

Communication in Clinical Practice, the Perspective of Patients with Cancer: Translation of the PACE (Patient Assessment of Cancer Communication Experiences) Questionnaire to European Portuguese



ARTIGO ORIGINAL

Comunicação na Prática Clínica, a Perspetiva dos Doentes com Cancro: Tradução do Questionário PACE (Patient Assessment Of Cancer Communication Experiences) para Português

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ABSTRACT

Introduction: Communication in clinical practice is essential to healthcare quality, especially in Oncology. The Patient Assessment of Communication Experiences questionnaire evaluates the perspective of cancer patients towards communication and identifies areas that can be improved. This study consists in its translation and validation to European Portuguese, to identify these areas.

Material and Methods: We performed a descriptive, observational, cross-sectional study. The translation was conducted according to the World Health Organization's guidelines. We applied the questionnaires to a convenience sample, in patients under systemic anti-neoplastic treatment at the Day Hospital of Centro Hospitalar Universitário do Porto, between January and March 2020. We calculated the Cronbach's Alpha for each phase of care, the bivariate and multiple correlations and, for each question, the percentage of "non applicable" and most positive answers.

Results: We had 100 participants. The instrument we obtained has good internal consistency, but the classification of some questions does not correlate sufficiently with the global opinion about the experiences with communication in the respective phase. The diagnosis phase revealed a lower proportion of positive experiences, particularly in terms of receiving the bad news.

Conclusion: This study translates and validates part of the communication assessment instrument PACE to the Portuguese language and elicits the necessity to invest in the phase of diagnosis and disclosure of bad news.

Keywords: Health Communication; Patient-Centered Care; Physician-Patient Relations; Portugal; Quality Assurance, Health Care; Surveys and Questionnaires; Translating

RESUMO

Introdução: A comunicação na prática clínica é essencial para a qualidade dos cuidados de saúde, com particular importância na Oncologia. O questionário *Patient Assessment of Cancer Communication Experiences* avalia a perspetiva dos doentes oncológicos sobre a comunicação e identifica áreas a melhorar. Este estudo consiste na sua tradução e validação para português, para identificar essas áreas.

Material e Métodos: Realizámos um estudo descritivo, observacional e transversal. O processo de tradução seguiu as normas da Organização Mundial de Saúde. Aplicámos os questionários numa amostra de conveniência, em doentes sob tratamento antineoplásico sistémico no Hospital de Dia do Centro Hospitalar Universitário do Porto, entre janeiro e março de 2020. Calculámos o coeficiente de Cronbach para cada fase dos cuidados, as correlações bivariadas e múltiplas e, para cada questão, a percentagem de respostas "não aplicável" e de resposta mais positiva.

Resultados: Participaram 100 doentes. O instrumento obtido possui boa consistência interna, mas tem questões cuja classificação não se correlaciona satisfatoriamente com a opinião global das experiências com comunicação na respetiva fase. O diagnóstico foi a fase que revelou menos experiências positivas, especificamente na transmissão da notícia.

Conclusão: Este estudo traduziu e validou uma parte do instrumento de avaliação de comunicação PACE, adaptando-o à realidade portuguesa, e demonstra a necessidade de investir na fase de diagnóstico, nomeadamente na transmissão de más notícias.

Palavras-chave: Assistência Centrada no Doente; Comunicação em Saúde; Garantia da Qualidade dos Cuidados de Saúde; Inquéritos e Questionários; Neoplasias; Portugal; Relações Médico-Doente; Tradução

INTRODUCTION

Communication in clinical practice has been the subject of research in Portugal^{1,2} and worldwide.^{3,4} The particular interest in doctor-patient communication regards its influence on the quality of healthcare. The relationship between

effective clinical communication and patient satisfaction, improved adherence to treatment, increased patient confidence, symptom relief and lower need for diagnostic tests and a reduction in health expenditure have been shown in

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literature.⁵⁻¹⁰ The importance of communication for health-care professionals has also been documented. Doctors with poorer communication skills are more affected by stress and burnout, with adverse effects on health, personal life and the provision of care.¹¹⁻¹³

Doctor-patient communication is particularly relevant in oncology, due to the physical and emotional impact of cancer. Its life-threatening characteristics, the multiple treatments and different impairments lead to increased vulnerability and frequent and prolonged contacts with the healthcare services. In addition, healthcare professionals get involved into emotionally demanding clinical situations, including facing uncertainty and death, dilemmas when deciding to discontinue active treatments and delivering this information to patients.^{8,14}

