

## **Adaptation of Arabic Translations of Cancer Patient-Reported Outcomes Assessment Tools: An Unmet Need**

**Loay Kassem<sup>1</sup> and Samy Alsirafy<sup>2</sup>**

<sup>1</sup>*Clinical Oncology Department, Kasr Al-Ainy Center of Clinical Oncology and Nuclear Medicine (NEMROCK), Kasr Al-Ainy School of Medicine, Cairo University, Cairo, Egypt.*, <sup>2</sup>*Palliative Medicine Unit, Kasr Al-Ainy Center of Clinical Oncology and Nuclear Medicine (NEMROCK), Kasr Al-Ainy School of Medicine, Cairo University, Cairo, Egypt.*

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**Corresponding Author:** Samy Alsirafy, Palliative Medicine Unit, Kasr Al-Ainy Center of Clinical Oncology and Nuclear Medicine (NEMROCK), Kasr Al-Ainy School of Medicine, Cairo University, Cairo, Egypt.

**Email:** alsirafy@kasralainy.edu.eg

Patient-reported outcomes (PROs) are defined as “reports coming directly from patients about how they feel or function in relation to a health condition and its therapy without interpretation by healthcare professionals or anyone else”<sup>1</sup>. Assessment of PROs is increasingly used in clinical cancer care and research work, not only to assess patient outcomes (e.g. quality-of-life) but also for clinical practice outcomes (e.g. monitoring of symptoms)<sup>2</sup>.

Tools to assess PROs pass through complex series including testing and validation to ensure accuracy, consistency and reliability of the measures. The majority of assessment tools we use in the Arab countries are translated from other languages. When it comes to translation into Arabic, PROs assessment tools are usually translated using the Modern Standard Arabic (MSA) which is an official language in all Arab countries.

The amount of clinical cancer research in the Arab countries has expanded over the last few years, whereas, many Arab centers had participated in international multicenter studies that include PROs as one of the study endpoints. Furthermore, many dedicated PROs studies have been conducted with native Arabic speakers in Arab countries<sup>3-5</sup>. In the majority of those studies the Arabic version used is a translation into MSA.

Although Arabic is considered a single language, there are many colloquial Arabic dialects that vary significantly from a region to another in the Arab World. In addition, there may be cross cultural differences especially in the description and meaning of specific medical terms, signs, symptoms and daily activities. Moreover, the high illiteracy rates that may exceed 30% among the Arabic speaking patients<sup>6</sup> can impede the value of MSA translations.

Under such circumstances, MSA translations may be misleading and may result in inaccurate measurement of PROs.

Limiting the use of MSA-translated self-assessment tools to educated Arab patients who can understand and respond in MSA will exclude a significant proportion of patients. Exclusion of illiterate and low-educated patients may limit the generalizability of research results, which affects the validity of research findings. Moreover, this will deprive a vulnerable population from utilizing MSA-translated assessment tools.

A possible solution to overcome illiteracy and dialect boundaries is the validated adaptation of MSA-translated PROs assessment tools using a colloquial Arabic dialect suitable for the corresponding region. Subsequently, consistency of the results will be assured using these adapted tools would be consistent across different studies.

Self-administration of PROs assessment tools is impossible for illiterates. Moreover, the mode of administration may be a very crucial condition to fulfill and should be the same as in the original questionnaire<sup>7</sup>.

Noteworthy, conversion of PROs assessment tool from self-administered to interview has several disadvantages. First, there might be inaccuracies in data collected as the assessment tools were designed, tested and validated to be self-filled. So, such complex process can't be guaranteed to be as effective and reproducible if done via an interviewer. Second, an interview is generally more susceptible to information bias. Besides, the interviewer effect may be a drawback that contradicts the idea, and importance, of a PRO measure. Furthermore, interviews are more time and money consumers than self-administered questionnaires. Finally, they might not

be convenient specially if involves a delicate or a subject sensitive to culture.

Limited attention has been paid to the adaptation of MSA-translated PROs assessment tools. In context, QOL assessment questionnaires developed by the European Organization for Research and Treatment of Cancer (EORTC) is widely used and is available in many languages including Arabic<sup>8</sup>. Eleven of 25 listed EORTC QOL questionnaires are translated into MSA. On the other hand, a little number of translations is available in only three colloquial Arabic dialects. Moreover, only one of these 25 questionnaires is translated into Egyptian-Arabic<sup>8</sup>.

There is an increasing awareness of the need for “dialect-adapted” PROs assessment tools in some of the Arab countries. In Morocco, four adapted QOL questionnaires related to cancer were validated in Moroccan-Arabic<sup>9-12</sup>, a dialect that is a lot different from those in other Arab regions.

In conclusion, there is an unmet need to adapt and validate cancer PROs assessment tools using colloquial Arabic dialects taking into consideration the cultural variations.

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