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Review Article

Fecal incontinence and quality of life assessment through questionnaires



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ABSTRACT

Background: Fecal incontinence causes a big impact on patient's quality of life. Our study analyzed the main questionnaires about fecal incontinence available internationally, aiming to delineate vantages and limitations of these instruments and their application, to mention the cultural aspects involved in the process of development and validation, as well as to suggest a reflection about the complexity of this matter. **Results:** Four of the instruments (Pescatori score, FISI, MSKCC bowel function instrument, and LARS score) do not include quality of life, working only as diagnostic tools. Two others, 'Jorge and Wexner Fecal Incontinence score', and 'St Marks' Fecal incontinence grading system' can diagnose and grade fecal incontinence, however they are very subtle in assessing quality of life. The 'EORTC Colorectal Cancer-specific', on the other hand, focuses exclusively on quality of life. Although the 'FIQL' questionnaire assesses quality of life related to fecal incontinence, it does not measure leakage. Lastly, the 'RAFIS' assesses both aspects but too superficially. **Conclusion:** None of the questionnaires analyzed were able to simultaneously assess both fecal incontinence and quality of life successfully. Furthermore, the concepts related to fecal incontinence have different meanings depending on the cultural and psychosocial context. These differences are even greater when individuals of developed countries like the ones where these questionnaires were developed are compared to the ones of developing countries, such as Brazil, which makes its very hard for these instruments to be used universally.

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Avaliação da incontinência fecal e impacto na qualidade de vida por questionários

R E S U M O

Palavras-chave:

Incontinência fecal
Qualidade de vida
Sinais e sintomas
Avaliação de resultados
(cuidados de saúde)
Índice de Incontinência Fecal
Avaliação de resultados de
intervenção terapêutica

Contexto: A incontinência anal acarreta grande impacto na qualidade de vida (QV) dos pacientes. Nosso estudo analisou os principais questionários sobre o tema disponíveis na literatura internacional, visando delinear vantagens e limitações desses instrumentos e de sua correta aplicação, bem como citar os aspectos culturais envolvidos no processo de sua criação e validação, e sugerir uma reflexão sobre a complexidade do tema.

Métodos: Nessa revisão assistemática, utilizamos três bases de dados eletrônicas (MEDLINE, LILACS, e DeCS) para encontrar os 9 questionários mais utilizados no mundo, e palavras-chave relacionadas.

Resultados: Quatro dos instrumentos estudados (Pescatori score, FIS, MSKCC bowel function instrument, e o LARS score) não abordam QV, funcionando apenas para diagnóstico. Outros dois, o 'Jorge and Wexner FI score', e o 'St Marks' FI grading system' diagnosticam e gradam bem a incontinência, porém apenas avaliam brevemente a QV. O 'EORTC Colorectal Cancer-specific', por sua vez, foca exclusivamente na QV. O questionário 'FIQL' apesar de conseguir avaliar a QV relacionada à função intestinal, não avalia vazamentos. Por fim, o 'RAFIS' avalia de forma muito simplificada esses aspectos.

Conclusão: Nenhum dos questionários analisados se mostrou eficiente na avaliação simultânea da incontinência e da QV. Além disso, os conceitos que envolvem incontinência anal apresentam significados diferentes dependendo do contexto cultural e psicossocial. Essas diferenças são ainda maiores quando se comparam indivíduos dos países desenvolvidos onde esses questionários foram desenvolvidos, com os de países subdesenvolvidos como o Brasil, dificultando sua aplicação de forma universal.

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Introduction

The fecal incontinence (FI) is an anorectal dysfunction characterized by stool, gas and/or liquid loss, which has serious impact on the patient's quality of life. This condition frequently leads to emotional and social disturbance, impairment of labor relations, loss of self-esteem and depression.^{1,2} Due to the severity of this condition, it is necessary to systematically diagnose patients with FI and assess their degree of impairment. There are several tools that can be used aiming this evaluation, which are known as fecal incontinence (FI) questionnaires. In addition to FI diagnosis, the assessment of quality of life (QoL) has also become an important measure of medical treatment outcomes. And in order to assess it, questionnaires are applied to patients. However, it is not that simple because measuring the functional outcome of a treatment, through a score, does not necessarily translate into a worse QoL even if it reveals the most severe score.