Communication is an important indicator of satisfaction with healthcare. Different studies have shown that dissatisfaction described by cancer patients is more often associated with experiences related to communication than with any other factors.^{15,16} Research on this subject has been carried out in Portugal, focused on patients referred for palliative care,¹⁷ and on younger age groups.¹⁸

The Patient Assessment of Cancer Communication Experiences (PACE) questionnaire was developed in the United States of America (USA) in 2016 (Appendix 1: https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/14352/Apendice_01.pdf), aimed at assessing the experience of patients as regards the communication throughout cancer care, and it has become a very useful instrument for strategies aimed at improving patient care.¹⁹ This questionnaire was written in English, and to our knowledge it has not been translated or validated to any other language.

This study was aimed at translating and adapting the PACE questionnaire into Portuguese, in addition to assessing its reliability and applicability to the perception of the communication experiences of cancer patients throughout the different stages of care. It was mainly aimed at the identification of aspects that could be improved in this area.

MATERIAL AND METHODS

This study was carried out at the day hospital of the *Centro Hospitalar Universitário do Porto* (CHUP) and was developed including translation and cultural adaptation of the PACE questionnaire (phase one) and application of the Portuguese version in a group of patients with cancer undergoing chemotherapy (phase two), which was developed as an observational, cross-sectional, and descriptive study with an analytical component.

The approval for translation and application of the original version of the PACE questionnaire was obtained from the first author. The study was approved by the Ethics Committee and institutionally approved by the CHUP. An informed consent was obtained from the participants.

Procedures

The questionnaire PACE includes 81 items, distributed

amongst seven groups, regarding the different phases of cancer care:

- From the suspicion of cancer through the present (16 items)
- Diagnosis (five items)
- Treatment decisions (19 items)
- Surgery (nine items)
- Chemotherapy (10 items)
- Radiotherapy (10 items)
- After treatment (five items).

Five response options were considered, ranging from “never” to “always”, or “totally disagree” to “totally agree” (4-point Likert scale), and a “not applicable” option was included.

Translation

The PACE questionnaire was translated into Portuguese according to the guidelines of the World Health Organisation (WHO), including English-Portuguese translation, Portuguese-English reverse translation, revision, and pre-test.²⁰

The English-Portuguese translation was carried out independently by four of the co-authors with experience in the field of health and research, whose mother tongue is Portuguese, and who are also fluent in English (IA, IF, DM and SM). Discrepancies between the four versions were discussed until a consensus was reached.

The reverse translation was carried out by a Portuguese-born translator with experience in translating documents in the medical field.

The final version was obtained by discussion between two co-authors, with revision by two external professionals fluent in both languages.

The graphic appearance of the PACE questionnaire, originally designed for online completion, was adapted to allow for an easier completion of the printed format.

Portuguese version of the PACE questionnaire

The Portuguese version of the PACE questionnaire (Appendix 2: https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/14352/Apendice_01.pdf) included 81 items aimed at the assessment of patients' perceptions of their experiences with communication throughout their care, from the time they suspected they had cancer until completion of the questionnaire.

In line with the original questionnaire, the 81 items in the Portuguese version of PACE were divided into seven groups. Each set of items addresses each phase of cancer care listed in its title:

- Core items – from the suspicion of cancer to questionnaire completion
- Diagnosis - delivering the initial diagnosis
- Treatment - discussion of treatment options from the time of diagnosis until questionnaire completion
- Surgery
- Chemotherapy - administration of intravenous systemic antineoplastic therapy from diagnosis. (This

group is called 'Chemotherapy' in the original questionnaire. We chose to translate it into 'Chemotherapy' rather than 'Systemic antineoplastic therapy' because this is a self-completion questionnaire and the term 'Chemotherapy' is more widely understood)

- Radiotherapy
- After treatment.

Since the questionnaire was administered to patients who were still undergoing treatment, the "After treatment" group was excluded; therefore, only 75 items were made available out of the 81 that emerged from the translation.

Pilot test

A total of 10 questionnaires were handled as a pilot test to check the validity of the questionnaire. We assessed whether the patients understood what was being asked and whether the responses corresponded to what was being asked. In this way, we ensured that the intended parameters were assessed by each item.

