How Patient Input Helped Create Culturally Sensitive Multinational Instruments Assessing Post Viral Symptoms

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Our study involves collaboration/participation in order to develop culturally sensitive multinational tools for assessing post viral symptoms. We discuss the creation of questionnaires using patient participation, and the translation of these questionnaires using international collaboration. Patient engagement in collaboration on the creation and use of these types of instruments is of particular importance for patients who historically have not been true partners in collaborative efforts to understand diseases. This has occurred for those with the post-viral illness called Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), which has generated considerable resentment and estrangement among the patient community. Our article reviews: 1) why participation of diverse groups/patients is important in the development of instruments to measure key symptoms of ME/CFS, 2) why the ME/CFS group of patients needs to be included specifically (as an example), and 3) why structured health questionnaires are important/useful. Our article also has an overall aim of demonstrating collaborative efforts with patients and others on creating multinational scales. We provide examples of participatory processes used in developing and translating patient-driven instruments so that they can be used in non-English speaking countries. Our article illustrates how patients and international researchers can be involved in efforts to develop and translate international assessment instruments to validly capture domains of unexplained illness like ME/CFS. With the onset of another post-viral illness, Long COVID, there is a world-wide need to create valid and culturally sensitive assessment instruments to measure critical symptoms, many of which are similar to ME/CFS.

Keywords: participatory process, survey translation, survey translation guidelines, survey development, DePaul Symptom Questionnaire, DePaul Post-Exertional Malaise Questionnaire, long-haul COVID

The participatory process is vital for diversity of views and holistic perspectives that bring all gatekeepers into the process of finding creative solutions for social and community challenges (Jason, et al., 2004). Engaging all parties in this discovery process is one of the hallmarks of Community Psychology, as it is a most informed and sound approach to building and supporting community partnerships that bolster science and effective interventions. Research performed with patients strengthens the quality of research by fostering accountability, transparency, and relevance (Close et al., 2021).

When key constituent patients or community groups are not allowed the opportunity to provide input into the scientific discovery process, there is a loss of valuable and critical input of those who are directly affected by the condition. As an example, patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) have been left out of key scientific decisions and policies that have been made over the past few decades. Scientists initially imposed the name chronic fatigue syndrome on their illness, and patients legitimately felt this name trivialized the seriousness of their condition (Jason et al., 2016). Case definitions have also been

imposed on the patient community, such as the Fukuda et al. (1994) criteria, even though patients have uniformly critiqued this case definition as lacking the requirement of core symptoms like post-exertional malaise (Jason & Johnson, 2020). In addition, patients have felt that assessments and treatments have consistently emphasized a more psychogenic explanation of their illness, as opposed to one that is more biologically based (Geraghty et al., 2019), thus invalidating the experiences of patients, which has also occurred among those with Long COVID (patients with unexplained symptoms who have not recovered from the COVID pandemic) (Goldberg et al., 2022).

Jason and Choi (2008) have shown that in the field of diagnostics, there is a need to provide operationally explicit, objectively debatable criteria so that researchers and clinicians know how to elicit the necessary information from a clinical interview to permit them to reliably diagnose a condition. Structured questionnaires ensure that clinicians in the same or different settings collect consistent data to maximize the accuracy of clinical diagnoses. Thus, structured questionnaires remove as much as possible of the unreliability introduced by differences in the way clinicians and researchers elicit clinical information. In this article, we chronicle the development of instruments that have involved more patient involvement in ME/CFS research, such as the DePaul Symptom Questions (DSQ), which measures symptoms of this illness. In addition, we describe how patients participated as co-creators of an instrument to measure post-exertional malaise, a core symptom of ME/CFS.

The second part of this article provides examples of how these questionnaires were adapted and translated in multinational, culturally sensitive ways; processes that made it more likely the questionnaires would be well received, gather meaningful and valid data, provide new avenues for research, and be useful for multiple ethnic groups across the world. Based on the lessons learned in translating these instruments, we provide guidelines/recommendation which might be applicable for ME/CFS, Long COVID, and other diseases that are studied internationally.

