYAs of all ages (14 years and older), suggest there is some progress in transition readiness skill development over time. However, while there is a desire to learn these skills, more than half of the skills have not yet begun to be practiced by AYAs aged 18 and older who are still seen in the pediatric setting.

The binary logistic regression analyses examined characteristics that were associated with having begun practicing domain-specific transition readiness skills. The findings are consistent with previous studies which found that older age and being female were associated with higher transition readiness overall [4,11,14,19]. A number of suggestions have been made in the literature that may explain these finding, such as the gradual maturation of the prefrontal cortex for older age, and potential sexual dimorphism in brain development for being female [19].

This study adds to the literature by finding that aspects of AYAs' psychosocial functioning are associated with domain-specific transition readiness skills. AYAs who reported higher emotional well-being were more likely to have acquired skills in Managing Medications. It may be that AYAs who experience more anxiety- and depression-related symptoms are more avoidant, forgetful, and have more difficulty concentrating [40]. AYAs who reported higher social quality

of life were more likely to have begun items related to Talking with Providers. This may be because better social functioning is associated with better social skills, such as assertiveness [41]. AYAs who reported better school/work functioning were more likely to have begun skills related to Managing Daily Activities. This may be because these transition readiness skills are related to everyday living, such as going to school [4]. AYAs' physical well-being was unrelated to their transition readiness, which may be because transition readiness requires more cognitive and social effort than physical [4].

Several limitations may be noted. First, the number of participants recruited from different outpatient clinics is heterogeneous (hematology-oncology: 40.3%; nephrology: 7.8%), and the vast majority of participants were White (89.4%) and under 19 years old (95.8%), which limits the generalizability of findings. However, these percentages are consistent with the projected percentage of visible minorities in the Canadian province of Quebec (11.0%) [42]. Second, information on AYAs' socioeconomic status, medical complexity or comorbidity, and proxy markers of autonomy (e.g., current living situation, pregnancy) was not collected, even though these may influence their level of transition readiness [4,11,12,14,16]. Finally, most subscales of the TRAQ showed low reliability estimates, which is often found in scales with few items (median=4) [43], and a number of TRAQ items may not apply to specific clinical populations (e.g., medication use).

There has been variability in the timing of the onset of the transition process in pediatric populations. Evidence-based guidelines have recommended a developmentally appropriate transition process [6,26], while patients and their caregivers report that the process often begins too late, with the ideal age being between 12-16 years [23]. Fortunately, the TRAQ has been validated with youth aged 14 and older, falling within this range [4,19]. Thus, future studies could examine the impact of incorporating the TRAQ into routine care for AYAs with chronic conditions starting

at age 14. Future research could also identify barriers and enablers to implementing the TRAQ in routine care to facilitate its systematic use by clinicians [44]. Clinically, the TRAQ could also inform clinicians of the health self-management skills that each AYA CCS should develop for an optimal transition, tailoring interventions to their needs. For example, based on our study results, most AYAs would benefit from support with financial literacy during the transition process, with information delivered in a developmentally appropriate format.

In sum, the TRAQ-FR can be used to screen for transition readiness skills and skill gaps in AYAs living with various chronic conditions. AYAs scored highest and lowest on the Talking with Providers and Tracking Health Issues subscales, respectively. Finally, there is a need to support males and to consider the impact of AYAs' emotional, social, and school/work functioning in acquiring transition readiness skills.

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Article 2

Title: Initial clinical implementation attempt using the Transition Readiness Assessment Questionnaire and a self-set goals prompt with childhood cancer survivors during the COVID-19 pandemic: Lessons learned

Running head: Clinical use of the TRAQ and a personal goals prompt with AYA CCS during COVID-19

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Abstract

Objectives: This study initially aimed to explore associations between adolescent and young adult (AYA) childhood cancer survivors (CCS)' transition readiness and self-reported goals. However, due to unforeseen difficulties in the administration of the TRAQ to survivors, TRAQ administration was discontinued and the study objectives were modified. As a result, we aimed to 1) describe AYA CCS' transition readiness and self-reported goals in a small sample where data was available; and 2) explore healthcare provider perceived barriers and facilitators to the clinical use of the Transition Readiness Assessment Questionnaire (TRAQ) in a long-term follow-up (LTFU) pediatric oncology clinic.

Participants: For the first objective, AYA CCS followed at the Sainte-Justine University Health Centre were recruited (*n*=7). For the second objective, healthcare providers (HCPs) of the LTFU oncology clinic were recruited (*n*=3).

Methods: During a scheduled follow-up appointment, AYA CCS completed the TRAQ and a personal goals prompt. Based on the determinants framework to implementation, semi-structured interviews were conducted with HCPs. Quantitative analysis and thematic coding were performed.

Findings: Patients scored highest to lowest on TRAQ subscales of Talking with Providers, Managing Daily Activities, Managing Medications, Tracking Health Issues, and Appointment Keeping. Pertaining to survivors' self-set goals, 3 themes were generated: 1) goal type; 2) means of achieving goals; and 3) goal motivation. With regard to clinical use of the TRAQ, 10 barriers, 7 facilitators, and 4 strategies were identified, such as tool-specific features and limited resources.

Conclusions: This study offers preliminary insights into clinical application of the TRAQ and AYA CCS' personal goals. A formal implementation plan of the TRAQ is needed to support this change in practice.

Implication for Psychosocial Providers: A greater understanding of the barriers and facilitators to the clinical use of the TRAQ may promote its implementation and use as an assessment and counseling tool within clinical practice.