At this moment, comments such as "the same questions are asked by different items" were obtained, suggesting that patients had some difficulty understanding which phase of care each item referred to. An explanatory subtitle was added to each set of items, and the problem was solved. After these changes, the questionnaire was clearly understood by the target population.

As these pre-test questionnaires were completed in full and the changes resulting from their application did not involve any significant changes or did not affect the information, the information obtained from these 10 patients was included into the final sample.

Study sample

The Portuguese version of the PACE questionnaire was applied to a consecutive convenience sample of patients undergoing intravenous systemic antineoplastic therapy at the CHUP Day Hospital. This was a cross-sectional support structure for the entire hospital centre, with its own organisation and physical space, where cancer patients undergo antineoplastic therapy. Since the questionnaire included items with the words "My oncology team", for the sake of consistency, only patients attending oncology were included (those attending haematology, or any other speciality were not included).

Patients who were not physically or psychologically able to respond to the questionnaire were excluded from the study, as well as patients with symptoms related to cancer or systemic treatment – including pain, severe prostration, fatigue, or dyspnoea - preventing them from taking part in the study, and patients who could not undergo treatment on that day due to test results.

The questionnaires were always administered by the same researchers and took place from 13 January to 2 March 2020.

Questionnaires were designed for self-completion, but some were read aloud to patients who have requested it due to physical or visual constraints or low education. Rel-

evant comments were considered, and basic demographic data were collected.

Statistical analysis

Data were entered into a database and statistical analysis was carried out using the Statistical Package for the Social Sciences (SPSS)[®] version 26.0.

Data analysis included descriptive statistics, with medians and interquartile ranges for continuous variables, and frequencies and percentages for categorical variables. The percentage of "not applicable" responses was estimated for the assessment of those details of communication that were valued the least by patients. The percentage of participants who selected the most positive responses in each item ("always", "totally agree" or "excellent") was calculated to find out the patients' perspective on the communication they have experienced during the sequence of care. The counting of the most positive responses showed that no aspect of communication fell short of patients' needs and expectations. Any lower rate of these responses would reveal that something should have been different and could therefore be improved.

Bivariate and multivariate correlations were considered for assessing whether the individual items were related to the overall experience with communication throughout the sequence of care:

- Bivariate correlation (Spearman's correlation), aimed at the analysis of the relationship between the score for each individual item and the corresponding score for the overall communication rating (total). For instance: the relationship between the item "Did you know who to contact if you had any questions or concerns?" and the score obtained in the item "Overall, how would you rate your experiences with communication during the period you were receiving chemotherapy?"
- Multivariate correlation aimed at analysing the collective relevance of the items in the overall communication rating, throughout the sequence of care.

In line with the original study, these analyses were used to check whether any of the individual items, or these as a whole, were able to show the most relevant aspects of the patient's communication experiences during the corresponding phase of cancer care. A high correlation between the scores obtained in the individual items and the scores obtained in the overall score would mean that the items in each set of items were able to explain a reasonable percentage of the variation individually and collectively in the corresponding overall rating. For all correlation analyses, "not applicable" responses were counted as missing values.

Cronbach's α coefficient was calculated for each group of items, to check the reliability and internal consistency of the instrument.

Global scores of the communication experience throughout the sequence of care were compared, considering age (< 65 and \geq 65) and time on chemotherapy (< 1 month, 1 and 6 months and > 6 months), using the Mann-Whitney

and Kruskal-Wallis non-parametric tests. A p -value < 0.05 was considered statistically significant.

RESULTS

Study sample

The questionnaire was applied to a group of 100 patients presenting with cancer and undergoing chemotherapy, considering the exclusion criteria as described above.

A 62-year median age was found (interquartile range 51 - 70), with a slight female predominance (52%). The demographic characteristics are shown in Table 1.

The questionnaire was not fully completed by six participants: five participants have not completed the questionnaire due to physical and psychological reasons, and one was found to be unaware of the diagnosis.