Early efforts to differentiate fatigue from ME/CFS

British investigators (Chalder et al., 1993) developed one of the first scales to measure fatigue among patients with what was then called chronic fatigue syndrome (CFS). Our group attempted to validate this scale by comparing patients with ME/CFS to patients with Lupus, MS, and healthy controls (Jason et al., 1997). The Chalder scale could not differentiate patients with ME/CFS from those with other fatiguing illnesses. Over time, other problems were noted with this scale including ceiling effects, difficulties in interpreting the stem "less than usual" if a patient has been sick for a long time, and problems in differentiating individuals with ME/CFS from those with primary depression (Friedberg & Jason, 2002).

Based on anecdotal information from the patient community, these types of fatigue scales had a major problem in not being able to differentiate ME/CFS from solely psychiatric conditions such as Major Depressive Disorder. Patients felt that symptoms such as fatigue and unrefreshing sleep were more severe in patients with ME/CFS than in other conditions, but the existing fatigue scales and Fukuda et al. (1994) case definitions lacked a severity matrix. In other words, many illnesses have fatigue as a part of their symptom constellation, such as a Major Depressive Disorder, however, it is only by considering the severity of fatigue that the conditions can be differentiated from ME/CFS. This clinical insight was explored by Hawk et al. (2006), with a sample of patients with ME/CFS versus those with Major Depressive Disorder. When comparing symptom occurrence versus severity ratings, the best predictors were severity ratings for the symptoms. A stepwise discriminant function analysis was performed in which it was possible to correctly classify 100% of the study participants into ME/CFS versus Major Depressive Disorder categories. Based on these results, which were strongly influenced

by patient feedback, we shifted our research in the development of a patient symptom survey to include severity of symptoms rather than just measuring the occurrence or frequency of symptoms.

Patients had indicated to us that while fatigue is experienced by all individuals at different times in their lives (such as when running a marathon), the fatigue of ME/CFS can be experienced with little exertion. This information was obtained during conversations at conventions and during phone calls and email exchanges with patients, which highlights the potential benefits of casual/opportunistic interactions with patients. With this input from patient groups, in our next investigation, Jason et al. (2009) tried to differentiate types of fatigue including Post-Exertional, Wired, Brain Fog, Energy, and Flu-Like. Using a newly created Likert scale, respondents were asked to provide details that described the symptom onset, frequency, and severity as it relates to the participant's experience. Factor analyses of this data revealed a five-factor structure for participants with ME/CFS but only a one-factor solution for the healthy control group. We now realized that healthy controls experienced one main undifferentiated domain of fatigue whereas patients with ME/CFS experienced many different distinct types of this symptom. This has comparability to the Inuit being able to identify many varieties of snow (Martin, 1986), just as patients with ME/CFS can identify many different types of fatigue.

DePaul Symptom Questionnaire

We next began work in 2009 on the DePaul Symptom Questionnaire (DSQ), which is a self- report instrument measuring ME/CFS symptomatology and illness history (Jason et al., 2010). As an example of a anecdotal form of feedback, we were urged by patients to develop this instrument so that we could help determine whether a person met the symptom criteria for several ME/CFS case definitions (Evans & Jason, 2015), including the Fukuda et al. (1994) criteria, Canadian Clinical Criteria (Carruthers et al., 2003), the International Consensus Criteria (Carruthers et al., 2011), and the Institute of Medicine (IOM, 2015) criteria. Using the DSQ, participants rate each symptom's frequency over the past six months on a 5-point Likert scale: 0=none of the time, 1=a little of the time, 2=about half the time, 3=most of the time, and 4=all of the time. Likewise, participants rate each symptom's severity over the past six months on a similar 5-point Likert scale: 0=symptom not present, 1=mild, 2=moderate, 3=severe, 4=very severe. The DSQ has evidenced good test-retest reliability (Jason, So, et al., 2015). Factor analytic studies of these symptoms have resulted in factors evidencing good internal consistency (Brown & Jason, 2014; Conroy et al., 2023; Jason et al., 2015). Murdock et al. (2016), and an independent group found that the DSQ demonstrated excellent internal reliability, and that among patient-reported symptom measures, it optimally differentiated between patients and controls.