In 1958, John Kenneth Galbraith created the concept of QoL differentiating from the classic quantitative economic perspective. In his concept, the improvement of men's living conditions is the focus of the political-economical and social goals, instead of economical and material growth.³ Similarly, Lyndon Johnson, the American president in 1964, said that the goals cannot be measured by a banks balance, but by the QoL provided to people. He was the first to use QoL as an expression.⁴

QoL and "standard of life" were concepts that interested only social scientists, philosophers and politicians. Whereas, the technological advancements in medical and scientific fields contributed even more to the weakening of the clear definition of these concepts. However, the concern about QoL within the human and biological sciences, in order to value parameters broader than symptom control, mortality decrease and life expectancy increase, contributed to its use in randomized clinical trials as an important aspect to be assessed, beyond drugs' efficacy and safety. The oncology specialty is a good example of how QoL is important, because treatments initially sought only to add "years of life", neglecting the relevance of adding "life to years".⁴

Based on this subject's importance and on the holistic understanding of the concepts surrounding this condition, this review discusses the specific questionnaires for fecal incontinence evaluation. The aim of this study was to suggest a reflection about the complexity of the involved concepts, the limitation of a proper questionnaire application, the transcultural aspect and the creation and validation process of the instruments.

Methods

This is a non-systematic review, which brought together the original FI questionnaires listed below. Medline was searched

by using the MeSH term “fecal incontinence” and others terms previously described in keywords.

The most common available incontinence scores are shown in [Table 1](#). Due to the importance of early diagnosis of this condition in order to prevent long-term psychosocial impairment, this review discusses the main incontinence score diagnostic questionnaires, their importance and their limitations.

Conceptual aspects

The concept of QoL or global health state evaluation is the impact measure of a patient's disease on their physical, social relations and psychological health, which highlights what is taught in colleges about patients being the main concern beyond the disease itself. Etiology is now only a coexisting factor to be fought.^{14,15} The expression QoL, as it has been used in medical literature, does not seem to have one single meaning and it has synonyms in the literature such as “Health conditions” and “social functioning”.⁴ In addition, QoL's definition itself does not appear in the majority of scientific journals that use or propose instruments for its assessment. Some authors say that QoL includes endless possibilities, which can impair not only health condition and medical intervention but perception, behavior and feelings related to full daily activities.⁴

The definition of health by the World Health Organization (WHO) is the complete state of physical, mental and social well being and not only disease absence.¹⁶ However, morbidity and mortality are usually the focus of health policy. Nowadays other aspects such as functional status, health perception and daily activities impairment are considered in order to evaluate health.¹⁷⁻¹⁹

Fecal incontinence questionnaires

Pedersen and colleagues²⁰ were the first researchers to concern themselves with the anal function of patients who underwent low anterior resection (LAR) procedure. This procedure is performed to treat rectal cancer and frequently leads to fecal incontinence (FI) as a complication, which cannot be neglected.

MOS 36-Item Short-Form Health Survey presents the basis to create any quality of life (QoL) questionnaire, pointing out that it is important to assess physical, social and mental aspects as well as general health perceptions of the patient.¹⁷

The Pescatori score, developed in Università Cattolica, in Rome, Italy, was one of the first questionnaires to evaluate fecal incontinence (FI).⁵ It evaluates degree such as frequency of symptoms in a very effective grading system. The degree of incontinence is classified in A, B or C categories, depending on the type of incontinence, respectively flatus/mucous, liquid stool, and solid stool. The frequency is classified as 1, 2 and 3, indicating respectively occasionally, weekly, and daily incontinence. A large number of patients participated in this study (335), and it allowed the authors to compare their FI throughout time. Since the ABC-123 grading system provided a way to diagrammatically represent the results of a treatment, it was very helpful to analyze the outcomes of surgical procedures that some of these patients underwent. Therefore, it is possible to conclude that this questionnaire can provide a precise

analysis of the patient's FI. However, this questionnaire lacks an assessment of the patient's own perception of their condition. Since the focus is only at the physiological function of the sphincter, the patients are not questioned about changes in their lifestyle and the resulting impacts of these changes. It would be advisable to assess whether or not they are still able to practice sports, have a normal diet, have social relationships, how they consider their mental health to be and how their QoL was affected.

