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Getting ready for transition to adult care: tool validation and multi-informant strategy using the Transition Readiness Assessment Questionnaire (TRAQ) in pediatrics

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1   **Manuscript**

2   Getting ready for transition to adult care: tool validation and multi-informant strategy using the

3   Transition Readiness Assessment Questionnaire (TRAQ) in pediatrics

4

5   **Abstract**

6   **Background:** Transitioning from pediatric to adult healthcare can be challenging and lead to

7   severe consequences if done suboptimally. The Transition Readiness Assessment Questionnaire

8   (TRAQ) was developed to assess adolescent and young adult (AYA) patients' transition

9   readiness. In this study, we aimed to 1) document the psychometric properties of the French-

10   language version of the TRAQ (TRAQ-FR), 2) assess agreements and discrepancies between

11   AYA patients' and their primary caregivers' TRAQ-FR scores, and 3) identify transition

12   readiness contributors.

13   **Methods:** French-speaking AYA patients (n=175) and primary caregivers (n=168) were recruited

14   from five clinics in a tertiary Canadian hospital and asked to complete the TRAQ-FR, the

15   Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0), and a sociodemographic

16   questionnaire. The validity of the TRAQ-FR was assessed using confirmatory factor analyses

17   (CFA). Agreements and discrepancies were evaluated using intra-class correlation coefficients

18   and paired-sample t-tests. Contributors of transition readiness were identified using regression

19   analyses.

20   **Results:** The five-factor model of the TRAQ was supported, with the TRAQ-FR global scale

21   showing good internal consistency for both AYA patients' and primary caregivers' scores

22   (α=.85-.87). AYA patients and primary caregivers showed good absolute agreement on the

1

23   TRAQ-FR global scale with AYA patients scoring higher than primary caregivers (ICC=.80;

24   d=.25). AYA patients' age and sex were found to be contributors of transition readiness.

25   **Conclusions:** The TRAQ-FR was found to have good psychometric properties when completed

26   by both AYA patients and primary caregivers. Additional research is needed to explore the

27   predictive validity and clinical use of the TRAQ-FR.

28

29   **Key words:** Psychometrics; Adolescent; Young Adult; Patient Transfer; Proxy Measure; Quality

30   of Life

31

32   **Key message box:**

33   • In a group of 343 participants recruited from 5 follow-up clinics in a tertiary pediatric

34   hospital, the French version of the Transition Readiness Assessment Questionnaire

35   (TRAQ-FR) showed good construct validity;

36   • The global scale of the TRAQ-FR was found reliable in both samples of AYA and

37   primary caregivers;

38   • Primary caregivers' and AYA patients' transition readiness ratings were similar,

39   supporting the validity of the proxy-version of the TRAQ-FR;

40   • On average, AYA rated their transition readiness slightly higher than their primary

41   caregivers did;

42   • Being a girl and older than 15 years of age contributed to higher transition readiness,

43   suggesting that younger and male AYA are more vulnerable subgroups.

Introduction

44

45   Despite recent infectious outbreaks, chronic conditions have been the leading cause of

46 death around the world (World Health Organization. 2019). Due to recent technological and

47 medical breakthroughs, 90% of adolescents and young adults (AYA) suffering from a chronic

48 condition are expected to survive into adulthood and go through the process of transition (Wood

49 *et al.* 2014; Blum. 1995). Transition refers to "a multi-faceted active process that attends to the

50 medical, psychological, and educational/vocational needs of [AYA] as they move from the child-

51 focused to the adult-focused health care system" (Blum *et al.* 1993, p. 573). Since a suboptimal

52 transition is associated with higher rates of acute complications and early mortality (Nandakumar

53 *et al.* 2018), an optimal transition is warranted.

54   Measuring AYA transition readiness is useful to identify necessary transition-related

55 skills and orient future interventions. To this end, a number of assessment instruments have been

56 developed. According to a recent systematic review, the Transition Readiness Assessment

57 Questionnaire (TRAQ) was the best instrument to measure transition readiness to date (Parfeniuk

58 *et al.* 2020). The TRAQ is a disease-neutral, self-administered questionnaire, and its final version

59 consists of 20 items divided into five subscales (Wood *et al.* 2014). The TRAQ has shown high

60 reliability and good validity (Sawicki *et al.* 2009; Wood *et al.* 2014). The transition of chronically

61 ill AYA being a worldwide issue, it is important to translate and culturally adapt the TRAQ to

62 make it available for use amongst non-English speakers. To date, the TRAQ has been translated

63 into Spanish (De Cunto *et al.* 2017; González *et al.* 2017) and Portuguese (Anelli *et al.* 2019).

64 Both versions had high reliability for the global scale and lower reliability for the five subscales

65 (Anelli *et al.* 2019; González *et al.* 2017). Both versions also showed good criterion validity.

66   The transition readiness of AYA has been found to be influenced by their sex (González

67 *et al.* 2017; Wood *et al.* 2014) and age (Anelli *et al.* 2019; González *et al.* 2017; Wood *et al.*

68   2014). There are reasons to believe that it may also be influenced by their quality of life. AYA

69   suffering from a more complex condition are likely to experience worse health than their healthy

70   peers (Varni *et al.* 2001) and rely more heavily on their parents (Blum *et al.* 1993) and <mark>healthcare

71   providers</mark> (Nandakumar *et al.* 2018), potentially undermining their emerging autonomy, which is

72   necessary for a successful transition (Blum *et al.* 1993; Sawicki *et al.* 2009; Wood *et al.* 2014).

73   To our knowledge, no French-language version of the TRAQ (TRAQ-FR) has yet been

74   developed and validated. Furthermore, the TRAQ has only been administered to AYA but never

75   to primary caregivers. Using a multi-informant approach would have the added benefits of

76   obtaining a more complete picture of AYA transition readiness (De Los Reyes *et al.* 2015). The

77   aims of the current study are to 1) document the psychometric properties of the TRAQ-FR, 2)

78   assess agreement between AYA patients' and primary caregivers' perceptions of AYA transition

79   readiness, and 3) identify potential contributors of transition readiness.

