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Citation Information

Culen, Caroline; Herle, Marion; Konig, Marianne; Johnson, Kiana; Wood, David L.; and Hausler, Gabriele. 2019. Be on TRAQ – Cross-cultural adaptation of the Transition Readiness Assessment Questionnaire (TRAQ 5.0) and pilot testing of the German Version (TRAQ-GV-15).. *Journal of Transition Medicine*. Vol.1(1). <https://doi.org/10.1515/jtm-2018-0005>

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Be on TRAQ – Cross-cultural adaptation of the Transition Readiness Assessment Questionnaire (TRAQ 5.0) and pilot testing of the German Version (TRAQ-GV-15).

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Original Article

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Be on TRAQ – Cross-cultural adaptation of the Transition Readiness Assessment Questionnaire (TRAQ 5.0) and pilot testing of the German Version (TRAQ-GV-15)

<https://doi.org/10.1515/jtm-2018-0005>

Received September 19, 2018; accepted June 12, 2019

Abstract

Objective: Transfer from pediatric care into the adult health care system is known to be a vulnerable phase in the lives of youth with special health care needs (YSHCN). Recommendations from the literature favor assessment of transition readiness rather than simply pass over YSHCN from pediatric to adult-centered care by the age of 18. Nevertheless, no validated and disease neutral assessment instrument in German exists to date. Hence, our aim was to cross-culturally adapt and to pilot-test a German version of the Transition Readiness Assessment Questionnaire (TRAQ 5.0). We wanted to provide a tool that can

be applied broadly during the health care transition (HCT) process of YSHCN.

Methods: The development included translating and adapting TRAQ 5.0 to German and conducting a pilot-study with 172 YSHCN between the ages of 14 and 23.

Results: Cross-cultural adaptation resulted in the TRAQ-GV-15. Exploratory factor analysis led to a 3 factor-structure. Internal consistency for the overall score was good with a Cronbach's alpha of 0.82. Age, in contrast to sex, had a significant effect on the TRAQ scoring. The administration of the TRAQ-GV-15 was well received and demonstrated good feasibility.

Conclusion: The TRAQ-GV-15 is an easily applicable and clinically usable instrument for assessing transition readiness in German speaking YSHCN prior to HCT.

Keywords: autonomy; health care self-management; health care transition; health literacy; pediatric onset chronic illness; youth.

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Introduction

The transfer from pediatric care to adult care carries a considerable health risk for youth with special health care needs (YSHCN [1–3]). This phase is associated with missed medical appointments [4, 5], poor health outcomes [6] and lower overall quality of life [7, 8]. Recommendations include structural changes in health care systems [9–11] as well as propositions on how to support patients while transferring [12–17]. Although various transition programs have been introduced [18–21], no gold standard in transitioning YSHCN from pediatric care to the adult centered care has been established so far [11, 22–24]. Nevertheless, an urgent need for enhanced success in transitioning is evident in the field of chronic and rare diseases [25, 26]. Internationally, experts are working on the implementation of standardized transition processes at pediatric clinics [27, 28].

Transfer is usually scheduled at the age of 18 [29–31]. In some practices, youth remain in pediatric care until the age of 24. Recent literature emphasizes focusing on readiness for transition [32] rather than on chronological age [33] and recommends to regularly assess and evaluate disease self-management and health literacy skills in YSHCN by objective and validated tools [7, 34]. However, psychometrically sound and reliable instruments are sparse [35, 36].

In follow-up of these recommendations, we performed a literature search, no validated disease neutral transition readiness assessment instrument was to be found in the German language. However, we encountered an instrument in the English language, developed in the USA – the TRAQ 5.0 (Transition Readiness Assessment Questionnaire) [37, 38]. The TRAQ has demonstrated good reliability and validity [34], and we considered this tool as adequate for our actual needs. Meanwhile, initial intervention trials using the English TRAQ have been conducted [39, 40]. Furthermore, several other cross-cultural adaptations of the TRAQ have been carried out recently [41–43]. This study is the first adaptation of the TRAQ 5.0 for German speaking YSHCN.