Key words: adolescent; young adult; cancer survivor; healthcare provider; transition; implementation

Introduction

According to the World Health Organization [1], an estimated 400,000 individuals under the age of 20 receive a cancer diagnosis each year. Although the vast majority of childhood cancer survivors (CCS) now survive into adulthood, they are at risk of developing late effects of cancer and its treatment [2–4]. It is recommended that CCS engage in long-term follow-up (LTFU) care designed to screen, monitor, and help alleviate long-term effects, and prepare them for transfer to the adult healthcare system [3–5]. Ideally, by the time of transfer, CCS are able to manage their healthcare needs independently, which requires communication, decision-making, and self-management skills [6].

Evidence-based guidelines on transitional care in pediatrics are regularly issued to support CCS and their healthcare providers (HCPs) [7]. These guidelines recommend the use of tools with reliable outcomes to formally evaluate and monitor transition processes. Such tools are recommended to facilitate the development of care plans and to meet healthcare needs in an appropriate and useful way for the patient, family, and healthcare team [7]. In particular, the Transition Readiness Assessment Questionnaire (TRAQ) has been identified as an optimal tool to this end [8,9].

The TRAQ is a condition-neutral, self-administered questionnaire, and its final version consists of 20 items divided into five subscales (Managing Medications, Appointment Keeping, Tracking Health Issues, Talking with Providers, Managing Daily Activities) [9]. It is the transition readiness assessment instrument with the best empirical support to date [10,11]. As a result, the TRAQ is now used internationally, being translated and validated into several languages, including Spanish, Portuguese, and French (TRAQ-FR) [12–15]. The TRAQ may also be used to support the

acquisition of transition skills as a basis for transition counseling activities (setting goals, monitoring progresses toward autonomy, etc.).

Further contributing to better transition readiness are transition planning and skill development, which may be facilitated by personal goal setting [16]. Specifically, goal and action setting are among the various strategies used by CCS to manage their health and well-being [17,18]. These strategies are considered active ingredients of behavior change and self-management interventions [19], leading to increased self-efficacy and autonomy [8,18,20]. Goal setting as a self-management strategy may improve coping with the challenges of cancer survivorship and enhance well-being [17]. Therefore, survivors' self-set goals and progressive autonomy development is key to their transition readiness.

In May 2022, the LTFU program of the Sainte-Justine Hospital set out to use the TRAQ and an accompanying goal-setting prompt in the routine clinical care of pediatric oncology survivors. Initially, the purpose of this study was to explore potential associations between adolescent and young adult (AYA) CCS transition readiness and personal goals. However, the planned one-year recruitment process was stopped after 3 months due to several clinical challenges. To document and address the challenges encountered in the use of an assessment tool in routine AYA CCS care, we wish to describe how activities unfolded and identify barriers and facilitators of this experience, which will be critical to future implementation planning. In implementation science, the determinants framework may guide implementation practice by documenting potential barriers and facilitators when undertaking an implementation endeavor [21]. The current study therefore has two objectives: 1) to describe clinical examples of AYA CCS' transition readiness and personal goals, and 2) to better understand the barriers that were encountered and facilitators for subsequent implementation planning in a pediatric oncology LTFU care clinic.

Methods

This is a multi-method study with quantitative and qualitative data being evaluated for objective 1, and qualitative information being collected and analyzed for objective 2. The Standards for Reporting Qualitative Research were followed to meet rigorous standards for reporting qualitative research [22]. The qualitative part was guided by the consensual qualitative research approach rooted in a post-positivist epistemology which aimed to generate a theoretical account of 1) AYA CCS self-set goals, and 2) the barriers and facilitators to TRAQ implementation in pediatric oncology LTFU care following the determinants framework for implementation [21,23,24].

Participants

Patients. To describe clinical examples of AYA CCS' transition readiness and goal setting, the inclusion criteria were that patients had to be 1) at least 14 years old, 2) survivors of childhood cancer, 3) followed annually at the LTFU oncology clinic of a tertiary pediatric hospital, and 4) able to speak and read in French or English.

Healthcare providers. To describe barriers and facilitators to the clinical implementation of the TRAQ, the LTFU oncology team was contacted to document their experience using the TRAQ and a goal-setting prompt with AYA CCS. At the time of patient data collection, the LTFU oncology clinic consisted of one pediatric physician, one clinical-administrative manager, and two nurse practitioners. However, by the time HCPs were recruited, one nurse practitioner was no longer working at the hospital.

Setting and data collection procedures

The study protocol was approved by the hospital research ethics committee (#2022-3592). Annually, the hospital LTFU oncology clinic provides care to approximately 500 AYA CCS. To

recruit eligible survivors, the initially planned study used convenience sampling from May 2022 to July 2022. Eligible patients were identified by the nurse practitioners as per study inclusion criteria. Recruitment took place at the LTFU oncology clinic coinciding with patients' scheduled appointment times. During eligible patients' in-person visit, a research assistant inquired if they would be interested in participating in a research project about transition readiness and, if so, proceeded to describe the study. Upon acceptance, patients gave their written informed consent. Per the expressed preference of the HCPs, the research assistant then provided AYA CCS with the TRAQ tool to complete individually, while a personal goals prompt was to be answered during an interaction with a nurse practitioner. Upon completion, the nurse practitioner privately reviewed and discussed both the TRAQ and self-set goals with patients and their accompanying caregivers during the visit. After the appointment, the original hard copies of the TRAQ and goal-setting document were scanned into the electronic health record.