80

Methods

82   *Participants*

83   Inclusion criteria for AYA were 1) being between 14-20 years old, 2) having a diagnosis

84   of chronic illness and being followed at least once a year at either the hematology-oncology,

85   diabetes, cystic fibrosis, epilepsy, or nephrology clinic of a tertiary pediatric hospital, and 3)

86   speaking and reading French. Primary caregivers who usually accompany patients to medical

87   follow-ups were also invited to participate <mark>given that they generally play an active role in AYAs'</mark>

88   <mark>care and preparation towards transition.</mark>

89

90   *Procedure*

91   The study protocol was approved by the local research ethics committee (#2016-1220).

92 Participants were recruited from October 2016 to January 2018. Eligible participants were told

93 about the study either over the phone or in person by a research assistant or healthcare

94 professional. AYA and primary caregivers who agreed to participate gave their written informed

95 consent and consecutively received an identification number as they were recruited at the

96 outpatient clinics. AYA and primary caregivers were asked to complete the questionnaires

97 separately and to answer them based on their perceptions of AYA patients' current situation.

98 They were given the option to complete them at the clinic or at home. The latter received a

99 stamped self-addressed envelope.

100

101 *Measures*

102   *Sociodemographic and medical questionnaire.* AYA sociodemographic and medical

103 information was collected from AYA and primary caregivers. The information collected was the

104 following: age (≤15 years old, >15 years old), sex (male, female), ethnicity (Black, Caucasian,

105 Hispanic, Middle Easterner, North African), education level (high school, college), chronic

106 condition (cancer, cystic fibrosis, diabetes, epilepsy, kidney disease), age at diagnosis (ages ≤5,

107 6-10, 11-15, ≥16), perceived health compared to that of others (not good, somewhat good, good,

108 very good, excellent), perceived health compared to that of the previous year (worse, slightly

109 worse, similar, slightly better, better), frequency of medical follow-ups (once every 1-3 months,

110 3-6 months, 6-12 months, 12+ months), level of perceived control over the condition (not good,

111 somewhat good, good, very good, excellent), and complications (yes, no). Primary caregivers

112 were also asked to identify the nature of their relationship (father, mother, other).

113   *French version of the Transition Readiness Assessment Questionnaire (TRAQ-FR).* The

114 TRAQ was translated into French by the Mapi Research Trust, a non-profit research organization

115 offering linguistic validation for patient-reported outcomes following a standardized procedure

116 involving forward translation, reconciliation, backward translation, and pilot testing for

117 comprehension (Mapi Research Trust, 2019). The final version was reviewed by a panel of 6

118 young cancer patients as part of the translation process. Furthermore, the TRAQ-FR was

119 reviewed by Canadian, Belgian, and French members of the research team to ensure

120 comprehension of the items (**Supplementary materials 1-3)**. The TRAQ-FR is composed of 19

121 items divided into five subscales: Managing Medication (4 items); Appointment Keeping (6

122 items); Tracking Health Issues (4 items); Talking with Providers (2 items); and Managing Daily

123 Activities (3 items; Wood *et al.* 2014). The item "Do you apply for health insurance if you lose

124 your current coverage" was removed as it did not culturally apply to several French-speaking

125 communities worldwide. Each item is rated on a five-point Likert scale ranging from "No, I don't

126 know how" to "Yes, I always do this when I need to," with higher scores indicating higher

127 transition readiness.

128 *Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL™ 4.0).* The PedsQL™ 4.0 is a

129 widely used instrument intended for the assessment of health-related quality of life in a pediatric

130 population (Varni *et al.* 2007; Varni *et al.* 2001). In this study, the validated French versions of

131 self-reports for AYA (either the version for ages 13-18 or 18-25) and of adult proxy-reports for

132 primary caregivers were used (Tessier *et al.* 2008). Scores were reverse-coded and transformed

133 into percentages (0=100, 1=75, 2=50, 3=25, 4=0), with higher scores indicating better quality of

134 life (Varni *et al.* 2007; Varni *et al.* 2001). In this study, the PedsQL™ 4.0 scale showed good

135 internal consistency (Kline. 1993; **Table S1**).

136

137 *Statistical analysis*

138   *Construct validity.* Confirmatory factor analyses (CFAs) were performed to assess the

139   construct validity of the TRAQ-FR separately for AYA and primary caregivers. The CFAs were

140   conducted to determine whether the factorial structure of the TRAQ-FR replicates that of the

141   original scale. Evaluation of goodness-of-fit was determined using the normalized chi-squared

142   (χ^2/d.f.), comparative fit index (CFI), Tucker-Lewis index (TLI), root mean square error

143   approximation (RMSEA), and standardized root mean square residual (SRMR). A model has a

144   good fit when χ^2/d.f. <2, CFI and TLI $\geq.95$, RMSEA $\leq.06$, and SRMR $\leq.08$ (Hu and Bentler.

145   1999). CFI and TLI values $>.90$ are acceptable (Lai and Green. 2016).

146   *Internal consistency.* The internal consistency of the TRAQ-FR was examined by

147   calculating Cronbach's alpha (α) separately for AYA patients' and primary caregivers' global

148   and subscale scores. An $\alpha \geq.70$ is considered acceptable (Kline. 1993).

149   *Agreement between AYA and primary caregivers.* Intra-class correlation coefficients

150   (ICCs) and paired-samples *t*-tests were performed to determine agreements and differences

151   within AYA-primary caregiver dyads. Based on a 95% confidence interval, ICCs $<.50$ suggest

152   poor agreement, .50-.75 moderate agreement, .75-.90 good agreement, and $>.90$ excellent

153   agreement (Koo and Li. 2016). A confidence interval of 95% was used to determine the statistical

154   significance of mean differences between AYA patients' and primary caregivers' scores on the

155   TRAQ-FR (Field. 2013). The effect size of mean differences was calculated using Cohen's *d*

156   with a *d* $<.20, .20-.50, .50-.80,$ and $>.80$ representing minimal, small, medium, and large effects

157   respectively (Cohen, 1988).