Materials and methods

Description of the original instrument

The TRAQ 5.0 [38] is a disease-neutral, self-administered questionnaire assessing transition readiness in adolescents and young adults (AYA) aged 12–26 years with chronic conditions and therefore with special health care needs. It comprises 20 items subdivided in 5 subscales (“Managing Medication”, “Appointment Keeping”, “Tracking Health Issues”, “Talking With Providers” and “Managing Daily Activities”). The response set of the English TRAQ is derived from the Transtheoretical Model [44]. Nevertheless, the items score in a range from 1 (“No, I do not know how”) to 5 (“Yes, I always do this when I need to”) with a maximum total score of 100 and a minimum total score of 20. A lower overall score indicates less transition readiness.

Translation and cross-cultural adaptation of the TRAQ

After approval of the authors of the TRAQ 5.0, the cross-cultural adaptation of the questionnaire was conducted according to recommendations from the pertinent literature [45]. Initially, two bilingual health care professionals

from the two study sites (Vienna, Austria and Freiburg, Germany) familiar with the TRAQ 5.0 independently translated the original 20-item TRAQ 5.0 to German. Then, two English native speakers (US American and Canadian, fluent in German) both blinded to the TRAQ and not otherwise involved in the study, independently translated it back to English. In a third step, we discussed our back-translated English versions with the authors of the TRAQ 5.0 via skype. Equivalents and discrepancies due to different health systems needed some considerations. Areas that lacked consistency or clarity were discussed. We looked for ways to translate English phrases and colloquialisms in German. These edits were incorporated into the German version. In the original American TRAQ 5.0 five items (item 14 and item 15 as well as item 18, item 19 and item 20, all three items assigned to the “managing daily activities” scale) did not add statistically relevant information in interpreting the TRAQ results: item 14 and item 15 showed low factor loadings, and furthermore, the “daily activities” subscale showed a lower Cronbach’s alpha than the other subscales. Therefore, the 5 items were omitted in the German Version of the TRAQ.

Hence, we obtained an instrument with 15 items where scores fall between maximum 75 and minimum 15. Finally, we pilot-tested the questionnaire for comprehensibility in a convenience sample of ten YSHCN aged 14–19 at the outpatient clinic of the Medical University of Vienna. Minimal changes led to our definite version, TRAQ-GV-15.

Survey sample

Our study population comprised AYA under medical care at two outpatient clinics, the Department of Pediatrics and Adolescent Medicine, Medical University of Vienna and the Center for Pediatrics, Medical Centre – University of Freiburg, Germany. Both clinics provide comprehensive primary care services for a broad variety of chronic conditions. The University of Freiburg is linked to a nationwide transition program [46], but no standardized transition readiness assessment has been implemented so far. In both clinics care providers can extend medical treatment of patients beyond the age of 18 if they think that a transfer to adult care in the present state would pose a health risk to the patients. Hence, the resulting convenience sample from the two study sites consisted of 194 YSHCN aged from minimum 14 to maximum 23 years of following outpatient clinics: Gastroenterology, Nephrology, Endocrinology (Diabetes, Growth and Bones), and Pulmonology. Exclusion criteria were severe cognitive impairment or poor German language skills.

Questionnaire administration

The questionnaire was administered to YSHCN at the two study sites from March 2017 to October 2017. The responses to the self-administered paper-and-pencil survey were collected during routine clinical care. Participants were instructed to answer the items on the survey on their own. However, a study investigator assisted whenever support was needed. Clinical data were obtained from medical records. Demographic data such as socioeconomic and family background, first language and educational level of the patients, were obtained by means of an additional anamnestic questionnaire. Supplementary information related to the feasibility of the TRAQ like “help needed”, “fill-in time” and “consulting time” were documented by the study investigators.