Percentage of “Not applicable” responses

The “Not applicable” response was selected by more than 10 per cent in seven of the 75 items:

- “My (...) team helped me dealing with difficult feelings such as fear, anxiety and feeling down” during chemotherapy (13%) and radiotherapy (28%).
- “The doctors and nurses listened to what I had to say about how (...) was affecting me” during chemotherapy (16%) and radiotherapy (22%). Comments including “I never showed” or “I came prepared for all that” were obtained.
- “My doctors respected my wishes about trying additional treatments” in surgery, chemotherapy and radiotherapy groups (87% - 94%).

Evaluation of the psychometric characteristics of the questionnaire

Bivariate correlations (item-total), multivariate correlations and Cronbach's α are shown in Table 2.

Bivariate correlations ranged from low to high by Cohen.²¹ The lowest bivariate correlations (< 0.20) throughout the questionnaire regarded the following items:

- Core items: “I knew who I could turn to in the health-care system if I was worried about something that might have gone wrong with my care” and “I felt free to talk about everything that was on my mind”.
- Treatment decision: “I realised why we made the decisions we did”. Comments such as “I didn't make the decisions, nor did I want to. The doctors know best” and “The disease isn't something you have to understand, it's something you have to treat” were obtained.
- Radiotherapy: “I knew who to contact if I had any questions or concerns” and “I was given enough information about how to avoid or deal with side effects”.
- The highest bivariate correlation was obtained in the item “I was told I had cancer in a sensitive and careful way”. The comments show that many patients learnt of their diagnosis away from a consultation setting, during imaging tests or from administrative staff. Others reported abruptness: “I didn't want to be operated on (...). To persuade me to stay, the doctor told me ‘bluntly’ that I had cancer. I was in shock

Table 1 – Demographic characteristics

	n	%
Total	100	100
Gender		
Female	52	52
Maale	48	48
Age (year)		
Median; interquartile range	62	51 - 70
Education		
1 st Cycle	40	40
2 nd Cycle	12	12
3 rd Cycle	2	2
Basic Education	8	8
Secondary Education	17	17
High Education	21	21
Marital status		
Single	8	8
Married	76	76
Divorced	9	9
Widowed	7	7
Occupational status		
Employed	8	8
Sick leave	49	49
Retirement	42	42
Unemployed	1	1
Time from diagnosis		
Less than 3 months	8	8
3 - 11 months	43	43
1 - 3 years	24	24
Over 3 years	23	23
Time since chemotherapy was started		
Less than 1 month	32	32
1 - 6 month	29	29
7 - 11 month	6	6
1 - 3 years	22	22
Over 3 years	11	11
Time from last cancer surgery (n = 55)		
Less than 1 month	2	3.6
1 - 6 month	22	40
7 - 11 month	4	7.3
1 - 3 years	16	29.1
Over 3 years	11	20
Time since last session of radiotherapy (n = 19)		
Less than 1 month	2	10.5
1 - 6 month	2	10.5
7 - 11 month	2	10.5
1 - 3 years	11	57.9
Over 3 years	2	10.5
Type of cancer		
Head/neck	1	1
Breast	13	13
Lung	11	11
Gastrointestinal	46	46
Urological	11	11
Gynaecological	9	9
Others	7	7
Does not know	2	2
Cancer staging		
Non-invasive	22	22
Invasive	62	62
Does not know	16	16

Table 2 – Reliability of dimensions

Phases of cancer care	n	Item-total correlation (rho)*	Multivariate correlation (R)	Cronbach's alpha
Core items	100	0.18 a 0.39	0.60	0.86
Diagnosis	98	0.41 a 0.64	0.76	0.81
Treatment decision	98	0.14 a 0.44	0.78	0.91
Chemotherapy**	96	0.32 a 0.44	0.61	0.88
Surgery**	53	0.39 a 0.60	0.61	0.89
Radiotherapy**	18	-0.03 a 0.55	0.64	0.95

* Spearman's correlation; ** Excluding the item with > 80% 'Non-applicable' responses

for a fortnight,” and discomfort at the use of medical jargon: “It was said with expensive words, I had to look it up. It's more human to use simpler words”.

The internal consistency assessment of the Portuguese version of the PACE questionnaire showed adequate Cronbach's α values for all dimensions, ranging from 0.81 to 0.95. For this determination, items with > 80% “Not applicable” responses were deleted.

Percentage of the most positive responses

Considering the whole sequence of care and excluding the items with >80% of “Not applicable” responses, the percentage of participants selecting the most positive response ranged from 50.5 per cent to 94.4 per cent.