158   *Contributors of transition readiness.* Pearson's correlation coefficient and analyses of

159   variance (ANOVAs) were used to evaluate the criterion validity of the TRAQ-FR. Subsequently,

160   multivariate regression analyses using the stepwise method were performed to identify the

161   variables most predictive of AYA transition readiness in each group of informants. Variables

162   with the smallest partial correlation were removed progressively to identify the best model of

163   contributors. The variables entered in these analyses were AYA patients' age, sex, ethnicity,

164   education level, chronic condition, age at diagnosis, perceived health compared to that of others',

165   perceived health compared to that of the previous year, frequency of medical follow-ups, level of

166   perceived control over the condition, complications, and PedsQL™ 4.0 global score. The

167   significance threshold was set at .05 (Field. 2013).

168   The statistical software R (version 1.1.643) and the Statistical Package for the Social

169   Sciences (SPSS, version 25) were used.

170

171   **Results**

172   *Sample characteristics*

173   The final sample of the study consisted of 343 participants (175 AYA; 168 primary

174   caregivers) with a participation rate of 62% (**Figure 1**). However, there were only 138 matched

175   AYA-primary caregiver dyads. Sociodemographic and medical data are presented in **Table 1**. As

176   missing values correspond to incomplete surveys, we decided not to impute them (**Table S2**).

177

178   *Construct validity*

179   For both informants' TRAQ-FR scores, the indices χ^2/d.f., RMSEA, and SRMR showed

180   good fit (Hu and Bentler. 1999) whereas the CFI and TLI showed acceptable fit (Lai & Green,

181   2016) to the original scale (**Table 2**). This finding supports the five-subscale model of the TRAQ.

182

183   *Internal consistency*

184   The global scale and the "Appointment Keeping" subscale showed good reliability in both

185   AYA (α=.85 and α=.81 respectively) and primary caregivers (α=.87 and α=.83 respectively). In

186   primary caregivers, the subscale of "Tracking Health Issues" also showed an acceptable internal

187   consistency coefficient (α=.85; Kline. 1993). The other subscales had low reliability (**Table S1**).

188

Agreement between AYA and primary caregivers

190   Within dyads, the TRAQ-FR showed good agreement on its global scale (ICC=.801),

191   moderate agreement on the subscales "Managing Medications" (ICC=.695), "Appointment

192   Keeping" (ICC=.733), "Tracking Health Issues" (ICC=.745), and "Managing Daily Activities"

193   (ICC=.745), and poor agreement on the subscale "Talking With Providers" (ICC=.335; Koo and

194   Li. 2016). AYA reported significantly higher transition readiness scores than their primary

195   caregivers on the global scale and two subscales of the TRAQ-FR, but the differences were small

196   (Cohen. 1988; **Table 3**).

197

Contributors of transition readiness

199   Bivariate associations between AYA patients' TRAQ-FR scores and potential

200   contributors showed that a higher transition readiness was associated with being further in one's

201   studies (r=.31, p<.001), older (r=.27, p<.001), and female (r=-.22, p<.01). Other associations

202   were not statistically significant (**Table S3**). In AYA patients' multivariate model, a unique

203   significant contribution was found for older age (B=.18, *ß*=.40, p<.001) and being female (B=-

204   .36, *ß*=-.28, p<.001), predicting 21% of their transition readiness scores (**Table S4**). In primary

205   caregivers' multivariate model, a unique significant contribution was found for female (B=-.29,

206   *ß*=-.23, p=.014) and older (B=.25, *ß*=.20, p=.032) AYA, predicting 8% of their transition

207   readiness scores (**Table S5**).

208

Discussion

210   This study was the first to explore the psychometric properties of a French-language

211   adaptation of the TRAQ in a sample of 343 participants, to assess agreement in 138 AYA-

212   primary caregiver dyads, and identify transition readiness contributors in 175 AYA and 168

213   primary caregivers.

214   The factorial structure of the TRAQ-FR is consistent with the original version when

215   completed by AYA and primary caregivers (Wood *et al.* 2014). This finding implies that the

216   items of the TRAQ-FR can be divided into five distinct subscales and that a global score may be

217   computed. These results differ from those of the Portuguese version of the TRAQ in which the

218   subscale "Talking With Providers" was removed from the model (Anelli *et al.* 2019). The

219   internal consistency of the TRAQ-FR global scale (α=.85-.87) is also consistent with previous

220   research, with coefficients ranging from .78-.94 in the literature for the global scale (Anelli *et al.*

221   2019; González *et al.* 2017; Wood *et al.* 2014). The majority of the TRAQ-FR subscales did not

222   show acceptable reliability, but this is often found in scales with few items (median=4), with

223   fewer items leading to a lower α (Streiner. 2003). Other analyses to ascertain the TRAQ-FR

224   subscales' reliability should be explored. The good response rate and the results suggest that the

225   questionnaire was feasible, accepted, and understood. One implication of these findings is that

226   the English and French versions of the TRAQ could be used concurrently and equally in English-

227   French bilingual settings such as in Canada.

228   AYA and primary caregivers showed good agreement on the TRAQ-FR global scale and

229   moderate agreement on most TRAQ-FR subscales (Koo and Li. 2016). The level of agreement in

230   dyads' assessment of AYA transition readiness may be due to the nature of their relationship and

231   to the ecological aspect of the TRAQ-FR items. Since most primary caregivers were AYA

232 patients' parents and the skills described in the instrument can be observed and performed in their

233 everyday life, primary caregivers were likely to know whether or not their child performed the

234 specific behaviors described in the items. However, poor agreement was found on the Talking

235 With Providers subscale, which may be explained by the fact that primary caregivers were less

236 likely to observe the specific behaviors described in these items at the moment they occurred.

237 This is coherent with a recent systematic review showing that parent-child agreement is enhanced

238 when measured with instruments assessing observable actions rather than feelings (Poulain *et al.*

239 2020). The results also underline the necessity to assess transition readiness in both populations

240 as perceptions may vary across subscales (e.g., subscale "Talking with Providers").