Statistics

We tested the TRAQ-GV-15 for reliability, construct validity, and scale-internal consistency. We applied the class mean imputation method for corrected mean sums to compensate for missing data. However, less than 0.5% of the values of any given item were missing. We conducted standard descriptive statistics for single items and overall TRAQ-GV-15 score description including frequency distribution, means, standard deviation, minimum, maximum and median [47]. To test validity for age and sex we conducted an ANOVA with Bonferroni adjustment for multiple comparisons [48]. A p-value of <0.01 was considered as statistically significant.

Because we eliminated five items from the original TRAQ 5.0 there was no evidence for a beforehand structure of our adapted 15 items instrument. Therefore, we conducted an exploratory factor analysis (EFA). We verified adequacy of the sampling with Kaiser-Meyer-Olkin- and Bartlett's-Test. We conducted Principal Component Analysis and Orthogonal Varimax Rotation with Kaiser Normalization. Internal consistency of the German questionnaire was estimated using Cronbach's alpha [47]. Statistical analysis was performed with IBM® SPSS® software Version 22.

Results

Sociodemographic characteristics of study sample

The final sample comprised the data sets of participants with given informed consent ($n = 172$). We included

patients with following conditions: Cystic Fibrosis ($n = 24$), Type 1 Diabetes Mellitus ($n = 76$), Juvenile Idiopathic Arthritis ($n = 49$), Chronic Renal Diseases ($n = 12$) and various rare conditions such as Turner syndrome or Glycogen Storage Disease ($n = 11$). Mean age of our population was 16.9 years ($SD \pm 1.8$) ranging from 14 to 23 with almost two thirds female respondents (60.5%). More than half of our respondents (62.2%) reported that German language was their first or main language, all participants however were fluent in German. Information on insurance status was not included in our survey since general social insurance applies to all our patients. Data on educational level and school type were either lacking (26.7%), inaccurate (6.4%) or grouped as middle school level (8.7%), vocational training (7.6%) or as high school level (50.6%). Sociodemographic characteristics are listed in Table 1.

Feasibility

Feasibility was tested by assessing if whether or not respondents could answer the questionnaire without help, and whether or not the questionnaire was completed within 10 min or if participants needed extra explanation in addition to a brief introduction. The majority (76.7%) completed the TRAQ-GV-15 within 5 min, about 20% within 10 min, respectively. Only 24 respondents (13.9%)

Table 1: Sociodemographic characteristics of the study sample included in the validation of the German version of the Transition Readiness Assessment Questionnaire (TRAQ-GV-15).

n	172	100.0%
Age		
14–15.99	55	32.0%
16–17.99	68	39.5%
18–23.99	49	28.5%
Sex		
Female	104	60.5%
Male	68	39.5%
Diagnosis		
CF	24	14.0%
DM	76	44.2%
JIA	49	28.5%
NE	12	6.9%
RD	11	6.4%
Language		
German	107	62.2%
Eastern Europe	28	16.3%
Western Europe	3	1.7%
Asia	10	5.8%
No data	24	14.0%
Type of education		
Middle school	15	8.7%
Vocational training	13	7.6%
Highschool	87	50.6%
Not specified	11	6.4%
No data	46	26.7%

needed help more than once. It became apparent that 15 min of explanation and introduction were sufficient for most participants (78.5%). Data shown in Table 2.

Exploratory factor analysis

EFA was conducted on our sample of 172 respondents to assess a factor structure of the TRAQ-GV-15. Model adequacy was verified with Kaiser-Meyer-Olkin (0.823) and Bartlett's-Test ($p < 0.001$), indicating suitability for factor analysis. In the first round of EFA (data not shown) using Orthogonal Varimax Rotation, four factors demonstrated an Eigenvalue ≥ 1 explaining 54.94% of the total variance. The scree plot showed a clear elbow with only the first factor, demonstrating an Eigenvalue of 4.38. Furthermore, factor 4 comprised only two items. Analysis of reliability is not meaningful with solely two items [47]. Therefore, we conducted another round of EFA extracting three factors accounting for 47.87% of the total variance. The new factor structure led to three clinically meaningful domains for the TRAQ-GV-15: domain 1 "Autonomy" (items 01, 04, 05, 07, 12, 13, 15), domain 2 "Health Literacy" (items 02, 09, 10, 11) and domain 3 "Adherence" (items 03, 06, 08, 14,). All items loaded on at least one factor at a level of more than 0.40 except item15 ("Do you answer questions that are asked by the doctor, nurse or clinic staff", factor loading 0.388). Factor loadings are demonstrated in Table 3.