Following various difficulties, such as the Covid-19 pandemic, the departure of a member of the LTFU oncology team and the workload being too heavy to allow the implementation of a new clinical tool in regular patient follow-up, the recruitment process was interrupted. Instead, in order to detail the challenges that led to the administration of the TRAQ and a self-set goals prompt to a limited number of patients, we contacted the healthcare team to document barriers and facilitators to the implementation of the tool. To recruit HCPs for this follow-up, email and virtual video exchanges occurred between the research team and members of the LTFU oncology team in the months of January and February 2023. Providers who agreed to participate also signed an informed consent before being interviewed. During these exchanges, HCPs were asked to share their perceived barriers and facilitators to TRAQ use implementation through semi-structured interviews.

Semi-structured interviews with LTFU HCPs were theory-informed and developed iteratively based on the determinants framework approach, which account for 5 types of characteristics: the implementation object (i.e., TRAQ), object users and developers (i.e., HCPs), end users (i.e., AYA CCS), context (e.g., LTFU oncology clinic of a tertiary pediatric hospital), and strategies or means of facilitating implementation [21]. The semi-structured interviews were conducted individually by the first author (PC) in February and March 2023, either in person or virtually on Microsoft Teams, and lasted on average 65 minutes (range: 26-135 minutes). The semi-structured interviews were audio-recorded and transcribed into verbatim.

Measures

Participant characteristics. Patients' sociodemographic (age, sex) and medical information (cancer diagnosis, age at diagnosis, cancer treatment[s]), TRAQ scores, and personal goals were collected from their electronic health record. HCPs' sociodemographic (age, sex) and occupational characteristics (professional title, years of experience in pediatric care, years of experience at the LTFU oncology clinic) were collected via questionnaire.

Transition Readiness Assessment Questionnaire. The TRAQ is a non-condition-specific questionnaire measuring transition readiness [8,9,15]. Both the English and French versions have been found reliable and valid in AYA patients diagnosed with a variety of chronic medical conditions, including cancer [9,15]. In this study, according to patients' preferred language, only the French version was administered. The TRAQ-FR is similar to the TRAQ, with the exception of one item that has low relevance within the Canadian healthcare context (health insurance). This version includes 5 subscales: Managing Medications (4 items), Appointment Keeping (6 items), Tracking Health Issues (4 items), Talking with Providers (2 items), and Managing Daily Activities (3 items) [15]. Each item is rated on a five-point Likert scale, ranging from "No, I do not know

how" to "Yes, I always do this when I need to," with higher scores indicating better transition readiness [8,9,15].

Personal goal setting. To further support the use of the TRAQ as a clinical activity, the research team and HCPs developed a prompt to be answered by patients in the consultation period with nurse practitioners during their visit: "By your next appointment, what goals would you like to have achieved?" This question was intentionally broadly worded to avoid directing patients' responses as a means to discover what matters to them personally and how it relates to their transition readiness. AYA CCS were thus invited to set their own personal goals, related or not to transition or TRAQ items. Nurse practitioners transcribed patients' self-set goals in an allotted space on the reverse side of the TRAQ.

Data analysis

Objective 1: To describe clinical examples of AYA CCS' transition readiness and goal setting. TRAQ item scores are reported for each patient. To describe AYA CCS self-set goals documented by HCPs, each patient response represented a unit of analysis, and the inductive thematic analysis approach was used following the procedure by Braun and Clarke (2012): data familiarization, generation of initial codes, search for themes, review of potential themes, definition of themes, and production of the report [25]. Coding and theme development was conducted by authors PC and AM. AYA CCS personal goals were analyzed separately by analysts (PC, AM), and disagreements were resolved by consensus. Final themes were approved by SS and LD.

Objective 2: To describe barriers and facilitators to the clinical implementation of the TRAQ in an oncology LTFU clinic. Each semi-structured healthcare interview transcript represented a single unit of analysis and was analyzed individually by PC and AM. A deductive-inductive hybrid thematic analysis approach was used, guided by the determinants framework and using the 6-step reflexive process by Braun & Clarke (2012) [21,25,26]. After analysing each

transcript, PC and AM reviewed the coding structure to identify emerging themes. Consensus discussion was used to refine theme development, and decisions were recorded in a reflexive log to create an auditable trail of the thematic analysis process. The research team met regularly throughout the process to compare and discuss differences in their coding system. Final implementation barriers, facilitators, and strategies were identified by PC and AM, and subsequently reviewed by SS and LD.

Results

Participant characteristics

With regards to patients, based on the schedule review from May 2022 to July 2022, 26 eligible AYA CCS were identified and 8 agreed to participate in the study (30.8%; **Figure 1**). The large discrepancy between those who met criteria and those who agreed to participate was due to no-shows, cancelled or rescheduled appointments, and unavailability of HCPs (absence due to illness). One patient's data were also not included in the analyses because of a language barrier, displaying comprehension difficulties according to the nurse practitioner, with neither French nor English as a first language. AYA participants' sociodemographic and medical information is presented in **Table 1**. HCPS' sociodemographic and occupation information is presented in **Table 2**.