The items with the highest percentage of positive responses were found in the radiotherapy group (n = 18). Excluding those at this phase of cancer care, the items with the highest percentage of positive responses were “I felt that everyone worked together as a team to look after me” (92%) and “I received the treatment that was best for me.” (91.7%)

The items with the lowest percentage of positive re-

sponses included “I was encouraged to give my opinion on which treatment options I preferred” and “I was told I had cancer in a sensitive and caring way”. Comments such as “What would I prefer? I don't know anything about this”; “Patients don't have to prefer any treatment, because they don't know medicine”; “That's how I wanted it”. However, some described that “There was no conversation about treatment”.

Many patients felt distressed because they didn't understand the reason why other patients had been submitted to different treatment options: “I realised that there are patients who are submitted to more aggressive treatments (...), and I don't understand why. I wasn't given a plan”; “I didn't understand why I had chemotherapy and then surgery. A friend of mine had surgery straight away. It was a difficult time, I just wanted to get rid of the disease”.

The patients' overall perception of communication throughout the sequence of care is shown in Fig. 1.

Specific aspects that represent communication strengths and weaknesses are shown in Figures 2 and 3.

No statistically significant differences were found between different age groups (< 65; \geq 65) or with different chemotherapy times (less than one month, between one and six months and more than six months).

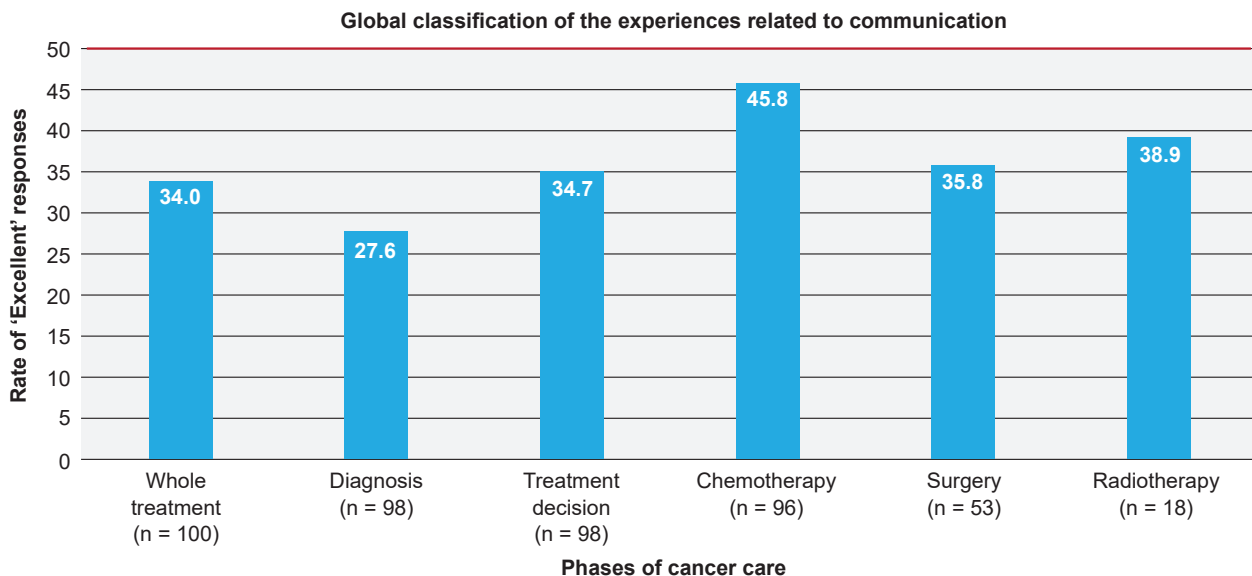


Figure 1 – Global classification of the communication throughout the sequence of care

DISCUSSION

This study consisted of the translation and adaptation into Portuguese of a questionnaire on the perspective of cancer patients regarding communication and the assessment of its reliability and applicability in the perception of their experiences with communication throughout the sequence of care.

The adaptation of the Portuguese version of the PACE questionnaire showed good internal consistency, reflecting homogeneity between the items, which is desirable in an instrument aimed at 'assessing' the experience of communication through multiple items.²² However, some of the correlations obtained between the score of the individual items and the overall score were very low (<0.20). These correlations (individual item - total score) have shown some aspects of the communication experience throughout the sequence of care, since individually and collectively they explain the variation in the overall score. Most of the correlations were lower than those obtained in the validation of the PACE questionnaire.