The Jorge and Wexner Score was created at Cleveland Clinic Florida, in Fort Lauderdale, USA⁶ and is one of the most frequently used to assess fecal incontinence. Regarding fecal incontinence itself, this score encompasses the same questions of the Pescatori score, however The Jorge and Wexner Score has more options for answers, graduating more precisely the degree of incontinence. In addition, the consideration of lifestyle alteration and the use of pads were implemented in the score, bringing the attention to the patient's welfare instead of being a purely quantitative questionnaire like the previous one. However, this questionnaire does not assess the presence of urgency during the defecation nor the re-evacuation (clustering).

Some years later, in 1999, a questionnaire module was created to be used in conjunction with the European Organization for Research and Treatment of Cancer (EORTC) QLQ C30.⁷ The EORTC QLQ C30 is a general questionnaire developed to assess the QoL of a broad spectrum of oncological patients. This new questionnaire module was published in the Netherlands and its aim was to develop a supplementary questionnaire specific for patients with colorectal cancer, covering relevant QoL issues for these patients.⁷ They called it QLQ-CR38 and it consists of 38 items covering important aspects of the patient's QoL, such as body image, sexuality, future perspective, symptoms and side-effects to different treatment modalities for colorectal cancer patients.⁷

Five cancer specialists were consulted during the development of the questionnaire. Then, the first version of the questionnaire was applied individually in 24 colorectal cancer patients, so that potential problems could be identified and solved. The patients were also asked to indicate any omissions, and to give their opinion about any other question that should be included in the final questionnaire.⁷ Patients contribution to the construction of the questionnaire allowed it to approach patient's QoL in a relatively simple and straightforward way, so that it can be filled out by patients themselves, with little or no assistance.⁷ An issue with the QLQ-CR38 however is the amount of time necessary for replying. The authors do not recommend it to be used as a free-standing instrument for assessing QoL of colorectal cancer patients, but rather that it be used together with the EORTC QLQ C30. However it took an average time of 10.3 min to complete both of them⁷ and that amount of time could be too long for very sick patients, and not easy to be reproduced in large scale in a daily clinical practice. Another important issue in this questionnaire was the items related to sexuality. Although it is an important subject, 3% of the men and 12% of the women declined to complete these items because they were considered too intrusive.⁷

In the same year at the St Marks Hospital, UK, Vaizey and Colleagues⁸ developed a new questionnaire known as St Marks' Fecal Incontinence Grading Score. In this study, three

Table 1 – Most used fecal incontinence questionnaires.

Questionnaires	Country of origin	Author/year
The Pescatori Score ⁵	Italy	Pescatori, M., et al./1992
Jorge and Wexner Fecal Incontinence Score ⁶	USA	Jorge, J.M.N. and S.D. Wexner/1993
EORTC Colorectal Cancer-specific Quality of Life Questionnaire (QLQ-CR38) ⁷	Netherlands	Sprangers, M.A.G., et al./1999
St Marks' Fecal Incontinence Grading Score ⁸	United Kingdom	Vaizey, C.J., et al./1999
The Fecal Incontinence Severity Index ⁹	USA	Rockwood, T.H., et al./1999
Rockwood and colleagues Fecal Incontinence Quality of Life Scale (FIQL) ¹⁰	USA	Rockwood, T.H., et al./2000
MSKCC Bowel Function Instrument ¹¹	USA	Temple, L.K., et al./2005
Emmertsen and Laurberg LARS Score ¹²	Denmark	Emmertsen, K.J. and S. Laurberg/2012
Rapid Assessment Fecal Incontinence Score (RAFIS) ¹³	Spain	de la Portilla, F., et al./2015