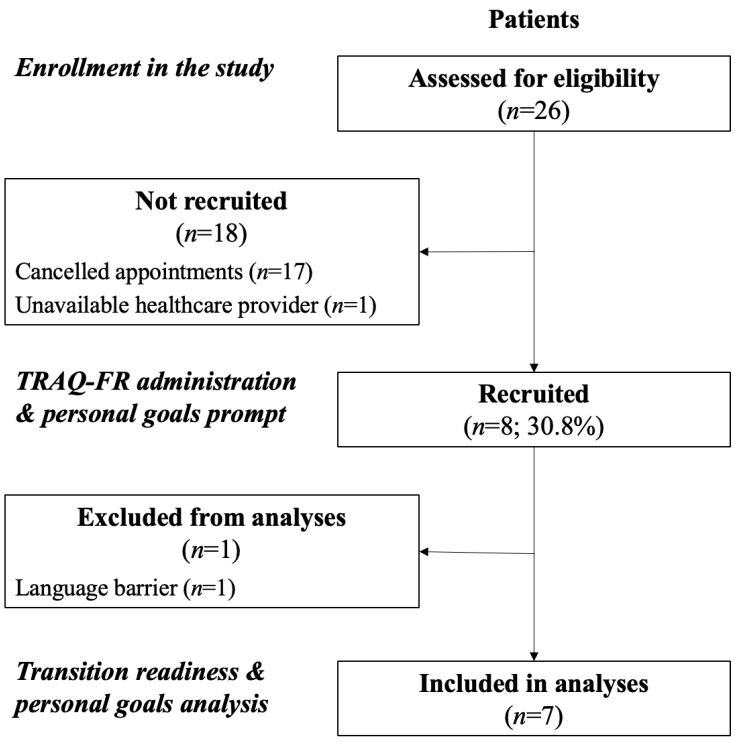

Figure 1. Patient recruitment flowchart from May 2022 to July 2022.
Note. n=number of individuals; TRAQ-FR=Transition Readiness Assessment Questionnaire—French version.

Table 1. AYA CCS sociodemographic and medical information (*n*=7)

Identification	Sex	Age	Age at diagnosis	Cancer diagnosis(es)	Cancer treatment(s)
1	Male	14	4	Wilm's tumor	Chemotherapy Surgery
2	Female	14	1	Pilocytic astrocytoma Optic chiasmatic-hypothalamic glioma	NA
3	Male	14	2	Rhabdomyosarcoma	Surgery Transplant
4	Male	14	2	Neuroblastoma	Surgery
5	Female	14	5	Acute lymphoblastic leukemia	Chemotherapy
6	Female	16	5	Osteosarcoma	Chemotherapy Surgery
7	Female	14	5	Wilm's tumor	Chemotherapy Surgery

Note. AYA=adolescent and young adult; CCS=childhood cancer survivors; *n*=number of respondents.

Table 2. HCPs' sociodemographic and occupational information (*n*=3)

Identification	Sex	Age	Professional title	Years of experience in pediatric care	Years of experience at the LTFU oncology clinic
1	Female	65	Pivot nurse	18.5	8.5
2	Female	30	Clinical-administrative manager	9.5	1.5
3	Female	50	Pediatric physician	19.0	19.0

Note. HCPs=healthcare providers; LTFU=long-term follow-up; *n*=number of respondents.

Objective 1: To describe clinical examples of AYA CCS' transition readiness and goal setting.

Transition Readiness. Patients' TRAQ item scores are reported in **Table 3**.

Goal setting. In response to the prompt "By your next appointment, what goals would you like to have achieved", 3 themes were generated from AYA CCS' self-set goals: 1) Goal type, 2) Means of achieving goal, and 3) Goal motivation (**Figure 2**).

Goal type. Although patients were not asked to set goals solely related to getting ready for transition, all respondents mentioned wanting to improve either broad or specific transition readiness skills related to the TRAQ. For instance, one patient (female, age 14) indicated that she *"Would like to learn how to book appointments"* as a personal goal, referring to the Appointment Keeping subscale of the TRAQ, while another patient (female, age 14) referred to a specific item on the TRAQ (item 17): *"More involvement in daily tasks, such as meals."* Another component is related to the level of skill acquisition implied in the self-set goals, such as identifying skills that were either in need of development or emerging. For instance, a patient (male, age 14) reported wanting to *"Start working to begin budgeting,"* while another (female, age 14) identified *"Continuing current learning: making non-medical appointments"* as a personal goal, representing to-be-developed and emerging skills, respectively.

Means of achieving goal. When setting their personal goals, patients varied in the degree of practicality of the means they would use to achieve them. For instance, one patient (male, age 14) suggested the general means of *"Sharing my desire to learn with my parents"* to reach his goal, while another patient (female, age 16) provided more specific details to achieve hers with regards to making medical follow-up appointments: *"Knowing the phone number, where, who to call."* In addition to the degree of concreteness in how they would reach their goals, a number of patients

Table 3. AYA CCS item and average overall TRAQ-FR scores (*n*=7)