The DSQ has been effectively used to diagnose patients with ME/CFS. Jason et al. (2015), used several methods (i.e. continuous scores of symptoms, theoretically and empirically derived cut-off scores of symptoms, data mining) to accurately identify core symptoms that best differentiate patients with ME/CFS from controls. Our study found a small number of core symptoms that have good sensitivity and specificity, and these included fatigue, post-exertional malaise, neurocognitive symptom, and unrefreshing sleep. Findings from our studies were used by the members of the IOM (2015) as they created a more simplified

ME/CFS clinical case definition with a rating of symptoms for both frequency and severity that our group has proposed. The DSQ has also allowed us to differentiate ME/CFS from other fatiguing illness groups. For example, Jason et al. (2017) found that individuals with ME/CFS reported significantly more functional limitations and significantly more severe symptoms than those with MS. Similar findings emerged when patients with post-polio were compared with those with ME/CFS (Klebek et al., 2019).

Post-exertional malaise

Post-exertional malaise (PEM) is a key symptom of ME/CFS, as this symptom is mentioned in almost all ME/CFS case definitions. The DSQ does measure a domain of PEM (Cotler et al., 2018). A NIH/CFS committee, trying to specify common data elements to describe and diagnose PEM, recommended the DSQ-PEM to be used for this core ME/CFS symptom (NINDS Common Data Elements (CDE) Group, 2018). Following the release of the NIH/CDC recommendations, patients were extremely concerned that this instrument did not comprehensively assess PEM. Although the first author of the current article was not part of this committee that made this recommendation, he was contacted by phone and email by multiple patients, and a patient poll (Simon, 2018) recommended the need for a more comprehensive measure of this core ME/CFS symptom (Holtzman et al., 2019). With patient input and guidance, the DePaul Post-Exertional Malaise Questionnaire (DSQ-PEM) was developed. Items for this questionnaire were first provided by patients to Jason, who then posted these questions on his facebook social media page as a beginning effort to more comprehensively assess PEM. Over the next month, hundreds of patients posted their feedback on the symptoms and ways to assess them, and those changes were re-posted on the author's social media page. We continued this iterative process of seeking patient input and reposting the questionnaire multiple times until patients felt that the items and domains were comprehensively assessing PEM (Jason et al., 2021). The final questionnaire assessed onset and possible triggers of symptoms, how patients experience PEM, their preference for common phrases used to describe PEM, and a list of symptoms that are exacerbated after physical and cognitive exertion. The DSQ-PEM also assessed the duration and length of recovery time of PEM, and the possible effects of pacing (staying within one's energy envelope). Preliminary validation was provided by the findings of significant and predictable relationships between different domains of this post-exertional malaise questionnaire and physical functioning (Jason et al., 2021).

Multinational Collaboration/Participation: Bidirectional Flow of Information

Over the past decade, there has been considerable interest in using our patient informed measures of ME/CFS from multinational researchers and patient groups in Canada, Mexico, Asia (e.g., Japan), the Middle East (e.g., Iraq), Great Britain, Ireland, Europe (e.g., Spain, Germany, France, Poland, Belgium, Netherlands, Finland, Denmark, Latvia, and Norway), and South Africa.

When engaged in this type of international collaboration, there is a need for cultural sensitivity when reaching marginalized ME/CFS and Long COVID patient groups in different parts of the world. Below, we highlight our collaborative efforts with groups outside the USA illustrating how we used participatory processes for creating different language versions of our ME/CFS questionnaires.

