Portuguese Translation and Cultural Adaptation of the Music in Dementia Assessment Scales (MiDAS)

Running title: MiDAS Portuguese Translation and Adaptation

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Abstract

Introduction: Music in Dementia Assessment Scales (MiDAS) is an observational, dementia-specific, visual analogue scale, developed to measure musical experiences of patients with dementia (PwD). It was derived from qualitative data of focus groups and interviews with PwD, carers, care home staff, and music therapists. Since its publication, there was a great interest in using MiDAS in several European countries, including Portugal. However, no adaptation to Portuguese language and culture was yet available. In this manuscript, we aim to describe the process of translation and cultural adaptation of MiDAS to European Portuguese, presenting the final MiDAS-PT version.

Method: We have followed a rigorous ten step approach, consisting of a Preparation stage; elaboration of two Forward Translations; Synthesis of the latter versions; Back Translation by a bilingual professional translator; Revision of that version by the original author of MiDAS; Harmonization with other versions of MiDAS in different languages; Testing and Debriefing of the final version with volunteer health professionals; Consensus meetings; Proofreading and finally the Reporting of the process.

Results: No major changes have been made to the actual content text of MiDAS. Some minor adjustments were made in wording and additional instruction details were added in order to increase clarity and adequacy to the Portuguese setting.

Discussion: Overall, Portuguese health professionals considered the instrument user friendly and intuitive in terms of content, structure and layout. To allow the use of MiDAS-PT for research and clinical purposes, the next step will be a study of its psychometric properties.

Key Words

Behavioral Rating Scales; Dementia; Music Therapy; Translation; Treatment Outcomes.

Introduction

In recent years various forms of music activities became increasingly popular as therapeutic interventions in dementia care. In particular, the use of music-based interventions (Mbi) highlights that music is widely accepted as beneficial for general wellbeing of people with dementia (PwD), potentially helping them to adjust and adapt, enabling the connection with people around them, environment and society (McDermott, 2020).

Music Therapy and other types of Mbi have also been suggested as viable strategies for the management of behavioral and psychological symptoms of dementia (BPSD) (Blackburn & Bradshaw, 2014; Chang et al., 2015; McDermott et al., 2013; Vink & Hanser, 2018). BPSD, defined as symptoms of disturbed perception, thought content, mood or behavior, are core burdensome features of dementia, known to affect up to 90% of the patients throughout the course of the disease, including depressive mood, anxiety, agitation, restlessness and psychotic symptoms (Finkel et al., 1996; van der Linde et al., 2016). Nonetheless, there is still a lack of robust evidence to support the effectiveness of Mbi in dementia care, particularly in BPSD management (Chang et al., 2015; Livingston et al., 2014b; McDermott et al., 2019; McDermott et al., 2013; Oestergaard & Moldrup, 2011; Olazaran et al., 2010; Ueda et al., 2013; van der Steen et al., 2018; Vink & Hanser, 2018). In future research, more holistic study designs and appropriate outcome measures should be considered.

The Music in Dementia Assessment Scales (MiDAS) is an outcome measure that has been specifically developed to evaluate how PwD with moderate to severe cognitive decline engage with Mbi, capturing what is meaningful for them in the musical experience (McDermott et al., 2015). By allowing the raters to score five observable signs (Interest, Response, Initiation, Involvement and Enjoyment), that PwD might express without the need of using verbal language, the instrument tries to capture a holistic picture of the therapy process and outcome in an objective and mensurable way, that can be used in quantitative research.

The original English version of MiDAS was rigorously developed using qualitative methods and consensus approaches (McDermott et al., 2015), targeting not only formal Music Therapy interventions but also other less structured Mbi, potentially delivered by non-music therapists. A preliminary psychometric evaluation indicated that it has adequate psychometric properties on a variety of attributes: high therapist inter-rater reliability (Intraclass Correlation Coefficients (ICC) range: 0.768-0.820), adequate

staff test-retest reliability (ICC range: 0.498 to 0.609), adequate concurrent validity with the Quality of Life in Alzheimer's disease (Logsdon et al., 1999) scale (Spearman's rank correlation coefficient: 0.524 (base-line), 0.469 (mid-treatment), 0.474. (end-treatment)) and good construct validity (correlation between items ranging from 0.947 to 0.754 in factor analysis) even though the study sample size was small (McDermott et al., 2014).

Since its publication, there has been a great deal of interest in using MiDAS in several European countries, as illustrated by the fact that the instrument has already been translated into five languages - Danish, French, Icelandic, Norwegian and Spanish (the last one not yet published) (Aalborg University, n.d). MiDAS has also been used in studies in Canada (Appel et al., 2019) and Australia (Garrido et al., 2020).

