Conducting a Multilingual Study Researching Traumatised Refugees Utilizing a Patient-Reported Outcome System

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Abstract. Approximately 300,000 asylum-seeking children arrived in Europe in 2015. The chance of experiencing a traumatic event is very high for fleeing children. Since the origin of the refugees is widespread, the languages spoken are diverse. Multilingual electronic patient-reported outcome systems (ePROs) can be used to gather medical data in a foreign language and display the results in the health professionals' language, which helps overcoming the language barrier. Utilizing such a system, a two-phase study aiming to screen refugee minors for potential mental health issues has started. Potential eligible participants are examined using questionnaires with good psychometric properties and cross-cultural applicability. To date, 75 minors and 21 of their relatives participated in the study, being German and Arabic the most desired languages for the electronic survey. Developing a system that provides multilingual questionnaires entails several drawbacks like a cumbersome translation process and dealing with writing directions. The proposed translation process and the ePRO can be re-used in similar studies.

Keywords. Patient-reported outcome, multilingualism, mental disorder

1. Introduction

Due to war, persecution, loss of home and security the number of refugees worldwide reached 65.3 million in 2015. Approximately one half of the asylum seekers in 2015 were children and 100,000 children worldwide were fleeing alone or without their families [1].

Nosè et al. demonstrated that experiencing a traumatic event, such as torture and war exposure, was very likely for asylum seekers or refugees: more than one-third suffered from clinically relevant psychological distress and one-fourth were diagnosed with a psychiatric condition like posttraumatic stress disorder (PTSD) [2]. In general, the

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vulnerability of children for mental health disorders increases [3]. Unaccompanied refugee minors are even at higher risk for mental health problems [4].

Migration is a worldwide phenomenon and languages spoken by refugees are diverse. Thus, health professionals often have to treat patients who do not speak a language the health professional understands. In this case, translators have to be used for communication, but they are not always available or requested or not paid by health insurances [5]. Despite challenging circumstances, health professionals are encouraged to use screening tools in order to prevent overlooking mental health problems and ensure early treatment. To overcome the language barrier translated patient-reported outcomes (PROs) can be used, which are defined as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" by the Food and Drug Administration of the United States [6]. PROs can be collected using an electronic patient-reported outcome system (ePRO), which avoids typewriting of pen and paper questionnaire results and ensures correctness of the data. At the University of Muenster, an ePRO named "Mobile Patient Survey (MoPat)" was implemented in 2014 and is currently used for routine and research collection of PROs [7].

The aim of this work is to propose an approach on how to support multilingual studies using MoPat and to point out encountered difficulties during the translation process.

2. Method

2.1. Study Design

The study is divided into two segments: short screening and a comprehensive diagnostic process. Screening focusses on posttraumatic stress symptoms and assesses emotional and behavioral symptoms. The screening process includes instruments oriented to proxies and self-reports as shown in Table 1. Children over 11 years receive self-report questionnaires; in case of younger children, their accompanying person(s) fill out external assessment forms.

Table 1. List of all translated questionnaires (*external assessment) and their assignment to the different events (Short screening and comprehensive diagnostic process).

Questionnaire	Screening children	Screening relatives	Diagnostic children	Diagnostic relatives
General Questionnaire	X	X	X	X
Strengths & Difficulties Questionnaire (SDQ)	X	X*		
Stressful life events questionnaire (SLE)	X	X*		
UCLA post-traumatic stress disorder reaction index (UCLA PTBS RI)	X	X*		
Connor-Davidson Resilience Scale (CD-Risc)			X	X
Kidscreen 10			X	X*
WHO Quality of Life (WHOQOL-BREF)				X
Life Events Checklist for DSM-5 (LEC-5)				X
Posttraumatic Checklist for DSM-5 (PCL-5)				X
Patient Health Questionnaire (PHQ-SADS) (PHQ-15, GAD-7, Panic, PHQ-9)				X

If the screening reveals potential mental health issues, children and their accompanying person(s) are invited to get an evaluation at the Department of Child and Adolescent Psychiatry, Psychotherapy and Psychosomatics at the University Medical Center Muenster (UMCM). Refugee minors who are in treatment at the UMCM fill out a more comprehensive set of questionnaires about several traumatic events, quality of life and resilience (see Table 1). Their accompanying person(s) also receive a survey to assess psychopathological symptoms of the child and fill out self-report questionnaires about mental health problems (see Table 1).

Ethics approval for the study was given by the ethics commission of the State Medical Association Westfalen-Lippe, Muenster, Germany (Ethics approval 2016-541-f-S: October 25, 2016). All patients and their legal representative gave informed consent.