Case Study in France

Semantic differences can occur when words that are understood easily in one culture/language group are perceived very differently by another group. For example, a patient with ME/CFS from France contacted us and she had been collaborating with a group of French infectiologists who were conducting a study on patients with long COVID, which has many similarities to ME/CFS (Anvari, personal communication, September 15, 2020). They expressed difficulties with translating one of our instrument's questions that had a symptom phrased in this way: "Dead, heavy feeling after starting to exercise". In French, the term "dead" would be interpreted as meaning a "brutal absence of energy causing a physical and mental paralysis-like

state." The patient explained her thoughts on the word "dead" in the following ways: "The closest phenomenon I can think of is the "dead" in deadlift: when the lifter is not applying their strength onto the barbell, it stays inert on the ground because no source of energy is making it move. But this only conveys the objective inertia of the barbell, not what it might feel if it were a real person."

To solve this problem in translation, their research team next created a list of French phrases that could have been substituted. We partnered with them in a discussion involving whether the list of translated words held the same equivalence of severity, the onset of the experience of the symptom, the inclusivity of the mental and physical aspects of feeling "dead", and the degree to which the phrase captures a subjective versus an objective phenomenon for the respondents. For example, they speculated about the phrase: "feeling of (total) numbness" ("sensation d'engourdissement (complet)"). After considering this phrase, it was decided that it did not sound strong enough to convey the intensity of "dead". Another possibility was "feeling stunned" – ("sensation d'étourdissement" "étourdissement"). When considering this phrase, there were concerns that while it conveyed either strong mental confusion or a black- out, it failed to fully convey the physical aspect of the dead term. Another phrase considered was "feeling of paralysis" ("sensation de paralysie"), but we agreed that this phrase conveyed the meaning of "inertia" rather than the subjective feeling of exertion-induced sickness. Finally, we reached a consensus that the expression: "feeling of being knocked out" ("sensation d'assommage") best captured both the physical and mental aspects of this symptom in the French language.

Case Studies in Norway

In Norway, we had been approached by several groups over time who were translating our questionnaires. The DSQ was first translated in 2012 into Norwegian (and retranslated) and validated by Strand et al. (2016). This translated DSQ had been used in Norwegian thematic register/biobank data sampling as well as a Rituximab study for patients with ME/CFS (Strand, personal communication, Nov. 8, 2020). During the translation processes, we were informed that a number of words in English did not translate well in Norwegian. This was brought up when another patient organization in Norway wanted to use our translated DSQ with an online survey of people with ME and other fatigue-type illnesses (Kielland, personal communication, March 30, 2021). The Norwegian translation faced semantic challenges with SF-36 items such as "Did you feel full of pep?" This translates in Norwegian to a "desire to take action" ("tiltakslyst"), which is quite different from "pep" which means energy. In other words, "tiltakslyst" means you could have wanted to do things, but many with ME/CFS desire to do things but lack the pep or energy. The Norwegian group solved this problem by substituting the phrase: "Did you have a lot of energy?"

Conceptual issues are also encountered with working on international translations. For example, the Chair of the Boards of the Norwegian ME-association was developing a large online ME/CFS patient survey using our DSQ with the aim to reach at least 3,000 persons with ME, CFS, ME/CFS, chronic fatigue, and Long Covid-19 patients (Getz Wold, personal communication, November 15, 2021). They were going to collect online data on diagnosis-history, symptoms, treatment and perceived impact of the treatment. Discussions were held about how to use a translated DSQ to help differentiate those who might have met CFS criteria based on the Fukuda et al. (1994) criteria versus ME that was closer to a more restrictive case definition such as the Canadian Consensus Criteria (Carruthers, et al., 2003) or the IOM (2015). They engaged in a collaborative process with our team to differentiate those with less severe symptoms that might have been caused by lifestyle factors from those who were more ill and might have biological explanations for their condition. This is a debate that was occurring within their country, and they looked to our questionnaire to help classify the patients according to the various broad versus narrow ME/CFS diagnostic criteria in order to contribute to the national discussion

on recommended diagnoses, research priorities, and treatments of patients with ME/CFS in Norway.