Internal consistency

We calculated Cronbach's alpha Coefficient for internal consistency. The TRAQ-GV-15 presented globally a Cronbach's alpha = 0.824 which indicates a good

Table 2: Feasibility of the administration of the TRAQ-GV-15.

Aspects assessed	n = 172	%
Help needed		
0–1 times	148	86.1%
2–3 times	20	11.6%
4+ times	4	2.3%
Time for completion		
2–5 min	132	76.7%
6–10 min	34	19.8%
10–20 min	5	2.9%
More than 20 min	1	0.6%
Time for counselling		
None	6	3.5%
Up to 15 min	135	78.5%
Up to 30 min	28	16.2%
Up to 60 min	2	1.2%
More than 60 min	1	0.6%

TRAQ-GV-15, Transition Readiness Assessment Questionnaire, German version, 15 items.

Table 3: Cronbach's alpha and factor loadings of the TRAQ-GV-15 overall Cronbach's alpha 0.824.

	Traq domain 1 autonomy	Traq domain 2 health literacy	Traq domain 3 adherence
n	166	170	169
Cronbach's alpha:	0.779	0.721	0.507
Factor loadings			
Item05	0.822		
Item01	0.692		
Item04	0.654		
Item07	0.622		
Item12	0.596		
Item13	0.422		
Item 15	0.388		
Item10		0.776	
Item09		0.774	
Item11		0.759	
Item02		0.489	
Item14			0.671
Item08			0.587
Item06			0.568
Item03			0.485

TRAQ-GV-15, Transition Readiness Assessment Questionnaire, German version, 15 items.

reliability [47]. For the three subscale domains, the values of Cronbach's alpha appeared as follows: Domain 1 Cronbach's alpha = 0.779, Domain 2 Cronbach's alpha = 0.721 and Domain 3 Cronbach's alpha = 0.507. Results are presented in Table 3.

TRAQ-GV item values and overall score

In line with the original TRAQ, the items of the TRAQ-GV-15 score in a range from 1 to 5. Of the expected 2580 (172 responses to 15 Items) values only 12 values were missing which corresponds to 0.47% missing values. We calculated the TRAQ-GV-15 mean overall item score (54.77 ± 10.17) (Table 4). Similarly, we analyzed the 15 items individually, see Table 5. Item11 ("Do you manage your money and budget household expenses – for example: use checking/debit card?") demonstrated the lowest mean score (2.28 ± 1.50) whereas item03 ("Do you take medications correctly and

Table 4: TRAQ-GV-15 overall mean score for age groups and sex.

	Mean	SD
TRAQ overall	54.77	10.17
Age group		
14.0–15.99	48.52*	9.48
16.0–17.99	55.86	7.78
18.0–23.99	60.27	10.29
Sex		
Female	55.44	10.00
Male	53.76	10.43

*p-value of < 0.01 .

Table 5: Descriptive statistics of the 15 TRAQ-GV items.

Item	n	msc	SD	min	max	median
Item01	170	3.22	1.45	1	5	4
Item02	171	3.63	1.50	1	5	4
Item03	170	4.75	0.56	2	5	5
Item04	171	3.61	1.42	1	5	4
Item05	169	3.52	1.36	1	5	4
Item06	171	3.85	1.33	1	5	4
Item07	171	3.90	1.35	1	5	4
Item08	172	3.95	1.32	1	5	4
Item09	171	2.32	2.09	1	5	2
Item10	172	2.36	1.52	1	5	2
Item11	172	2.28	1.50	1	5	2
Item12	172	4.53	0.93	1	5	5
Item13	172	3.94	1.36	1	5	4
Item14	172	4.35	1.02	1	5	5
Item15	172	4.66	0.62	1	5	5

msc, mean scores; SD, standard deviation; min, minimum; max, maximum.

on your own?") demonstrated the highest mean score (4.75 ± 0.56).