Source: MEDLINE.

established scales (Pescatori, Wexner, American Medical Systems) and the new questionnaire were prospectively evaluated by two independent clinical observers in a 28-day-diary.⁸ This was the first time these scales have been compared with a diary system, although the number of patients assessed was reduced (twenty three), all four scales correlated highly and significantly with the clinical impression of the two independent clinicians.⁸ Furthermore, this new score included details about urgency and antidiarrheal drugs, which were not found in previous questionnaires, and have shown to be helpful. At first, because the need for antidiarrheal medications may mask and underestimate the underlying condition and interfere on the patient's perception of symptoms. Second, because the presence of fecal urgency forces patients to remain close to a toilet.⁸ This has a large impact on their quality of life since the ability to postpone defecation is essential to allow the patient to be involved in many social situations, affecting their psychosocial life and behavior.

Apparently, at that time all major scientists of the field had realized that lifestyle change is of great importance on patient's quality of life, and thus, needs to be addressed like the anal dysfunction itself. However, despite the improvements when compared to previous questionnaires, St Marks' Fecal Incontinence Grading Score does not make it clear whether or not patients are asked about their own perception of their condition, and how they feel about it, and how well they are dealing with it. These questions might be really important to assess the QoL.

Also in 1999 Rockwood et al.⁹ developed in the USA the Fecal Incontinence Severity Index (FISI), based on patient and surgeon rankings of the severity of symptoms associated with fecal incontinence. Although the index evaluates adequately the level of sphincter dysfunction, it does not consider patient's QoL or their psychosocial situation. According to the authors, different patients are affected by the same level of incontinence in different ways and consequently QoL questions were not included in the index. Despite that explanation, an assessment regarding patient's QoL should be considered as an indicator as far as a severity index is concerned. The index could perhaps include a specific tool to measure how QoL is affected by the FI. Such a tool would allow the gathering of data that could improve the accuracy of the index.

In addition, the FISI is based on a type versus frequency matrix presented to surgeons and patients who evaluated and defined the level of severity of each type of dysfunction. The matrix was based on the four components of fecal

incontinence (gas, mucous, liquid and solid stools), and on five frequency timeframes.⁹ However, the timeframes were pre-established: two or more times per day, once per day, two or more times per week, once per week, and one to three times per month.⁹ That is a limitation of the method, once different frequencies are placed on the same timeframe. For example, a patient with a solid stool incontinence of once per month has a very different condition when compared to another with a solid stool incontinence of three times per month, and still these two cases were not separately considered.

Furthermore, 12 patients completed the form through the mail, while 22 completed the form in a surgery clinic.⁹ Even though the authors affirmed there was no significant difference in the ranking of these two groups, it would be expected that all participants filled out the form under the same conditions, as there could be influence of outside factors.⁹

In 2000, Rockwood et al.¹⁰ developed another questionnaire, the FIQL, which evaluates the psychosocial aspect of patients. The questionnaire is composed of 4 categories of questions: Lifestyle (10 items), Coping/Behavior (9 items), Depression/Self-Perception (7 items), and Embarrassment (3 items). Rockwood and colleagues stated the importance of patient's quality of life in this paper, starting the questionnaire with an uncommon question so far: "In general, would you say your health is – excellent, very good, good, fair or poor."⁹ It seems reasonable to start a conversation with any patient asking what is the impression about their own health, however, none of the scales before had asked that. It was a groundbreaking novelty, however, there are still some key points to criticize the FIQL. The authors considered that the questionnaire met psychometric criteria, making it both reliable and valid, but it is important to point out that FIQL, specific to FI, was compared to SF-36, a general quality of life scale, which may not be appropriate. Also, it is not clear what is the appropriate moment to assess the patient's quality of life. How long after the surgery? During which post-operative period stage? During the design this was not considered. It is interesting that this questionnaire takes into account aspects related to mental health, however, other psychiatric diseases, which can affect the patient's perception, such as personality and bipolar disorders were not considered during patient's recruitment while designing the scale. A pre-existing psychiatric disorder could generate significant bias to the patient's answers to the FIQL. Also in the Depression/Self Perception scale, it is important to point out that person's mental health is assessed in the present instead of assessing the evolution. The patient could

already have depression, anxiety or another disorder, before the FI.