Case Studies in Germany

Questionnaires require revision to ensure that they are relevant and kept up to date with current knowledge of conditions such as ME/CFS. For example, the COVID 19 epidemic introduced unique challenges for patients with ME/CFS and this prompted a revision of the DSQ. For example, in Germany, we worked with Laura Froehlich, a post-doctoral researcher in social psychology at the University of Hagen. She is a volunteer for the German Association for ME/CFS, where she summarizes the latest research on ME/CFS in monthly science updates for physicians and a general audience. Together with Daniel Hattesohl (Chair of the German Association for ME/CFS) and Carmen Scheibenbogen (Professor of immunology at the Charité University Hospital in Berlin), they have translated our questionnaires (L. Froehlich, personal communication, Oct. 11, 2019) for their work on ME/CFS attributions and stigmatization (Froehlich et al., in press) and a project on demographics and the ME/CFS medical care situation (Froehlich et al. 2021). They have found that access to and satisfaction with medical care could be even more limited for patients with ME/CFS because they might avoid going to the doctor/hospital due to being afraid of contracting COVID-19 in the waiting room or because they are not able to travel to the doctor's office/ hospital due to the lockdown. In modifying our questionnaires, they now include control questions about the coronavirus, e.g., "My daily life and activities are affected by the coronavirus" (not at all - very much)/ "I feel anxious because of the coronavirus" (not at all - very much) and they adapted the items on medical care access to a different time frame because our time period stretched beyond the onset of the pandemic. As with the other translations, when we were sent the backtranslation, only minor adjustments to our translation were necessary.

Other challenges for those translating questionnaires involve adapting adult derived scales for used with child or adolescent samples. Uta Behrends' ME/CFS research group based at the Children's Hospital of the Technical University Munich in Germany (A. Leone, personal communication, September 1, 2021) were seeing children, adolescents, and young adults with post-infectious ME/CFS. They encountered conceptual challenges in their German translational process. For example, there were pediatric issues in trying to make clear differences between terms used on the DSQ such as "slightest effort", "minimum exercise", and "mild activity" on the DSQ. We helped differentiate these terms as "effort" is general and can include both physical and mental domains. "Exercise" is something that is more planned and involves physical activity, whereas activity might be more daily physical life tasks that one has to accomplish. They also were uncertain of the difference between "physically tired" and "physically drained." Through discussions, we were able to convey that "tired" is something many youth experience but being "drained" is just a much more intense feeling of exhaustion. The German team used a professional translator who specialized in medical text to back-translate the survey(s) and then made adjustments.

Case Study in Denmark

As another example, we were contacted by a physician in Denmark who felt that it was a challenge to translate our questionnaires as many social and cultural norms in Denmark are different in the US (L.S. Brinth, Personal Communication, June 3, 2021). Cultural issues such as this commonly impact on answer selection. Research by Johnson et. (2005) has shown that particular cultures can elicit extreme response styles and acquiescent responses. Different cultures might be willing to spend varying amounts of time filling out long questionnaires, and the types and formatting of questions might also encounter differing reactions in varying cultures.

The Danish translation group debated whether to translate the original DSQ-1 or a more updated and longer DSQ-2. Even though the DSQ-2 is longer and takes more time to complete, the translaters felt that the people in their country were willing to complete a more difficult and taxing task. Next, three members of their team translated English to Danish independently, and then made a consensus version that they back-translated. Rather than use all items, they started with a core list of symptoms which were translated and validated in- depth. This involved forward and back translating, focus groups with preliminary testing, adjusting, and then an actual subsequent validation with bilingual patients and healthy controls included. Following this, they translated the rest of the questions.