TRAQ-FR item and overall scores	1	2	3	4	5	6	7
Managing Medications							
1.Do you fill a prescription if you need to?	1	4	1	1	1	1	2
2. Do you know what to do if you are having a bad reaction to your medications?	1	2	2	1	5	2	5
3. Do you take medications correctly and on your own?	5	5	4	5	5	5	1
4. Do you reorder medications before they run out?	4	4	1	1	2	3	2
Appointment Keeping							
5. Do you call the doctor's office to make an appointment?	4	3	1	2	4	2	2
6. Do you follow-up on any referral for tests, check-ups or labs?	5	2	1	2	1	2	1
7. Do you arrange for your ride to medical appointments?	5	3	1	1	1	2	2
8. Do you call the doctor about unusual changes in your health (For example: allergic reactions)?	4	2	1	2	1	2	2
9. Do you know what your health insurance covers?	1	2	1	2	1	3	1
10. Do you manage your money & budget household expenses (For example: use checking/debit card)?	4	4	1	4	1	1	2
Tracking Health Issues							
11. Do you fill out the medical history form, including a list of your allergies?	1	5	3	1	1	4	2
12.Do you keep a calendar or list of medical and other appointments?	1	3	1	2	5	5	3
13. Do you make a list of questions before the doctor's visit?	1	5	4	2	1	4	1
14. Do you get financial help with school or work?	1	1	1	1	1	1	1
Talking with Providers							
15. Do you tell the doctor or nurse what you are feeling?	5	5	5	4	4	5	5
16. Do you answer questions that are asked by the doctor, nurse, or clinic staff?	5	5	5	5	5	5	5
Managing Daily Activities							
17. Do you help plan or prepare meals/food?	4	5	4	4	5	5	5
18. Do you keep home/room clean or clean-up after meals?	4	4	5	5	5	5	5
19. Do you use neighborhood stores and services (For example: grocery stores and pharmacy stores)?	5	5	3	5	5	5	3

Note. AYA=adolescent and young adult; CCS=childhood cancer survivors; *n*=number of respondents; TRAQ-FR=Transition Readiness Assessment Questionnaire—French version. Scores of 1, 2, 3, 4, and 5 represent the following TRAQ-FR answer options respectively: "No, I do not know how," "No, but I want to learn," "No, but I am learning to do this," "Yes, I have started doing this," and "Yes, I always do this when I need to."

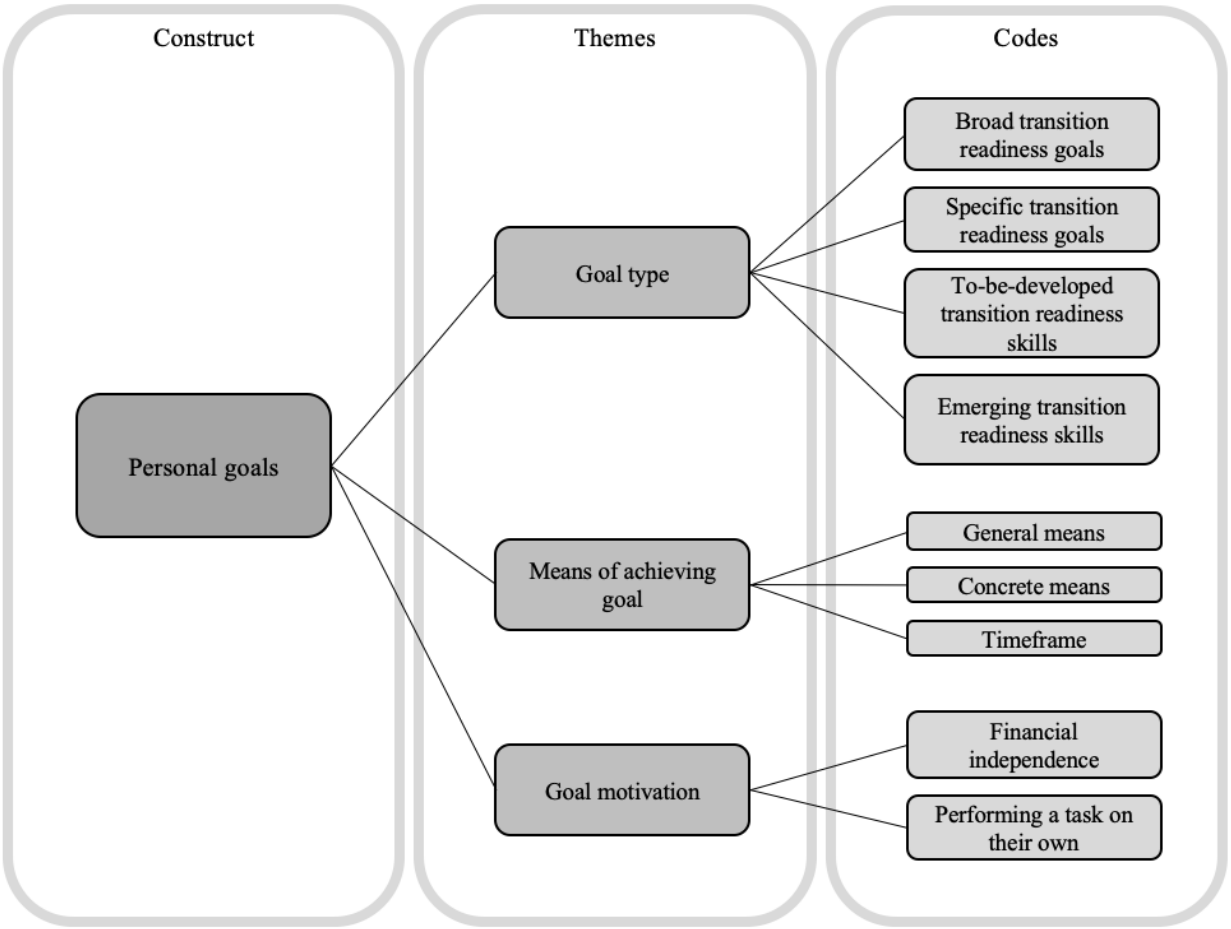

Figure 2. Thematic tree of patients' personal goals.

Goal motivation. Two patients stood out from the others by setting a personal goal related to completing tasks on their own ("by myself") or being independent, referring to the motivation behind the achievement of their goals: *"Going to the pharmacy by myself to get my medication"* (male, age 14). By specifying that they want to do something on their own, these patients report a desire for autonomy, which corresponds to an intrinsic determination to achieve a goal.