There is a repeated question, “Q2. f. Whenever I am away from home, I try to stay near a restroom as much as possible” and “Q2. m. I try to prevent bowel accidents by staying very near a bathroom”. Was this deliberated? If so, there is no explanation in the paper. Wouldn't it give more weight to this session of the questionnaire?

This scale also evaluates the changes in lifestyle asking about different social situations, which can impact socially and psychologically. However, it is controversial what is the role of each social situation on the patient's QoL. Which changes should weight more or less? How do we give a value for something that is totally subjective? Social situations that impact on someone's life vary among the patients, even further, among countries and cultures, which states the need of building a FI score specific for our population, in Brazil. Part of this aspect was already flagged in their discussion and is a problem that remains.

In New York, 2005, Temple and colleagues published the MSKCC Bowel Function Instrument.¹¹ Their instrument was built basically to assess bowel function, especially after sphincter-preserving surgery for rectal cancer and, according to the questionnaire, its questions were only about bowel movement related situations.¹¹ It looks like a more detailed Wexner Incontinence Score, although it does not assess any aspects of mental health and quality of life. However, they have used QoL questionnaires to compare with their instrument,¹¹ instead of using Wexner's. MSKCC Bowel Function Instrument is able to determine poor bowel function of the patients, but it was highlighted that there was no significant correlations on divergent validity, in all subscales, with the QoL instruments used in their study. It is suggested that bowel function might be confounding the studies on QoL instruments that assess both QoL and fecal incontinence, which states the importance of continuing the studies on instruments like MSKCC.¹¹ These conclusions need to be considered when developing a questionnaire for the Brazilian population. We still do not have specific Fecal Incontinence Scores for the Brazilian population, which means we are well behind the studies required for it.

In Denmark, in 2012, Emmertsen and Laurberg published the LARS Score.¹² It was developed to evaluate the low anterior resection syndrome, which is an important cause of fecal incontinence after rectal cancer treatment. This is also a good example of a score that assess the patient's symptoms in which the authors correlated their score to the impact on QoL, although other grading systems have already shown that these correlations are not well understood and the results are variable. The LARS Score was specifically made to classify patients in three categories: without LARS, with minor LARS or with major LARS. All of the questions ask only about fecal incontinence situations or about bowel habit, similar to the questions in the MSKCC Bowel Function Instrument. However, MSKCC's instrument is a much longer questionnaire compared with LARS Score, which is shorter and easier to use in daily practice.

In their study, Emmertsen and Laurberg¹² highlighted the importance of an instrument that could quantify QoL, instead of only symptoms. Therefore they aimed to build a score

capable of assessing the patient as a whole, specifically for bowel dysfunction after low anterior resection (LAR). Despite pointing out important aspects and deficiencies especially about the Wexner Incontinence Score, the Rockwood Fecal Incontinence Severity Index and the St Mark's Fecal Incontinence Grading Score, the authors did not mention available QoL scores for validation such as the FIQL, which would be important for comparing to LARS score.

Finally, in Seville, Spain, the RAFIS was published by de la Portilla et al. in 2015.¹³ It is an innovative incontinence score and the most one recently created to our knowledge. It is simple and fast to be used. In their article, de la Portilla and colleagues compared their instrument to both Jorge-Wexner and FIQL in order to show the reliability of their tool to assess incontinence and QoL.

The RAFIS is interesting because of its simplicity. It is composed of basically two aspects: the patient's impression about their feeling and the frequency of leaks (gas, liquid or solid stool). The first question is composed by a visual scale, in which the patient sees different facial expressions and chooses one among six to represent their feelings about their clinical condition. It is easy understanding and correlate to reality, which wholly fits into a purpose of creating a rapid assessment. The second question is impressive in simplifying the measure of leakage once the authors do not discriminate between gas, liquid and solid stool leakage and also, do not ask about different social situations related to fecal incontinence, use of medications or urgency. The patient is basically asked about frequency of leaks.