Lessons Learned

In the examples above, we used a participatory approach to survey translation, by incorporating the patients' and scientists' active involvement in all aspects of the survey translation process. There are many solutions and approaches used for effective translation such as single person (direct) translation, committee translation and adjudication, back-translation, field testing, and machine translation. Some collaborators attempted to translate the DSQ-PEM into their language on their own or with a team. This appeared to reflect the availability of resources pertaining to each group or project. Challenges in translation were addressed by deriving solutions and checking in with us for clarification and suggestions.

In general, we have found that a good survey translation consists of equivalence across surveys in semantic, conceptual, and normative characteristics (Behling & Law, 2000). In other words, the word and sentence structure should be comparable, the same concept must be measured, and the social norms of each culture must be respected. This is not always easy as there are minor to significant linguistic and cultural differences among groups of people. An example of a cultural, and even legal, difference is that in some countries participants cannot be asked their ethnicity (Melchior et al., 2021). Other challenges to survey translation include variations in the frequency of word use and in word difficulty, grammatical forms not having equivalences, and syntactical style (Ercikan, 1998); matching semantics and structure of both questions and answer scales (Harkness et al. 2004); and equivalence of ordinal values of response options, interval differences between response options, and response labels (Keller, et al., 1998).

As we worked with international groups of patients and scientists, three key areas relevant to measuring questionnaire equivalence across language versions were semantic equivalence, conceptual equivalence, and normative equivalence. This can be accomplished by the use of forward-and-back translation, collaborating with the originator of the surveys to adjudicate issues; choosing answer responses mindfully; piloting, gathering qualitative and quantitative feedback about the questionnaire from participants; and validation with bilingual participants and healthy control groups. control groups.There are a few other methods that could benefit the translation process but require resources. These include machine translation, committees to translate and/or monitor and decide on the translation process and versions for further development and testing, and others. The process of translating a survey is never finished, as demonstrated in the instrument created in Norway. Once a strong translation is created and more diverse people use the translated survey, the data gathered can be used to assess ways to increase its validity and reliability.

The role of culture on survey responses is an area for further research as well. Johnson et al. (2005) studied the influence of culture on response biases. Using Hofstede's dimensions of culture, they found that power distance (e.g. supervisors and employees are considered almost equals lower power distance in flat organizations) and masculinity were positively and independently related to extreme response behaviors; and individualism, uncertainty avoidance, power distance, and masculinity were each negatively related to acquiescent response behaviors. It would be helpful to determine the cultural make up, using Hofstede's

cultural orientations, for each target population. This can be conducted a priori and post hoc any survey development and administration – and then piloting various question and answer formats.

There were several limitations that should be noted in the processes used to translate the DSQ. Firstly, forward-translation conducted by one person is limited in perspective, knowledge base, and skillsets and hence may not be representative of the community they come from or the target population (Harkness & Schoua-Glusbert, 1998). Secondly, the same translation process was not used by all our collaborators, which can limit comparability among the various language versions. This can be addressed by using the guidelines provided earlier, particularly if resources are available for such activities. Thirdly, it is possible not every step in the translational process was documented, which is vital for replication of those processes. This can also help track the different survey versions and how it functioned during pretests (US Census Bureau, 2005).

Implications for Long COVID

Our collaborative work with ME/CFS has implications for the COVID-19 pandemic, which has had devastating health consequences for patients around the world (Cutler & Summers, 2020). Islam et al. (2020), reviewed the literature regarding prior epidemics and infections and found a certain percentage of those infected have long-term complications, including the development of severe fatigue. Among the millions who have been infected with the SARS CoV-2 virus, many with Long COVID will ultimately be classified as having ME/CFS (Kedor et al., 2022). Some view Long COVID as a legitimate medical illness and others dismissing it as malingering or due to a psychiatric illness (Devine, 2021), a similar debate that has occurred with ME/CFS (Goldberg et al., 2023).