The data followed a normal distribution, no skew was found. The two-way (2×3) ANOVA showed no significant difference for sex. However, age had a significant ($p < 0.001$ after Bonferroni adjustment for multiple comparisons) effect on the overall TRAQ score. Adolescents of the youngest age group (14–15.99 years) scored significantly lower than YSHCN of the two other age groups comprising adolescents and young adults from 16.00 to 17.99 and 18.00–23.99 years. TRAQ overall mean scores were 48.52 vs. 55.86 and 60.27, respectively (Table 4).

Discussion

This work followed the urgent need [5, 10, 25] of improving the preparation for transfer of YSHCN to the adult medical care. Objective of the study was to translate and to adapt the English TRAQ 5.0 [38] for use in German speaking countries. Thus, the process of adaptation resulted in the TRAQ-GV-15.

For cross-cultural adaptation and pilot-testing of the TRAQ-GV-15, we collected data from 172 YSHCN at two academic pediatric clinics in Austria and Germany, respectively. Administration proved to be easy and feasible. Most of our respondents finished the survey in less than 10 min. The low number of missing values may be the result of face-to-face intervention including the offer of support whenever needed. We also collected data on parental education, family status of the parents and family income.

Unfortunately, this data were incomplete or contradictory. Therefore, we could not include them into our analysis.

EFA resulted in 3 subscales. In our opinion, the newly defined 3 subscales (Domain 1: “Autonomy”, Domain 2: “Health Literacy” and Domain 3 “Adherence”) reflect domains contributing to transition readiness [37, 38].

Our TRAQ-GV-15 differs from the TRAQ 5.0 in some aspect. First, the TRAQ 5.0 study was a re-evaluation of the 29-item TRAQ whereas our study was the first adaptation in German language of the TRAQ 5.0 and a pilot-study of the TRAQ-GV-15. Next, the TRAQ 5.0 includes 20 items, while the TRAQ-GV-15 comprises 15 items. Moreover, the English TRAQ has a 5-subscale structure, as opposed to the 3-subscale structure of the German version. Concerning psychometric properties, internal consistency of the TRAQ-GV-15 was lower for both the overall score (0.94 vs. 0.82) and for the subscales compared to the original TRAQ 5.0. Subscale 1 and subscale 2 of the TRAQ-GV-15 subscales indicated an acceptable internal consistency (0.78 and 0.72) whereas the third subscale demonstrated poor internal consistency with a Cronbach’s alpha coefficient under 0.60. Finally, comparing criterion validity, we did not find significant effects of sex on the TRAQ-GV-15 mean scores after adjusting for age. This contradicts findings in earlier TRAQ studies [37, 38, 41]. In line with previous studies [35, 37, 38, 41], higher age increased TRAQ-GV-15 scores in our sample.

This finding underpins that transition readiness improves with age [38]. Nevertheless, individual maturation follows an unequal pace and needs positive reinforcement especially in YSHCN as health risk behaviors are known to be linked to chronic conditions [49]. Thus, assessing transition readiness in YSHCN could provide a good basis to discriminate between YSHCN ready for transition and AYA in need of intensified attention. Literature indicates that attitudes such as compliance and adherence are strongly linked to individual support [50].

Consequently, clinical value of our study results from raising awareness for the process of HCT in providers, patients, and parents. Furthermore, the TRAQ-GV-15 could be used to identify target areas for patient education and to enhance self-reliance in managing the disease. The repeated use of the TRAQ-GV-15 could help to evaluate the individual transition readiness process of adolescent patients.