The simplicity of RAFIS is admirable. However, the sample size used to develop this instrument should be higher in order to improve correlation and significance rates. Moreover, the test-retest tool was not performed, which was already highlighted by the authors. Despite those limitations, it would be interesting to see such a simple instrument validated in Brazil to analyze its performance in our population, in which the average educational status is low.

Discussion

Many studies have been misusing questionnaires made to assess the functional status of the anal sphincter, such as LARS Score, to measure QoL. Emmertsen and Laurberg themselves stated in their article that their instrument is a diagnostic one, not a QoL measurement.¹² The concepts surrounding this matter are complex as it is stated under “Conceptual Aspects” in this article. They change over time and have different meanings depending on people's background. QoL is different from standard of life, and many people confuse the terms. Standard of life is a measure that quantifies the quality and quantity of goods and services that a person or a group can have access to. As a consequence, there is no instrument capable of evaluating QoL with an international perspective, which stimulated WHO to create the WHO-QoL Group to look for the best concept of QoL and build instruments capable of measuring it transculturally. The specialists from WHOQOL have defined QoL as the “*individual's perception of its position in life in the cultural context and values system, in*

which it lives, and in regards to its objectives, expectations, standards and concerns".²¹

In parallel to the concept's complexity, there are the limitations of the questionnaires, which are so many that there is no consensus of whether it is better to use one instrument to assess and diagnose QoL simultaneously or two instruments, one for each aspect. None of the available questionnaires are able to precisely measure both FI degree and QoL. The Pescatori score, FISl, MSKCC bowel function instrument and LARS score are only diagnostic instruments, which ask strictly about bowel function.^{5,9,11,12} The Jorge and Wexner FI score and St Marks' FI grading system are great in diagnosing FI and grading it, however are very subtle in assessing QoL despite showing some interest in this topic.^{6,8} The EORTC Colorectal Cancer-specific only assesses QoL, no diagnostic feature of FI is considered.⁷ The FIQL is great in assessing QoL related to FI, considering many day-to-day contexts related to bowel function, however it does not measure leakage.¹⁰ And RAFIS measures both FI and QoL, however it is such a simple questionnaire that it is not clear whether or not it is appropriate, requiring more studies.¹³

In addition, there is the limitation of applying the questionnaires in different populations, groups and cultures. As stated before, QoL depends on people's background and change over time. It leads us to question if it is appropriate to apply these questionnaires, for example, in populations from the intertropical zone while they were made in studies with populations from areas that have severe winter. In Brazil, people are not used to cold weather like in Europe and therefore, there is no culture of using heavy clothing and covering the whole body for long periods, the notion of body exposure and body image is completely different. And the barrier between different groups goes in all kinds of contexts, habits, religions, sports, work, daily activities. It is even possible that within the same population, there are some groups, which have different performances on the same questionnaire.

During the creation process of the ideal FI questionnaire, it is necessary to consider all the aspects stated above, in order to create a timeless and no cultural instrument or to realize that each population needs its own questionnaire. It is an undeniable fact that the creation and validation of instruments for different languages are affected by the transcultural aspect of each population.

The patients need our empathy while we create questionnaires to measure any of their conditions, which lead us to imagine how difficult it is to understand any question sometimes and how difficult it is to answer a question when you are not completely sure you understand it. We use to interpret things based on our psycho-social-cultural background and, that can change between individuals and between different regions in the same country (North, Northeast, Southeast, South and Midwest), especially in a country as big as Brazil. And definitely there are remarkable cultural differences between developed and developing countries. Thus, this discussion is important, as it is hard for doctors to use a tool that is not adapted to their countries' epidemiology, hence making the questions, applying the questionnaires and obtaining precise answers and evaluations is a difficult process.

The countries of origin of each questionnaire were intentionally cited to highlight the fact that no incontinence score was ever created in Brazil. Until the present moment, no incontinence score was developed and published by Brazilian institutions. Furthermore, all the incontinence scores used worldwide were created by studies in the developed countries.