Researchers do not know whether symptoms among those with Long COVID increase, stay the same, or reduce over time, differ among the COVID-19 variants, and whether such patterns occur for all symptoms or are differential. Determining this type of evidence can be enhanced by the use of standardized and validated instruments to measure symptoms at different time points in this illness. It is imperative that well-established and easily translatable questionnaires are available to help resolve these types of debates and identifying similar patients in different settings is critical for the identification of homogeneous samples for research purposes. Bringing patient input into the questionnaire development process has multiple benefits as was illustrated by several of our international collaborations. The DSQ-PEM is currently being used in the US in the large RECOVER randomized trial of anti-virals in the treatment of Long COVID (Clinical Trials.gov, 2023). The DSQ is also being used by a team of 200 research collaborators in 28 countries involving 20,000 patients to study COVID-19 (Shaheen & Shaheen. 2022).

Conclusion

Our study showed how the participatory process was an effective approach to bringing multiple partners into the scientific process of questionnaire development for a marginalized illness group. The DSQ and the DSQ-PEM are two examples of how questionnaires can be improved by input from key gatekeepers including patients and international collaborators. As stated in this article's introduction, patients have frequently been left out of critical decisions regarding their illness for several decades, and as a result, they often feel alienated from the work done by many within the research community We contend that intentionally involving patients in the process of development and translation will result in greater collaboration and accurate measures that empirically capture illnesses. This may lead to restored trust, increased engagement by all stakeholders, and ultimately improve the quality of scientific inquiry and impactful treatments for patients.

When the opportunity does come up to create an assessment or measurement tool and/or the international group engagement to translate the tool, it can be beneficial to use the

participatory process at step one. Doing so can help share knowledge across international research groups regarding the subject and to design questionnaires that avoid confusing linguistic and cultural anomalies. This early participatory approach will also help create a more resilient survey that can translate easily across linguistic, cultural, and national differences (Brislin, 1970). Furthermore, when patients and practitioners are included in the survey development process, qualitative data can be gathered so to inform conceptual validity, questions, sound wording, and greater survey accesses and administration. In addition, this early and continued participatory approach can increase the chance that researchers create robust communications between key gatekeepers in the scientific process, including patients.

Evaluating the translational challenges of the DSQ and DSQ-PEM and related measures, it seems that survey translation is optimal when it involves many people and interactive communication among these individuals. The following steps represent what we have learned as possible best practices in survey translation. Contact is made with the developers of the original survey so to elicit any help they might be able to provide, such as prior translated surveys and potential collaborators who are interested or started working on the specific language translation. In addition, there might be different dialect groups that might need to be considered, as many countries have multiple dialects as well as languages. The survey is translated separately by two or more individuals. These versions are compared, and differences adjudicated. After translation effort occurs, the instrument is back-translated by a native bilingual speaker who is familiar with the discipline of the questionnaire. The back- translated version is compared to the original source survey and problem areas addressed with the back-translator, revisions are made, and a version is agreed upon by the research team. Pilot study of the version is conducted with a group of single language speakers who come from the target population. Open and closed-ended questions are included at the end of the survey, which inquiries about the clarity and ease of the survey and a section for additional comments is provided as well. The research team uses the feedback to make further revisions if necessary. The revised survey may be piloted again, until a final version is ready to be tested on a sample size that will allow for validity and reliability testing of the translated survey. Once the data are analyzed, results are published, disseminated, and added to multiple repositories, such as national and field specific data bases, and websites of both the research team and survey originator.

Our article provided examples of using participatory processes to develop psychometrically sound instruments to measure symptoms of patients with ME/CFS, and itsuggested ways that participatory methods can help validate the experiences of patients that lead to more culturally sensitive, multinational research. Patient involvement in research is becoming more common (Tomlinson et al., 2019) and occasionally, patients even lead or do the research (Hoddinott et al. 2018), as occurred with several of the international efforts described in the current article. Even though patient involvement in research is still underreported (Cluley et al. 2022), such work is particularly important with marginalized populations and social contexts involving power differentials (Ponterotto et al., 2013) and biases (Berger, 1977).

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