Objective 2: To describe barriers and facilitators to the clinical implementation of the TRAQ in an oncology LTFU clinic.

Based on the semi-structured interviews, 10 barriers, 7 facilitators, and 4 strategies were identified following the determinants framework for implementation (**Table 4**). Every participant (*n*=3) reported implementation barriers and facilitators related to 1) the implementation object (TRAQ), 2) object users and developers (HCPs), 3) end users (AYA CCS), and 4) the context (tertiary pediatric hospital and COVID-19), as well as 5) potential implementation means and strategies.

Barriers to TRAQ implementation. Following the determinants framework for implementation, a total of 10 barriers were identified.

Characteristics of the TRAQ. First, difficulties related to the tool itself were noted, such as non-intuitive response options and a language barrier for non-native speakers. For example, a HCP reported that *"Ticking in the right place [in the 5-point Likert scale], that seemed difficult."* Furthermore, the TRAQ scores of one of the AYA CCS were judged invalid after revision, observing major discrepancies between written and verbal answers. Second, completing and reviewing the TRAQ required additional time in a busy schedule. For instance, a HCP explained, *"Time is a barrier, you know? Because you tell yourself: 'I have to do this in addition to what I already have to do.'"* Consequently, the additional time needed to administer and clinically use the TRAQ may hinder its implementation.

Characteristics of HCPs. Next, only one barrier was identified at the level of HCPs more broadly throughout oncology care, namely concerns about TRAQ administration. In particular, a lack of training with the TRAQ and with AYAs in general were highlighted by a HCP, saying that, *"Not all nurses in oncology feel comfortable administering a questionnaire such as this one to teenagers."*

Table 4. Presentation of barriers, facilitators, and strategies identified in the mixed deductive/ inductive thematic analysis following the determinants framework for implementation (*n*=3)

Categories	Themes
Barriers to implementation	
Implementation object (TRAQ)	• Difficulties in completing the TRAQ • Additional time required to complete and review the tool
Object users and developers (HCPs)	• Concerns about TRAQ administration
End users (AYA CCS)	• Magical thinking: lack of understanding of the relevance of LTFU care • Comprehension difficulties related to cancer or the French language
Context (tertiary pediatric hospital, COVID-19)	• Lack of a distinct LTFU oncology clinic • Limited resources: staffing and offices • Government and institutional measures • "Survival mode": changes in HCPs' daily work lives • HCPs and CCS: general increase in distress level
Facilitators	
Implementation object (TRAQ)	• Tool-specific features • Support HCPs in transition planning with AYA CCS
Object users and developers (HCPs)	• Personal and professional characteristics of HCPs • Positive attitude towards TRAQ
End users (AYA CCS)	• CCS commitment level to preparing for transition • Parental involvement in CCS transition readiness
Context (tertiary pediatric hospital, COVID-19)	• Adequate material resources
Implementation means and strategies	
	• TRAQ implementation plan: 5W1H • Nursing resources: staffing and training • Adapting working conditions to facilitate TRAQ implementation • TRAQ sample item with AYA CCS

Note. AYA=adolescent and young adults; CCS=childhood cancer survivors; COVID-19=corona virus; HCPs=healthcare providers; LTFU=long-term follow-up; *n*=number of respondents; TRAQ=Transition Readiness Assessment Questionnaire

Characteristics of AYA CCS. According to HCPs, AYA CCS and their parents sometimes doubt the relevance of LTFU care after their remission or want to avoid remembering their cancer experience, including the administration of the TRAQ. For example, a HCP answered, *"For patients, I'd say magical thinking […]. Thinking that it's all over, wondering why we ask these questions. They don't always understand the issues at stake,"* especially younger AYA CCS (14-year-olds). Another HCP reported that *"It's not unusual for [patients] to want nothing to do with [cancer]."* Furthermore, patients' comprehension of the TRAQ may be affected by cognitive sequelae related to their cancer diagnosis and treatment, or by general difficulties with the French language. For instance, HCPs perceived that AYA CCS who had a brain tumor or received intense radiotherapy had more difficulty than others in completing the TRAQ. A HCP was also surprised by *"How weak [patients'] French skills were,"* affecting their understanding and answers to the TRAQ.

Characteristics of the context. In this case, the context refers to both the tertiary pediatric hospital and the COVID-19 pandemic. Related to the hospital, 2 barriers were identified: 1) the lack of a distinct LTFU oncology clinic, and 2) limited resources. Indeed, according to a HCP, the absence of a distinct clinic entails *"That we don't have a specific time allocated for the LTFU clinic"* and that the clinical populations followed up were heterogeneous, which *"Is a bit confusing sometimes. […] I can see a patient at the LTFU clinic, followed by two benign hematology patients."* As a result, it may be challenging to differentiate between patients to whom the TRAQ can be administered versus not. In terms of resources, insufficient staffing and offices would respectively increase HCPs' workload and limit appointment spaces for AYA CCS, as mentioned by a HCP, *"There really is a staffing issue. […] At one point, what happens is work overload. When we only have one person [while they] should already be two."* Indeed, one of the two nurses left the LTFU program around the time of study initiation and was not replaced for several months,