The adaptation of a questionnaire concerns not only its translation. The cultural adaptation of an instrument requires its application to a target group of patients and the identification of weaknesses that were not detected in the small group used in the pre-test of this study. The application of the Portuguese version of the questionnaire to a group of 100 patients allowed the identification of some constraints in the applicability of the items, suggesting that some of these were not suitable for these participants. We believe that this may be due to the different cultural and medical realities, which have already been mentioned in some studies.^{17,23}

The adaptation of the questionnaire to our context would be an interesting task, showing the relevant issues in cancer care. This was the method used by the authors of the

PACE questionnaire, who carried out semi-structured interviews to construct the questionnaire.^{14,24}

Only seven of the 75 items had a >10% "Not applicable" response rate. Four of these relate to the support in managing emotions during care and sharing how treatment has affected patients. This may mean that patients do not expect oncology teams to play an active role in these areas. The comments showed that the topic is not usually addressed either by patients or doctors. Respecting the patient's wish for additional treatments was also undervalued by the participants, showing a high rate of "Not applicable" responses. This suggests that this issue is not so relevant in our reality.

The lowest bivariate correlation in the entire questionnaire was found in the item "Did you know who to contact if you had any questions or concerns?" during radiotherapy. We did not consider the results given the small sample and the fact that the procedure was not carried out at CHUP. The second lowest correlation was obtained for the item "I realised why we made the decisions we did". The comments described by patients show that some don't feel the need to understand all the decisions regarding their care. They assume that this is the role of doctors, and some prefer not to be involved in any decision. It is therefore understandable that their responses to this item does not influence their rating of communication in the treatment decision. This could be explained by the fact that 62 per cent of the participants had only completed primary education.

The highest bivariate correlation was found in the item "I was told I had cancer in a sensitive and careful way", suggesting that patients value the way this is communicated. We received reports of negative experiences in this area, which may have influenced the perception of communication at this stage. The data shows the relevance of these events for patients and the need to invest in training in this area.

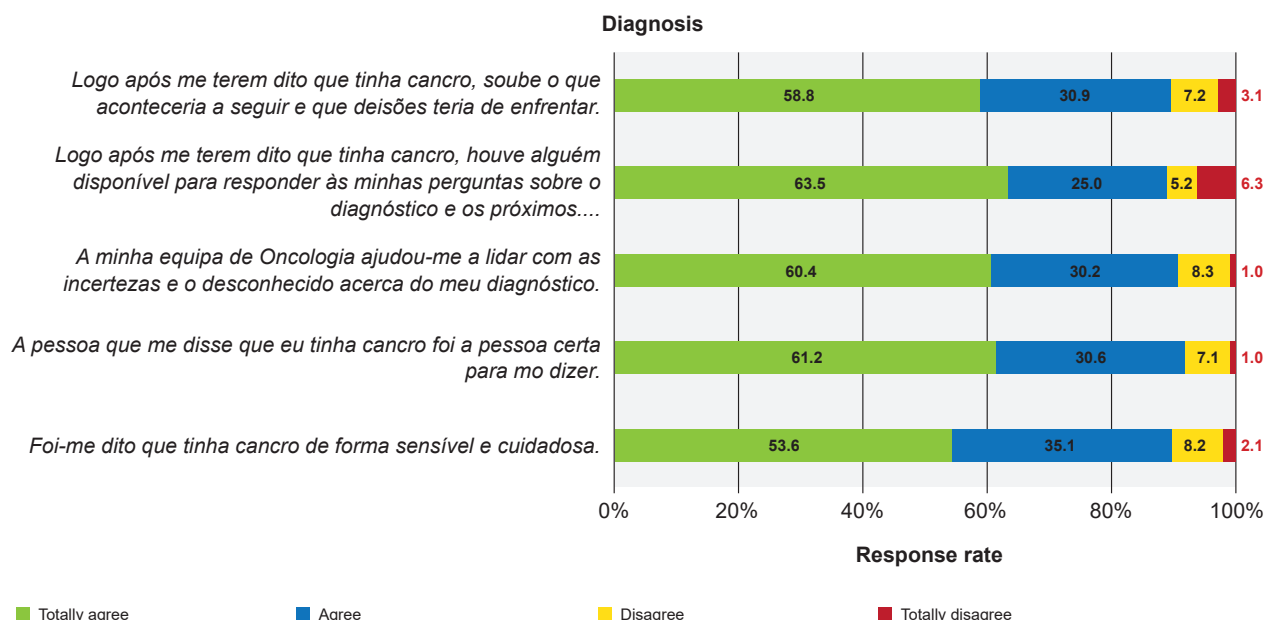


Figure 2 – Classification of the experiences related to the communication at the moment of diagnosis