2.2. Study Preparation

All study questionnaires were translated forwards and backwards from German into the respective national languages (Arabic, Dari, Farsi and Kurdish) by a certified translator. The initial and resulting version were then reconciled in the next step by consensus. Importing questionnaire meta-data in MoPat is possible using the CDISC Operational Data Model standard (ODM) [8]. Using ODMedit [9], student workers converted the textual questionnaires to machine-readable ODM files, which contained all translations for the questionnaires. After import and adaptation within MoPat, local translators checked every questionnaire to prevent transcription and conversion errors and reported any issue via email to a student worker who corrected the text. In addition, the graphical user interface of MoPat was translated to enable the users to interact with the system in their native language. An in-house research database called Exchange for Trials (x4T) is being used to store the exported survey data [10]. This system enables health professionals to view the responses in any language (e.g. German).

Figure 1. Bundle selection page within MoPat (A) and one example question in Arabic with activated help mode (B) where the participant can click the predefined information buttons to get additional information about the content and the usage of the current page.

3. Results

The translation of the questionnaires represented a cumbersome process. Since the modifications reported by the translators via email led to several inquiries, the process was adapted and the translators visited MoPat's developing lab to modify the texts themselves, supervised by the student worker, directly within MoPat.

The user interface of MoPat is shown in Figure 1. The upper part of the figure (A) displays the bundle and language selection. After selecting one of the bundles, here "Screening Children", one of the available languages, can be chosen to answer the questionnaires. The lower part of Figure 1 (B) shows exemplary a multiple-choice question in the chosen language with activated help mode. The participant can interrupt the survey at any time and resume it. After the participant has finished the survey, the questionnaires are exported to x4T and displayed in German for the health professionals.

To date 96 surveys were carried out using MoPat, divided into 59 screenings of children, 16 screenings of relatives, 16 diagnostic surveys for children and 5 for relatives. The country of origin of the refugees was mostly Afghanistan with 31 out of 75 (41%) and Syria with 17 (22%). The most used language for adults was Arabic with 13 out of 21 encounters (62%), followed by German with 4 (19%). In contrast, children speak mostly German (26 out of 75 - 35%) and less Arabic (20 out of 75 - 27%).

4. Discussion

This work has shown the possibility to survey study participants in foreign languages using an electronic patient-reported outcome system and provide the results in the common language for the medical professionals. Thus, the language barrier for assessing basic medical information and questionnaires-based instruments can be decreased.

To determine mental health problems it is important to use standardized questionnaires. Using non-validated questionnaires may result in pathologization of healthy individuals and/or overlooking of health problems and consequently preventing treatment. Therefore, only internationally established questionnaires for trauma and mental health with proven psychometric quality were selected for this study. Nevertheless, the questionnaires are only valid in German and should be validated for the recently translated languages Dari, Farsi, Sorani and Arabic.

The translation process was one of the most difficult and time-consuming parts for the preparation of the study. Direct communication with the translators should have been established from the beginning of the translation process. An even more efficient process could have been to invite the translation agency to include the translated texts directly in the data collection system. A basic knowledge of the languages or even the alphabet of the languages being translated is highly recommendable for the developing team, as it would help dealing with "simple" mistakes such as incongruence when copy-pasting text from the translated files.

Another drawback was the usage of languages using right-to-left writing like Arabic script. Firstly, the whole application has to use a character encoding like UTF-8, which supports the desired scripts like Arabic or Chinese script. Secondly, displaying web page content with both right-to-left and left-to-right oriented text is very difficult. To display the content correctly, the website could be mirrored at the central shaft of the web page, but this is not applicable due to diverse content on the page. However, best usability could only be achieved if the user interface would be justified culture specific, because

the understanding and interpretation of user interfaces is depending on the cultural background of the specific user [11]. Since the text on buttons and answers is mostly single-lined, MoPat only gives the opportunity to display question texts in right-justified format to be more accurate in displaying questions in right-to-left script. Thirdly, copying the right-to-left script and pasting it into a left-to-right text editor interchanges several characters resulting in wrongly allocated text. The solution adopted was to modify the editor to right-to-left, copy the content and change the editor back to left-to-right.

5. Conclusion

This work has demonstrated the feasibility of conducting a multilingual study utilizing an ePRO. The process of translating and integrating multilingual questionnaires into an electronic system has been optimized and could be reused in similar settings. Once the execution of the study is finished, questionnaire translations will be validated and made openly available if the corresponding licensor agrees.

6. Conflict of Interest

The authors declare that there is no conflict of interest.

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