significantly impacting workflow and the ability to take on the new task of TRAQ administration. Related to COVID-19, 3 barriers were found: 1) government and institutional measures, 2) being in a "survival mode", and 3) a general increase in distress level. At the government and institutional level, after receiving a positive COVID-19 test, HCPs were unable to attend work for some time: *"In fact, everyone had COVID in turn, with varying periods of isolation. […] Now, we're down to 5 days, then we're working."* Furthermore, since CCS were considered to be at high risk for COVID-19, their LTFU appointments were either cancelled or adapted to tele-practice, limiting paper TRAQ administration during the study period. The pandemic also brought changes in HCPs' daily work lives, including regular mandatory COVID-19 meetings and frequent task reorganization, as explained by a HCP, *"A lot a time was lost in never-ending meetings on patient care pathways. […] The goal was to survive what was happening, because there was so much reorganization of tasks for everyone."* Finally, a general increase in distress was reported by HCPs, including COVID-19-related fears and an increase in mental health disorder symptoms among AYA CCS. As a result, distress assessment *"Was part of every follow-up appointment"* according to a HCP, taking priority over TRAQ administration.

Facilitators to TRAQ implementation. Next, 7 facilitators of TRAQ implementation were identified.

Characteristics of the TRAQ. First, a number of features specific to the tool were highlighted as facilitating its implementation, such as its psychometric properties, self-administration, and annual completion. Furthermore, a HCP noted that the TRAQ items represented concrete examples of transition readiness skills, which was also appreciated: *"What is an autonomous teenager? […] That's someone who is able to book their appointments; when they have a prescription, they feel comfortable filling it, and so on."* Second, the TRAQ also supported HCPs at follow-up appointments, providing a measure of transition readiness, and facilitating

conversations about transfer as well as transition readiness skills and skill gaps. For instance, a HCP said, *"You know, it helps to know where you're starting from with the patient. […] Then, to see where it's more worthwhile to invest time in that particular appointment."*

Characteristics of HCPs. Although a number of oncology nurses do not feel comfortable administering the TRAQ to AYA CCS, the interviewed HCPs indicated that other nurses have personal and professional characteristics that facilitate the implementation of the tool. Personal qualities included being passionate, experienced, caring, trustworthy, available, and able to create a bond of trust with patients. Professional characteristics included skillful clinical use of the TRAQ with AYA CCS and their parents, such as using it for psychoeducational purposes or addressing indirect barriers to transition. For example, a HCP said, *"I want to give myself, like, 3, 4 minutes to look over [the TRAQ] before I begin the appointment. You know, so that I already have some content before I start."* Another facilitator to tool implementation is a general positive attitude towards the TRAQ, such as believing that it would bring added value to LTFU care and understanding the relevance of its systematic administration. For instance, a HCP stated, *"Personally, I like this questionnaire. […] If I use it with some [patients], then I'll use it with everyone, because I've seen that there's added value in it."*

Characteristics of AYA CCS. According to HCPs, patient-related facilitators to TRAQ implementation included AYA CCS' commitment level to preparing for transition and parental involvement in CCS transition readiness. Indeed, patients' understanding of the issues at stake and desire to develop transition readiness skills appeared to promote the completion of the TRAQ, particularly in older AYA CCS, as a HCP indicated, *"Usually, the older teenagers get, the more they understand what's at stake, […] especially when we talk about the last appointment [in pediatric settings]. Then, they start to realize that things are about to change."* Furthermore, using

the TRAQ also enabled parents to know which tasks their children should be able to perform on their own before transfer, and to offer them autonomy support during the transition process.

Characteristics of the context. Only 1 facilitator to TRAQ implementation was identified related to tertiary pediatric hospital and none to COVID-19. In terms of the pediatric setting, HCPs noted that useful technology, including a list of eligible AYA CCS for TRAQ administration, was readily available, facilitating its implementation: *"In terms of equipment, here, it's not really a problem, because I think there was money for that."*

Implementation means and strategies. Finally, 4 broad strategies to TRAQ implementation were identified. First, during the semi-structured interviews, many questions were raised that could be answered in a formal implementation plan for the TRAQ, such as determining the who, what, when, where, why, and how of the systematic administration of the tool would be pursued. Second, all participants suggested that having sufficient staffing resources with adequate training may facilitate its implementation. Third, adapting current working conditions to allocate specific time and space for the LTFU care of AYA CCS could facilitate TRAQ implementation. Lastly, and more directly related to the completion of the TRAQ, a means to facilitate its implementation would be to do a sample item verbally with AYA CCS who have greater difficulty understanding the tool, before letting them complete it on their own. As a HCP said, *"When we're saying it out loud, it's easier for [patients] to answer [the TRAQ]."*

Discussion

Although this study initially intended to explore potential associations between AYA CCS transition readiness and personal goals, unforeseen difficulties led us to interrupt this initial research project. We instead had the opportunity to identify barriers and facilitators to TRAQ implementation in a LTFU oncology clinic two years into the COVID-19 pandemic.