Future studies will have to further evaluate the psychometric properties of the TRAQ-GV-15 among larger study samples. We realize that subscale three needs additional study. Of utmost interest is the predictive validity of the TRAQ-GV-15, which will have to be assessed in follow-up and longitudinal studies measuring transition

outcome. Eventually, upcoming studies will give clear evidence of what scores to expect from youth differing in age, sex and condition. Longitudinal data might widen our understanding of the development of transition readiness and could eventually lead to the establishment of cut-off scores, helping to identify patient samples at risk for potentially failed HCT timely [1]. The effect of intervention programs on TRAQ scores might also be worth investigating. Goal setting embedded within tailored interventions is another way to evaluate or improve TRAQ outcomes.

Limitations

The TRAQ-GV-15 is a self-reporting questionnaire which always holds the risk of socially-desirable answers. Moreover, the possibility of underestimation or rather overestimation of one's own competencies and skills is a frequent phenomenon. External observation like expert-rating or caregiver's assessment can compensate for these limitations. However, we did not include an external validation in our study design because we aimed at cross-cultural adaptation and validation of the TRAQ-GV structure.

Non-response was primarily caused by the fact that parents did not give informed consent. Therefore, we could not include data collected from YSHCN ($n = 20$) who managed their hospital appointments without parents or otherwise caregivers. Consequently, we had to exclude AYA who were ready to meet their doctor's on their own before the age of 18. This might attribute to a bias in our data.

Conclusions

We believe that our German version of the TRAQ has a direct benefit for YSHCN. In our experience, the TRAQ-GV-15's administration inevitably led to transition centered communication with health professionals, encouraged caregivers to enhance AYA's autonomy and sensitized YSHCN for transition specific issues. Based on the results of our study, we are convinced of the viability of the implementation into daily hospital routine.

Acknowledgements: Many thanks to our bilingual friends and colleagues Caroline Jerabek, Jennifer Kernreiter and Lilian Strobl. Best wishes to our students Sophia Wörndl, Max Hofleitner, Amelie Landt and Anna Ratheiser. Special thanks to all our young patients who made this study possible.

Author Contributions: Caroline Culen contributed to the conception and design of the study, to writing grant applications, to data collection and assessment, to statistical data analysis, interpretation of results, drafted and revised the manuscript, approved the final version of the article submitted. Marion Herle contributed to study conception, to managing and conducting the study, to interpreting the findings, critically revised the manuscript and approved the final version of the article submitted. Marianne König contributed to the translation and cultural adaptation of the TRAQ, contributed to conducting the study and gave final approval of the version submitted. Sophie-Helene Hemberger und Sanja Seferagic contributed to conducting the study and to data collection, critical revision of the manuscript and gave final approval of the version submitted. Carolin Talaska contributed to the translation and cultural adaptation of the TRAQ, to data collection and gave final approval of the version submitted. Diana-Alexandra Ertl contributed to conducting the study, final approval of the version submitted. Gudrun Wagner critically revised the manuscript and approved the final version of the article submitted. Christine Straub contributed to the translation and cultural adaptation of the TRAQ, to data collection, critical revision of the manuscript and gave final approval of the version submitted. Kiana Johnson and David L. Wood contributed to conception and design of the study, supplied to the translation and cultural adaptation of the TRAQ, critical revision of the manuscript and gave final approval of the version submitted. Gabriele Häusler was the PI of the study, contributed to planning and designing the study, to writing grant applications, supervised the study and had final responsibility, approved of the final version of the manuscript submitted.

Research funding: This work was supported in part by a research grant from the "Medical Scientific Fund of the Mayor of the City of Vienna", number of project: 15203.

Competing interests: The authors have nothing to disclose in the context of this paper.

Informed consent: Both, parental consent and informed assent were mandatory for all participants under the age of 18. Participants older than 18 years gave informed consent. No parental consent was required.

Ethical approval: The study was approved by the ethical committee of the Medical University of Vienna (EK Nr. 1456/2016) as well as the institutional review board of the Medical Centre – University of Freiburg, Germany (369/17). Participation was voluntary, adjusted study information was handed out.

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- Supplementary Material:** The online version of this article offers supplementary material (<https://doi.org/10.1515/jtm-2018-0005>).