Chemotherapy

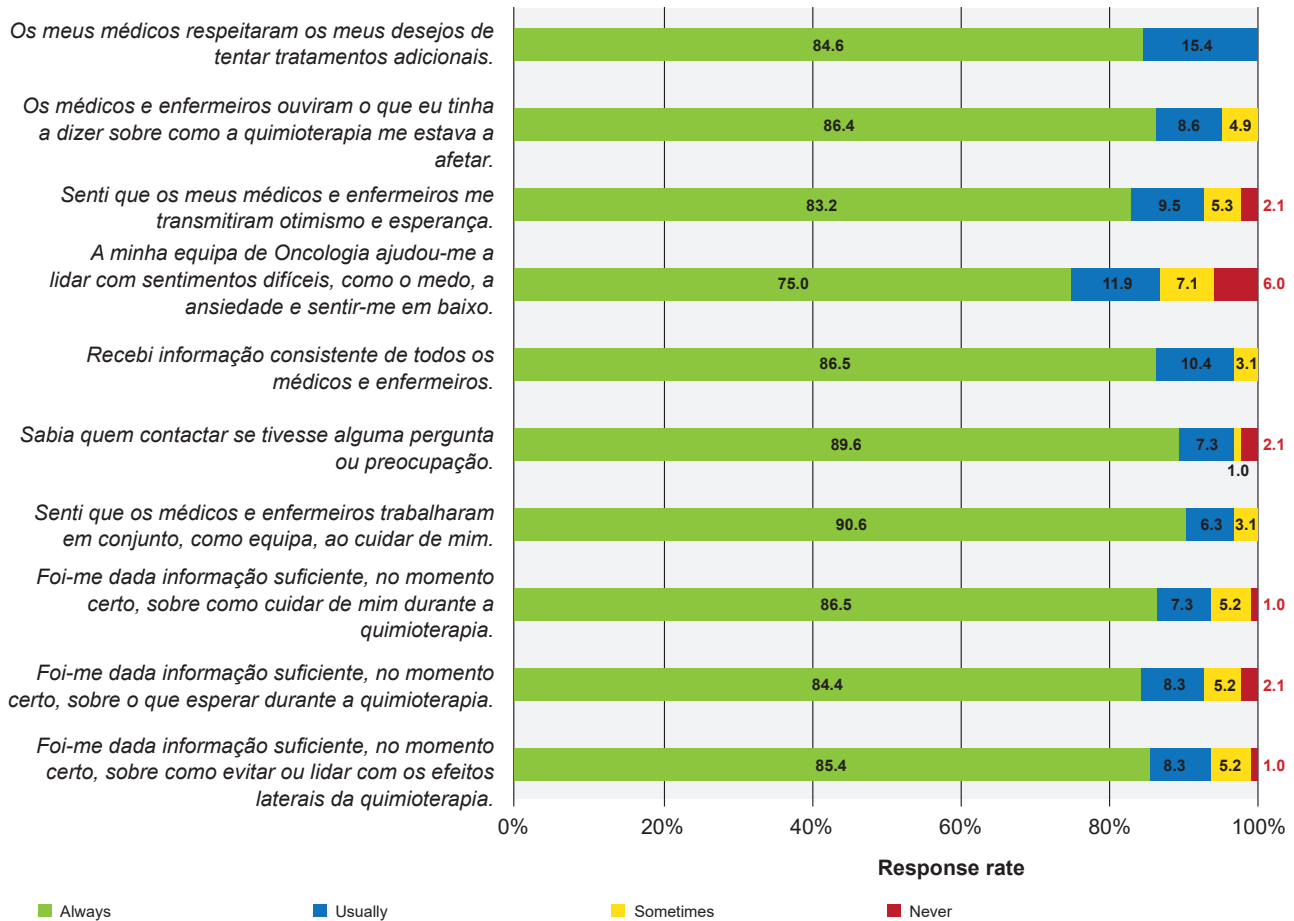


Figure 3 – Classification of the experiences related to communication during chemotherapy