In Portugal, the profession of music therapist is not yet formally recognized and music therapy or other Mbi are not routinely used in clinical practice within the national health care system. Nonetheless, several long-term care institutions, such as private and semi-private nursing homes, already use musical interventions with PwD, with perceived positive results and good acceptability. However, those interventions have mainly a recreational aim, consisting of informal programs with very little structure, that have not been academically investigated. There are also anecdotal reports of Mbi being delivered to PwD in the community, but also without formal reports and evaluations. The fact that there is no outcome instrument, adapted to the Portuguese context, enabling a rigorous and standardized evaluation of the effects of Mbi, impedes the realization of sound research, that could better inform stakeholders, potentially changing standards of practice and improving the caring experience of PwD in the national health system.

Importantly, in the Portuguese clinical setting, older patients represent a vast proportion of the acute care admissions. Those patients stay longer in hospital, with a high proportion of admissions lasting longer than 30 days and have high readmission rates (Campos, 2008). Older patients, including those with dementia, are generally admitted to undifferentiated medical wards that are not well prepared to offer an age-appropriate person-centered care. In fact, non-pharmacological interventions are not routinely used in dementia care and the management of BPSD is actually quite problematic. The existing normative guidelines (Carvalho, 2011; Costa, 2011) on BPSD management and the use of antipsychotic and physical restraint are not specific to patients with dementia, which creates vagueness and significant variation in its interpretation and implementation. In practice, the management of agitation in PwD involves frequent prescription of high doses of antipsychotics and the institution of physical restraint measures.

We believe the use of Mbi is a promising option to improve standards of care and at the same time is realistic, since music is widely available, inclusive and Mbi are relatively affordable (Bellelli et al., 2012; Livingston et al., 2014a). The existence of a Portuguese version of MiDAS could foster research on Mbi in the country, potentially leading to the identification of objective benefits of its utilization and to its subsequent integration in dementia care at a larger scale.

With this paper, we aim to describe the MiDAS translation and cultural adaptation process to European Portuguese (PT) and to present a final MiDAS-PT version, that was tested by several health professionals from different backgrounds and in different dementia care settings (clinical and non-clinical). The developers of MiDAS explored the procedures used for outcome measure translation and cultural adaptation and derived a ten-step procedure recommendation (Ridder et al., 2015). We followed the latter, as closely as possible, in order to develop the MiDAS-PT.

Method

The process of developing MIDAS-PT consisted essentially of 3 main tasks - Portuguese Translation; Cross-cultural Adaptation; Testing and Debriefing - as suggested by (Ridder et al., 2015).

Ethical Considerations

Approval was obtained from the ethics committee of the hospital where the study took place and all participants gave their informed consent/assent.

Participants

The in-country researchers team consisted of 3 researchers. Researcher 1 (R1) and 2 (R2) were both psychiatry trainees with clinical experience in dementia care. Researcher 1 has also been previously involved in academic research of music in dementia care. Researcher 3 (R3) is a senior psychiatrist and professor, with expertise in old age psychiatry, both clinical and academic, specifically concerning non-pharmacological interventions in dementia care. A bilingual professional translator, with experience in translating psychological instruments for academic purposes, was hired to perform the back-translation of the instrument.

A convenience sample of volunteer health professionals was recruited in a Portuguese General Hospital. The inclusion criterion was having previous experience in dementia care and being willing to participate in testing and debriefing of the Portuguese version of MiDAS. Seven health professionals from different backgrounds participated in the study (three nurses; two psychiatrists; two non-medical staff members). The nurses and the psychiatrists had extensive clinical experience in dementia care, but no formal training in music therapy. The non-medical staff had only some experience in caring for people with dementia in the acute hospital setting. None of the volunteers had relevant academic experience regarding translation and adaptation of psychological instruments.

Instrument

MiDAS consists of 5 Visual Analogue Scales (VAS), each capturing a different dimension of the music intervention's effect on the patients: Interest, Response, Initiation, Involvement and Enjoyment. These were formulated on the basis of qualitative interviews with PwD, relatives, staff members and music therapist. The response to each dimension of the scale is marked vertically on a 100mm line and then converted to a score ranging from 0 to 100. This may be illustrated with additional information regarding whether the person has had some important responses beyond the usual. Therefore, six additional optional behaviors can be selected at the end of the 5 VAS (agitated/aggressive; withdrawn/low in mood; restless/anxious; relaxed; attentive/interests; cheerful/smiling) and there is also a free field where more detailed responses can be written.