241 As in prior studies on the TRAQ, the criterion validity of the TRAQ-FR was tested by

242 exploring bivariate associations. Significant relationships were found based on AYA patients'

243 age and sex but not on their ethnicity, which is consistent with previous research on transition

244 readiness (Anelli *et al.* 2019; González *et al.* 2017; Wood *et al.* 2014). Additionally, AYA who

245 were further in their studies reported higher transition readiness scores. This may be because

246 AYA at higher levels of education tend to be more conscientious, i.e., likely to plan in advance

247 and be goal-directed (Mike *et al.* 2015), to respond to the increased cognitive demands of post-

248 high school education, which may increase their transition readiness.

249 This study was also the first to attempt identifying contributors of AYA patients' and

250 primary caregivers' perceptions of AYA transition readiness. Interestingly, even though the

251 analyses were conducted separately, the best contributors were AYA patients' age and sex across

252 informants. Higher transition readiness scores were reported for older and female AYA. Older

253 age may contribute to higher transition readiness since it is likely that healthcare professionals

254 have addressed the topic of transition more often with older than with younger AYA patients, the

255 process of transition starting at age 14 and transition occurring around age 18. It may also be due

256   to change in daily life and the gradual maturation of the prefrontal cortex of the developing brain.

257   This brain area is essential for executive functions that are responsible for planning, organizing,

258   and skills related to a successful transition (Steinberg. 2005). Similarly, being female may lead to

259   higher transition readiness as brain maturation begins earlier in women (Ellison and Nelson.

260   2009). This potential sexual dimorphism in brain morphology may result in female AYA

261   acquiring the skills related to a successful transition earlier than male patients.

262   The present study has limitations. First, only 76.2% of participants were included in the

263   analyses as 23.8% of participants had missing data on either the TRAQ-FR or PedsQL™ 4.0.

264   This may result in a selection bias, including more AYA with higher functioning and a better

265   profile in terms of autonomy or social participation, which influence their transition readiness.

266   For ethical reasons, data from individuals who refused to participate in the study were not

267   collected, preventing us from estimating this selection bias. Second, due to clinical constraints, an

268   unequal number of participants was recruited from the five participating clinics. However, the

269   sample represents the experiences of a wide variety of individuals suffering from different

270   chronic conditions. Finally, causal interpretations should be made cautiously as this is a cross-

271   sectional study.

272   Future studies could use alternative approaches to explore validity such as the item

273   response theory, as documented in a recent validation study of another transition readiness

274   questionnaire (Mellerio *et al.* 2019). Furthermore, future research could explore the predictive

275   value of the TRAQ-FR to determine whether higher scores predict a more successful transition.

276   Additionally, future use of the TRAQ-FR in clinical practice could have the added benefits of

277   initiating conversations within AYA-professional dyads or AYA-caregiver-professional triads

278   about the transition process. This could strengthen partnerships between families and the

279   healthcare team, potentially fostering AYA self-management and consequently facilitating their

280   transition (Fu *et al.* 2018).

281   To conclude, in a sample of 343 participants, the TRAQ-FR global scale was found to

282   have good psychometric properties when completed by AYA and primary caregivers. AYA and

283   primary caregivers showed good agreement on the TRAQ-FR global scale with small mean

284   differences. Finally, for both AYA and primary caregivers, the contributors of transition

285   readiness were older age and being female. Additional research is needed to explore the

286   predictive value of the TRAQ-FR and to evaluate its clinical utility.

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Table 1. Participants' sociodemographic and clinical information

AYA (n=175)	n (%)	Mean ± SD	Range
Sex			
Female	73 (41.7)		
Male	102 (58.3)		
Age groups			
≤ 15 years old	76 (43.4)	14.61 ± .518	14 – 15
> 15 years old	99 (56.6)	16.90 ± 1.01	16 – 20
Ethnicity			
Caucasian	162 (92.6)		
North African	5 (2.9)		
Hispanic	4 (2.3)		
Black	2 (1.1)		
Other	2 (1.1)		
Education			
High school level	137 (78.3)		
College level	33 (18.9)		
Clinics			
Hematology-oncology	71 (40.6)		
Diabetes	35 (20.0)		
Cystic fibrosis	30 (17.1)		
Epilepsy	25 (14.3)		
Nephrology	14 (8.0)		
Primary caregivers (n=168)			
Nature of the relationship with AYA patients			
Mother	134 (79.8)		
Father	33 (19.6)		
Other[a]	1 (0.6)		

Note. AYA=Adolescent and young adult; n=Number of respondents; SD=Standard deviation.
[a] One of the primary caregivers was an AYA patient's grandfather.

Table 2. Confirmatory factor analysis indices of the TRAQ-FR

	Indices				
	χ^2/d.f.	CFI	TLI	RMSEA	SRMR
AYA patients' TRAQ-FR scores (n=175)	1.37	.94	.92	.05	.07
Primary caregivers' TRAQ-FR scores (n=168)	1.56	.93	.92	.06	.07

Note. AYA=Adolescent and young adult; CFI=Comparative Fit Index; n=Number of respondents; RMSEA=Root Mean Square Error Approximation; SRMR=Standardized Root Mean Square Residual; TLI=Tucker-Lewis Index; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire; χ^2/d.f.=Model Chi-Square.

Table 3. Absolute agreement and mean differences between AYA patients' and their primary caregivers' scores on the five subscales and global scale of the TRAQ-FR in 138 dyads

Measures	AYA Mean (SD)	Caregivers Mean (SD)	ICC	Cohen's *d*	Paired *t*-test	95% CI of difference	
						Lower	Upper
Managing Medications	2.63 (0.979)	2.35 (0.889)	0.695***	0.30	3.76***	0.134	0.431
Appointment Keeping	1.68 (1.085)	1.35 (0.942)	0.733***	0.32	4.20***	0.171	0.474
Tracking Health Issues	1.59 (1.093)	1.48 (0.927)	0.745***	0.11	1.52	- 0.036	0.271
Talking With Providers	3.53 (0.758)	3.51 (0.625)	0.335**	0.03	0.24	- 0.130	0.166
Managing Daily Activities	3.06 (0.819)	3.01 (0.808)	0.745***	0.06	0.81	- 0.073	0.174
Overall TRAQ-FR	2.50 (0.666)	2.34 (0.602)	0.801***	0.25	3.71***	0.074	0.243

Note. AYA=Adolescent and young adult; CI=Confidence Interval; ICC=Intra-class correlation coefficients; SD=Standard deviation; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.