With respect to AYA CCS self-set goals, 3 themes were generated in our study: 1) goal type, 2) means of achieving goals, and 3) goal motivation. According to Schwartz and Parisi's model, there are 9 broad categories for AYA self-identified goals: Academic, Administrative, Body, Health, Interpersonal, Intrapersonal, Job, Leisure, and Religion [27]. In our study, survivors *only* set goals related to the health, interpersonal, and administrative categories, which are also constructs referred to in the TRAQ items, unlike the other goal categories described by Schwartz and Parisi [9,15,27]. Therefore, our findings may have been influenced by the priming effect of the TRAQ; implicitly encouraging AYA CCS to identify goals related to transition readiness despite the non-directive goals prompt [28]. Schwartz and Parisi also suggested that survivors' goals should be realistic and long term in order to improve their quality of life and preparation to adulthood [27]. As such, asking AYA CCS to identify a specific personal goal to achieve by their next annual follow-up appointment may improve these aspects of their psychosocial functioning. Furthermore, the motivation of patients recruited in our study differed from that of AYA CCS in two other studies on survivors' personal goals. In our study, we found that AYA CCS were motivated by a desire for independence, whereas other research concluded that survivors were motivated by a desire to be normal, to fit in, or to feel in control [27,29]. Interestingly, although perhaps not surprisingly, all these desires refer to the basic psychological needs of autonomy, competence, and relatedness of the Self-Determination Theory of motivation [30], which could be used to guide future intervention efforts in transition readiness. In other words, the desire for independence refers to the need to determine for oneself the behaviors one wishes to adopt (i.e., autonomy); the desire to be normal and to fit in refers to the need to feel connected to others (i.e., relatedness); and the desire to be in control refers to the need to experience mastery in one's activities (i.e., competence) [30].

With regards to TRAQ implementation, a number of studies have reported barriers and facilitators to administering the TRAQ among various clinical populations in pediatric healthcare settings [31–38]. However, none of them attempted to implement the TRAQ with AYA CCS, despite the importance of LTFU for survivors [5], or followed the determinants framework as a valid means to document implementation barriers and facilitators [21]. Nonetheless, several of our study findings are consistent with prior research. For instance, in this study, barriers identified at the level of HCPs (e.g., lack of training with AYAs) [33,36], patients (e.g., lack of knowledge about transition) [31], and institution (e.g., limited clinical staff) reiterate previous findings of TRAQ implementation challenges in AYAs with different chronic conditions [38]. Within cancer survivors more specifically, a recent study identified several barriers with respect to LTFU care of AYA CCS, including lack of time for follow-up appointments, low priority given to follow-up, and being in good health, supporting the current study findings [39]. In terms of facilitators, the properties of the TRAQ (e.g., a structured assessment tool) [36], as well as characteristics of HCPs (e.g., experienced clinicians) and of patients (e.g., stakeholder support) have also been noted in prior research [33,38]. Furthermore, the implementation strategies of formalizing a healthcare transition policy [36] and of improving HCPs' training in transition readiness screening with AYAs have been suggested in previous studies [33].

However, unlike prior research, with the exception of Pauley (2022) [38], another important component of the current study is that it took place during the COVID-19 pandemic. Given that fluctuations in the COVID-19 epidemiology may continue for an indefinite period of time and that LTFU care of AYA CCS is a necessity, exploring how the pandemic affected the implementation of the TRAQ seems essential to develop strategies to promote a successful transition process for survivors despite the current global pandemic [21,40]. Unsurprisingly, in this study, the COVID-19 outbreak did not appear to facilitate the implementation of the TRAQ, but it did bring its share

of challenges, including frequent cancellations of LTFU appointment and increased levels of distress. This finding is supported by a recent study reporting that COVID-19 led to imposed restrictions for in-person clinic visits of AYA CCS and worry among HCPs for survivors' risk of exposure to the coronavirus [40].

This study adds to the scientific literature by identifying barriers related to the TRAQ itself, to AYAs' difficulties with the French language, and to frequent changes in HCPs' work lives as a result of the pandemic. The current study also highlights new facilitators to TRAQ implementation, including the tool's perceived valuable contribution to HCPs' clinical work, clinicians' positive attitude toward the TRAQ, and useful material resources. In addition, two new implementation strategies have been suggested, such as adapting HCPs' working conditions to facilitate TRAQ implementation and doing a sample item with AYA CCS verbally. We hope that understanding the barriers and facilitators to the systematic use of the TRAQ has a positive impact on the implementation and sustainability of its use as an assessment and counseling tool within clinical practice [36].

This research project has several limitations. The sample size of AYA CCS was small (n=7) and consisted mostly of 14-year-olds (n=6; 85.7%), limiting the external validity of the study findings to older survivors and in general. In addition, although the sample size of HCPs was also small (n=3), data saturation was reached among HCPs, with the information collected often being redundant in the three semi-structured interviews. As such, adding any more participants would not have necessarily yielded more information [41]. Another limitation pertains to the internal validity of the study. Indeed, patients' self-set goals were initially transcribed by a nurse and then analyzed by PC and AM, rather than being completed by the patients themselves, which could threaten data integrity. Furthermore, the research team assisted in administering the TRAQ to AYA CCS when this activity was supposed to be carried out by the clinical staff only. That being noted,

the research team's contribution had been requested by the clinical staff to lighten their workload, suggesting that TRAQ use in the clinic was too burdensome, supporting the study findings. Finally, the present study focused only on HCPs' views of barriers and facilitators to TRAQ implementation. While this is a rich source of information, it would benefit from being complemented by the perspectives of survivors and their parents.

In terms of future directions, the current research lacked a structured plan for implementing the TRAQ, which may have contributed to the failure of our initial study objective, leading to the administration of the tool to a small sample of survivors. This failure in itself suggests a need for a scientific approach to implementation when changing clinical practice to implement the TRAQ in a LTFU oncology clinic. By identifying implementation barriers, facilitators, and strategies, the study findings offer guidance for the formal implementation of the TRAQ. Therefore, future research could develop a plan for implementing the TRAQ, including all stakeholder input into implementation planning, and test its feasibility in a large hospital providing LTFU care to AYA CCS.

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