MiDAS has two forms, one to be completed by a staff member and the other for the music therapist. In the staff version, an assessment is given several hours before and after music therapy, on the same day, ideally by the same caregiver, who knows the PwD well. In the music therapist version, the music therapist marks the participant's response to the music therapy itself, with a retrospective assessment of the participant's behavior in both the beginning of the music therapy and at the clinically most relevant time during the intervention. There are thus two forms for each patient, that look alike, each of which is filled twice. Since they measure two different things, it is not possible to compare them instantly. The staff version can be used to assess the effect of music therapy based on the staff's subjective assessment and the music therapist version can provide more information about changes in the clinical context itself. The two forms should then be analyzed separately to mutually inform each other (McDermott et al., 2014).

Translation Procedures

The inaccurate or incorrect translation of a standardized measurement tool may hamper its psychometric properties. To avoid this, we have followed a rigorous ten step approach as recommended by (Ridder et al., 2015) and illustrated in Figure 1.

[Figure 1 near here].

Step 1: Preparation

a. Authorization for Portuguese translation of the original English version (V1) was obtained from the MiDAS developers.

b. Two MiDAS developers (D1 and D2) were involved in the translation process via mail and Skype® meetings.

c. R1 had a dual role as both developer and project manager. To ensure that the project manager had a thorough knowledge of the target group, terminologies and context, meetings were held with D1.

Step 2: Translation

a. MiDAS was translated from English to Portuguese in parallel by two health professionals (R1 and R2). The two translations (forward translations) were made independently of each other so that the result was two preliminary Portuguese versions (T1 and T2).

b. During this process, D1 answered by mail and Skype® calls to some understanding questions, but without going into the translation itself.

Step 3: Synthesis

The two translations were reviewed by R1 and R2 and a consensus version was derived (V2). In the event of discrepancy between the translations, word choice was discussed in detail and adapted according to cultural and contextual aspects. Other health professionals (psychiatrists, nurses and non-medical staff members), working with PwD in Portugal, were consulted at the debriefing stage.

Step 4: Back translation

The Portuguese V2 was back-translated to English by a bilingual professional translator who did not have access to the original scale.

Step 5: Linking

The back-translated English version was compared to the original version (V1) of the developers by D1. There were minor deviations, but the overall meaning was correct.

Step 6: Harmonization

Harmonization with the Spanish version of MiDAS, which was also in progress, was performed in order to assure versions of closely related languages are comparable, applying parallel terminologies and similar discourse style.

Step 7. Testing and debriefing

MiDAS forms were tested in different dementia care settings (one acute hospital ward; one day-center) by health professionals from different backgrounds (three nurses; two psychiatrists; two non-medical staff members) who provided important feedback regarding comprehensibility and adequacy to the Portuguese context. Informal interviews were held in the participants workplace and notes were taken by the project manager, regarding the raised issues and suggested alterations to the MiDAS Portuguese version. This was an extensive and central process in the translation/adaptation work.

Step 8: Consensus

The results of tests and interviews were discussed in joint meetings of the research team and later reported to the author of MiDAS original version. This guided additional changes to the Portuguese version, leading to a revised version of MiDAS-PT (V4). These alterations are described in more detail and discussed later in the article, along with changes to the layout nature of the original version.

Step 9: Proofreading

All the researchers and volunteer health professionals involved in the translation and adaptation process proofread the final version of MiDAS-PT, in order to identify further errors or inconsistencies. Only minor alterations were undertaken at this stage, leading to a new version (V5).

Step 10: Reporting

The aggregate data, translation process and final results were made available and discussed with the developers of the assessment tool and then finally presented here.

Cross-Cultural Adaptation

R1 was responsible for keeping track of the alterations introduced in each MiDAS version highlighting changes and reporting the respective justifications with minutes. In

the translation from V1 to V2, each word or phrase was discussed personally by the two researchers (R1 and R2), sometimes with consultation with other health professional with experience in dementia care - researcher 3 (R3) - to resolve discrepancies and ensure adequacy to the Portuguese cultural and clinical context. The main themes/meanings discussed in the comparison with the original version are presented in the results section.

Testing and Debriefing

This step consisted of an iterative process, conducted simultaneously with the 7 volunteers previously described (psychiatrists, nurses and non-medical staff members) and discussed among the research team. Over the period of one month, each volunteer health care participant was contacted multiple times by R1. Data collected with MiDAS was included as part of their daily practice and they gave informal feedback on their experience.