**p<.01.

***p<.001.

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Figure 1.
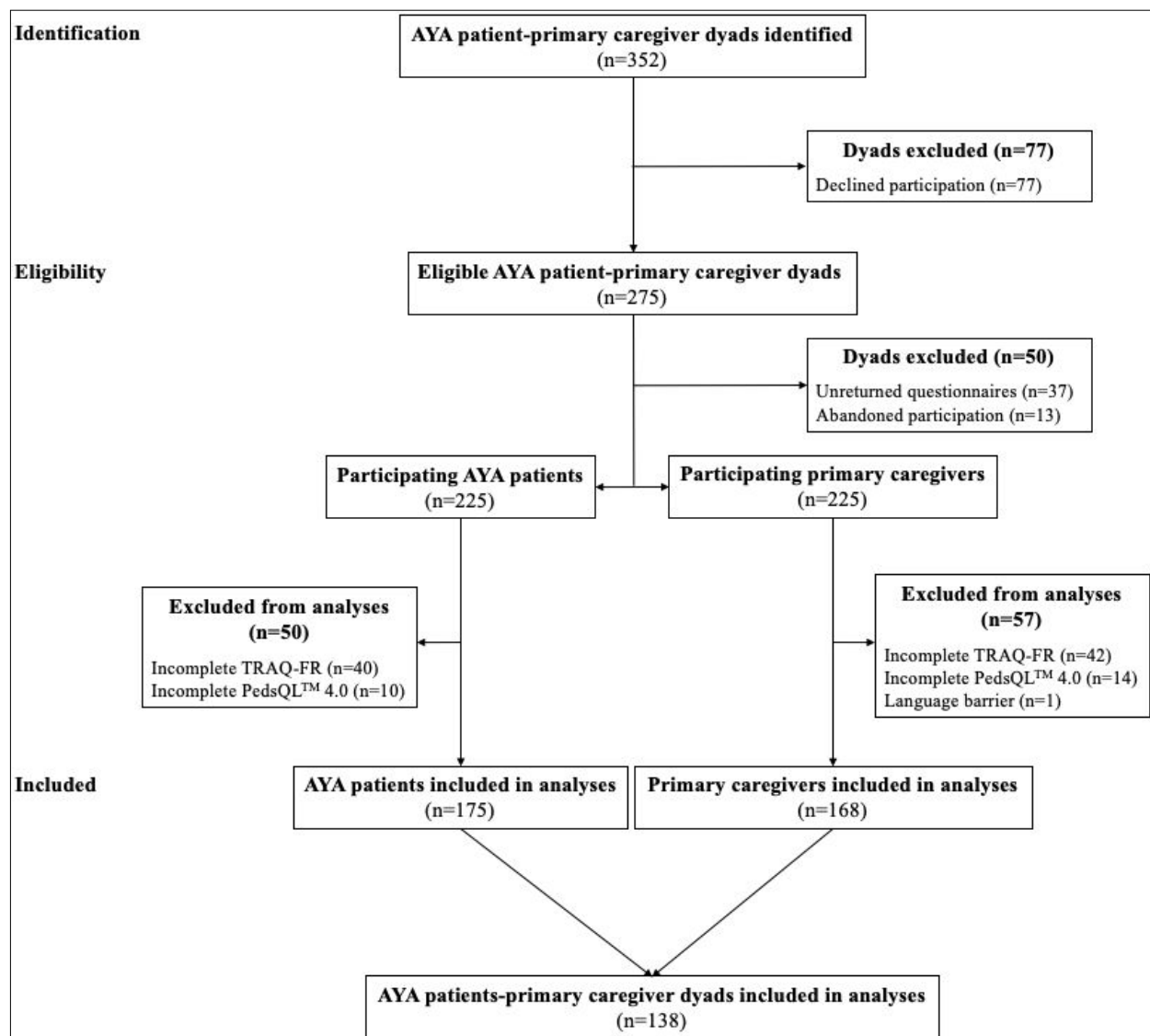
Note. AYA=Adolescent and young adult; n=Number of individuals; PedsQL™ 4.0=Pediatric Quality of Life Inventory™ version 4.0; TRAQ-FR= French version of the Transition Readiness Assessment Questionnaire.

Table S1. Cronbach's alpha coefficient of the five subscales and global scale of the TRAQ-FR and of the four subscales and global scale of the PedsQL™ 4.0

| | | Cronbach's alpha | |
TRAQ-FR	Number of items	AYA (n=175)	Primary caregivers (n=168)
Managing Medications	4	.62	.61
Appointment Keeping	6	.81	.83
Tracking Health Issues	4	.62	.70
Talking With Providers	2	.42	.62
Managing Daily Activities	3	.50	.66
TRAQ-FR global scale	19	.85	.87
PedsQL™ 4.0			
Physical Health	8	.75	.83
Emotional Functioning	5	.76	.85
Social Functioning	5	.86	.86
School Functioning	5	.64	.77
PedsQL™ 4.0 global scale	23	.89	.91

Note. AYA=Adolescent and young adult; n=Number of respondents; PedsQL™ 4.0= Pediatric Quality of Life Inventory™ version 4.0; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.