The steps in the sequence of care with room for improvement are shown in Fig. 1, while the specific aspects of communication that could be improved are shown in Figs. 2 and 3. Most weaknesses were found in diagnosis, specifically in delivering the diagnosis to patients and explaining the treatment decisions. This is consistent with what was discussed earlier. In a 2016 European study, oncologists at the Hospital de S. José (Lisbon) rated their confidence in their ability in delivering bad news at an average of 84, from 0 to 100.¹¹ At the Coimbra Central Hospital, 85 per cent of professionals admitted needing training in communicating bad news.²⁵ At the Instituto Português de Oncologia do Porto, 47 patients were interviewed about their opinions on communication at this stage, and 47 per cent rated it as poor.¹⁷ In the article that validated the PACE questionnaire, the delivery of cancer diagnosis also proved to fall short of patients’ needs.¹⁹ This reinforces the usefulness of investing in clinical communication during pre- and postgraduate training.

“I was encouraged to give my opinion on which treatment options I preferred” was the item with the lowest percentage of positive responses, in line with what was described, regarding patients not usually being involved in treatment decisions. Although many participants say that this should

be the doctors’ decision, others admit that there was no joint decision and feel the need to understand whether there would be a different strategy. This could be minimised by asking each patient how they want to be involved in making treatment decisions.

No significant differences were found between the overall score in patients with different ages and lengths of chemotherapy treatment. This suggests that communication needs are general and continuous.

This study has some limitations. The PACE questionnaire was not entirely validated and only a small group of patients who have undergone surgery and radiotherapy was included. There was a predominance of older participants with basic education; therefore, generalisability of the results to younger populations or those with more advanced education is limited. As this was a cross-sectional study, patients at different phases of cancer care were included, with varying lengths of chemotherapy treatment. In addition, by applying the questionnaire to a single cancer care unit, the results are not sufficiently representative of the entire Portuguese population. On the other hand, the fact that the participants were undergoing treatment could influence their responses; if patients who had already completed their treatment were also included, in line with the original

questionnaire, we would have access to another perspective and different results would have been obtained. Almost a quarter of the patients were diagnosed more than three years ago, so some memory bias could exist.

It would make sense increasing the sample size of the study and its application to other hospitals. We hope that the preliminary results of this research will trigger the interest of other institutions, and that a multicentre study will be designed in the future. We also intend to develop a shorter version of the questionnaire adapted to the Portuguese reality.

CONCLUSION

The Portuguese version of the PACE questionnaire is the first translation of this instrument and shows the need for the development of a questionnaire more adapted to our culture and clinical context. The results have shown strengths and weaknesses in communication, providing guidance for teams to improvements in this area. Communication in the diagnostic phase of cancer care has a significant impact, particularly in terms of delivering bad news to patients; the investment in these aspects of communication would be very relevant in medical training.

AUTHOR CONTRIBUTION

IA: Study design; English-Portuguese translation of the Patient Assessment of Communication Experiences (PACE) questionnaire; revision of the translation, application of the Portuguese versions of the PACE questionnaire; writing the manuscript.

IF: Study design; English-Portuguese translation of

the Patient Assessment of Communication Experiences (PACE) questionnaire; statistical analysis; writing and revision of the manuscript.

DM: Study design; English-Portuguese translation of the Patient Assessment of Communication Experiences (PACE) questionnaire; revision of the translation, application of the Portuguese version of the PACE questionnaire; revision of the manuscript.

IB: Revision of the manuscript.

SM: Suggestion of the study concept and study design; English-Portuguese translation of the Patient Assessment of Communication Experiences (PACE) questionnaire; revision of the manuscript.

HUMAN AND ANIMAL PROTECTION

The authors declare that this project complied with the regulations that were established by the Ethics and Clinical Research Committee, according to the 2013 update of the Helsinki Declaration of the World Medical Association.

DATA CONFIDENTIALITY

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

CONFLICTS OF INTEREST

The authors declare that there were no conflicts of interest in writing this manuscript.

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