At the end of this period, individual interviews were conducted with each of the volunteers. These were informal semi-structured interviews with the aim of clarifying whether MiDAS-PT worked in the Portuguese clinical context. Personal identifiable data was not disclosed and interviews focused mainly the applicability of MiDAS and whether it could be understood and of cultural relevance. The questions were not pre-defined in detail (with only main topics being pre-established) and the researcher (R1) tried to extract participants views as much as possible using her clinical knowledge and insight to guide the interviews but without imposing personal opinions, in an effort to collect data that could optimize health professionals experience of using MiDAS.

During interviews with volunteer health professionals, it was specifically analyzed: 1) time spent completing the form, practical application, clarity of the instruction for other professional groups; 2) understanding of content and diagrams; 3) necessary background for completing the measurements. Field notes were taken throughout this process by the project manager (R1) and were later analyzed in a group meeting of the research team. Collected data was refined and condensed, using a deductive approach, in order to finalize the language and instruction alterations to the forms. After this, notes and alterations to MiDAS form were taken back to participants for member checking, during another round of individual interview, ensuring accuracy of the process. To achieve a final consensus on wording/phrases and layout, another team meeting was held and the final version of MiDAS was further discussed with an in-country dementia care research expert and with the original developers of MiDAS.

Results

Translation and Cross-cultural Adaptation

During the translation and adaptation phases several minor alterations have been made by the authors to the actual wording of the original scale. Those are illustrated and justified below.

The term “scales” was considered confusing to health professionals, since they are only performing one assessment. Thus, the term “scale” was adopted instead, considering MiDAS a single instrument. It was also deliberated that the term “resident” would be best translated to Portuguese as “person with dementia”, since the term “resident” is not commonly used, even in long-term care setting, and could then be a source of confusion. The expression “completed by” was translated to “evaluation performed by” that both forward translators agreed would be easier to understand. The word “form” was not directly translated to Portuguese, and it was replaced by the term “scale”, which is more understandable for health professionals. “Form” is not a term commonly used in our culture, neither in formal or informal care setting. “Score” was replaced by “answer”, since we felt that “score” would mislead the person performing the evaluation to use a numeric value. “None at all” was converted in a Portuguese term more closely related to the English word “nothing”, and “highest” was substituted by the Portuguese term for “maximum”, since it was agreed by the research team that it would increase clarity for the responders. As there are no terms in Portuguese specifically meaning “awareness”, we used the equivalent for “conscience”. This Portuguese term has a broader meaning than the English term, but it is clear what is intended in a specific context. “Initiation” was replaced by the term “initiative”, which was considered more suitable. Similarly, the translation of “enjoyment” was considered to be more adequate with the term “satisfaction”. The expression “brighter mood” does not have a literal translation to Portuguese, so “improvement in mood” was used. The same criterion was applied to the substitution of “major reaction” by “important reaction” and “low in mood” by “depressive”.

Testing and Debriefing

Regarding the testing and debriefing of the preliminary MiDAS-PT version, although interviews intended primarily to reveal whether the text made sense to health

professionals, there were no major comments on the actual wording. On the other hand, some remarks were made about the form structure, layout and application.

In general, experience was that the 5 categories made sense and that MiDAS was fast to complete once the health professionals had achieved a certain routine. In that case, it could be done in less than a minute. Nevertheless, it was difficult for staff to complete MiDAS due to time pressure and trouble remembering to fill out the form twice in a day. Another critique that some volunteers made was that the VAS carried a high degree of subjectivity. Additionally, when scoring a group of patients, it was easy to fall into the mistake of comparing patients to each other and then score them in comparison with each other, instead of scoring in context of their unique minimum/optimum levels. We also verified that several professionals had overlooked the indication for not completing the 5 VAS if the patient was asleep for most of the time.

In the original MiDAS as in the Portuguese final version, there is a box to write the measured number value at end of the 5 VAS. This was easily understood by Portuguese health professionals, in comparison with what was reported by the authors of the Danish translation (Ridder et al., 2018), who stated that many forms were filled in with numbers, rather than the mark on the line.

In relation to the sixth question of MiDAS - where it is possible to tick 6 major reactions that the patient might present - some participants had difficulty figuring out how to value “major reactions”. We also observed that some were ticking the boxes if a patient was exhibiting a reaction that is common for that person during the day, thus not being a major reaction related to the music intervention. Ultimately, most participants chose not to answer this. It was argued by some that these categories were not informative since they were not tailored to specific patients. Nonetheless, it was suggested that they could be informative if some sort of gradation was possible. In this stance, most volunteers expressed the opinion that, if there is a need to evaluate additional symptoms in a PwD, it should be done with a validated and more sensitive device and that MiDAS should be kept simple.