In Brazil, there are only three incontinence scores validated in Portuguese, which are the Wexner score, FIQL and LARS score.²²⁻²⁴ Therefore, we are limited to three tools, which are validated to our reality, to assess fecal incontinence and FIQL, the only one appropriate for QoL. The others we use in our routine, we have to improvise, to translate and use as protocol, adapt the best we can for each situation.

Although the Human Development Index (HDI) is not the most reliable index to determine a country's human development, it can be used along with other parameters to see the differences between developed and developing countries. Brazil, for example, has an HDI of 0.755, 75th in the world, a Gross National Income (GNI) per capita of US\$ 15,175.00, a Gini coefficient of 52.7.²⁵ In addition, in our country only 57.6% of the population has internet access and 53.6%, above 25 years old, have at least some secondary education. On the other hand, the United States of America (USA), for example, has an HDI of 0.915, 9th in the world, a GNI per capita of US\$ 52,946.50, a Gini coefficient of 41.1, associated with a population, in which 87.4% has internet access and 95% has at least some secondary education. The USA population has a greater educational level, internet access, an income at least three times higher and a lower level of inequality.²⁵

Real problems have been being neglected by academics due to overvaluation of rigor, which is related to the increasing use of sophisticated mathematical or econometric quantitative techniques. In many centers, rigor has acquired more importance than practical relevance. Against this tendency, we scientists, have the duty to highlight the consequences of overvaluing rigor rather than relevance while analyzing biopsychosocial problems. According to Galbraith, real and practical problems under economical analysis "need to consider the information from other disciplines as well as political reality, not easily lending ourselves to highly technical and mathematical treatment".³

In ideal conditions, even a validated questionnaire would work properly,⁴ but in Brazil we have a completely variable reality. In 2016, a PhD thesis to validate LARS Score to Portuguese faced a 12.6% rate of patients that could not read and a 52% rate of patients that did not have even a primary school education.²⁴

These instruments have a wide variety of applications, including individual clinical practice and, evaluation of treatment effectiveness and health service functioning among them. Life's complexity is pictured in the existing difficulties in developing instruments and in understanding the concepts.^{4,26}

Considering all the complexity surrounding the concepts QoL and health and, their determinants, creating one single instrument to assess both FI and QoL of the patients is a tough task. And due to the limitations of applying original and validated questionnaires in populations completely different from the ones of developed countries, we would like to raise the question: would it be more effective to create our

own instrument, as suggested by the fact that it is not only needed to validate fecal incontinence questionnaires, it is also necessary as a means to go further?

All of the fecal incontinence questionnaires were created in a developed country and, four out of nine analyzed in this review were built in the United States of America (USA). Comparing those data from Brazil to the USA, it is not difficult to conclude that validating questionnaires from developed countries in developing countries might not be appropriate. The work involved in creating a questionnaire is much greater than the validation process. So Brazilian researchers and institutions need to work on developing this capacity. So, why not create our own questionnaires with our own scores? Our opinion as authors of this article is that subjectivity may not be copied, but created. The rate of success would be higher if questionnaires about patient's intimacy were not copied from a completely different culture, but developed locally instead. If the scenario were ideal, we could envision a medical team attending a patient capable of responding to a questionnaire in a reliable way, even if this questionnaire were validated.

We would like to congratulate all of the authors who dedicate their time, studying this area, producing high level publications, which will always serve as the starting point for new research.

Conclusions

The application of questionnaires for fecal incontinence and QoL assessment has a positive impact because they include the improvement not only of individual clinical practice, but also of evaluating the effectiveness of treatments and the functioning of health services. In addition, they can be important guides for health policies. Certainly, there are innumerable conceptual and real developing difficulties, during the development of these tools in a reliable and reproducible way to evaluate quality of life and that these challenges need to be addressed. Despite all the difficulties and restrictions, it is already possible to better identify and treat patients who are evaluated using questionnaires than without applying them. This reflects the beginning of a new understanding and expectation.

Conflicts of interest

The authors declare no conflicts of interest.

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