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Table S2. Raw number of responses for each item of the TRAQ-FR in a sample of AYA (n=225) and primary caregivers (n=225) and percentage of missing data

	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	Yes, I always do this when I need to	Total
Q1.	42 (19.7%)	44 (20.6%)	30 (14.1%)	34 (16.0%)	63 (29.6%)	213 (94.7%)
	52 (23.7%)	*60 (27.4%)*	*31 (14.2%)*	*40 (18.3%)*	*36 (16.4%)*	*219 (97.3%)*
Q2.	47 (21.9%)	42 (19.5%)	11 (5.1%)	31 (14.4%)	84 (39.1%)	215 (95.6%)
	43 (19.9%)	*45 (20.8%)*	*21 (9.8%)*	*54 (25.0%)*	*53 (24.5%)*	*216 (96.0%)*
Q3.	3 (1.4%)	0 (0.0%)	11 (5.1%)	40 (18.4%)	163 (75.1%)	217 (96.4%)
	7 (3.2%)	*7 (3.2%)*	*13 (6.0%)*	*36 (16.5%)*	*155 (71.1%)*	*218 (96.9%)*
Q4.	35 (16.4%)	31 (14.6%)	25 (11.7%)	27 (12.7%)	95 (44.6%)	213 (94.7%)
	53 (25.2%)	*41 (19.5%)*	*29 (13.8%)*	*43 (20.5%)*	*44 (21.0%)*	*210 (93.3%)*
Q5.	71 (33.2%)	57 (26.6%)	35 (16.3%)	22 (10.3%)	29 (13.6%)	214 (95.1%)
	78 (35.6%)	*75 (34.2%)*	*30 (13.7%)*	*19 (8.7%)*	*17 (7.8%)*	*219 (97.3%)*
Q6.	73 (34.0%)	55 (25.6%)	31 (14.4%)	16 (7.4%)	40 (18.6%)	215 (95.6%)
	81 (36.7%)	*77 (34.8%)*	*29 (13.1%)*	*16 (7.3%)*	*18 (8.1%)*	*221 (98.2%)*
Q7.	62 (29.0%)	29 (13.6%)	23 (10.7%)	26 (12.1%)	74 (34.6%)	214 (95.1%)
	81 (37.3%)	*49 (22.6%)*	*26 (12.0%)*	*28 (12.9%)*	*33 (15.2%)*	*217 (96.4%)*
Q8.	77 (36.2%)	55 (25.8%)	29 (13.6%)	22 (10.3%)	30 (14.1%)	213 (94.7%)
	84 (39.1%)	*72 (33.5%)*	*22 (10.2%)*	*20 (9.3%)*	*17 (7.9%)*	*215 (95.6%)*
Q9.	80 (37.2%)	48 (22.3%)	28 (13.0%)	17 (7.9%)	42 (19.6%)	215 (95.6%)
	88 (40.9%)	*43 (20.0%)*	*27 (12.6%)*	*21 (9.8%)*	*36 (16.7%)*	*215 (95.6%)*
Q10.	44 (20.3%)	23 (10.6%)	22 (10.1%)	46 (21.2%)	82 (37.8%)	217 (96.4%)
	46 (21.0%)	*30 (13.7%)*	*33 (15.1%)*	*69 (31.5%)*	*41 (18.7%)*	*219 (97.3%)*
Q11.	50 (23.3%)	24 (11.1%)	9 (4.2%)	51 (23.7%)	81 (37.7%)	215 (95.6%)
	32 (14.5%)	*51 (23.1%)*	*22 (9.9%)*	*74 (33.5%)*	*42 (19.0%)*	*221 (98.2%)*
Q12.	71 (32.9%)	31 (14.4%)	29 (13.4%)	35 (16.2%)	50 (23.1%)	216 (96.0%)
	53 (24.3%)	*66 (30.3%)*	*34 (15.6%)*	*40 (18.3%)*	*25 (11.5%)*	*218 (96.9%)*
Q13.	95 (44.6%)	31 (14.6%)	25 (11.7%)	30 (14.1%)	32 (15.0%)	213 (94.7%)
	50 (22.9%)	*71 (32.6%)*	*35 (16.1%)*	*41 (18.8%)*	*21 (9.6%)*	*218 (96.9%)*
Q14.	149 (74.1%)	10 (5.0%)	4 (2.0%)	11 (5.5%)	27 (13.4%)	201 (89.3%)
	145 (72.9%)	*20 (10.1%)*	*6 (3.0%)*	*18 (9.0%)*	*10 (5.0%)*	*199 (88.4%)*
Q15.	19 (8.9%)	10 (4.7%)	12 (5.6%)	50 (23.3%)	123 (57.5%)	214 (95.1%)
	7 (3.2%)	*18 (8.2%)*	*12 (5.5%)*	*72 (32.9%)*	*110 (50.2%)*	*219 (97.3%)*
Q16.	1 (0.5%)	1 (0.4%)	3 (1.4%)	24 (11.1%)	187 (86.6%)	216 (96.0%)
	3 (1.4%)	*3 (1.4%)*	*3 (1.4%)*	*40 (18.3%)*	*169 (77.5%)*	*218 (96.9%)*
Q17.	19 (8.7%)	18 (8.3%)	36 (16.5%)	67 (30.7%)	78 (35.8%)	218 (96.9%)
	16 (7.2%)	*20 (9.0%)*	*34 (15.4%)*	*87 (39.4%)*	*64 (29.0%)*	*221 (98.2%)*
Q18.	10 (4.6%)	7 (3.2%)	37 (17.0%)	69 (31.6%)	95 (43.6%)	218 (96.9%)
	12 (5.4%)	*20 (9.0%)*	*28 (12.6%)*	*72 (32.5%)*	*90 (40.5%)*	*222 (98.7%)*
Q19.	9 (4.2%)	4 (1.8%)	7 (3.2%)	44 (20.4%)	152 (70.4%)	216 (96.0%)
	6 (2.7%)	*7 (3.1%)*	*12 (5.5%)*	*82 (37.3%)*	*113 (51.4%)*	*220 (97.8%)*

Note. AYA=Adolescent and young adult; n=Number of participants; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire. In regular font are the responses from AYA. In italic font are the responses from primary caregivers. Items were renumbered as a result of the removal of Q9 from the original version. Consequently, Q9 in the translated version corresponds to Q10 of the original version, Q10 to Q11, and so on.
Q1. Do you fill a prescription if you need to?
Q2. Do you know what to do if you are having a bad reaction to your medications?
Q3. Do you take medications correctly and on your own?
Q4. Do you reorder medications before they run out?
Q5. Do you call the doctor's office to make an appointment?