Health professionals also had trouble in understanding what were they supposed to annotate on item 7. Most of them used this space to write if the person was asleep, thus justifying not being able to answer the 5 VAS. Finally, following the comments of the volunteers, we have introduced some clarifications in the instructions section. We specified that - by “health professional” we intend someone that cares for the PwD (either formally or informally) but who is not directing the music intervention - and that - by

"music therapist" we mean the professional who is conducting the music intervention, even if it is not a registered music therapist but someone conducting another therapeutic music intervention. This was discussed with the original developers of MiDAS, who considered that this form is not only strictly applicable in the context of formal Music Therapy.

Discussion

Through collaboration with Portuguese health professionals with experience in dementia care, the assessment tool Music in Dementia Assessment Scales (MiDAS) has been officially translated and culturally adapted from English to European Portuguese, following a rigorous ten steps approach recommended by the original authors of MiDAS.

The translation/adaptation process has not led to major changes in the tool itself, but only to a number of minor formal adjustments. No changes have been made to the core content text of MiDAS and only minor changes have been made in wording. In summary, the following alterations were made in the translation/adaptation from MiDAS-UK to MiDAS-PT: Translation from English to Portuguese; Cultural adaptation (for example: staff is referred to as health professional); and Harmonization with the Spanish MiDAS version. Staff and therapist version are divided into two separate forms to avoid confusion and the 5 VAS are presented on the first page with explanations on the back.

MiDAS-PT is approved by the developers of the original English MiDAS, and is presented here in its final version (Appendix: Figure 2 and Figure 3). It should be printed in A4 size so each of the 5 lines is 100 mm long. The translated version, MiDAS-PT, is freely available and can be used to inform clinical music therapy (Music Therapist Version) and to evaluate the effect of music therapy by other health professionals (Staff Version). This instrument may also be used to evaluate the effect of other Mbi, delivered by non-music therapists, as recommended by the authors of the original scale (McDermott et al., 2015) and reflected here in the fact that none of the volunteer health professionals that tested MiDAS-PT had previous training in Music Therapy and still did not have major issues in using the instrument. Currently available versions of MiDAS, in different languages, can be consulted on the website www.midas.aau.dk.

Despite the rigorous methodology adopted, this work has some limitations. The number of participants that provided their feedback regarding the adapted Portuguese version of MiDAS is relatively small and, as a convenience sample recruited form one single site, they are not necessarily representative of the population of Portuguese health

professionals dedicated to dementia care. Additionally, none of them had relevant experience in participating in the translation and adaptation of psychological instruments and their experience in participating in Mbi was also rather limited, with none of them having formal music therapy training. This could hamper the conclusions regarding the adequacy of the instrument for the intended purposes here considered. Due to time and resource limitations, qualitative data collection and analysis heavily relied on one researcher (R1), who took notes during the interviews, being primarily guided by her clinical experience. Audio records and transcripts were not available, so it is possible that not all relevant opinions were fully explored. Another potential bias is that participants previously knew R1 personally and thus they might tend to provide a more positive feedback than they would if interviewed by an unknown researcher.

In conclusion, MiDAS-PT is the first instrument developed to evaluate how PwD engage with music interventions to be translated into Portuguese. It will provide an opportunity for health professionals working in Portugal to assess in a more objective way the effects of music interventions in dementia care. This seemed to be welcomed by Portuguese hospital staff in a preliminary approach. We are conducting further studies to assess MiDAS-PT psychometric properties to ensure its usefulness for the Portuguese clinical and research settings. Data has already been collected for this purpose and is currently being analysed. This work could be an important milestone in the progress of obtaining sound evidence of the benefits of using music interventions in dementia care and generalizing its utilization, thus contributing to further development of holistic dementia care.

Disclosure statement

The authors report no conflict of interest.

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Appendix

Figure 2 - *Music and Dementia Assessment Scales – Portuguese version (Music Therapist form).*

Figure 3 - *Music and Dementia Assessment Scales – Portuguese version (Staff Form)*

Figures

Figure 1 *- Ten steps followed in the translation and adaptation process, adapted from (Ridder et al., 2015).*

Legend: FT: forward translation; BT: back-translation; V1: original version of the instrument in the source language (English); V2, V3, V4 and V5: subsequent translated versions in the target language (Portuguese).