Q6. Do you follow-up on any referral for tests, check-ups or labs?

Q7. Do you arrange for your ride to medical appointments?

Q8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?

Q9. Do you know what your health insurance covers?

Q10. Do you manage your money & budget household expenses (For example: use checking/debit card)?

Q11. Do you fill out the medical history form, including a list of your allergies?

Q12. Do you keep a calendar or list of medical and other appointments?

Q13. Do you make a list of questions before the doctor's visit?

Q14. Do you get financial help with school or work?

Q15. Do you tell the doctor or nurse what you are feeling?

Q16. Do you answer questions that are asked by the doctor, nurse, or clinic staff?

Q17. Do you help plan or prepare meals/food?

Q18. Do you keep home/room clean or clean-up after meals?

Q19. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?

Table S3. Relations between AYA patients' scores on the global scale of the TRAQ-FR and their sociodemographic and medical data (n=175)

Sociodemographic and medical data	Overall TRAQ-FR		
	M	*SD*	*F*
Age			14.00***
≤15 years old (n=76)	2.30	0.61	
>15 years old (n=99)	2.66	0.64	
Sex			8.56**
Male (n=102)	2.38	0.59	
Female (n=73)	2.67	0.69	
Ethnicity			0.46
Caucasian (n=162)	2.50	0.66	
North African (n=5)	2.38	0.48	
Hispanic (n=4)	2.88	0.45	
Black (n=2)	2.30	0.80	
Middle Easterner (n=2)	2.35	0.75	
Education level (n=170)			18.22***
High school (n=137)	2.41	0.62	
College (n=33)	2.92	0.59	
Chronic condition			1.24
Cancer (n=71)	2.63	0.61	
Diabetes (n=35)	2.47	0.67	
Cystic Fibrosis (n=30)	2.39	0.73	
Epilepsy (n=25)	2.39	0.73	
Kidney disease (n=14)	2.37	0.38	
Age at diagnosis			2.05
≤ 5 years old (n=86)	2.40	0.64	
6-10 years old (n=32)	2.57	0.70	
11-15 years old (n=46)	2.63	0.61	
≥ 16 years old (n=9)	2.78	0.57	
Perceived health compared to that of others (n=172)			2.13
Not good (n=10)	2.67	0.53	
Somewhat good (n=17)	2.29	0.61	
Good (n=65)	2.38	0.62	
Very good (n=59)	2.66	0.71	
Excellent (n=21)	2.47	0.59	
Current health compared to the previous year (n=173)			1.03
Worse (n=1)	2.88	.	
Slightly worse (n=9)	2.54	0.81	
Similar (n=93)	2.45	0.63	
Slightly better (n=48)	2.46	0.68	
Better (n=22)	2.74	0.60	
Frequency of medical follow-ups – once every… (n=172)			1.85
1-3 months (n=29)	2.46	0.44	
3-6 months (n=67)	2.52	0.74	

		M	SD	F
	6-12 months (n=46)	2.35	0.65	
	12+ months (n=30)	2.70	0.59	
Perception of control over the condition (n=171)				2.60
	Not good (n=5)	2.61	0.39	
	Somewhat good (n=25)	2.25	0.64	
	Good (n=52)	2.42	0.71	
	Very good (n=89)	2.62	0.61	
Complications (n=171)				1.37
	Yes (n=128)	2.48	0.63	
	No (n=43)	2.62	0.69	

Note. AYA=Adolescent and young adult; d.f.=Degrees of freedom; F=F-value; M=Mean; n=Number of respondents; SD=Standard deviation; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.

**p<.01.

***p<.001.

Table S4. Contributors of AYA transition readiness as measured by the TRAQ-FR global scale

	R^2	R^2 Adjusted	B	β	*t*	CI 95% Lower	CI 95% Upper
Model	.21***	.20***					
AYA patients' age			.19	.41	5.99***	.13	.25
AYA patients' sex			-.32	-.25	-3.64***	-.50	-.15

Note. This model was generated using the stepwise method, including p-values under .05 and excluding p-values over .10. The variables included in the model are AYA patients' age and AYA patients' sex. The variable of AYA patients' age was coded as follows: 0=13-15 years old; 1=Over 15 years old. The variable of AYA patients' sex was coded as follows: 0=Female; 1=Male. The variables excluded from the model are AYA patients' ethnicity, chronic illness, age at the time of diagnosis, perceived health compared to that of others', perceived health compared to that of the previous year, frequency of medical follow-ups, level of perceived control over the chronic condition, presence or absence of complications, and quality of life as measured by the global scale of the PedsQL™ 4.0 on the global scale of the TRAQ-FR. AYA=Adolescent and young adult; B=Unstandardized regression coefficient; β=Standardized regression coefficient; CI=Confidence interval; PedsQL™ 4.0=Pediatric Quality of Life Inventory™ version 4.0; R^2=R-squared value; *t*=t-value; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.
***p<.001.

Table S5. Contributors of primary caregivers' perception of AYA transition readiness as measured by the TRAQ-FR global scale

	R^2	R^2 Adjusted	B	β	*t*	CI 95% Lower	CI 95% Upper
Model	.08*	.06*					
AYA patients' sex			-.29	-.23	-2.50*	-.51	-.06
AYA patients' age			.25	.20	2.18*	.02	.48

Note. Note. This model was generated using the stepwise method, including p-values under .05 and excluding p-values over .10. The variables included in the model are AYA patients' age and AYA patients' sex. The variable of AYA patients' sex was coded as follows: 0=Female; 1=Male. The variable of AYA patients' age was coded as follows: 0=13-15 years old; 1=Over 15 years old. The variables excluded from the model are AYA patients' ethnicity, chronic illness, age at the time of diagnosis, perceived health compared to that of others', perceived health compared to that of the previous year, frequency of medical follow-ups, level of perceived control over the chronic condition, presence or absence of complications, and quality of life as measured by the global scale of the PedsQL™ 4.0 on the global scale of the TRAQ-FR. AYA=Adolescent and young adult; B=Unstandardized regression coefficient; β=Standardized regression coefficient; CI=Confidence interval; PedsQL™ 4.0=Pediatric Quality of Life Inventory™ version 4.0; R^2=R-squared value; *t*=t-value; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire;
*p<.05.

Patient Name: _____ Date of Birth: ___/___/____ Today's Date ____/_____/____ (MRN# _____)

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: <u>Please check the box that best describes</u> ***your*** <u>skill level</u> in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes ***your*** skill level. <u>**Check here**</u> if you are a parent/caregiver completing this form. ☐

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

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Child: Care, Health and Development

Code du participant _ _ _ / _ _ _   Date du jour : ____/_____/____

Questionnaire sur l'évaluation de l'aptitude à la transition (TRAQ)

Directives pour les adolescents et les jeunes adultes : <u>Coche la case qui décrit le mieux ton niveau de compétence</u> dans les domaines suivants qui sont importants pour la transition vers les soins de santé pour adultes.

Il n'y a pas de bonnes ni de mauvaises réponses et celles-ci demeureront confidentielles et privées.

	Non, je ne sais pas comment le faire	Non, mais je veux apprendre à le faire	Non, mais je suis en train d'apprendre à le faire	Oui, j'ai commencé à le faire	Oui, je le fais toujours quand c'est nécessaire
Gestion des médicaments					
1. Achètes-tu des médicaments sur ordonnance quand c'est nécessaire?					
2. Sais-tu quoi faire si tu as une mauvaise réaction à tes médicaments?					
3. Prends-tu des médicaments correctement et par toi-même?					
4. Commandes-tu des médicaments avant d'en manquer?					
Respect des rendez-vous					
5. Appelles-tu le médecin pour prendre un rendez-vous?					
6. Prends-tu les rendez-vous pour aller passer les tests, et les examens médicaux ou de laboratoire recommandés?					
7. Prends-tu des dispositions pour ton trajet afin de te rendre aux rendez-vous médicaux?					
8. Appelles-tu le médecin au sujet de changements inhabituels dans ton état de santé (par ex. des réactions allergiques)?					
9. Sais-tu ce qui est couvert par ton assurance maladie?					
10. Gères-tu ton argent et le budget des dépenses du ménage (par ex. les comptes de chèques ou de débit)?					
Suivi des problèmes de santé					
11. Remplis-tu le formulaire d'antécédents médicaux **(le questionnaire qu'on donne au premier RDV dans une clinique),** y compris une liste de tes allergies?					
12. Conserves-tu un calendrier ou une liste des rendez-vous médicaux et autres?					
13. Rédiges-tu une liste de questions avant la visite chez le médecin?					
14. Obtiens-tu une aide financière pour l'école ou le travail?					
Discussion avec les prestataires de soins					
15. Informes-tu le médecin ou l'infirmière de ce que tu ressens?					
16. Réponds-tu aux questions qui sont posées par le médecin, l'infirmière ou le personnel de la clinique?					
Gestion des activités quotidiennes					
17. Aides-tu à planifier ou à préparer les repas/les aliments?					
18. Gardes-tu la maison/ta chambre propre ou fais-tu le nettoyage après les repas?					
19. Fréquentes-tu les magasins et les services du quartier (par ex. les épiceries et les pharmacies)?					

Code du participant _ _ _ / _ _ _   Date du jour : ____/_____/____

Questionnaire sur l'évaluation de l'aptitude à la transition (TRAQ)

Directives pour les parents : veuillez cocher la case qui décrit le mieux le niveau de compétence de votre enfant dans les domaines suivants qui sont importants pour la transition vers les soins de santé pour adultes.

Il n'y a pas de bonnes ni de mauvaises réponses et celles-ci demeureront confidentielles et privées.

	Non, il ne sait pas comment le faire	Non, mais je veux qu'il apprenne à le faire	Non, mais il est en train d'apprendre à le faire	Oui, il a commencé à le faire	Oui, il le fait toujours quand c'est nécessaire
Gestion des médicaments					
1. Achète-il des médicaments sur ordonnance quand c'est nécessaire?					
2. Sait-il quoi faire s'il a une mauvaise réaction à ses médicaments?					
3. Prend-il des médicaments correctement et par lui-même?					
4. Commande-t-il des médicaments avant d'en manquer?					
Respect des rendez-vous					
5. Appelle-t-il le médecin pour prendre un rendez-vous?					
6. Prend-il les rendez-vous pour aller passer les tests, et les examens médicaux ou de laboratoire recommandés?					
7. Prend-il des dispositions pour son trajet afin de qu'il se rende aux rendez-vous médicaux?					
8. Appelle-t-il le médecin au sujet de changements inhabituels dans son état de santé (par ex. des réactions allergiques)?					
9. Sait-il ce qui est couvert par son assurance maladie?					
10. Gère-t-il son argent et le budget des dépenses du ménage (par ex. les comptes de chèques ou de débit)?					
Suivi des problèmes de santé					
11. Remplit-il le formulaire d'antécédents médicaux **(le questionnaire qu'on donne au premier RDV dans une clinique)**, y compris une liste de ses allergies?					
12. Conserve-t-il un calendrier ou une liste des rendez-vous médicaux et autres?					
13. Rédige-t-il une liste de questions avant la visite chez le médecin?					
14. Obtient-il une aide financière pour l'école ou le travail?					
Discussion avec les prestataires de soins					
15. Informe-t-il le médecin ou l'infirmière de ce qu'il ressent?					
16. Répond-il aux questions qui sont posées par le médecin, l'infirmière ou le personnel de la clinique?					
Gestion des activités quotidiennes					
17. Aide-t-il à planifier ou à préparer les repas/les aliments?					
18. Garde-t- il la maison/sa chambre propre ou fait-il le nettoyage après les repas?					
19. Fréquente-t-il les magasins et les services du quartier (par ex. les épiceries et les pharmacies)?					